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Correspondence of the functional independence measure (FIM) self-care subscale with real-time observations of dementia patients' ADL performance in the home.

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CORRESPONDENCE OF THE FUNCTIONAL INDEPENDENCE MEASURE (FIM) SELF-CARE SUBSCALE WITH REAL-TIME OBSERVATIONS OF DEMENTIA PATIENTS' ADL PERFORMANCE IN THE HOME

by

ELLEN MARGARET COTTER

A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

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ABSTRACT OF DISSERTATION
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Title Correspondence of the Functional Independence Measure (FIM) Self-Care Subscale With Real-Time Observations of Dementia Patients' ADL Performance in the Home

Accurate assessment of activities of daily living (ADLs) is vital for maximizing the quality of life of elderly individuals. However, previous ADL assessment studies have not incorporated detailed observations of ADL performance. Without direct evidence of how well paper-and-pencil ADL assessments correspond to actual ADL performance, the utility of these assessments is questionable. This project explored the external validity of the Self-Care subscale of the Functional Independence Measure (FIM) by comparing caregiver ratings of dementia patients' ADL performance with direct observations of ADL performance in the home. Dementia patients and their caregivers participated in videotaped observations of seven ADLs: bathing, dressing above the waist, dressing below the waist, eating, grooming, toileting, and transferring into/out of a bed, chair, or wheelchair. Prior to observation, the caregivers completed a modified version of the FIM Self-Care subscale and measures of demographic and psychosocial variables. Data analysis examined (a) the degree to which caregiver-reported FIM scores corresponded to FIM scores derived from the observational data; (b) the extent to which caregivers' estimates of ADL assistance time corresponded to the assistance time observed during

ADL interactions; and (c) the relationships of cognitive status, depression, and behavior problems to the caregiver-reported and observation-derived ADL data. Results indicated that for all ADLs, caregiver-reported FIM scores were significantly correlated with observation-derived FIM scores, suggesting that caregivers can accurately describe the nature of the ADL assistance they provide. For four of the seven ADLs, significant relationships were found between reported and observation-derived duration of assistance when caregivers who reported providing no assistance were assigned a reported assistance duration of zero. When these caregivers were removed from analysis, only one ADL showed a significant assistance duration correlation (although several correlations approached significance). However, caregivers' reported assistance durations were roughly three times the observed assistance durations, indicating that caregivers systematically overestimate their ADL assistance time. Factors such as caregiver and patient depression, patient cognitive status, and patient behavior problems showed variable patterns of correlation with each other and with reported and observed ADL data.

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This work, and all that came before it, could not have been done without my parents, who taught me to read and write.

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CHAPTER 1

INTRODUCTION

The term dependence has been operationally defined to denote "concrete, observable behaviors referring to requests for or acceptance of help, or to no reaction when asked to do something for oneself either in self-care or social activity settings" (Baltes, Kindermann, Reisenzein, & Schmid, 1987, p. 391). The need for assistance to complete activities such as eating, dressing, and grooming constitutes dependence in the performance of activities of daily living (ADLs). Assistance needs can include environmental modification, use of an adaptive device, or provision of verbal or physical support by one or more helpers. ADL dependence and the resulting need for assistance elevate medical expenditures by increasing cost factors such as burden of care, expenses incurred from hiring an aide or purchasing special equipment, and extra time spent assisting with activities; thus, there is great interest among researchers and health care professionals in identifying the causes and nature of dependence. ADL dependence can develop regardless of age, source of impairment, or living environment, and is therefore regarded as a universal health care problem. However, because ADL dependence tends to increase with age (Baltes & Carstensen, 1991; Maddox, Clark, & Steinhauser, 1994; Teri, Borson, Kiyak, & Yamagishi, 1989), most studies of ADL impairment, including the present study, focus on ADL impairments in older adults.

The study of ADL dependence is marked by a need to consider both its source and the resulting pattern of assistance needs. For example, ADL dependence following a primarily physical illness such as limb amputation or emphysema is likely to result in increased need for physical assistance or use of adaptive devices, but little need for cognitively-based aid such as verbal prompts or signs. In contrast, some people experience ADL limitations due to a condition with both physical and cognitive sequelae, such as a traumatic brain injury or mental retardation. In these cases, ADL assistance may involve not only hands-on support but also cognitively-based assistance such as verbal reminders, memory aids, and supervision. Like mental retardation and brain injury, the various types of dementia also affect both physical and cognitive ability to perform ADLs. Unlike other forms of brain damage, however, dementia typically involves a progressive decline of both cognitive and physical functioning, which in turn necessitates increased assistance over time. The nature of dementia-related decline also involves frequent, sometimes daily, fluctuations in patient ability, resulting in continual need for caregivers to adjust their expectations and learn new skills.

Typology and Definition of ADLs

The general category of ADLs consists of two subtypes. Basic ADLs are activities related to self-care, such as eating, dressing, bathing, and toileting. Performance of basic ADLs relies heavily on physical abilities and use of overlearned skills. When physical abilities are impaired, adaptive devices or assistance from another person may be required; when cognitive skills have deteriorated to the point where previously overlearned routines break down, verbal cues or external memory aids, as well as increased physical assistance from others, are necessary for successful performance. Late in the course of dementia, complete physical assistance with basic ADLs is often required due to severe impairment in cognitive and physical functioning.

Instrumental ADLs, or IADLs, are tasks that require higher-order cognitive functions such as skill and judgment. These tasks often involve social functioning and interactions with the environment outside of the home (Kovar & Lawton, 1994). Using public transportation, taking medications, balancing a checkbook, and shopping are examples of IADLs. People who experience difficulty performing ADLs will almost always have difficulty performing IADLs (Zarit, Johansson, & Malmberg, 1995), although the converse is not necessarily true.

Both ADLs and IADLs depend on both physical and cognitive functioning, but to varying degrees. For example, cognitive skills are more important for balancing a checkbook than for eating; however, physical abilities are more important for eating than for balancing a checkbook. Similarly, ADLs and IADLs show differential decline in the presence of dementia; IADLs tend to decline sooner in the disease course, while basic ADLs appear to be more resistant to decline. These variations in skill decline determine, in part, the amount and type of assistance needed. While someone who is impaired in IADLs may be able to function somewhat independently with appropriate environmental support, someone who is dependent on assistance for performance of basic ADLs will have a more difficult time living outside of an institutional setting or without 24-hr physical care. Therefore, performance of basic ADLs is generally considered to be the best indicator of assistance need and subsequent utilization of health care resources. In this vein, the term ADLs as used throughout the remainder of this paper should be construed to refer to basic ADLs unless otherwise specified.

Assessment of ADLs

The importance of ADL performance for independent functioning renders the accurate assessment of ADLs vital for several reasons. One reason is that deterioration in ADL performance often results in institutionalization (Warren et al., 1989; Wolinsky, Callahan, Fitzgerald, & Johnson, 1993), and inaccurate ADL assessments may cause patients to be institutionalized unnecessarily. Second, the assessment of ADLs can also aid in monitoring the progress of an impairment or illness, because differential patterns of ADL impairment are associated with different types of illnesses (Reisberg, Ferris, & Franssen, 1985). Furthermore, in late dementia, the verbal abilities of the patient are poor, and assessment of ADLs may be the only means of obtaining useful information on patient status (Auer, Sclan, Yaffee, & Reisberg, 1994). Third, accurate ADL assessment is necessary for maximizing independent ADL performance. It is crucial to know how much assistance needs to be provided, because providing too much assistance can lead to overdependence on caregivers and excessive decline of patient skills (excess disability) as well as unnecessary financial, physical, and psychosocial burden for caregivers. Fourth, ADL assessment can help evaluate the necessity for and effects of various interventions on task performance (Albert et al., 1998; Cohen-Mansfield, Werner, & Reisberg, 1995; Green et al., 1993), although intervention research is not a focus of this paper. Finally, regular assessment of ADLs can highlight those patients who need additional services or are at risk for further decline or death (Green, Mohs, Schmeidler, Aryan, & Davis, 1993) and can guide public policy on issues such as insurance reimbursement regulations, eligibility for home health care services, and the economic impact of illness. Determining the costs of caring for a dementia patient involves multiplying the hours spent by unpaid (usually familial) caregivers by projected hourly wages (e.g., Brookmeyer, Gray, & Kawas, 1998), and accurate documentation of the amount and type of unpaid home care provided is crucial for obtaining reliable economic statistics.

Problems with ADL Assessment

Traditionally, accurate assessment of ADLs has been variably successful. Although the problems with ADL assessment are for the most part well identified, finding solutions to alleviate these problems has not been as straightforward. Problems with ADL assessment can be divided into three general categories: (a) characteristics and biases of respondents, (b) patient-related characteristics, and (c) variables inherent in the assessment instruments.

Respondent variables. In particular, it appears that whether the person rating ADL performance is the patient, a family member, or a health care professional can greatly affect the results of an ADL assessment. While patient-related variables warrant a separate discussion, it should be noted here that patients tend to rate their abilities higher than do proxy respondents (Burns, Mortimer, & Merchak, 1994; Magaziner, Itkin-Zimmerman, Gruber-Baldini, Hebel, & Fox, 1997), who in turn vary in their bias and accuracy depending on whether they are physicians, home health aides, or familial caregivers (Dorevitch et al., 1992; Elam et al., 1991).

Some researchers have attempted to verify the accuracy of ADL ratings by comparing ratings from different sources to direct observations of ADL performance (e.g., Dorevitch et al., 1992; Elam et al., 1991; Magaziner et al., 1997; Sager et al., 1992). In general, when compared to direct observations, self-ratings appear to be most accurate, although it is unclear whether familial caregivers or physicians are more accurate at rating ADL performance (Dorevitch et al., 1992; Elam et al., 1991). However, these studies have not systematically included patients with dementia, whose self-reports are likely to have questionable validity. When dementia is involved, a proxy respondent must be used to obtain information on functional status unless direct observation can be conducted.

Because the validity of a proxy responder's ratings will depend on the proxy's motivations and familiarity with the patient, numerous problems are associated with using proxy respondents to assess ADL performance. One issue is that proxies may have different goals or place different values on different ADLs than do patients (Barer & Nouri, 1989). For example, an older woman who can not shop for herself may not perceive this restriction to be a problem because her daughter shops for her; her daughter may also not perceive this arrangement to be problematic, but a social worker may consider it to be a situation requiring intervention. In another example, an overburdened caregiver might exaggerate his ratings of his mother's dependence in hope of gaining some assistance. On a related note, caregiver ratings may reflect only what the caregiver allows the patient to do, rather than the patient's actual capabilities (Albert et al., 1998; Skurla, Rogers, & Sunderland, 1988).

The issue of caregiver familiarity becomes especially salient when ADL assessments are conducted by evaluators who are not familiar with patients' abilities (e.g., hospital nurses, occupational therapists) or when performance-based assessments are used. Unfamiliar raters and performance-based tests may not obtain an accurate representation of ability. An occupational therapist administering the Functional Independence Measure (FIM; Granger, Hamilton, Keith, Zielezny, & Sherwin, 1986; Keith, Granger, Hamilton, & Sherwin, 1987) to a stroke patient to determine a rehabilitation plan may not have access to necessary information or may not elicit valid behavior simply by virtue of being a stranger. Similarly, if functional ability is assessed through a single observation of performance, true abilities may not be demonstrated due to environmental constraints, patient illness, observer reactivity, or other factors. Currently, no standardized ADL instrument exists that examines performance of ADLs over several occasions. Sometimes an instrument is administered several times to assess the progress made through therapy, but such an approach is not commonly used to assess ADL function over several occasions in the short term. However, an instrument for this purpose, the Motor Activity Log (Taub, Crago, & Uswatte, 1998; Taub et al., 1993; Uswatte & Taub, in press), is currently being tested with stroke patients and other rehabilitation clients.

Patient variables. A patient's status on various demographic factors can influence assessment results. For example, there is some evidence for a gender bias in some activities, particularly IADLs and particularly in older adults (Lawton & Brody, 1969). At this time, it is not uncommon to find elderly men who have never cooked or cleaned the house, and elderly women who have never managed their finances. However, this trend is likely to become less salient with future cohorts of elders. Socioeconomic differences may also influence opportunity to perform IADLs because these activities are more likely to be limited by factors such as income or education (Hill, Bäckman, & Fratiglioni, 1995). Although it is difficult to examine variables such as years of education separately from their overall relationship with socioeconomic status, it is possible that a high amount of education may affect abilities by providing a broader base of coping skills on which to fall back when skills start to decline (Hill et al., 1995). Because ADLs are less likely than IADLs to be affected by demographic factors, evaluation of these more basic tasks may be the most useful approach for determining functional status.

As with proxy respondents, the motivations of patient respondents may affect the results of an ADL assessment. The patient's perception of his or her own abilities, particularly as related to disability, aging, or both, can manifest itself in poor ratings of ADL performance. On a related note, depression may play a part in patients' ratings of their ADL ability (Laukkanen, Kauppinen, Era, & Heikkinen, 1993). Previous research has found that in the general population, individuals with depression exhibit lower self-care skills than nondepressed individuals (e.g., Katz, Streim, & Parmelee, 1994; Zeiss, Lewinsohn, Rohde, & Seeley, 1996). Depressed patients also rate their abilities lower than nondepressed patients, possibly because of negative attributions and feelings of ineffectualness or because the depression genuinely interferes with ADL performance. Other personal characteristics such as pride, loneliness, and desire for support or independence may also influence self-ratings (Skruppy, 1993). The degree of functional impairment may also affect ADL assessment results. Skruppy (1993) found that when no ADL limitations existed, subjects' self-reports of their abilities correlated well with actual observed task performance. However, when ADL limitations were present, the subjects tended to overrate their abilities compared to their observed performance.

Instrument-related variables. Many barriers to accurate ADL assessment are imposed by the instruments themselves. One of these variables is the lack of uniformity in ADL assessment instruments (Reuben, Valle, Hays, & Siu, 1995). Different instruments contain not only different items but also different combinations of ADLs and IADLs (Law, 1993; Myers & Huddy, 1985), and "there is no universally accepted list of activities" included on these assessments (Kovar & Lawton, 1994, p. 61). The purpose for which an instrument was developed can also complicate measurement (Law, 1993). For example, the FIM was developed to examine the progress made through rehabilitation services. Thus, it has been used extensively with rehabilitation patients of various ages and impairments, including multiple sclerosis, stroke, traumatic brain injury, and spinal cord injury (e.g., Brosseau & Wolfson, 1994; Granger, Cotter, Hamilton, & Fiedler, 1993; Granger, Divan, & Fiedler, 1995; Roth, Davidoff, Haughton, & Ardner, 1990). However, the Physical Disability Index (Gerety et al., 1993) was developed for a very specific use with a very specific population--namely, to measure "physical function in frail nursing home residents without severe cognitive impairment" (p. M33). An instrument such as the Physical Development Index, although potentially adequate for that patient population, may be limited in its ability to assess ADLs in other populations.

Another problem is that response choices vary greatly among instruments (Law, 1993; Reuben et al., 1995). For example, the FIM scores ADL performance on a 7-point scale that distinguishes fine differences among types of assistance (e.g., complete independence vs. independence with assistive device). The Barthel Index (Mahoney & Barthel, 1965), on the other hand, rates abilities only on a 4-point scale, reducing the amount of available detail regarding different dependence levels. For example, a person who needs hands-on physical assistance to dress himself is more dependent than a person who requires constant verbal cues, yet both patients could be construed as falling in the category "Can do with help" as it appears on the Barthel Index. Even more problematic are variations in the operational definitions of the various ADLs, particularly with regard to what constitutes independent performance (Eakin, 1989; Reuben et al., 1995). For example, the FIM defines "locomotion" to include effective use of a wheelchair, while the Barthel Index penalizes those patients who use a wheelchair. On the Barthel Index, independent eating is operationalized to include effective use of a knife and fork for cutting and spreading, while the Katz Index (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) specifically excludes cutting and spreading from the definition. The end result of this lack of uniformity is that comparisons across instruments are rendered questionable and potentially invalid.

Global content issues aside, the format of individual questions can undermine the reliability and validity of the assessment instruments. Using the words "can" or "could" versus "do" may greatly alter the results of the assessments (Glass, 1998; Kovar & Lawton, 1994; Lawton, 1988). For example, a man who is able to bathe independently but does not should be distinguished from a man who actually does bathe himself, as this distinction highlights the excess disability of the former patient; merely asking "Can he bathe himself?" does not provide adequate information to make this discrimination. However, an advantage of asking if a patient "can" or "could" do something is that questions about potential performance remove bias introduced by gender or availability factors (Lawton, 1988). For example, a woman whose husband has managed the family finances throughout their marriage may have sufficient cognitive ability to perform this task but does not, because someone else has always done it for her. Likewise, people who live in rural areas may never have used public transportation simply because it is not available where they live. Their ability to use public transportation, were buses and trains available, might be intact. Phrasing the question "Does she manage her finances?" or "Does he ride the bus?" may yield a more accurate representation of actual performance (Lawton, 1988). It has been noted, however, that using these particular "tenses of functioning" decontextualizes older adults' performance and downplays the role of compensatory strategies (Glass, 1998). (It should be acknowledged that some of these issues are less pertinent when ADLs, as opposed to IADLs, are being assessed.) When selecting or administering an ADL assessment, it is necessary to decide whether the goal of evaluation is to measure actual performance or potential performance, and to remain faithful to the wording of the individual questions.

Some assessment instruments require the respondent to estimate the length of time required to perform ADLs, either to determine level of independence or to estimate caregiver burden and the economic costs associated with providing assistance. Sometimes, the phrasing of such a question requires the respondent to decide whether or not activities are performed "within a reasonable amount of time." However, respondents' estimations of whether or not activities are performed within reasonable time limits may be unreliable both within and between evaluators. Furthermore, no objective guidelines have been provided denoting what constitutes a "reasonable time" (Eakin, 1989). Although the FIM has operationalized this concept to indicate that performance of the ADL takes no more than three times as long as a nonimpaired person, data regarding normative ADL performance times are not widely available, forcing the evaluator to rely on clinical judgment. Baltes and colleagues have collected self-report data regarding the amount of time elderly Germans spend performing individual ADLs, but these data are preliminary and may not generalize to elders residing in other countries. For example, in Baltes and colleagues' recent study of 83 German elders, 77% of the sample reported that they gave themselves extensive daily sponge baths, but only 36% reported taking regular tub baths or showers (P. Klumb, personal communication, April 29, 1997), rendering cross-cultural comparisons of bathing times difficult due to differences in bathing method.

Caregiver assistance time estimates are also used to describe assistance-associated caregiver burden and economic costs of the illness in question. Economic issues of this nature generally center around the indirect costs of caring for someone with dementia. Indirect costs are those related to the time spent by the family providing ADL care, transporting the patient to and from the doctor, and performing other functions such as managing the patient's finances. Also included in indirect costs are imputed wages lost either because the patient is no longer able to work or because the caregiver has had to give up a job in order to care for the patient. Computation of indirect costs requires estimation of the hours of care provided to the patient. The most common method of obtaining these estimates involves asking caregivers to report their hours spent providing care to or managing the affairs of the patient (e.g., Albert et al., 1998; Brookmeyer et al., 1998; Hu, Huang, & Cartwright, 1986; Huang, Cartwright, & Hu, 1988; Rice et al., 1993). However, these reports have never been checked against observations of care provision, raising the same issues of proxy familiarity, motivations, and reliability mentioned earlier. Caregivers who are unfamiliar with the patient's level of functioning, who are in need of services, who fear institutionalization of the patient, or who are distressed at their caregiving situation may provide inaccurate reports of their assistance time, either deliberately or unconsciously, due to their perceptions of their caregiving situation. Accurate documentation of the validity of these perceptions is crucial for determining the economic impact of dementia on families.

Despite the wide availability of psychometrically reliable and valid instruments, general questions still remain regarding the utility of assessment results. Without direct observation of ADL performance, it may be difficult to determine the accuracy of reported ADL skills (Burns et al., 1994; Law, 1993; Myers, Holliday, Harvey, & Hutchinson, 1993). To date, no studies of ADL assessments have incorporated detailed behavioral observations of basic ADL performance, raising questions about how well ADL assessments measure “real-world” abilities. Some ADL evaluations have attempted to include a performance-based component, but even these evaluations carry questions of bias. First, many performance-based functional ability tests do not measure actual performance of basic ADLs, but instead make predictions based on performance of IADLs or physically-based tasks involving range of motion or speed of movement; these analog tasks may not correspond to real-world ADL performance. Second, because these performance-based assessments generally have a timed component, the ADLs in question may be performed in a manner atypical to the patient’s usual manner of functioning, rendering the utility of the assessment results questionable (Greene, Williams, Macera, & Carter, 1993; Oakley et al., 1991). Third, simulated ADL tests, which are the most common type of performance-based evaluations, may lack important environmental cues simply because they are assessed in clinical settings rather than the natural living environment (Oakley et al., 1991). On a related note, environmental factors, and the way in which the patient interacts with his or her environment, can affect both perceived and observed ADL performance (Sager et al., 1992). Certain settings, such as nursing homes or hospitals, may not give patients the opportunity to display competence in certain activities. Hospital patients are not often expected to dress or bathe themselves independently due to factors such as hospital liability policies and presence of IV tubes or catheters. In this situation, the institutional environment introduces a measurement artifact into the assessment process, clouding the validity of the results.

The Functional Independence Measure (FIM)

The FIM is currently the most comprehensive and detailed ADL assessment available, making it ideal for resolving some of the difficulties associated with accurate measurement (McDowell & Newell, 1996; Morris & Morris, 1997). As stated previously, the FIM was developed to provide a uniform system for assessing progress made through rehabilitation services. It was initially developed as a performance-based measure of functional ability, although a telephone-administered version does exist (Smith, Hamilton, & Granger, 1989; see also Segal, Gillard, & Schall, 1996; Smith, Illig, Fiedler, Hamilton, & Ottenbacher, 1996). The FIM consists of 18 items in the areas of self-care (6 items), sphincter control (2 items), mobility (3 items), locomotion (2 items), communication (2 items), and social cognition (3 items). Each item is rated on a 7-point scale, with higher scores indicating greater levels of independence (see Figure 1 for a representation of the different scores and the questions used to derive them). A total FIM score (range = 18-126) and separate scores for each subscale are derived by adding the scores on the items. The FIM is designed to be used by all health care professionals, regardless of discipline, and to be used with many different types of rehabilitation populations. However, learning to use the FIM does require training, including a certification process, to ensure accuracy of the scores.

Reliability and Validity of the FIM

Studies of the FIM's statistical reliability and validity have for the most part yielded favorable results. Fricke, Unsworth, and Worrell (1993) conducted an inter-rater reliability study with occupational therapists who were divided according to FIM experience and randomly assigned to a training group or a nontraining group. The results demonstrated that ratings were most reliable when conducted by clinicians who had participated in the FIM training group but had no previous FIM experience. Fricke and colleagues suggest that the occupational therapists without FIM training began their FIM exposure without preconceived notions, which improved their reliability. The two subject groups with previous FIM experience may have been influenced by their previous work with the FIM. Subsequent studies providing support for the importance of FIM training have used Kappas and intraclass correlation coefficients to calculate the inter-rater reliability of the FIM, concluding that although the FIM was sufficiently reliable, training and frequent testing are necessary to achieve these high levels of reliability (Hamilton, Laughlin, Fiedler, & Granger, 1994). A similar study conducted with a population of community-dwelling elders also yielded positive results regarding the FIM's inter-rater and test-retest reliability, but again appropriate FIM training was found to be necessary to obtain this high reliability (Ottenbacher et al., 1994). However, Grey and Kennedy (1993)

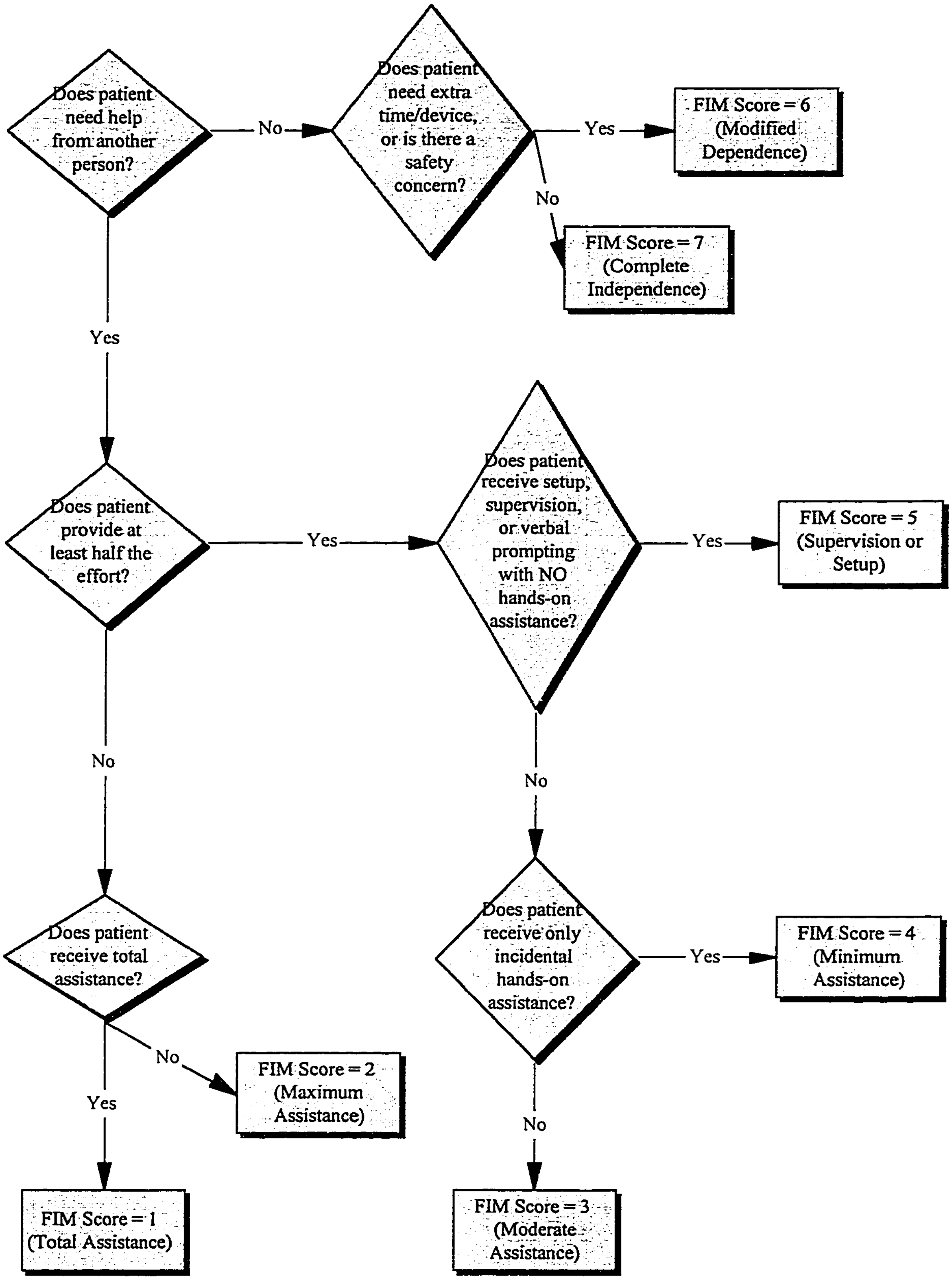

Figure 1. FIM Decision Tree.

found that self-ratings of FIM performance correlate well with clinician ratings, suggesting that the FIM can be given to patients as a self-report measure and questioning the need for training and certification to use the FIM accurately.

