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**MEASURING COMPETENCE IN THE PERFORMANCE OF
ACTIVITIES OF DAILY LIVING:
THE FORGOTTEN HALF OF ALZHEIMER'S DISEASE**

by

Susan Elizabeth Doble, MS

Interdisciplinary Studies PhD Programme

**Submitted in partial fulfilment of the requirements
for the degree of Doctor of Philosophy**

at

**Dalhousie University
Halifax, Nova Scotia
March 28, 2000**

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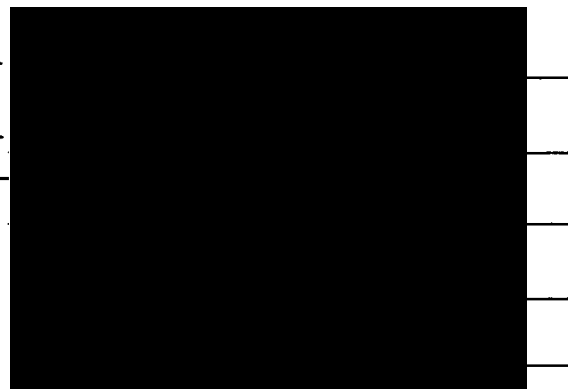
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by Susan Elizabeth Doble

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

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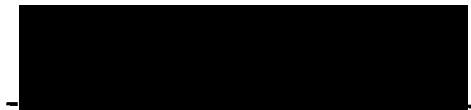
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Dedication

This work is dedicated to my husband, Dr. John Fisk, and to our sons, Jordan and Ryan, who accompanied me on this journey of learning and development. The journey to complete my PhD is one that can be likened to one of our many family canoeing adventures. When I started, I had a clear vision of where I was headed. The waters were calm and the paddling was easy. However, soon the winds began to shift, and the waves deepened. While there were times that I questioned where I was headed and if I would ever get there, your strength, wisdom, and never ending love helped me regain my focus. Despite the many rocks, waves and other challenges, you kept me safe, and enabled me to steer my way through the rough waters, push off from sandy shoals that held me back, and deal with submerged logs and rocks that often tested my balance and self-confidence. Like the white granite rock Jordan gave me during a special canoe adventure in the summer of 1994, you each gave me something very precious to hold on to when the challenges seemed to be more than I could handle. While many may think of completing one's PhD as a personal accomplishment, those of us who have paddled these waters know that it is one that could not have been done alone. Thank you for being willing to continue this journey with me, for conveying a strong belief in me even when my doubts were increasing, and for being my light at the end of the journey.

Table of Contents

Table of Contents.....	v
List of Tables.....	viii
List of Figures.....	ix
List of Appendices.....	x
Abstract.....	xi
Acknowledgements.....	xii
Chapter 1. Introduction.....	1
Chapter 2. A Conceptualization of Occupational and Social Behaviour.....	10
Summary.....	15
Chapter 3. Criteria for Evaluating ADL Assessments.....	16
Introduction.....	16
Criterion 1: Evaluates the Key Elements of Occupation.....	17
Criterion 2: Measures a Unidimensional Construct.....	19
Criterion 3: Generates Unbiased Ability Measures.....	21
Criterion 4: Generates Stables Ability Measures.....	23
Criterion 5: Generates Responsive Ability Measures.....	24
Criterion 6: Is Cost-Effective.....	25
Summary.....	27
Chapter 4. ADL Assessments in AD: Do They Meet the Criteria?.....	28
Introduction.....	28

Criterion 1: Evaluates the Key Elements of Occupation.....	29
Criterion 2: Measures a Unidimensional Construct.....	36
Criterion 3: Generates Unbiased Ability Measures.....	38
Criterion 4: Generates Stables Ability Measures.....	39
Criterion 5: Generates Responsive Ability Measures.....	40
Criterion 6: Is Cost-Effective.....	42
Summary.....	43
Chapter 5. Proxy-Report Assessments: Directions for Development.....	45
Introduction.....	45
Social Cognitive Processes Involved in Making Judgements.....	47
Psychosocial Factors that May Systematically Bias Proxy-Reports.....	49
Depressive Symptomatology.....	51
Perceived Caregiver Burden.....	52
Quality of the Informant-Subject Relationship.....	54
Summary.....	57
Chapter 6.....	59
Purpose.....	59
Methods.....	60
Design.....	60
Sample Size.....	61
Subjects.....	61
Instrumentation.....	65

Global Deterioration Scale.....	65
Mini-Mental State Examination.....	65
Assessment of Motor and Process Skills.....	66
Assessment of Motor and Process Skills–Proxy-Report.....	68
Beck Depression Inventory.....	69
Caregiver Burden Inventory.....	70
Interpersonal Relationship Inventory.....	71
Family Informant Rater Intervention.....	72
Procedures.....	75
Chapter 7.....	77
Analysis 1 - Examination of the Psychometric Properties of the AMPS-PR.....	77
Analyses.....	77
Results.....	81
ADL Motor Scale.....	81
ADL Process Scale.....	87
Analysis 2 - Factors Affecting Family Informants' Reports of AD subjects' ADL Competence.....	92
Analyses.....	92
Results.....	92
Analysis 3 - Effectiveness of a Brief Educational Intervention on the Family Informants' Ratings.....	95
Analyses.....	95
Results.....	95
Chapter 8: Discussion.....	98
Appendices.....	109
References.....	120

List of Tables

Table 6.1	AD Subjects' and Family Informants' Demographic Data.....	64
Table 7.1	AMPS-PR ADL Motor Scale Item Difficulty Calibrations.....	83
Table 7.2	Mean AMPS and AMPS-PR ADL Motor and ADL Process Ability Measures (logits).....	84
Table 7.3	AMPS-PR ADL Motor Ability Measures (logits) and Z Scores that Differed Significantly Between Sessions 1 and 2.....	85
Table 7.4	AMPS-PR ADL Process Scale Item Difficulty Calibrations.....	87
Table 7.5	AMPS-PR ADL Process Ability Measures (logits) and Z Scores that Differed Significantly Between Sessions 1 and 2.....	91
Table 7.6	Regression Analysis Examining the Contributions of Psychosocial Variables to the Difference in AMPS-AMPS-PR Measures of ADL Motor Ability Measures	93
Table 7.7	Regression Analysis Examining the Contributions of Psychosocial Variables to the Difference in AMPS-AMPS-PR Measures of ADL Process Ability Measures.....	94
Table 7.8	Mean Differences in the AMPS-AMPS-PR ADL Ability Measures over Sessions 1 and 2 by Group.....	96
Table 7.9	Proportion of Agreement, Overestimation, and Underestimation by Family Informants.....	97

List of Figures with Figure Captions

<u>Figure 1.</u>	Relation between AMPS and AMPS-PR ADL motor ability measures ($n = 106$) ($r = .58$).....	86
<u>Figure 2.</u>	Relation between AMPS and AMPS-PR ADL process ability measures ($n = 119$) ($r = .55$).....	90

List of Appendices

<u>Appendix A.</u>	Assessment of Motor and Process Skills Proxy-Report (AMPS-PR)...	109
<u>Appendix B.</u>	Intervention Guidelines.....	115
<u>Appendix C.</u>	Handout for Family Informants in the Intervention Group.....	119

Abstract

Other than the Assessment of Motor and Process Skills (AMPS) (Fisher, 1999), ADL assessments are not grounded in a clear conceptualization of occupation. The AMPS, an observational assessment, evaluates the quality of individuals' ADL motor and ADL process skills when they perform meaningful and relevant ADL tasks, and generates unbiased and stable measures of individuals' ADL ability. Despite these strengths, the AMPS has not been widely adopted in dementia-focused clinical and research settings.

In this study, the AMPS proxy-report (AMPS-PR) was developed and its potential utility was evaluated. The AMPS ADL ability measures for 60 subjects with AD were compared with the AMPS-PR ADL ability measures generated by their family informants. When item response validity was examined, 75% of the 16 ADL motor skill items and 70% of the 20 ADL process skill items demonstrated acceptable goodness-of-fit with the measurement model. The low infit and outfit *MnSq* values of the items that failed to demonstrate acceptable goodness-of-fit with the measurement model suggest that these items were redundant. The person-response validity of the AMPS-PR was low; many proxy ratings were invariable. The reliability of many subjects' ADL ability measures was compromised by high standard errors. Nevertheless there was no significant difference between 62.5% of the observed and proxy-report ADL motor ability measures, and 56.5% of the observed and proxy-report ADL process ability measures. Although most observed and proxy-report ADL measures were comparable, overestimation by proxies was very common. In contrast to the AMPS, rater bias cannot be accounted for when generating AMPS-PR ADL ability measures. Therefore, a model comprised of five psychosocial factors (i.e., informants' depressive symptomatology and time-dependence caregiver burden; and perceptions of social support, reciprocity, and conflict within their relationships with the subjects) was examined to determine if these factors systematically biased proxies' ratings. The model, however, accounted for only a small proportion of the discrepancy between observed and proxy-report ADL process ability measures. A brief educational intervention, designed to enhance family informants' ability to make complex judgements about family members' ADL abilities, had no significant effect in reducing the discrepancies between the observed and proxy-report ADL motor ability measures, or the observed and proxy-report ADL process ability measures.

The findings illustrate the complexity inherent in rating AD subjects' ADL abilities. Although family informants can make good observations, their abilities to make complex judgements and assign ratings that accurately reflect the AD subjects' ADL abilities is questionable. Since proxy-report measures cannot account for proxies' biases, and factors that systematically bias their ratings are difficult to determine, it may be more feasible for trained AMPS examiners, whose biases can be accounted for, to complete ratings based on proxies' observations. Despite its current limitations, the AMPS-PR has potential use in clinical practice settings to identify family informants' perceptions of AD subjects' ADL motor and ADL process skill competencies, and to develop insights into the effects that family informants may have on their relatives' ADL task performances.

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CHAPTER 1

Introduction

Alzheimer's disease (AD) is the most common cause of dementia accounting for between 50 and 80% of all dementias (Blennow, Wallin, & Gottfries, 1994; Canadian Study of Health and Aging Working Group [CSHAWG], 1994; Henderson, 1983; Lauter, 1985; Rockwood & Stadnyk, 1994). Although the overall prevalence of this progressive, neurodegenerative disorder is estimated to be 5.1% (CSHAWG, 1994), prevalence increases with age. Only 1% of those aged 65 to 74 years are diagnosed with AD, but this percentage increases to 26% for those 85 and older (CSHAWG, 1994). About half of the 300,000 Canadians who are now living with a diagnosis of AD continue to reside in the community with family members assuming responsibility for day-to-day decision making and the provision of care. As our population ages, the number of Canadians with AD is expected to rise so that by the year 2020 about 750,000 Canadians will be living with AD.

The cerebral pathological changes associated with AD (e.g., neurofibrillar tangles, senile plaques) can only be identified definitively on autopsy. Therefore, diagnosis is made by evaluating various symptoms and signs to decide if they are consistent with the key criteria for AD defined within the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* (American Psychological Association [APA], 1994), and by the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA) (McKhann et al., 1984).

AD is typically understood as a condition in which there is a progressive deterioration of a variety of cognitive capacities. Although memory loss is the earliest, most obvious, and most pervasive feature of AD (APA, 1994; Zec, 1993), changes in attention, visual spatial abilities, language, and executive capacities are also characteristic of AD. Changes in cognition, however, are not the only features of AD. Behavioural and other psychiatric symptoms are common and distinctive features (Baumgarten, Becker, & Gauthier, 1990).

Behavioural symptoms may include agitation, aggressiveness, repetitive gestures and questions, wandering, and hoarding; psychiatric symptoms may include agitation, depression, and psychosis (Cohen et al., 1993; Green et al., 1999; Merriam, Aronson, Gaston, Wey, & Katz, 1988; Patterson et al., 1990; Seltzer & Buswell, 1994; Teri, Borson, Kiyak, & Yamagishi, 1989; Teri, Larson, & Reifler, 1988). The *DSM-IV* (APA, 1994) criteria for dementia also suggest that an individual's cognitive impairment must be of sufficient severity to interfere with his or her *occupational or social functioning*.

Tests of individuals' cognitive capacities have a long history of development through the discipline of psychology, but assessments of occupational and social functioning have not shared this same history. Although we have witnessed the development of a plethora of assessments of activities of daily living (ADL) over the last 30 years, ADL assessments have been criticized largely for lacking in sophistication (McDowell & Newell, 1996; Poon, 1994; Snowden, 1990; Spector, 1997). Moreover, ADL assessments do not provide a complete picture of individuals' occupational and social functioning. Instead, occupation refers to the process of *engaging* in tasks alone or with others to meet our needs not just for self-care but also for home maintenance, productivity, and leisure/play (Fisher, 1998, 1999; Kielhofner, 1995; Law, Polatajko, Baptiste, & Townsend, 1997). Furthermore, the argument has been made that impairment "of sufficient severity to interfere with occupational or social functioning" (APA, 1994) is too vague to be operationalized adequately in the diagnosis of dementia (Evans et al., 1989). This view, coupled with the lack of state-of-the-art assessments of occupational and social functioning, has had broad effects in AD research and clinical practice.

Epidemiological research designed to estimate the prevalence of dementia and AD has produced varied results depending on if and how occupational and social functioning was operationalized (cf. Larrea, Fisk, Graham, & Stadnyk, in press). Rockwood, Trip, Stadnyk, and Fisk (1994) found that proxy-report ADL assessments incorporated into a screening assessment for cognitive impairment failed to contribute any significant

diagnostic information. In a study of the prevalence of dementia in East Boston, Evans and colleagues (1989) limited their assessment of function to the domain of cognition using neuropsychological and cognitive assessments. They argued that it was too difficult to apply the criterion of occupational and social functioning “in a uniform, meaningful way” (p. 2553). Instead, they assumed that if individuals’ neuropsychological test scores suggested that they were cognitively impaired, then their occupational and social functioning would also be impaired. Adopting this view, Evans and colleagues (1989) estimated that the prevalence rate of probable AD was 10.3% for persons 65 years and older. In contrast, in the Canadian Study of Health and Aging (CSHA) (CSHAWG, 1994), “functional impairment” was defined as assistance to do personal and instrumental activities of daily living as reported by a proxy. Compared with Evans and colleagues’ prevalence estimate of 10.3%, the CSHA prevalence estimate of probable AD was lower, at 5.1%. This discrepancy suggests that even when neuropsychological assessments indicate that individuals are cognitively impaired, proxies do not necessarily report that individuals require assistance to perform ADL tasks. When Larrea and colleagues (in press) re-examined the CSHA data, they found that the prevalence of dementia was greater when estimates were based on impaired neuropsychological test performance only and not clinical consensus. However, when proxy-report data from section H of the Cambridge Mental Disorder Examination (Roth et al., 1986) were used to determine if individuals met the criterion for occupational and social disability, and were considered with neuropsychological test scores, prevalence estimates decreased.

These discrepancies suggest that cognitive functioning, and occupational and social functioning, are different constructs, and that impairment in one domain of functioning does not necessarily lead to disability in the other domain. However, we must also question whether these discrepancies reflect how individuals’ occupational and social functioning, or more specifically, their ADL functioning, has been evaluated. These findings may reflect a failure of proxy-report ADL assessments to identify individuals who are in the early and undiagnosed stage of AD. It is in the early stages of AD that subtle

changes in individuals' abilities to complete globally-defined self-care and home maintenance tasks may be overlooked if only their needs for physical assistance are evaluated (Doble, Fisk, & Rockwood, 1998). Furthermore, family informants' proxy-reports may be biased by their own unique perceptions of their family members. Their reports may reflect their own acceptance and understanding of changes they have noticed in their family members' overall functioning more than specific changes in their occupational and social functioning. Our understanding, however, will remain limited until we can identify which individuals remain stable over time, and which individuals demonstrate changes in cognitive and/or occupational and social functioning. These findings also highlight the need for the diagnostic criterion of occupational and social functioning in dementia to be clearly operationalized.

The implications of our failure to generate valid measures of individuals' occupational and social functioning also extend beyond the field of epidemiology. Assessments of individuals' ability to perform independently globally-defined self-care and home maintenance tasks may be adequate to determine individuals' general need for home supports or institutionalized care. However, more sensitive assessments of occupational and social functioning are required if we are to address other important issues in the care of persons with AD. Although the disease process cannot yet be reversed, efforts are being made to maintain or enhance individuals' occupational and social functioning and prevent further disability by using a variety of pharmacologic, behavioural, social, and environmental interventions. Thus, there is a significant need for assessment tools that can be used to identify those who are less competent in their performance of occupations, and those who may benefit from particular interventions. Moreover, assessments are needed that will enable us to detect meaningful changes in individuals' occupational and social functioning over time either as a consequence of disease progression or as a consequence of various interventions (Smyth et al., 1997; Spector, 1997). Although considerable strides are being made in the development of pharmacological interventions for persons with AD, only a few studies have reported significant improvements in individuals'

occupational and social functioning (cf. Oakley & Sunderland, 1997). This may, in part, reflect problems inherent in many ADL assessments.

Several problems have contributed to our failure to develop assessment tools to determine if individuals meet the *DSM-IV* (APA, 1994) criteria for dementia and to identify changes in individuals' occupational and social functioning over time. First, the term *functioning* has been a difficult construct to operationalize. The term is typically used to refer to any or all cognitive and noncognitive aspects of behaviour including "emotional and personality changes, psychiatric and behavioral symptoms, difficulties fulfilling occupational or social roles, and impaired performance of basic everyday tasks" (Niederehe & Oxman, 1994, p. 23). Given such diversity, the term is vague. Since the essential idea within the *DSM-IV* (APA, 1994) criterion for dementia embodies what individuals *do*, reference to occupational and social *behaviour* that can be observed directly would be more appropriate and more easily operationalized.

Second, it has been assumed that we share a common understanding of the terms *occupational* and *social*. This is reflected in the notion that individuals' physical capacity to do self-care tasks and/or home maintenance tasks independently, and individuals' occupational and social functioning are synonymous terms (Katz, Down, Cash, & Grotz, 1970; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; Lawton & Brody, 1969). With the development of the Katz Index of ADL (Katz et al., 1963), our attention shifted from the traditional focus of disease presence/absence to the effects of disease on older adults' physical abilities to do everyday activities (Nagi, 1965; Nagi, 1976). Building on this concept, Lawton and Brody (1969) developed the Physical Self-Maintenance Scale but also extended the range of tasks being assessed by developing the Instrumental Activities of Daily Living Scale. Instrumental activities of daily living (IADL) refer to home maintenance and community living tasks. Given the basis for rating individuals' abilities within these scales, *disability* is generally accepted as an individual's need for physical assistance to do self-care and home maintenance tasks (Jette, 1984; Spector, 1997;

Verbrugge, 1990). Others, however, recognized that occupation is not limited to the performance of self-care and home maintenance tasks (Pfeffer, Kurosaki, Harrah, Chance, & Filos, 1982; Reuben & Solomon, 1989). When Pfeffer and colleagues (1982) developed the Functional Activities Questionnaire, they included tasks such as comprehending current events, participating in recreational or avocational activities, reading, and balancing a chequebook, to the list of IADL tasks identified by Lawton and Brody (1969). Reuben and Solomon (1989) proposed the term advanced activities of daily living to describe tasks assumed to be more challenging than IADL tasks. These efforts to identify a range of daily tasks (e.g., tasks related to home maintenance, work, leisure) beyond those initially defined as self-care highlight the need to adopt a broader view of individuals' occupational and social behaviour.

The third issue in understanding the occupational and social behaviour of individuals relates to the assumption that we must determine if difficulties experienced when doing everyday tasks can be attributed solely to impairments in individuals' underlying cognitive capacities. The Index of ADL (Katz et al., 1963) and the Physical Self-Maintenance and Instrumental Activities of Daily Living Scales (Lawton & Brody, 1969) were originally designed for use with older adults with physical health problems. The utility of such assessments for persons with cognitive impairments has been questioned (cf. Spector, 1997), and efforts have been made to develop assessments that are more appropriate to use to evaluate the occupational and social behaviour of adults with dementia.

One approach has been to categorize individuals' general functioning as it relates to specific stages of dementia. Within assessments such as the Brief Cognitive Rating Scale (Reisberg & Ferris, 1988) and Global Deterioration Scale (GDS) (Reisberg, Ferris, DeLeon, & Crook, 1987), a broad view of functioning is adopted. Changes in individuals' occupational and social behaviour, and the emergence of psychiatric symptoms and other behaviours, are all viewed as being a direct consequence of impairments in individuals' underlying cognitive capacities (cf. Reisberg & Ferris, 1988; Reisberg et al., 1982).

Moreover, decline in ADL task performance in AD is postulated as being characterized by a single, hierarchically defined pattern in which significant changes in individuals' abilities to do ADL tasks are described as occurring only in the later stages. This issue, however, has been challenged by several researchers (e.g., Doble et al., 1998; Eisdorfer et al., 1992).

Another approach has been to link cognitive functioning directly with individuals' occupational and social behaviour by using neuropsychological assessments to predict individuals' abilities to do everyday tasks, including driving a car and managing finances (Poon, 1994). Efforts to improve the face validity of neuropsychological tests for this use have resulted in the development of assessments in which individuals' underlying cognitive capacities are assessed while they are observed performing simulated self-care and home maintenance tasks (e.g., putting on a sweater, recalling a grocery list) as in the Functional Performance Measure (Carswell, Duhlberg, Carson, & Zgola, 1995) and the Direct Assessment of Functional Status (Loewenstein et al. 1989). Although such tests of cognitive competence are often referred to as ADL assessments, our ability to predict individuals' performance of everyday tasks based on their performance of contrived tasks in settings that bear little resemblance to their usual environments is unclear. Moreover, we must question whether we are measuring individuals' occupational and social behaviour, their level of cognitive impairment, or a hybrid of the two (Spector, 1997). In fact, efforts to make a direct link between individuals' performance of everyday tasks and their underlying cognitive capacities is neither realistic nor feasible, and may further contribute to our failure to understand individuals' occupational and social behaviour.

Drawing on the work of Katz and colleagues (1963) and Lawton and Brody (1969), ADL assessments have been developed that are focused less on physical capacities and more on social capacities (e.g., Pfeffer et al., 1982; Reuben & Solomon, 1989). This approach is based on the premise that while our performance of some everyday tasks is more dependent on our underlying physical capacities (e.g., gardening, doing woodworking projects), our

performance of other tasks is more dependent on our underlying social capacities (e.g., employment, travelling, hobbies, participation in social and religious groups). Reuben and Solomon (1989), however, acknowledged that this simple categorization was insufficient because some activities may reflect an individual's underlying physical and social capacities (e.g., playing softball). When we focus solely on the contribution of underlying physical, cognitive, or social capacities to the occupational and social behaviour of adults with dementia, we fail to acknowledge the combined influence of individuals' underlying capacities, as well as the effects of their internal motivations, and their physical and social environments on their performance of everyday tasks. This issue is discussed further in Chapter 2.

The final challenge facing us when we attempt to assess the occupational and social behaviour of persons with dementia relates to the ongoing debate about how to balance our needs for valid measures of individuals' abilities and the costs associated with generating such measures. Self-report and proxy-report ADL assessments have been assumed to be easier and less expensive to administer than performance-based assessments that typically require specialized equipment and space as well as trained and professionally qualified personnel to administer them (Meyers, 1992). However, persons with cognitive impairment have been found to overestimate their level of ADL independence when their reports are compared with their family members' reports (Kiyak, Teri, & Borson, 1994; Loewenstein et al., 1989). Since the validity of the self-report assessments of persons with AD has been questioned (Barberger-Gateau et al., 1992; Cress et al., 1995; Griffiths et al., 1987; Kelly-Hayes, Jette, Wolf, D'Agostino, & Odell, 1992; Rozzini, Frisoni, Bianchetti, Zanetti, & Trabucchi, 1993; Sager et al., 1992), proxy-report assessments are more widely used in dementia research and clinical practice.

Although the demand for proxy-report ADL assessments in research and clinical practice settings is strong, the validity of such assessments has been questioned. When findings of proxy-report and performance-based ADL assessments completed by trained professionals

have been compared, informants have generally been found to underestimate the level of independence of persons with cognitive impairment (DeBettignies, Mahurin, & Pirozzolo, 1993; Karagiozis, Gray, Sacco, Shapiro, & Kawas, 1998; Mulnard & Cotman, 1992; Zanetti, Geroldi, Frisoni, Binetti, Bianchetti, & Trabucchi, 1997). Although these differences have been assumed to reflect informant bias, the validity of these comparisons is questionable since the assessments used to elicit the proxy-reports and to assess individuals' ADL performance were different. To address this challenge, Doble, Fisk, and Rockwood (1999b) compared the findings of a performance-based ADL assessment and a proxy-report ADL assessment to a clinician's rating of the subjects' level of ADL competence. Agreement with a clinician's ratings of the subjects' level of ADL competence was higher for the performance-based assessment than for the informants' ratings. Moreover, in all cases of disagreement, the informants overestimated their family members' level of ADL independence. This study, however, did not enable us to determine whether the differences in disability estimates reflected differences in information sources (i.e., family members vs. trained occupational therapists) or differences in how disability was defined within each assessment (i.e., level of independence vs. level of competence).

In the following chapters, four important issues will be addressed. First, a framework for conceptualizing occupational and social behaviour will be presented. Second, several criteria for evaluating ADL assessments will be proposed. Third, proxy-report and performance-based ADL assessments used in clinical practice and research settings with persons with dementia will be reviewed to determine the extent to which they meet the proposed criteria. Fourth, factors that may systematically bias family informants when rating the ADL ability of persons with dementia will be explored.

CHAPTER 2

A Conceptualization of Occupational and Social Behaviour

As McDowell and Newell (1996) suggested many of the assessments of “functional disability. . . pay little more than lip service to the idea of a conceptual approach to the topic” (p. 493). Therefore, before reviewing existing ADL assessments or developing new ones, we need to begin with a clear understanding of the construct of occupational and social behaviour. Only then can we be assured that the assessments we choose to use or develop will enable us to identify individuals who will benefit from interventions designed to enhance or maintain their occupational and social behaviour, and to identify meaningful changes in the occupational and social behaviours of individuals with AD.

