ASSESSING COGNITIVE IMPAIRMENT AND ITS IMPACT ON NURSING HOME PLACEMENT OF FRAIL ELDERLY

by

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CHAPTER I

INTRODUCTION

Living to an advanced old age may indeed be a blessing, but it can also be a curse. To live through the eighth or ninth decade of life can bring both physical and mental deterioration. For some, this results in institutional placement while others are able to remain in the community with varying degrees of support. The factors which influence residence decisions of the frail elderly are not well understood despite recent research interest. The most obvious explanation for nursing home versus community placements, such as family foster care or adult day care, is level of functioning. Theoretically, the poorer the level of physical and mental functioning, the more structured the living situation would need to be. Ideally, the frail elderly form a continuum, i.e. the most severely disabled would be institutionalized while the least disabled would be at home with minor community support. However, a growing body of research does not support this notion. Zarit, Reever and Bach-Peterson (1980) found that 90 percent of elderly with senile dementia can and do remain in the community. Brody, Poolshock & Masciocchi (1978), in a needs assessment study in Philadelphia, discovered that the choice of staying home, rather than going to an institution, depended almost entirely on the resources and ability of family members and the community to compensate for the disability and not on the disability itself.

The Placement Information Base (PIB) is a functional assessment tool developed for a state FIG/Waiver continuum of care project for the elderly (1979). Project data revealed comparable ranges of scores of functioning between a group of elderly in institutions and those in the community. To examine this phenomenon, a longitudinal exploratory study was designed by Archbold and Hoeffer (1981). This investigator focused on a subsample of the study, the nursing home population. During the data collection process it became obvious that despite similar functional assessment scores, there were major differences in the community and nursing home subsamples being studied. The elderly at home in the community were able to give informed consent and complete the interview. The elderly in the nursing homes were usually not able to give informed consent or participate in an interview because of cognitive impairment.

The literature has suggested that declines in cognitive functioning are the most difficult deficits for families to manage (Berg, Browning, Hill and Wenkert, 1970; Haley, 1983; Kane, Rubenstein, Brook, Van Ryzin, Masthay & Schoenrich, 1981b; Robinson & Thurnher, 1979; Sands & Suzuki, 1983; Sloane, 1980; Smyer, 1980; Zarit, et al., 1980). If this is so, at what point do families utilize nursing homes for difficulties related to cognitive impairment? If the functional assessment scores were similar, why was the nursing home sample so much more cognitively impaired? Does

the current assessment tool adequately screen for cognitive impairment? Are the scores accurate?

Significance of the Study

Nursing has long been the champion of vulnerable groups such as the frail elderly. Those elderly individuals who are also cognitively impaired are even more vulnerable. Nurses are often required to make recommendations about placement decisions based on level of care assessments. Since, as previously cited, families find cognitive impairment one of the most difficult areas to manage, it is important that an assessment instrument be sensitive to this area of functioning.

The PIB is a functional assessment tool used in placement decisions which does not assess cognitive functioning as a separate dimension. Can such a tool be used with any confidence? Is it indirectly sensitive to cognitive impairment?

Mental health nursing is the area of nursing most familiar with the assessment of cognitive functioning and its impact on the ability to care for self. The significance of this study is that it provides an assessment of the PIB's sensitivity to cognitive impairment from the perspective of a mental health nurse.

REVIEW OF LITERATURE

The scope of the problem under study requires an understanding of the literature in four areas: 1) characteristics of the elderly residing in nursing homes; 2) use

of functional assessment tools in elderly placement decisions; 3) weighting of cognitive functioning variables in elderly placement assessments; and 4) factors involved in the decision to utilize nursing home placement.

Characteristics of the Elderly Residing in Nursing Homes

Van Nostrand (1981) drawing from the National Health statistics described the average nursing home resident as a white, widowed female, age 81 with cerebrovascular disease. This average resident needed help with bathing, dressing, bathroom activities and mobility. In a study done in London and Ontario, one-half of the nursing home residents had some difficulty walking, one-third had periods of incontinence and one-fourth had loss of mentation (Cape, Shorrock, Tree, Pablo, Campbell & Seymour, 1977).

Most research on nursing home residents was comparative in nature. Relative to the community, the elderly in nursing homes were older, living with a spouse less often, had low incomes, more cerebrovascular disease, incontinence, recent loss of independence in activities of daily living, dementia, recent hospitalization, loneliness and depression, and had received more extensive help from relatives and friends (Kraus, Spasoff, Beattie, Holden, Lawson, Rodenburg & Woodcock, 1976a; Tobin & Lieberman, 1976). Smyer (1980) added to this description, noting that the nursing home population had had more previous service contact with community service providers, had less support available from family and friends and were more impaired in the areas of

mental health and social resources. Indeed, he found that mental health status, not physical health status, distinguished between the institutionalized and non-institutionalized elderly (Smyer, 1980). With the advent of deinstitutionalization of the chronically mentally ill, intermediate care facilities have replaced many state mental hospitals as the final destination for many mentally impaired elderly (Smyer, 1980).

Two studies compared elderly residents in skilled nursing facilities with those in intermediate care facilities. Both studies described the elderly in the skilled nursing facilities as having more severe deficits in activities of daily living and higher levels of disorientation and confusion (Greene & Monahan, 1981; Haddad, 1981). Greene, et al. (1981) further characterized the skilled nursing facility residents as having transitory contact with the social environment and a propensity to wander. Haddad (1981) found the same population needed more personal and professional nursing care.