Applications of the FIM

The FIM has been successfully used in clinical settings with several rehabilitation patient populations, including spinal cord injury, multiple sclerosis, stroke, and traumatic brain injury. Numerous research studies with these populations have documented not only the FIM's statistical reliability and validity (e.g., Brosseau & Wolfson, 1994; Granger et al., 1995; Kaplan & Corrigan, 1994), but also its utility for such tasks as predicting life satisfaction (Granger et al., 1993) and adjustment to community re-entry (Bell & Tallman, 1995). In contrast, the FIM has not been used to assess functioning in patients with dementia except to determine the associations between cognitive factors and functional outcomes in geriatric rehabilitation settings (Goldstein, Strasser, Woodard, & Roberts, 1997; Hajek, Gagnon, & Ruderman, 1997; Hanks & Lichtenberg, 1996; MacNeill & Lichtenberg, 1997; Seidel, Millis, Lichtenberg, & Dijkers, 1994). Subjects in these studies typically include both cognitively-impaired and nonimpaired patients, with no significant emphasis placed on cognitive status apart from its ability to predict outcomes such as rehabilitation progress and post-discharge living environments. Furthermore, the subjects in these studies are not selected based on cognitive status but rather due to the presence of a particular medical condition such as stroke (Hajek et al., 1997) or hip fracture (Goldstein et al., 1997); cognitive impairment in these subjects, when it occurs, is more or less incidental. No patients with diagnoses of dementia have been systematically included in any of these studies.

One possible reason for this gap is that, as previously noted, the FIM was developed for use with a rehabilitation population, which typically does not include people with dementia. However, the FIM has no characteristics or questions that preclude its use with a dementia population; in fact, it has been proposed that some of its elements render it quite appropriate for use with this group of patients. Spector (1991) noted that functional disability in people with dementia often involves a need for supervision or verbal cues rather than physical assistance, particularly in the early and middle stages of the disease process. Building on this concept, Kane, Saslow, and Brundage (1991) observed that most paper-and-pencil ADL measures do not contain a category corresponding to a need for supervision or verbal cues and, citing the (then) newly-developed FIM as an example, recommended that such a distinction between physical and non-physical assistance be made to increase the sensitivity of ADL measurements used with dementia patients. Currently, a modified version of the FIM is included in the assessment battery of the federally-funded cooperative agreement Resources for Enhancing Alzheimer's Caregiver Health (REACH), a study of psychosocial interventions for improving functioning and quality of life among dementia patients and their caregivers.

Directions for Research

Further research is necessary to determine the degree of correspondence between paper-and-pencil ADL assessment instruments and the amount and type of assistance provided in the natural caregiving environment. Moreover, a particular gap exists in our knowledge of ADL assistance provided to people with dementia, especially community-dwelling individuals. The FIM has several characteristics that make it suitable for a comparison with a detailed observation of ADL performance. First, the 7-point scale allows for fine distinctions between levels of assistance, including "hands-on" assistance and less intensive assistance such as setup, supervision, and verbal cuing (see Figure 1). These categories lend themselves well to operational definitions of behaviors likely to be exhibited in an ADL interaction, whereas the more nebulous categories found on other instruments (e.g., "Can do with help") are not as easily described. Second, when used in clinical settings, the FIM is used to describe ADL performance as it occurs; this observational focus renders it appropriate for such a comparison and also ensures that FIM assessment is not setting-bound, making it potentially useful for community settings. Comparing caregivers' FIM score judgments with direct observations of in-home ADL performance would augment the known reliability and validity of the FIM as well as provide vital information regarding the utility of caregiver ratings of task performance.

Similarly, conducting a detailed analysis of ADL interactions would also help address the issue of the validity of caregiver assistance time estimates. Because such time estimates are often used for research and public policy purposes, yet remain largely unchecked against objective measures, a study of this nature could prove valuable on several levels. An observational study of ADL interactions would yield data regarding caregiver assistance time that could then be compared to reports of assistance time, adding greater validity to reports of caregiver burden or estimates of dementia-related indirect costs.

The Role of Caregiver and Patient Factors

Although of secondary importance to this study, the influence of particular caregiver or patient characteristics on caregiver-rated ADL performance and the amount and type of assistance provided during ADL interactions should not be ignored. Investigating these variables is a logical extension of the observational data and provides a way to explore any differences systematically. One caregiver characteristic (depression) and three patient characteristics (cognitive status, depression, and behavior problems), all of which have been demonstrated or hypothesized to affect functional ability, are of particular relevance to this investigation.

Caregiver Characteristics

The caregiver characteristic of most interest for this study is depression. Depression is common among caregivers in general and also among caregivers of people with dementia (e.g., Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Zarit, Reever, & Bach-Peterson, 1980; Zarit & Zarit, 1982). Although many studies have measured caregiver depression as an independent phenomenon or as an outcome variable, the relationship of this depression to patient functional abilities or the caregiver's perceptions of these abilities has not been explored in detail. For example, Shields (1992) examined the relationship between caregiver depression and family functioning in families caring for a patient with dementia. In that study, caregiver depression was not significantly correlated with the patient's functional status as measured by the Personal Self Maintenance Scale (Lawton & Brody, 1969); however, ADL performance was not directly observed.

The relationship of caregiver depression to reported and observed ADL performance, it was felt, could go in one of two directions. Depressed caregivers may feel that their job is “not worth it” and thus put less effort into assisting their patients. This scenario is especially likely in the case of dementia, which is a progressively debilitating disease that requires increasing caregiver effort. On the other hand, depressed caregivers may perceive their patients to be more impaired than they actually are, and thus put an excessive amount of effort into assisting with ADLs or rate their patients’ abilities to be inappropriately low.

Patient Characteristics

Previous studies (e.g., Ford, Haley, Thrower, West, & Harrell, 1996; Warren et al., 1989) have demonstrated that there is a high correlation between scores on the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) and measures of functional ability. However, the inclusion of performance-based ADL assessment in studies of this nature has been rare and, when included, often incomplete. Warren and colleagues (1989) compared MMSE scores to a paper-and-pencil ADL assessment and a “task-oriented test of daily living” (p. 97) that involved boiling an egg, using the telephone, writing a check, and shopping. That study noted a significant correlation between MMSE scores and both of the functional ability measures, and recommended that some measure of functional ability be incorporated into existing techniques for dementia assessment and diagnosis. However, basic ADLs were not examined. It was hypothesized that data from the present study would be congruent with previous results, and that there would be a direct and positive correlation between cognitive and functional decline. A related hypothesis was that there would be a negative correlation between MMSE scores and caregiver ADL assistance time, such that patients with lower cognitive functioning would receive greater amounts of assistance from their caregivers. It was also believed that these relationships would be present regardless of the mode in which functional ability were measured (i.e., lower MMSE scores would be associated both with lower scores on the FIM Self-Care subscale and with more intensive and longer caregiver assistance provided during observed ADLs).

The occurrence and severity of patient depression was another variable of interest. As noted previously, depression has a negative impact on functional ability in the general population. This pattern has also been demonstrated among people with dementia (Laukkanen et al., 1993; Meeks, Gibson, & Walker, 1992; Pearson, Teri, Reifler, & Raskind, 1989), although the relationship between depression and ADL performance may vary according to cognitive status (Fitz & Teri, 1994). Depression is frequently associated with decreased energy, fatigue, and feelings of hopelessness. These symptoms can create a perpetuating cycle of defeat and decline as existing skills deteriorate from lack of use and the depressed individual receives negative feedback from his or her environment. Additionally, the social withdrawal and psychomotor retardation also associated with depression may give caregivers of depressed individuals lowered perceptions of their patients' true abilities. However, despite this knowledge of the effects of depression on functional ability, the results of depression screening instruments have not been compared to observed performance of ADLs. In this study, it was hypothesized that the severity of patient depression would be significantly related both to lower caregiver-reported and observed ADL data, and to greater durations of reported and observed caregiver assistance such that more depressed patients would receive more intensive and longer durations of ADL assistance.

Unlike the previous two patient characteristics included for analysis, the effects of patient behavior problems on caregiver-rated FIM scores and caregiver-provided ADL assistance have not been clearly delineated. Kane and colleagues (1991) suggested that behavior problems might increase the need for assistance due to safety concerns, although they also noted that "behavioral problems are not the sole criteria [sic] for need for assistance" (p. 63). In the present study, two potential effects of patient behavior problems were acknowledged. First, it was possible that caregivers would avoid providing intensive physical assistance to agitated patients, which would result in more independent ADL performance, but longer time to ADL completion. Conversely, it was also possible that caregivers would provide greater amounts of assistance to behaviorally disruptive patients to reduce ADL duration and possibly preempt agitation. However, it may be difficult to separate the influence of the behavior problems from the cognitive decline; that is, determining whether increased caregiver assistance to disruptive patients was the necessary outcome of declining cognitive abilities or an attempt to prevent disruptive behaviors might be impossible (Aronson, Post, & Guastadisegni, 1993).

Summary

In the study described here, a slightly modified version of the FIM Self-Care subscale was administered verbally to caregivers of people with dementia. The caregiver-provided scores on this instrument were then compared to precise behavioral observations of these same ADLs. Thus, in addition to proving data regarding the external validity of the FIM, this study also examined the utility of obtaining caregivers' proxy ratings of functional ability and the time needed to assist with ADLs. The inclusion of caregiver and patient factors such as depression, behavior problems, and cognitive status offered a method for examining between-subject differences as well as the possibility of identifying avenues for intervention.

The first aim of this study was to examine the correspondence between caregiver ratings of ADL performance and direct observation of the assistance provided by caregivers of dementia patients during those ADLs. Caregiver ratings of ADL performance were assessed using the Self-Care subscale of the FIM, which measures the amount of assistance required with six ADLs: bathing, dressing above the waist, dressing below the waist, eating, grooming, and toileting. Additionally, the assistance required with bed, chair, or wheelchair transfer, an item on the FIM Mobility subscale, was included with these questions; in the remainder of this document, the terms FIM and FIM Self-Care subscale will be used to refer to this set of questions unless otherwise noted. These seven ADLs (bathing, dressing above the waist, dressing below the waist, eating, grooming, toileting, and transferring) were then directly observed for comparison to the caregiver-reported FIM scores. The experimenter unobtrusively videotaped naturalistic ADL caregiving interactions in the dyad's home on three occasions over a 2-week period. Using a system of real-time recording, these interactions were coded for the amount and type of assistance provided, and data from these direct observations were compared with the corresponding caregiver-reported FIM item scores for each ADL.

The second aim of this study was to evaluate the degree of correspondence between dementia caregivers' estimates of the time required to provide ADL assistance and the actual amounts of time spent assisting with ADLs in the home. In the course of completing the paper-and-pencil ADL measure, caregivers were asked to estimate how much time they spent each day helping with specific ADLs. Because the observational system described above records the duration of caregiver assistance provided during ADL observation, the caregiver time estimates could be compared to the actual durations recorded during direct observation.

The third aim of the study was to investigate the relationships between subject factors such as caregiver and patient depression, patient cognitive status, and severity of patient behavior problems (measured by the Center for Epidemiological Studies Depression Scale, the MMSE, and the Revised Memory and Behavior Problem Checklist, respectively) and the reported and observed ADL data. Although this aim was not directly related to the other aims and can thus be considered secondary, it was felt that collecting this information was a natural step in this examination of ADL performance. Because declines in cognitive status correspond to declines in ADL performance (e.g., Ford et al., 1996), it was hypothesized that patients with lower scores on the MMSE would receive more reported and observed ADL assistance from their caregivers. Similarly, it was hypothesized that the severity of patient depression would be significantly related both to lower caregiver-reported FIM scores and to higher amounts of caregiver assistance observed during the ADL interactions. The potential effects of caregiver depression and patient behavior problems on patient dependence, on the other hand, had not been investigated in detail when this study was conducted. As a result, specific hypotheses regarding the effects of these variables were not proffered.

CHAPTER 2

METHOD

Due to the detailed nature of the methodology in this study, a brief overview of the procedures is provided to facilitate ease of reading. The subjects in this project were caregiver-patient dyads in which the patient was an adult with dementia and the caregiver was a co-residing relative of the patient. During participation in the study, the caregiver and patient completed several paper-and-pencil instruments assessing caregiver and patient depression, patient cognitive status, the occurrence and severity of patient behavior problems, and various demographic variables such as age, household income, and number of medications taken. Each caregiver also completed a paper-and-pencil measure of the patient's ADL functioning. This measure, referred to as the FIM Self-Care subscale, assessed seven ADLs on the FIM's 7-point scale and included three follow-up questions assessing the caregiver-reported frequency and duration of assistance as well as the caregiver-reported distress associated with providing assistance. Following administration of all paper-and-pencil measures, the dyads participated in videotaped observations of the seven ADLs measured on the paper-and-pencil FIM completed by the caregiver. These videotaped observations were coded using a computer-assisted data collection system and provided observation-based ADL data for comparison to the caregiver-reported ADL data. For the first aim of the study, a computer program was written to convert the continuous observational data into categories that corresponded to the points on the FIM rating scale, and the correlations between these caregiver-reported and observation-derived FIM scores were computed. For the second aim of the study, the amount of caregiver assistance time was averaged by dyad and by ADL, and these observed assistance times were correlated with the caregiver-reported assistance durations. For the third aim, correlations were computed to explore the relationships among the various paper-and-pencil measures and the caregiver-reported and observation-derived ADL data.

Subjects and Setting

The dyads in this project were taken from a general pool of people referred to the University of Alabama at Birmingham (UAB) site of the National Institutes of Health-funded REACH cooperative agreement, a multi-site study of psychosocial interventions to improve the health and well-being of caregivers of dementia patients. Potential REACH dyads, and therefore potential dyads for this study, were recruited from the Visiting Nurses Association, the UAB Alzheimer's Family Care Program, and the UAB Geriatric Primary Care Clinic, Geriatric Assessment Clinic, and Alzheimer's Disease Center Memory Disorders Clinic, as well as support groups, health fairs, and newspaper and radio advertisements. The stringent entry criteria of the REACH project (see Burgio, Stevens, Haley, & Guy, 1995) resulted in a pool of caregivers who were ineligible for REACH for reasons such as lack of a secondary caregiver, fewer than three patient behavior problems, or patient MMSE score of zero and concurrent "bedbound" status (i.e., spending 22 hr per day in a bed or chair for four of the past seven days). Because ADL status was the entry criterion most relevant to the specific aims of this dissertation project, these dyads were deemed eligible for consideration in this study. Participation in this project did not affect later REACH eligibility or participation.

A total of 141 dyads were referred to the current study. Of these potential dyads, 134 came through one of the REACH referral sources, 2 were recruited through support groups, and 5 had responded to an advertisement in a newsletter for caregivers of patients with Alzheimer's disease. Approval from the Institutional Review Board was obtained prior to the start of screening; a copy of this approval form is contained in Appendix A. Fifteen dyads could not be contacted during the study period; 44 were declared ineligible due to lack of patient ADL impairment (n = 16), patient institutionalization (n = 8), residence too far away (n = 1), non-familial caregiver-patient relationship (n = 1), patient death (n = 10), concurrent enrollment in REACH (n = 4), or caregiver inability to comprehend the nature and purpose of the project (n = 4), resulting in 82 dyads who were determined to be eligible for this study. Lack of patient ADL impairment did not permanently exclude dyads from later participation, as it was possible that this factor could change during the course of the study. However, no initially ineligible dyads became eligible at a later point. Changes in reason for ineligibility involved either patient death or institutionalization; in the discussion that follows, the final reason for ineligibility is the one used to classify the dyads.

Out of the 82 dyads that were eligible for inclusion in the study, 7 caregivers refused to answer any questions regarding their caregiving situation. Of the 75 caregivers who completed screening, 7 declined participation due to lack of time, 4 refused due to concern that the patient would react negatively to having a stranger in the home, 5 declined due to patient illness, 4 refused because they themselves were ill, and 19 refused for unspecified reasons. These refusals resulted in 36 caregivers who initially agreed to participate. However, 8 caregivers refused at or before consent, and 5 caregivers signed consent forms but dropped out before collection of observational data due to patient illness (n = 1), caregiver illness (n = 1), patient suspicion of the experimenter (n = 1), or unknown reasons (n = 2). Additionally, 2 dyads were excluded because the patient thought the experimenter wanted to place them in a nursing home, creating a final total of 21 dyads (26.83% of the 82 eligible dyads) who completed participation in the project.

Thus, data were obtained from 21 caregiver-patient dyads in which the patient was a non-institutionalized adult with dementia (as determined either through medical diagnosis or a score of 23 or less on the MMSE) and the caregiver was a co-residing relative of the patient. This sample was stratified into three groups according to the degree of reported ADL impairment, with a minimum of one reported ADL impairment (defined based on caregiver reports that the patient required setup, verbal prompting, supervision, or physical assistance) necessary for inclusion. For stratification, tertiles were formed based on ADL data collected from the first 108 patients screened for REACH. According to these tertiles, requiring assistance with one to three ADLs was determined to represent mild ADL impairment, requiring assistance with four to six ADLs constituted moderate impairment, and requiring assistance with all seven ADLs was considered severe impairment. Seven patients in each impairment group and their caregivers were entered into the study. This study was conducted in the homes of the dyads to observe ADL interactions in the natural environment.

Paper-and-Pencil Measures

All paper-and-pencil measures except the MMSE were administered orally to the caregiver, who was given a response booklet containing the range of possible answers to each question. The MMSE was the only paper-and-pencil measure completed by the dementia patient; all other instruments dealing with the patient (e.g., functional ability, depression, behavior problems) were completed by the caregiver.

Caregiver Data

Each caregiver completed a form that assessed various sociodemographic characteristics such as caregiver age, race, gender, and relationship to patient. Each caregiver also showed the experimenter the prescription and over-the-counter medications currently being taken by the caregiver, and the experimenter noted the names (but not the dosages) of each medication. Demographic and medication information was collected using forms originally created for and currently being used by all six REACH sites.

Information regarding caregiver depression was collected with the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977), a self-report measure ($\alpha = 0.86$) consisting of 20 items rated on a Likert-type scale containing the points Rarely or none of the time, Some or a little of the time, Occasionally or a moderate amount of the time, and Most or almost all of the time. A score above 15 on the CES-D is thought to indicate clinical depression. The CES-D is widely used to study stress and coping, the effects of caregiving, and the prevalence of depression in different minority and age groups (Gatz & Hurwicz, 1990; Radloff & Teri, 1986).

Patient Data

Caregivers answered questions regarding sociodemographic factors pertaining to the patient, as well as the medications currently being taken by the patient, using the same approach as outlined above. Again, the forms originally created to collect this information at the REACH sites were used.

The Mini-Mental State Exam (MMSE; Folstein et al., 1975) is a widely-used brief test of global cognitive functioning. Areas of cognitive ability that are measured include verbal reasoning, memory, language, and orientation. Test-retest and inter-rater reliabilities are 0.89 and 0.83, respectively. Scores on the MMSE can range from 0 to 30, and a score of 24 or above on the MMSE is thought to reflect the absence of cognitive impairment.

To assess the occurrence of and distress caused by patient behavior problems, caregivers completed a modified version of the Revised Memory and Behavior Problem Checklist (RMBPC; Teri et al., 1992). The original RMPBC consists of 24 problems rated by the caregiver on two 5-point scales, with one scale measuring the frequency of problem occurrence and the other scale measuring the degree of distress the behavior causes the caregiver. The RMBPC provides a global rating of behavior problems as well as three subscale ratings of memory-related, depressive, and disruptive behaviors. Overall scale reliability yields alphas of 0.84 for patient behavior and 0.90 for caregiver reaction. The version of the RMBPC used in the present study is the version currently being used by the REACH cooperative. It assesses in a binary fashion whether or not a particular problem has occurred in the past week (i.e., frequency data are not collected) as well as how bothered or upset the caregiver is by the behavior, on a 5-point Likert-type scale containing the points Not at all, A little, Moderately, Very much, and Extremely. Caregivers were asked about 24 specific behavior problems and were given the opportunity to name 3 more not contained on the instrument, for a possible total of 27 behavior problems rated.

Patient depression was assessed with a proxy version of the CES-D, with the caregivers rating the CES-D items according to their impressions of how the patient had been feeling or behaving during the past week. The wording of the questions was altered slightly to reflect third-person ratings (e.g., "His/her sleep was restless"). The response options for the proxy CES-D were the same as those used for the caregiver CES-D. Precedence for this format and this use of the CES-D can be found in several previous studies (Magaziner et al., 1997; Radloff & Teri, 1986; Teri & Truax, 1994).

A modified version of the Self-Care subscale of the FIM was used to collect caregiver-reported data regarding the dementia patents' functional status. The reliability and validity of the FIM have been discussed previously. The version of the FIM Self-Care subscale employed here is the version currently being used by REACH (Appendix B). It is composed of the six Self-Care subscale items (bathing, dressing upper body, dressing lower body, eating, grooming, and toileting) plus one of the Mobility subscale items (bed, chair, or wheelchair transfer), forming a list of items comparable to those on other standardized ADL assessment instruments. These items were administered and scored by a certified FIM rater using the FIM's standard 7-point scale to yield what will subsequently be called the caregiver-reported FIM score. The decision tree used to obtain these caregiver-reported FIM scores has been altered slightly from the format used in the original FIM (see Figures 1 and 2) to increase the ease of scoring. These changes are consistent with the telephone-administered version of the FIM (Smith et al., 1989).

The caregiver-reported FIM score was supplemented with three follow-up questions that provided additional information regarding the ADL interactions. For each ADL, the caregivers were asked how many times during the past week they had helped the patient with this task (caregiver-reported frequency) and how much time, on average, was spent each time they helped the patient (caregiver-reported duration). Following each item, the caregivers were asked to rate how much helping with that activity bothered or upset them (caregiver-reported distress). The rating scale used for this latter question contained the response options Not at all, A little, Moderately, Very much, and Extremely. Data obtained during administration of the modified FIM Self-Care subscale will sometimes be referred to as "ADL data," and includes for each ADL the caregiver-reported FIM score, caregiver-reported assistance frequency, caregiver-reported assistance duration, and caregiver-reported assistance-associated distress.

During administration of the ADL measure, it was learned that eight caregivers employed home health aides to help with bathing, dressing, or both. In cases in which the caregiver bathed and dressed the patient when the aide was absent or in which the caregiver assisted the aide during the ADL, the aide's input regarding assistance need and time was not solicited. In the former situation, only the caregiver was observed helping with these ADLs. However, if the aide were solely responsible for bathing or dressing a patient, then the aide was asked to complete only the FIM items assessing the amount and type of assistance provided (i.e., the aide provided a FIM score and reports of the frequency and duration of assistance, but was not asked to rate the distress she experienced from helping with these ADLs). This situation occurred only twice; thus, these data were not considered separately for data analysis.

Observational Measure

ADL performance in the home was videotaped using a micro-video camera designed specifically for this study by the Southern Electronics Corporation in Opelika, AL. It consisted of a Watec WA502A black-and-white video camera with zoom pinhole lens, a custom microphone and amplifier with cables (model SOU 101AUD), and a Panasonic AG505 VCR-monitor combination. The camera was cylindrical and measured approximately 15 cm x 3.5 cm x 3 cm. The microphone measured 1.2 cm x 0.8 cm and was connected to the VCR-monitor by a 240-cm cable. The size and appearance of the camera minimized subject reactivity in that the camera was relatively small, did not look like a traditional video camera, could be set down in an unobtrusive place, and could also film activity through small openings, such as a door that was slightly ajar.

The videotaped ADLs were later coded using a computer-assisted observation system that assigned keys on a laptop computer keyboard to record specified events. Videotaping the activities was chosen over in-vivo coding for several reasons. First, activities in an ADL interaction can be intermingled (e.g., being bathed while sitting on the toilet). This intermingling makes reliable in-vivo coding of discrete ADLs difficult, particularly when the duration of ADL assistance time is a variable of interest. Recording the data on videotape allowed overlapping ADLs to be isolated for coding purposes, thereby precluding the need for decision rules regarding the priority of different simultaneously occurring ADLs. (It is acknowledged that interactions containing intermingled

ADLs can be considered to be qualitatively different from interactions in which ADLs are done separately. However, the use of videotaped samples allows the topography of these intermingled ADLs to be examined separately as well as together, although the latter was not done for this study.) Second, the presence of an observer in the room can increase reactivity. Although previous studies of ADL interactions in nursing homes (e.g., Burgio et al., 1994) and staged social interactions in private dwellings (Cotter, Burgio, Hsu, & Hardin, 1998) have involved observer presence without apparent reactivity, naturalistic observations of ADLs in private dwellings had not previously been conducted. Videotaping the ADL interactions with an unobtrusive video camera apparatus insured that the observer could remain out of the room if her presence were too disruptive. Third, the need for reliability coding necessitated that another observer have access to the ADL interactions, and it was thought that having two observers in the home would increase observer reactivity. Recording the ADL sessions on tape allowed the reliability observer to view them without placing more stress on the dyad.

Hardware and Software

A Northgate ZX Portable laptop computer with 16 megabytes of RAM, a 1.4-gigabyte hard drive, and a 3.5-in. floppy disk drive was used to collect and code observational data in this project. Data were collected directly into the hard drive, transferred to a floppy disk, and then transferred into an SPSS data structure on a separate personal computer, where the data were stored and analyzed either in SPSS or in SAS, depending on the nature of data analysis. For analysis in SAS, the data were exported from SPSS using DBMS Copy software.