An individual’s occupation may include listening to music alone, playing cards with friends, preparing a meal for his or her family, shovelling a neighbour’s sidewalk, baking cookies with his or her grandchildren, folding laundry, tending to plants in the garden, and organizing fund raising tasks for a lobby group. The discipline of occupational therapy has developed a theoretical basis for integrating this diverse behaviour into a unifying construct of occupational behaviour. Recently, Fisher (1998) described occupation as “*the* action of seizing, taking possession of, or occupying space or time” (p. 511). Occupation does not refer to an end-product or the consequence of actions (e.g., winning a card game, having a sidewalk cleared of snow, or having a cookie jar full of homemade cookies). Instead, occupation refers to the *doing* or the process of *engaging* in a series of goal-directed actions by which we act on tools and materials that are available within our physical and social environments (Fisher, 1998, 1999; Fisher & Kielhofner, 1995).

When individuals engage in the process of doing, we are able to observe their actions of doing. These observable goal-directed actions have been categorized as motor skills, process skills, and social interaction skills (Fisher, 1999; Fisher & Kielhofner, 1995). Motor skills refer to the goal-directed actions we use to move our bodies and task objects

while engaged in occupation (Fisher, 1999). We reach to the top shelf of a cupboard, bend to look in the bottom drawer of the refrigerator, lift an ironing board, and manipulate scissors to cut a piece of paper. Our process skills are evident when we sequence the actions of task performance logically, choose and use appropriate tools and materials, and adapt to problems or difficulties (Fisher, 1999). We choose an appropriate plate for serving a sandwich, handle a vegetable peeler to remove the peel from a potato, and initiate the action of moving a chair out of the way before sweeping under a kitchen table. Social interaction skills are used to “communicate our needs and motivations to others and to respond to the messages of others in a competent manner” (Doble & Magill-Evans, 1992, p. 146). We acknowledge others’ comments and actions, send messages, communicate our emotions, time our responses to ensure a smooth flow to the interaction, and coordinate our messages with our social partners’ and the expectations of the environment.

Currently, the development of assessments of individuals’ motor and process skills is far more advanced than is the development of assessments of social interaction skills. Through a series of studies over the past 15 years (cf. Fisher, 1999), the Assessment of Motor and Process Skills (AMPS) (Fisher, 1999) has been developed. Taxonomies of specific ADL motor and ADL process skills were derived following a comprehensive review of information processing, sensory integration, and motor control literature (cf. Fisher, 1999). To date, the universality of 16 motor skills and 20 process skills observed within the performance of 76 specific self-care and home maintenance tasks (ADL tasks) has been verified (Fisher, 1999). This means that the same ADL motor and ADL process skills can be observed whether an individual sets the table for dinner, weeds a garden, or vacuums a carpet. The skills within each taxonomy can be ordered hierarchically on the basis of difficulty, and this hierarchical ordering remains the same across all ADL tasks. That is, skills such as Lifts and Reaches are more likely to be easy for all individuals, while other skills such as Calibrates and Positions are more likely to be hard for all individuals, no matter what ADL tasks they perform. Further research, however, is needed to identify and validate whether these 16 ADL motor and 20 ADL process skills

are universally observable when individuals perform other tasks such as school, work, and recreational tasks, and whether the hierarchical ordering of the skills varies across the domains of occupation.

Identification of a universal taxonomy of social interaction skills is far less well developed (cf. Englund, Bernspång, & Fisher, 1995), but preliminary research findings suggest that we can observe individuals use the same social interaction skills whether they are playing bridge with three friends, eating a meal with family members, or asking for assistance at a store. Social interaction skills were not included in the AMPS (Fisher, 1999) since they could not be universally observed during the performance of all self-care and household tasks. While further research is needed to develop our understanding of how AD affects individuals' social behaviours, the focus of this research will be limited to the motor and process skills of persons that can be observed consistently within the performance of ADL tasks.

Individuals' occupational skills are usually considered competent when they complete tasks in an acceptable way with acceptable outcomes, given the expectations of their cultures (Polatajko, 1992). While we often refer to the importance of doing tasks independently, independence fails to capture the complexities of doing. Fisher (1999) has furthered this argument by proposing that we focus on the quality of the doing process. That is, we should observe how effectively individuals do goal-directed actions, and how effectively they link the various goal-directed actions toward the achievement of a specific goal (Fisher, 1998, 1999; Fisher & Kielhofner, 1995). Within this framework, we must consider the effort required, how efficiently actions are carried out, and the level of safety demonstrated in addition to individuals' need for assistance. ADL motor and ADL process skills are learned. Rarely do we perform competently when we first try a new skill or a new task. However, with experience and practice, we learn to do tasks with less effort, more efficiency, greater safety, and greater independence (Fisher, 1999).

Although ADL skills “represent the component actions of task performance, they do not relate directly to impairments of anatomical structures or functions of the mind-brain-body performance subsystem” (Fisher, 1999, p. 22). For example, high levels of underlying cognitive capacities do not ensure that an individual will perform a task competently. Conversely, ineffective skill performance cannot be directly attributed to impairments in individuals’ underlying cognitive capacities. Several studies have verified that cognitive test performance accounts for only limited amounts of observed variances in individuals’ ADL performance scores (cf. Butler, Anderson, Nanerow, & Satz, 1989; Carswell & Eastwood, 1993; Doble, Fisk, MacPherson, Fisher, & Rockwood, 1997; Little, Hemsley, Volans, & Bergmann, 1986; Loewenstein & Rubert, 1992; Loewenstein et al., 1992; Reed, Jagust, & Seab, 1989; Skurla, Rogers, & Sunderland, 1988; Teri et al., 1989). Individuals’ ADL motor and ADL process skills are not simply a reflection of the integrity of their underlying physical and cognitive processes (Fisher, 1999; Fisher & Kielhofner, 1995). Instead, they are influenced also by their level of motivation, level of experience with the specific task, and elements of the physical and social environments.

As a neurodegenerative disorder, AD affects individuals’ underlying cognitive capacities including attention, perception, memory, problem solving, and motor planning. These deficits are reflected in individuals’ ADL process skills, although the effect on specific ADL skills will not be uniform. Persons with AD typically experience changes in the quality of their ADL process skills including the skills involved in heeding the goal of the task, initiating goal-directed actions, and making adaptations when problems or difficulties are encountered (Cooke, Fisher, Mayberry, & Oakley, in press). However, high levels of motivation, lifelong routines, over learned behaviours, and supportive physical and social environments enable many individuals to continue to perform ADL tasks independently, particularly in the earlier stages of the disease (Dick, 1992; Tulving, 1983).

As changes in individuals’ physical capacities (e.g., changes in muscle tone, reaction time, and balance), and when frontal release signs become more evident (Franssen, Kluger,

Torossian, & Reisberg, 1993; Funkenstein et al., 1993; Förstl et al., 1992; Gordon & Carson, 1990; Kischka, Mandir, Ghika, & Growdon, 1993; Krenz, Larson, Buchner, & Canfield, 1988; Mahurin, DeBettignies, & Pirozzolo, 1991), the quality of ADL motor skills such as walking, flowing, transporting, and pacing is affected (Cooke, 1995). Moreover, when more effort is required to perform ADL motor skills, increased demands are placed on individuals' ADL process skills, particularly their skills used to effect adaptations and adjustments (Cooke, 1995; Cooke et al., in press; Doble et al., 1997; Robinson & Fisher, 1996), and, thus, ADL process skill deficits will be more pronounced.

Occupation is deeply embedded within the concepts of meaning and purpose (Fisher, 1998, 1999; Kielhofner, 1995). We engage in the process of doing in order to meet our own needs, as well as the expectations of others. Through doing, we occupy time and the spaces within our environment; we organize our behaviour into patterns; and we provide our lives with meaning (Fisher, 1998, 1999; Nelson, 1988; Reilly, 1962; Rogers, 1983). The meaningfulness of our occupational behaviour is reflected in the choices we make about what we do. Within western culture, we typically organize our time and spaces in relation to the occupational and social roles that we occupy. For example, we may identify ourselves as a home-maintainer, community volunteer, grandparent, service club member, golfer, quilter, and friend. Within these roles, we do tasks that meet our needs, including our needs for self-care, home maintenance, productivity, and leisure/play (Fisher, 1998, 1999; Kielhofner, 1995; Law et al., 1997). Self-care tasks are those we do to care for ourselves. Home maintenance tasks refer to those we do to maintain our homes and lives in our communities. Productivity tasks give us a sense of mastery and enable us to make a contribution to the social and economic fabric of our communities. Play and leisure tasks enable us to derive feelings of satisfaction and pleasure, and give us opportunities to experience a sense of belonging and connection with our communities.

The tasks we each choose to do will differ (Kielhofner, 1995). Moreover, while some tasks may be common to many of us, other tasks reflect our unique needs, values,

interests, and perceptions of our skills. Occupations provide us with opportunities to express our individuality, connect with others, and influence our physical and social environments (Kielhofner, 1995). Our culture provides us with guidelines about what is acceptable given such factors as age, gender, marital status, socioeconomic background, and educational level. Thus, by providing a context for doing, our culture shapes what we do; how, when, and where we do tasks; and what tools and materials we will use. Even when two individuals within the same culture share a common role, they will organize and structure their performances in different ways. For example, most people prepare something to eat in the morning. Depending on the individual, however, making breakfast may be defined as pouring cereal and milk into a bowl, preparing brewed coffee, preparing toast, cooking scrambled eggs, or all of the above. Not only do we define occupations differently based on our values, interests, and personal motivations, but our performance of occupations is shaped by our cultural group membership, and the structure and organization of our physical and social environments. While some individuals need only to prepare breakfast for themselves, others are expected to prepare breakfast for other family members as well. For others, preparing breakfast is something that is done for them, either by family or paid caregivers at home, or by professionals at a restaurant.

Summary

Many of the difficulties experienced in examining and developing a better understanding of individuals' occupational and social behaviours reflect our failure to begin with a clear conceptualization of what these constructs mean. Within this research, individuals' occupational behaviour is defined as the goal-directed actions individuals' perform when doing something they perceive to be meaningful. Occupation does not refer to the end product or the consequence of individuals' actions, but instead, is represented by the actions of doing (i.e., motor, process, and social interaction skills) as performed within tasks that meet our needs for self-care, home maintenance, productivity, and leisure/play.

CHAPTER 3

Criteria for Evaluating ADL Assessments

Introduction

Traditionally, decisions about which assessments were adopted for clinical practice and research were made by reviewing the content of the assessment to determine if it “look[ed] reasonable” (Streiner & Norman, 1995, p. 5), and thus, tapped the underlying construct. Data to support the reliability, content validity, criterion validity (concurrent and predictive), and construct validity of an assessment were also examined. However, our conceptualization of validity has changed. As McDowell and Newell (1996) state “validity is no longer a property of the measurement, but rather of the interpretation we place on the results” (p. 30). Streiner and Norman (1995) have suggested that validity of an assessment is established through an ongoing process of hypothesis testing designed to “explain a broader range of findings, explain them in a more parsimonious manner, or make more accurate predictions about a person’s behaviour” (Streiner & Norman, 1995, p. 151). The challenge now is to determine what an individual’s scores or measures mean, and what we can learn about the person who obtained these scores or measures.

While variability is evident when we examine how older adults, including those with AD, choose to occupy space and time, there is a societal expectation that adults who live in the community should be capable of caring for themselves in their own home environments even if they do not perform such tasks on a regular basis (Baltes, Wahl, & Schmid-Furtoss, 1990; Diehl, 1998; Greiner, Snowdon, & Greiner, 1996; Reuben & Solomon, 1989; Spector, 1990). In fact, many healthy, elderly adults spend at least half of their waking hours engaged in self-care and home maintenance tasks (Baltes et al., 1990). Self-care and home maintenance tasks typically become even more important as individuals with AD withdraw from tasks that formerly met their needs for productivity and leisure. Therefore, within the context of this research, individuals’ occupational behaviour was further narrowed to self-care and home maintenance tasks.

From a practical perspective, we need to consider how we intend to use the scores or measures that are generated (McDowell & Newell, 1996; Streiner & Norman, 1995). As discussed earlier, assessments of occupational behaviour of persons with AD should enable us to classify individuals into specific groups on the basis of their ADL ability; predict their ability to benefit from specific types of interventions, supports, and services; guide the development of interventions; and measure meaningful changes in their ADL ability. In the following section, six criteria that can be used to determine if specific ADL assessments will, in fact, enable us to achieve these goals, have been proposed. These criteria include that ADL assessments: reflect the key elements of occupation; be comprised of items that reflect a unidimensional construct; account for rater bias to ensure that the ADL ability measures generated approximate individuals' actual ADL abilities; generate measures that are stable; and generate measures that are responsive to small, but meaningful changes in individuals' ADL abilities over the various stages of AD. The final criterion refers to the need to weigh the extent to which an assessment meets these first five criteria against the cost of administering, scoring, and interpreting the assessment findings.

Criterion 1: Evaluates the Key Elements of Occupation

Assessments of occupational behaviour should be clearly grounded in a theoretical understanding of occupation. Based on the conceptualization of occupational behaviour presented in Chapter 2, assessments of occupation should provide us with the means of evaluating the *quality* of individuals' *occupational skills* (i.e., goal-directed actions) when they perform tasks that they *need and want to do*. Given that this research is focused on the ADL tasks that individuals need and want to do, and since ADL tasks provide a context for evaluating a universal taxonomy of motor and process skills, ADL assessments should evaluate individuals' motor *and* process skills. This is of particular importance given our understanding that the effects of AD are not limited to individuals' ADL motor or ADL process skills (Cooke, 1995; Cooke et al., in press; Doble et al., 1997; Nygård, Bernspång, Fisher, & Winblad, 1994; Robinson & Fisher, 1996).

Although persons with AD become increasingly dependent on others to perform ADL tasks as their disease progresses (Eisdorfer et al., 1992; Levy, 1987; Reisberg et al., 1986; Robinson & Fisher, 1996; Rogers, 1986), ADL assessments should not be limited to evaluating the level of assistance individuals need to perform tasks (Verbrugge, 1990). If we restrict our focus to the level of assistance needed, we risk overlooking other changes that affect individuals' skilled performance of tasks, particularly in the early and middle stages of AD (Doble et al., 1998). However, when evaluating the quality with which individuals enact specific occupational skills, we must acknowledge that there is no single "normal" or "correct" way to perform any ADL task. Instead of adopting a norm-referenced view, ADL assessments should be criterion-referenced. We should evaluate how skilled their performance is, or more precisely we should consider how effectively, efficiently, and safely they enact their occupational skills when performing ADL tasks without reference to their age, gender, diagnosis, or culture. In other words, raters must determine whether an individual's skills are competent based on what was observed, rather than making judgements prefaced with such statements as "he did well for a 93-year-old" or " he did well for someone with AD." While individuals' need for assistance should not be completely dismissed, assistance should only be provided when individuals' enactment of specific occupational skills is so ineffective, inefficient, and/or unsafe that the outcome is no longer acceptable, or the risk of danger or damage is imminent (Fisher, 1999). Far too often, however, assistance is provided prematurely such that individuals do not have adequate time and space to recognize performance difficulties, and resolve those difficulties by changing their approach to the task or making changes to the task environment.

The importance of meaning was discussed in Chapter 2, and this concept should also be reflected in ADL assessments. Although the role of self-care and home maintenance tasks in the lives of elderly adults is recognized, not all individuals need and want to do the same self-care and home maintenance tasks. Therefore, if ADL assessments are to accurately reflect the conceptualization of occupation as presented in Chapter 2, they must be designed such that we can account for individual variation in meaning. Not only will the

estimates of individuals' ADL abilities be more representative of their real ADL abilities, but individuals will be more likely to tolerate assessments that are perceived to be relevant to their everyday lives.

Criterion 2: Measures a Unidimensional Construct

There are two critical issues that must be determined when developing any measure: all items comprising a scale must be related to the "same" underlying construct, and we must measure in "equal units" representative of that construct (Michell, 1990). To address the first issue, ADL assessments should be comprised of scales and/or items that represent a single abstract continuum of greater or lesser ADL ability. If items representing diverse constructs such as underlying cognitive and physical capacities, underlying motivation, changes in social behaviour, or qualities of the task or task environment, are combined in a single scale, we will be unable to interpret the resulting score clearly. If assessments are comprised of two or more scales that evaluate different dimensions of individuals' ADL ability, the scores from these separate scales should be not summed to generate a single ADL ability total score. Instead, they should be identified as representing different, albeit, related aspects of ADL ability (cf. Merbitz, Morris, & Grip, 1989; Silverstein, Kilgore, & Fisher, 1989; Wright & Linacre, 1989).

In addition, we must determine whether the items or tasks comprising an ADL assessment represent a single dimension. While Suurmeijer and colleagues (1994) found that the unidimensionality of self-care and home maintenance items was compromised when items were combined into a single scale, other researchers have endorsed combining self-care and home maintenance items into a single ADL scale (Doble & Fisher, 1998; Finch, Kane, & Philp, 1995; Kempen & Suurmeijer, 1990; Siu, Reuben, & Hays, 1990; Silverstein, Fisher, Kilgore, Harley, & Harvey, 1992; Spector, Katz, Murphy, & Fulton, 1987).

Nevertheless, the importance of determining that the specific self-care and home maintenance items comprising an assessment tool reflect a single dimension was illustrated

by Doble and Fisher (1998). They analysed seven self-care task items and seven home maintenance task items that comprise the Older Americans Resources and Services (OARS) ADL Scale (Fillenbaum, 1985). Five of the self-care and all seven of the home maintenance items were found to evaluate a single construct. However, the item evaluating individuals' ability to remain continent did not demonstrate goodness-of-fit with the measurement model, probably because it reflected individuals' underlying physiological functioning rather than their ADL ability (Fisher et al., 1994; Linacre, Heinemann, Wright, Granger, & Hamilton, 1994). Similarly, the bathing item failed to demonstrate acceptable goodness-of-fit with the measurement model although, for different reasons. While most respondents interpreted assistance with bathing to mean needing assistance to be washed and dried or to physically get in and out of the bathtub, others rated individuals as needing assistance if help was given to provide a sense of security even when the person was physically able to get in and out of the bathtub independently. In another study, Bray, Fisher, and Duran (1999) conducted an analysis of 21 new tasks for possible inclusion in the AMPS (Fisher, 1999). They found that the shopping task failed to meet the expectations of the Rasch measurement model (Linacre, 1993). Unlike the other ADL tasks included in the AMPS, the shopping task had a clear social component (i.e., the individual must interact with the cashier and in some cases, with other persons in the store). It is possible that the additional social demand within the shopping task influenced the structure and ordering of the process skill items. These diverse examples illustrate the need to examine the unidimensionality of all items and all tasks comprising ADL tasks using appropriate statistical analyses, as reliance on expert judgements may fail to detect items and tasks that do not measure the same underlying construct.

The second issue related to the measurement of ADL ability is that we must acknowledge that "measurement is a cultural phenomenon . . . no variable is directly and immediately observed as a quantity; anything that is counted is counted as something" (Fisher, Harvey, & Kilgore, 1995, p. 3). In fact, *scores* are simply numerical codes that reflect qualitative increments in ability (Michell, 1990), and the distance between any two scores is unknown

(Merbitz et al., 1989; Wright & Linacre, 1989). Ordinal scores assigned during an evaluation do not contribute equally to the measurement of the underlying construct. In contrast, measurement implies that we can *measure* a construct in equal units of “same” or “like kind” (Michell, 1990). Some items are easier for most people to pass while other items are harder for most people to pass (Wright & Stone, 1979). The items comprising a scale will be located in different places along a linear continuum of ADL ability such that each item represents “*qualitative increments of ADL ability*” (Fisher, 1999, p. 18). Individuals with more ADL ability are more likely to pass harder items or be awarded higher ratings on items than are persons with less ADL ability.

Assessment methodologies such as Rasch analysis, a latent trait measurement model, can be used to identify where on this linear continuum each item is located (Wright & Masters, 1982). Consequently, ordinal scores can be transformed into “equal interval units of measurement -- *quantitative units of like kind -- ADL ability units*” (Fisher, 1999, p. 18) that are additive (Silverstein et al., 1989; Wright & Linacre, 1989). An ideal ADL assessment is comprised of items that vary in difficulty and are spaced along the linear continuum without obvious gaps. However, the relative location of the items on the linear continuum should remain fairly consistent no matter who is evaluated. That is, an easier item should be easier for most persons and a harder item should be harder for most persons (Wright & Stone, 1979).

Criterion 3: Generates Unbiased Ability Measures

“The assessment of disability is affected by all of the human reactions and variations that can occur when individual persons are the observers and the observed” (Feinstein, Josephy, & Wells, 1986, p. 413). All estimates of individuals’ ADL abilities are influenced by raters’ personal biases and unique perceptions (Fisher, 1993; George & Fillenbaum, 1985; Lawton, 1987; Lunz & Stahl, 1990, 1993; Lunz, Wright, & Linacre, 1990; Patterson et al., 1992; Rubenstein, Schairer, Wieland, & Kane, 1984). Each rater has his or her own understanding of the situation; some raters will have more positive

views and others will have more negative ones (Lezak, 1986; Patterson et al. 1992). Given the importance of generating accurate estimates of individuals' ADL abilities that are neither consistently overestimated or underestimated, we need to account for rater bias. The consistency of raters' judgements can be enhanced by improving the standardization of the administration and scoring process. Strategies to reduce measurement error, however, cannot eliminate rater bias that arises from consistent differences in rater perspective and severity (Lunz & Stahl, 1990, 1993; Lunz et al., 1990).

When the self-reports of elderly adults are compared with the reports of informants or trained observers, the reports of older adults are usually more optimistic (Fried et al., 1996; Magaziner, Simonsick, Kashner, & Hebel, 1988; Rubenstein et al., 1984; Weinberger et al., 1992; Zimmerman & Magaziner, 1994). Moreover, those with cognitive impairment tend to overestimate their level of ADL independence relative to their family members' reports (Kiyak, Teri, & Borson, 1994; Loewenstein et al., 1989). We should consider, however, the possibility that these findings suggest a tendency for informants to underestimate the ADL abilities of older adults. Although it is unclear how these findings should be interpreted, it has been assumed that, unlike family informants, trained professionals' ratings are less influenced by rater bias. Therefore, considerable effort has been directed towards the development of dementia-specific performance-based ADL assessments that are administered by trained professionals (e.g., Baum & Edwards, 1993; Carswell et al., 1995; Loewenstein et al., 1989; Mahurin et al., 1991; Tappen, 1994). Although research findings have confirmed lack of agreement between proxy-report and performance-based ADL assessments when persons with cognitive impairment are assessed (DeBettignies et al., 1993; Doble, Fisk, Lewis, & Rockwood, 1999a; Karagiozis et al., 1998; Mulnard & Cotman, 1992; Zanetti et al., 1997), it is unlikely that these differences simply reflect biases in informants' ratings. In fact, the validity of such comparisons is questionable given that different assessments were used to elicit proxy-reports and to assess the individuals' ADL performance in each of these studies. Moreover, the assumption that rater bias in performance-based assessments can be

controlled by assigning numbers to ordinal ratings and thus, “quantifying” ADL ability is both naive and misleading (cf. Fisher, 1993; Merbitz et al., 1989; Wright & Linacre, 1989). The severity of ratings of health professionals, even those specifically trained in the administration of a particular assessment, vary (Fisher, 1999; Lunz & Stahl, 1990, 1993; Lunz et al., 1990), and thus, should be accounted for when generating ADL ability measures.

Criterion 4: Generates Stable Ability Measures

Within traditional reliability theory, an individual’s measure or score on a test is assumed to reflect the individual’s “true” ability as well as some degree of standard error (*SE*) or noise. Test-retest reliability refers to the stability or consistency of the assessment process such that individuals’ measures or scores are comparable over time (McDowell & Newell, 1996) and any differences in individuals’ scores or measures are attributable to true differences among those individuals (Streiner & Norman, 1995). Reliability is, therefore, increased when error or noise is reduced. Measurement error related to *how* individuals’ performance is scored may be reduced using strategies designed to improve uniformity among raters.

One important strategy involves developing standardized test administration procedures that specify how to set up the testing environment, what instructions to provide, criteria for examiner intervention, definitions of items, and rating criteria. All of this information should be documented (McDowell & Newell, 1996). Raters may also be required to participate in a rater training programme. The adoption of standardized procedures is particularly important when raters are required to make complex judgements about individuals’ skills within the context of challenging and variable ADL tasks (Fisher, 1993; George & Fillenbaum, 1985; Lawton, 1987; Rubenstein et al., 1984). Otherwise, their abilities to make consistent judgements about what is acceptable or unacceptable performance will be compromised. For example, when changing sheets on a bed, we typically expect that any blankets or bedspreads will be removed, unclean sheets and pillow

cases will be removed, clean sheets and pillow cases will be put on the bed and pillows, and the blankets or bedspreads will be restored on the bed such that the bed is neat. How individuals achieve this outcome will, however, vary from one person to the next. Moreover, raters' judgements must be grounded in the notion of competent performance. Examples that guide raters when they make judgements about the quality of individuals' performance will also serve to improve the reliability of the raters' judgements.

Criterion 5: Generates Responsive Ability Measures

Assessment tools that are intended for clinical use must generate measures that will enable us to detect meaningful changes in individuals' ADL ability over time. Reliability is a necessary property of a responsive measure (Streiner & Norman, 1995). Unless an assessment generates measures that are stable over the short-term, we cannot, with any level of confidence, attribute differences in individuals' measures of ADL ability over the long-term to real changes in their ADL abilities. However, assessments that are reliable are not necessarily responsive. Responsiveness is a separate and distinct measurement property that must be demonstrated if an assessment is to be used to detect change in individuals' ADL abilities over time (Streiner & Norman, 1995).

As discussed earlier, we should be able to arrange assessment items and tasks hierarchically on a linear continuum on the basis of difficulty or challenge. Within any pool of items, some items will be easier, and other items will be harder to perform competently. The responsiveness of an assessment to meaningful long-term changes in ADL ability will be enhanced when the assessment is comprised of items that are well-targeted to the study population, and offer individuals a reasonable challenge (Kirkley & Fisher, 1999). If all of the items are too hard, individuals will score at the minimum level on most or all items. Conversely, if individuals are evaluated using items that are too easy, they will score at the maximum level on most or all items. In either situation, the measures generated will not be valid estimates of their ADL abilities, and thus, we will be unable to differentiate those with more ADL ability from those with less ADL ability.