Thus, the literature clearly demonstrates that it is the interaction of many variables and not one factor alone which characterizes the elderly in nursing homes. The physical variables of health status and activities of daily living deficits interact with both the psychological variables of confusion, disorientation, and their behavioral sequelae, as well as the social support variables of family availability and community resources.

Use of Functional Assessment Tools in Elderly Placement Decisions

Clinical assessment tools are often used to evaluate the overall level of functioning of an elderly individual as a measure of the advisability of changing residences. The most useful tools tap the elderly person's ability to function despite disease, physical and mental disability and social deprivation (Kane & Kane, 1981a). The OARS (Older Americans Research and Service Center Instrument), a multidimensional functional assessment questionnaire developed at Duke University was the most frequent tool used by researchers (Lawton, Moss, Fulcomer, & Kleban, 1982; Moore & Goldstein, 1980; Pfeiffer, Johnson, & Chiofolo, (1981). It measures physical, mental, social, economic and activities of daily living impairments.

To be useful, a tool must have certain characteristics. It should be brief, inexpensive and capable of administration by personnel who have little or no professional training (Kane, et al, 1981a; Lawton, et al., 1982). Lawton, et al., (1982) noted that time is at a premium in clinical settings and the endurance of the elderly is limited.

Instruments have five functions: description, screening, assessment, monitoring and prediction. A tool used for screening purposes should merely indicate the need for more intensive assessment (Kane, et al., 1981a). Clinical decisions regarding placement can be made one of two ways: 1) utilizing professional judgment; or 2) by predetermined

decision rules. Grauer and Birnbom (1975) developed a Geriatric Functional Rating Scale to determine the need for institutional care. It requires professional judgment to rate the physical and mental condition of the elderly individual. In a system where professionals do the screening activities, this tool has been well received (Kane, et al., 1981a). In a system where non-professionals administer the assessment tool, Kane, et al., (1981a) suggest that the scoring formula be such that the tool is not easily manipulated by the rater to reflect his or her clinical impression. Kane, et al. (1981a) caution that the elderly individual may or may not be the appropriate person to interview. In a study by Reifler, Cox and Hanley (1981), cognitively impaired persons living in the home saw themselves as suffering no significant problems in activities of daily living, personal health or family relationships while professional persons and family caregivers saw them with difficulties in all areas. The elderly subjects' lack of insight into their deficits would invalidate any assessment where they were the primary source of information.

Functional assessment tools are often used for multiple purposes. A comprehensive assessment may be expected to influence a clinical decision, provide data on program effectiveness and serve as research data (Kane, et al., 1981a). An instrument can rarely be designed to do justice to all areas. Clinical assessments and research assessments

may vary on the same tool with the same subject because of the systems variables impacting on the results.

To summarize this section, the literature suggests that a functional assessment tool should be multidimensional, brief, inexpensive, easy to administer and require little time. Clinical decisions made by professionals should utilize professional judgment while those made by non professionals should have predetermined decision rules and a non-obvious scoring formula. Assessments made on cognitively impaired elderly should include a second source of information for reliability. Finally, one tool can rarely be developed to serve clinical, research, program evaluation and resource allocation needs all at once.

Weighting of Cognitive Functioning Variables in Elderly Placement Assessments

It has been estimated that for every cognitively impaired elderly person in the nursing home, two equally impaired individuals are in the community (Brody and Kleban, 1983; Kane, et al., 1981a). The institutionalized elderly have a 50% to 60% prevalence rate of organic mental disorders (Brody, et al., 1983).

The literature reflects several different approaches to examining the weight given to the importance of cognitive impairment in placement assessments. Zarit, et al., (1980) studied cognitively impaired elderly individuals in the community and their caregivers. The researchers found that the extent of burden experienced by the caregivers was

related to the strength of the social network of the caregivers and not to the level of cognitive impairment present in the elderly member. Sands and Suzuki (1983) studied patients in an adult day care center with Alzheimer's disease. Their findings attributed the presence of ambulatory patients with cognitive disorders in nursing homes to a lack of community alternatives such as adult day care. They state that nursing homes were not designed to provide care for cognitively impaired ambulatory individuals. Thus, neither study of cognitively impaired elderly in the community assigned any weight to the presence of cognitive impairment as a factor in placement assessment.

Other researchers have reported cognitive impairment variables as crucial to placement assessments. Sloane (1980) studied hospital in-patients and found that high mental status and activities of daily living scores, as well as the presence of family members willing to help, predicted those individuals suitable for a less restrictive placement than the nursing home. Smyer (1980) was able to discriminate between institutionalized and non-institutionalized elderly solely on the basis of mental status. Perhaps the most crucial findings were in the literature related to the family's ability to care for its elderly members. Families found the decrease in cognitive functioning and its concommitant behavioral sequelae the most difficult variable with which to cope (Berg, et al., 1970; Grauer, et al., 1975; Haley, 1983; Reifler, et al., 1981; Robinson, et al.,

1979; Sainsbury & Grad de Alarcon, 1970; Sands, et al., 1983). "The inability of families to manage behavior problems related to cognitive impairment is a major reason for institutionalization of the elderly and a major stress in caretakers" (Haley, 1983, p. 18).

In summary, the literature lacks agreement with respect to the significance of cognitive impairment as a variable in nursing home placement. Those studies conducted in the community with cognitively impaired elderly did not assign any weight to cognitive functioning as a placement variable; those studies which compared the elderly in nursing homes with those in other settings assigned great importance to the level of cognitive functioning. Families are crucial buffers between community residence and nursing home placement and have great difficulty when cognitive impairment is present in an elderly member.