Data were coded using the Portable Computer Systems for Observational Research software, originally developed by Communitech International in DeKalb, IL. This software assigns keys on the laptop computer to record various behaviors of the experimenter's specification. Using this software, keys can be assigned to record an event's frequency alone or both the frequency and the duration of an event. Event keys assign a default 1-s duration to that event. Duration keys must be turned on and off individually unless they are members of a mutually exclusive and exhaustive category, in which case only one key is pressed within a category at a given time. Pressing a key within a mutually exclusive and exhaustive category automatically turns off a previously pressed key. It should be noted that the observational system allows only four categories of behaviors to be designated as mutually exclusive and exhaustive, regardless of whether the operational definitions of the categories as determined by the researcher are mutually exclusive and exhaustive.

Categories and Codes

The operational definitions of the behavioral-environmental categories and the specific event codes within them were based not only on previous observational studies (e.g., Burgio et al., 1994; Cotter et al., 1998; Rogers et al., in press; Scilley, Burgio, Hardin, Hsu, & Mitchell, 1993), but also on the definitions of the ADLs and participant behaviors provided in the FIM. All categories and codes were constructed to match as closely as possible any specifications given in the FIM. The categories and codes measured three main types of behaviors: patient performance of specific ADLs, assistance provided by the caregiver during these ADLs, and additional elements thought to influence the behaviors exhibited during the ADL interaction (e.g., patient disruptive behaviors, use of assistive devices). The operational definitions of these categories and codes are provided in Appendix C.

Figure 2 depicts the keyboard layout used to classify the components of the ADL interaction. The occurrence and duration of the ADL was assessed with two binary keys (i.e., either the ADL was occurring, or it was not occurring), using the operational definition of that ADL found in the FIM. The task analysis differed by ADL and was designed to correspond to the task analyses presented on the FIM. Across all ADLs, the other behaviors coded during the interaction (i.e., assistive device use, caregiver verbal behavior, caregiver physical assistance, patient disruptive behavior, caregiver presence, and patient ADL performance) had the same basic operational definitions. The category of "patient performs ADL" measured the length of time the patient performed or attempted to perform the ADL. This category differs from ADL duration in that the latter category recorded the total amount of time spent conducting the ADL, regardless of who did the work, whereas only the patient's performance was measured in the "patient performs ADL" category. It should be clarified that patient performance is measured independent of whether or not the caregiver also helps with the ADL. In other words, it is considered possible for both caregiver and patient to participate in the ADL simultaneously, such as a situation in which a patient washes her face while the caregiver brushes her hair.

To obtain data regarding the type of assistance provided during the ADLs, two categories of keys recorded the caregivers' verbal and nonverbal behaviors. The category "caregiver verbal behavior" documented the occurrence and duration of cautionary

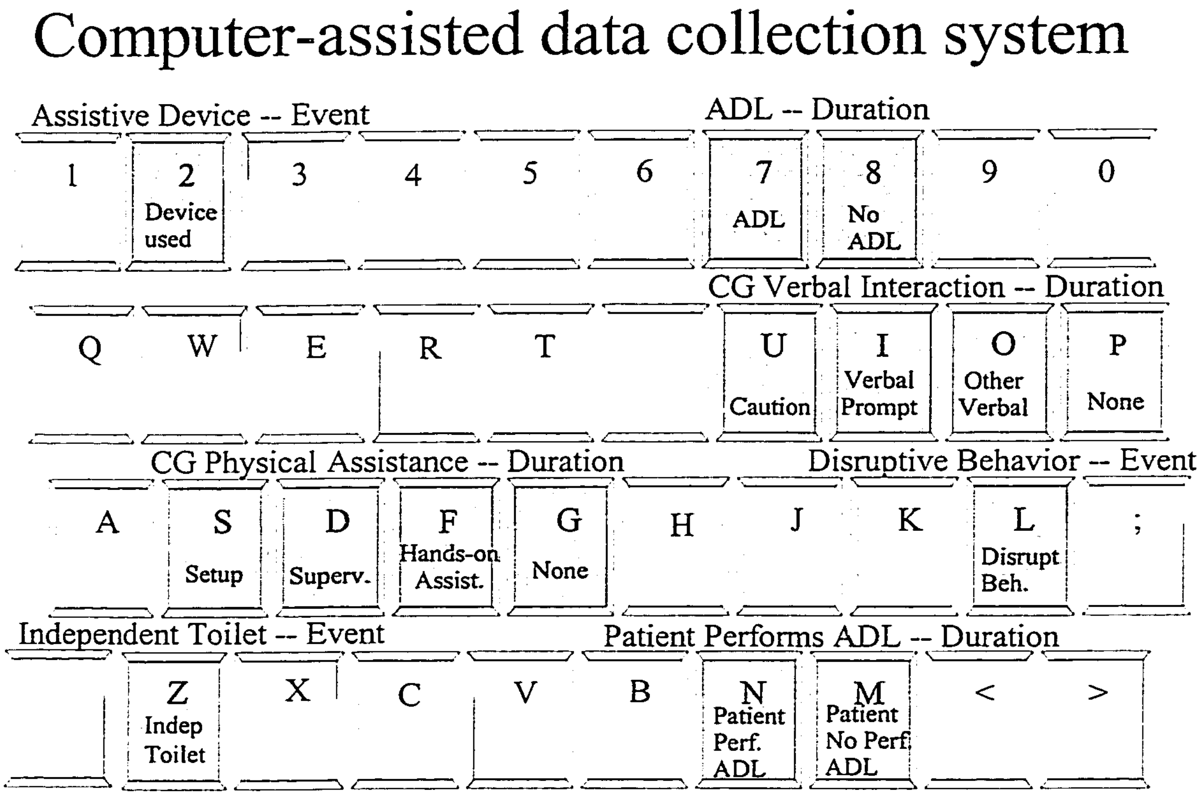

Figure 2. Keyboard Layout Depicting the Observational System.

statements (e.g., "Be careful"), prompts (e.g., "Lift your arm"), and miscellaneous or other statements (e.g., "How are you feeling today?"), as well as the absence of caregiver verbal statements. The physical assistance provided by the caregiver was calculated by recording activity setup, supervision, and hands-on physical assistance, as well as the absence of assistance. Additionally, one event key was used to code instances of independent toileting that occurred too quickly for the experimenter to record with the video camera.

The observational system also recorded other variables believed to influence caregiver and patient behavior during the ADLs. Two binary keys were used to assess whether or not an assistive device had been used to perform the ADL. The type of device used was not recorded on the keyboard but was documented in the field notes (see below). One event key was used to record the occurrence of patient disruptive behaviors (e.g., agitation, physical aggression, disruptive vocalization).

In addition to documenting participant behaviors and environmental or contextual variables, the observational system also allowed the rater to record field notes at the end of a session. Here, field notes expanded on the quantitative information regarding ADL performance by noting qualitative factors such as the number of caregivers present during an ADL, the relationship of the caregiver(s) to the patient, or the type of assistive device used. The field notes were also used to record unusual occurrences such as intermingled ADLs, disruption in the household, or a delay between materials setup and patient ADL participation.

Because the primary goal of this study was to examine the relationship between FIM items rating ADL performance (as reported by caregivers) and actual performance of

ADLs in the home, it was vital that the observational system have the capacity to capture all of the possible ability levels on which these items could be scored. Table 1 displays the correspondence between the definitions contained in the observational system and the FIM categories. For example, recording caregiver verbal and physical behaviors denoted whether an ADL was performed independently or with caregiver assistance. On the FIM, this information distinguishes individuals who score a 6 or 7 from those individuals who score a 5 or below. FIM scores of 4, 3, 2, and 1 all indicate estimates of the amount of effort put forth by the patient in performing ADLs. The validity of these estimates was examined by comparing them to the duration of patient ADL performance recorded by the observational system. Additionally, because the observational system also recorded the duration of caregiver assistance, these quantitative measures were available for comparison to the caregiver's estimates of assistance time.

Procedure

Potential dyads first underwent a telephone screening process to determine eligibility (i.e., whether or not the patient had needed help with any of the seven ADLs during the past week). For each ADL, the caregiver reported in a yes or no fashion whether or not the patient had needed help. Specific FIM scores and other caregiver-reported ADL data were not obtained at this point.

Following the initial telephone screening, the experimenter scheduled a time to meet with eligible dyads in their home to describe the study in more detail and answer any questions. Consent forms were signed and paper-and-pencil measures completed

Table 1

Representation of FIM Levels of Function on the Observational System

FIM level (numerical score)	FIM definition	Observational system definition
Complete independence (7)	All tasks which compose the activity are performed safely, within a reasonable time, and without modification, assistive devices, or help from another person.	No assistive devices used No concern for safety expressed Caregiver does not supervise, prompt, or touch patient No setup of materials provided Patient does not take more than three times as long as normal to perform ADL
Modified independence (6)	Patient requires an assistive device, the activity takes more than reasonable time to perform, or there are safety considerations.	Caregiver does not supervise, prompt, or touch patient No setup of materials provided Assistive device used, concern for safety expressed, and/or patient takes three times as long as normal to perform ADL
Supervision or setup (5)	Patient performs at least 50% of the task and requires only task set-up, standby, or cuing or coaxing with no physical contact from the caregiver.	Caregiver provides verbal prompts, setup, and/or supervision only and has no physical contact with patient
Minimum assistance (4)	Patient requires no more help than touching and expends 75% or more of the effort.	Patient spends at least 75% of ADL time performing the task
Moderate assistance (3)	Patient requires more help than touching or expends 50-75% of the effort.	Patient spends 50-75% of ADL time performing the task
Maximum assistance (2)	Patient expends 25-50% of the effort.	Patient spends 25-50% of ADL time performing the task
Total assistance (1)	Patient expends less than 25% of the effort.	Patient spends less than 25% of ADL time performing the task

during this visit. To ensure the validity of the informed consent process, the caregiver gave proxy consent for the patient. However, the patient participated in the discussion of the nature and purpose of the study as much as possible and was encouraged to ask questions and express his or her opinion about it. It was explained to the patient that the experimenter was doing a project for school and would be coming back to visit several more times to observe the daily routine in the household. None of the 21 study patients objected to the experimenter's visits; however, as noted previously, two other patients had to be excluded because they could not be persuaded that the experimenter was not there to admit them to a nursing home.

At this time, the experimenter determined the best days and times to conduct the observations based on each family's schedule. Although attempts were made to observe each of the seven ADLs three times per dyad, various factors such as caregiver time limitations, omission of ADLs, or patient noncompliance resulted in ADLs sometimes being observed less than three times per dyad. When patient noncompliance was the reason for a failed observation, it was clarified by the caregivers that the experimenter's presence in the home was not the reason for the patients' refusal to cooperate with ADLs. Noncompliance was rare and occurred in only three dyads. Out of a possible 63 observation times per ADL across all dyads, the following numbers were obtained: bathing, 52 times; dressing above the waist, 56 times; dressing below the waist, 58 times; eating, 55 times; grooming, 53 times; toileting, 53 times; and transferring, 58 times. All 21 patients had at least one observation of each ADL, with three exceptions: Two patients had no grooming observations due to noncompliance, and another patient had no transferring observations because she was never removed from her bed.

Efforts were also made to distribute observations throughout the day to capture a variety of ADL performance situations (e.g., differences in meal composition). However, maintaining the validity of the observational data required that the experimenter disrupt or alter the caregivers' schedules as little as possible; thus, the experimenter was bound by caregivers' established routines and schedule limitations in arranging observational visits. As a result, all but three dyads' observations were conducted solely in the morning because this time was most convenient for the majority of the caregivers and, frequently, most productive for maximizing efficient data collection, as all seven of the target ADLs tended to be conducted in close temporal proximity in the mornings. All dyads were asked whether they thought that patient performance or their assistance varied at different times of the day (e.g., if the caregiver cut up the patient's meat at suppertime, but provided no assistance with other meals). Only one caregiver reported this situation, and thus this dyad was observed both in the morning and at night to capture this variation.

The experimenter attempted to complete each dyad's observations within a 2-week period to ensure that no significant declines in patient functioning would occur. However, data collection for four dyads spanned a period of 3-4 weeks due to unexpected situations (e.g., out-of-town guests or patient illness). In these cases, caregivers did not complete a new version of the FIM, but they were asked about sudden changes or declines in patient functioning. No changes of this nature were noted by these four caregivers.

After arriving at the home for ADL observation, the experimenter prepared the video recording device for use. It was explained to the dyad that the experimenter was there to do some work, and that the dyad should try to ignore her and conduct the daily activities as usual. Further patient inquiries about the experimenter's presence were answered in a variety of ways depending on degree and awareness of cognitive impairment. For example, knowledgeable patients with mild dementia were told that the experimenter was learning about how memory problems affected people's ability to do things for themselves, while patients with moderate to severe dementia rarely asked questions apart from an occasional “Who’s that?” and were easily mollified with a statement such as “That’s just Ellen; she’s here to visit us.” Patients who were unaware of their dementia diagnosis were told that the experimenter was studying “older adults and how they went about their daily activities.” When possible, the caregiver explained the experimenter’s presence to add further validity.

To decrease observer reactivity, attempts were made to have the experimenter out of the room during ADL performance. However, due to spatial limitations in the home, this arrangement was not always possible. When the experimenter was unable to videotape the ADLs from another room or out of sight of the dyad, she sat or stood in an unobtrusive location and did not initiate verbal interaction or eye contact with the dyad. Patients rarely objected to either the experimenter or the video camera. If a patient expressed embarrassment during an ADL (specifically, toileting or bathing), the door was closed and the experimenter inserted the microphone under the door to record the sound of the ADL. Only the closed door was filmed until the patient opened it or emerged. This situation occurred in only five dyads and in all but two cases was associated with a patient who was sufficiently high-functioning to require no caregiver assistance.

Following the ADL observation sessions, videotape coding was performed by the experimenter and one reliability observer trained following the methods outlined in Burgio et al. (1994). To prepare the tapes for coding, the time counter on the VCR was used to identify the time span during which each performance of each ADL occurred, and these time spans were noted on an external log attached to the videocassette case. An ADL session was coded by advancing the videotape to the beginning of the time span during which the ADL occurred (as noted on the tape case), pausing the tape, and turning on the four “no activity” keys (i.e., “no ADL,” “no caregiver verbal activity,” “no caregiver assistance,” and “no patient ADL performance”) in a predetermined order, with a set interval during the press of each key. Simultaneous with the activation of the “no patient ADL performance” key, the videotape was started, and the dyad’s activities were coded as they occurred. At the end of the session, again noted on the tape case, the coding of that ADL was terminated and the data file saved.

It was noted during videotaping that ADLs were sometimes conducted in several segments (e.g., the caregiver gets out the patient’s clothes, after which the patient bathes, eats breakfast, and then gets dressed). Depending on the dyad’s established routine, the time span between different segments of a particular ADL session could last from several seconds to 30 min or more. However, the activities occurring during this delay were not always of interest. In the above example, the dyad’s activities during the bath and the meal are not considered pertinent to the provision of assistance during the dressing tasks that precede and follow them. To prevent the coders from having to maintain coding during long time spans (i.e., more than 5 min) when unrelated activities were occurring, the duration of each segment of the ADL was noted, and each segment was coded separately. When an observation was divided in this way, the observers coded one segment at a time within a file. The coding session was begun as described above; however, at the end of a segment, the observers pressed the “\” key, which turned off all codes simultaneously but did not end the file. The tape was then advanced to and paused at the point where the next segment of the ADL began, and the observers reactivated the code keys in the same order as described above. Because the “\” key has an automatic 1-s duration and temporarily halts the progression of time within the data file, variations in the interval between different segments of the ADLs were nullified. This process allowed multiple segments to be coded as part of the same ADL session.

During reliability sessions, the experimenter and reliability observer viewed the videotaped ADL interactions and coded them independently. Inter-rater reliability was assessed during 18% of the total observation time of the study and calculated using Cohen's Kappa, a measure of reliability that adjusts for chance agreements based on a second-by-second comparison of the files of the two observers (Burgio et al., 1994). Kappas of .65 or above are considered to represent acceptable inter-rater reliability. Kappas for the behavioral categories and event codes can be found in Table 2.

Data Analysis

Paper-and-Pencil Measures

Descriptive statistics were calculated to summarize the sample characteristics with regards to demographic variables and all paper-and-pencil measures of caregiver and patient functioning. These statistics were calculated using the SPSS software package. Additionally, correlational analyses were performed, also using SPSS, to determine the nature and strength of relationships among paper-and-pencil variables of interest.

Observational Data

The computer-assisted data collection system generates a stream of data for each dyad during each block of observation time. This data stream consists of a start time, a

Table 2

Kappas for Behavioral Categories and Event Codes

Category and code	Kappa
Occurrence of ADL	
ADL occurring	.86
ADL not occurring	.86
Caregiver verbal behavior	
Caution statements	--
Verbal prompts	.68
Other verbal statements	.67
No verbal activity	.75
Caregiver physical assistance	
Setup	.77
Supervision	.70
Hands-on assistance	.86
No physical assistance	.88
Patient ADL performance	
Patient performing ADL	.76
Patient not performing ADL	.82
Assistive device use	.77
Disruptive behavior	.78

Note. A kappa of .65 or higher is considered acceptable. Dashes (--) indicate that this behavior was not observed during reliability sessions.

stop time, and a behavior code. The start and stop times are both recorded in seconds. After the ASCII data files were read into SAS, the percentage of total time during which a behavior code was observed during each ADL was calculated for each dyad by adding the amount of time a particular behavior was recorded during each observation session and dividing this sum by the total time of the observation sessions for that dyad.

First aim. The first aim was to examine the degree to which caregiver-reported FIM scores, which yield information regarding typical provision of ADL assistance, corresponded to the assistance actually provided during ADL interactions as recorded through direct observation. To achieve this aim, the observational data were subjected to a SAS program that converted these continuous observational data into ordinal designations that corresponded directly to the FIM categories. This conversion was possible because each of the seven levels of the FIM has at least one defining characteristic that distinguishes it from the remaining levels (see Table 1). "If-then" SAS statements, based on the presence or duration of certain events, were used to identify the defining characteristics for each level and thereby derive the scores. For example, if hands-on assistance was not provided but the caregiver did supervise, prompt, or get materials out for the patient, then the FIM score would be 5. If, however, the caregiver provided hands-on assistance, then the occurrence of setup, supervision, or prompting was rendered irrelevant, and the duration of patient ADL performance was used to determine whether the observation-derived FIM score should be 4, 3, 2, or 1.

After the percentages for each key in the observational system were calculated as described above, these percentages were read into SAS for conversion to FIM categories. Each ADL was examined separately. In other words, the data used to create the observation-derived FIM score represent not the individual observations but the averaged percentages, durations, and occurrence rates across all observations of a particular ADL for a particular dyad. Thus, a single occurrence of a variable (such as assistive device use) anywhere in a dyad's observations for a particular ADL was sufficient to affect the program used to calculate the observation-derived FIM scores. Additionally, the use of averages does not discriminate between observations wherein a caregiver provided hands-on assistance one day but only supervision the next. However, this non-discrimination is consistent with the paper-and-pencil FIM. On the paper-and-pencil FIM used in this study and in REACH, a patient who uses an assistive device only once a week to bathe would receive the same FIM score as a patient who uses an assistive device every day. Similarly, because the paper-and-pencil FIM assesses the assistance provided during the past week, a patient who required help tying her shoelaces only once would receive the same FIM score as a patient whose shoelaces were tied for her three times. Thus, averaging performance across several observations, as was done here, is reasonable and consistent with the standardized method used to obtain the paper-and-pencil FIM scores.

In devising the decision metric for calculating the observation-derived FIM score, three factors became especially noteworthy and deserve special mention here. First, one of the criteria for determining a whether a patient exhibits "complete" or "modified independence" (FIM scores of 7 and 6 respectively; see Table 1) involves assessing whether or not the patient performed the ADL within a reasonable time. (This issue is irrelevant when caregiver assistance is provided.) The FIM guidelines (UB Foundation Activities, Inc., 1993) indicate that determining a reasonable time is a clinical judgment performed by the FIM rater but "usually...equals three times the normal time required to complete an activity" (p.2). Unfortunately, data regarding "normal" ADL performance times could not be found in the United States. However, in 1997, Baltes and colleagues completed a study in which they asked healthy, cognitively intact German elders to describe the amount of time spent performing ADLs. While complete correspondence cannot be claimed due to cultural differences and aforementioned issues with self-reporting, the data collected by Baltes and colleagues do provide a metric for making preliminary comparisons in the current study. For each ADL of interest, the average duration time reported by the German elders (P. Klumb, personal communication, April 30, 1997) was multiplied by three and entered into the decision tree for use in determining the observation-derived FIM score.

The second factor involved a distinction made on the original FIM that proved impractical for working with the observational data. When a patient requires assistance, the FIM asks whether the patient provides at least half the effort (see Figure 1 for a pictorial representation of the FIM scoring levels). Patients who do provide at least half the effort are further subdivided according to whether or not they require any hands-on assistance: Patients who provide at least half the effort receive a FIM score of 5, those who require only incidental hands-on assistance (e.g., the caregiver buttons the patient's shirt after the patient puts the shirt on independently) receive a FIM score of 4, and those patients who provide at least half the effort but require more than incidental hands-on assistance receive a FIM score of 3. (In contrast, patients who do not provide half the effort are subdivided according to whether or not they require total assistance, with those patients who do not require total assistance receiving FIM scores of 2 and those who receiving FIM scores of 1.) However, in converting the observational data to FIM scores, a problem with this "half the effort" distinction was noted. Several patients did not actively participate in the ADL for at least 50% of the observation time, yet they received no hands-on physical assistance. If the FIM were interpreted strictly, these patients could not be scored. For example, one patient was easily distracted during meals, and frequently spent long periods of time looking around the room instead of eating. Because his plate of food was still in front of him, the ADL was considered to be ongoing during these times, but his participation was not. As a result, he was actively engaged in the ADL of eating during only 43.73% of the ADL observation time. However, he received only verbal prompting and supervision (i.e., no hands-on assistance). Thus, the type of caregiver assistance, and not the amount of patient participation, was considered to be the most pertinent variable for deriving an observation-based score for this and similar patients. In this situation, the patient was considered to have a FIM score of 5 based on the nature of the caregiver assistance provided. This modification is also consistent with the version of the FIM used in REACH, which eliminates the "half the effort" distinction and only distinguishes between the need for hands-on physical assistance and "hands-off" assistance such as setup, supervision, and prompting (see Figure 3).

The third factor involved determining the degree of patient participation exhibited during the ADL. Because patient effort is also a clinical judgment, participation was, for the purposes of this project, considered to be the percentage of ADL time during which active patient participation was coded. It is recognized that the percentage of participation time may not perfectly correspond to the amount of effort provided; as with the "reasonable time" designation, this figure was used as a metric for comparison and calculation purposes.

Again, Table 1 depicts the criteria used to derive the observation-derived FIM scores. For a patient to receive a FIM score of 7, the following conditions were necessary: In the observational data, no hands-on or "hands-off" assistance (i.e., either supervision or setup), no verbal prompting, no assistive device use, and no cautionary statements

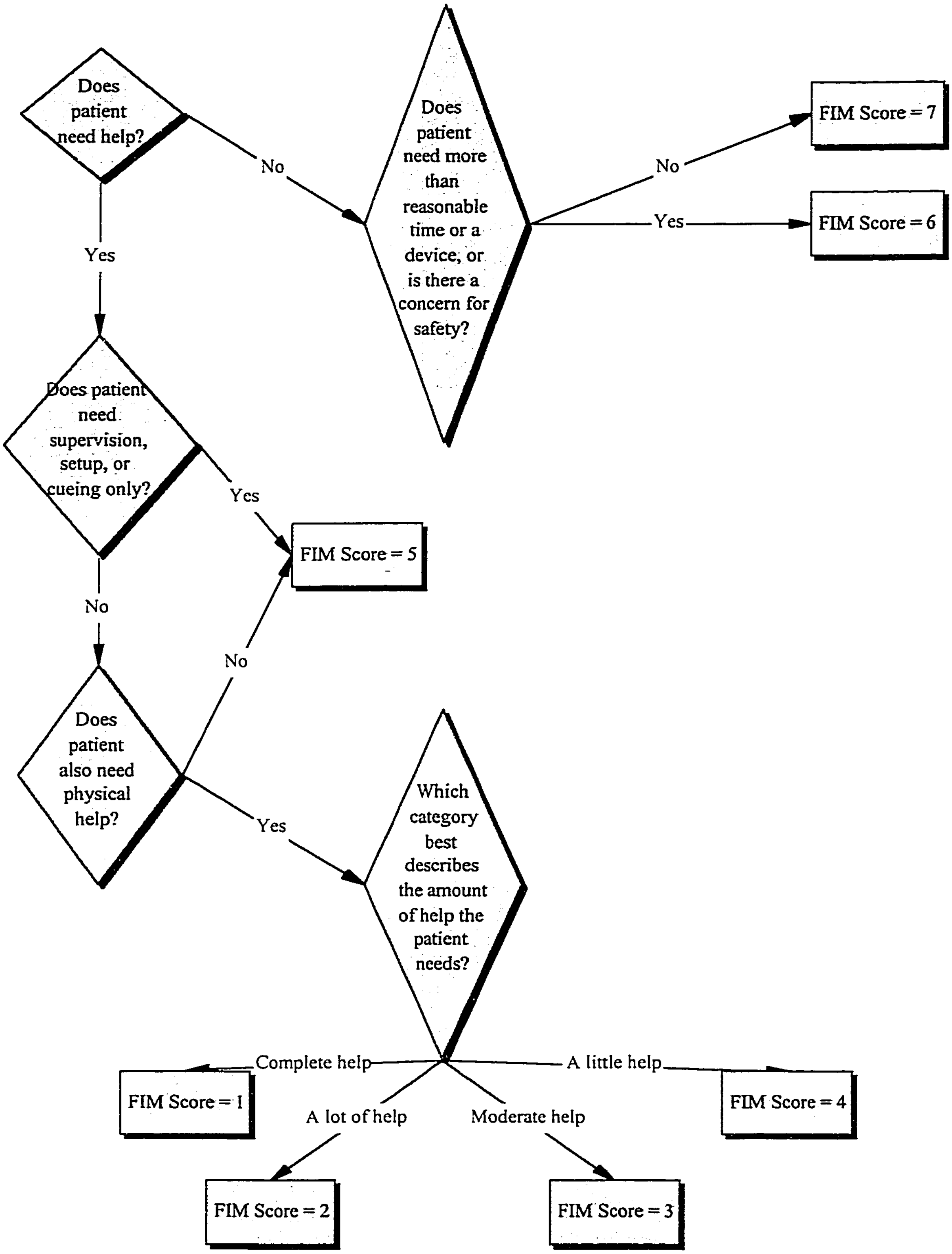

Figure 3. Decision Tree for the Modified FIM Used in REACH.

could occur. Additionally, the patient could not take "more than reasonable time" to complete the ADL, as determined above.