Responsiveness of an assessment is influenced by the length of the linear continuum. The more the items vary in level of difficulty, the greater the likelihood that we will be able to detect differences between more able and less able individuals, and to detect changes in individuals over the duration of the disease progression. Similarly, the responsiveness of an assessment is influenced by the extent to which the items are spaced tightly and uniformly along the linear continuum of ADL ability. When assessment items overlap and are closely spaced along the linear continuum, we are better able to detect small, but meaningful changes within an individual or between individuals whose ADL ability is more homogeneous.

Criterion 6: Is Cost-Effective

While we can discuss the ideal properties of assessment instruments at length, the issue of cost-effectiveness cannot be ignored. Cost-effectiveness is a particularly important criterion in this era when decisions made within both clinical practice and research settings are influenced by efforts to keep costs low. Moreover, reductions in funding for health care provision and for research mean that informed decisions must be made when designing assessment protocols within clinical and research settings. Decisions about which ADL assessment will be selected should be based on our determination that the assessment evaluates individuals' occupation (i.e., the quality of their doing of meaningful tasks) and generates valid, reliable, and responsive measures of individuals' ADL abilities. When we consider costs, we must consider costs associated with the basic expertise required of personnel; costs of training personnel in the administration, scoring, and interpretation of the assessment; costs of securing specialized spaces, materials, and equipment; and ongoing and related costs associated with the actual administration, scoring, and interpretation of the data. We must acknowledge, however, that an assessment that costs little but generates measures that are neither valid, reliable, or responsive has no practical value.

Costs related to personnel relate primarily to the basic educational level required. Can personnel with a high school education and on-the-job training administer the assessment, or are professionals with specialized undergraduate or graduate qualifications required? We must also consider whether specific training in the administration, scoring, and interpretation of the assessment is required. Can qualified personnel participate in a self-training process, or must they participate in a specified training and/or certification process? If so, how is the training obtained, how long does it take, and at what cost? Moreover, how soon after participating in the course are trained personnel able to competently and efficiently administer, score, and interpret the assessment?

The need for specialized space, equipment, and materials must also be taken into account when estimating costs. Specialized space or testing environments can be difficult to find in clinic and research settings. However, if we consider that observational assessments of ADL ability are most effectively conducted in individuals' own home environments (Darragh, Sample, & Fisher, 1998; Nygård et al., 1994; Park, Fisher, & Velozo, 1994), concerns about the need for specialized space should be considered in relation to the costs associated with travel but also within the context of time requirements and patient/subject acceptability. For example, to administer an assessment within subjects' own homes, personnel must travel to the subjects' own homes. However, such an assessment procedure is more likely to be tolerated by subjects than one that requires them to travel to a clinic setting, even if the assessment time is somewhat longer. Specialized equipment can be costly, but such costs must be considered as one-time expenses and an investment in all future administrations of the assessment. The costs of materials necessary to maintain the assessment process are, however, an ongoing cost.

Finally, we must consider the time required to prepare for and administer the assessment, complete the scoring, and interpret the assessment data. We must evaluate the demands of the specific assessment on both subjects and staff with the constraints imposed by available resources. Within clinical practice and research settings, a variety of assessments

are typically administered by different clinicians and researchers. Therefore, the time required to administer any single assessment must be judged within the context of the entire assessment protocol, although also in terms of the utility of the information being elicited. Clearly, any assessment considered to be the primary outcome measure should be given priority, while decisions regarding how much time will be allotted for secondary measures, will largely depend on the perceived value of the assessment information to address the research or clinical questions being posed.

Summary

Much of our confusion surrounding the issue of how to evaluate the ADL abilities of persons with AD reflects our failure to develop ADL assessments that are firmly based on a clear conceptualization of occupational behaviour. In contrast, the vast majority of available ADL assessments are based on the idea that we must all be able to perform certain self-care and home maintenance independently to live in the community, and that more able persons are those who are more independent. Six criteria that can be used to determine if an ADL assessment meets our needs were proposed. The first criterion reflects the need to ensure that ADL assessments evaluate individuals' occupational behaviour. Moreover, individuals' ability to competently perform goal-directed actions must be evaluated within the context of tasks that are meaningful and relevant to individuals' everyday lives. Second, the items and/or tasks that comprise an assessment must represent a single abstract continuum of greater or lesser ADL ability. Third, measures of individuals' ADL abilities are only meaningful if the personal biases and unique perceptions of raters have been taken into account. Fourth, ADL ability measures should be stable over the short term. Fifth, ADL ability measures should be responsive to meaningful changes in individuals' ADL abilities. Finally, the costs associated with generating ADL ability measures should be considered but only in relation to the validity of the data that is generated.

CHAPTER 4

ADL Assessments in AD: Do They Meet the Criteria?

Introduction

Over the years, a wide-array of proxy-report ADL assessments have been developed. Some represent modifications of the original ADL Index (Katz et al., 1963) and Physical Self-Maintenance and Instrumental Activities of Daily Living Scales (Lawton & Brody, 1969) such as the OARS ADL Scale (Fillenbaum, 1985), while others have been developed specifically for use with persons with dementia. These latter assessments include: the Blessed Dementia Scale (Blessed, Tomlinson, & Roth, 1968), the Cleveland Activities of Daily Living Scale (Patterson et al., 1992), the Functional Activities Questionnaire (Pfeffer et al., 1982), and most recently, the Disability Assessment in Dementia (Gélinas, Gauthier, McIntyre, & Gauthier, 1999). Several performance-based assessments of ADL have been developed including the Performance Test of Activities of Daily Living (Kuriansky & Gurland, 1976), the ADL Situational Test (Skurla et al., 1988), the Direct Assessment of Functional Status (Loewenstein et al., 1989), the Functional Performance Measure (Carswell et al., 1995), the Kitchen Task Assessment (Baum & Edwards, 1993), the Refined ADL Assessment Scale (Tappen, 1994), and the Structured Assessment of Independent Living Skills (Mahurin et al., 1991). Most of these assessments, however, remain untested with only preliminary findings on small samples of selected demented subjects reported in the literature. Although it was not developed exclusively for the assessment of individuals with dementia, the validity of the AMPS (Fisher, 1999) has been tested extensively and has been used in clinical practice and research with persons with dementia (Cooke et al., in press; Doble et al., 1999a; Doble et al., 1997; Fisher, 1999; Hartman, Fisher, & Duran, 1999; Nygård et al., 1994; Oakley & Sunderland, 1997; Robinson & Fisher, 1996).

The importance of evaluating the abilities of individuals with AD to perform self-care and home maintenance tasks in clinical practice and research is clearly recognized (Maslow & Whitehouse, 1997; Poon, 1994; Spector, 1997) and a plethora of generic and dementia-specific ADL assessments have been developed and used. There is, however, considerable uncertainty about how individuals' performance of self-care and home maintenance tasks is most effectively evaluated (cf. Kovar & Lawton, 1994; Maslow & Whitehouse, 1997; Spector, 1997). No one ADL test has been adopted as the *gold standard* (Eakin, 1989; Guralnik et al., 1989; Jongbloed, 1986; Keith, 1984; Law & Letts, 1989; Poon, 1994; Spector, 1997). Moreover, the use of different ADL assessments in research has limited our ability to make meaningful comparisons between the findings of different research studies (Spitzer, 1987). Smyth and colleagues' (1997) review of the assessment tools selected for use in multi-site projects investigating aspects of dementia revealed wide variation in how individuals' occupational behaviour was evaluated. Interestingly, none of the studies adopted a performance-based ADL assessment. Instead, they relied either on modifications of existing proxy-report ADL assessments including the Index of ADL and the Instrumental Activities of Daily Living Scale; developed research-specific proxy-report assessments; or extracted data from the Minimum Data Set for Nursing Homes (a multidimensional assessment tool that includes nurses' opinions about individuals' assistance requirements related to their physical function and self-care). In the following sections of this chapter, ADL assessments designed specifically for or used extensively with persons with AD will be examined to determine the extent to which they successfully meet the six criteria proposed and described in Chapter 3.

Criterion 1: Evaluates the Key Elements of Occupation

The majority of ADL assessments are *not* grounded in the concept of occupation as outlined in Chapter 2. As proposed in Chapter 3, ADL assessments should enable us to evaluate the *quality* of individuals' *occupational skills* when they perform the self-care and home maintenance tasks that they *need and want to do*. Connolly and Dalglish (1989) suggested that "skills are always jointly determined by the organism, the task, and the

precise environment in which the actions take place” (p.894). Therefore, ADL assessments should give consideration to each individual’s own view of what constitutes *meaningful doing* in his or her own life (e.g., making a tuna sandwich), how a specific task is uniquely defined by the individual (e.g., a sandwich prepared using whole wheat bread, tuna, chopped celery, and a small amount of mayonnaise), and how the individual’s task performance is influenced by his or her task environment (e.g., what tools and materials are available, how the physical space is designed). However, the concept of assessing individuals within the context of tasks that are meaningful and that reflect their unique occupational histories, their current needs and expectations, and the expectations of others in their environment has been largely ignored.

Instead, individuals are typically assessed using the same tasks and items. In the case of performance-based ADL assessments, the problem is magnified by the adoption of contrived or simulated ADL tasks that individuals are asked to perform in unfamiliar, and often, irrelevant, environments (Glass, 1998; Spencer et al., 1993; Spector, 1997). Simulations of everyday tasks fail to capture the complexities of ADL tasks as they are normally performed (Guralnik et al., 1989; Meyers, 1992; Zimmerman & Magaziner, 1994). For example, the ability to move a candy on a spoon to their mouths as is done in the Performance Test of ADL (Kuriansky & Gurland, 1976) cannot really be expected to provide us with an accurate indication of individuals’ ability to feed themselves. Although cutting with scissors, one of the tasks within the Structured Assessment of Independent Living Skills (Mahurin et al., 1991), may be something most individuals need and want to do, when observed as a discrete action rather than as an action embedded within a meaningful task such as cutting paper to wrap a birthday present, the validity of the observation may be limited. Individuals are expected to prepare cooked pudding within the Kitchen Task Assessment (Baum & Edwards, 1993), but the relevance of such a task to those who never cook pudding and have little or no motivation to do this in the future will be limited. The logic of being asked to put on and then immediately take off a sweater provided by an examiner as is done in the Functional Performance Measure (Carswell et

al., 1995) may also be questioned, particularly if individuals are already wearing sweaters or it is too hot for individuals to want to put on sweaters.

In contrast, the Refined ADL Assessment Scale (Tappen, 1994) is designed to evaluate individuals' self-care abilities within the context of their normal morning routines. However, attempts to standardize the evaluation process have led to narrowed definitions of the tasks which, in turn, has limited its potential relevance to a wider population. For example, while the definition of dressing as putting on pants, shirt/blouse, and shoes, may be relevant for many individuals, its relevance for those who prefer to wear skirts, or dresses is questionable. Moreover, since all individuals are expected to be assessed using all of the assessment tasks and items, omitting some tasks and items leads to other problems.

The AMPS (Fisher, 1999), however, does evaluate individuals' ADL abilities within the context of relevant and meaningful tasks. From a pool of 76 possible standardized ADL tasks that range from simple to complex, and include both self-care and household tasks, individuals are observed while they perform any two tasks that are relevant and meaningful to them and that offer sufficient challenge. Examples of task options are upper body dressing, brushing teeth, making a standard bed, folding laundry, setting the table, vacuuming, repotting a plant, making toast and coffee/tea, and preparing a salad. Each task is clearly described with guidelines that delineate: the essential aspects of each task, criteria for what should be done, and necessary tools or materials (Fisher, 1999), but there is sufficient flexibility to enable tasks to be tailored to individuals' needs. For example, in the AMPS "Vegetable Preparation" task, the individual prepares two fresh vegetables that are not already peeled. The vegetables chosen will, however, depend on availability and the individual's preference. Given the options available within each of the ADL tasks, it is unlikely that an examiner could not identify two appropriate and relevant tasks for an individual.

The second issue we need to consider in determining whether ADL assessments reflect the key elements of occupation relates to the evaluation of the process of *doing*, or more specifically, evaluating the *quality* of individuals' *occupational skills*. Traditional proxy-report ADL assessments evaluate the level of assistance individuals need or receive when performing globally defined ADL tasks (e.g., housework, meal preparation, dressing). Examples of such assessments include: the ADL Index (Katz et al., 1963), the Physical and Self-Maintenance and Instrumental Activities of Daily Living Scales (Lawton & Brody, 1969), the OARS ADL scale (Fillenbaum, 1985), the Blessed Dementia Scale (Blessed et al., 1968), the Cleveland Scale of ADL (Patterson et al., 1992), and the Functional Activities Questionnaire (Pfeffer et al., 1982). Typically, level of assistance received or needed is rated using a 3-point scale where one end of the continuum reflects independent task performance and the other end of the continuum represents total dependence or inability. When we limit our definition of disability to level of assistance received or needed, two important issues are overlooked. First, the rater's attention is directed to the ability of the person to produce a satisfactory outcome rather than on how the individual does the task. Second, ratings of the level of assistance received or the need for assistance provide us with as much or more information about the rater's standards for performance, availability, and willingness to provide assistance, than about the person's ability to "do." Raters who are uncomfortable with the speed of individuals' responses, or who become impatient when individuals make mistakes, are more likely to provide assistance or assume full responsibility for completing tasks. In an effort to provide a more precise rating, some performance-based ADL assessments such as the ADL Situational Test (Skurla et al., 1988), the Kitchen Task Assessment, and the Refined ADL Assessment Scale further specify the level and type of assistance needed (i.e., verbal prompts, visual prompts, or physical prompts). Although it is largely assumed that individuals who need only verbal prompts are more able than individuals who need nonverbal or physical prompts, this assumption has never been subjected to systematic evaluation. Problems with such a rating scheme are evident when we consider how such ratings would clearly disadvantage individuals with aphasia who have specific difficulties responding to verbal instructions.

In an effort to direct our focus on the process of doing, several ADL assessments have been designed to evaluate whether individuals successfully complete steps of a task as defined within each test. For example, within the ADL Situational Test (Skurla et al., 1988) individuals' ability to make a cup of instant coffee is evaluated by observing and rating whether an individual places the pot on the burner, turns the burner on to the correct temperature, opens the jar of instant coffee, and measures a reasonable amount of coffee, sugar, and cream into a cup. While placing the focus on observable steps of a task is an attempt to evaluate *doing*, it fails to reflect the complexity of the *doing* process. For example, we may observe that the individual is unable to open the jar of instant coffee and score him or her as unable to do this step. However, we need to look beyond the step and observe what aspect of the individual's performance of that step was not skilled. Did the individual experience difficulties in gripping, coordinating, initiating, or sequencing the actions comprising the step? Did the individual's hand slip during the action of gripping the lid? Did the jar slip and slide on the counter when the individual tried to stabilize the jar with one hand and turn the lid with the other hand? Did the individual initiate the action of opening the jar of instant coffee? Did the individual close the jar before spooning out the instant coffee? Although such assessments appear to evaluate doing, they do not enable us to evaluate how skilled the performance was, and thus, to understand why individuals are unable to competently perform steps, and how such difficulties may generalize to more challenging and less challenging ADL tasks.

When ADL tasks are defined on the basis of specific steps, a simple dichotomous rating system is often used to indicate whether the specified steps were completed successfully. These rating systems fail to provide a means to evaluate the quality of the individual's performance. Moreover, uncertainties about how to rate items can arise when individuals do not perform the steps of the task in the "expected" order, in an "reasonable" amount of time, or with an "acceptable" level of accuracy. For example, within the Direct Assessment of Functional Status (Loewenstein et al., 1989), individuals are expected to fold a letter in half, put it in an envelope, seal the envelope, stamp the envelope, address

it exactly as indicated on the examiner's copy, and correctly write their return address in the upper left corner of the envelope. One individual may do all of the steps in an efficient and effective manner, but neatly write his return address on the back of the envelope instead of the upper left corner. Another individual may fold the letter with difficulty, seal the envelope without inserting the letter, lick the stamp and after some delay finally place it in a sloppy manner on the envelope, address the letter correctly, but only after having corrected several errors, and then write his own return address in the upper left corner. Using the rating criteria established for this assessment, both individuals would receive the same total scores on this task and thus, be assumed to have the same level of ADL ability.

In an effort to avoid some of these difficulties and to ensure that sequencing of actions is evaluated, a "correct" order may be imposed even though the validity of such a rating scheme is highly questionable. For example, even though it was difficult to determine "whether most people wet the toothbrush before or after applying toothpaste" (Tappen, 1994, p. 37), a single "correct" order was still imposed within the rating system of the Refined ADL Assessment Scale (Tappen, 1994). When this type of rating system is used, we fail to acknowledge that individuals may use different, albeit equally effective, efficient, and safe approaches to do a given task.

Both the Refined ADL Assessment Scale (Tappen, 1994) and the Structured Assessment of Independent Living Skills (Mahurin et al., 1991) record and score the time that individuals take to perform tasks. While timing individuals' performance gives the appearance of generating objective measures (i.e., time taken to complete a task), ADL ability is not being measured. Furthermore, our attention is diverted away from the important issue, that is, the quality of individuals' occupational skills. For example, individuals may perform quickly but leave out important steps; or conversely, individuals may perform slowly but accurately.

Several more recent assessments of ADL, including the proxy-report Disability Assessment in Dementia (Gélinas et al., 1999), the performance-based Kitchen Task Assessment (Baum & Edwards, 1993), and the performance-based Functional Performance Measure (Carswell et al., 1995) are really focused on underlying capacities. For example, the Disability Assessment in Dementia uses globally defined tasks such as dressing, meal preparation, and leisure tasks as a context for evaluating individuals' initiation, planning and organization, and effective task performance. However, the intent of the evaluation is to have informants make global judgements about their observations in order to provide insights into the cognitive capacities involved in making decisions, solving problems, planning, and making judgements. Similarly, to rate many of the items within the Kitchen Task Assessment and the Functional Performance Measure, trained raters must make inferences about individuals' underlying cognitive and/or physical capacities on the basis of what they have observed. For example, we cannot observe an individual's thought processes involved in *recognition*. However, within the Kitchen Task Assessment, raters must determine if the individual stopped the task because he or she "*recognized* that the task was finished". Likewise, within the Functional Performance Measure, raters must make complex judgements about individuals' underlying physical and cognitive capacities on the basis of what was observed to determine if, for example, an individual "*demonstrates motor planning adequate for the task*" and "*maintains attention to the end of the step (persistence)*" (Carswell et al., 1995, p. 65).

As discussed in Chapter 2, skills are observable goal-directed actions that are small units of occupational performance. We can observe individuals *lifting* a kettle, *reaching* for a jar, *choosing* an appropriate coffee mug and teaspoon, *responding* to a boiling kettle by unplugging it or removing it from the burner and turning the burner off, and *restoring* an unused spoon to the cutlery drawer. Only the AMPS (Fisher, 1999) evaluates these observable ADL motor and ADL process skills. Moreover, the same 16 ADL motor skills and 20 ADL process skills are observed when individuals do any ADL task. Whether an individual is making a sandwich or ironing a shirt, individuals can be observed *moving*,

lifting, and *choosing* tools and materials, and *initiating*, *sequencing*, and *terminating* actions. The AMPS adopts a criterion of competence and the detailed rating examples reflect the amount of effort required, the level of efficiency, and the degree of safety with which individuals enact their skills, as well as their need for assistance. Using these examples as guides, each skill is rated as 1 = *deficit* performance as indicated by the need for intervention or assistance, task breakdown, unacceptable delay, or risk of damage or danger, 2 = *ineffective* performance that slows the task progression or interferes with effective task completion, 3 = *questionable* performance in which the effectiveness of the performance is questioned, or 4 = *competent* performance in which there is no evidence of increased effort or ineffective performance. Not only does this rating scheme acknowledge that there is no one correct way to do a task, it enables us to recognize if problems exist, and to gain insights into why individuals are experiencing those problems. We can then recommend how tasks may be structured or how task environments may be organized to support individuals' engagement in meaningful and relevant occupations.

Criterion 2: Measures a Unidimensional Construct

When we examine the individual items comprising most ADL assessments, most do not even give the appearance of measuring a unidimensional construct, that is, ADL ability. Instead, we commonly see a wide variety of items representing constructs other than ADL ability. For example, the Blessed Dementia Scale (Blessed et al., 1968) includes items that evaluate individuals' underlying cognitive capacities (e.g., "inability to remember short list of items, as when shopping," "inability to recall recent events"). A leisure item is included in the Disability Assessment in Dementia (Gélinas et al., 1999) in addition to the more typical self-care and household maintenance task items. The Cleveland Scale for ADL (Patterson et al., 1992) includes items to evaluate social behaviour and communication skills. The Structured Assessment of Independent Living Skills (Mahurin et al., 1991) includes items to evaluate physical capacities, cognitive capacities, instrumental activities, and social interaction skills. Problems associated with assessments that tap different domains are compounded when the ordinal item scores are summed to

achieve subscale scores, and again when subscale scores are summed to generate a total ADL score (cf. Merbitz et al., 1989; Silverstein et al., 1989; Wright & Linacre, 1989).

Another common problem, although often harder to recognize, is when assessments appear to measure a unidimensional construct, but the construct is something other than ADL ability. Although not formally tested, assessments such as the Disability Assessment in Dementia (Gélinas et al., 1999), the Functional Performance Measure (Carswell et al., 1995), and the Kitchen Task Assessment (Baum & Edwards, 1993) may measure a unidimensional construct, but rather than measuring ADL ability, the integrity of individuals' underlying cognitive capacities is evaluated based on observations made while individuals perform ADL tasks.

Not only do we need to consider whether the tasks in an assessment reflect a unidimensional construct of ADL ability, but depending on the design of an assessment, we may also need to determine whether the specific items that comprise the test represent a unidimensional construct. Within the AMPS (Fisher, 1999), the unidimensionality of the 16 ADL motor skill items and 20 ADL process skill items has been confirmed through a series of studies (cf. Fisher, 1999). Although the AMPS ADL motor and ADL process scales are related ($r = .58$), they each represent a unidimensional linear continuum of ADL ability (i.e., ADL motor ability and ADL process ability). Since the AMPS is designed to evaluate individuals' occupational skills within the context of different ADL tasks, the unidimensionality of the 76 specific self-care and home maintenance tasks comprising the AMPS also had to be established. This, in fact, was confirmed through a series of studies (cf. Bray et al., 1999; Fisher, 1998; Fisher, 1999) using many-faceted Rasch (MFR) analyses (Linacre, 1993). As illustrated earlier by Bray and colleagues (1999), this formal evaluation of unidimensionality is essential. When new ADL tasks, including shopping, were being considered for inclusion in the AMPS, the AMPS shopping task failed to demonstrate acceptable goodness-of-fit with the measurement model.

Criterion 3: Generates Unbiased Ability Measures

While efforts to standardize the administration protocol and scoring criteria, and to develop intensive training procedures may serve to improve uniformity among raters, such efforts have done little to reduce rater bias (i.e., consistent tendencies to either over or underestimate). Moreover, the issue of rater bias has not been addressed by the developers of ADL assessments except by Fisher (1999) when developing the AMPS. Through the use of MFR analysis (Linacre, 1993), the influence that examiners' personal biases have on their ratings is identified and accounted for when individuals' ADL measures are generated (Fisher, 1993; Lunz & Stahl, 1990, 1993) using the AMPS. Although raters vary in their level of severity, each individual rater tends to be consistent in his or her level of severity over time (Lunz & Stahl, 1990, 1993). As part of the 5-day AMPS rater training process, occupational therapist examiners evaluate several videotaped task performances, and then administer the AMPS to 10 individuals following completion of the course. Each examiner's ratings are analysed using the MFR model for the AMPS (Linacre, 1987-1994). This rater calibration process ensures that examiners interpret and rate the assessment items in the expected manner given the measurement model. This means that all raters are more likely to assign low scores to harder items than to easy items, all raters are more likely to assign low scores when observing someone performing a more challenging task compared to a less challenging task, all raters will assign lower scores when the person being assessed is less able than one who is more able, and severe raters are more likely to assign low scores than are lenient raters. After completing the calibration process, each rater is provided with a personal copy of the AMPS computer-scoring software (Computer Adaptive Technologies [CAT] & Fisher, 1994-1999). Each rater's own severity level is entered into the program so that all subject measures generated using the rater's software program will account for the influence that the rater's personal biases have on subjects' ability measures. Currently over 1,000 occupational therapists have been trained and calibrated as raters. Of these raters, 98% have demonstrated acceptable fit to the measurement model (infit and outfit mean square values ≥ 0.6 and ≤ 1.4 with $z > -2$ and < 2) (Fisher, 1999).

Criterion 4: Generates Stable ADL Measures

The general lack of information about the stability of many ADL assessments may, in part, reflect their current stage of development, although there is little reported evidence of the reliability of even older ADL assessments such as the Index of ADL (Katz et al., 1963), the Physical Self-Maintenance and Instrumental Activities of Daily Living Scales (Lawton & Brody, 1969), the Performance of Activities of Daily Living Test (Kuriansky & Gurland, 1976), the Blessed Dementia Scale (Blessed et al., 1968), and the Functional Activities Questionnaire (Pfeffer et al., 1982). However, because many of these assessments are perceived to be well standardized, it has been assumed that they generate stable ratings. When examined more closely, however, we find that most proxy-report ADL assessments are, in fact, quite limited in terms of standardization. For example, within the OARS ADL Scale (Fillenbaum, 1985), individuals' ability to do their own housework is evaluated. "Doing housework" however, may be interpreted very differently depending on individuals' living situation, personal standards and expectations, and other resources available to them. While one individual may need to wash and dry dishes by hand, another may use a dishwasher. Although the use of vaguely defined task items enable us to individualize our interpretation of the items, we cannot expect to generate stable ratings when individuals' interpretations of questions may vary from one time to another.