Factors Involved in the Decision to Utilize Nursing Home Placement

There was a preponderance of literature on why nursing homes are utilized. Cath (1972), in his classic article stated that adult children are extremely reluctant to suggest institutionalization for their parents. No one wants to render a "death sentence". The functional and psychosocial assessments which are central to placement decisions can also relieve the family burden by legitimizing the need for a change in residence (Kleh, 1977). One interesting study examined the recommendations of visiting

nurses and elderly individuals when presented with an elderly placement situation (Grier, 1977). More than twice as many elderly people assessed that a nursing home was as necessary as visiting nurses. Nursing homes appear to be viewed as necessary, realistic options by some of the elderly population. The factors which lead to a decision to seek nursing home placement can be divided into five categories: 1) state of residence; 2) health status; 3) social support; 4) activities of daily living; and 5) cognitive impairment. These will be discussed individually.

State of Residence. There was a small body of research which suggested that the state in which a person resided and how well the state guidelines were defined was predictive of long-term placement (Foley & Schneider, 1980). However, researchers in Arizona, a non-medicaid state with less restrictive regulations, conducted a study on consistency of placement decisions (Greene, et al. 1981). The results revealed no significant differences between practices in Arizona and those in medicaid regulated states.

Health Status. Foley, et al. (1980) also suggested that an elderly person's placement was dependent on his/her health status. Kraus, et al. (1976a) concur citing specific health problems as a frequent reason for application to a nursing home.

Social Support. Barney (1977) noted that no degree of long term health care or other supportive services automatically indicates the setting in which that care should be

provided. All levels of care can be given at home. Spouses were the primary source of help for married elderly with impaired capacity; adult daughters were the major helpers when a spouse was not present or when the level of support provided by the spouse was not sufficient (Barney, 1977; Stoller & Earl, 1977). The availability of care at home determined, to an extent, the rate and timing of nursing home use (Barney, 1977; Callahan, Diamond, Giele, & Morris, 1980; Lawton, 1981; Lefroy, 1978; McAuley & Prohaska, 1981; Smallegan, 1981). Factors such as aging children's health problems or the death of an adult caregiver precipitated nursing home admissions (Brody, 1966; Lawton, 1981). Studies have shown that only when an elderly person reaches a point where care involves a high level of inconvenience and hardship did the family begin to consider institutionalization (Barney, 1977; Callahan, et al., 1980; Kraus, et al., 1976b; Smallegan, 1981). Social support, then, acts as a buffer between independence and institutionalization.

Activities of Daily Living. There was general agreement in the literature that the amount of assistance needed with activities of daily living was a factor in nursing home placement (Barney, 1977; Kane, et al., 1981b; McAuley, et al., 1981; Sherwood & Feldman, 1970; Sherwood, Morris & Barhart, 1975; Sloane, 1980; Smallegan, 1981). The weighting of specific activities of daily living was not well reported. When it was present, mobility and transferring

activities were given the greatest weight (Kane, et al., 1981b; Smallegan, 1981).

Cognitive Impairment. A deterioration in mental status was the single most difficult variable for families to manage (Berg, et al., 1970; Haley, 1983; Robinson, et al., 1979). Confusion alone, while stressful for caregivers, was not enough to precipitate an admission. The potentially harmful behaviors, such as wandering, were what caused families to consider nursing home placement (Haley, 1983; Reifler, et al., 1981; Ross & Kedwood, 1977).

Mental status was a significant variable in all comprehensive assessments (Kane, et al., 1981b; Reigler, et al., 1981; Sloane, 1980). Its impact on placement decisions is not well understood. Its weighting in elderly placement assessments has previously been discussed.

Thus, a multitude of factors are considered when making a decision to utilize a nursing home. The literature focused on the following factors: state of residence, health status, social support, activities of daily living and cognitive impairment.

Summary of the Review

The elderly in nursing homes have been described as having deficits in multiple systems which are greater than those seen in the elderly in community placements. These include cognitive, physical and social deficits. The functional assessment tools used to measure the deficits should be brief, inexpensive and easy to administer. A

functional assessment tool can rarely serve clinical, research and resource allocation needs all at once. Results, then, may differ based on the reason for using the tool. In addition to the cognitively impaired elderly individual, a second source of information is required for reliable results.

The literature was divided with respect to the significance of cognitive impairment as a variable in nursing home placement. However, it was clear that families and social networks are crucial buffers between community residence and nursing home placement when cognitive impairment is present. Other factors considered when deciding to utilize nursing home placement were state of residence, health status and skill levels in activities of daily living.

Purpose of the Study

The purpose of the study is twofold: to examine and describe the ability of the PIB to screen for cognitive impairment in the elderly; and to examine the impact of cognitive functioning in the elderly on the decisions made regarding their placement in a nursing home.

Research Questions

Three questions evolved from the analysis of the data.

1) How do scores on PIB items that assess cognitive functioning compare for investigator's and state evaluator's ratings of elderly subjects?

2) Is the PIB sensitive to cognitive impairment despite a lack of direct assessment?

3) How do the factors that impacted on nursing home placement decisions compare for the non-cognitively impaired and the cognitively impaired elderly subjects?

CHAPTER II

METHODOLOGY

Research Design

This study was part of a longitudinal, exploratory study of utilization of institutional and community based services by frail elderly in rural areas by Archbold and Hoeffer (1981). Both this study and the larger study utilized the qualitative methods of in-depth interviews and participant observation, and quantitative measures (PIB).