In contrast, for a FIM score of 6, no verbal prompting or hands-on or hands-off assistance could occur, but some occurrence of device use, caregiver cautionary statements, or both was necessary. To remain faithful to the paper-and-pencil FIM, the duration of device use and cautionary statements were not considered to be relevant for this purpose. Additionally, patient participation that amounted to more than three times the length of ADL participation time reported by Baltes and colleagues would also result in a FIM score of 6, although it should be noted that no observation-derived FIM scores were created based on this criterion alone.

If any hands-off assistance or verbal prompting occurred, but no hands-on assistance was recorded, then the FIM score was considered to be 5. Again, the duration of these behaviors was not evaluated, consistent with the paper-and-pencil FIM. It should be noted that when any type of assistance or verbal prompting is provided, the questions regarding assistive device use, cautionary statements, and whether or not the ADL was conducted in a "reasonable time" become irrelevant. These conditions will be the same through the remaining levels on the FIM.

If any hands-on assistance occurred, regardless of the co-occurrence of hands-off assistance or verbal prompting, then the highest FIM score that could be derived was 4. Determining whether the observational data corresponded to FIM scores of 4, 3, 2, or 1 then involved examining the percentage of patient ADL performance time. If patient performance amounted to 76% or more of the ADL time, then the FIM score was determined to be 4. Patient performance time between 51% and 75% was given a FIM score of 3. Patient performance time between 26% and 50% received a FIM score of 2, and patients who exhibited active participation during 25% or less of the ADL observation time were given a FIM score of 1.

The above decision rules were expressed in SAS programming language and applied to the averaged observational data for each subject by ADL. This SAS program produced a range of observation-derived FIM scores that, upon examination, appear to have been logically obtained from the statements in the computer program and are consistent with the rules used to determine scores during the paper-and-pencil FIM completion.

Second aim. The second aim of the study was to examine, through correlational analysis, the extent to which the caregiver-reported assistance duration corresponded to the actual assistance duration observed during the ADL interactions. To perform these analyses, a new variable called "observed caregiver assistance time" was created by averaging for each subject and each ADL the durations of the keys on the observational system that corresponded to supervision, setup, hands-on assistance, and verbal prompting. Although supervision, setup, and hands-on assistance were mutually exclusive and exhaustive on the observational system, verbal prompting could overlap with any or all three of those behaviors and thereby artificially inflate the observed assistance time. Thus, these instances of overlap were identified and accounted for in the data. This new variable representing the overall observed duration of caregiver assistance was correlated with the caregiver-reported assistance duration estimates provided on the paper-and-pencil ADL measure.

Although the use of cautionary statements could be considered to be assistance, these statements were excluded from the observation-derived "assistance" variable to remain consistent with the FIM. On the FIM, "concern for safety" is a criterion for determining whether a subject is classified as exhibiting "complete" or "modified independence," but is not a criterion for deriving any other scores. In the observational system, the caregiver's use of cautionary statements such as "Be careful" during ADL sessions was considered to be a marker for safety concern, because subjective (i.e., thought, but not expressed) concern for safety cannot be assessed through observational techniques. (It is, of course, recognized that the caregivers may have felt concern for safety that was not overtly expressed.) Thus, the use of cautionary statements was not considered, for the purposes of this project, to be part of assistance provision in the observational system or these analyses.

Third aim. The third aim of this study was to examine relationships among caregiver and patient factors (e.g., depression, cognitive status, and number and severity of behavior problems) and the reported and observed ADL data. Correlations were conducted involving the caregiver and patient CES-D, RMBPC, MMSE, and both the caregiver-reported and observation-derived ADL measures.

CHAPTER 3

RESULTS

Paper-and-Pencil Measures

Caregivers

Demographic data. Descriptive data regarding caregivers can be found in Table 3. The caregivers in this sample ranged in age from 43 to 84 years ($\underline{M}$ = 62.29 years). Women constituted 76% of the sample, and 71% of the sample was White. Regarding the caregiver's relationship to the patient, this sample was composed of eight daughters (38%), five wives (24%), three sons (14%), two husbands (10%), and one (5%) each sister, sister-in-law, and cousin. Fourteen caregivers (66%) were married, 4 (19%) were divorced, 2 (10%) had never been married, and 1 (5%) was a widow. On average, the caregivers had lived with the patients for approximately 22 years ($\underline{M}$ = 22.24 years, range = 1-58 years), although nine caregivers (43%) had lived with the patient for 5 years or less. Eleven caregivers (52% of the sample) reported that they had begun to live with the patient specifically to take care of him or her.

Approximately 86% of the caregivers in this sample had a high school education or greater. Only seven caregivers (33%) were employed outside the home, with four (19% of the total sample) holding full-time jobs. The seven employed caregivers worked, on average, approximately 33 hours per week ($\underline{M}$ = 33.43 hours, range = 10-52 hours). Out of the total sample, seven caregivers (33%) stated that they had either retired ($\underline{n}$ = 4, or

Table 3

Caregiver Demographics

Variable	Frequency (%)	M (SD)	Range
Gender			
Female	16 (76)		
Male	5 (24)		
Ethnicity			
African American	6 (29)		
White	15 (71)		
Relationship to patient			
Daughter	8 (38)		
Wife	5 (24)		
Son	3 (14)		
Husband	2 (10)		
Cousin	1 (5)		
Sister	1 (5)		
Sister-in-law	1 (5)		
Marital status			
Married	14 (66)		
Divorced	4 (19)		
Never married	2 (10)		
Widowed	1 (5)		
Employment status			
Retired	10 (48)		
Employed full-time	4 (19)		
Employed part-time	3 (14)		
Unemployed	3 (14)		
Homemaker	1 (5)		
≥High school education	18 (86)		
Age in years		62.29 (11.59)	43-84
Length of coresidence in years		22.24 (21.83)	1-58

Table 3 (continued)

Variable	Frequency (%)	M (SD)	Range
CES-D score		12.10 (9.9)	0-35
Number of medications taken		4.48 (2.16)	1-8
Household income bracket		$30,000-39,999	($5,000-9,999)-($70,000-79,999)

Note. N = 21 with the exception of the CES-D (n = 20). Percentages may not sum to 100 due to rounding.

19%) or reduced their working hours (n = 3, or 14%) to provide additional care to the patient. The mean annual household gross income reported by this sample was in the lower end of the $30,000-39,999 bracket; the range of reported incomes extended from the $5,000-9,999 bracket up to the $70,000-79,999 bracket. When asked how difficult it was to pay for basic necessities such as food and housing, 10 caregivers (47%) reported that it was not difficult at all, 7 (33%) reported that it was not very difficult, and two groups of 2 caregivers (10% each) endorsed the statements somewhat difficult and very difficult.

Caregiver depression and medications. The mean caregiver CES-D score is based on a sample size of 20 because one caregiver provided several "don't know" answers, rendering his score invalid. Caregivers obtained an average CES-D score of 12.10 (range = 0-35). However, six caregivers (30%) had scores of 15 or higher, suggesting clinical depression. Of these six caregivers, four were taking a prescribed psychoactive medication, although one reported taking St. John's Wort. Overall, eight caregivers reported taking a prescribed psychoactive medication. All caregivers reported taking between one and eight prescribed or over-the-counter medications of any type on a regular basis, with an average of approximately four medications regularly taken (M = 4.48).

Patients

Demographic data. Patient sociodemographic data are shown in Table 4. The patients in this sample were mostly women (67%) and White (71%), with an average age of 79.62 years (range = 60-92 years). Regarding the patient's relationship to the caregiver, this group of patients was composed of 10 mothers (47%), 5 husbands (24%), 2 wives (10%), and 1 each father, sister, sister-in-law, and cousin (5% each). One patient had never married, 7 (33%) were currently married, and the remaining 13 (62%) were widowed. Slightly over half of the patients (52%) had a high school education or greater. Caregivers rated the patients' physical health as follows: poor, 10%; fair, 19%; good, 33%; very good, 33%; and excellent, 5%. The average patient took approximately four prescribed or over-the-counter medications (M = 4.05, range = 1-9) of any kind on a regular basis. Fifteen (71%) of the patients were taking at least one psychoactive medication for management of depression, anxiety, or behavioral problems. Additionally, six patients (27% of the total sample) were taking Aricept, and one was noted to take ginkgo biloba capsules.

Table 4

Patient Demographics

Variable	Frequency (%)	M (SD)	Range
Gender			
Female	14 (67)		
Male	7 (33)		
Ethnicity			
African American	6 (29)		
White	15 (71)		
Relationship to caregiver			
Mother	10 (47)		
Husband	5 (24)		
Wife	2 (10)		
Father	1 (5)		
Cousin	1 (5)		
Sister	1 (5)		
Sister-in-law	1 (5)		
Marital status			
Widowed	13 (62)		
Married	7 (33)		
Never married	1 (5)		
Caregiver-rated health			
Poor	2 (10)		
Fair	4 (19)		
Good	7 (33)		
Very good	7 (33)		
Excellent	1 (5)		
≥High school education	11 (52)		
Age in years		79.62 (8.53)	60-92
CES-D score[a]		13.67 (10.38)	0-35
MMSE score[b]		7.84 (9.02)	0-24

Table 4 (continued)

Variable	Frequency (%)	M (SD)	Range
Total RMPBC behavior problems		8.38 (5.00)	0-20
Occurrence of depressive problems		1.29 (1.19)	0-4
Occurrence of disruptive behaviors		1.57 (1.33)	0-5
Occurrence of memory problems		3.90 (2.07)	0-7
Number of medications taken		4.05 (2.27)	1-9

Note. N = 21 unless otherwise noted. Percentages may not sum to 100 due to rounding.
[a]n = 12. [b]n = 19.

Cognitive status. MMSE data are based on a sample size of 19, as two patients refused to answer the questions on this instrument. The average score on this instrument was 7.84, which represents severe cognitive impairment. Scores on the MMSE ranged from 0 to 24. These MMSE scores reflect a sample with a range of cognitive impairment and are representative of the general population of patients with dementing illnesses.

Behavior problems. Caregivers reported an average of 7.52 patient memory and behavior problems (range = 0-17) from the standardized list on the RMBPC. The most commonly-reported problems were forgetting the day (n = 19, or 90%), forgetting recent events (n = 16, or 76%), forgetting past events (n = 13, or 62%), and appearing anxious or worried (n = 13, or 62%). Caregivers' ratings of the degree to which each problem bothered or upset them indicated that the highest average ratings (3 out of a possible 4, or very much upsetting) were given to the behaviors of crying, expressing feelings of hopelessness or sadness about the future, and destroying property. However, these behaviors were reported only one time each. The behaviors of waking people up at night, displaying verbal aggression, expressing feelings of loneliness, and being argumentative were reported by at least four caregivers each and received the maximum distress ratings of 4 (extremely upsetting). Thus, these behaviors can be considered to be the most distressing of those listed on the RMBPC. When asked if the patient exhibited any memory or behavior problems not listed on the RMBPC, caregivers reported a total of 15 additional problems. Twelve of these problems received one endorsement each, and the behaviors of resisting care, hitting others, and babbling were each reported twice. These three "write-in" behaviors also received the highest possible distress ratings.

The occurrence of problems and caregiver-reported distress for the three subscales on the RMBPC (i.e., disruptive behaviors, depressive behaviors, and memory-related problems) were examined separately. In general, memory-related problems such as forgetting the day were most frequently reported, M = 3.90, and received the highest overall distress ratings (M = 3.33 on the 0-4 scale, where 0 represents not at all upsetting and 4 represents extremely upsetting). Disruptive behaviors such as waking people up at night occurred an average of 1.57 times across all the subjects, with an average overall distress rating of 2.38. Depressive behaviors such as complaining of loneliness were reported an average of 1.29 times across all subjects and received an average overall distress rating of 2.43.

Patient depression. Patient depression as reported by caregivers could not be reliably measured for nine patients because their caregivers had difficulty answering the questions, resulting in missing data. Caregivers seemed to have the most difficulty with items on which they had to rate the patient's feelings. The 12 patients for whom a complete proxy CES-D score could be computed had an average score of 13.67 (range = 0-35); this score, like the caregivers' average CES-D score, approaches but does not reach the clinical depression cutoff point. Four patients (33% of this subsample) obtained scores above 15, suggesting clinically significant depression.

Caregiver-reported ADL data. The paper-and-pencil FIM used in this study and in REACH yields four caregiver-reported variables for each ADL: a FIM score ranging from 1-7 (caregiver-reported FIM score), an estimate of the number of times ADL assistance was provided during the past week (caregiver-reported assistance frequency), an estimate of the duration of this ADL assistance each time it occurred (caregiver-reported assistance duration), and a rating of caregiver distress associated with providing ADL assistance (caregiver-reported assistance-associated distress). Each of these variables will be discussed in this section and in the corresponding tables.

Table 5 displays the distribution of caregiver-reported FIM scores for each of the seven ADLs assessed. Caregivers reported providing hands-on assistance (represented by FIM scores of 1-4) most frequently with grooming (71%), bathing (71%), and dressing above (86%) and below the waist (67%). A score of 5, which indicates the provision of supervision, setup, or verbal prompting, was most frequently reported for eating (29%), bathing (19%), and dressing below the waist (24%). Independent ADL performance, indicated by scores of 6 or 7, was most frequently reported for toileting (38%) and

Table 5

Distribution of Caregiver-Reported FIM Score Ratings by ADL

	FIM score frequency (%)						
ADL	1	2	3	4	5	6	7
Bathing	9 (43)	5 (24)[a]	--	1 (5)	4 (19)	1 (5)	1 (5)
Dressing above the waist	9 (43)	--	4 (19)	5 (24)	2 (10)	--	1 (5)
Dressing below the waist	9 (43)	1 (5)	2 (10)	2 (10)	5 (24)[b]	--	2 (10)
Eating	4 (19)	1 (5)	2 (10)	2 (10)	6 (29)	--	6 (29)
Grooming	7 (33)	2 (10)	3 (14)	3 (14)	1 (5)	1 (5)	4 (19)
Toileting	8 (38)	1 (5)	--	--	4 (19)	1 (5)	7 (33)
Transferring	5 (24)	1 (5)	1 (5)	3 (14)	1 (5)	3 (15)	7 (33)

Note. N = 21 in all cases. Dashes (--) indicate that a particular score was not reported. Percentages may not sum to 100 due to rounding.

[a] Two of the scores in this category were from paid caregivers. [b] One score in this category was from a paid caregiver.

transferring (47%), although the figures for independence approached those for hands-on assistance for these two activities.

Caregivers' reports of ADL assistance-associated distress are shown in Table 6. This question was asked only of those familial (i.e., not professional) caregivers who had provided a FIM score of 5 or below for a particular activity. Assistance-associated distress cannot reasonably be assessed when no assistance is provided, and it was also felt that paid caregivers' ratings of assistance-associated distress would not be appropriate for

Table 6

Distribution of Caregiver-Reported Assistance-Associated Distress Ratings by ADL

		Distress score frequency (%)					
ADL	*n*	0	1	2	3	4	*M* (*SD*)
Bathing	16	12 (75)	1 (6)	2 (13)	--	1 (6)	.56 (1.15)
Dressing above the waist	19	16 (84)	2 (11)	1 (5)	--	--	.21 (.54)
Dressing below the waist	17	13 (77)	2 (12)	1 (6)	1 (6)	--	.41 (.87)
Eating	15	11 (73)	3 (20)	1 (7)	--	--	.33 (.62)
Grooming	16	12 (75)	2 (13)	1 (6)	--	1 (6)	.50 (1.10)
Toileting	13	8 (62)	2 (15)	2 (15)	1 (8)	--	.69 (1.03)
Transferring	10	7 (70)	2 (20)	1 (10)	--	--	.40 (.70)

Note. 0 = *Not at all upsetting*; 1 = *A little upsetting*; 2 = *Moderately upsetting*; 3 = *Very much upsetting*; 4 = *Extremely upsetting*. Percentages are based on the *n* for a particular row, which represents familial caregivers who had reported a FIM score of 5 or below and who had helped with that ADL during the past week. Dashes (--) indicate that a particular score was not reported.

comparison to the ratings of family members. Also omitted from this analysis was one caregiver who had reported a FIM score of 1 for dressing above the waist but also claimed that he had not helped with this activity during the past week, rendering the follow-up distress question inapplicable. Thus, the percentages shown in Table 6 are based only on the subsamples of caregivers who provided a rating of their assistance-associated distress, and not on the total sample size of 21. Providing assistance with toileting received the highest average caregiver-reported distress ratings (.69 on a scale from 0 to 4, with 0 indicating not at all upsetting and 4 indicating extremely upsetting). This point most closely corresponds to the answer a little upsetting on the distress scale. Providing assistance with dressing above the waist was reported to be least distressing (M = .21). Overall, however, the caregiver-reported assistance-associated distress ratings were low.

The caregiver-reported assistance frequency and duration for each ADL are shown in Table 7. The questions assessing these variables were asked of both familial and professional caregivers whenever a FIM score of 5 or below was reported for an ADL. Table 7 also excludes the caregiver who reported a FIM score of 1 for dressing above the waist but claimed that he had not helped with this activity in the past week. Caregivers reported helping with toileting and transferring most frequently (M = 21.54 times per week, range = 2-70 times; and M = 15.60 times per week, range = 3-35 times, respectively). It was reported that assistance was provided with bathing least frequently (M = 4.67 times per week, range 1-7 times). Regarding caregiver-reported assistance durations, helping with bathing and eating took the most reported caregiver time (M = 20.27 min, range = 5-60 min; and M = 15.27 min, range = 1-45 min, respectively). Assistance with transferring was reported to take the least amount of time (M = 2.40 min, range = 1-5 min). Caregiver-reported assistance duration in this case refers to the reported amount of time spent assisting with a particular ADL each time it occurred, not total amount of time per week.

It should be noted that directly comparing caregiver-reported frequency and duration means for each ADL is difficult because these variables do not always correspond. For example, although caregivers reported the highest mean duration of assistance

Table 7

Caregiver-Reported Frequency and Duration of Assistance by ADL

ADL	n	Frequency M (SD)	Frequency range	Duration M (SD)	Duration range
Bathing	19	5.58 (2.30)	1-7	20.27(16.16)	5-60
Dressing above the waist	19	6.68 (4.69)	1-14	5.30 (4.89)	1-20
Dressing below the waist	19	12.44 (12.17)	2-35	7.68 (6.33)	2-20
Eating	15	10.20 (8.45)	1-21	15.27 (14.38)	1-45
Grooming	16	7.38 (4.44)	1-14	12.67 (14.39)	2-60
Toileting	13	21.54 (19.71)	2-70	9.77 (8.09)	1-30
Transferring	10	15.60 (10.35)	3-35	2.40 (1.90)	1-5

Note. Both professional and familial caregivers were asked these questions for those ADLs which had received a FIM score of 5 or below and with which the caregiver had helped during the past week. Frequency = number of times caregiver reported providing assistance in the past week; duration = average amount of time in minutes reported spent by caregiver each time assistance was provided.

for bathing, they also reported helping with bathing less frequently than any other ADL. When the mean reported duration is multiplied by the mean reported frequency to obtain a measurement of reported time per week spent assisting with each ADL, the activity reported to require the most caregiver assistance time is toileting (210.45 min per week), followed by eating (155.75 min), bathing (113.11 min), dressing below the waist (95.54 min), grooming (93.51 min), transferring (37.44 min), and dressing above the waist (35.40 min).

Observation-Derived ADL Data

Key Percentages

This section, along with Tables 8 and 9, presents basic descriptive statistics regarding the data derived from the real-time observational system. The analyses comparing the observation-derived ADL data to the caregiver-reported ADL data will be presented in a subsequent section, as will the analyses of the correlations between the observation-derived ADL data and caregiver and patient factors (i.e., depression, cognitive status, and behavior problems). The statistics reported in Table 8 represent the total time across all dyads and all observation sessions that a particular behavior was observed. Results are presented separately for each ADL to preserve the unique topography of the ADL sessions. Because certain keys in the observational system recorded the duration of activity and other keys recorded only the occurrence, the data obtained from these keys are calculated and presented differently. Data for the keys representing caregiver verbal activity, caregiver physical assistance, and patient task performance are presented as the percentage of the total observation time across all dyads during which that activity occurred. Data for the keys that measured assistive device use and patient disruptive behavior are presented as frequency across observations and rate per hour, respectively. Percentages may not sum to 100 percent due to rounding. Furthermore, because the data files from which these statistics were computed include segmented observations (as described in the Method section) as well as sessions during which ADLs were intermingled, the duration and therefore the percentage of time during which no caregiver verbal activity, no caregiver physical assistance, and no patient ADL performance were observed will be slightly affected. However, because the variables of interest

Table 8

Overall Percentages of Total Observation Time Spent in Each Activity on the Observational System by Each ADL

	BA	DA	DB	EA	GR[a]	TO[b]	TR[c]
Setup	17.66	14.50	13.95	1.87	14.36	10.69	1.39
Supervision	9.86	3.67	7.33	16.49	12.59	10.40	10.00
Hands-on assistance	31.04	32.43	24.48	18.23	37.49	26.26	20.78
No assistance	40.48	44.86	51.09	62.84	32.78	49.94	50.92
Verbal prompts	9.73	5.70	6.92	2.97	6.93	9.20	11.95
Other verbal	21.31	20.42	19.31	14.75	20.42	18.19	15.02
Caution	0.03	0.00	0.00	0.04	0.00	0.00	0.32
No verbal	68.46	70.79	71.66	81.82	70.78	70.60	60.52
Patient performance	32.75	30.41	27.72	62.30	31.43	21.73	24.08
No patient performance	65.63	64.08	68.11	37.01	64.91	74.93	54.87
Disruptive behavior[d]	9.39	5.35	11.66	0.93	9.21[a]	8.25[b]	4.90
Assistive device[e]	8	0	0	3	5	2	4

Note. BA = bathing; DA = dressing above the waist; DB = dressing below the waist; EA = eating; GR = grooming; TO = toileting; TR = transferring. N = 21 unless otherwise noted. Percentages may not sum to 100 due to rounding.

[a] n = 19. [b] n = 14. Does not include instances of toileting that occurred out of camera range. [c] n = 20. [d] Mean rate per hour. [e] Number of subjects who used an assistive device at least once during any of the ADL sessions.

are the ones in which some type of ADL-related activity occurred, the effects of these intermingled and segmented observation sessions are considered to be negligible.

It should be noted that the occurrence of disruptive behavior in these patients was, in general, low. Only four patients displayed any disruptive behavior during the ADL observations. Thus, the overall rates of observed disruptive behavior presented in Table 8 are biased by this subsample of behaviorally disruptive patients, as the majority of patients did not exhibit any disruptive behavior during the observation sessions. It is interesting to note that all four of these patients were classified as having severe ADL impairment. These four disruptive patients, who had at least one occurrence of disruptive behavior during any of their ADL observations, are examined separately in Table 9. These results, as well as the disruptive behavior rates reported in Table 8, demonstrate that although disruptive behavior was generally infrequent, it did vary by ADL, with rates and occurrence of disruptive behavior lowest during eating. The overall rate of disruptive behavior was highest for dressing below the waist; however, only three of the four disruptive patients exhibited disruptive behavior during this ADL. All four disruptive patients exhibited disruptive behavior during bathing and toileting.

It should also be emphasized here that a lack of recorded caregiver verbalizations or assistance does not necessarily indicate that a caregiver was absent during a particular ADL. In other words, the variables "no caregiver verbal activity" and "no caregiver assistance" encompass not only scenarios in which the caregiver was absent from an ADL but also situations in which the caregiver was present but not interacting with the patient or otherwise providing any assistance.

Table 9

Hourly Rates of Disruptive Behavior for the Subsample of Disruptive Patients

ADL	Patient ID number 8	25	32	44
Bathing	2.12	25.42	136.78	32.84
Dressing above the waist	0	0	59.80	52.61
Dressing below the waist	0	40.71	93.35	110.77
Eating	14.93	0	0	4.49
Grooming	0	26.45	148.62	0
Toileting	7.22	35.42	16.82	56.09
Transferring	102.86	0	0	0

Note. Patient ID numbers go above 21 because the ID numbers of dyads who dropped out or refused at consent were not recycled.

A total of 41.56 hr of observational data was collected from the 21 dyads in this study. Of the total observation time, 9.73 hr were devoted to bathing, 3.00 to dressing above the waist, 4.62 to dressing below the waist, 16.60 to eating, 4.53 to grooming, 2.40 to toileting, and 0.68 hr to transferring. Specific percentages of time for which key activity variables were observed are presented below for each ADL.

Bathing. Eight patients were noted to use at least one assistive device during at least one of their bathing observations. The three types of devices used were shower chairs, grab bars on the side of the bathtub, and detachable sprayers held by caregivers. Four patients exhibited disruptive behaviors, such as hitting, screaming, moaning, and pitting. The rate per hour of disruptive behavior for these four patients ranged from 2.12 incidents to 136.78 incidents, with a mean rate of 48.29 incidents per hour.

Regarding physical assistance, caregivers provided supervision during 9.86% of the total observation time, setup of materials 17.66% of the time, and hands-on support (including complete performance of the task) 31.04% of the time. No physical assistance was provided during 40.48% of the total bathing observation time. A wide range of assistance duration was noted for each activity in this category: supervision, 0.00%-43.75%; setup, 0.00%-39.54%; hands-on support, 0.00%-74.34%; and no assistance, 1.45%-99.43%.

Caregivers provided verbal prompts an average of 9.73% of the time during bathing sessions. Cautionary statements (e.g., "Watch out") were extremely low in frequency, only used by two caregivers and occurring during less than 1% of the total observation time. Miscellaneous verbal statements occurred during 21.31% of the bathing time, and no patient-directed caregiver verbal activity occurred during 68.46% of the observation time. The range of occurrence for each activity was as follows: verbal prompts, 0.00%-56.18%; cautionary statements, 0.00%-0.56%; other verbal statements, 0.00%-57.94%; and no caregiver verbal activity, 21.91%-99.62%.

Patients were observed actively participating in dressing below the waist during 32.75% of the total observation time (range = 0.00%-95.05%). No patient participation occurred 65.63% of the time (range = 3.64%-99.17%). These figures represent seven patients who did not participate at all in the ADL.