Only three of the ADL assessments reviewed actually reported any test-retest or stability data. The reported stability of task scores generated using the Direct Assessment of Functional Status (Loewenstein et al., 1989) ranged from .55 to .92 using a small sample of 14 persons with memory impairment. The stability of the reports of 45 proxies of persons with AD within a 1 week time period using the Disability Assessment in Dementia (Gélinas et al., 1999) was more convincing with a reported inter-class correlation coefficient (ICC) of .96. The most extensive stability data has been reported for the AMPS (Fisher, 1999). Even though individuals are assessed using different ADL tasks, the challenge of each of the 76 standardized ADL tasks has been identified (Fisher, 1999b) and is taken into account when individuals' ADL motor and ADL process ability measures are

generated using MFR analyses (Linacre, 1993). Support for the use of different tasks for different individuals was provided by the findings of a study by Kirkley and Fisher (1999). When they examined alternate forms reliability of 91 subjects who did four different AMPS tasks within a 7 day period, they reported reliability coefficients of $r = .91$ for the AMPS motor scale and $r = .85$ for the AMPS process scale. Doble and colleagues (1999b) reported on the test-retest reliability in a heterogeneous sample of 55 older adults, including persons with AD, who were assessed twice within 1 to 10 days. They found the retest-retest reliability to be high for the AMPS motor skill scale ($r = .88$) and AMPS process skill scale ($r = .86$). Furthermore, 93% of the subjects' ADL motor and 91% of the subjects' ADL process ability measures were stable over the two sessions.

Criterion 5: Generates Responsive Ability Measures

Given the limited examination of the reliability of scores and measures generated using various ADL assessments, it is probably not surprising that the responsiveness of most ADL assessments has not been examined. As noted earlier in Chapter 3, although reliability and responsiveness are different constructs, meaningful changes in ADL ability will not be accurately detected if short-term stability of the assessment cannot be confirmed.

Oakley and Sunderland (1997) reported that the Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969) is the most widely used ADL assessment in studies of the efficacy of various pharmacological interventions for persons with AD. However, only two of the 12 studies reviewed by Oakley and Sunderland reported a significant improvement in subjects' ADL ability when using the Instrumental Activities of Daily Living Scale (cf. Davis et al., 1992; Villardita, Griolo, Lomeo, Cattaneo, & Parini, 1992). Based on these findings, it is difficult to determine whether the pharmacological interventions were ineffective in enhancing individuals' ADL abilities or the specific ADL assessment employed was not responsive to changes in subjects' ADL abilities. The latter explanation is, however, highly probable for two reasons. First, the Instrumental

Activities of Daily Living (IADL) Scale includes only a limited number of IADL items that do not represent a wide range of difficulty. Therefore, ceiling and floor effects are highly probable. Secondly, each item is rated using a fairly gross scaling system that evaluates individuals' level of independence. Consequently, it is unlikely that the IADL Scale is able to detect small but meaningful changes in individuals' ADL abilities.

Preliminary research on the responsiveness of the AMPS (Fisher, 1999) for persons with dementia has been initiated, but findings are unclear. Oakley and Sunderland (1997) used the AMPS as an outcome measure in a study of 11 AD inpatients participating in a 3 1/2 month, double-blind, placebo-controlled, crossover study of two different medications administered as single agents and in combination with another medication. A significant difference in the ADL process ability of the subjects under different drug conditions was detected using the AMPS. However, in a cross-sectional follow-up study in which the ADL abilities of individuals with AD were reassessed every 6 months, Doble and colleagues (1996) found that the subjects' AMPS ADL motor and ADL process abilities remained stable when they were examined as a group. When these same subjects' ADL abilities were rated by family informants using the OARS ADL and IADL Scales (Fillenbaum, 1985), their ADL abilities appeared to have declined. While these findings suggest that the AMPS ADL motor and ADL process scales were not responsive to changes in the AD subjects' ADL motor and ADL process abilities when examined as a group, significant changes were evident in some of the AD subjects' ADL motor and ADL process abilities. As Streiner and Norman (1995) have suggested, when there are individual differences in rate of change, our ability to demonstrate responsiveness of an assessment is reduced. Given the high level of stability within AMPS measures (Doble et al., 1999a) and the variation in change within the AD group, it is possible that the individual differences in change obscured our ability to detect an overall change effect. It is also possible that the decline reported by family informants reflected a lack of stability in the scores generated using the OARS ADL and IADL Scales. Further research is needed to examine the responsiveness of the AMPS ADL motor and ADL process scales.

Criterion 6: Is Cost-Effective

The obvious advantage of many proxy-report assessments is that they can be administered either in person or over the telephone by individuals who are self-trained in the administration of the assessment. Furthermore, there is no need to elicit the cooperation or involvement of the person with AD in the assessment process. Although not always reported, it is generally assumed that most proxy-report ADL assessments can be administered in about 10 to 15 minutes.

Performance-based assessments, however, generally require more forethought and planning. First, the examiner must gain the cooperation of the individual with AD. Although, this is less problematic when assessments are used that reflect the needs and interests of each individual being evaluated, this must be acknowledged as a potential challenge. Examiners must also ensure that all necessary tools, materials, and furnishings are available in the test environment. Although performance-based ADL assessments usually take more time to administer than most proxy-report assessments, the average time to complete each assessment has not always been reported. Moreover, administration time may vary considerably depending on the ability of each person being evaluated. For example, it has been reported that the Refined ADL Assessment Scale (Tappen, 1994) can take anywhere from 20 minutes to more than an hour to administer; the Direct Assessment of Functional Status (Loewenstein et al., 1989) can usually be completed in about 30 to 35 minutes; the AMPS (Fisher, 1999) can be administered and scored by experienced examiners in about 30 to 45 minutes.

Some level of training is typically required to learn how to administer, score, and interpret performance-based assessments. In general, examiners can undergo a process of self-training by using the administration manual of assessments available from the developers such as the Direct Assessment of Functional Status (Loewenstein et al., 1989), the Kitchen Task Assessment (Baum & Edwards, 1993), the Refined ADL Assessment Scale (Tappen, 1994), and the Structured Assessment of Independent Living Skills (Mahurin et al., 1991).

In contrast, training procedures for assessments such as the AMPS (Fisher, 1999) are monitored by the assessment developer. To train to administer the AMPS, qualified occupational therapists participate in the 5-day training course, and complete the rater calibration requirements. Thus, the AMPS represents one end of a continuum of ADL assessment training requirements, and this may explain why its adoption in clinical and research settings has not been widespread.

Summary

Most of the available ADL assessments, including dementia-specific ADL assessments, do not adequately meet the criteria for test validity. Primarily, they fail to reflect the proposed conceptualization of occupational behaviour, and instead assess the presence or absence of physical dependence on others when performing specified tasks or actions, or evaluate underlying cognitive capacities. The AMPS (Fisher, 1999), however, meets many of the proposed evaluation criteria. It embraces the concept of occupation or meaningful doing within the unidimensional construct of self-care and home maintenance tasks. Individuals' ADL motor skills and ADL process skills are evaluated within the context of relevant and familiar ADL tasks. Differences in rater bias are accounted for through the use of MFR analysis (Linacre, 1993). Although more research is needed, research supporting the stability of measures generated over the short-term and some preliminary findings of its responsiveness in a drug trial suggest that it has potential as an outcome measure in AD research.

As a performance-based assessment, however, the AMPS (Fisher, 1999) requires the cooperation and participation of individuals with dementia. While this has generally not been a concern since the assessment context is tailored to meet each individuals' own interests, values, and goals, it must always be considered a potential obstacle. Moreover, while the intensive rater training and calibration process serves to reduce measurement error, training is limited to occupational therapists.

Rather than continue to utilize ADL assessments that do not reflect the key elements of occupation, we should use assessments, such as the AMPS (Fisher, 1999), that provide us with valid and reliable measures of individuals' ADL abilities. Moreover, we need to reexamine the biases of clinicians and researchers that appear to value ADL assessments that are inexpensive to administer over ADL assessments that generate valid, reliable, and responsive measures of individuals' actual ADL abilities.

CHAPTER 5

Proxy-Report Assessments: Directions for Development

Introduction

Given the demand in clinical practice and research settings for ADL assessments that can be administered quickly, with ease, and for minimal cost (Spector, 1997), one direction for the development of ADL assessments is to build on the strengths of the AMPS (Fisher, 1999) while attempting to make it more feasible for use in clinical practice and research settings. A proxy-report version of the AMPS (AMPS-PR) may have potential as an outcome measure in clinical trials and other intervention studies. It may also be useful in providing family members with a structured format for reporting on and conveying their concerns about their demented family members' everyday task performance, and as a means of developing an effective collaborative relationship between clinicians and family members. By eliciting the views of those involved in supporting the everyday task performance of the person with AD, clinicians could determine if those involved share a common view of concerns and difficulties; and identify those concerns that family members are most motivated to address. This type of collaborative approach acknowledges the expertise of those individuals who are dealing directly with the changes associated with AD (Gitlin, Corcoran, & Leinmiller-Eckhardt, 1995).

The AMPS-PR was designed to be administered by a trained and calibrated AMPS rater who is familiar with the 76 standardized ADL tasks, and the ADL motor skill and ADL process skill item definitions and examples for scoring. Therefore, although the AMPS-PR requires the involvement of a highly trained occupational therapist, costs may be reduced if the assessment takes less time to prepare, administer, score, and interpret than the observational AMPS (Fisher, 1999). Since no special materials or tools are required, it could be administered anywhere. It could be used to assist in the development of a collaborative relationship between the occupational therapist and family member by introducing family members to the role that occupation plays in their demented family

members' everyday lives, and providing them with an opportunity to identify personal concerns about their family members' ADL task performances.

Although the FACETS Rasch measurement model (Linacre 1987-1994) is used to account for rater bias in the observational AMPS (Fisher, 1999), there are limitations in the extent to which the Rasch model can be used to account for rater bias. In order to account for the severity of each rater, a network of links must be made between raters through common items and tasks (Lunz et al., 1990). While this process is feasible when relying on trained raters who rate many individuals, it is not a realistic option when developing proxy-report assessments that are completed by family members. In proxy-report assessments, raters typically evaluate the ADL ability of one person with whom they have a personal, and often, intimate relationship (e.g., spouse, sibling, adult child). Therefore, the rater's personal biases and perceptions are bound in the unique interpersonal relationship with the individual.

Since it is not feasible to employ MFR analysis to account for rater bias in proxy-reports, an alternative approach is to identify variables that systematically influence the perceptions of raters. Somewhat surprisingly, such potential factors, have rarely been examined. Even when they have been examined, no conceptual framework or clear justification for the study variables has been provided. In the next section, social cognition research will be briefly reviewed to provide insights into the processes involved when individuals perceive stimuli and make decisions. This knowledge may improve our understanding of the processes that are at work when individuals are asked to make judgements about their family members' ADL abilities. Drawing on gerontological research that examines the relation between "objective levels of burden" (i.e., proxy-report assessments of individuals' ADL ability and psychiatric and behavioural symptoms, and subject scores on tests of cognitive functioning) and caregiver variables such as depression and burden, psychosocial variables that may affect family informants' judgements will be identified.

Social Cognitive Processes Involved in Making Judgements

Inference-making is a process by which individuals collect and combine often diverse and complex information to form a judgement (Fiske & Taylor, 1991). When family informants are asked to evaluate their demented family members' ADL abilities, they must make complex judgements under conditions that are not well suited to accuracy. While we may assume that they have had adequate opportunities to observe their family members' task performances and thus, will have a reasonable basis for making a judgement, this is not the case in all situations. Instead, family informants may only see the outcome of task performances (e.g., sandwich, clean rug, basket of folded laundry). In some cases, family informants may engage in tasks jointly with their demented family members and, thus, may not have adequate opportunities to see how they perform without ready supports. Alternatively, individuals with AD may be provided with few opportunities to perform if family members or paid caregivers have assumed responsibility for many ADL tasks.

Proxy-report assessments, by their very nature, require family informants to make judgements based on their recollections of their family members' ADL task performances. The time lag between observing and reporting may interfere with the accuracy of their recollections. Even more importantly, however, they cannot judge what they have not noticed. When family informants observe their AD family members' task performances, they attend selectively to the stimuli that they judge to be most salient, and the things they choose to observe will reflect their own personal standards or expectations for performance. Their attention will be drawn to those actions that represent discrepancies between what they expected and what they actually observed. Consequently, their attention will be redirected away from other potentially important and relevant stimuli.

Third, individuals' perceptions are transformed or encoded into schema (i.e., cognitive structures that represent their understanding) of usual or competent performance of everyday tasks. Accuracy of ratings is also enhanced when family informants' knowledge of the construct being rated, in this case, their general understanding of what constitutes

ADL motor and ADL process skills, and when their knowledge of their family members' ADL abilities is high. However, our lack of a universal framework for describing what we do and how competently we enact ADL motor and ADL process skills means that it is unlikely that individuals have developed comprehensive schema for encoding their perceptions and interpretations. In part, this problem reflects the illusion that performing everyday tasks such as making a sandwich, sweeping a floor, and making a bed is simple and easy. Unfortunately, the common and routine nature of such tasks lead us to overlook the complexities of such task performances. When we lack clear schema for organizing our perceptions, we will experience more difficulty recalling stored information, and the accuracy of our judgements will be reduced (Fiske & Taylor, 1991). If and when family informants have developed schemas for evaluating their family members' ADL performances, they are most likely grounded in their previous experiences of completing proxy-report ADL assessments that frame disability in terms of dependence level or need for assistance.

When asked to make judgements, family informants must retrieve information that they deem is relevant to the process. Given the wide array of information that most family informants have access to, including their knowledge of how the person performed in the past, they must utilize some type of sampling framework. Although individuals may use the most relevant information available, the sampling process is often biased, with individuals drawing strong inferences from small and unreliable samples of observations (Fiske & Taylor, 1991).

Individuals generally resist changing their former impressions (Feldman, 1994; Fiske & Taylor, 1991). Compared to experts, novice or inexperienced raters are less likely to perceive and use inconsistent information. Individuals must be emotionally prepared to abandon their former impressions, make sense of inconsistent information, and rebuild more coherent and consistent images of their family members' ADL abilities. Only when inconsistencies are clear, strong, or evoke an evaluative effect, will informants attend to

and remember the inconsistent information when making their judgements. Instead, they may selectively focus on new information that validates their already formed impressions. In the case where family informants' impressions about their family members' ADL competence are strongly held, family informants may even discount incompatible information (Feldman, 1994; Fiske & Taylor, 1991). Inconsistent information may also be attributed to situational factors (e.g., he did poorly on that task because he was tired, or he did poorly because things have been rearranged in the kitchen) (Fiske & Taylor, 1991) rather than leading individuals to change their judgements.

When informants are unsure about their family members' ADL abilities (e.g., when they have little or no specific performance information to draw upon), "halo effects" are common (Feldman, 1994). This means that family informants draw on their most accessible impressions of their family members, and use their overall evaluative impression of their family members as the basis for their judgements about their ADL abilities. A similar, but slightly different effect, is referred to as a "dimension similarity halo effect" (Feldman, 1994). Again, if a family informant lacks adequate information, or if the available information is ambiguous, family informants may draw on their impressions of how well their demented family members perform within some other dimension. Using this constructive inference process, they may base their ratings not on their impressions of the their family members' ADL abilities, but on their perceptions of their underlying cognitive, physical, or social capacities. In the next section, psychosocial issues which may influence raters' biases are examined.

Psychosocial Factors that May Influence Proxy-Reports

Family members who support and care for individuals with AD, must deal with a wide array of potential stressors. These include stressors that are associated with assuming responsibility for the health and well-being of their family members. Caregivers must address the personal care needs of family members with AD; manage various cognitive and behavioural symptoms; and organize and supervise the individual's overall care. In

addition to caregiving tasks, they must also deal with the effects that caregiving has on other aspects of their personal lives. They must deal with the loss of their own independence and freedom when their AD family member either will not stay home alone or is assumed to be unsafe when alone at home. Family caregivers' social contacts with others may be reduced, especially if they withdraw from their participation in other occupational roles outside the home setting (George & Gwyther, 1986; Mace & Rabins, 1981; Pearlin, Mullan, Semple, & Skaff, 1990; Scharlach, Sobel, & Roberts, 1991; Zarit, Orr, & Zarit, 1985). Consequently, caregivers may be confronted with feelings that they are losing their own sense of identity (Skaff & Pearlin, 1992).

Numerous studies have examined the effects of such stressors on family members' coping ability. These studies have suggested that family members experience major changes in their psychological, social, and health functioning, and these changes, in turn, affect their overall quality of life (e.g., Haley, Levine, Brown, & Bartolucci, 1987a; Pearlin et al., 1990; Pruchno & Kleban, 1993; Pruchno & Resch, 1989; Quayhagen & Quayhagen, 1988; Williamson & Schulz, 1993). Family caregivers also report that their relationships with their demented relatives are affected by increased feelings of hostility (Anthony-Bergstone, Gatz, & Zarit, 1988). Socially, family caregivers report significant reductions in their social activities with friends and less satisfaction with their social networks (Haley et al., 1987b). Changes in caregivers' physical health are evidenced in their reports of poorer health, their greater use of prescription medications, and their higher utilization of health care services (Haley et al., 1987b). Psychological changes include increased emotional distress and increased depressive symptomatology (Haley, Levine, Brown, Berry, & Hughes, 1987b; Pruchno & Resch, 1989). These research findings also suggest that, at least in some caregivers, the stresses associated with the caregiving role contribute to caregivers' feelings of depression and burden. These variables, in turn, may affect caregivers' perceptions of their family members' ADL abilities.

Depressive Symptomatology

Clinical depression and significant depressive affect are reported in numerous studies of family members caring for persons with AD (Coppel, Burton, Becker, & Fiore, 1985; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Haley et al., 1987b; Pruchno & Potashnik, 1989). Family members who habitually attribute negative events to stable, global causes, are more vulnerable to depression (Abramson, Metalsky, & Alloy, 1989; Seligman, 1975), and thus, are more likely to appraise personal actions and those of others in a negative way. A more hopeless and negative outlook, coupled with high performance expectations, may lead depressed family members to focus more on their demented family members' inabilities or deficits than on their residual abilities. This, in turn, may contribute to systematic underestimation of individuals' ADL abilities. Research, however, suggests that the effects of negative mood on individuals' perceptions are quite variable (Fiske & Taylor, 1991).

Research also indicates that persons who are depressed demonstrate memory problems and are less able to manipulate and process information in complex ways (cf. Hartlage, Alloy, Vázquez, & Dykman, 1993; Hertel & Hardin, 1990). These cognitive impairments may, in turn, limit the capacity of depressed family informants to encode and retrieve information, particularly new information that is inconsistent with their previous impressions. As discussed earlier, the process of changing perceptions requires considerable effort; individuals who are depressed may be less motivated or able to alter and reshape their former impressions. This suggests that individuals who are depressed may be more likely to retain former images of their family members' ADL abilities which may result either in overestimation or underestimation.

Very little research has been designed to examine how family informants' depressed mood influences their perceptions of their demented family members' ADL abilities. Cook, Ahrens, and Pearson (1995), in a study of attributions and depression in caregivers of persons with AD, found that caregiver depression was not related significantly to their

perceptions of their family members' level of independence in ADL tasks as evaluated using the Index of ADL (Katz et al., 1963) and Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969) (both $r_s < .20$). In contrast, when Zanetti and colleagues (1997) examined the influence of depression on caregivers' reports of individuals' ability to perform specific ADL tasks (i.e., toileting, dressing, walking, telephone use, shopping, and money management), they found that caregivers' self-reported depressive symptomatology had a significant influence only on their reports of their family members' independence when walking. Specifically, family informants with higher levels of depressive symptomatology reported that their AD family members were less able to walk independently. Nevertheless, caregivers' level of depressive symptomatology did not have a significant influence on any of their other ratings. Obviously the relationship between family informants' level of depressive symptomatology and their ratings of AD subjects' ADL ability was not clarified by these findings. Therefore, the issue appears to warrant further investigation, especially when we consider the high rates of depression among family caregivers (Coppel et al., 1985; Gallagher et al., 1989; Haley et al., 1987b; Pruchno & Potashnik, 1989), and the potential effect that depression may have on their evaluations of their AD family members' ADL abilities.

Perceived Caregiver Burden

George and Gwyther (1986) emphasized that caregiver well-being and caregiver burden are essentially "opposite sides of the same coin" (p. 253). In contrast to caregiver well-being, caregiver burden has been defined as "the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults" (George & Gwyther, 1986, p. 253). Gottlieb (1989) suggested that the extent to which burden is experienced is related to an individual's understanding of the role; readiness to accept the role; expectations about the timing, nature, and duration of the role; past experiences caring for older adults; and the expected impact that caregiving will have on other occupational roles. It is generally expected that caregivers are more vulnerable to feelings of burden when they experience increased levels of depression,

decreased life satisfaction, reduced participation in social activities, decreased physical health, and strained relationships with the persons with AD prior to the onset of AD (Haley et al., 1987b; Pratt, Schmall, Wright, & Cleland, 1985; Pruchno & Resch, 1989; Williamson & Schulz, 1990).

Numerous caregiver burden scales exist, although only a few have been developed specifically for use with persons caring for individuals with dementia. Most caregiver burden scales are designed to address fairly similar dimensions of burden such as health status, financial strain, social activity, and disturbed feelings (cf. Vitaliano, Young, & Russo, 1991). Vitaliano and colleagues (1991) suggested that efforts to establish the construct validity of burden assessments have been hampered by our "uncertainty about expected relationships between burden and functioning of the impaired elder" (p. 67). This has been borne out in the research conducted to date.

Some researchers have reported finding no significant association between family caregivers' perceptions of burden and their reports of their demented family members' task independence in self-care and home maintenance (Barusch & Spaid, 1989; Coen, Swanwick, O'Boyle, & Coakley, 1997; Kosberg, Cairl, & Keller, 1990). Others, however, have reported that informants' perceptions of caregiving burden is related to their reports of their family members' ADL abilities (cf. Hadjistavropoulos, Taylor, Tuokko, & Beattie, 1994; Zanetti et al., 1997). In a sample of 136 demented elderly adults and their caregivers, Hadjistavropoulos et al. (1994) found that caregivers' appraisals of the demented subjects' independence in performing IADL tasks (e.g., handling money, going shopping) were related to their feelings of burden. However, this same association was not found when their perceptions of the AD subjects' independence in self-care tasks (bathing, dressing) were examined. These findings suggest that burden was greatest when AD subjects needed assistance with more complex IADL tasks only, and not when they needed assistance in self-care tasks. Caregiver burden may be greatest in the earlier stages of AD. This is, in fact, a time when individuals with AD begin to move from being able

to perform independently to needing direction or supervision to perform tasks that they performed formerly with ease. Caregivers must also decide how they can best offer assistance when their family members are still trying to maintain an active role in the performance of everyday tasks. The provision of such assistance is often more demanding, since it usually takes more time to enable someone to maintain their independence than it does to actually do the task for them. In contrast, by the time individuals with dementia require physical assistance to perform self-care tasks, they may be more receptive, the family caregiver may have become more skilled and effective in providing assistance, and others, besides the family caregiver, may be providing support. In a similar study of 83 mildly demented individuals, Zanetti and colleagues (1997) found that the proxies who reported that their family members' self-care ability was more impaired also had higher "time dependence caregiver burden" subscale scores on the Caregiver Burden Inventory (Novak & Guest, 1989) but not higher development, physical, social or emotional burden subscale scores. These findings suggest that it is the burden associated with the amount of time spent caring for the demented person, not overall burden, that is related to caregivers' perceptions of their family members ADL ability. This finding supports George and Gwyther's (1986) contention that "reliance upon summary scores masks dimension-specific patterns of caregiving impact and precludes identification of the different antecedents or correlates of specific dimensions of caregiver burden" (p. 254). Rather than using caregiver burden assessments that ignore the multidimensionality of burden (e.g., Morycz, 1985; Zarit, Reever, & Bach-Peterson, 1980), we may gain more insight into the relation between these constructs if we use caregiver burden assessments such as the Caregiver Burden Inventory that generate scores for different domains of burden.

Quality of the Informant-Subject Relationship

The effects of dementia are not isolated to the individual diagnosed with AD, but instead, exert a widespread influence on others within the individual's support network. Unfortunately, the effects of dementia on the relationship between the person with AD and

other family members has received little attention (Gottlieb, 1989). As Gottlieb (1989) noted, “despite its fundamental importance in colouring the supporter’s perceptions of the value of her role, in amplifying or minimizing the amount of effort necessary for its enactment, and in aggravating or smoothing transactions with other significant actors within and outside the household, the support inherent in the relationship between the two central figures has been largely ignored” (p. 602-603). Moreover, the way in which the nature of the informant–subject relationship influences informants’ perceptions of the subjects’ ADL abilities has not been examined.

Family relationships are typically categorized by kinship tie and may include generational relations (i.e., spouse, sibling) or intergenerational relations (i.e., adult child, son- or daughter-in-law, niece or nephew, grandchild). However, kinship tie does not provide information about the quality of the interactions within the relationship. Although numerous social support assessments have been reported in the literature, Tilden, Nelson, and May (1990a, 1990b) have proposed that the balance between support, conflict, and reciprocity should be examined more directly. Social support typically refers to the extent to which individuals perceive positive feelings and a sense of well-being from others (Cutrona, 1990; Stewart, 1993). Social support enables individuals to experience a sense that others care and are concerned about their well-being. This is reflected in others’ comments and actions that convey that they are perceived to be capable and competent. Social support also refers to the receipt of help to perform everyday tasks, and the provision of advice or guidance to address problems more effectively (Cutrona, 1990; Stewart, 1993). The more supportive an informant perceives his or her demented family member to be, the more likely he or she may be to overestimate the individual’s ADL abilities. Or as discussed earlier, if family informants are unsure about their family member’s ADL abilities, dimension similarity halo effects (Feldman, 1994) may be evident such that they base their judgements on their evaluative impression of the individual.

The tendency to overemphasize the positive aspects of interpersonal relationships must be balanced by acknowledging that interpersonal relationships can be problematic (Rook, 1985). In fact, negative or conflictual aspects of interpersonal relationships may overshadow the positive effects of support provision (Coyne & DeLongis, 1986; MaloneBeach & Zarit, 1995). Family members' efforts to provide support, and to assume a more active role in regulating and controlling the behaviour of their family members with AD may not be accepted. Instead, these efforts may generate feelings of anger and frustration on the part of the person with AD. When interpersonal relationships are viewed as conflictual, informants' ratings may be more negative, and thus, underestimate their family members' ADL abilities. If family informants fail to understand the changes they see in their family members' ADL abilities, they may attribute difficulties they observe to willful attempts to be difficult; or as a lack of motivation, depression, or laziness; rather than as a consequence of the dementing process. If resentful, informants may react by becoming overprotective (Coyne, Ellard, & Smith, 1990; Thompson & Solbolew-Shubin, 1993). They may then see their AD family members as less able, and assume increased responsibility for many ADL tasks. Such an approach further reduces the opportunities informants have to observe their AD family members' residual abilities (Avorn & Langer, 1982). Furthermore, more negative ADL ability ratings may reflect their perceptions of high levels of conflict within their relationships with their AD family members (Feldman, 1994).