Subjects and Setting

Subjects for this study were drawn from clients participating in the on-going study of Archbold and Hoeffer (1981). Data collection for that study began in August, 1981 and concluded in October, 1982.

A state service agency provided the researchers with the names, placements and a quantified assessment of functional status of medicaid eligible aged individuals 65 years old and over receiving medicaid in four rural counties. Residents whose functional assessment scores fell within specific parameters were approached regarding participation in the study.

Sample Selection Criteria

The functional assessment scores of the elderly residents in their own homes, in homes for the aged, in foster care and in nursing homes demonstrated significant overlap. The researchers defined the most functionally impaired group in their own homes as those whose functional

assessment scores fell within the 15 to 31 range. These in-home community residents were then matched with groups of residents from each of the other placement areas on functional assessment score. Residents who qualified for the study, based on the matching procedure, were approached regarding participation in the study. A family member or primary support person for each elderly participant was also asked to participate. This person will hereafter be referred to as the primary caregiver.

Subjects

The subjects in this investigation consisted of twelve of the elderly medicaid recipients in six nursing homes in two counties, and fourteen people identified by them or the nursing home personnel as their primary caregiver. One elderly subject's caregiver declined the interview due to family problems. Two family members were involved in the interview process for three of the elderly subjects.

The national profile of the average nursing home resident is a person who is female, widowed, caucasian and age 81 years (Van Nostrand, 1981). Of the frail elderly in this study, ten were female and two were male. Their ages ranged from 68 to 98 years with a mean age of 86.3 years. Ten of the elderly were widowed, while two were still married. The spouses, one male and one female, remained at home with neighbor or family support. Regarding their education, seven of the twelve elderly had completed 5 to 8 years of schooling. Two had some high school and two

finished high school. Only one member attended college. All of the subjects in this study were Caucasian. This sample was therefore older, but otherwise closely resembled the national profile.

The primary caregiver group consisted of eleven women and three men. Their ages ranged from 23 to 79 years with a mean of 60.2 years and a median of 62 years. Ten were married currently, two were widowed, one was single and one was divorced. Regarding their education, two had completed 5 to 8 years of school, five had some high school, five completed high school and two had 1 to 3 years of college.

Data Collection Instruments and Methods

The data was collected using the following instruments: 1) the Placement Information Base (PIB); 2) focused, in-depth interview and 3) participant observation.

Placement Information Base (See Appendix A)

The PIB is a functional assessment tool developed for a state project aimed at increasing the co-ordination of federal, state and county services, and diverting Medicaid funds from institutional care to community-based care. The instrument measures the individual's functional status at the time of administration in seven areas:

A. Communication (Questions 1 through 3)

B. Mobility (Questions 4 through 6)

C. Household and food management (Questions 7 through 11)

D. Social and emotional functioning (Questions 12 through 18)

E. Finances (Question 19)

F. Health (Questions 20 and 21)

G. Self care (Questions 22 through 25).

Each area is assessed by using a five level format ranging from average or better functioning (level 1) to severe problems with functioning (level 5). The responses are weighted and scored according to the guidelines provided by the state agency (Appendix B). Validity and reliability were established through field tests of five versions of the instrument. The purposes of the field tests were to: 1) ensure that the scales span the continuum of functional levels in each of the categories, and 2) to measure inter-rater reliability in a variety of settings. This observational schedule was used by the state evaluators as part of a data base for matching individual needs of frail elderly with institutional and community-based services.

The state provided the researchers with a PIB training manual describing how the level determinations should be made. A case study was used to demonstrate utilization of the guidelines.

Cognitive functioning is not one of the seven areas directly assessed by the PIB. Since the investigator's overall PIB scores were sensitive to the three groupings, and the groupings were made based on differences in cognitive functioning, the instrument may have been sensitive to

cognitive impairment without explicitly evaluating it. Using clinical judgment, then, the investigator identified those items in the PIB which might have been sensitive to cognitive impairment. Five items were identified: #1, self-identification; #12, social activities; #14, emotional control; #16, orientation for living alone; and #21, managing medications. These items will be discussed further in Chapter 3.

Focused, In-depth Interview

Focused, in-depth interviews were conducted with the subjects. The starred items (see Appendices C & D) were taken from the OARS (Older American Research and Service Center Instrument), a multidimensional functional assessment. Reliability and validity of the OARS items are reported to be adequate (Fillenbaum & Smyer, 1981). However, in this study the investigators used items from the OARS as probes. The remaining questions are qualitative probes. The interview questions can be divided into 9 areas:

Questions 1-18 describe the setting and the interviewee.

Questions 18-21 tap the elderly person's perception of his/her financial status.

Questions 22-25 examine his/her perception of his/her health and living situation.

Questions 26-28 assess specific daily functioning items.

Questions 29-40 determine the type, extent, expectations and changes in the social network.

Questions 41-44 assess personal and family emotional patterns during stress.

Question 45 appraises life satisfaction.

Questions 46-52 examine the utilization of and attitude toward present and potential community services.

Participant Observation

Participant Observation (Cook & Reichardt, 1979; Lofland, 1971; McCall & Simmons, 1969) was used throughout the data collection process to obtain information about the physical environment of the institutions and homes, the functional status of the frail elderly individuals. Note was also made of the investigator's thoughts and feelings during the data collection process.