Dressing above the waist. No assistive devices were used during this activity. Disruptive behavior was exhibited by only two subjects for an average rate per hour of 56.21 incidents (range = 52.61 to 59.80 incidents).

Supervision was provided during 3.67% of the total observation time for this ADL (range = 0.00%-25.71%). Setup occurred during 14.50% of the observation time (range = 0.00%-30.29%). Caregivers provided hands-on physical assistance during 32.43% of the observation time (range = 0.00%-62.50%). No caregiver physical assistance was provided during 44.86% of the observation time (range = 3.61%-95.71%).

Caregivers did not use any cautionary statements in verbal interaction that occurred during this ADL. Verbal prompts were used 5.70% of the time (range = 0.00%-17.58%), and other verbal statements occurred 20.42% of the time (range = 0.00%-59.02%). No verbal statements occurred during 70.79% of the total observation time for this ADL (range = 30.38%-96.79%).

Patients displayed active participation in dressing above the waist during 30.41% of the observation time (range = 0.00%-85.36%). No participation occurred during 64.08% of the time (range = 8.93%-95.02%). These figures reflect five patients who did not exhibit any ADL-related activity.

Dressing below the waist. Again, no assistive devices were used during this activity. Three patients exhibited disruptive behaviors at an average rate of 81.61 incidents per hour (range = 40.71 to 110.77).

Caregivers provided supervision during 7.33% of the observation time (range = 0.00%-37.67%), and setup during 13.95% of the observation time (range = 0.00%-

31.16%). Hands-on physical assistance occurred during 24.48% of the total observation time (range = 0.00%-54.17%), and no physical assistance of any kind was provided during 51.09% of the observation time (range = 13.49%-97.88%).

As with dressing above the waist, no cautionary statements were used during this ADL. Caregivers used verbal prompts 6.92% of the time (range = 0.00%-34.72%), and other verbal statements directed at the patient occurred 19.31% of the time (range = 0.00%-52.54%). No verbal statements were used 71.66% of the time (range = 28.18%-98.41%).

Patients actively participated in this ADL during 27.72% of its total observation time (range = 0.00%-60.18%), and did not actively participate during 68.11% of the time (range = 33.19%-97.75%). Five patients did not participate at all in this ADL.

Eating meals. An assistive device or environmental modification was used by three dyads. One patient was fed through a syringe, another could feed herself but only ate pureed food, and a third patient had to keep his cup in a bowl because a hand tremor caused him to spill when he lifted or put down the cup. It should be noted that although three other patients also ate pureed food, which is considered to be a stimulus modification, these patients were fed by their caregivers. Because the FIM distinguishes a patient who eats pureed food independently (modified independence) from patients who are spoon-fed pureed food (total assistance), the use of pureed food with the latter three patients is considered to be a qualitatively different situation, and thus these three dyads will be accounted for under the discussion of provision of physical assistance. Two patients exhibited disruptive behavior (specifically, moaning) while eating, with incidence rates of 4.69 and 14.93 incidents per hour, respectively.

Caregivers supervised the patients during 16.49% of the total observation time for eating (range = 0.00%-91.96%). Setup, which included pureeing and cutting food, was observed for an average of 1.87% of the time (range = 0.00%-15.49%). Hands-on physical assistance (i.e., spoon-feeding) was provided during 18.23% of the observation time (range = 0.00%-97.25%), and no assistance occurred during 62.84% of the time (range = 1.68%-99.65%).

As with previous ADLs, cautionary statements were rare, occurring less than 1% of the observation time. Verbal prompts were provided during 2.97% of the observed time (range = 0.00%-13.49%), while caregiver verbalizations in the "other" category occurred during 14.75% (range = 0.00%-53.89%) of the time. Caregivers did not speak to the patients during 81.82% (range = 43.61%-99.62%) of the observed eating time.

Patients actively participated in the observed meals during 62.30% (range = 0.00%-98.75%) of the observation time. During 37.01% of the observation time, no patient participation occurred (range = 0.65%- 99.45%). These figures reflect four patients who received complete caregiver assistance to eat.

Grooming. An assistive device was used by five dyads to accomplish grooming tasks. In all cases, the device in question was an electric razor. While an electric razor is not considered de facto to be an assistive device, in all cases the caregivers reported that the electric razor had been adopted out of concern for the patient's safety or as a response to diminishing ability, rendering its characterization as an assistive device appropriate and consistent with the paper-and-pencil FIM. Two patients exhibited disruptive behavior at rates of 26.45 and 148.62 incidents per hour, respectively.

Patients were supervised during 12.59% of the observation time (range = 0.00%-65.01%). Setup was provided during 14.36% of the grooming observation time (range = 0.00%-53.26%), and hands-on assistance occurred during 37.49% of the observation time (range = 0.00%-84.66%). Caregivers provided no physical assistance during 32.78% of the total observation time for grooming (range = 5.33%-98.43%).

No cautionary statements were used during this ADL. Caregivers used verbal prompts during 6.93% of the observation time (range = 0.00%-51.19%), and miscellaneous verbal statements were used during 20.42% of the observation time (range = 0.00%-62.35%). During an average of 70.78% of the observation time (range = 30.80%-98.82%), no patient-directed caregiver verbalizations occurred.

Patients participated actively in this ADL an average of 31.43% of the time (range = 0.00%-90.67%), and no patient participation was observed during 64.91% of the observation time (range = 6.37%-98.13). These figures include four patients who were not noted to participate in any way in their grooming.

Toileting. As noted above, toileting was documented a total of 53 times during the course of the study. Twenty of these incidents occurred out of sight of the video camera for various reasons (e.g., during a mealtime observation, the patient left the table, toileted independently, and returned to the table before the experimenter was able to move the video camera from the eating area to the bathroom); these incidents will not be considered in this section but will be included in other correlational analyses from this study.

The results reported below are for the 33 toileting sessions that occurred within camera range. It should be noted that because more independent patients are less represented in these statistics, the results below are skewed toward lower-functioning patients, many (but not all) of whom received caregiver assistance with toileting.

Assistive devices such as raised toilet seats were used by two patients. Four patients exhibited disruptive behavior during toileting, with a mean rate of 28.89 incidents per hour and a range of 7.22 to 56.09 incidents per hour.

Caregivers supervised the patients during 10.40% of the total toileting observation time (range = 0.00%-44.04%). They provided setup during 10.69% of the time (range = 0.00%-31.58%) and physical assistance during 26.26% of the time (range = 0.00%-85.51%). No assistance was given during 49.94% of the time (range = 4.21%-96.11%).

Again, caregivers used no cautionary statements during this ADL. Verbal prompts occurred during 9.20% of the observation time (range = 0.00%-55.95%), and miscellaneous caregiver verbalizations occurred during 18.19% (range = 0.00%-77.74%) of the observation time. No caregiver verbalizations were observed during 70.60% (range = 20.75%-96.82%) of the total observation time for toileting.

Active patient participation in toileting was observed during 21.73% of the total observation time (range = 0.00%-91.52%). No participation was noted during 74.93% of the time (range = 3.53%-98.40%). Five patients were recorded as not displaying any participation.

Transferring into or out of bed, chair, or wheelchair. An assistive device was used during transfers for four patients. The specific devices used were a Hoyer lift, a cane, a recliner that elevated its seat, and a belt around the patient's waist that was held by the caregiver to stabilize the patient. One patient exhibited disruptive behavior during transfers at the rate of 102.86 incidents per hour.

An average of 10.00% (range = 0.00%-46.51%) of the observation time for this ADL was spent in caregiver supervision. Setup was less common for this ADL than for any other, occurring with only two caregivers exhibiting this behavior (overall M = 1.39 and specific percentages 4.95% and 22.78%, respectively). Caregivers provided physical assistance during 20.78% of the observation time (range = 0.00%-62.71%), and no assistance during 50.92% of the total transferring observation time (range = 5.88%-82.67%).

Here, as in other ADLs, cautionary statements were used rarely by caregivers, occurring during less than 1% of the total observation time. Verbal prompts were used during 11.95% of the observation time (range = 0.00%-36.43%), and miscellaneous caregiver verbalizations occurred during 15.03% of the total observation time (range = 0.00%-32.94%). During 60.52% of the observation time (range = 20.00%-89.81%), no caregiver-to-patient verbalizations occurred.

Active patient participation in transferring was recorded during 24.08% of the total observation time (range = 0.00%-62.16%). No participation was observed during 54.87% of the time (range = 14.86%-97.60%). It should be noted here that transfers are, in general, ADLs of short duration, lasting only several seconds in the absence of significant physical or visual impairment. Because the transfers were so brief, effective second-by-second coding could only be accomplished by including several extra seconds of "cushion time" in front of and after the transfer so that the coders were able to prepare themselves for the activity. Thus, the proportion of time during which no ADL-related activity occurred is somewhat inflated for the ADL of transferring.

Activity Key Differences by Impairment Groups

As stated previously, a stratified sampling procedure was used during subject recruitment to ensure that a range of impairment was represented. To investigate whether the dyads in the three impairment groups differed significantly in the percentages of time spent in the various activities on the observational system, a one-way analysis of variance was conducted, with Scheffe tests performed to examine the nature of group differences for significant F-tests in the overall model.

For all ADLs, the analysis of variance tests indicated overall group differences for the observational system key representing patient ADL performance. In general, the nature of these differences was that patients classified as having severe ADL impairment spent less time participating in their ADL care than did patients classified as having mild or moderate impairment. For bathing, the Scheffe test on the overall analysis, $F(2, 18) = 11.00$, $p = .0008$, indicated that patients in the mild impairment category were significantly different from subjects in the severe impairment category. This pattern also held true for the ADLs of grooming, $F(2, 16) = 7.92$, $p = .004$, and transferring, $F(2, 17) = 7.83$, $p = .004$. Patients with mild and moderate impairment were not significantly different from each other, but were significantly different from patients with severe impairment, on the amount of ADL participation exhibited during the ADLs of dressing above the waist, $F(2, 18) = 12.38$, $p = .0004$; dressing below the waist, $F(2, 18) = 20.76$, $p = .0001$; and eating, $F(2, 18) = 21.39$, $p = .0001$. Finally, patients with moderate impairment were significantly different from patients with severe impairment on the amount of ADL participation exhibited during toileting, F(2, 11) = 7.28, p = .01. These results suggest that the stratification procedure used during recruitment effectively separated patients based on their reported impairment level, although the degree of separation varied by ADL.

Group differences in the nature of assistance provided during ADLs were also examined. Caregivers provided significantly more hands-on physical assistance to patients with severe impairment than to patients with mild impairment for the ADLs of bathing, F(2, 18) = 5.56, p = .01; dressing below the waist, F(2, 18) = 11.79, p = .0005; and transferring, F(2, 17) = 32.76, p = .0001. It should be noted that for the ADL of transferring, group differences in the amount of hands-on assistance provided were also statistically significant between moderately and severely impaired groups, but the groups with mild and moderate impairment did not significantly differ from each other. Caregivers of patients with mild impairment provided significantly less hands-on assistance than did caregivers of patients with moderate or severe impairment during dressing above the waist, F(2, 18) = 17.45, p = .0001. Significantly more hands-on assistance was provided to patients with severe impairment during eating than was provided to patients with mild or moderate impairment, F(2, 18) = 12.87, p = .0003.

Significantly more verbal prompts were provided to patients with moderate impairment than to patients with mild or severe impairment during dressing above the waist, F(2, 18) = 12.29, p = .0004, and dressing below the waist, F(2, 18) = 5.02, p = .019. In both cases, the patients with severe impairment received the least verbal prompting of the three impairment groups. These trends held true across all ADLs (with the exception of toileting, where mildly impaired patients received less prompting than severely impaired patients), although not all group differences were statistically significant. Finally, caregivers provided more setup assistance to severely impaired patients compared to mildly impaired patients during the ADLs of bathing, $F(2, 18) = 5.49$, $p = .013$; and grooming, $F(2, 16) = 7.27$, $p = .006$.

Correlations Involving Caregiver-Reported and Observation-Derived ADL Data

In comparing the caregiver-reported ADL data to the observation-derived ADL data, two variables common to both data sets were of interest: the FIM score, which measures the type of assistance provided, and the duration of caregiver assistance. Because most dyads had multiple observations of each ADL, the observations for each subject were averaged. Thus, the variables of FIM score and caregiver assistance duration were obtained twice per subject for each ADL: once based on caregiver report, and once based on the average of the ADL observations.

Aim 1: Correspondence of Caregiver-Reported and Observation-Derived FIM Scores

The purpose of this aim was to examine the correspondence between caregiver-reported and observation-derived FIM scores. For these analyses, the observational data were subjected to a series of statistical procedures, using the SAS software package, to convert these continuous data to a categorical score analogous to the FIM score. (These procedures were described above in the Data Analysis section, and the criteria used to make this transformation can be found in Table 1). The main observational variables of interest were the percentage of ADL time during which the patient was coded as actively participating in the ADL, the use of assistive devices, the use of verbal prompts by the caregiver, and the caregiver's provision of supervision, setup, or hands-on assistance. The correlation between the caregiver-reported and observation-derived FIM score was then calculated using SAS. Because FIM scores are measured on an ordinal scale, Spearman's rho (r_s) was used as the test statistic. Each ADL was examined separately. The distribution of the observation-derived FIM scores can be seen in Table 10, and correlations are presented in Table 11.

All ADLs were observed at least once per dyad (i.e., $N = 21$) with the exception of grooming ($n = 19$) and transferring ($n = 20$). The correlations for each ADL are thus based on only those dyads for whom both caregiver-reported and observation-derived data exist. All correlations between caregiver-reported and observation-derived FIM scores were statistically significant at $p = .005$ or better. The specific correlations were as follows: bathing, $r_s = .904$, $p = .0001$; dressing above the waist, $r_s = .909$, $p = .0001$; dressing below the waist, $r_s = .818$, $p = .0001$; eating, $r_s = .862$, $p = .0001$; grooming, $r_s = .620$, $p = .005$; toileting, $r_s = .858$, $p = .0001$; and transferring, $r_s = .701$, $p = .0006$. In sum, there is a strong correspondence between caregivers' reports of the nature of ADL assistance provided and the assistance recorded during real-time observation. Caregivers tended to overestimate patients' independence, but not to a significant degree, with the largest discrepancy being for the ADL of toileting (11 overestimates and 3 underestimates). Means of caregiver-reported and observation-derived FIM scores for each ADL are in Table 12.

Table 10

Distribution of Observation-Derived FIM Scores by ADL

ADL	FIM score frequency (%)						
	1	2	3	4	5	6	7
Bathing	12 (57)	1 (5)	2 (10)	1 (5)	3 (14)	1 (5)	1 (5)
Dressing above the waist	8 (38)	4 (19)	3 (14)	1 (5)	3 (14)	--	2 (10)
Dressing below the waist	9 (43)	2 (10)	3 (14)	--	5 (24)	--	2 (10)
Eating	5 (24)	--	1 (5)	2 (10)	11 (52)	1 (5)	1 (5)
Grooming[a]	10 (48)	3 (14)	1 (5)	2 (10)	1 (5)	1 (5)	1 (5)
Toileting	8 (38)	2 (10)	1 (5)	--	1 (5)	--	9 (43)
Transferring[b]	5 (24)	2 (10)	2 (10)	2 (10)	6 (29)	1 (5)	2 (10)

Note. N = 21 unless otherwise noted. Dashes (--) indicate that a particular score was not obtained. Percentages may not sum to 100 due to rounding.
[a] n = 19. [b] n = 20.

In addition to examining the correspondence between caregiver-reported and observation-derived FIM scores, it was also deemed desirable to obtain a measure of inter-rater reliability specific to the observation-derived FIM scores. The inter-rater reliability process described previously computed Cohen's Kappa based on a second-by-second comparison of observational data files from a subset of the data. FIM scores were not examined in that analysis. However, that inter-rater reliability process resulted in the creation of a subset of data for which both primary and reliability observer data were available. These data were subjected to the SAS program that converted the continuous

Table 11

Correlations Between Caregiver-Reported and Observation-Derived FIM Scores, and Between Observation-Derived and Caregiver-Reported Assistance Time

ADL	Correlation coefficients		
	Rep FIM/ obs FIM[a]	Rep duration/ obs duration[b] (all subjects)	Rep duration/ obs duration[b] (subsample)
Bathing	.904**	.506*	.394[c]
Dressing above the waist	.909**	.037	-.037[d]
Dressing below the waist	.818**	.564**	.493*[c]
Eating	.862**	.187	-.055[e]
Grooming	.620**[a]	.046[a]	-.093[e]
Toileting	.858**	.586**	.492[f]
Transferring	.701**[b]	.560*[b]	.452[g]

Note. Rep = reported by caregiver on paper-and-pencil FIM; obs = observed during videotaped ADL sessions; duration = average amount of time in minutes either reported or observed spent by caregiver each time assistance was provided. N = 21 unless otherwise noted.

[a]Spearman's rho. [b]Pearson correlation coefficient. [c]n = 19. [d]n = 20. [e]n = 15. [f]n = 13. [g]n = 10.

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

observational data to the observation-derived FIM scores, enabling the comparison of "primary" and "reliability" observation-derived FIM scores. Correlations between these two scores were computed for each ADL using Spearman's rho. The correlation coeffi-

Table 12

Mean (SD) Caregiver-Reported FIM Scores and Observation-Derived FIM Scores by ADL

ADL	Rep FIM score	Obs FIM score
Bathing	2.67 (2.01)	2.48 (2.02)
Dressing above the waist	2.76 (1.79)	2.76 (2.00)
Dressing below the waist	3.05 (2.13)	2.91 (2.12)
Eating	4.38 (2.22)	4.00 (1.87)
Grooming	3.16 (2.27)	2.37 (1.92)
Toileting	4.05 (2.71)	3.95 (2.85)
Transferring	4.65 (2.39)	3.65 (2.06)

Note. Rep = reported on paper-and-pencil FIM; obs = observationally-derived based on videotaped ADL sessions. FIM scores range from 1 to 7, with lower scores denoting more caregiver assistance.

cients ranged from .820 to 1.000, with all seven ADLs statistically significant at $p = .024$ or higher, indicating excellent agreement.

Aim 2: Correspondence of Caregiver-Reported and Observed Duration of ADL Assistance

The purpose of the second specific aim was to examine the correlation between caregiver-reported assistance duration and observed caregiver assistance time. For these analyses, the observed caregiver assistance time was averaged across all observations of a particular ADL for each dyad. These means were then correlated with the caregiver-reported assistance duration using Pearson correlation coefficients.

The decision-tree format of the FIM used in this project and in REACH presented a unique situation for analyses of assistance duration. Specifically, caregivers who reported a FIM score of 6 or 7, denoting that the patient was independent in that ADL, were not asked the follow-up questions pertaining to ADL assistance frequency, duration, or associated distress. These data are not “missing” in the traditional sense, because patient independence connotes that the caregiver did not assist with the ADL and therefore spent no time in assistance-related activities (i.e., it can be inferred that the caregiver-reported duration of assistance is zero for these dyads). However, it was felt that preserving the data as they were collected could yield useful information regarding the validity of caregivers’ assistance time estimates. Thus, two sets of analyses were conducted to investigate the relationship between caregiver-reported and observed assistance duration. In the first, caregivers who had reported a FIM score of 6 or 7 for a particular ADL were assigned a caregiver-reported assistance duration of zero and included in the analyses. These analyses will be discussed as representing the entire or overall sample and are based on $\underline{N} = 21$ unless otherwise noted. In the second, these caregivers were excluded from analysis, such that only caregivers who had reported a FIM score of 5 or below (i.e., who had reported providing assistance with an ADL during the past week) were represented. These analyses will be discussed as representing a subset or subsample of the overall subject pool. For both sets of analyses, only those dyads with both caregiver-reported and observed assistance duration data are discussed; if a dyad did not have videotaped observational data for a particular ADL, then that dyad was excluded from analysis. The results of correlational analyses are in Table 11, and the means of the caregiver-reported and observed assistance durations are in Table 13.

Bathing. Among the entire sample of caregivers, the observed duration of caregiver assistance was significantly correlated with the caregiver-reported duration of assistance, $r = .506$, $p = .019$. This correlation approached but did not attain significance when only the subset of caregivers reporting that they had provided assistance with this ADL during the past week ($n = 19$) were examined, $r = .394$, $p = .095$.

Dressing above the waist. In the overall sample, the correlation between the observed and caregiver-reported duration of assistance was not statistically significant, $r = .037$, $p = .872$. This correlation was also nonsignificant in the subsample ($n = 20$), $r = -.037$, $p = .876$.

Dressing below the waist. In the entire sample, the correlation between caregiver-reported and observed assistance duration was significant, $r = .565$, $p = .008$, as was this correlation among the subset of caregivers who reported providing assistance during the past week ($n = 19$), $r = .493$, $p = .032$.

Eating meals. The relationship between observed and caregiver-reported assistance duration was not significant in either the overall sample, $r = .187$, $p = .417$, or the subsample ($n = 15$), $r = -.055$, $p = .844$.

Table 13

Mean (SD) Caregiver-Reported Assistance Durations and Observation-Derived Assistance Durations by ADL

ADL	Rep duration	Obs duration (all subjects)	Obs duration (subsample)
Bathing	20.27 (16.16)	7.43 (4.52)	8.22 (3.99)
Dressing above the waist	5.30 (4.89)	1.73 (1.30)	1.82 (1.27)
Dressing below the waist	7.68 (6.33)	2.54 (2.12)	2.81 (2.04)
Eating	15.27 (14.38)	7.77 (9.30)	10.37 (9.84)
Grooming	12.67 (14.39)	3.55 (2.10)	3.87 (1.92)
Toileting	9.77 (8.09)	1.42 (1.62)	2.04 (1.53)
Transferring	2.40 (1.90)	0.42 (0.87)	0.74 (1.17)

Note. Obs = observed during videotaped ADL sessions; rep = reported on paper-and-pencil FIM; duration = average amount of time in minutes either reported or observed spent by caregiver each time assistance was provided.

Grooming. Because only 19 of the 21 dyads engaged in grooming activities during observation, this analysis was done using $N = 19$ as the overall sample. Nonsignificant relationships were found for the correlations between observed and caregiver-reported assistance duration for both the overall sample of 19 caregivers ($r = .046$, $p = .851$) and the subsample of caregivers ($n = 15$) who had reported providing assistance during the past week ($r = -.093$, $p = .743$).

Toileting. These results include those observations in which patients' toileting activities were not captured on tape but instead documented with the "independent toileting" key on the observational system. For those observations, the observed caregiver assistance was considered to have a duration of zero. The exclusion procedure based on the caregiver-reported FIM score (i.e., caregivers reporting a FIM score of 6 or 7 were excluded from analysis) was still followed to identify the subsample of caregivers providing assistance (n = 13). The relationship between caregiver-reported and observed assistance duration was significant in the overall sample, r = .586, p = .005, but not the subsample, r = .491, p = .088, although this correlation approached significance.

Transferring into orout of bed, chair, or wheelchair. Because only 20 of the 21 dyads engaged in this activity during observation, this analysis was done using N = 20 as the overall sample. A significant relationship was found for the correlations between observed and caregiver-reported assistance duration for the overall sample of 20 caregivers (r = .560, p = .010), but not for the subsample of caregivers (n = 10) who reported providing assistance during the past week (r = .452, p = .190).

Differences in duration means. Despite some strong correlations between caregiver-reported and observed assistance durations, examination of the means (Table 13) indicates that the caregiver-reported assistance durations were, on average, two to three times the size of the observed assistance durations. The magnitude of the differences varied somewhat depending on the ADL and whether caregivers reporting FIM scores of 6 and 7 were removed from analysis; however, in all cases, the caregiver-reported assistance duration exceeded the observed assistance durations. If the observed assistance durations, which are more objective than caregiver reports, are regarded as the "gold standard," then the caregivers can be considered to have overestimated their ADL assistance time. Thus, the significant correlations obtained in the above analyses indicate not that the caregiver-reported assistance durations correspond well to observed assistance durations, but rather that for certain ADLs, caregivers' patterns of misestimation were more consistent than for other ADLs. It should be noted that these differences were not examined statistically.

Aim 3: Relationships Between Subject Factors and ADL Data

The third specific aim of the study involved examining the relationships between the ADL data (both caregiver-reported and observation-derived) and the other paper-and-pencil measures. Correlations were computed to investigate relationships among the caregiver and patient CES-D, MMSE, and RMBPC scores as well as each ADL's caregiver-reported and observation-derived FIM scores and assistance duration. The purpose of these analyses was to attempt to identify factors influencing caregivers' ratings of ADL performance as well as add credence to the validity of caregiver reports by identifying common patterns of association across the caregiver-reported and observation-derived ADL data. Spearman's rho was used as the test statistic.

Correlations Between Caregiver-Reported ADL Data and Subject Factors

Correlational analyses were conducted to explore the relationship among the caregiver-reported ADL data (FIM scores, assistance frequency, assistance duration, and distress) and the other paper-and-pencil measures (caregiver and patient CES-D, MMSE, and RMBPC).

Caregiver CES-D score/caregiver-reported ADL data. Among the analyses correlating caregiver CES-D scores both with caregiver-reported FIM scores and with caregiver-reported duration and frequency of assistance, only one relationship achieved statistical significance: For toileting, caregiver-reported assistance frequency was significantly correlated with caregiver depression, $r_s = -.641$, $p = .025$. Because the direction of this relationship suggests that caregiver depression and assistance frequency are inversely related, a relationship which is drastically counterintuitive, this result is regarded as spurious. However, greater levels of caregiver depression were positively correlated with caregiver ratings of assistance-associated distress. Statistically significant relationships were found for bathing ($r_s = .595$, $p = .019$), dressing above the waist ($r_s = .542$, $p = .020$), dressing below the waist ($r_s = .614$, $p = .011$), toileting ($r_s = .692$, $p = .013$), and transferring ($r_s = .814$, $p = .004$). It is possible that caregivers view helping with these tasks to be more unpleasant than helping with the other ADLs (i.e., eating and grooming), although ADL-associated distress levels were uniformly low.

MMSE score/caregiver-reported ADL data. These correlations are shown in Table 14. As hypothesized, the MMSE and FIM scores had strong positive correlations for all seven ADLs assessed, and all correlations were significant at $p < .01$. MMSE scores were negatively correlated with caregiver-reported assistance frequency for all ADLs except bathing ($r_s = .424$, $p = .079$); however, these negative correlations reached significance only for dressing above ($r_s = -.496$, $p = .031$) and below the waist ($r_s = -.728$, $p = .001$). These negative correlations indicate that, as could be expected, patients with lower MMSE scores received more frequent assistance with ADLs.