Individuals' perceptions of actual and psychological equity or reciprocity within the relationship may also influence their perceptions (Globerman, 1996; Gottlieb, 1989). Social exchange theory (Burgess & Huston, 1979) and equity theory (Messick & Cook, 1987) suggest that interpersonal relationships are dependent on the exchange of both emotional support and tangible aid. Conflict may arise when expectations for a fair exchange of support are not met (Hatfield, Traupmann, Sprecher, Utne, & Hays, 1984). Within closer, more intimate, relationships, reciprocity may be viewed as a less immediate exchange. and instead, as an ongoing series of exchanges throughout the duration of the

relationship (Antonucci & Jackson, 1990; Clark & Reiss, 1988). When one individual within an interpersonal relationship has dementia, the inequity within the relationship will continue to increase. However, family members may view the current inequity as an opportunity to express their love, affection and concern; and/or to repay their family member for the support and attention they provided in the past (i.e., earlier rewards offset current costs) (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Fitting, Rabins, Lucas, & Eastham, 1986; Motenko, 1989; Neufeld & Harrison, 1995). In an effort to convey their support, family members may even idealize their relative (Taylor & Koivumaki, 1976). Informants may also enter into a pattern of behaviour and reporting, in which their efforts are directed towards preserving their image of the dementing person as a competent and capable individual (Doble, Townsend, & Banks, 1995). Spouses and siblings may also overestimate their AD relatives' ADL abilities if they are having difficulty coming to terms with the vulnerability of their own abilities as a result of the aging process.

Although there is currently no research available to confirm the notion that an informant's perceived quality of the subject-informant relationship may influence his or her evaluation of the subject's ADL abilities, from a theoretical standpoint this inquiry appears to be warranted. More specifically, there is a need to examine the effects of perceived support, conflict, and reciprocity on family informants' evaluations of their demented family members' ADL abilities.

Summary

Given the demand in clinical practice and research settings for ADL assessments that can be administered quickly and easily, and that do not require the cooperation and direct participation of individuals with AD, it is reasonable to examine the potential of developing a proxy-report assessment that is modelled on the AMPS (Fisher, 1999). The major question we must ask, however, is whether family informants will be able to provide valid estimates of their demented family members' ADL motor and ADL process abilities. In

other words, we need to determine if proxy-report ADL measures are comparable to observed ADL ability measures derived from a thorough performance evaluation. Differences between observational and proxy-report ADL ability measures are typically attributed to rater bias. Although we can account for rater biases when generating the observational AMPS measures using MFR analysis (Linacre, 1993), we cannot account for the biases inherent in the ratings made by individual family informants so easily. Family informants' evaluations are more likely to be accurate when they have in-depth and recent knowledge of their family members' ADL abilities, and when they make judgements on the basis of only relevant information. However, other personal and situational variables may exert a systematic effect on the proxy-reports of family informants of persons with AD. Five psychosocial variables (i.e., informants' level of depressive symptomatology and perceived time-burden; and their perceived level of social support, conflict, and reciprocity within their relationship with the AD subject) have been identified as variables that may exert a significant effect on family informants' evaluations of their demented relatives' ADL abilities.

CHAPTER 6

Purpose

The purpose of the initial phase of this research was to examine the validity and stability of the AMPS-PR when administered to family informants of individuals diagnosed with possible or probable AD. Using MFR analysis (Linacre 1993), the item and person response validity of the AMPS-PR ADL motor and ADL process ability measures was examined. The 16 ADL motor skill items and the 20 ADL process skill items were examined to determine if they fit the expectations of the MFR model for the AMPS-PR. The AMPS-PR ADL motor and ADL process scales were examined to determine if they were appropriately targeted to the ADL motor and ADL process abilities of the AD subjects. The AMPS-PR ADL motor and ADL process ability measures were examined to determine if they were stable over approximately 1 week. The validity of the AMPS-PR ADL motor and ADL process ability measures was also examined by comparing the AD subjects' AMPS and AMPS-PR ADL ability measures. The subjects' AMPS ADL motor and ADL process ability measures were treated as the gold standard in this study.

As discussed earlier in Chapter 5, factors that influence the severity or biases of family informants are unknown. Based on previous findings (Doble et al., 1999) that suggested that there would be some discrepancy between the observed and proxy-report ADL measures, the research was designed to examine the extent to which a model comprised of five psychosocial variables (informants' level of depressive symptomatology and time-dependence caregiver burden; and perceptions of level of social support, reciprocity, and conflict within the AD subject-informant relationship), accounted for the observed variance between the two measures. If factors were found to systematically bias family informants' ratings, it may be possible to account for the bias when generating the proxy-report ADL motor and ADL process ability measures.

Finally, a brief dyadic interactional educational intervention was provided to half of the family informants with the goal of reducing any measurement error related to inadequate

preparation by informants to make judgements and ratings. The process of making retrospective judgements about another individual's abilities is highly dependent on having adequate opportunities to observe the targeted abilities. Moreover, the accuracy of family informants' ratings is dependent on (a) the attention raters direct towards specific aspects of the individuals' task performances, (b) the schema raters use to encode their observations for later retrieval, and (c) the compatibility of the raters' encoding schema with the format imposed by the specific assessment rating guide. The purpose of the intervention was to provide family informants with a framework or a way to organize their observations into schema that they could retrieve later when asked to complete the AMPS-PR. Moreover, they were asked to informally observe their family members' ADL performances before the next assessment session. The effect of the intervention was determined by examining whether the discrepancy between the observed and proxy-report ADL measures was less for those who participated in the intervention than for those family informants who were part of the control group.

Methods

Design

A cross-sectional, descriptive design was used to examine the psychometric properties of the AMPS-PR when administered to a sample of family informants of community-dwelling elderly diagnosed with possible or probable AD. To control for the effect that subjects' level of dementia may have on family informants' reports, an equivalent number of AD subjects with mild and moderate dementia were recruited. Mild dementia was defined as a Global Deterioration Scale (GDS) (Reisberg et al., 1982) score of 3 or a GDS score of 4 with a Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) score of more than 20. Moderate dementia was defined as a GDS score of 4 with a MMSE score of 20 or less, or a GDS score of 5 or 6. A cross-sectional descriptive design also was used to examine if variables related to the mood and feelings of the proxy, and variables related to the interpersonal relationship between the proxy and subject exerted any systematic influence on the proxy-report ADL ability measures. A controlled trial was

used to examine the effectiveness of the educational intervention in increasing the level of agreement between observed and proxy-report ADL ability measures. The stability of the AMPS-PR over approximately 1 week was determined by examining the proxy-report ADL ability measures for Session 1 and 2 for those informants who were part of the control group, and thus, did not receive any intervention.

Sample Size

A minimum sample of 52 AD subject–informant pairs was needed to conduct all planned analyses, including a 3-way repeated measures ANOVA and a multiple regression analysis. A 3-way repeated measures ANOVA to determine if the intervention had a significant effect on proxy-generated ADL motor and ADL process abilities of the AD subjects where the effect size was large (.80), $(1-\beta) = .80$ and $\alpha = .05$, would require 21 family informants in each of the two groups for a total of 42 family informants (Cohen, 1992). To conduct a multiple regression analysis using five informant variables (i.e., informants' level of self-reported depressive symptomatology and time-dependence caregiver burden; and informants' perceived social support, perceived reciprocity, perceived conflict within their relationship with the AD subjects) data for a minimum of 50 subject–informant pairs was required. Therefore, a minimum sample of 50 AD subject–informant pairs was needed to address the research questions.

Subjects

Subjects were recruited from patients referred to the memory disability clinics at the Queen Elizabeth II (QEII) Health Sciences Centre, Halifax, Nova Scotia, who were 50 years and older, lived in the community (nursing home residents were excluded), and had a diagnosis of possible or probable AD. All subjects met the *DSM-IV* criteria for dementia (APA, 1994) and the NINCDS-ADRDA criteria for probable AD or possible AD (McKhann et al., 1984). Each subject had a family member who was willing to participate as an informant in the study. Only those subject–informant pairs who lived within a 3 hour drive of the QEII Health Sciences Centre were recruited. Names of potential subjects were

provided by staff working within the geriatric clinics. Potential informants were identified as the family member listed in each subject's medical record.

One hundred and thirty-nine potential subject–informant pairs were mailed letters of invitation and a description of the research study by Dr. Kenneth Rockwood, a geriatrician at the QEII Health Sciences Centre. Individuals were provided with the option of contacting the ward clerk of the memory disability clinics at the QEII Health Sciences Centre if they did not want to receive a follow-up telephone call from the researcher. Six families could not be contacted using the telephone numbers listed in their medical records. Five potential subjects had died recently. Thirteen potential subjects no longer met all of the inclusion criteria (i.e., did not live in the community but resided in nursing homes). Of the remaining 115 potential subject–informant pairs, 60 subject–informant pairs agreed to participate. During the follow-up telephone calls, confirmation of the willingness of both the subject and family member was determined. The subject's current participation in at least some self-care or home management tasks (e.g., dressing, folding laundry, washing dishes) was confirmed. In several cases, the family member initially contacted suggested the name of another family member who was more familiar with the subject, and thus, was deemed to be a more appropriate potential informant.

The AD sample was comprised of 39 females and 21 males (Age: $M=77.0$ yrs; $SD=7.5$ yrs; $range=52$ to 93 yrs). Most ($n=55$) met the NINCDS-ADRDA Work Group criteria for probable AD (McKhann et al., 1984); the remaining five subjects met diagnostic criteria for possible AD (McKhann et al., 1984). Based on the reports of the family informants, the AD subjects had, on average, been diagnosed 2.4 years earlier ($SD=2.8$ yrs) although symptoms of memory impairment were evident much earlier ($M=4.8$ yrs, $SD=4.0$ yrs). The sample was comprised of 30 subjects with mild dementia and 30 subjects with moderate dementia. Mild dementia was defined in this study as a GDS (Reisberg et al., 1982) score of 3, or a GDS score of 4 and a MMSE (Folstein et al., 1975) score of more than 20. Moderate dementia was defined as a GDS score of 4 with an

MMSE score of 20 or less, or a *GDS* score of 5 or 6. Most (73.3%) of the AD subjects also reported having at least one other health concern including cardiac, musculoskeletal, respiratory, other medical conditions (e.g., diabetes, thyroid problems), and sensory problems (e.g., hearing loss, glaucoma). The subjects resided in the community with their spouses (55%), with other family members (20%), alone (18%), or in a residential facility (7%). The subjects' mean number of years of education was 11.4 ($SD=4.0$ yrs; range=5 to 23 yrs). None of the subjects were employed at the time of the study.

Family informants included spouses (53%), adult children (33%), siblings (5%), daughter-in-laws (3%), adult grandchildren (3%), and nephews (2%). Most family informants were female (67%). The informants' mean years of education was 13.0 ($SD=3.7$ yrs; range=4 to 23 yrs). The majority of the family informants lived with the AD subjects (73%). All family informants were cognitively intact as determined by a MMSE (Folstein et al., 1975) score of 24 or more (Tombaugh & McIntyre, 1992).

The 60 subject-informant pairs were alternately assigned to either the intervention or control group. Both groups were comprised of 15 AD subjects with mild cognitive impairment and 15 AD subjects with moderate cognitive impairment. There were no significant differences between the two groups on the basis of the AD subjects' MMSE scores ($t=1.07$, $p=.29$), gender ($X^2=0.07$, $p=.79$), age ($t=-1.90$, $p=.06$), years of education ($t=0.37$, $p=.71$), years since diagnosis ($t=-0.21$, $p=.83$), years since the onset of initial symptoms ($t=-1.09$, $p=.28$), and presence of other medical conditions ($t=0.0$, $p=1.0$). Although the intervention and control groups were comparable on the basis of their ADL motor ability measures ($t=1.72$, $p=.09$), the intervention group was more able in terms of their ADL process abilities than was the control group ($t=2.22$, $p=.03$; Intervention group: $M=0.14$ logit vs. Control group: $M=-0.29$ logit). The informants in the two groups did not differ significantly on the basis of gender ($X^2=0.30$, $p=.58$), age ($t=-1.31$, $p=.19$), years of education ($t=0.14$, $p=.89$), living situation ($X^2=0.34$, $p=.56$), or generational relationship to the AD subjects ($X^2=0.07$, $p=.79$). The control

group, however, was less likely to have daily contact with the AD subjects ($X^2=4.3$, $p=.04$). See Table 6.1.

Table 6.1

AD Subjects' and Family Informants' Demographic Data

	Groups	
	Intervention ($n=30$)	Control Group ($n=30$)
AD Subjects		
Gender (% women)	63.0%	67.0%
Mean age (<i>SD</i>)	75.2 (7.4)	78.8 (7.2)
Mean years education (<i>SD</i>)	11.6 (3.7)	11.2 (4.2)
Mean years since AD diagnosis (<i>SD</i>)	2.3 (2.5)	2.5 (3.1)
Mean years since onset of symptoms (<i>SD</i>)	4.3 (3.3)	5.4 (4.7)
Other health conditions (% yes)	73.3%	73.3%
Informants		
Gender	63.3%	70.0%
Mean age (<i>SD</i>)	59.8 (13.9)	64.2 (11.9)
Mean years education (<i>SD</i>)	13.1 (4.0)	13.0 (3.3)
Living situation (% live with subject)	76.7%	70.0%
Informants (% spouse of subject)	56.7%	60.0%
Contact with subject (% daily contact)	93.3%	73.3%

Instrumentation

Global Deterioration Scale (GDS)

The GDS (Reisberg et al., 1982) is a 7-point scale used to categorize individuals' stage of dementia from "no cognitive decline" (Stage 1) to "very severe cognitive decline (terminal dementia)" (Stage 7). Stage 1 is considered to be normal with no evidence of cognitive decline. Stage 2 describes very mild cognitive decline and is characterized by forgetfulness, but no objective deficits in social functioning. Stage 3 or "mild cognitive impairment" is characterized by getting lost in unfamiliar places, co-workers becoming aware of poor performance, forgetting names, and misplacing objects. Mild to moderate anxiety tends to be evident. Stage 4 or "mild dementia" is characterized by decreased knowledge of current and recent events, impaired concentration, reduced ability to travel and handle finances, flattened affect, and withdrawal from challenging situations. In Stage 5 or "moderate dementia," the individual can no longer survive without some assistance from others; some disorientation to time and place is evident; the person may be unable to name close family members. Individuals may require assistance to choose proper clothing. In Stage 6 or "severe dementia," individuals still know their own name but occasionally forget the names of those closest to them. Knowledge of their past is sketchy; they may become incontinent; personality and emotional changes may be evident. Stage 7 or the "terminal" stage is characterized by the loss of all verbal abilities; individuals are unable to walk, are incontinent of urine, and require assistance with toileting and feeding. The average of the scores on the first five axes of the Brief Cognitive Rating Scale (Reisberg & Ferris, 1988) (i.e., concentration, recent memory, past memory, orientation, functioning, and self-care) is considered to reflect the GDS stage.

Mini-Mental State Examination (MMSE)

The MMSE (Folstein et al., 1975) is the most widely used screening tool for assessing cognitive functioning in North America (McDowell & Newell, 1996; Tombaugh & McIntyre, 1992). The mental abilities tested with the MMSE include orientation, registration, attention and calculation, recall, language, and visual construction. Total

scores can range from zero to 30 with higher scores suggesting higher levels of cognitive functioning. A score of 23 or less has generally been accepted as an indicator of cognitive impairment compatible with a diagnosis of dementia (Tombaugh & McIntyre, 1992).

In a comprehensive review of studies designed to examine the psychometric properties of the MMSE, Tombaugh and McIntyre (1992) reported that when the MMSE was readministered within a 2 month period or less, test-retest reliability was high with reliability coefficients for cognitively intact and impaired subjects falling between .80 and .95. Examination of the validity of the MMSE suggests that it is as good as, or slightly better than, those of other scales (McDowell & Newell, 1996; Tombaugh & McIntyre, 1992). More specifically, the MMSE is highly sensitive for moderate to severe levels of dementia. Construct validity studies indicate that the MMSE scores correlate highly with other cognitive screening tests; and psychological and neuropsychological tests of intelligence, memory, and specific cognitive abilities.

Assessment of Motor and Process Skills (AMPS)

The AMPS (Fisher, 1999) was used to generate measures of the subjects' ADL motor and ADL process abilities. It is a standardized, observational assessment used by occupational therapists to evaluate the quality of individuals' performance of meaningful and relevant ADL tasks. The validity of the AMPS for use across age groups, cultures, gender, and among different diagnostic subgroups, including persons with and without medical, cognitive, psychiatric, and motor impairments, has been supported in several studies (Bernspång & Fisher, 1995a, 1995b; Cooke et al., in press; Dickerson & Fisher, 1993, 1995; Doble, Fisk, Fisher, Ritvo, & Murray, 1994; Doble et al., 1997; Duran & Fisher, 1996; Fisher, 1997, 1999; Fisher, Liu, Velozo, & Pan, 1992; Girard, Fisher, Short, & Duran, 1999; Goldman & Fisher, 1997; Goto, Fisher, & Mayberry, 1996; Hartman et al., 1999; Magalhães, Fisher, Bernspång, & Linacre, 1996; Pan & Fisher, 1994; Robinson & Fisher, 1996).

Subjects were observed while they performed at least two of the 76 possible standardized self-care and household ADL tasks (Fisher, 1999) that were representative of ADL tasks they normally perform in the context of their everyday lives. The tasks range from easy (e.g., upper body dressing, folding laundry, setting the table) to hard (e.g., vacuuming, repotting a plant, preparing a salad). Each task is clearly described with guidelines that delineate: the essential aspects of each task, any criteria for what should be done, and tools or materials that must be made available (Fisher, 1999). Subjects were encouraged to perform tasks in their usual manner.

The quality of subjects' performances on each task was rated on 16 ADL motor skills and 20 ADL process skills using a 4-point scale (i.e., 4=competent; 3=questionable; 2=ineffective; 1=markedly deficit). The detailed rating criteria outlined in the AMPS manual (Fisher, 1999) reflect how much effort was required, how efficiently actions were performed, how safely actions were completed, and how independently the subject performed each action.

FACETS (Linacre, 1987-1994), a MFR analysis computer program, was used to generate an ADL motor ability measure and an ADL process ability measure for the subjects from their ordinal data (Fisher, 1999). MFR analysis (Linacre, 1993) accounts for both the challenge of the tasks performed by the individual, the difficulty of each of the 16 motor and 20 process skill items, and the severity of the examiner completing the ratings. Subjects' ADL motor and ADL process ability measures are reported in logits (log-odds probability units); higher logit ADL motor and ADL process ability measures suggest a higher level of ADL ability. Each of the 16 ADL motor skill and 20 ADL process skill items have been shown to fit the measurement model (infit and outfit mean square values ≥ 0.6 and ≤ 1.4 associated with $z > -2$ or < 2) (Fisher, 1999). Although the ADL motor and ADL process scales are related ($r=.58$) (Fisher, 1999), they each represent a unidimensional linear continua of ADL ability (i.e., ADL motor ability and ADL process ability) (Fisher, 1993, 1997; Fisher et al., 1994).

Of the 10,455 subjects from North America, Scandinavia, the United Kingdom, Australia, New Zealand, Holland, Israel, Taiwan, Japan, and Hong Kong who were used to estimate the calibration values used in the second international version of the AMPS computer scoring program (CAT & Fisher, 1994-1999), 94% demonstrated acceptable fit to the model (infit and outfit mean square values ≥ 6 and ≤ 1.4 and $z > -2$ and < 2) (Fisher, 1999). High inter-rater and intrarater reliability, and internal consistency have been demonstrated (Bernspång, 1999; Fisher, 1993, 1997), as well as test-retest and alternate forms reliability (Doble et al., 1999b; Kirkley & Fisher, 1999). Expected moderate positive relations have been found between the ADL motor skill and ADL process skill scales and global assessments of ADL dependence (Doble et al., 1994; Doble et al., 1997; Robinson & Fisher, 1996), assessments of cognitive functioning (Doble et al., 1997; Robinson & Fisher, 1996), neurologic impairment (Doble et al., 1994), and level of dementia (Doble et al., 1997). The AMPS can be used to identify individuals who are likely to need assistance to live in the community (Fisher, 1999), although the ADL process scale has been found to discriminate best among levels of function (Fisher, 1999). All 1,608 subjects who comprised a heterogeneous sample were identified by examiners to require assistance to live in the community. When they were assessed using the AMPS, 93% scored below the ADL process scale cut-off score (i.e., 1.0 logit or less). Hartman and colleagues (1999) also found that although both the ADL motor and ADL process scales were able to discriminate between independent persons, persons with AD who required minimal assistance to live in the community, and persons with AD who required moderate to maximal assistance, the ADL process scale was a more discriminative measure of ability to function in the community. The utility of the AMPS as an outcome measure in clinical pharmaceutical trials also has been suggested by the findings of a double-blind, placebo-controlled, crossover study of 11 persons with AD (Oakley & Sunderland, 1997).

Assessment of Motor and Process Scale-Proxy-Report (AMPS-PR)

The AMPS-PR was modelled on the AMPS (Fisher, 1999). The 16 ADL motor skill and 20 ADL process skill items that comprise the AMPS (Fisher, 1999) were defined in

everyday language (see Appendix A). The AMPS-PR was administered by a trained and calibrated AMPS rater who was familiar with the ADL tasks, items, and rating criteria. Self-care and home maintenance tasks that the family informant had observed the AD subject perform within the past few weeks were identified. Using this information and the examiner's understanding of AD subjects' general ADL ability, the range of possible task choices was narrowed from three to five from the 76 standardized ADL tasks (Fisher, 1999). From this smaller pool of tasks, the family informants each identified two ADL tasks that they had observed their family members perform recently. Family informants rated the subjects' ADL motor and ADL process skills using each item using a 4-point scale (i.e., 4=competent; 3=questionable; 2=ineffective; 1=deficit). Before initiating the rating process, the examiner clarified the expected outcome for each task as described in the AMPS manual (Fisher, 1999). The examiner also explained that some of the skill items are more difficult for most persons while other skill items are easier for most persons, and thus, they should expect to rate their family members as questionable, ineffective, and possibly even as deficit on at least some of the skill items. If they were unsure which of two possible ratings to assign, they were encouraged to assign the lower rating. This is the same protocol adopted by trained and calibrated AMPS raters when completing ratings based on direct observation. Each assessment, which involved completing 16 motor and 20 process skill ratings for two AMPS ADL tasks, took approximately 15 to 20 minutes to complete.

Beck Depression Inventory

A wide array of depression questionnaires exist, some of which have been developed specifically for use with older adults. The Beck Depression Inventory (Beck & Steer, 1987), was selected so the same depression questionnaire could be used for the older adults with dementia as well as their family informants. The Beck Depression Inventory is based on the presumption that as depression deepens, the number of symptoms and the intensity of each symptom increases (Beck, 1967). It has been widely used as a community screening instrument and for clinical research (Beck et al., 1988; Newell & McDowell,

1996). Previous studies have indicated that the Beck Depression Inventory is a valid and reliable assessment of depressive symptomatology (Beck et al., 1988; Newell & McDowell, 1996). Although the Beck Depression Inventory was developed for use with younger adults, it is also appropriate for use with older adults (Gallagher, Breckenridge, Steinmetz, & Thompson, 1983; Gallagher, Nies, & Thompson, 1982). Among older adults, test-retest reliability at 6 to 21 days was $r = .79$ for those who were depressed, and $r = .86$ for nondepressed control subjects (Gallagher, 1986; Gallagher et al., 1982). In a study of 102 elderly outpatients, the Beck Depression Inventory had a sensitivity of 93.3% and a specificity of 81.5% compared to the Schedule for Affective Disorders (Gallagher et al., 1983).

The Beck Depression Inventory is a 21-item self-report measure of the emotional (15 items), behavioural (4 items), and somatic (6 items) components of depression. Items are graded such that there are four levels of intensity for each of the 21 items. When self-administered, individuals are instructed to choose the statement that best describes the way they felt during the past week. The reading level required for completion of the Beck Depression Inventory is the 5th or 6th grade (Beck, Steer, & Garbin, 1988). The examiner read the items aloud, while the AD subjects and family informants read along with their own copy. Individuals recorded their own responses unless they preferred to state their choice aloud, in which case the examiner recorded their responses. If a subject selected more than one statement in any one group, the item with the higher value was used to calculate the total score. Scores for each of the 21 items were summed to give a total score that ranged from zero to 63. Higher scores suggest more severe depression. The Beck Depression Inventory took approximately 10 minutes to administer.

Caregiver Burden Inventory

The Caregiver Burden Inventory (Novak & Guest, 1989) is a 24-item multidimensional assessment of caregiver burden that generates scores that reflect burden in five separate (non-additive) subscales (i.e., time-dependence, development, physical, social, and

emotional burden). Only the “time-dependence” burden subscale was used in further analyses. This 5-item subscale evaluates the burden associated with restrictions on the caregiver’s time. Respondents rated each item using a 5-point rating scale anchored at either end with “not at all descriptive” (zero) and “very descriptive” (4). The Caregiver Burden Inventory shows good internal reliability (alpha coefficients ranging from $r = .73$ to $.86$), moderate intercorrelations of subscales (ranging from $r = .06$ to $.62$), and high factor loadings (ranging from $r = .53$ to $.88$) (Novak & Guest, 1989). The Caregiver Burden Inventory was completed in 5 to 10 minutes.