Data Collection Process

The process which culminated in the data collection consisted of the following steps. The researchers sent a letter to each elderly individual identified by a state service agency as a potential subject. The letter informed the elderly person that a study was being conducted by two researchers from a school of nursing on the use of community-based and institutional services for elderly people in rural settings. They were further advised that their name had been selected as a potential candidate for the study and that an investigator would be contacting them in person in the weeks to come about participating. A

letter was also sent to each nursing home administrator explaining the purpose of the study and listing the potential subjects in the facility.

Once the investigator was in the rural area, a telephone call was made to the nursing home administrator or contact person identified by the state agency. The purpose of the study was stated along with the names of the elderly residents who were potential subjects. Permission was secured to visit the nursing home, meet with the contact person, show them the interview schedule, answer any questions and discuss the possibility of meeting with the potential elderly subjects. All of the nursing home contact people agreed to allow the investigator to speak with the potential subjects. One of them had already approached the potential subjects and asked them if they wanted to talk with the investigator. He had a list of who would and who would not consent to talk.

Other contact people informed the investigator that particular potential subjects would be unable to participate in an interview because of cognitive impairment. They often offered to let the investigator speak with other nursing home residents who would be glad to participate. The investigator was allowed to approach all of the potential subjects after being introduced by one of the nursing home staff members.

The nursing home contact person was also asked to identify a significant other for each of the potential

subjects and supply their phone numbers. The investigator found the nursing home personnel were willing to provide phone numbers but reluctant to give out addresses. They felt that the primary caregiver in the community could provide the address if they desired to participate.

Each potential subject was approached about participation in the study. Those potential subjects who were identified by the nursing home caregiver as cognitively impaired were not asked to sign the consent form or answer any interview questions. The investigator visited with each of these elderly individuals from 15 to 30 minutes each with their verbal permission. The purpose of the visit was to directly observe the level of physical and cognitive impairment experienced by the elderly individual.

The potential subjects who were identified by their nursing home caregivers as cognitively intact were given an explanation of the purpose of the study and what it would involve for them. They were given a copy of the large print consent form (Appendix E) which they were allowed to keep. The investigator also read the consent form to them and answered any questions before they made their decision about whether to participate.

Refusals

Three potential subjects were not included in the study. One cognitively intact male refused to participate. One cognitively impaired female was not included because she had no primary caregiver in the community. Inability to

locate one potential subject resulted in the final incidence of an elderly person's non-participation in the study.

Elderly Participants

Four elderly subjects signed the consent form and completed the interview. Three of these were cognitively intact; the fourth subject was a women who had periods of confusion lasting up to 3 weeks at a time interspersed with 6 to 8 week periods of no confusion. She was not confused when the investigator approached her.

Eight elderly subjects were unable to respond to questions in the interview due to cognitive impairment. They were included in the study only after their primary caregiver in the community consented to be in the study.

After the interview was completed, the investigator found a quiet place nearby to write field notes about the setting and the interview experience. The PIB items, which were directly observed, were rated at this time. Total time required for the interview, the field notes and the PIB was $1^{1}/2$ to 3 hours for the cognitively intact elderly, and 45 minutes to 1 hour for the cognitively impaired elderly.

Primary Caregiver Participants

Once the contact with an elderly individual was completed, the primary caregiver in the community as identified by the elderly subject and/or the nursing home personnel was contacted by phone. The purpose of the study was explained. The primary caregiver was told that the investigator had already seen the elderly individual. The

primary caregiver was then asked if they would consent to a meeting where the investigator could further explain the study. All but one primary caregiver agreed. The one refusal came from an individual who explained he was having severe family problems and did not wish to participate.

The place for the meeting was determined by the primary caregiver. While the majority of interviews occurred in the caregivers' homes, interviews were also conducted at the caregiver's place of employment and at the nursing home where their elderly family member resided.

The primary caregiver was given a copy of the consent form to keep and the investigator read the consent form aloud for them. Questions were answered and the consent form signed. The in-depth interview was followed by the administration of those PIB items not directly addressed in the interview and observed during the contact with the elderly subject. The time spent with each primary caregiver ranged from $1^{1}/2$ hours to $2^{1}/2$ hours. Within 1 hour of family contact, field notes were taken regarding the setting, the interview process and the investigator's impressions. This process was completed in 30 to 60 minutes.

CHAPTER III

FINDINGS

In reviewing the data, several findings were striking. The first was that the elderly subjects seemed to naturally fall into three groups based upon the type of care they required. The PIB was sensitive to these three groupings. The mean weighted score obtained by the investigator for Group I (N=3) was 22.0; Group II (N=4) was 32.75; and Group III (N=5) was 42.0.

Group I (N=3), the least impaired group was cognitively intact. They could attend to and complete the interview. The primary reasons for their being in the nursing home were mobility deficits and physical illnesses.

Group II (N=4), the middle group, had some cognitive impairment. They could not complete the interview but could converse. The conversations were loose, rambling, tangential and usually rooted in the past. The middle group had few physical disabilities and seemed to be in the nursing home because they wandered at night. Less restrictive placements such as foster care and homes for the aged had been unable to manage the need for nighttime care.

Group III (N=5), the most impaired group, had severe cognitive impairment. They were unable to participate in any conversation in a meaningful way. Their verbalizations included chanting names, swearing, one word utterances seemingly unconnected to anything in the environment and crying for no reason.

The second striking finding was that the state's weighted PIB scores were markedly different from those obtained by the investigator. Indeed, the group means were weighted in reverse order. (See Table 1).