All but one of the correlations between MMSE scores and caregiver-reported assistance duration were negative (the exception being transferring, for which the correlation was positive but nonsignificant), with statistically significant correlations found for dressing below the waist ($r_s = -.493$, $p = .038$), eating ($r_s = -.649$, $p = .009$), grooming ($r_s = -.628$, $p = .009$), and toileting ($r_s = -.897$, $p < .001$).

Somewhat surprisingly, MMSE scores were not significantly correlated with caregiver-reported assistance-associated distress. Correlation coefficients ranged from -.013 for dressing above the waist to .394 for toileting (respective p-values ranged from .959 to .183).

RMBPC behavior problems/caregiver-reported ADL data. The total number of behavior problems reported on the RMBPC was not significantly correlated with the caregiver-reported FIM score or the caregiver-reported frequency or duration of ADL assistance. However, positive correlations were obtained for the relationship between caregiver-reported assistance-associated distress scores and total number of behavior problems reported on the RMBPC, with the relationships for bathing ($r_s = .550$, $p = .027$), dressing below the waist ($r_s = .522$, $p = .031$), grooming ($r_s = .516$, $p = .041$), toileting ($r_s = .656$, $p = .015$), and transferring ($r_s = .746$, $p = .013$) being statistically significant. These results indicate that caregivers of patients with more behavior problems were more distressed at helping with ADLs. Although this relationship is not unexpected, it should

Table 14

Correlations of MMSE Scores with Caregiver-Reported FIM Scores, Reported Frequency and Duration of ADL Assistance, and Reported Assistance-Associated Distress Ratings

	Correlations (Spearman's rho)			
ADL	MMSE/ FIM score	MMSE/ frequency	MMSE/ duration	MMSE/ distress
Bathing	.837**	.424	-.393	-.031
Dressing above the waist	.846**	-.496*	-.106	-.013
Dressing below the waist	.844**	-.728**	-.439*	-.058
Eating	.753**	-.354	-.723**	.342
Grooming	.716**	-.287	-.659**	.025
Toileting	.862**	-.280	-.891**	.394
Transferring	.790**	-.455	-.616**	.325

Note. MMSE = Mini-Mental State Exam score; FIM = Functional Independence Measure score based on caregiver report; frequency = the number of times caregiver reported providing assistance in the past week; duration = the average amount of time in minutes reported spent by caregiver each time assistance was provided; distress = the caregiver-reported distress associated with providing ADL assistance.
*$p < .05$. **$p < .01$.

be noted that the RMBPC does not specifically measure the occurrence of behavior problems during ADLs.

Patient CES-D score/caregiver-reported ADL data. The patient CES-D score was not significantly correlated with any of the four caregiver-reported ADL variables for any of the ADLs, although the correlation between patient CES-D scores and caregiver-reported assistance duration approached significance for the ADL of bathing, $r_s = -.553$, $p = .074$. Correlation coefficients for all other possible relationships for each ADL ranged from .000 to -.667 (respective p-values ranged from 1.00 to .102). These data will not be presented in tabular format nor discussed further in this section.

Correlations Between Observation-Derived ADL Data and Subject Factors

Caregiver CES-D score/observation-derived ADL data. Caregiver CES-D scores were not significantly correlated with either the observed caregiver assistance time or the observation-derived FIM score. Correlations ranged from -.032 to -.291, with respective p-values ranging from .894 to .214.

MMSE score/observation-derived ADL data. All observation-derived FIM scores were, like the caregiver-reported FIM scores, significantly (and positively) correlated with MMSE scores, indicating that patients with higher MMSE scores displayed greater independence during the videotaped ADL sessions (Table 15). Correlations for all ADLs were significant at $p = .0001$ with the exception of grooming, which was significant at $p = .014$.

For the ADLs of bathing ($r_s = -.469$, $p = .032$), dressing below the waist ($r_s = -.424$, $p = .05$), eating ($r_s = -.719$, $p = .0002$), and transferring ($r_s = -.806$, $p = .0001$), significant negative correlations were found between observed caregiver assistance time and MMSE score (Table 15). For all seven ADLs, the correlations were negative, although not all were statistically significant. These results follow the general pattern

Table 15

Correlations of MMSE Scores with Observation-Derived FIM Scores and Observed ADL Assistance Duration

ADL	Correlations (Spearman's rho)	
	MMSE/ obs FIM	MMSE/ obs duration
Bathing	.782**	-.469*
Dressing above the waist	.832**	-.121
Dressing below the waist	.846**	-.424*
Eating	.744**	-.719**
Grooming	.555*	-.291
Toileting	.812**	-.346
Transferring	.821**	-.806**

Note. FIM = Functional Independence Measure score derived from observational data; duration = average amount of time in minutes observed spent by caregiver each time assistance was provided; obs = observed during videotaped ADL sessions.
*p < .05. **p < .01.

observed in the analysis of caregiver-reported assistance duration (see Table 14) and indicate that higher patient MMSE scores, and therefore higher cognitive functioning, are associated with shorter amounts of caregiver ADL assistance.

RMBPC behavior problems/observation-derived ADL data. The total number of RMBPC problems was not significantly correlated with the observation-derived ADL data. The subscale RMBPC scores were correlated with observed caregiver assistance time, although the patterns of correlations varied by ADL and RMBPC subscale. Observed caregiver assistance time was, for isolated ADLs, significantly correlated with the occurrence of RMBPC memory-related problems (dressing above the waist, $r_s = .522$, $p = .015$), occurrence of depression-related RMBPC items (toileting, $r_s = -.638$, $p = .014$), and caregiver distress associated with depression-related RMBPC items (toileting, $r_s = -.585$, $p = .028$). Observation-derived FIM scores were not significantly correlated with either the total or subscale scores on the RMBPC.

Patient CES-D score/observation-derived ADL data. Like the caregiver CES-D scores, patient CES-D scores were not significantly correlated with either the observed assistance durations or the observation-derived FIM scores, with one exception: The relationship between patient depression and observed assistance time was significant, $r_s = -.829$, $p = .021$. The direction of this relationship is somewhat surprising, as it suggests that more depressed patients receive shorter durations of toileting assistance, but it is consistent with the significant correlations involving the occurrence of and caregiver distress associated with patient depressive problems on the RMBPC (see above).

Correlational Analyses with Paper-and-Pencil Measures

Although not a specific aim of the study, it was thought worthwhile to examine relationships among the caregiver and patient CES-D, the RMBPC, and the MMSE. Correlational analyses were conducted to explore the strength of the relationship among caregiver and patient CES-D scores, patient MMSE score, and total number of patient behavior problems reported on the RMBPC. Because the CES-D scores were measured on an ordinal scale, Spearman's rho was used as the test statistic. The only relationship among these correlations that reached statistical significance was the correlation between caregiver depression and number of behavior problems, $r_s = .588$, $p = .0067$. This correlation indicates that the more depressed caregivers were dealing with more patient behavior problems, and suggests that these behavior problems may contribute heavily to caregiver depression.

Although the overall number of RMBPC behavior problems was not significantly correlated with any of these paper-and-pencil measures other than the caregiver CES-D, it was thought that the subscales on the RMBPC may have interesting relationships with some of these measures. Thus, correlations were computed to examine the relationship between the subscales of the RMBPC and the total number of behavior problems reported on the RMBPC, scores on the MMSE, and caregiver and patient CES-D scores. Results can be found in Table 16. As anticipated, strong positive correlations were found between the total number of behavior problems reported on the RMBPC and both the total number of problems reported on and distress associated with the three behavior problem subscales. High scores on the caregiver CES-D were associated with more memory-related behavior problems and more distress reported on all three RMBPC subscales. More patient depression was associated with more depressive behavior problems reported on the RMBPC ($r_s = .602$, $p = .038$), but not with any other type of behavior problem or with caregiver distress (although the relationship with depression-associated distress approached significance, $r_s = .561$, $p = .058$). None of the RMBPC behavior problem occurrence and distress subscales were significantly correlated with MMSE scores.

Table 16

Correlations Between RMBPC Subscales and Total Number of Behavior Problems, Caregiver and Patient Depression, and Patient MMSE Score

	Correlations (Spearman's rho)			
	RMBPCtot	Caregiver CES-D[a]	Patient CES-D[b]	MMSE[c]
Memory Occurrence	.768**	.463*	.090	.178
Memory Distress	.489*	.541*	.406	.100
Disruption Occurrence	.667**	.360	.146	-.240
Disruption Distress	.539*	.544*	.263	.085
Depression Occurrence	.635**	.351	.602*	.068
Depression Distress	.598**	.510*	.561	.051

Note. N = 21 unless otherwise noted. RMBPCtot = number of behavior problems reported on the Revised Memory and Behavior Problem Checklist; MMSE = Mini-Mental State Exam Score; CES-D = Center for Epidemiological Studies Depression Scale; memory = memory problems subscale; disruption = disruptive problems subscale; depression = depressive problems; occurrence = number of behavior problems reported by caregivers in this area; distress = caregivers' reported distress associated with each type of behavior problem.

[a]n = 20. [b]n = 12. [c]n = 19.

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

CHAPTER 4

DISCUSSION

Primary Findings

In this section, three sets of results, corresponding to each of the primary aims, will be discussed. The first set of results concerns the relationship between caregiver-reported and observation-derived FIM scores (Aim 1). The second concerns the relationship between caregiver-reported ADL assistance duration and observed caregiver assistance time recorded during the videotaped ADL sessions (Aim 2). The relationships between these variables and the measured subject characteristics of patient cognitive status and behavior problems and both caregiver and patient depression, as well as the relationships among these characteristics, constitute the third set of analyses (Aim 3).

Correspondence Between Caregiver-Reported and Observation-Derived FIM Scores

The first aim of this study was to examine whether FIM scores obtained from caregiver report corresponded to FIM scores derived from direct observation of ADL performance in the home. Because it was recognized that caregivers' perceptions and biases could influence their objective ratings of performance, it was viewed as possible that caregivers' ratings would not correspond closely with observed ratings. Conversely, it was also possible that the daily occurrence of many ADL tasks, combined with the need for caregivers to operationalize and prepare for assistance with these tasks, would eliminate some of the bias associated with obtaining these ratings.

In this study, it was learned that dementia caregivers' descriptions of their assistance and the degree of patient independence are similar to what is exhibited during ADL interactions conducted in the home. Correlations between caregiver-reported and observation-derived FIM scores were significant and positive for all seven ADLs assessed, indicating that agreement was not dependent upon a specific ADL or type of ADL (e.g., those involving several steps, such as dressing, versus those involving relatively fewer steps, such as transferring). Furthermore, examining plots of the data indicated that there was no significant systematic bias in over- or underestimating patient independence, although a slight tendency existed for caregivers to overestimate FIM scores. These results indicate that the FIM's 7-point rating scale, when applied to the items in the current ADL assessment, has good external validity and is an appropriate tool for use with this population.

The process of determining the agreement between caregiver-reported and observed assistance involved computing a FIM score based on the observational data. As stated earlier, such a computation was possible due to the detailed operational definitions of each score level on the original FIM in that each level had at least one factor that differentiated it from the others (Table 1). These factors, and the differences between score levels, appear to have been adequately represented on the observational system. The transformation of the continuous observational data into categorical FIM scores resulted in the full range of scores being represented, similar to the distribution obtained through the traditional paper-and-pencil assessment process.

Despite the strong relationship between caregiver-reported and observation-derived FIM scores, an important caveat exists. These correlations between caregiver-reported and observation-derived patient independence should not be taken to mean that these independence levels accurately represent patients' true abilities. In other words, these data only reflect what caregivers allow the patients to do, rather than what the patients are truly able to do. In this manner, caregivers' biases and perceptions involving patient ability may be reflected not only in their ratings of ADL performance but also in their overt behavior during ADL interactions. Statements regarding the functional abilities of dementia patients should thus be phrased and interpreted cautiously until more conclusive data regarding the relationship between potential and actual independence can be obtained.

Behaviors observed during ADL interactions. The detailed nature of the observational system allowed specific patterns of behavior during the ADL interactions to be examined, although statistical analyses were not conducted to examine inter-ADL differences in caregiver and patient behavior. For example, it appeared that the caregiver activity of supervision occurred most commonly during eating. It should be noted that the operational definition of supervision on the observational system specifically excludes situations in which the caregiver and patient are engaged in the same activity. Thus, the high rate of caregiver supervision while the patient was eating meals is not inflated by the inclusion of scenarios in which the caregiver and patient were eating together. Although such a definition may have excluded caregivers who modified their own eating schedule so that they could always eat with the patient, and may therefore underestimate the occurrence and duration of supervision during meals, this definition is consistent with the social nature of meals and the well-preserved ability of dementia patients to feed themselves until fairly late in the disease process. Consistent with this theory, the percentage of patient ADL performance was higher during eating than during any other ADL.

Hands-on physical assistance occurred most often during grooming and dressing above the waist, both of which are tasks that involve manual dexterity and judgments of appearance. Additionally, grooming tasks, particularly shaving, often have a safety component to them, and this increased hands-on assistance may reflect caregiver concern in a way that cautionary statements may not. On that note, cautionary statements were brief and extremely rare, occurring during less than 1% of the total observation time across all ADLs.

Bathing contained more activity setup and assistive device use than any other ADL and was exceeded in verbal prompt occurrence only by transferring. The high rates of setup may at least partially reflect the patients who received sponge baths in bed, as preparation of the washing basins and retrieving towels and washcloths would be recorded as setup.

The occurrence of disruptive behavior during the ADL observations was surprisingly low in this study given that care situations are often associated with disruptive behavior (e.g., Mahoney et al., 1999). Out of the 21 patients in this sample, only 4 displayed any disruptive behavior during any of the ADL observation sessions. Consistent with previous research (e.g., Burgio et al., 1994), disruptive behaviors were more common in patients with severe ADL impairment. The rate of disruptive behavior varied by ADL, with eating associated with the lowest rates of disruptive behavior. It is thought that the low rate of disruptive behavior observed during meals could be attributed to the nature of the ADL in that eating is generally considered to be a pleasurable and intrinsically reinforcing activity. In contrast, ADLs such as bathing and dressing below the waist were associated with higher rates of disruptive behavior. Additionally, all four disruptive patients exhibited disruptive behavior during the ADLs of bathing and toileting. These activities can be considered to be somewhat invasive and potentially frightening to dementia patients, which may explain the greater occurrence of disruptive behavior during these activities. However, it should be reiterated that some of the patients in this sample were ineligible for REACH because they did not meet REACH's criterion of having exhibited at least three behavior problems during the previous week. Thus, this sample was somewhat biased toward low occurrence of behavior problems, although again the presence of ADL impairment, not behavior problems, was the most pertinent factor for inclusion.

Correspondence Between Caregiver-Reported and Observed ADL Assistance Time

The second main goal of this study was to examine the degree of correspondence between caregivers' reports of their ADL assistance time and the amount of assistance time observed during the videotaped ADL sessions. Although no specific hypotheses regarding the nature or strength of these relationships were proffered, experiences during data collection both for this project and for the NIA-funded REACH project (which used the same paper-and-pencil ADL instrument) suggested that no consistent relationships would exist between caregiver-reported and observed assistance time. In particular, caregivers in both projects appeared to experience extreme difficulty when asked to provide these time estimates. From this experimenter's work on the REACH project, caregivers' difficulties in forming time estimates appear to be maintained even after several data collection points at which these estimates are solicited. Time estimate data from REACH cannot yet be assessed because data collection for that project is ongoing, but data from the current study highlight some patterns of behavior. Initially, caregivers tend to answer "I don't know" to this type of question, but when pushed to provide a numerical answer, will eventually do so after an extended period of thought. Even then, however, time estimates from the caregivers in the current study appeared to be somewhat arbitrary, with "5 min" reported about 23% of the time and "10 min" reported about 16% of the time.

Data analysis indicated that, for four of the seven ADLs, caregivers' reports of assistance time were significantly correlated with observed assistance time when caregivers who reported providing no assistance were inferred to have a reported assistance duration of zero. When these caregivers were removed from analysis such that correlations were computed only for those caregivers who had reported providing assistance with an ADL during the past week, only one of the seven ADLs demonstrated significant correlations between caregiver-reported and observed assistance duration, although another relationship approached statistical significance. However, examination of the respective means indicated that caregivers overestimated their ADL assistance time, although the degree of overestimation varied depending on the ADL and whether the caregivers who had reported providing no assistance were excluded from analysis. There was much variability in both reported and observed assistance times, with the standard deviations often similar in size and sometimes larger than the mean. Mean differences were not statistically examined. It should be noted that this tendency for caregivers to overestimate their assistance time was not consistent with the above-mentioned tendency for caregivers to overestimate patient independence. The reason for that lack of correspondence is unclear but may be most fundamentally related to the small sample size, which could have obscured any larger patterns of misestimation in either the FIM score or assistance time data.

Thus, the results of the correlational analyses are misleading without the additional knowledge of the caregiver-reported and observed assistance duration means. If only the correlational analyses are examined (Table 11), it appears that caregivers can describe the duration of their ADL assistance time somewhat accurately. However, when the mean assistance duration times are examined (Table 13), it becomes obvious that caregivers are actually overestimating their ADL assistance time, often by a factor of three or more. Thus, the significant correlations indicate not that caregivers accurately estimate their ADL assistance time, but rather that their patterns of overestimation are more consistent for some ADLs than for others.

This overall conclusion is not surprising. Previous research has demonstrated that caregivers of Alzheimer's disease patients display significant burden related to their caregiving duties (e.g., Zarit et al., 1980; Zarit & Zarit, 1982). It could thus be reasonably expected that these burdened caregivers would overestimate the duration of their ADL assistance due to the frequency of and stress associated with providing assistance, as well as the stressful nature of caregiving in general. Issues mentioned earlier pertaining to caregiver motivations, expectations, and other thought processes are also likely to be pertinent here.

Along these lines, the method used to calculate the observed caregiver assistance time in this study provides a conservative figure because it mathematically eliminates any overlap between verbal and physical assistance. In reality, caregivers may not compartmentalize their ADL assistance in this way. Assisting with an ADL care interaction can involve getting out or preparing materials, providing verbal cues, supervising patient performance, <u>and</u> providing hands-on assistance all in the span of one care session. Given the potential complexity of ADL assistance, caregivers may consider these activities in an additive or even a multiplicative fashion, because they feel that they are doing so much. For example, when asked to estimate ADL assistance time, a caregiver may think of verbal prompting as something done in addition to, rather than during, hands-on assistance, thereby inflating reported estimates of assistance times. In the case of activities that involve several steps or require heavy use of gross motor skills (e.g., bathing), that style of estimation may be more accurate than with activities that involve less hands-on assistance (e.g., eating) or involve fine motor skills (e.g., grooming).

The last point may help answer the question of why caregiver-reported and observed assistance time were significantly correlated for some ADLs but not others. Caregivers may conceptualize hands-on and hands-off (i.e., setup, supervision, verbal prompting) assistance differently. The hands-off assistance recorded on the paper-and-pencil FIM and in this study is characterized by brief physical activity (setup), mental alertness (supervision), or some joint cognitive and verbal activity (prompting). In contrast, hands-on assistance requires more intensive physical involvement from the caregiver, as well as mental activity. It is not unreasonable to suggest that hands-on physical assistance may be more salient to caregivers than less involved types of assistance such as supervision, setup, or verbal prompting. It could thus be hypothesized that caregivers would be more accurate at describing the duration of their hands-on assistance than describing the duration of less intensive assistance. Additionally, hands-on assistance requiring gross motor skills may be more salient than hands-on assistance involving more fine motor activity (e.g., putting a person's shirt on versus merely assisting with buttons). Although these types of assistance can be isolated in the observational system, the paper-and-pencil ADL measure used in this project did not ask caregivers to estimate these assistance times separately, so this issue cannot be resolved from these data.

However, the bottom line appears to be that regardless of the reason, caregivers overestimate the duration of their ADL assistance time by a significant degree. Although caregiver reports of this assistance time are used to evaluate the economic impact of Alzheimer's disease and thereby influence public policy, these ADL assistance time estimates as solicited in previous studies have not been compared to objective measures of assistance time. The results of the current study indicate that these caregiver reports may be seriously invalid, and although more information regarding the nature and cause of this discrepancy is still needed to determine the source of the disagreement, it appears that these time estimates should be used with caution.

Relationships Between Caregiver and Patient Factors and ADL Variables

The third aim of the study was to explore the caregiver-reported and observation-derived FIM scores and assistance times and their relationships with various caregiver and patient factors such as cognitive status, depression, and occurrence and severity of behavior problems. This investigation yielded mixed results. Some hypothesized relationships were demonstrated, other hypothesized relationships were not observed, and some research questions for which specific hypotheses had not been generated could not be answered conclusively.

Caregiver depression. Although the nature and direction of relationships between caregiver CES-D scores and other data were not a priori hypothesized, it is acknowledged that certain relationships were more anticipated than others. For example, the significant positive correlations between the caregiver CES-D score and both the total and the subscale RMBPC scores were not unexpected. The occurrence of memory-related patient problems, but not the occurrence of disruptive or depressive patient problems, was significantly associated with caregiver depression, suggesting that memory problems are the most distressing for caregivers. Interestingly, higher CES-D scores were significantly associated with more memory-related problems and associated distress on the RMBPC, but not with the MMSE score. This pattern indicates that the relationship between caregiver depression and memory-related behavior problems is not affected by disease stage; in other words, the significant correlation between caregiver CES-D scores and the occurrence of memory-related RMBPC problems does not excessively represent caregivers dealing with the early stages of dementia and the coping process associated with that situation. Although the causal relationship cannot be determined, it seems reasonable to infer that the caregiver depression is a result of the patient behavior problems, although the converse could also be true: Caregiver depression could lead to increased patient behavior problems as the patient perceives but cannot discuss verbally the caregiver's depressed state, causing the patient to exhibit disruptive behaviors (see Cohen-Mansfield & Werner, 1998, for a similar explanation of the relationship between verbally aggressive behavior, depressed affect, and poor physical health in older adults). It is also possible that depressed caregivers are less attentive to patients' needs, resulting in behavior problems. However, a significant relationship was found only for memory problems, which seem less likely to be affected by caregiver depression than disruptive or depressive behaviors would be.

Also, as could be expected, positive correlations were found for the relationship between caregiver depression and caregiver-reported ADL assistance-associated distress, although not all correlations were significant. It is possible that caregivers viewed helping with tasks such as bathing, dressing, toileting, and transferring to be more unpleasant than helping with less invasive tasks such as eating. However, caregiver depression was not significantly associated with the caregiver-reported or observation-derived FIM scores or with the caregiver-reported or observed duration of assistance. Neither was this variable significantly correlated with reported frequency of ADL assistance. It could reasonably be assumed that helping with ADLs more frequently, helping with ADLs that took long periods of time, or providing more intensive levels of assistance would be associated with caregiver depression. This assumption was not borne out in either the caregiver-reported or the observation-derived ADL data. These results suggest that merely assisting with ADLs is associated with greater caregiver depression, and that the frequency or duration of assistance, type of assistance provided, and nature of the ADL are of lesser importance.

Further study is needed to document more completely the source of the relationship between caregiver depression and ADL assistance.

The significant positive correlations between caregiver-reported assistance-associated distress and caregiver depression deserves some additional mention. Although the direction of this relationship is not surprising, causality cannot be determined. It is unclear whether caregivers' depressive states cause them to view ADL assistance in a more negative light or whether caregivers' distress at having to assist with ADLs results in more general depression. If the latter, it is additionally unclear whether assistance-related distress is caused by the unpleasant nature of many ADLs or the caregivers' awareness that increased functional impairment indicates increased decline, a situation which in itself is stressful. It should be reiterated at this point, however, that ADL assistance-related distress scores were generally low, and care must be taken not to over-interpret these results.

Patient cognitive status. As expected, MMSE scores were consistently and significantly correlated with both the caregiver-reported and the observation-derived FIM scores and assistance durations. The patterns of these correlations were such that patients with higher MMSE scores had higher FIM scores and smaller durations of caregiver assistance time. In other words, patients with lower cognitive functioning were more dependent during ADL activities and received more caregiver assistance time, regardless of whether ADL data were obtained through caregiver report or direct observation. These findings are consistent with those noted in previous studies of the relationship between cognitive and functional decline (e.g., Ford et al., 1996).

Contrary to expectations, the MMSE was not significantly correlated with either the total number of behavior problems reported on the RMBPC or with any of the subscales. This lack of association is surprising given that the RMBPC was developed for use with Alzheimer's patients (Teri et al., 1992). Of course, it is possible that the small sample size in this study obscured any significant relationships between these variables. Alternatively, this sample was selected based on ADL impairment, not behavioral disturbance, and although a diagnosis of dementia was necessary for inclusion, specific MMSE scores were not entry criteria. Several of the dyads in this study contained patients who did not have enough behavior problems to warrant inclusion in REACH, resulting in a pool of subjects who had a relatively low occurrence of behavior problems. Thus, the low occurrence of behavior problems among this sample may be the source of the lack of association between behavior problems and MMSE scores.

<u>Patient behavior problems.</u> Although the RMBPC was already discussed in some detail in the previous section pertaining to MMSE scores, some more elucidation of its use in the study is warranted here. Because patient behavior problems as measured by the RMBPC had not been included in previous studies of ADL assistance, no specific hypotheses regarding RMBPC scores' relationships to FIM scores and caregiver assistance duration were formed prior to initiation of the study. However, overall and subscale scores on the RMBPC were not significantly correlated with the caregiver-reported or observation-derived FIM scores or duration of assistance. The total number of behavior problems reported on the RMBPC showed a significant correlation with the degree of ADL-related distress reported during FIM administration, suggesting that caregivers of

patients with more behavior problems were more distressed at helping with ADLs. Although this relationship is not unexpected, it should be noted that the RMBPC does not specifically measure the occurrence of behavior problems during ADLs. Additionally, because behavior problems were exhibited by only four patients during ADL observation, the generalizability of this relationship is unclear.

It should be noted that many caregivers reported behavior problems that were not observed during ADL sessions. It is possible that the low occurrence of behavior problems during ADL observations was caused by observer reactivity in that the patients were "on good behavior" due to the presence of the experimenter in the home. However, based on caregiver reports, it appeared that the display of behavior problems was not always predictable, and care should be taken not to overinterpret the lack of widespread behavior problems recorded during ADL observations.