Interpersonal Relationship Inventory

The Interpersonal Relationship Inventory (Tilden et al., 1990a, 1990b) consists of three separate (non-additive) subscales designed to identify the respondents’ perceptions of the quality of the social support they receive (13 items), the degree of reciprocity with others in their social network (13 items), and the degree of conflict within their social relationships (13 items). For the purposes of this study, informants rated each item in reference to their AD family member only, rather than rating items in reference to all individuals within their social networks. Twenty-two items refer to perceived sentiment and are rated on a 5-point agree–disagree continuum (strongly agree, agree, neutral, disagree, strongly disagree). The remaining 17 items refer to the frequency of certain behaviours and are rated on a 5-point often–never continuum (very often, fairly often, sometimes, almost never, never). Three scores were generated: a social support score, a reciprocity score, and a conflict score. The Interpersonal Relationship Inventory was completed in 5 to 10 minutes.

Internal consistency reliability coefficients for each of the three subscales are $r = .92$ for support, $r = .83$ for reciprocity, and $r = .91$ for conflict (Tilden et al., 1990a). When test-reliability was examined upon readministration of the scale following a 2 week time period, the correlation coefficients were $r = .91$ for the support subscale, $r = .84$ for the reciprocity subscale, and $r = .81$ for the conflict subscale. Construct validity was examined by

comparing the three subscales to measures of stress, mental health, social support, and support and reciprocity. Intercorrelations between the three subscales were generally as expected (i.e., $r=.75$ between support and reciprocity, $r=-.38$ between support and conflict, and $r=-.27$ between reciprocity and conflict). Moderate relations were found between the three subscales and psychological symptoms ($r=-.22$ to $.44$). However, stress was not significantly related to either the support ($r=-.07$) or reciprocity subscales ($r=.02$); although the conflict subscale did correlate with stress at a low level ($r=.25$). Using an exploratory principal components factor analysis with Varimax rotation, the three subscales were extracted. All 13 conflict items loaded on Factor 2. Although all 13 support items loaded on Factor 1, five reciprocity items related to the theme of balance also loaded on this factor; the remaining 8 of the 13 reciprocity items loaded on Factor 3. The reciprocity items appear to evaluate balance as a part of support, that is, doing for and giving back to one another within the relationship. Given these findings, however, the validity of the reciprocity subscale scores is more questionable.

Family Informant Rater Intervention

The intervention for family informants was based on the premise that “before performance can be appraised accurately, it must be observed accurately” (Feldman, 1994, p. 379). Using a dyadic educational approach, the researcher provided family informants with information designed to enhance their abilities to observe their family members’ ADL motor and ADL process skills. The overall intent was to increase the accuracy of their observations so that they could detect relevant changes in the non-standardized and informationally-noisy environments in which they typically make their observations.

The intervention was provided at the end of the first assessment session after family informants had already completed a battery of assessments in which their perceptions of depression, caregiver burden, and the quality of their interpersonal relationship with their AD family member, were elicited. They rated their AD family members’ ADL motor and ADL process skills using the AMPS-PR. The examiner had also completed the

observational assessment of the AD subjects' ADL motor and ADL process skills using the AMPS.

During the intervention, the challenge and importance of eliciting accurate reports of their family members' ADL abilities was discussed. The utility of proxy-report assessments as outcome measures in clinical trials, and as clinical tools in the development of effective interventions for home support programmes was emphasized. In the next stage, the intervention was designed to provide family informants with an opportunity to share their own experiences and to articulate the changes they had observed in their family members' performance of everyday tasks, as well as in other behaviours (see Appendix B). Through this discussion, the researcher was able to share information, clarify family informants' understandings, answer questions, and correct any inaccurate perceptions family informants had about AD. Throughout this intervention, the central role of occupation in the lives of persons with dementia was emphasized.

The interaction was then directed towards the clarification of the AMPS-PR items and rating scale. Having completed the AMPS-PR during Session 1, the family informants were familiar with the format of the assessment. The unique focus of the AMPS (Fisher, 1999) on observable ADL motor and ADL process skills and competent skill performance was emphasized (see Appendix B). The intent was to convey the unique orientation of the AMPS-PR, while emphasizing the complexity of deceptively simple actions and tasks. The assumption that for all persons some items are easier (e.g., Lifts, Moves, Uses, Navigates) while others are harder (e.g., Positions, Paces, Accommodates, Notices/Responds, Benefits) was explained (cf. Fisher, 1999). The expectation that they should try to use the full range of the scale when completing their ratings, rather than assigning all maximum or all minimum ratings was emphasized.

Rather than overwhelming the family informants with a discussion about each of the 16 ADL motor skills and 20 ADL process skills, the intent was to direct their attention to

those skills that may be most difficult to understand and observe; and that present the greatest challenge to individuals with AD (cf. Cooke, 1995; Cooke et al., in press; Fisher, 1999). These included ADL motor skills such as Walks, Flows, Transports, and Paces; and such ADL process skills as Attends, Chooses, Heeds, Inquires, Continues, Notices/Responds, and Benefits. Examples of behaviours that family informants might observe were provided. If relevant, the effects that other health conditions may have on individuals' performance of specific skills were discussed. The focus of this part of the intervention was to help family informants focus their attention, and consider new ways of encoding their observations. They were not, however, provided with a copy of the AMPS-PR to use as a reference between assessment sessions.

Family informants were then encouraged to make a concerted effort to observe their relative perform at least two of the possible 76 ADL tasks during the interval between the two assessment sessions. Relevant task choices were reviewed with the family informant. In cases where the demented family members participated in only a few self-care and home maintenance tasks, suggestions were made of other task options that could be offered (e.g., folding a basket of laundry, getting a cold drink from the refrigerator). During their observations, family informants were encouraged to not intervene but, instead, to adopt the role of discreet observer. The importance of focusing on what they observed without making interpretations was highlighted. They also were encouraged to observe how efficiently their family member performed various ADL motor and ADL process skills, how much effort was required, and how safely skills were performed. Family informants were encouraged to give their family members an opportunity to make mistakes, recognize problems, and attempt to resolve them independently; and provide assistance only if they deemed it absolutely necessary. The researcher noted that this may require them to change their usual way of interacting with their relative. They also were given guidance on how to respond to different questions. For example, if their family member asked them if the way they were folding a shirt was acceptable, they should reassure them and convey that they should just do it the way they normally would. At the end of the session, they were

provided with a handout (see Appendix C) that they were asked to review before initiating their two ADL task observations.

Procedures

During the initial assessment session, informed consent was obtained from the AD subjects and their family informants. The AD subjects and their informants were assessed separately. The decision as to who would be assessed first was left to the AD subject and family informant. AD subjects were administered a battery of assessments that included the MMSE and the Beck Depression Inventory. Their level of cognitive impairment was determined using the first five axes of the Brief Cognitive Rating Scale. AD subjects were asked questions to elicit their concentration abilities, recent memory, past memory, and orientation. Their “functioning and self-care abilities” were rated on the Brief Cognitive Rating Scale Axis 5 using information gleaned from the AD subjects’ self-report, the family informants’ proxy-report, and the researcher’s own observations during the administration of the AMPS. The average of the scores of these five axes was used to determine the subjects’ GDS stage. The AD subjects were then interviewed to determine which ADL tasks they normally perform, and which tasks might be possible options for choices when completing the AMPS. Each subject was observed while he or she performed at least two ADL tasks as outlined in the AMPS manual (Fisher, 1999). Demographic data including the subject’s age, gender, education level, and living situation were elicited from the subject, confirmed with the family informant, and recorded.

Family informants were administered a battery of assessments that included the MMSE to ensure that they met the inclusion criterion of being cognitively intact (i.e., scored 24 or more on the MMSE) (Tombaugh & McIntyre, 1992). All 60 family informants met this criterion (MMSE score: $M=28.9$, $SD=1.7$). Other assessments in the family informant test battery included the Beck Depression Inventory, the Caregiver Burden Inventory, and the Interpersonal Relationship Inventory. Informants completed the AMPS-PR by rating their AD family members’ ADL motor and ADL process skills based on their recollections

of their AD family members' recent performance of two ADL tasks. Demographic data, such as age, gender, education level, and living situation were recorded. The 30 family informants who were randomly assigned to the intervention group participated in a 20 to 30 minute intervention session at the end of the first session. Arrangements were made to complete a second home visit approximately 7 to 10 days later, although this time interval was not always possible ($M=7.6$ days, $SD=2.4$, $range=3$ to 19 days).

During the second assessment session, the MMSE and the AMPS were readministered to the AD subjects. Family informants rated the subjects' ADL motor and ADL process skills using the AMPS-PR, again, based on their recollections of the AD subjects' recent performance of two ADL tasks. Family informants comprising the control group were provided with the opportunity to receive the intervention after all assessments were completed.

CHAPTER 7

Analysis 1: Examination of the Psychometric Properties of the AMPS-PR

Analyses

The 60 family informants completed the AMPS-PR during Session 1 and then again during Session 2 for a total of 120 proxy-report ADL motor ability measures and 120 proxy-report ADL process ability measures. Each subjects' proxy-report ADL motor ability measure was based on ratings of the 16 ADL motor skill items on each of two ADL tasks, giving a total of 32 ADL motor skill item ratings. Similarly, each proxy-report ADL process ability measure was generated from ratings of the 20 ADL process skill items for each of two ADL tasks, giving a total of 40 ADL process skill item ratings. The total possible raw ordinal score for the AMPS-PR motor scale ranged from 32 to 128 and from 40 to 160 on the AMPS-PR process scale.

All analyses presented are based only on AMPS-PR measures of AD subjects whose total raw ordinal scores on one or both of the two scales were not at the maximum level (i.e., were not assigned 4s on all items). When scores are at a maximum level, we are unable to reliably estimate individuals' abilities. Of the possible 120 AMPS-PR ADL motor ability measures, 14 (12%) were at the maximum level; thus, further analyses were based on 88% of the original sample ($n=106$). Only 1 of the 120 proxy-report ADL process ability measures was at the maximum level; therefore, all further analyses were based on 99% of the original sample ($n=119$). Chi-square analyses and independent sample t tests were used to identify if the family informants who rated the AD subjects' ADL motor skills at the maximum level differed from the remaining informants on the basis of the AD subjects' level of dementia (mild vs. moderate), other medical diagnoses of the subjects, the subjects' observed ADL ability, and the informants' gender, age, and education.

FACETS (Linacre, 1987-1994), an MFR computer-scoring program, was used to perform two separate analyses, one for the ADL motor skill items and one for the ADL process skill items. Using Rasch analyses, the proxy-report ordinal ratings of the AD subjects'

ADL skills were transformed into equal interval, linear person ADL motor ability measures and ADL process ability measures. Normally, four facets are considered when subjects' ability measures are generated using the MFR model of the AMPS (Fisher, 1993, 1994, 1997; Fisher et al., 1994). These facets include items that vary in level of difficulty, ADL tasks that vary in challenge, raters who vary in the severity of their ratings, and persons who vary in ADL ability. All four facets are calibrated on the same line that represents the construct of ADL ability. The person ability measures generated are corrected for differences in the difficulty of the items, the challenge of the tasks performed, and the severity of the rater. These analyses are possible because all four facets are linked; that is, any subject's AMPS data can be linked to that of other subjects either through common rater(s), task(s), and/or item(s).

As discussed earlier, in these analyses of the AMPS-PR data, links could not be made between raters since no two family informants evaluated the same subject. Consequently, rater severity estimates could not be generated, and rater severity could not be accounted for when individuals' AMPS-PR ADL ability measures were generated. Therefore, all raters' severities were equated by anchoring this facet at zero, the average rater calibration.

The ADL task challenge facet was anchored using values included in the AMPS computer-scoring software (CAT & Fisher, 1994-1999). The number of family informants who used the different ADL tasks as contexts for their ratings varied considerably, with many tasks rated by only one or two raters. Consequently, adequate linkages could not be made between tasks. However, as noted earlier, the AMPS computer-scoring software is based on the data of 10,455 subjects who vary by age, gender, and medical diagnosis. Therefore, the task challenge values that were used to generate the AMPS computer-scoring software (CAT & Fisher, 1994-1999) were grounded in people's experiences in doing, and were identified as being accurate for most people most of the time (Fisher, 1999).

With both the rater severity and task challenge facets anchored, FACETS (Linacre, 1987-1994) was used to generate a variety of statistics to examine the internal scale and person response validity of the AMPS-PR ADL motor and ADL process scales, and to determine if the AMPS-PR ADL motor and ADL process scales were appropriately targeted to the AD sample. The internal validity of the AMPS-PR ADL motor and ADL process scales was examined to verify that each of the two scales conformed to the requirements for linear measurement; that is, easy skill items are more likely to be easier for all persons than are hard items, and a person is more likely to obtain a higher score on an easy skill item than on a hard skill item (Wright & Stone, 1979). The associated goodness-of-fit statistics for each item were examined. The expected value of the mean square residual (*MnSq*) (i.e., differences between observed and expected scores) is 1.0; the expected value of the standardized goodness-of-fit statistics (*z*) is zero. Items are considered to conform to the expectations of the measurement model when the infit and outfit *MnSq* values for an item are ≥ 0.6 and ≤ 1.4 with associated $z > -2$ or < 2 (Wright & Linacre, 1994). High infit and outfit *MnSq* values indicate that an item measures a different construct than the other items comprising the scale; thus, inclusion of an item with high infit and outfit *MnSq* values is problematic. In contrast, low infit and outfit *MnSq* values are less problematic. They do, however, either indicate a lack of variability in how an item was rated (i.e., most proxies assigned the same rating when rating the item), or that the item was redundant (i.e., correlated with another item and thus, the two items measured the same construct). If more than 5% of the items fail to demonstrate acceptable goodness-of-fit with the measurement model, the validity of a scale is suspect (Wright & Masters, 1979; Wright & Stone, 1982).

In a similar manner, person response validity was determined by examining each subject's *MnSq* and *z* goodness-of-fit statistics. These statistics measure the extent to which a person's pattern of responses to the skill items meet the pattern of responses predicted by the Rasch model. High goodness-of-fit statistics (i.e., $MnSq > 1.4$ and $z \geq 2.0$) and low goodness-of-fit statistics (i.e., $MnSq < 0.6$ and $z \leq -2$) both indicate that a person's pattern

of response failed to meet the expectations of the measurement model (Wright & Masters, 1982; Wright & Stone, 1979). However, high goodness-of-fit statistics indicate that the ratings for a particular subject were inconsistent with the expectations of the measurement model (i.e., the person received high scores on harder items and low scores on easier items), and thus fail to provide a good estimate of the subject's ADL ability. Low goodness-of-fit statistics, while less problematic, indicate that the ratings assigned to a subject were not variable (i.e., the person performed similarly on most items). If more than 5% of the subjects' AMPS-PR ADL ability measures fail to demonstrate acceptable goodness-of-fit with the measurement model, the validity of the scales is suspect (Wright & Masters, 1979; Wright & Stone, 1982).

The targeting of the AMPS-PR ADL motor and ADL process scales was determined by examining the relative location of the items to the proxy-reported ADL abilities of the subjects on the same linear continuum. The item difficulty calibrations indicate the location of each item on the scale's linear continuum of difficulty. Well-targeted scales are characterized by two things. First, when the items are spread out along the linear continuum without obvious gaps, the scale will be more successful in differentiating individuals on the basis of their ADL abilities. Harder items are expected to be located at one end of the linear continuum and easier items are expected to be located at the opposite end. Second, most of the subjects' person ability measures will be located close to and within the boundaries set by the hardest and easiest items, and the most challenging and least challenging tasks; and the subjects' mean ability measure will be close to the mean task challenge and item difficulty calibrations (centred at a logit value of zero). Moreover, the smaller the standard error (*SE*) associated with the subjects' AMPS-PR ADL ability measures, the better targeted the items are to the abilities of the sample. The average *SE* associated with the observed ADL ability measures for the subjects within this sample (i.e., Motor: $SE=0.29$; Process: $SE=0.21$) was used as a standard and compared with the *SE* associated with the AMPS-PR ADL motor and ADL process ability measures.

The relation between the AMPS and AMPS-PR ADL motor ability measures, and the AMPS and AMPS-PR ADL process ability measures, was examined by computing Pearson-product moment correlation coefficients. Moreover, the standardized difference (Z) was used to determine if each subject's AMPS-PR ADL measures differed significantly from those that were generated using the AMPS (Wright & Masters, 1982; Wright & Stone, 1979). The standardized difference was calculated for each subject using the difference between the AMPS ADL ability measure (d_1) and the AMPS-PR ADL ability measure (d_2) and the estimated standard error of each measure (SE) such that $Z = [d_1 - d_2] / [SE_1^2 + SE_2^2]^{1/2}$ (Wright & Stone, 1979). This statistical analysis is possible because the SE for each subject's ability measure is calculated by the FACETS Rasch analysis program (Linacre 1987-1994). A 95% confidence interval defined by $Z \pm 2.0$ was used to determine if subjects' proxy-report ADL ability measures were significantly different than the subjects' observed ADL ability measures. Proxy-report ADL ability measures were overestimated when $Z < -2$; proxy-report ADL ability measures were underestimated when $Z > 2$. Chi-square analyses were used to examine whether the subjects' level of dementia (mild vs. moderate) differentiated those subjects for whom proxy-generated measures were consistent with the observed measures from those subjects whose proxy-generated measures were overestimated and underestimated.

The stability of the AMPS-PR ADL ability measures over the two sessions was examined using the standardized difference (Z) (Wright & Masters, 1982; Wright & Stone, 1979). Only the data of those subjects whose family informants were in the control group and did not assign maximum scores when rating the subjects' ADL motor and ADL process skills were used in this analysis.

Results

ADL Motor Scale

As identified earlier, 14 (12%) of the AMPS-PR ADL motor ability measures were at the maximum level, and thus, all further results are based on 88% of the original sample's data

($n=106$). Family informants were more likely to rate their AD family members' ADL motor skills at the maximum level when the AD subjects were mildly demented ($X^2(1)=5.2, p=.02$), and had higher observed measures of ADL motor ability ($t(118)=-6.03, p<.001$). Family informants were also more likely to rate the AD subjects' ADL motor skills at the maximum level when the informants were older ($t(33.9)=-4.11, p<.001; M=69.5$ yrs, $sd=6.0$ vs. $M=61.0$ yrs, $sd=13.4$). Finally, all 14 of the family informants who rated at the maximum level were spouses.

Of the 16 AMPS-PR ADL motor skill items, 12 (75%) items demonstrated acceptable goodness-of-fit with the measurement model (infit and outfit *MnSq* values ≥ 0.6 and ≤ 1.4 with $z > -2$ and < 2) (see Table 7.1). All four ADL motor skill items that failed to demonstrate acceptable goodness-of-fit with the measurement model (i.e., Lifts, Aligns, Transports, Positions) had low infit and outfit statistics. When examined more closely, the raters assigned the subjects the same rating on each of these four items.

Of the 106 family informants whose ratings of the subjects' ADL motor skills contributed to the item difficulty calibrations, 36 (34%) failed to demonstrate acceptable goodness-of-fit with the measurement model. Most ($n=35$) of the subjects' associated infit and outfit *MnSq* values were low (< 0.6 with $z \leq -2$). These subjects' proxy-report ADL motor skill ratings lacked variability (i.e., raters assigned almost all 4s, all 3s, or all 2s); and thus these items failed to discriminate between subjects. Only one subject's associated infit and outfit *MnSq* values were high (> 1.4 with $z \geq 2$), indicating that the proxy's responses were inconsistent with the expectations of the measurement model (i.e., easy items were rated low and hard items were rated high).

Table 7.1

AMPS-PR Motor Scale Item Difficulty Calibrations (logits)

Items	Measure	se	Infit		Outfit	
			MnSq	z	MnSq	z
Lifts	0.56	0.14	0.6	-5	0.5	-3*
Moves	0.53	0.13	0.6	-4	0.6	-2
Grips	0.33	0.12	0.8	-3	0.8	-1
Aligns	0.26	0.15	0.4	-8*	0.4	-4*
Reaches	0.25	0.12	0.6	-4	0.6	-2
Transports	0.20	0.14	0.5	-6*	0.5	-3*
Positions	0.06	0.13	0.5	-6*	0.6	-3
Coordinates	-0.03	0.12	0.7	-3	0.7	-2
Bends	-0.05	0.13	0.6	-5	0.6	-3
Manipulates	-0.08	0.11	0.8	-2	0.8	-1
Endures	-0.11	0.11	0.8	-2	0.9	0
Calibrates	-0.18	0.11	0.7	-3	1.0	0
Stabilizes	-0.20	0.11	0.9	-1	1.0	0
Flows	-0.27	0.11	0.8	-1	1.0	0
Walks	-0.33	0.13	0.6	-5	0.6	-3
Paces	-0.92	0.10	1.0	0	1.1	0

Note: * *MnSq* values < 0.6 or > 1.4 with $z \leq -2$ or ≥ 2

The AMPS-PR ADL motor item skill difficulty calibrations ranged from -0.92 to 0.56 logit (see Table 7.1), and were well spaced along the linear continuum, except for a large gap of 0.59 logit between the two hardest items, Walks (-0.33 logit) and Paces (-0.92 logit). This gap between Walks and Paces is somewhat problematic as our ability to differentiate between subjects whose ADL motor ability measures are within this range is reduced. The subjects' mean proxy-report ADL motor ability measure was 1.26 logits ($SD=1.2$ logits) (see Table 7.2). At 0.38 logits ($SD=0.16$; range=0.23 to 1.57 logits), the mean *SE* associated with their AMPS-PR ADL motor ability measures was much greater than the *SE* of the same subjects' observational ADL motor ability measures (i.e., $SE=0.29$). The large *SE* associated with the subjects' AMPS-PR ADL motor ability measures indicates that the items were not well targeted to the sample. Moreover, almost 20% ($n=21$) of the

AD subjects' AMPS-PR ADL motor ability measures were greater than 3.0 logits with the associated SE ranging from 0.42 to 1.82 logits. In general, the family informants did not use the full range of available ratings (1 through 4) when evaluating the AD subjects' ADL motor abilities: 37% of their ratings were at the competent level (4), 38% at the questionable level (3), and 23% at the ineffective level (2), but only 3% of their ratings were at the deficit level (1). This pattern of rating is inconsistent with expectations based on the subjects' observed ADL motor ability measures, and indicates that many subjects in this sample were ineffective in their performance of ADL motor skills.

Table 7.2

Mean AMPS and AMPS-PR ADL Motor and ADL Process Ability Measures (logits)

	AMPS		AMPS-PR	
	<i>M</i>	(<i>SD</i>)	<i>SE</i>	(<i>SD</i>)
Motor (<i>n</i> = 106)	0.77	(1.05)	.29	(.06)
Process (<i>n</i> = 119)	-0.08	(0.76)	.21	(.04)

The relation between the AD subjects' AMPS and AMPS-PR ADL motor ability measures was only moderate ($r(106) = .60$) (see Figure 7.1). More specifically, 70% ($n = 84$) of the AD subjects' AMPS and AMPS-PR ADL motor ability measures were not significantly different ($Z > -2$ and < 2). The remaining 30% of the AMPS and AMPS-PR ADL motor ability measures were significantly different; 25.8% ($n = 31$ including the 14 proxy-reports that assigned maximum scores) of their ADL motor ability measures were overestimated by the family informants, while only 4% ($n = 5$) were underestimated. Subjects' level of dementia did not differentiate those subjects whose family informants' reports were concordant with the observed measures from those whose family informants' reports were overestimated ($X^2 = 1.2, p = .27$) or underestimated ($X^2 = 0.35, p = .55$).

The AMPS-PR ADL motor ability measures generated by the 26 family informants who participated in the control group and whose ratings of their family members were not at the maximum level were compared. Almost 85% ($n=22$) of the Session 1 and 2 AMPS-PR ADL motor ability measures were stable (i.e., $Z > -2$ and $Z < 2$) when reevaluated a mean of 7.6 days later ($sd=2.4$; $range=3$ to 19 days). Of the four family informants whose Session 1 and 2 AMPS-PR ADL motor ability measures were significantly different, all rated their relatives as being more able at Session 2 (see Table 7.3).