Table 1

Comparison of Weighted PIB Score Means by Group

	State Evaluator	Investigator
Group I	27.67	22.00
Group II	23.00	32.75
Group III	22.60	42.00

The least impaired group, Group I had the highest mean score on the State's weighted PIB scores while Group III, the most impaired group had the lowest mean score. While the five point difference from highest to lowest mean scores is not significant in itself, the fact that the scoring trend was in opposite directions seemed significant. The individual weighted PIB scores are compared in Appendix F. The difference in time between the two administrations of the PIB ranged from 2 months to 7 months.

With the exception of one self-identification item, the PIB does not directly assess cognitive functioning. Because the three groups could objectively be differentiated on the basis of mental status alone and because the overall PIB scores were sensitive to the three groupings despite a lack of direct assessment of cognitive functioning, a subject by

TABLE 2

COMPARISON OF PIB ITEMS RELATED TO COGNITIVE FUNCTIONING

	Self-Identification				Social Activities				Emotional Control				Orientation for Living Alone				Managing Medications				Weighted Score Totals	
	Raw Score		Weighted Score		Raw Score		Weighted Score		Raw Score		Weighted Score		Raw Score		Weighted Score		Raw Score		Weighted Score			
Subject	S	I	S	I	S	I	S	I	S	I	S	I	S	I	S	I	S	I	S	I	S	I
Group I																					8.00	4.30
a	1	1	0	0	2	1	0	0	1	1	0	0	4	3	1	1	5	2	8	1		
b	1	1	0	0	4	2	1	0	2	2	0	0	5	3	4	1	1	5	0	8		
c	2	1	0	0	3	2	1	0	1	2	0	0	3	3	1	1	5	2	8	1		
Mean			0	0			0.7	0			0	0			2.0	1.0			5.3	3.3		
Group II																					6.25	12.25
d	1	1	0	0	3	2	1	0	1	2	0	0	4	4	1	1	2	5	1	8		
e	3	3	1	1	2	3	0	1	2	2	0	0	4	5	1	4	5	5	8	8		
f	2	2	0	0	2	2	0	0	2	2	0	0	4	5	1	4	1	5	0	8		
g	3	3	1	1	4	4	1	1	1	2	0	0	3	5	1	4	5	5	8	8		
Mean			0.5	0.5			0.5	0.5			0	0			1.0	3.25			4.25	8.0		
Group III																					9.20	13.00
h	2	5	0	1	3	3	1	1	2	2	0	0	4	4	1	1	4	5	2	8		
i	1	5	0	1	2	2	0	0	3	3	2	2	4	5	1	4	5	5	8	8		
j	1	4	0	1	2	3	0	1	1	2	0	0	4	5	1	4	5	5	8	8		
k	3	5	1	1	3	3	1	1	2	2	0	0	4	5	1	4	5	5	8	8		
l	3	5	1	1	3	3	1	1	1	2	0	0	4	4	1	1	5	5	8	8		
Mean			0.4	1.0			0.6	0.8			0.4	0.4			1.0	2.8			6.8	8.0		

S = state evaluator
I = investigator

subject analysis of the items related to cognitive functioning was undertaken. The investigator's results as well as the state evaluator's results were examined since the scores were so widely discrepant.

There were five items in the PIB which were related to cognitive functioning: 1) The self-identification item tested orientation to self and situation. 2) The social activities question looked at the ability of the elderly individual to meaningfully interact with others. This item had the potential to evaluate the elderly person's flow of thought and recent and remote memories. 3) The emotional control item appraised the presence or absence of any destructive tendencies. Person's judged to have difficult personality traits and elderly people in need of psychiatric attention scored higher on this item. 4) The orientation for living alone question examined the elderly person's ability to remember and carry out activities of daily living. A propensity to wander was included at the most impaired level of this question. 5) The managing medications item determined the ability of the elderly individual to remember and take one's own medication. A comparison of the scores of the state evaluator and the investigator on these five PIB items related to cognitive functioning is presented in Table 2.

A detailed description of the elderly subjects abilities in each of the five areas follows. The descriptions are organized by the three groupings. The detail is

provided in an effort to allow the reader to fully appreciate the cognitive difficulties experienced by each elderly individual. Following the description of the elderly subjects cognitive abilities, the impact of cognitive functioning on the decisions made regarding the elderly subject's placement in the nursing home will be presented.

Description of PIB Items Related to Cognitive Functioning

Group I

Subject a had no difficulty with self-identification or emotional control according to both raters. On the social activities item, the investigator found that the subject was involved regularly in activities with family, church and social organizations. The state evaluator disagreed, rating the subject as involved with only one of these groups. The investigator's rating was based on the subject's report of weekly audio tapes or phone calls from family members, weekly visits from a long time friend and her description of bi-weekly participation in Bingo games and church services as they came to the nursing home. She knew most of the nursing home residents and had several friends among them. Her interactions with the nursing home personnel were friendly and personal. Her social relationships appeared extensive and satisfying. The 1 point difference in raw PIB score did not produce a weighted PIB score difference.

On the orientation for living alone item, the raters agreed that the subject needed help with activities of daily

living. They disagreed about whether she was fully oriented or sometimes confused.

The investigator found the subject fully oriented and able to participate meaningfully in a 2 hour interview. The state evaluator rated the subject as sometimes confused. The nursing home administrator and nurse assigned to the elderly person validated the investigator's rating. The 1 point difference in raw PIB score did not yield a weighted PIB score difference.