Patient depression. Patient depression, as measured by a proxy version of the CES-D, was initially hypothesized to be negatively correlated with FIM scores and positively correlated with caregiver assistance time. However, these relationships were not consistently demonstrated for either caregiver-reported or observation-derived ADL data. Patient CES-D scores were also not significantly correlated with caregiver CES-D scores or with overall or subscale RMBPC scores (with the exception of occurrence of depression-related problems, a relationship which is not entirely unexpected).

The lack of significant patterns of findings related to patient depression may be an artifact of the method used to assess patient depression in this project--a method which, it must be acknowledged, appeared to be unsuccessful. It appears that using the CES-D in proxy format is not an appropriate method of assessing depression in dementia patients. In particular, the CES-D's proxy utility appears to be greatly compromised with increasing levels of cognitive decline. Caregivers expressed difficulty in judging the frequency of statements assessing the patient's feelings (e.g., "He/she felt hopeful about the future"), particularly in the case of late-stage dementia patients who were nonverbal and did not display much affect. This difficulty resulted in a high number of items given a response of unknown and complicated the task of computing a valid score on this measure. Items on the CES-D that assessed more overt behavioral symptoms of depression, such as crying spells or loss of appetite, were more easily assessed. However, even some of these items were deemed difficult to rate by caregivers, particularly the item "He/she talked less than usual" when asked of a late-stage patient who had not spoken in months. Additionally, the items "He/she had trouble keeping his/her mind on what he/she was doing" and "His/her sleep was restless" are of questionable utility because the high prevalence of concentration problems and sleep disturbances in both dementia and depression confounds the attribution of these behaviors to one condition or the other. In summary, it is recommended that future studies of depression in dementia patients use an instrument that concentrates on the behavioral, rather than the emotional or cognitive, aspects of depression. It should also be noted that the CES-D is a well-validated tool for obtaining self-reports of depression in cognitively intact older adults; the difficulties mentioned here appear to be unique to the challenges of obtaining proxy reports of depression in dementia patients.

Methodological Advances

Other gaps filled by this study are methodological in nature. Methodologically, this study demonstrated that it is possible to conduct videotaped observations of ADL interactions in the home. Previous observational studies of ADL performance or care-giving interactions had examined either ADL interactions in institutional settings (e.g., Burgio et al., 1994), social interactions (e.g., Cotter et al., 1998), performance of IADLs (e.g., Doble, Fisk, MacPherson, Fisher, & Rockwood, 1997; Oakley et al., 1991), or performance of motorically-based tasks considered to be analogous to ADLs (e.g., Greene et al., 1993; Kuriansky & Gurland, 1976; Oakley et al., 1991; Reuben & Siu, 1990). The current study improves upon this earlier research by incorporating true basic ADLs rather than analogs, generalizing earlier institutional studies into the home setting, examining in microanalytical detail the amount and type of assistance provided during these interactions, and comparing the observational data to identical tasks measured on the paper-and-pencil ADL assessment.

Another methodological improvement of this study concerns its subject population. Earlier studies of ADL performance had examined dementia patients rarely, if at all (Dorevitch et al., 1992; Elam et al., 1991; Magaziner et al., 1997; Sager et al., 1992). Although it had previously been suggested that the FIM would be appropriate for use with this population (Kane et al., 1991; Spector, 1991), and although the federally-funded REACH cooperative agreement uses a modified version of the Self-Care subscale and the standard scoring procedure as part of its core assessment battery, subjects with cognitive impairment had not been systematically included in previous studies of the FIM. Instead, subjects with cognitive impairment had been included only if the cognitive impairment was comorbid with the condition of interest (Goldstein et al., 1997; Hajek et al., 1997). The inclusion of dementia patients and their caregivers in the current study also represents an addition to our existing knowledge on ADL performance in old age by documenting in microanalytic detail the amount and type of assistance provided by caregivers during ADL interactions. Furthermore, this study demonstrates that the FIM's scoring procedure is appropriate for assessing ADL performance in people with dementia. The strong correlations between reported and observed ADL performance (both of which were assessed using the FIM's 7-point rating scale) indicate not only that the FIM has good external validity but also that the 7-point rating scale can adequately describe ADL interactions involving people with dementia.

Other Issues

Four issues that arose during examination of the specific aims of this study deserve additional, though brief, mention because they can be considered to be separate from the main goals of the study. These issues involve the use of the stratified sampling procedure, caregiver-reported ADL-associated distress, the use of cautionary statements during observation sessions, and the topography of the observation sessions involving non-ADL activities.

Analysis of variance indicated that the stratification procedure used during subject recruitment was generally effective at obtaining a sample that distinguished between patients with different impairment levels. More specifically, relatively consistent patterns of patient performance and caregiver assistance were differentiated with the use of this procedure, although the best distinctions were made between patients with mild and severe impairment. These analyses further support the notion that the subjects in this sample represented a range of ADL impairment.

Caregivers' reported distress associated with providing ADL assistance was, in general, low and had little variability, with only two reports each that helping with an ADL was very much or extremely upsetting. It is possible that caregivers downplayed their actual distress to avoid creating a negative impression; alternately, and as stated previously, the main burden associated with caregiving may come from situations other than assisting with ADLs. Although these assistance-associated distress scores had some strong and consistent patterns of correlations with other variables of interest (i.e., caregiver CES-D score and total number of behavior problems reported on the RMBPC), the data incorporating these scores must be interpreted with caution. Only 25.47% of the caregiver-reported distress scores were nonzero scores, too few to justify a separate analysis of score distributions.

The low rate of caution statements observed during data collection was surprising. It was assumed at the beginning of this study that caregiver utterances such as "Be careful" or "Watch out" were appropriate markers for caregiver concern about patient safety. However, it is possible that caregivers worried about safety chose to stay in the patient's presence rather than issue cautionary directives. This behavior would instead be represented as supervision on the observational system. Alternately, caregivers may feel concern that is not expressed in any overt way, either verbal or physical. It is also possible that correct and efficient performance of the ADL, which is theoretically associated with less caregiver assistance time, is a more important goal than patient safety. In this line of thinking, caregiver presence or assistance accomplishes two goals simultaneously: It provides for the patient's safety and also ensures that the ADL is performed in a manner that the caregiver deems to be most appropriate. Thus, caregiver presence or assistance would result in less of a need for cautionary statements. It should be noted that on both the caregiver-reported and the observation-derived FIM scores, the score rating of 6 (the category for which concern for patient safety is a defining criterion) was less common than any other FIM score, although these distributions were not examined statistically.

Examining the videotaped data from the observational sessions revealed another feature of the daily care routines not captured in the observation-based ADL data. Many of the observational sessions involved not only the specific ADLs listed on the FIM but also other activities that were not coded because they did not fit the FIM's operational definitions on the Self-Care or any other subscale. Activities such as shampooing the hair, caring for pressure ulcers, or putting on lotion, deodorant, or talcum powder are not assessed anywhere on the FIM, yet they are part of the daily routine for many caregivers and their patients and were observed numerous times during this study. Thus, caregivers' estimates regarding the amount of time spent providing personal care to the dementia patient must be interpreted with the realization that caregivers also provide assistance for tasks that do not fall under the traditional ADL designation. With regard to this study, however, the protocol used for administering the paper-and-pencil FIM utilizes a system of prompts designed to exclude these extraneous activities from the caregivers' estimates of ADL assistance type, frequency, and duration. In sum, it is felt that the caregiver-reported data included here validly represent caregivers' impressions of their assistance-related activities for the specific ADLs in question. The validity of these impressions, of course, is another issue, which has previously been addressed.

Limitations of the Study

Perhaps the most obvious limitation of this study, which has been alluded to in the discussion of the results, is the small sample size. Although it is felt that this sample is generally representative of the larger population of dementia patients and their caregivers, the issue of sample size is important for analysis and interpretation of the data. The calculated confidence interval for the correlation coefficients includes zero (for $\underline{r} = .20$, range = -.28 to .68), and many of the reported correlations did not exceed the boundaries of this confidence interval. Thus, the possibility that some of the results are spurious cannot be ignored. Additionally, the large number of correlational analyses conducted for data analysis raises the issue of inflated alpha error. Unfortunately, due to the small sample size, more advanced and potentially more concise statistical procedures could not be used. In the future, it may for some analyses be desirable to examine the ADLs together, not separately (e.g., by summing the individual FIM scores for each subject), which would reduce the number of correlations performed. Such a procedure would reduce the number of correlations, but would also reduce the amount of information available regarding the unique aspects of the individual ADLs. It should be reiterated that this study is fairly unique and, particularly in the case of the third specific aim, was designed to give us information for future studies of this nature. In addition, the data do appear cohesive and show consistent patterns of relationships, thus providing confidence for the conclusions drawn from this study.

Another issue is that the response rate in this study was only 26%, which raises questions regarding selection bias. To address this issue, the caregiver demographic data from this study were compared to demographic information collected at the UAB REACH site as of 3/29/99. These comparisons indicate that the sample in the current study was wealthier, more educated, and more likely to be White than the UAB REACH sample. In the current study, 52.4% of the caregivers reported a household income of at least $40,000, whereas only 31.3% of the UAB REACH caregivers reported a household income in that range. Similarly, 86% of the caregivers in the current study had a high school education or greater, compared to 59.5% of the UAB REACH caregivers. Finally, 71% of the caregivers in the current study were White, while only 56% of the UAB REACH caregivers were White. Although race per se does not necessarily provide information regarding caregiver behavior, it is a marker for other phenomena, such as lower socioeconomic status and educational disadvantage. Furthermore, African American Southerners tend to be suspicious of research, partly due to the Tuskegee Syphilis Study (for a more in-depth discussion of this issue, see Corbie-Smith, 1999; Talone, 1998; and Harris, Gorelick, Samuels, & Bempong, 1996). The high representation of White caregivers in this sample suggests that this sample, overall, may have been more attuned to the nature and purpose of research. Thus, it is possible that the caregivers in the current study are not wholly representative of the general population of dementia caregivers. Regarding the patients, however, the sample did not appear to be biased. The patients in this study represented the full ranges of both cognitive and functional impairment, and there were equal numbers of patients in the three impairment groups established at recruitment. Had the sample been overly represented by patients with particular levels of impairment, such as patients with severe dementia who are less likely to react to an observer's presence, less confidence could be had in the strength of the results.

The use of microanalytical behavioral observations in this study highlighted a limitation of the FIM that deserves mention here. It had been stated previously that the FIM's 7-point rating scale provided greater discrimination than the 4-point scales used in other ADL assessments. The example given was that the Barthel Index category "Can do with help" could encompass the need for either supervisory or physical assistance, although the caregiver burden created by these two types of assistance would be quite different. This study discovered that even a 7-point rating scale has its limitations, particularly at the lower end of the scale. For example, three patients who had received a FIM score of 1 were observed to receive complete physical assistance with eating; in all cases, the caregiver modified the consistency of the food as necessary and spoon-fed the patient. However, one patient was still able to chew solid food such as toast and scrambled eggs, the second only ate pureed food but could still open his mouth when the spoon with food was presented, and the third was orally fed liquid mixtures through a syringe inserted into the corner of her mouth. Thus, for all the strengths of the FIM, there are still nuances of behavior that are not differentiated by its rating scale.

The issue of observer reactivity can never be ignored in observational research. In the current study, numerous measures were taken to minimize this reactivity. The video camera used to record the ADL interactions was cylindrical in shape and relatively small in size, rendering it less conspicuous than traditional video equipment. The camera could also be aimed through small openings and/or around corners, rendering the observations less intrusive. Additionally, the experimenter did not initiate verbal interaction or eye contact with the dyad during ADL observation. Ideally, a study of this nature would involve video surveillance equipment that was completely out of sight (e.g., installed in the home), although of course the use of such equipment was beyond the scope of the current study.

Separate from the issue of reactivity, it could be suspected that the caregivers in this study altered their behavior during the ADL sessions to match what they had reported during the paper-and-pencil FIM administration, and that these changes in behavior artificially inflated the correlations between caregiver-reported and observed behavior. However, such a scenario seems unlikely. Caregivers were not told that the purpose of the study was to compare reported and observed behavior, nor were they shown the FIM decision tree or their own responses in the process of completing the paper-and-pencil ADL assessment. The FIM scores themselves, had the caregivers seen them, are single-digit numbers and do not provide sufficient information to give the caregivers clues as to how they "should" behave during the ADL sessions. Although the span between the completion of the paper-and-pencil ADL assessment and the initiation of the observation sessions varied somewhat depending on the dyad's routine and schedule, a delay of 3 days to 1 week was typical. It is unlikely that these caregivers would have the time or motivation to note mentally their responses and then modify their behavior accordingly. Thus, concerns of this nature are thought to be unwarranted.

As mentioned earlier, the ADL measures used in this study did not differentiate between hands-on and hands-off assistance when examining the duration of caregiver ADL assistance. This lack of differentiation was consistent with the paper-and-pencil ADL measure used in REACH and also with some previous studies that utilized caregiver reports of ADL assistance time (e.g., Brookmeyer et al., 1998; Ernst & Hay, 1994). Although it could be argued that assistance is assistance, it is likely that the various types of assistance mean different things to caregivers. For example, providing hands-on assistance may be more distressing, more time-intensive, or more salient to caregivers than providing supervisory assistance. Some studies have attempted to examine hands-on assistance separately from other types of assistance (Hu et al., 1986) or from "total time spent with an elder" (Albert et al., 1998, p. 706), but to date these studies have only yielded descriptive data regarding disease progression or reported caregiving time. Future studies of caregiving assistance time need to differentiate between hands-on and hands-off assistance, particularly when issues of caregiver burden and the validity of caregiver reports are of interest. The interplay between different types of assistance and the nature of specific ADLs should also be examined, as should the thought processes that caregivers use to estimate ADL assistance time.

Another limitation, although also one that provides a direction for future research, is that the present study does not differentiate between assistance provided and assistance needed. Several caregivers speculated during data collection that they may provide more assistance to the patient than was actually needed; unfortunately, it was beyond the scope of this project to examine this possibility in adequate detail. Documenting the difference between provided and required assistance would highlight avenues for interventions to increase patient independence, which could provide numerous benefits for both caregiver and patient. It should be noted, however, that increased patient independence is not necessarily correlated with reduced caregiver burden. Some caregivers in this study stated that excessive assistance, if and when it occurred, was driven by a desire to "make things simpler" by reducing patient frustration, the length of time required to perform an ADL, or the amount of correction or clean-up required after ADL performance. Thus, in some situations, increasing patient independence may actually increase caregiver burden by giving the caregiver more to cope with than merely the task of assisting with an ADL.

A limitation that deserves detailed discussion is really a limitation not of the study but rather of the measures used in the study and the method in which they assess patient ADL participation. In the paper-and-pencil FIM scoring system, the categories of 4, 3, 2, and 1 are scored by determining the amount of effort contributed by the patient. However, a concept such as "amount of effort" is difficult to quantify without the use of physical performance equipment such as dynamometers. In the observational system, the proportion of time during which the patient exhibited active ADL performance was considered to approximate patient effort. The percentage of time that the "patient performs ADL" key was recorded during the ADL sessions was averaged for each patient, and these time durations were used to distinguish between observation-derived FIM score categories of 4, 3, 2, and 1. It should be acknowledged that the duration of effort may not correspond to the actual effort put forth during a task, although the duration of patient effort recorded during observation was, for the purposes of this study, considered to be analogous to the amount of effort exerted during ADLs.

However, regardless of these potential or actual limitations, it is important to remember that the primary goals of this study were to obtain information regarding the external validity of the FIM and the utility of caregiver reports, and that this goal was attained. Both the paper-and-pencil (i.e., caregiver-reported) FIM scoring system and the observation-based scoring system use the same basic definitions and, it can be argued, are equal in their ability to discriminate among different levels of performance. Thus, any issues pertaining to the sensitivity of the measure relative to patient ADL performance are common to both measures, with neither being more likely to assess effort than the other. It could also be argued that by using a measurable quantity (i.e., time during which the patient was observed participating in the ADL), the observation-derived FIM scoring system is actually more sensitive than the paper-and-pencil FIM, which does not define amount of effort in such concrete terms.

Directions for Future Research

As stated previously, an examination of predicted and actual ADL performance would help identify caregiver and patient characteristics that lead to excess disability and possibly guide the development of interventions to reduce caregiver burden and increase patient independence. Such a study would have to measure not only caregiver perceptions of patient functioning and the assistance provided during ADLs, but also the degree of patient task performance when the patient is provided the least amount of assistance possible. Thus, an appropriate assessment of excess disability would require the presence of a trained professional, such as an occupational therapist, during ADLs. The therapist would temporarily assume sole responsibility for providing assistance during these ADLs and would use appropriate techniques for maximizing patient independence (e.g., a system of least prompts, along with positive reinforcement for attempts at independent task performance). Such an approach was used by Rogers and colleagues in a study (in press) examining nursing home residents' participation in morning care routines following a minimal prompting intervention. Under these conditions, residents increased their independent self-dressing behavior and decreased the amount of physical help received.

The study by Rogers et al. (in press) demonstrated that nursing home residents' ADL performance can be improved by providing minimal assistance in a structured, occupational therapy-oriented intervention. A logical next step is to conduct a similar study among community-dwelling dementia patients and their caregivers. Although home health aides are the most obvious choice of interventionist, recent changes in federal funding and insurance reimbursement for home health care have reduced the numbers of dementia patients currently receiving home health care services. Thus, it is likely that much of the responsibility for implementing such techniques would fall to family caregivers. However, because few family caregivers receive direct training in this area, the use of such an intervention in the home setting would require an initial outlay of time and instruction to ensure that the caregivers were able to implement these techniques safely and effectively. As in the nursing home, it is expected that patient in-home ADL independence exhibited in a "minimal assistance" situation guided by a therapist would surpass that seen in typical caregiving interactions. However, it is unlikely that effects of a minimal assistance condition would be seen immediately due to the need for habituation to the therapist and the time required to overcome previously learned patterns of unnecessarily dependent behavior. This approach, if successful, would be useful for training caregivers to provide more appropriate and supportive assistance during ADLs, with the inter-related goals of maintaining patient independence, reducing caregiver burden, and delaying or avoiding the need for nursing home placement.

Another possible study relates less to patients' performance potentials and more to the need to explore in more detail the observational system and the method in which its continuous data were converted to a categorical FIM score. As stated previously, the observation-derived FIM score used in this project was derived by subjecting the videotaped ADL interactions to a detailed decision metric written in computer programming language. Thus, the use of the term observation-derived does not denote that observational ADL data were given a FIM score by a rater who viewed the videotape and assigned a FIM score based on the behaviors observed in the interaction. It would be desirable to conduct a study that would simultaneously cross-validate the caregivers' reported FIM scores, add support to the utility of the observation-based FIM scores, and provide more information regarding the validity of the program used to convert the observational data to FIM scores. Such a study would involve having a trained FIM rater, blinded to both observed and reported ADL data, view the videotaped ADLs and assign to each interaction a FIM score that could then be compared to the currently existing data from these dyads.

Another avenue for future research involves utilization of the entire FIM and not just the items incorporated in this study. It appears from the data reported here that basic ADLs (as measured by the six Self-Care subscale items and the one Mobility subscale item included on the paper-and-pencil ADL assessment) can adequately be assessed in dementia patients using the FIM's 7-point scale. However, these data alone do not indicate that the entire FIM is suitable for use with dementia patients, although again it has been suggested that the FIM is an appropriate tool (Kane et al., 1991; Spector, 1991), and the federally-funded REACH cooperative agreement project has enough faith in the

FIM scoring system to incorporate it into its core assessment battery. Further research needs to use the entire FIM "as is," including all its subscales, before generalizations regarding the FIM's utility with dementia patients can be determined.

Finally, it is desirable to explore in more detail the differences between various types of assistance (e.g., hands-on versus hands-off) with regard to reported caregiver burden and ADL assistance time. Such a study would primarily involve asking caregivers to consider hands-on and hands-off assistance activities separately when estimating their ADL assistance time or when describing their distress at helping with ADLs. Comparing these differentiated assistance reports to observed ADL data could help determine which type of assistance is, for example, more closely correlated with accurate estimates of assistance duration. These data would also further our knowledge of how best to use caregiver reports of the nature and duration of ADL assistance to maximize the applicability of research and public policy initiatives.

Conclusions

Dependence of disabled individuals on caregivers, while not unique to older adults, is a commonly encountered phenomenon in both institutional and community-dwelling populations (Baltes & Carsensen, 1991; Baltes et al., 1987; Burgio et al., 1994; Maddox et al., 1994; Teri et al., 1989). Intertwined with the study of dependence are issues related to excess disability (e.g., Baltes & Carsensen, 1991; Baltes et al., 1987) and the purpose and administration of various assessments of functional ability (Law, 1993). Because functional ability is vital to maintaining good health and quality of life (Green et al., 1993; Warren et al., 1989; Wolinsky et al., 1993), accurate assessment of this ability is also crucial. Without accurate assessment of ADL performance abilities, inappropriate treatment strategies may be prescribed, treatment may be overlooked altogether, and abilities may be allowed to decline to a point where rehabilitation is either costly or impossible.

Although a great deal of research has been conducted on the assessment of functional ability, it is clear that the field still lacks knowledge in many important areas. In particular, many of the inter-instrument differences, such as different operational definitions or rating scales, need to be clarified or at least carefully considered when using the instruments in clinical or research settings (Eaken, 1989; Kovar & Lawton, 1994; Law, 1993; Myers & Huddy, 1985; Reuben et al., 1995). Alternately, more specific guidelines regarding which instrument should be used with a particular subject population or within a particular environment would be helpful (Law, 1993). A more realistic picture of the relative importance of various ADLs and IADLs is also necessary to determine appropriate targets for intensive study or rehabilitation (Auer et al., 1994; Reisberg et al., 1985; Zarit et al., 1995).

Of primary importance to this study, an area in which ADL assessment research needs to be improved relates to the correspondence of ADL instruments to real-world activity performance. If an ADL assessment instrument does not accurately depict the use of functional skills in the natural living environment, then the issues of operational definitions and rating scales are moot, because the scale will be useless. As such, external validation of ADL instruments is needed to verify the utility of these tools. In this paper, the FIM was chosen as a worthy candidate for such a study because its fine-grained analysis of ADL performance provides sufficient detail to derive observational categories and event codes for comparison with actual ADL performance. Less sensitive instruments contain rating categories that are too large and nebulous (e.g., "Can do with help") to be externally validated. The results reported here indicate that the use of the FIM was effective for this purpose.

The conclusions of this study as relevant to the specific aims are threefold. First, data show that caregivers of dementia patients can accurately describe the amount of assistance they provide during ADL interactions. These caregiver-reported data were validated by direct observation of ADLs and also indicate that the FIM's 7-point rating scale and the operational definitions of the ADLs have good external validity and are appropriate for use with dementia patients. Second, comparing caregiver-reported and observed ADL assistance times indicated that caregivers overestimate the duration of their ADL assistance time, sometimes by a factor of three or more. Although the consistency of this overestimation varied somewhat by ADL, it appears that caution should be used when deriving and using caregivers' time estimates. Additional research is needed to document the nature and source of these discrepancies. Third, the findings suggest that significant correlations exist between some aspects of ADL functioning and caregiver and patient factors such as caregiver depression and patient cognitive functioning. On a methodological note, this study also demonstrated that videotaping ADL interactions in the home is feasible and, by incorporating dementia patients as its subjects, added to the existing knowledge regarding functional performance in this group. However, other issues remain unanswered, most importantly the relationship between the assistance provided and the assistance actually needed to maximize patient independence and, hopefully, help decrease caregiver distress.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL FORM

OMB No. 9999-0020
Approved for use through 7/31/94

Protection of Human Subjects
Assurance Identification/Certification/Declaration
(Common Federal Rule)

POLICY: Research activities involving human subjects may not be conducted or supported by the Departments and Agencies adopting the Common Rule (56FR28003, June 18, 1991) unless the activities are exempt from or approved in accordance with the common rule. See Section 101(b) the common rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate Institutional Review Board (IRB) review and approval to the Department or Agency in accordance with the common rule.

Institutions with an assurance of compliance that covers the research to be conducted on file with the Department, Agency, or the Department of Health and Human Services (HHS) should submit certification of IRB review and approval with each application or proposal unless otherwise advised by the Department or Agency. Institutions which do not have such an assurance must submit an assurance and certification of IRB review and approval within 30 days of a written request from the Department or Agency.

1. Request Type
☐ ORIGINAL
☐ FOLLOWUP
☐ EXEMPTION

2. Type of Mechanism
☐ GRANT ☐ CONTRACT ☐ FELLOWSHIP
☐ COOPERATIVE AGREEMENT
☐ OTHER: ____________

3. Application or Proposal Identification No. *(if known)*

4. Title of Application or Activity
Correspondence of the Self-Care Subscale of the Functional Independence Measure (FIM) with Real-Time Observations fo Dementia Patients' ADL*

5. Name of Principal Investigator, Program Director, Fellow, or Other
Ellen M. Cotter, M.D.

6. Assurance Status of this Project *(Respond to one of the following)*

☐ This Assurance, on file with the Department of Health and Human Services, covers this activity:
Assurance identification no. M- 1149 IRB identification no. 01NR

☐ This Assurance, on file with *(agency/dept.)* ____________, covers this activity.
Assurance identification no. ____________ IRB identification no. ____________ *(if applicable)*

☐ No assurance has been filed for this project. This institution declares that it will provide an Assurance and Certification of IRB review and approval upon request.

☐ *Exemption Status:* Human subjects are involved, but this activity qualifies for exemption under Section 101 (b), paragraph ________.

7. Certification of IRB Review *(Respond to one of the following IF you have an Assurance on file)*

☒ This activity has been reviewed and approved by the IRB in accordance with the common rule and any other governing regulations or subparts on *(date)* 3-9-97 by: ☐ Full IRB Review or ☒ Expedited Review.

☐ This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by the common rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments

*Performance in the Home

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed and certification will be provided.

10. Name and Address of Institution
The University of Alabama at Birmingham
1170R Administration Building
701 South 20th Street
Birmingham, AL 35294-0111

11. Phone No. *(with area code)* (205)934-3789

12. Fax No. *(with area code)* (205)975-5977

13. Name of Official
Marguerite Kinney, DNSc

14. Title
Vice Chair - IRB

15. Signature
Marguerite Kinney

16. Date
3-9-97

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OPTIONAL FORM 310 (9-92)
Sponsored by HHS/PHS/NIH

APPENDIX B

MODIFIED FIM SELF-CARE SUBSCALE

Reach
Resources For Enhancing Alzheimer's Caregiver Health

NIA/NINR

Resources for Enhancing Alzheimer's Caregiver Health

ADL/IADL (AD)

Completion Log		
	Person	Date
Data collected		__ __/__ __/__ __
Data entered		__ __/__ __/__ __
System ID		
Data verified		__ __/__ __/__ __
Data cleaned		__ __/__ __/__ __
Data transferred		__ __/__ __/__ __
Subject ID		

It should be noted that the ADL measure used in REACH assesses IADLs as well as the basic ADLs included in the present study. However, IADLs were not examined in the research reported here. To avoid confusion, the pages dealing with IADLs (pages 1-10) have been removed. Additionally, page 17 contains a question assessing the number of days in the past week that other people have provided ADL assistance. This question too was used in REACH but not the current study; thus, that page has also been removed.