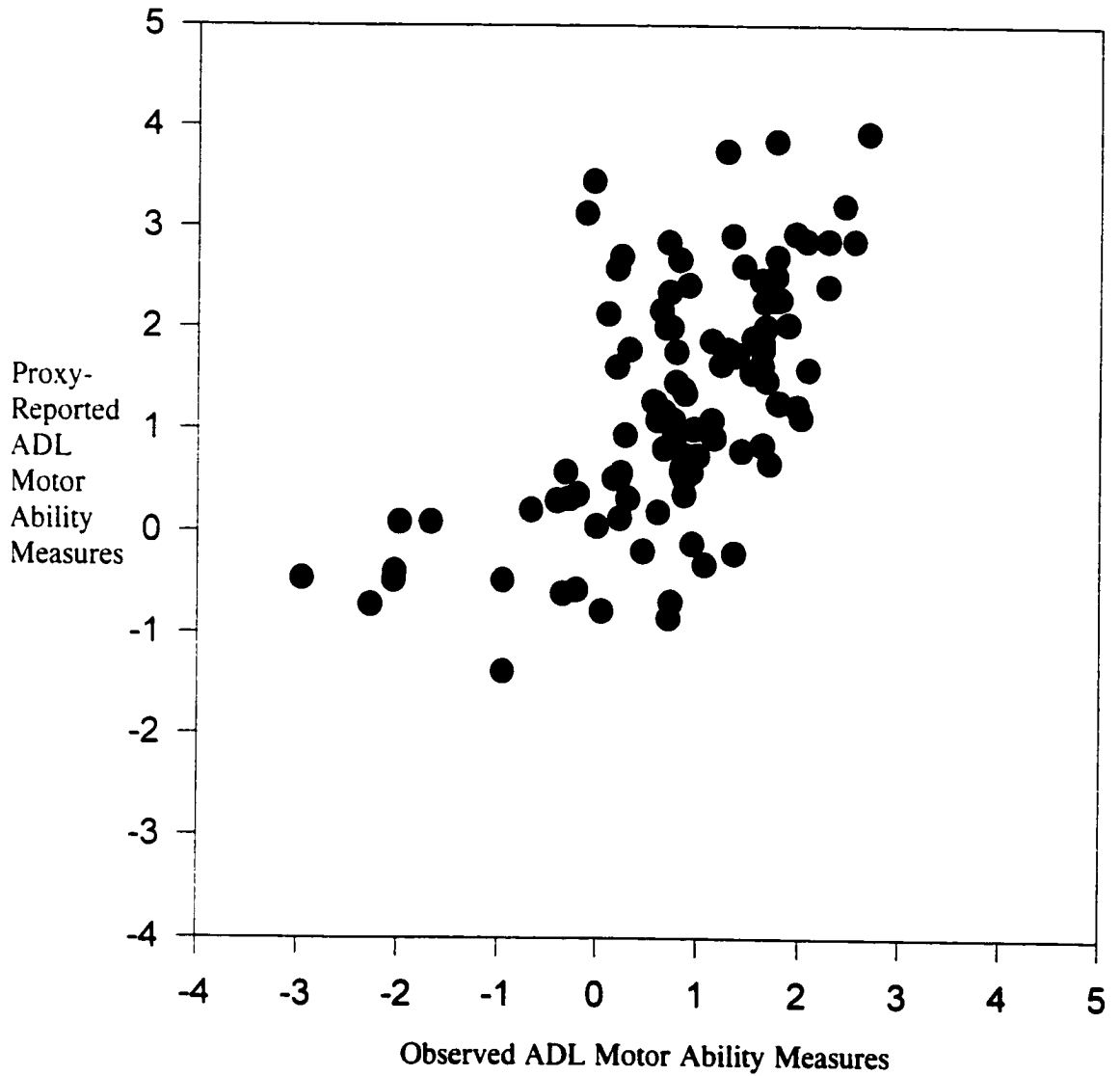
Table 7.3

AMPS-PR ADL Motor Ability Measures (logits) and Z that Differed Significantly Between Sessions 1 and 2

Subject Number	Session 1		Session 2		Z
	Ability Measure	SE	Ability Measure	SE	
38	0.92	0.34	2.67	0.45	-3.10
42	0.63	0.39	2.84	0.38	-4.06
47	0.13	0.28	0.94	0.23	-2.24
56	0.57	0.35	2.35	0.39	-3.40

Figure 7.1

Relation between AMPS and AMPS-PR ADL motor ability measures ($n=106$)
($r=.58$)



ADL Process Scale

Only 14 (70%) of the 20 AMPS-PR ADL process skill items demonstrated acceptable goodness-of-fit with the measurement model (infit and outfit *MnSq* values ≥ 0.6 and ≤ 1.4 with $z > -2$ and < 2)(see Table 7.4). All six items that failed to demonstrate acceptable goodness-of-fit with the measurement model had low infit and outfit statistics which suggested that these items were redundant. Initiates, Continues, and Organizes represent time and spatial organization skills. Informants generally rated a given subject the same for each of these items. Similarly, the lack of variability in proxies' ratings of Adjusts, Accommodates, and Benefits suggested there was redundancy between these items.

Table 7.4

AMPS-PR Process Scale Item Difficulty Calibrations (logits)

Items	Measure	SE	Infit		Outfit	
			<i>MnSq</i>	<i>z</i>	<i>MnSq</i>	<i>z</i>
Uses	1.76	0.14	1.4	2	1.1	0
Handles	0.56	0.11	0.6	-5	0.7	-2
Navigates	0.41	0.11	0.6	-6	0.6	-3
Terminates	0.36	0.11	0.6	-5	0.6	-3
Continues	0.20	0.11	0.5	-7*	0.6	-4
Inquires	0.14	0.09	0.7	-3	0.7	-2
Organizes	0.12	0.11	0.5	-7*	0.5	-5*
Sequences	0.08	0.10	0.6	-5	0.7	-3
Restores	0.07	0.10	0.7	-3	0.7	-2
Chooses	-0.10	0.10	0.6	-5	0.6	-3
Notices/Responds	-0.10	0.09	0.7	-3	0.9	0
Paces	-0.11	0.09	0.8	-2	0.9	0
Heeds	-0.14	0.10	0.7	-4	0.7	-3
Adjusts	-0.20	0.11	0.5	-7*	0.5	-5*
Accommodates	-0.33	0.11	0.5	-6*	0.6	-4
Gathers	-0.37	0.10	0.6	-5	0.7	-3
Attends	-0.42	0.09	0.7	-3	0.8	-2
Initiates	-0.52	0.12	0.5	-7*	0.5	-6*
Searches/Locates	-0.61	0.09	0.9	-1	0.9	0
Benefits	-0.81	0.12	0.5	-7*	0.5	-6*

Note: * *MnSq* values < 0.6 or > 1.4 with $z \leq -2$ or ≥ 2

Of the 119 AMPS-PR evaluations that contributed to the item difficulty calibrations, 55 (46%) failed to demonstrate acceptable goodness-of-fit with the measurement model (infit and outfit *MnSq* values < 0.6 and > 1.4 with $z \leq -2$ and ≥ 2). Six subjects' associated infit and outfit *MnSq* values were high (> 1.4 with $z \geq 2$), which indicated that the proxies' responses were inconsistent with the expectations of the measurement model (i.e., easy items were rated low and hard items were rated high). The remaining 49 subjects' associated infit and outfit *MnSq* values were low (< 0.6 with $z \leq -2$). This indicated that there was a lack of variability in the family informants' ratings of the 20 ADL process skill items for these subjects (i.e., all 4s, all 3s, or all 2s).

The AMPS-PR ADL process skill item difficulty calibrations ranged from -0.81 to 1.76 logits (see Table 7.4) and were generally well spaced along the linear continuum except for a large gap of 1.20 logits between the two easiest items Uses (1.76 logits) and Handles (0.56 logit). This gap is of limited concern since all subjects were rated as being more able than these items. Therefore, the potential challenge associated with differentiating between subjects whose AMPS-PR ADL process ability measures were low was not relevant in this sample. The AD subjects' mean AMPS-PR ADL process ability measure of 0.39 logit ($SD = 1.03$) was well within the effective range of the AMPS-PR ADL process scale (see Table 7.2). Compared to the mean *SE* of 0.21 logit for the same subjects' AMPS ADL process ability measures, the mean *SE* associated with their AMPS-PR ADL process ability measures was higher ($M = 0.29$ logit; $SD = .07$; $range = 0.18$ to 0.51 logit). Seven of the nine AMPS-PR ADL process ability measures that were above 2.0 logits had an associated *SE* of .42 logit or more. Compared to their ratings of the ADL motor skill items, the proxies made better use of the range of available ratings (1 through 4) when evaluating their family members' ADL process skills with 91% of their ratings fairly evenly divided between the competent (4), questionable (3), and ineffective (2) levels (i.e., 26%, 37%, and 29% respectively).

There was a moderate relation between the AMPS and AMPS-PR ADL process ability measures ($r(119) = .55$) (see Figure 7.2). Only 56.7% ($n=68$) of the AD subjects' AMPS and AMPS-PR ADL process ability measures were not significantly different ($Z \leq 2$ and ≥ -2). Of the remaining AMPS and AMPS-PR ADL process ability measures that were significantly different, 37.5% ($n=45$; including the one family informant who assigned maximum scores) of the AMPS-PR ADL ability measures were overestimated ($Z < -2$) while only 6% ($n=7$) were underestimated ($Z > 2$). Subjects' level of dementia did not differentiate those subjects whose family informants' reports were concordant with the observed measures from those whose family informants' reports were overestimated ($X^2 = 1.2, p = .26$) or underestimated ($X^2 = 0.88, p = .35$).

Session 1 and 2 AMPS-PR ADL process ability measures generated by the 29 family informants who participated in the control group and whose ratings of their family members were not at the maximum level were compared using a standardized difference (Z). Seventy-six percent ($n=22$) of the AD subjects' Session 1 and 2 AMPS-PR ADL process ability measures were stable ($Z \geq -2$ and ≤ 2), when reevaluated a mean of 7.6 days later ($SD = 2.4$; $range = 3$ to 19 days). Of the seven Session 1 and 2 AMPS-PR ADL process ability measures that were significantly different, five were higher at Session 2 while two were lower (see Table 7.5).

Figure 7.2

Relation between AMPS and AMPS-PR ADL process ability measures ($n=119$)
($r=.55$)

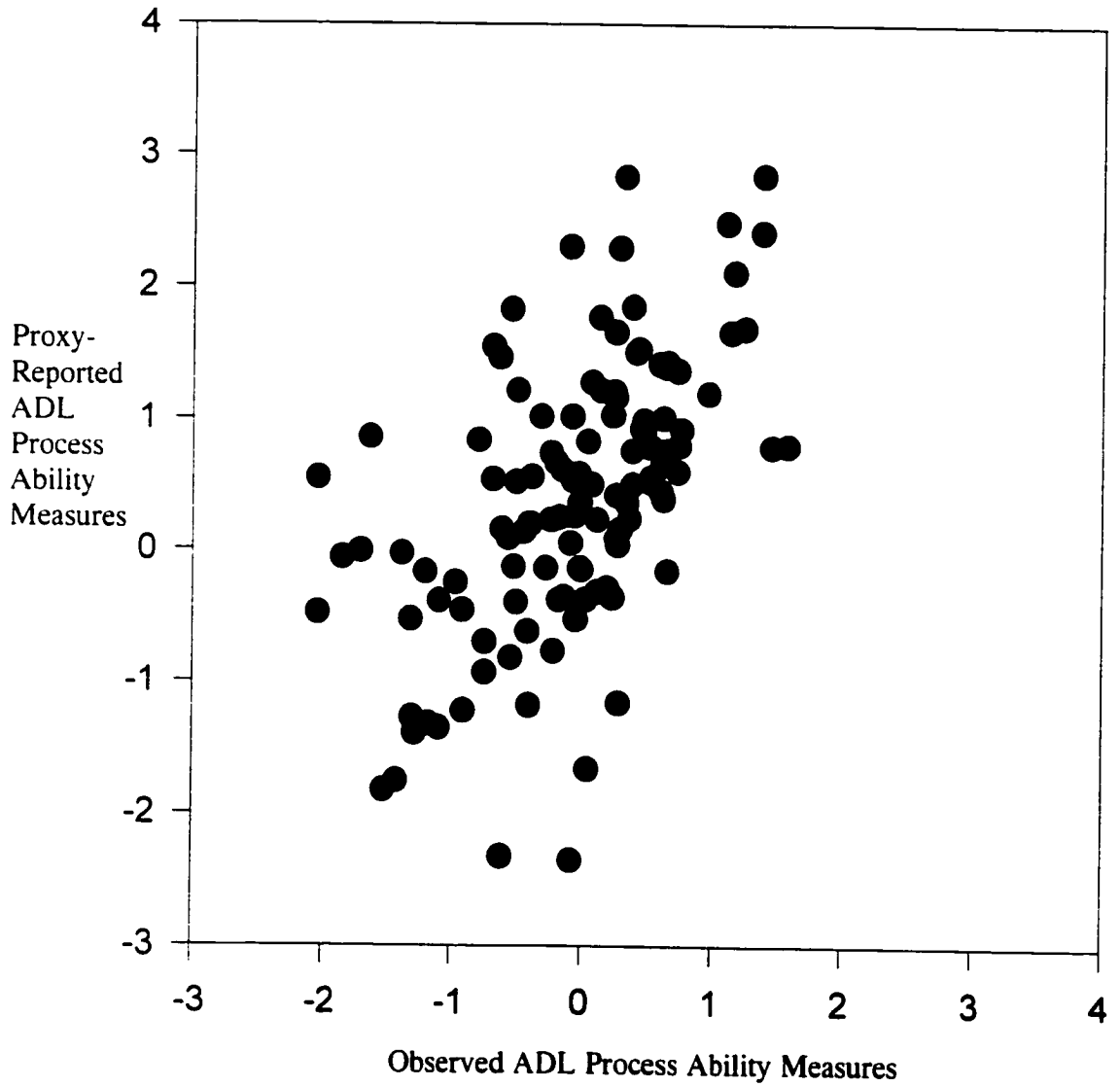


Table 7.5

AMPS-PR ADL Process Ability Measures (logits) and Z that Differed Significantly Between Sessions 1 and 2

Subject Number	Session 1		Session 2		Z
	Ability Measure	SE	Ability Measure	SE	
2	0.93	0.24	1.77	0.29	-2.23
22	0.54	0.20	-0.40	0.24	3.01
42	0.60	0.42	2.83	0.49	-3.46
47	-1.18	0.25	0.20	0.21	-4.23
56	-0.48	0.28	0.55	0.25	-2.74
57	-0.53	0.23	-1.32	0.24	2.38
60	-0.06	0.27	0.86	0.36	-2.04

Analysis 2: Psychosocial Factors Affecting Family Informants' Reports of AD Subjects' ADL Competence

Analyses

Differences in the AMPS and AMPS-PR ADL ability measures at Session 1 were calculated for each subject whose AMPS-PR ADL measures were not at the maximum level (Motor: $n=54$; Process: $n=59$). Using multiple regression analyses, a model comprised of five psychosocial factors was examined to determine if the AMPS-PR ADL motor and AMPS-PR ADL process ability difference scores were systematically biased by these psychosocial variables. The psychosocial variables examined included family informants' reports of their perceived level of depressive symptomatology (Beck Depression Inventory); time-dependence caregiver burden (Caregiver Burden Inventory time-dependence subscale); and level of social support, reciprocity, and conflict within their relationship with the AD subject (Interpersonal Relationship Inventory Social Support, Reciprocity, and Conflict subscales).

Results

The mean difference between the observed and proxy-report ADL motor ability measures at Session 1 was -0.4 logit ($SD=0.94$; range = -3.25 to 1.56 logits) such that proxy-report ADL motor ability measures were higher. The relative contribution of the five psychosocial variables in the AMPS and AMPS-PR ADL motor ability measures was examined. A regression analysis yielded a multiple R of 0.24 , $F(5,48)=0.58$, $p=.71$ (see Table 7.6). Accounting for less than 6% of the total variance in the AMPS and AMPS-PR ADL motor ability difference, these results indicate that informants' level of depressive symptomatology, time-dependence caregiver burden, and three aspects of the quality of the informant-subject relationship (i.e., social support, reciprocity, and conflict) do not contribute significantly to the difference in the observed-proxy ADL motor ability measures.

Table 7.6

Regression Analysis Examining the Contributions of Psychosocial Variables to the Difference in AMPS and AMPS-PR ADL Motor Ability Measures (logits)

Variables	Beta Weights	<i>F</i>	<i>p</i>	Zero-order Correlations <i>r</i>
Depression	-0.16			.12
Time-Burden	0.01			.01
Conflict	0.06			-.02
Reciprocity	0.24			-.14
Social Support	-0.15	0.58	.71	-.03

The mean difference between the AMPS and AMPS-PR ADL process ability measures at session 1 was -0.42 logit ($SD = .77$; range = -2.01 to 1.70 logits) such that proxy-report ADL process ability measures were higher. In the regression analysis of the AMPS-AMPS-PR ADL process ability measure difference, the model comprised of the same five psychosocial variables yielded a multiple R of 0.42, $F(5,53) = 2.29$, $p = .06$. The model accounted for less than 18% of the total variance in the difference in the AMPS-AMPS-PR ADL process ability measures. Examination of the beta weights in this regression equation revealed that only perceived social support contributed any significant variance to the prediction of the difference in the AMPS-AMPS-PR ADL process ability measures (see Table 7.7), although there was evidence of a trend for self-reported depressive symptomatology.

Table 7.7

Regression Analysis Examining the Contributions of Psychosocial Variables to the Difference in AMPS-AMPS-PR ADL Process Ability Measures (logits)

Variables	Beta Weights	<i>F</i>	<i>p</i>	Zero-order Correlations <i>r</i>
Depression	0.28*			.22
Time-Burden	0.36			.08
Conflict	-0.29			.05
Reciprocity	0.07			-.10
Social Support	-0.43**	2.29	0.06	-.32**

Note: * $p = .06$; ** $p \leq .01$

Analysis 3: Effectiveness of a Brief Educational Intervention on Family Informants' Ratings

Analyses

The difference between the AMPS-AMPS-PR ADL ability measures for each subject for each of the two assessment sessions was computed. Then the difference between Session 1 and Session 2 AMPS-AMPS-PR ADL ability measure difference was calculated. A 3-way repeated measures analysis with two within subject factors (i.e., Type -- Motor vs. Process difference -- and Time -- Session 1 vs. Session 2) and one between subject factor (intervention vs. control group) was used to determine if the intervention was effective in reducing the difference between the subjects' AMPS and AMPS-PR ADL ability measures.

A standardized difference (Z) was calculated for each subject using the Session 1 difference between the AMPS-AMPS-PR ADL ability measures (d_1), the Session 2 difference between the AMPS-AMPS-PR ADL ability measures (d_2), and the estimated standard of error of each difference (SE) such that $Z = [d_1 - d_2] / [SE_1^2 + SE_2^2]^{1/2}$ (Wright & Stone, 1979). A 95% confidence interval defined by $Z \pm 2.0$ was used to determine if the Session 1 and Session 2 differences in the AMPS-AMPS-PR ability measure difference for subjects in the intervention group were significantly different from subjects in the control group. A significant difference ($Z < -2$ and > 2) indicates that relative to the observed ADL ability measures, the AMPS-PR ADL ability measures were either overestimated ($Z < -2$) or underestimated ($Z > 2$). Rates of agreement and disagreement (both overestimation and underestimation) were also calculated. Chi-square analyses were computed to determine if there were significant differences between the intervention and control groups on the basis of the rate of agreement and disagreement between the AMPS-AMPS-PR ADL ability measures.

Results

There was a significant group effect ($F(49,1)=4.7, p=.03$). More specifically, the control group had a greater discrepancy between the observed and proxy-report ADL motor ability

measures at Session 1 and Session 2 (see Table 7.8). There were, however, no time ($F(49,1)=1.17, p=.28$), type ($F(49,1)=1.35, p=.25$), group by time ($F(49,1)=0.32, p=.57$), group by type ($F(49,1)=3.22, p=.08$), or group by time by type ($F(49,1,1)=0.60, p=0.44$) effects. Moreover, there was no significant difference in the rate of agreement–disagreement with the observationally-generated ADL ability measures between the two groups ($\chi^2(2)=0.63, p=0.43$) (See Table 7.9).

Table 7.8

Mean Differences in the AMPS–AMPS-PR ADL Ability Measures at Sessions 1 and 2 by Group

	Intervention Group (n=25)		Control Group (n=26)	
	Session 1	Session 2	Session 1	Session 2
AMPS–AMPS-PR Mean Difference	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
Motor	-0.19(0.90)	-0.24(0.95)	-0.59(0.99)	-0.89(1.08)
Process	-0.35(0.81)	-0.28(0.95)	-0.49(0.74)	-0.72(0.94)

Table 7.9

Proportion of Agreement, Overestimation, and Underestimation by Family Informants

	Intervention Group		Control Group	
	Session 1	Session 2	Session 1	Session 2
ADL Motor Ability	(n=25)		(n=26)	
Agreement	18 (72%)	18 (72%)	20 (77%)	16 (61.5%)
Overestimation	4 (16%)	5 (20%)	6 (23%)	10 (38.5%)
Underestimation	3 (12%)	2 (8%)	-----	-----
ADL Process Ability	(n=30)		(n=29)	
Agreement	17 (57%)	20 (67%)	16 (55.0%)	15 (52%)
Overestimation	10 (33%)	7 (23%)	12 (41.5%)	14 (48%)
Underestimation	3 (10%)	3 (10%)	1 (3.5%)	-----

CHAPTER 8

Discussion

ADL assessments have a variety of potential uses in clinical practice and research settings. These include: differentiating and classifying individuals into specific groups; predicting individuals' potential to benefit from specific types of supports and services; guiding the development of interventions; and measuring meaningful change over time. Whatever ADL assessment is selected for use, it should clearly evaluate the actions of doing meaningful tasks; measure a unidimensional construct of ADL ability; and generate unbiased, stable, and responsive ADL ability measures. Only when these criteria are met, should the issue of cost-effectiveness be considered.

Both observational and proxy-report assessments have potential for use. In some situations, one type of assessment may be the ideal choice. For example, in occupational therapy clinical practice settings, only observational assessments can provide the clinical examiner with an indepth understanding and first-hand appreciation of an individual's strengths, problems, and potentials. However, in research settings, some individuals with AD may be unwilling or unable to participate in the observational assessment process, or family caregivers may be concerned that the need for individuals' active participation in an observational assessment may cause undue upset. In these situations, proxy-report ADL assessments may prove to be a useful substitute. Moreover, when data collection is restricted to telephone interviews, proxy-report assessments may be an accessible alternative. In clinical practice settings, proxy-report assessments, completed on the basis of information from family informants, may be used by clinicians to assess family informants' understanding of the AD subjects' situation and develop collaborative working relationships based on shared understandings. Most importantly, however, the decision about whether to use an observational or proxy-report ADL assessment should be grounded in a clear understanding of why the assessment is being administered.

The findings of this research suggest that, despite several existing problems, further development of the AMPS-PR may be warranted. Its direct focus on the meaningful doing of ADL tasks yields advantages over other available proxy-report ADL assessments. These preliminary findings also suggest that the AMPS-PR ADL motor and ADL process scales have potential for further development for use in clinical practice and research settings. Although only 75% of the AMPS-PR ADL motor skill items and 70% of the ADL process skill items demonstrated acceptable goodness-of-fit with the expectations of the measurement model, the remaining 12 ADL motor skill items and 14 ADL process skill items likely represent unidimensional constructs of ADL motor and ADL process ability. Moreover, all of the items that failed to demonstrate acceptable goodness-of-fit with the measurement model had low infit and outfit *MnSq* values. Since these items were redundant and did not make a significant or unique contribution to the subjects' ADL ability measure estimations, some or all of these items could potentially be eliminated during future revisions. As these items are removed, however, the unidimensionality of all remaining items must be formally examined.

Currently, the person-response validity of the AMPS-PR is unacceptable. Only 66% of the subjects' proxy-report ADL motor ability measures and 54% of the subjects' proxy-report ADL process ability measures demonstrated acceptable goodness-of-fit with the expectations of the measurement model. Although the family informants' ratings were not erratic or markedly inconsistent given the measurement model (i.e., easy items were not rated low and hard items were not rated high), some family informants appeared to have had a set response pattern such that they rated most items the same way. Moreover, the high *SEs* associated with the subjects' AMPS-PR ADL motor and ADL process ability measures indicated that the measures did not provide precise estimates of these subjects' ADL abilities. These findings reflect the difficulty experienced by many family informants when required to make complex judgements on the basis of their recollections of their AD relatives' ADL abilities. Changes in the way the AMPS-PR is administered may serve to

improve the person-response validity of the AMPS-PR ADL motor and ADL process scales and will be discussed later in this chapter.

When AMPS and AMPS-PR ADL ability measures were compared, there was agreement in the case of 62.5% of the ADL motor ability measures and in 56.5% of the ADL process ability measures. While the majority of family informants provided reports of family members' ADL competence that were consistent with observations made by an experienced occupational therapist, there were numerous discrepancies. Moreover, when there were discrepancies, family informants were more likely to overestimate the AD subjects' ADL abilities than underestimate them. In this study, those family informants who were most likely to overestimate their AD family members' ADL motor and/or ADL process abilities could not be identified. Moreover, substantial systematic or unsystematic biases that affected their ratings could not be identified. While this is not a unique problem of the AMPS-PR, it warrants further consideration.

The pattern of overestimation of AD family members' ADL abilities by family informants was consistent with the findings of an earlier study by Doble and colleagues (1999b). The proxy-reports of family informants using the OARS ADL Scale were compared to an assessment of an occupational therapist's ratings of the subjects' level of ADL competence. For all cases in which there was disagreement between the therapist's overall rating of the subjects' level of ADL competence and the family informants' ratings, the informants overestimated their family members' level of ADL independence. These findings, however, are in sharp contrast to the conclusions drawn by other researchers (cf. DeBettignies et al., 1993; Karagiozis et al., 1998; Mulnard & Cotman, 1992; Zanetti et al., 1997). When compared with highly structured ADL assessments that actually evaluated individuals' underlying cognitive capacities within the context of simulated ADL tasks, family informants are more likely to underestimate their AD family members' level of independence.

It is possible that these discrepancies are attributable to how occupation is conceptualized within the different ADL assessments, and to the raters' views of what constitutes occupation. In the AMPS and AMPS-PR, the quality of individuals' task performance is evaluated while they perform real-life tasks. As part of their training, AMPS examiners focus their observations on the quality of doing. Even though the AMPS-PR skill items are designed to focus family informants' attentions to the quality of doing, family informants are still more likely to focus their attention on *what* their family members did rather than *how* they did it. If individuals with AD are able to complete the task, even if the quality of the completed task is compromised, family informants will generally have a positive impression of what they did. Similarly, most performance-based assessments (other than the AMPS), and proxy-report ADL assessments (other than the AMPS-PR) are focused on individuals' ability to independently complete tasks or specific task steps. As long as individuals are able to complete tasks, assigned ratings will typically indicate that individuals are independent, and thus overestimation may be evident. In contrast, when others judge that individuals are unable to perform at an acceptable standard without assistance, lower ratings will be assigned, and underestimation of individuals' ADL abilities may occur (Doble et al., 1999).

In the current study, when the responses of the family informants who overestimated their AD family members' ADL motor and ADL process abilities were examined, two different response patterns were found. First, some family informants assigned maximum or unexpectedly high scores when asked to rate each of the 16 ADL motor and 20 ADL process skill items for two tasks. In fact, 12% of the family informants rated their family members' ADL motor skills at the maximum level (i.e., they assigned ratings of 4 or competent on all 16 motor skill items for both ADL tasks evaluated). Second, the *SE* associated with these subjects' AMPS-PR ADL motor and ADL process ability measures was high, and thus, the reliability of the AMPS-PR ADL ability measures generated by these family informants is suspect.

This pattern of rating may indicate the individuals' occupational skills are being evaluated when performing a task that does not present sufficient challenge (Fisher, 1999; Kirkley & Fisher, 1999). Some family informants' contact time is limited to doing ADL tasks for the AD subjects (e.g., paying their bills, preparing meals, doing their laundry, taking them shopping), or simply spending time together, where the focus is more on socializing than doing. This potential problem must be acknowledged when family informants are identified. The possibility that no informed proxy is available must be recognized; in such cases, proxy-report ADL assessments should not be used as outcome measures for intervention studies.