The final item, managing medications, revealed widely discrepant assessment ratings. The investigator found that the subject could take her medications properly if they were laid out for her on a weekly basis. The state evaluator rated the elderly individual as completely unable to manage her own medications. The investigator's rating was based on the subject's correct recitation of her medication regime and her awareness of when her medications were due. Her limited vision required that the medications be laid out for her. The 3 point difference in raw PIB scores produced a 7 point weighted PIB score difference.

Subject b received identical scores from both raters on the self-identification and emotional control items. He could easily and appropriately identify himself. His infrequent frustrated outbursts posed no difficulty in the nursing home setting. On the social activities scale, the investigator rated him as involved regularly in activities with at least one group. The state evaluator scored the

elderly person as "will go to or be present at activities of at least 1 of these 3 kinds of groups (family, neighbor, other organization) if reminded and/or assisted to, but needs prompting and encouragement to actually participate or is responsive when visited by only a limited number of people". The investigator's rating was based on the subject's report of weekly visits from his wife and letters from his children. The wife's interview confirmed these occurrences. During the interview the elderly subject was friendly, outgoing, jovial and needed no encouragement to participate. The 2 point difference in raw PIB score produced a 1 point weighted PIB score difference.

On the orientation for living alone item, the investigator rated the subject as fully oriented but needing help with activities of daily living. The state evaluator disagreed finding the subject sometimes or frequently confused, needing reminders and/or help with activities of daily living and physically wandering off regularly. The investigator's rating was based on several facts. The elderly person did not demonstrate any confusion during the $1^{1}/2$ hour interview. The nursing home personnel assigned to the subject and the wife both reported no confusional periods. The subject was extremely hard of hearing, had limited vision and significant mobility deficits, all of which contributed to his need for assistance with activities of daily living. His long standing mobility deficits rendered him incapable of physically wandering off. The 2

point difference in raw PIB score resulted in a 3 point weighted PIB score difference.

The managing medications item finds the raters at opposite ends of the scale. It was a difficult item for the investigator to rate. The state evaluator found that the subject could manage his medications alone. The investigator agreed that he knew what to take and when, but his near blindness and severe mobility deficits rendered him incapable of managing his medications on his own. For the last 10 years, his wife had been administering his medications to prevent errors. The investigator therefore rated the item as "does not manage own medications, needs to have some medication administered to him/her by someone else regularly, and daily or more frequently". The item was difficult in that the couple did not need outside intervention to manage the medications, but the elderly subject did need his wife's help because of his physical disabilities. For this subject, the score on managing medications item reflects a physical impairment rather than a cognitive impairment. The 4 point difference in raw PIB score produced an 8 point weighted PIB score difference.

Subject c received identical scores from both raters on the orientation for living alone item. He was fully oriented but needed help with activities of daily living. The investigator also found the subject able to identify himself and his situation accurately and appropriately on the self-identification item. The state evaluator agreed

that the elderly person could identify himself but found him unable to adjust the information to the situation. The investigator's rating was based on the subject's ability to complete a hour long interview handling probes accurately and appropriately. The accuracy of his information was verified by his daughter. The 1 point difference in raw PIB score did not result in a weighted PIB score difference.

The raters evaluations were also discrepant on the social activities item. The investigator rated the elderly subject as involved regularly in activities with at least one group. The state evaluator found that the subject required reminding to be involved with one group. The investigator's rating was based on the subject's report of bi-monthly weekend outings with his sons. He spoke of them with great relish and knew when the next outing was to occur. The subject also had one roommate with whom he played cards and watched television. The 1 point difference in raw PIB score produced a 1 point weighted PIB score difference.

On the emotional control item, the investigator found that personal problems, disturbances and emotional states restricted the type of living arrangement possible for the subject but the situation was satisfactory in the nursing home. The state evaluator's rating denied the need for any restrictions on type of living arrangements. The investigator's rating was based on the knowledge that the decision to place him in a nursing home, instead of one of his

children's homes, was made because of his difficult personality style. The subject adamantly refused to comply with oxygen therapy and diet restrictions in his children's homes: He was the father and they had no business telling him what to do. He would, however, comply with the regime in the nursing home. The 1 point difference in raw PIB score did not produce a difference in weighted PIB scores.

The managing medications item produced widely discrepant scores between the raters. The state evaluator rated the subject as completely unable to manage his own medications. The investigator found that the subject knew what to take and when; his limited vision required that someone else lay the medication out for him weekly. The elderly individual did have some resistance to taking the medications and undoubtedly mismanaged them at times, but the cognitive ability to manage his medications was intact. The 3 point difference in raw PIB score produced a 7 point weighted PIB score difference.

Summary

Overall in Group I, out of 15 items there were 10 instances of rater disagreement resulting in a 19 point raw PIB score difference and a 27 point weighted PIB score difference. Nineteen of these weighted PIB score points yielded a higher score for the state evaluator. The remaining 8 weighted PIB score points resulted in a higher score for the investigator.

The state evaluator rated all three subjects confused on at least one item. The investigator found no evidence of confusion in any of the three subjects. Higher scores by the investigator were the result of physical and not mental impairments in this group.

Group II

Subject d received identical ratings from both the state evaluator and the investigator on the self-identification and the orientation for living alone items. She could identify herself accurately and appropriately but was sometimes confused and needed help with activities of daily living.