Subject ID ___ ___ ___ ___ ___ ___ ___ ___ ___

13. (RC1) **During the past week, has (CR) needed any kind of help getting into or out of a bed, chair or wheelchair?**

0 ( ) *No* *(Semi-core: Go to FIM; record FIM total (13.1))*
1 ( ) *Yes* *(Semi-core: Go to FIM; record FIM total (13.1))*
-3 ( ) *Unknown*
-4 ( ) *Refused*

13.1 *FIM total:* ______ *(If 1 to 5, go to 13.2; If 6-7 go to 14)*

13.2 (RC1) **Did you help with this?**

0 ( ) *No* *(Go to 14)*
1 ( ) *Yes* *(Go to 13.2.1)*
-3 ( ) *Unknown*
-4 ( ) *Refused*

13.2.1 **In the past week, how often did you help (CR) getting into or out of a bed, chair or wheelchair?**

__________ *times/week*

13.2.2 **On average, how much time does it take each time you help (CR) with getting into or out of a bed, chair or wheelchair?**

__________ *minutes* *(Semi-core: Go to 13.2.3)*

13.2.3 (RC5) **How much does helping with this bother or upset you?**

0 ( ) Not at all
1 ( ) A little
2 ( ) Moderately
3 ( ) Very much
4 ( ) Extremely
-3 ( ) *Unknown*
-4 ( ) *Refused*

13.2.4 **How confident do you feel about being able to help your (CR) in this area?**

1 ( ) **Not at all confident**
2 ( ) **A little confident**
3 ( ) **Neutral**
4 ( ) **Fairly confident**
5 ( ) **Very confident**
-3 ( ) *Unknown*
-4 ( ) *Refused*

14. (RC1) **During the past week, has (CR) needed any kind of help eating meals?**

0 ( ) *No* *(Semi-core: Go to FIM, record FIM total (14.1))*
1 ( ) *Yes* *(Semi-core: Go to FIM, record FIM total (14.1))*
-3 ( ) *Unknown*
-4 ( ) *Refused*

14.1 *FIM total:* ________ *(If 1 to 5, go to 14.2; If 6-7 go to 15)*

14.2 (RC1) **Did you help with this?**

0 ( ) *No* *(Go to 15)*
1 ( ) *Yes* *(Go to 14.2.1)*
-3 ( ) *Unknown*
-4 ( ) *Refused*

14.2.1 **In the past week, how often did you help (CR) with eating?**

__________*times/week*

14.2.2 **On average, how much time does it take each time you help (CR) with eating?**

__________*minutes* *(Semi-core: Go to 14.2.3)*

14.2.3 How much does helping with this bother or upset you? (RC5)

0 ( ) Not at all
1 ( ) A little
2 ( ) Moderately
3 ( ) Very much
4 ( ) Extremely
-3 ( ) *Unknown*
-4 ( ) *Refused*

14.2.4 **How confident do you feel about being able to help your (CR) in this area?**

1 ( ) **Not at all confident**
2 ( ) **A little confident**
3 ( ) **Neutral**
4 ( ) **Fairly confident**
5 ( ) **Very confident**
-3 ( ) *Unknown*
-4 ( ) *Refused*

Subject ID ___ ___ ___ ___ ___ ___ ___ ___ ___

15. **During the past week, has (CR) needed any kind of help bathing, either in the tub, shower, or a sponge bath, such as rinsing or drying the body, excluding the back?**
(RC1)

0	( )	*No*	*(Semi-core: Go to FIM; record FIM total (15.1))*
1	( )	*Yes*	*(Semi-core: Go to FIM; record FIM total (15.1))*
-3	( )	*Unknown*	
-4	( )	*Refused*	

15.1 *FIM total:* ______ *(If 1 to 5 go to 15.2;*
If 6-7 go to 16)

15.2 **Did you help with this?**
(RC1)

0	( )	*No*	*(Go to 16)*
1	( )	*Yes*	*(Go to 15.2.1)*
-3	( )	*Unknown*	
-4	( )	*Refused*	

15.2.1 **In the past week, how often did you help (CR) with bathing?**

__________ *times/week*

15.2.2 **On average, how much time does it take each time you help (CR) with bathing?**

__________ *minutes* *(Semi-core: Go to 15.2.3)*

15.2.3 **How much does helping with this bother or upset you?**
(RC5)

0	( )	**Not at all**
1	( )	**A little**
2	( )	**Moderately**
3	( )	**Very much**
4	( )	**Extremely**
-3	( )	*Unknown*
-4	( )	*Refused*

15.2.4 **How confident do you feel about being able to help your (CR) in this area?**

1	( )	**Not at all confident**
2	( )	**A little confident**
3	( )	**Neutral**
4	( )	**Fairly confident**
5	( )	**Very confident**
-3	( )	*Unknown*
-4	( )	*Refused*

Subject ID ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

16. **During the past week, has (CR) needed any kind of help dressing above the waist?**
(RC1)

0 ( ) *No* *(Semi-core: Go to FIM, record FIM total (16.1)).* ____________
1 ( ) *Yes* *(Semi-core: Go to FIM, record FIM total (16.1))* ____________
-3 ( ) *Unknown*
-4 ( ) *Refused*

16.1 *FIM total:* ______ *(If 1 to 5, go to 16.2;*
If 6-7 go to 17)

16.2 **Did you help with this?**
(RC1)
0 ( ) *No* *(Go to 17)*
1 ( ) *Yes* *(Go to 16.2.1)*
-3 ( ) *Unknown*
-4 ( ) *Refused*

16.2.1 **In the past week, how often did you help (CR) with dressing above the waist?**

__________ *times/week*

16.2.2 **On average, how much time does it take each time you help (CR) with dressing above the waist?**

__________ *minutes* *(Semi-core: Go to 16.2.3)*

16.2.3 How much does helping with this bother or upset you?
(RC5)
0 ( ) Not at all
1 ( ) A little
2 ( ) Moderately
3 ( ) Very much
4 ( ) Extremely
-3 ( ) *Unknown*
-4 ( ) *Refused*

16.2.4 **How confident do you feel about being able to help your (CR) in this area?**
1 ( ) Not at all confident
2 ( ) A little confident
3 ( ) Neutral
4 ( ) Fairly confident
5 ( ) Very confident
-3 ( ) *Unknown*
-4 ( ) *Refused*

Subject ID ___________________________

17. **During the past week, has (CR) needed any kind of help dressing from the waist down?**
(RC1)

0 ( ) *No* *(Semi-core: Go to FIM, record FIM total (17.1))*
1 ( ) *Yes* *(Semi-core: Go to FIM, record FIM total (17.1))*
-3 ( ) *Unknown*
-4 ( ) *Refused*

17.1 *FIM total:* ______ *(If 1 to 5 go to 17.2; If 6-7 go to 18)*

17.2 **Did you help with this?**
(RC1)

0 ( ) *No* *(Go to 18)*
1 ( ) *Yes* *(Go to 17.2.1)*
-3 ( ) *Unknown*
-4 ( ) *Refused*

17.2.1 **In the past week, how often did you help (CR) with dressing from the waist down?**

__________ *times/week*

17.2.2 **On average, how much time does it take each time you help (CR) with dressing from the waist down?**

__________ *minutes* *(Semi-core: Go to 17.2.3)*

17.2.3 **How much does helping with this bother or upset you?**
(RC5)

0 ( ) **Not at all**
1 ( ) **A little**
2 ( ) **Moderately**
3 ( ) **Very much**
4 ( ) **Extremely**
-3 ( ) *Unknown*
-4 ( ) *Refused*

17.2.4 **How confident do you feel about being able to help your (CR) in this area?**

1 ( ) **Not at all confident**
2 ( ) **A little confident**
3 ( ) **Neutral**
4 ( ) **Fairly confident**
5 ( ) **Very confident**
-3 ( ) *Unknown*
-4 ( ) *Refused*

Subject ID ___ ___ ___ ___ ___ ___ ___ ___ ___

18. (RC1) **During the past week, has (CR) needed any kind of help toileting, such as adjusting clothing before and after toilet use or cleansing?**

0 ( ) *No* *(Semi-core: Go to FIM, record FIM total (18.1))*
1 ( ) *Yes* *(Semi-core: Go to FIM, record FIM total (18.1))*
-3 ( ) *Unknown*
-4 ( ) *Refused*

18.1 *FIM total:* ______ *(If 1 to 5, go to 18.2; If 6-7, go to 19)*

18.2 (RC1) **Did you help with this?**

0 ( ) *No* *(Go to 19)*
1 ( ) *Yes* *(Go to 18.2.1)*
-3 ( ) *Unknown*
-4 ( ) *Refused*

18.2.1 **In the past week, how often did you help (CR) with toileting?**

__________ *times/week*

18.2.2 **On average, how much time does it take each time you help (CR) with toileting?**

___________ *minutes* *(Semi-core: Go to 18.2.3)*

18.2.3 **How much does helping with this bother or upset you?**
(RC5)

0 ( ) **Not at all**
1 ( ) **A little**
2 ( ) **Moderately**
3 ( ) **Very much**
4 ( ) **Extremely**
-3 ( ) *Unknown*
-4 ( ) *Refused*

18.2.4 **How confident do you feel about being able to help your (CR) in this area?**

1 ( ) **Not at all confident**
2 ( ) **A little confident**
3 ( ) **Neutral**
4 ( ) **Fairly confident**
5 ( ) **Very confident**
-3 ( ) *Unknown*
-4 ( ) *Refused*

Subject ID ___________

19. (RC1) **During the past week, has (CR) needed any kind of help grooming, such as brushing teeth, combing or brushing hair, washing hands, washing face, and either shaving or applying makeup?**

0	( )	*No*	*(Semi-core: Go to FIM, record FIM total (19.1))*
1	( )	*Yes*	*(Semi-core: Go to FIM, record FIM total (19.1))*
-3	( )	*Unknown*	
-4	( )	*Refused*	

19.1 *FIM total:* ______ *(If 1 to 5, go to 19.2; If 6-7 go to 20)*

19.2 (RC1) **Did you help with this?**

0	( )	*No*	*(Go to 20)*
1	( )	*Yes*	*(Go to 19.2.1)*
-3	( )	*Unknown*	
-4	( )	*Refused*	

19.2.1 **In the past week, how often did you help (CR) with grooming?**

__________*times/week*

19.2.2 **On average, how much time does it take each time you help (CR) with grooming?**

__________*minutes* *(Semi-core: Go to 19.2.3)*

19.2.3 (RC5) **How much does helping with this bother or upset you?**

0	( )	**Not at all**
1	( )	**A little**
2	( )	**Moderately**
3	( )	**Very much**
4	( )	**Extremely**
-3	( )	*Unknown*
-4	( )	*Refused*

19.2.4 **How confident do you feel about being able to help your (CR) in this area?**

1	( )	**Not at all confident**
2	( )	**A little confident**
3	( )	**Neutral**
4	( )	**Fairly confident**
5	( )	**Very confident**
-3	( )	*Unknown*
-4	( )	*Refused*

APPENDIX C

OBSERVATIONAL CATEGORIES AND EVENT CODES

I. Assistive Device Use (Event): Assistive device use is recorded with an Event key. The type of device used is not recorded on the keyboard but is documented in the field notes. Examples of assistive devices include but are not limited to raised toilet seats, tub/shower chairs, wall grab bars, and Hoyer lifts. It should be noted that, consistent with the FIM, wheelchairs are not considered to be assistive devices, but crutches, walkers, canes, and braces are. Additionally, any object reported by the caregiver or patient to be used due to safety or impairment considerations, such as electric razors, is also recorded as an assistive device, although these objects should not be assumed to be assistive devices without clarification from the subjects. This category also includes various environmental modifications such as labels on drawers and cabinets. Furthermore, if a patient can feed herself but only eats pureed food, this pureed food should be coded under this category.

II. ADL (Duration): Record when the ADL of interest occurs. The specific actions being coded depend on the specific ADL in question and are based on the operational definitions of the ADL found in the FIM. Record the logical opposite, "No ADL," if no ADL-related behaviors are occurring. The following ADLs are observed, separately:

A. Bathing: Washing, rinsing, and/or drying the body from the neck down, excluding the back. Bathing may occur in a tub, shower, or sponge bath. Although washing, rinsing, and drying can be considered to be separate activities, they are not recorded separately. Rather, the "ADL" key is recorded whenever any of these activities occurs. Begin recording when the caregiver or patient first makes contact with bathing materials. Stop recording when the patient's towel is hung up, dropped to the floor, or otherwise discarded after use.

1. Washing: Scrubbing the body with soapy hands or a soapy washing apparatus (e.g.,washcloth, sponge).

2. Rinsing: Applying water to parts of the body previously washed. Water may be dispensed through pouring or splashing water over the body or by squeezing water from a washcloth or sponge.

3. Drying: Rubbing the body with a towel.

B. Dressing/Undressing: Obtaining, putting on, and taking off clothing. Consistent with the FIM, dressing/undressing of the upper and lower body are recorded separately. Start recording when the caregiver or patient makes contact with clothing (e.g., caregiver removes shirt from drawer, patient picks up pants) and stop recording when the caregiver and/or patient stops putting on/taking off clothing.

1. Dressing/undressing upper body: Retrieving clothes from their customary places, managing undergarments such as a bra or undershirt, and putting on or taking off items such as a pullover sweater or front-opening

shirt. Managing fasteners such as zippers, buttons, and snaps is also included.

2. Dressing/undressing lower body: Retrieving clothes from their customary places, managing undergarments, putting on or taking off items such as zip-front pants or a pull-on skirt, and putting on and tying shoes. Managing fasteners such as zippers, buttons, and snaps is also included.

C. Eating Meals: Using suitable utensils to bring food to the mouth, as well as chewing and swallowing food. Food preparation is not considered to be a part of this activity; however, modifications such as cutting up or pureeing food should be coded under the Caregiver Physical Assistance category as Setup (see category IV, code B). Start recording at first caregiver or patient contact with food or utensils after the food has been placed in front of the patient. Stop recording when the dishes are removed or the patient moves away from the table, or there is verbal indication that the patient has stopped eating. If the patient's plate is not empty but the patient has stopped eating, ADL activity should still be coded, but patient performance should not.

D. Grooming: Oral care, brushing or combing hair, washing hands and face, and either shaving or applying makeup. These activities are not recorded separately; rather, the "ADL" key is recorded whenever any of these activities occurs. Begin recording when the caregiver or patient makes contact with grooming materials, and stop recording when the caregiver or patient breaks contact with grooming materials. The following activities are considered to constitute grooming but are not separately coded:

1. Oral care: Cleaning teeth or dentures, either by brushing or soaking. Includes use of mouthwash and preparatory actions such as putting toothpaste on a toothbrush.

2. Brushing/combing hair: Using a comb and/or brush to untangle, style, or smooth the hair. Does not include cutting, curling, washing, or drying hair. Also does not include beard and moustache care.

3. Washing hands: Applying soap to hands, rubbing them together, and rinsing them off either under running water or in standing clean water.

4. Washing face: Applying soap to hands or washing apparatus, rubbing soap on face, and rinsing face either by splashing clean water on it or by rubbing face with clean, wet washing apparatus.
(Note: Washing the face is sometimes done in the tub or shower during the course of bathing, rather than while standing at the sink. Care must be taken not to code the former situation as bathing instead of grooming.)

5. Shaving: Applying shaving foam or gel to the face, creating suitable lather, and using a razor to shave the face. If an electric razor is used, then it is not necessary to use shaving foam or gel.

6. Applying makeup: Putting makeup on the face. Makeup used can include but is not limited to foundation, lipstick, eye shadow, mascara, and rouge. Perfume, lotion, and talcum powder do not fall into this category.

E. Toileting: Getting to the toilet, adjusting clothes before and after urination and/or bowel movements, and cleansing after voiding. These activities are not recorded separately. Rather, the "ADL" key is recorded whenever any of these activities occurs. Begin coding when the patient enters the bathroom and stop coding when the patient's clothes are back in place after toileting.

1. Getting to the toilet: Ambulating to the toilet. Includes maneuvering around furnishings and objects in the room as well as seating oneself on the toilet.

2. Adjusting clothes: Managing clothes as needed to keep them clean and out of the way during voiding, as well as ensuring that clothes are properly worn after voiding. Includes actions such as zipping and unzipping pants and tucking in a shirt. May also involve use of continence care garments.

3. Cleansing: Wiping the perineal area as needed after urination and/or bowel movements.

F. Transfer into/out of bed, chair, or wheelchair: Getting into or out of a bed, chair, or wheelchair. The specific type of transfer is not recorded; rather, all types of transfers are assessed with the "ADL" key. However, operational definitions of the possible types of transfers are as follows:

1. Sitting to standing: Begin coding when the patient's buttocks leave the surface of the bed, chair, or wheelchair and stop coding when the patient is standing upright.

2. Sitting to sitting: Begin coding when the patient's buttocks leave the surface (e.g., bed) and stop coding when the patient has finished repositioning or being repositioned on a different surface (e.g., wheelchair). If the patient is just shifting in his or her seat, do not code. Only code when one surface has been vacated for another.

3. Lying to sitting: Begin recording when the patient's legs move from the foot of the bed and stop when the patient is sitting upright in a chair or wheelchair and has finished repositioning or being repositioned.

4. Lying to standing: Begin recording when the patient's legs move from the foot of the bed and stop when the patient is standing upright.

5. Standing to sitting: Begin recording when the patient starts to bend his/her legs after coming to a stop within one foot of a chair, sofa, or other surface. Stop recording when the patient has finished repositioning or being repositioned.

6. Standing to lying: Begin recording when the patient's legs start to bend after the patient comes to a stop within one foot of a bed, sofa, or other surface. Stop recording when the patient has finished repositioning or being repositioned.

III. Caregiver Verbal Behavior (Duration): Verbal statements directed to the patient during ADL sessions. Statements made by the caregiver to other people, including the observer, are not recorded. The content of the statements, not the tone, is the primary focus; i.e., statements that could be interpreted as sarcastic are coded at "face value", although tone may be described more fully in the field notes.

A. Verbal prompt: Any statement or question in which the caregiver requests or tells the patient to perform an action or asks the patient a question that suggests a course of action. When ADLs are intermingled, it should be noted that prompts are context-specific. For example, if a patient is being bathed while sitting on the toilet and the caregiver says "Lift your arm so I can wash it," this statement is coded as a prompt if bathing is being coded, but not if toileting is being coded. In the latter situation, this statement would be coded as "other verbal."

B. Caution: Any statement in which the caregiver expresses concern for the patient's safety or well-being (e.g., "Be careful").

C. Other verbal statement: Any statement in which the caregiver offers a commentary on the events or continues the flow of conversation. Also includes situations in which the caregiver prompts for an ADL not currently being coded.

D. No verbal statements: Record if the caregiver is not speaking to the patient.

IV. Physical Assistance (Duration): Physically based assistance provided to the patient during ADL performance. May occur simultaneously with caregiver verbal behavior.

A. Supervision: Record if the caregiver is in the same room as the patient, has the patient in his or her line of sight, or is approaching and within 3 feet of the patient. If the caregiver touches the patient to provide assistance, then Physical Guidance, not Supervision, must be coded. Do not code if the caregiver and patient are engaging in the same activity (e.g., eating breakfast together) or if the caregiver is in the same room but engaging in another purposeful activity (e.g., washing dishes). Also do not code if the caregiver is "just passing through" to get to another destination and does not interact with the patient.

B. Setup: Getting necessary materials for and/or preparing them for use by the patient. Examples include cutting or pureeing food, setting out clothes, and putting toothpaste on a toothbrush. Begin recording when caregiver first makes contact with the materials, and stop recording when the necessary materials are placed within reach of the patient.

C. Hands-on assistance: Providing some type of hands-on contact to assist the patient, including helping to balance or steady the patient. This code also encompasses situations in which the caregiver assumes complete responsibility for performance of the ADL (e.g., spoon-feeding the patient).

D. No assistance: Record if the caregiver does not provide physical assistance to the patient.

V. Disruptive Behavior (Event): Disruptive behavior exhibited during the ADL. Examples of disruptive behavior include physical aggression in which contact is made, self-injurious behavior, spitting, audible disruptive verbalizations (high-volume unintelligible utterances, repetitive talk, or self-talk/singing), and general agitation.

VI. Patient Performs ADL (Duration): Record when the patient is participating or attempting to participate in the ADL. Record its logical opposite, "No performance," if the patient is not participating or attempting to participate in the ADL, regardless of what the caregiver is doing. The success of patient attempts at ADL performance should not be evaluated in determining whether or not to code performance. Definition of this category is ADL-specific as provided on the FIM, as follows:

A. Bathing: If the patient is holding bathing materials but not using them appropriately (e.g., throwing soap, holding washcloth but not doing anything with it), do not code patient participation. Extending an arm or leg while the caregiver performs bathing-related activities is, however, considered to be participation.

B. Dressing (both upper and lower body): If the patient is just holding clothing, patient participation should not be coded. If patient moves clothing in a functional manner, patient participation can be coded. Extending an arm or leg while the caregiver dresses the patient is also considered to be participation.

C. Eating: Merely chewing and/or swallowing food does not constitute independent patient performance if the caregiver is responsible for bringing all food and liquids to the mouth. For patient participation to be coded, the patient must either make contact with utensils or cups, bring food or liquid to the mouth, or place food on an appropriate utensil.

D. Grooming: If the patient is touching grooming materials but not using them appropriately (e.g., holding hairbrush but not doing anything with it, smearing toothpaste), do not code patient participation. Also, merely cooperating by holding the head still while hair is being combed or opening the mouth while teeth are being brushed does not constitute patient participation.

E. Toileting: Behaviors such as fecal smearing or digging in the rectum are not considered to be part of toileting and should not be coded. However, inappropriate toileting due to factors such as "poor aim" or episodes of incontinence should be considered as patient participation. Merely sitting on the commode does not constitute patient participation; it is only when clothing is being adjusted or the patient is wiping the perineal area after toileting that participation occurs.

F. Transferring: Movement must be present for patient participation to be coded.

VII. Independent Toileting (Event): This key should only be used when the patient toilets independently, but this activity was not recorded on videotape for various reasons. Instances of independent toileting are noted on the videotape label and cannot be coded for reliability.

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I certify that I have read this document and examined the student regarding its content. In my opinion, this dissertation conforms to acceptable standards of scholarly presentation and is adequate in scope and quality, and the attainments of this student are such that she may be recommended for the degree of Doctor of Philosophy.

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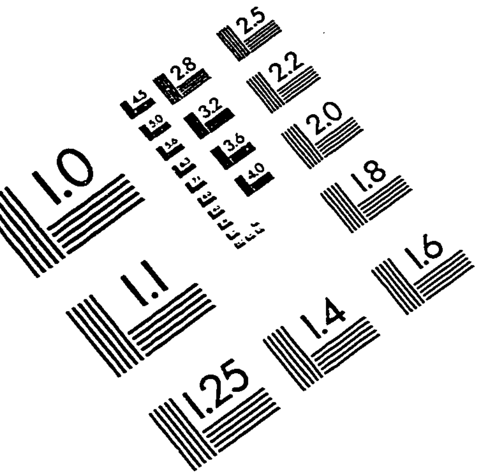

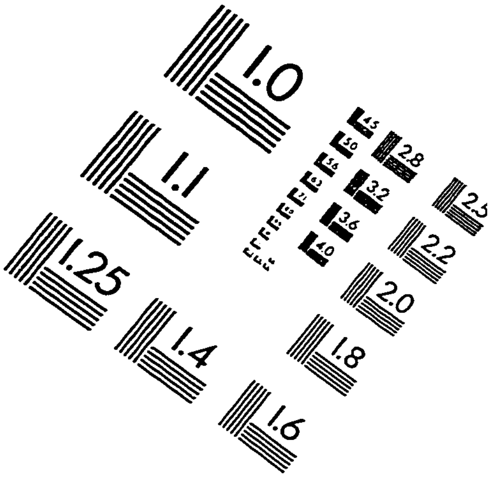

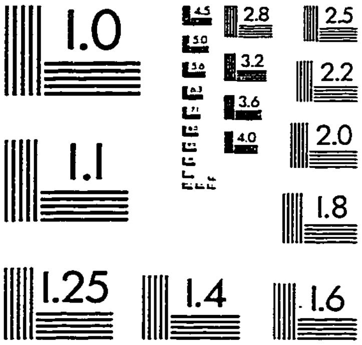

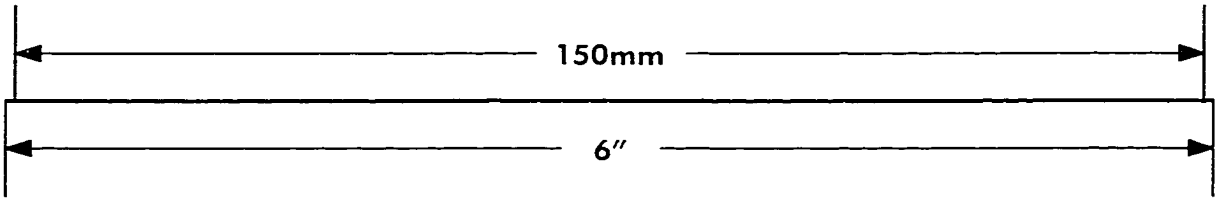

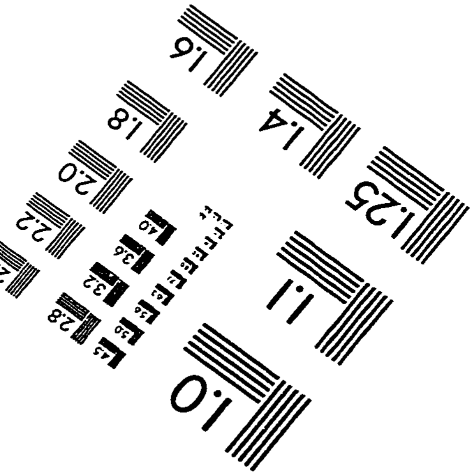

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