Second, some family informants who overestimated their family members' ADL abilities, appeared to perceive their family members' ADL abilities accurately, as judged by the verbal descriptions they gave the examiner of their observations of their family members. Nevertheless, incongruity between their statements and their assigned ratings were evident, such that they overestimated the AD subjects' abilities. Despite the examiner's efforts to clarify rating strategies such as "rate what you actually saw" and "when in doubt between two ratings, always assign the lower rating," these family informants still assigned higher than expected ratings. Numerous anecdotal examples of this situation exist. One family informant reported that she noticed that her husband hesitated before initiating many steps of a specific task and made what she called "false starts." However, rather than rating his initiating skill as ineffective, as would be expected of an experienced AMPS rater, the family informant assigned a rating of 4 (competent). This may indicate that some items were not clearly defined, or that the rating criteria were not understood by the informants. This pattern of reporting also may reflect the challenge facing family informants who must reconcile their desires to maintain their former images of their family members as competent individuals despite increasing evidence that the quality of their doing is changing. If this is the case, the accuracy of the ratings of this subgroup of family informants may be improved if they are first provided with an opportunity to reconcile their conflicting feelings.

These examples illustrate the importance of accounting for individual rater bias in ADL assessments. As long as raters do not assign maximum or minimum ordinal ratings for all items, it is theoretically possible to account for an individual rater's bias by entering their bias as a facet in the MFR analysis. However, as discussed earlier, such linkages can only be achieved by having overlap between raters who each rate some of the same individuals. This requirement for multiple data linkages, unfortunately, is neither a practical nor feasible alternative when we consider applying this type of analysis to family informants' proxy-reports.

In an effort to address this problem in the current study, an alternative approach was taken. Five psychosocial variables were selected because of their theoretical potential to exert a systematic bias. If these variables were found to exert a systematic bias on family informants' ratings and account for a large amount of the variance between AMPS and AMPS-PR ADL ability measures, routine evaluation of these factors might enable us to account for rater biases when generating AMPS-PR ability measures.

The proposed model, however, failed to account for a significant amount of the variance in the difference between AMPS and AMPS-PR ADL motor ability measures, and accounted for only 17% of the variance in the AMPS and AMPS-PR ADL process ability measures. Only family informants' level of perceived social support within their relationship with their AD relatives was significantly correlated to the difference in the AMPS and AMPS-PR ADL process ability measures ($r = .32$), and contributed significantly to the variance in the difference in the AMPS and AMPS-PR ADL process measures ($\beta = 0.433$, $p = .009$). This finding indicates that AMPS and AMPS-PR ADL ability measures were more discrepant when family informants perceived that they received a high level of social support from their AD relatives. As discussed earlier in Chapter 5, when family informants perceive that their AD family members provide or would want to provide them with appropriate social support, a halo effect may be evident (Feldman, 1994). Thus, the validity of proxy-reports of their AD family members' capacity for

providing social support and their competence when performing ADL tasks may both be biased and not accurately reflect the actual amount of social support provided by AD subjects or accurately reflect their ADL ability. As Feldman (1994) suggested, when family informants lack adequate information; possess only ambiguous or inconsistent information; or lack a clear conceptualization of the construct being evaluated; their judgements and ratings are more likely to reflect their general regard for their AD family members. Although family informants may be able to make appropriate observations, these findings suggest that they do not use all of the available information to make their judgements.

Although family informants' level of self-reported depressive symptomatology did not contribute significantly to the variance in the AMPS-AMPS-PR ADL process difference measure ($\beta = -0.278, p = .06$), the trend was sufficient to warrant further examination. The inverse relation between the variables indicates that the difference in the AMPS-AMPS-PR ADL process measures was greatest for family informants who reported low levels of depressive symptomatology. In contrast, the AMPS-PR ADL measures generated by family informants who reported high levels of depressive symptomatology were more likely to be comparable to those generated by the researcher. This trend, however, also may be attributed to a tendency for persons with low levels of depressive symptomatology to under-report the extent to which their own mood is affected by the caregiving situation, and under-report the difficulties their AD family members experience performing ADL tasks.

In an effort to address the problem of informant bias, a brief educational intervention was provided. The goals were to improve family informants' understanding of the importance of occupation in individuals' daily lives, and their abilities to make relevant observations related to their AD family members' ADL motor and ADL process skills. The intervention was based on the assumption that family informants may lack adequate preparation which, in turn, may reduce the accuracy of their observations and their abilities

to make valid judgements. The results of the analysis, however, indicated that the intervention was not effective. Although the mean difference between the AMPS and AMPS-PR ADL motor ability and ADL process ability measures decreased at Session 2 for the intervention group, the effects were not statistically significant. Given the variability within the rates of agreement and disagreement between the AMPS and AMPS-PR ADL ability measures for the intervention and control groups, the expectation that the intervention would have a large effect (Cohen, 1992) may have been unrealistic. Therefore, the size of the sample may have played a role in these nonsignificant findings. However, if the intervention was not as brief and easy to administer as a proxy-report assessment, any inherent advantages of using a proxy-report assessment rather than an observational assessment would be diminished.

Although most of the family informants whose reports were comparable to the occupational therapist examiner's reports at Session 1 remained comparable at Session 2, some informants became more lenient at Session 2. This subgroup of family informants may have been affected by the context in which the ratings were elicited. During Session 1, all family informants completed the AMPS-PR only after they had completed a battery of other assessments. These assessments provided the family informants with a foundation for reflecting on how AD had affected their family members' occupational behaviour, cognitive abilities, and social behaviours; as well as how their family members' diagnosis affected their own lives. However, during Session 2, only the AMPS-PR was readministered to the family informants. Perhaps because family informants were not given an opportunity to become immersed again in feelings aroused by their AD family members' condition, their level of rater severity shifted such that they became more lenient. Their ratings at Session 2 may also have reflected a tendency to make light of some problematic issues revealed during Session 1, and to assume a more protective stance when reporting on their family members' ADL abilities during Session 2.

In contrast, there was a shift in some of the family informants whose initial Session 1

reports were not comparable to those generated by the occupational therapist examiner, such that their Session 2 reports were comparable to those of the researcher. While the brief educational intervention provided may have been effective for those family informants who participated in the intervention group, this same reporting shift was evident in some family informants who were part of the control group. It is possible that for these informants, simple exposure to the AMPS-PR during Session 1, regardless of their participation in the intervention or control groups, was sufficient to refine their observations and ratings. By completing the AMPS-PR during Session 1, they may have become more familiar with the ADL motor and ADL process skill items, and directed their attention to consider how much effort was exerted, and how efficiently, safely, and independently their family member performs these skills. Even though not instructed to, this subgroup of control group family informants may have made a more concerted effort to observe their AD relatives' ADL motor and ADL process abilities during the time between the two assessment sessions.

What are the implications for future research? The findings of this study together with other research findings have failed to provide clear insights into how family informants' reports may be biased by psychosocial variables such as informants' perceived level of depressive symptomatology; time-dependence caregiver burden; and social support, reciprocity, and conflict within the informant–subject relationship. It is possible that the lack of significant findings reflect problems associated with the assessments used to evaluate these constructs. These findings, however, do not rule out the possibility that some, all, or other psychosocial variables may affect the ratings of family informants. Given the complexity of individuals' feelings, social relationships, and the processes involved in making judgements about others' observed behaviours, a clear and comprehensive theoretical framework is also warranted.

Even though the intervention had no significant effect in reducing the difference in the intervention group's AMPS–AMPS-PR ADL motor and ADL process ability measures

when compared to that of the control group, the difference between the two measures for the control group actually increased. Strategies for selecting family informants who might benefit most from the intervention should be tested. It may be feasible to develop a self-instructional videotaped intervention program or computer-based intervention program that family informants could use at their own convenience.

Although there would be no cost savings, congruence between AMPS and AMPS-PR ADL ability measures may be improved by having the trained AMPS examiners rate the subjects' ADL abilities on the basis of information elicited from family informants. This approach would enable the trained AMPS examiners to use their own knowledge and understanding of the rating criteria. If such proxy-report measures were comparable to those generated when an occupational therapist directly observed AD subjects' actual task performance, this version may be a feasible alternative in some research settings. When a change in individuals' ADL abilities is not the primary focus of a study, a proxy-report measure may be appropriate. Further research is, however, needed to examine both the short-term stability and the responsiveness of this revised AMPS-PR to meaningful changes in the ADL abilities of persons with AD.

Even in its current state, the AMPS-PR has potential use as a valuable clinical assessment tool. It provides clinicians with an opportunity to elicit family informants' perceptions of the AD subjects' ADL motor and ADL process skill competencies. Family informants' expectations of their AD relatives' competence; information about assistance provided to their relatives; the extent to which they set up and prepare the physical task environment ahead of time; when and why they provide assistance; and their feedback to their AD relative about their task performances, can be gleaned during administration of the AMPS-PR. This information, in turn, will enhance clinicians' understanding of the context of the AD person's performance, and may help direct the focus of intervention plans. Moreover, when the language used to describe observations of individuals' occupational behaviour is shared by all partners involved in the intervention process, the foundation on which

interventions are based will be stronger. The psychosocial factors that may influence the impact of supportive educational interventions targeting family caregivers should be determined in future research. Finally, supportive educational interventions acknowledging these factors could be tested in randomized control trials involving a larger sample.

Appendix A.

Assessment of Motor and Process Skills Proxy-Report (AMPS-PR)

Introduction

"Sometimes, when people have memory problems, they may experience changes in their ability to perform everyday tasks even if these were tasks they did regularly over the years. I am going to ask you to rate the competence of your family member's actions when doing two different everyday tasks."

Identifying and Targeting Task Choices

Follow same procedure when administering the *AMPS* in order to identify the tasks that the informant's family member usually does. The examiner then needs to determine which of these tasks the informant has had an opportunity to observe his/her family member perform, and which he or she feels most comfortable evaluating.

Clarifying Rating Process

- a. The motor and process skill items vary in difficulty -- some are easier to do well and others are harder to well on a consistent basis.
- b. The rating scale consists of 4 ratings -
4 = competent (does easily)
3 = questionable (does okay or alright)
2 = ineffective (has some difficulty; uses more effort, uses more time, question person's safety)
1 = deficit (has great difficulty; uses much more effort, does very slowly, is unsafe, needs the help of others).

Provide a copy of the rating scale for the informant to use as a visual guide. Reinforce that any time someone has to help the person complete the specified skill, they should rate the person's performance as "1" (i.e., as "deficit").

- c. Persons who have no disabilities will encounter some problems when performing routine tasks especially on some of the harder motor and process skill items. Therefore, some variation in ratings is expected -- getting 4s on all the items is not expected.
- d. If in doubt about which rating is most appropriate, the informant should select the lower of the two ratings.

Appendix A (cont'd)

- e. Indicate that the examiner will ask informant first about their family member's ability to move their body and objects when doing the specific task, and then about their family member's ability to organize, plan, and problem solve when doing the same task.
- f. Clarify the task again before beginning rating process. Refer to AMPS Manual (Fisher, 1999).
- g. Informants may provide examples of things they think relate to the item being rated. If the example isn't relevant to the specific item being rated, clarify this for the informant and indicate what skill(s) it seems to reflect. This may mean that you will need to ask the informant to re-rate specific items based on this new information.

AMPS-PR Skill Items

Stabilizes...When he/she [name task]...does he/she keep his/her balance when sitting, standing, walking, turning, reaching, and moving objects? Or does he/she sometimes stumble or lose his/her balance momentarily? Does he/she ever lean or prop by using the wall or furniture for support?

Aligns...When he/she [name task]...does he/she keep his/her body upright? Or does he/she lean to one side or stoop forward?

Positions...When he/she [name task]...does he/she position him/herself so that he/she can move his/her body and arms easily, and handle tools easily and safely? Or does he/she sometimes use awkward body movements or get into awkward positions?

Walks...When he/she [name task]...does he/she walk easily and steadily? Or does he/she seem unsteady when walking? Does he/she shuffle? wobble? lurch? Does he/she sometimes use the furniture or walls for support? Does he/she use a cane? walker? or wheelchair?

Reaches...When he/she [name task]...does he/she reach objects easily without having to use a lot of effort or appearing stiff? Or does he/she have to try hard to reach?

Bends...When he/she [name task]...does he/she bend easily when picking up objects that are low to the ground or out of easy reach? Or does he/she experience difficulty when bending or twisting his/her body and when getting back up to a standing or sitting position?

Appendix A (cont'd)

Coordinates... When he/she [name task]... does he/she stabilize tools and objects with ease while doing a different action with his/her other hand? **Give task specific examples.** Or does he/she sometimes have trouble stabilizing objects? Do tools and objects sometimes slip from his/her grasp?

Manipulates... When he/she [name task]... does he/she manipulate small objects within his/her fingers and hands with ease? Or are his/her finger and hand movements sometimes slow or awkward?

Flows... When he/she [name task]... does he/she move his/her arms and hands in a smooth, fluid way? Or are his/her arm and hand movements less fluid and smooth? Are they stiff? Do his/her arms or hands sometimes shake?

Moves... When he/she [name task]... does he/she push, shove, pull, or drag objects easily? open and close doors (including the refrigerator) and drawers easily? Or does he/she have to use more effort?

Transports... When he/she [name task]... does he/she carry objects from one place to another with ease? Or does it take more effort to carry objects? Does he/she sometimes appear unsteady when carrying objects? Does he/she sometimes slide things along a flat surface so he/she doesn't have to carry them? Does he/she ever drop things when carrying them?

Lifts... When he/she [name task]... does he/she lift objects easily and safely without a lot of effort? Or does he/she have to use more effort? Does he/she sometimes slide objects along a flat surface that would normally be lifted?

Calibrates... When he/she [name task]... does he/she use controlled actions when doing things? Does he/she use the right amount of force and speed with his/her arms and hands when doing things? Or does he/she sometimes use too much force? move too quickly? push too hard? knock things over? Does he/she sometimes use too little force? or move too slowly to make effective movements?

Grips... When he/she [name task]... does he/she pinch or grasp handles easily? open fastenings and containers easily? remove coverings easily? Is he/she unable to grip objects firmly? Do things sometimes slip out of his/her grip? Does he/she need others' help to open fastenings and containers?

Endures... When he/she [name task]... does he/she persist and complete the task without getting physically tired or short of breath? Or does he/she slow down? get short of breath? have to pause or rest? Is he/she unable to complete the task because he/she is too tired?

Appendix A (cont'd)

Paces... When he/she [name task]...does he/she keep up a consistent pace when [name of task]? Or does he/she work too quickly or too slowly? Does his/her pace vary? Does he/she start off at a good pace and then slow down as he/she continues?

Attends... When he/she [name task]...does he/she maintain his/her attention and stay focused on the task? Or does he/she sometimes get distracted by other things around him/her? Does he/she sometimes get too focused on one part of the task? Does he/she ignore some parts of the task? or lose track of what he/she is doing? Does someone else have to help him/her refocus his/her attention back to the task?

Chooses... When he/she [name task]...does he/she find it easy to choose the things he/she needs to do the task? Or is he/she unsure of what to choose? Does he/she hesitate? forget to choose some things? Does he/she sometimes choose things just because they are convenient rather than because they are the most appropriate available tools? Does he/she sometimes choose more things than he/she really needs? or not enough? Does someone else have to remind him/her to choose certain tools or materials?

Uses... When he/she [name task]...does he/she use tools and materials for their intended purpose? Or does he/she use tools and materials in unexpected ways? Does he/she follow sanitary practices when [name of task]?

Handles... When he/she [name task]...does he/she support, stabilize, and hold tools and materials in an appropriate way? Or does he/she sometimes hold things awkwardly? have trouble figuring out the best way to hold or support tools and materials? Does he/she sometimes fumble with things or drop them because he/she isn't holding or supporting them appropriately? Does he/she need others' help to figure out how to use or operate some tools or materials?

Heeds... When he/she [name task]...does he/she approach the task with a clear idea of what he/she is going to do? Does he/she complete the task as planned? Or does he/she change the plan as he/she proceeds with the task? Does he/she sometimes forget what it was he/she initially planned to do? Does he/she get sidetracked and complete the task differently than planned? Does he/she sometimes forget to do key aspects of (name of task)? Do others need to remind him/her what the goal of the task is to ensure that it is completed as planned?

Inquires... When he/she [name task]...does he/she recognize when he/she needs to ask others for information or help? Does he/she sometimes hesitate to ask for information or help? Does he/she sometimes ask others rather than figuring things out on his/her own? Does he/she ask too many questions? Does he/she ask the same question repeatedly?

Appendix A (cont'd)

Tasks are made up of different steps and actions.

Sequences... When he/she [name task]...does he/she do the different steps that make up the task in an order that is logical? and that makes good use of his/her time and effort? Or does he/she sometimes do things in a more unplanned, random order? Does he/she sometimes lose track of what he/she has already done and end up repeating steps again?

Initiates... When he/she [name task]...does he/she start or begin actions or steps without hesitation? Or does he/she sometimes hesitate? Is he/she sometimes unsure about what to do next and have to stop and think? Does he/she sometimes make "false starts" or turn in circles trying to figure out how to start? Does he/she ever leave some steps of the task out completely?

Continues... When he/she [name task]...once he/she starts an action or step, does he/she continue it without interruption or hesitation? Or does he/she sometimes start a step, stop to do something else, then come back to what he/she was doing before?

Terminates... When he/she [name task]...does he/she finish actions when it is appropriate? Or does he/she appear to be unsure when he/she should stop an action? Does he/she sometimes stop before an action is really finished? or not stop soon enough?

Searches/Locates... When he/she [name task]...does he/she find the tools and objects he/she needs easily and quickly? Does he/she use a logical approach to look for the things he/she needs? Or does he/she look for things in a random way? Does he/she open several cupboards or drawers, or search in the same place several times before he/she finds what he/she is looking for? Does he/she need others' help to find the things he/she needs?

Gathers... When he/she [name task]...once he/she finds what he/she needs, does he/she collect the tools and materials into his/her work space before he/she begins the task? Or does he/she gather items one at a time? get what he/she needs as he/she needs it? Does he/she sometimes find what he/she needs but not bring it into his/her work space?

Organizes... When he/she [name task]...does he/she organize the tools and materials he/she has gathered in a way that makes it easy to do the task? Or is his/her work space too crowded? or too spread out?

Restores... When he/she [name task]...does he/she put tools and materials away when he/she is finished with them? Does he/she clean up his/her work space when finished? Or does he/she sometimes leave some materials or tools out? put them back somewhere different than where he/she got them? not both to tidy things up at all?

Appendix A (cont'd).

Navigates... When he/she [name task]...does he/she anticipate potential obstacles and then change how he/she is moving his/her arms and body so that he/she doesn't bump into things or knock things over?

The next items are concerned with problem solving abilities.

Notices/Responds... When he/she [name of task]...does he/she notice things that give him/her information about how he/she is doing, how well the task is going? **Give task specific examples.** Does he/she respond to these cues right away? Or does he/she hesitate before responding? Does he/she miss important cues completely?

Problems can sometimes arise when we [name task] -- [give some task specific examples].

Accommodates... When problems arise, does he/she try to change something about how he/she does the task? Do his/her solutions usually work? Or does he/she have to try several different things before the problem is fixed? Is he/she sometimes unable to solve the problems he/she encounters without the help of others?

Adjusts... When problems arise, does he/she try to change something about his/her work space or the things he/she is using to do the task? Does he/she sometimes try to change or adjust something in his/her work space? or get more appropriate tools and materials? Do these changes usually work? or does he/she have to make several adjustments before the problem is fixed? Is he/she sometimes unable to solve the problems he/she encounters without the help of others?

Benefits... When he/she [name task]...does he/she learn from problems he/she has encountered before? If he/she encounter problems or difficulties while doing the task, does he/she do things to ensure that the problems don't persist or continue? Or does he/she sometimes encounter the same or similar problems throughout the task?

Appendix B

Intervention Guidelines

Issues that will be discussed include:

1. Disease course and prognosis:

What have you been told about your family member's diagnosis?

What does Alzheimer's disease mean to you?

How does (and will) it affect your family member?

What do you think the future holds for your family member?

What changes did you see in your family member that suggested that there was a problem?

What is your understanding of how Alzheimer's disease will affect your family member's ability to do everyday tasks? What changes have you noticed already? What other changes do you expect that you will see?

Do you think your family member will show steady decline? rapid deterioration? fluctuations in his/her abilities?

Emphasize that the rate and severity of decline is variable.

Do you expect to that you will see changes in your family member's physical abilities? motor skills?

These changes don't happen right away, but over time, you may see changes in the smoothness of their movements due to increased tone, their movements may slow, they may react slower, and their ability to walk will decline.

Do you realize that your family member won't demonstrate the same rate of change or decline in all areas of functioning?

Research indicates that some abilities are relatively preserved. Many individuals can still learn new motor skills. Most persons will still know **how** to do something -- how to use materials and tools (e.g., a knife, scissors, brush), how to handle them, how to gather things together, how to organize their work space, and how to navigate around their work space without bumping into things.

Appendix B (cont'd)

But their ability to know **what to do** with the tools and materials they need to use when doing tasks is what is most affected. They experience problems in:

- starting actions,
- doing actions in a logical order,
- stopping actions when appropriate,
- adapting to difficulties that arise.

You may see changes in their ability to remain focused on the task, to notice and respond to cues within their environment that signal the progress of the task or potential problems, to choose what they need to use, to stay focused on the goal of the task, to continue actions without disruption (e.g., may begin to change the sheets on one bed and then rather than finishing, continue to remove the sheets from other beds in the house; or begin to make one sandwich and just keep going until run out of bread), to learn from their previous mistakes, and to know when and how to ask for information that they need.

But tasks and actions that are over learned or habituated will remain relatively well preserved.

You may also see changes that are distressing or upsetting. For example, someone who was always fastidious about their grooming, may still want to be well-groomed but may lack the ability to engage in the actions that will enable them to remember to brush their hair, etc.

Does your family member have other health problems that may also affect his or her ability to do everyday tasks?

2. Compensatory strategies which their impaired family members may use to mask any changes in their ADL functioning:

How might different people who are experiencing problems with their memory and who see changes in their ability to do everyday activities react?

- possibly withdraw from others, stop doing tasks, use lots of excuses for changes in their abilities including not having glasses on.
- may also use reminders, double-check on things, etc.

AD threatens their sense of order and control over themselves, as well as tasks and objects within their environment. Person will try hard to maintain an appearance of competence but recognize that this is hard work and person may respond with anger, frustration, etc.

Appendix B (cont'd)

Person will retain a good repertoire of social manners and phrases and may be able to use these to hide the extent of his deficits.

Overall goal is to preserve and present their most valued images of themselves; may emphasize former competencies or avoid possibility of being identified as incompetent.

3. Compensatory strategies that they may be using to help their family members

Have you changed the way you interact with your family member around the performance of tasks? Do you provide more direction? Do you make sure you are available? Do you set things out for your family member? Do you tell your family member what to do?

Are you aware that you help your family member by doing these things? What would happen if you didn't provide this kind of assistance?

Do you find that you react in a more negative way when you see your family member having trouble? Do you discourage them from helping you do tasks?

4. Performance expectations and evaluation criteria family informants use when evaluating their family members' functioning,

The extent of disability isn't always obvious and may be misjudged by others. Failure to perform may be interpreted as laziness or disinterest, willful attempts to be difficult or contrary.

Family may make unrealistic demands on the person so that he/she may react negatively -- lash out, withdraw. Or family may assume person is more disabled than they are and not provide the person with opportunities to contribute to the family and experience a sense of achievement.

Don't expect the person to just try harder or to be able to correct problems.

There are different things we can use to judge whether someone did a task well or not. Often, we just focus on whether the end result is alright or not. Is the meal tasty and attractively presented? Are the dishes clean? Is the floor clean? Is the laundry folded neatly and sorted in a reasonable way? We may also focus on whether we think they need help from others or not. But we also need to consider the process an individual uses to get to that outcome. Think about how much physical effort it takes the person to do the task? -- how much physical difficulty or fatigue the person demonstrates when performing task? Focus on how efficiently they perform the task? -- how disorganized are they? do they use time, space and objects inappropriately? And also consider how safely they do the task -- what is the chance that the person's actions will result in injury to himself?

Appendix B (cont'd)

cause damage to the environment? Then consider how independent the person is. And consider both physical and verbal assistance; and how frequently that assistance is needed.

5. Context they use to elicit information about their family members' ADL competence.

How do you learn about your family member's ability to perform tasks? Do you actually observe him/her do activities? What role do you assume when you are observing your family member? Do you just see the outcome of the task -- i.e., a meal made, dishes washed and draining in the sink, laundry folded, bed made. Do you actually watch them do a task? What role do you assume when you observe your family member? Do you possibly distract your family member? make him/her nervous? interrupt their actions by suggesting more effective ways to do things? offer assistance before they ask for it? Try to wait and see what they do when they encounter problems? Do you they ask you for help right away? try to figure out a solution themselves?

Appendix C

Handout for Family Informants in the Intervention Group

Before my next visit on _____, I would like to encourage you to:

- a. Observe your family member performing at least two everyday tasks. These should be tasks that your family member has done in the past. You might ask your family member to make a pot of tea or coffee, set the table, or sweep the floor, make a bed, or fold some laundry.

During your observations, try to just observe. Most people will feel nervous if they think someone is watching them, so try to blend in and make your presence less noticeable. You might find it helpful to work near your family member or sit back and have a cup of tea or coffee and read the newspaper. But don't distract your family member by trying to engage them in a conversation. Let your family member focus his or her attention on the task they are doing. Let your family member try to do things on his or her own. This means that you need to stand back and just watch; say as little as possible. If your family member seeks your advice and asks if they are doing the task correctly, just encourage them to "do it the way they usually do it". Don't offer to help unless your family member asks for your help, or unless you think that your family member's actions may place him or her in an unsafe situation. Otherwise, don't be afraid to let your family member struggle a bit or make some mistakes. This is your chance to see whether your family member can overcome these difficulties or not.

2. When you think about your family member's performance, think about:
 - a. how efficiently he or she performed various actions,
 - b. how much effort he or she had to use,
 - c. how safely he or she performed, and
 - d. how much assistance they needed.
3. If your family member offers explanations for the difficulties they are experiencing, think about how valid they are. Is your family member just having a bad day? or are the problems you are seeing more permanent? Does your family member really need your help as much as they say they do? If you give them the opportunity, can they do more than they think they can?

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QE-RS/97-162

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