On the social activities item, the investigator found that the subject was involved regularly with at least one group. The state evaluator rated the subject as slightly more impaired, needing reminding or assistance to join a group activity. The investigator's rating was based on the subject's knowledge of the social activities available in the nursing home, the observation of friendly socializing with her roommate and her report of weekly letters from a friend in another state. The 1 point difference in raw PIB scores produced a 1 point difference in weighted PIB scores.

On the emotional control item, the state evaluator's rating was that the subject's personal problems, disturbances and emotional states did not restrict her type of living arrangement. The investigator found that the elderly individual's personal problems and emotional states did

restrict the type of living arrangement available to her but that the situation was satisfactory in the current set-up. The investigator's rating was based on the subject's foster care worker's report of mood lability and difficulty managing her during her confusional periods. The 1 point difference in raw PIB score did not produce a weighted PIB score difference.

The final item, managing medications, revealed widely discrepant scores. The state evaluator rated the subject as able to take her medication properly if it was laid out for her a week at a time. The investigator found the subject unable to handle her medications. The investigator's rating was based on the foster care worker's description of the subject's confusional episodes lasting several weeks in duration. The 3 point difference in raw PIB score produced a 7 point weighted PIB score difference.

Subject e received identical ratings from both evaluators on three of the items: self-identification, emotional control and managing medications. The subject could identify herself only sometimes or only partly. Her emotional control restricted the type of living arrangements available to her, but her current situation was satisfactory. The elderly person was unable to manage her own medications.

The raters disagreed on the social activities and the orientation for living alone items. Socially, the state evaluator rated the subject as involved regularly with at

least one group of people. The investigator found that the subject would participate in limited activities if reminded and encouraged to do so. The investigator's rating was based on a pervasive sense of fear emanating from the subject during a short interaction and the daughter's report of her mother becoming withdrawn and fearful after a traumatic assault 6 years earlier. The caregiver reported the subject was fearful and avoided other people. The 1 point difference in raw PIB score resulted in a 1 point weighted PIB score difference.

On the orientation for living alone item, ratings from both interviewers indicated that the subject was sometimes confused and needed reminders for activities of daily living. The difference in ratings was whether or not the subject physically wandered off. The state evaluator ruled that she did not wander while the investigator found that she did. The investigator's finding was based on the daughter's report of wandering as a 6 year problem and the observation that the elderly individual was indeed physically capable of wandering. Her mobility was excellent. The 1 point difference in raw PIB scores produced a 3 point weighted PIB score difference.

Subject f received identical scores from both raters on three items: self-identification, social activities and emotional control. She could identify herself accurately but could not adjust the data to the situation. She was involved in regular social activities with her family and

her level of emotional control restricted the type of living arrangement available to her but was not a problem in the nursing home.

On the orientation for living alone item, both raters agreed that she was sometimes confused and needed reminders for activities of daily living. Whether or not the elderly subject physically wandered off was the issue. The investigator's positive rating was based on the daughter's report of both day and nighttime wandering for several years. The 1 point difference in raw PIB score produced a 3 point weighted PIB score difference.

On the managing medications item, the raters scores were widely discrepant. The state evaluator rated the subject as needing no medication. The investigator rated the elderly individual as unable to manage her medications. The daughter stated that the subject was on no medication for physical problems, but that she required medication occasionally for agitation or sleep. The fact that the subject was cognitively unable to manage any medications was the basis for the investigator's rating. The 4 point difference in raw PIB score produced a 7 point weighted PIB score difference.

Subject g received identical ratings on three items: self-identification, social activities and managing medications. She could identify herself only sometimes or only partly. She was involved regularly in activities with her family and she was unable to manage her own medication.

The state evaluator rated the subject's personal problems, disturbances and emotional states as not restricting the type of living arrangements available to her. The investigator found that they did restrict her living arrangement options but that the situation was satisfactory in the nursing home. The investigator's rating was based on the son and daughter-in-law's report of a dramatic, demanding individual who became physically aggressive and verbally abusive whenever she did not get that to which she felt entitled. This behavior was described as longstanding. The 1 point difference in raw PIB score did not produce a weighted PIB score difference.

On the orientation for living alone item the state evaluator rated the subject as fully oriented but needing help with activities of daily living. The investigator found the subject frequently confused, needing help with activities of daily living, and wandering off sometimes. The investigator's rating was based on the son's report that his mother frequently did not recognize him and rarely remembered his visits. The nursing home personnel had stated prior to the interview that the investigator might or might not be able to talk with the subject depending on her level of coherence that day. The 2 point difference in raw PIB scores resulted in a 3 point difference in weighted PIB scores.

Summary

Overall in Group II, out of 20 items, there were 9

instances of rater disagreement resulting in a 15 point raw PIB score difference and a 26 point weighted PIB score difference. Twenty-five of these weighted PIB score points yielded a higher score for the investigator. The remaining 1 weighted PIB score point resulted in a higher score for the state evaluator.

All of the subjects demonstrated some cognitive impairment on at least one item according to both raters. The investigator rated the cognitive deficits as more severe than the state evaluator.

Group III

Subject h received identical scores from both raters on three items: social activities, emotional control, and orientation for living alone. She could participate in a group activity if reminded or assisted to do so. Her emotional states restricted the type of living arrangement possible for her but the situation was satisfactory in the nursing home. The elderly subject was confused and needed help with her activities of daily living but she could not physically wander off. It is interesting to note that prior to her most recent cerebrovascular accident two months ago, the elderly individual did physically wander off regularly and had been doing so for 6 years according to her daughter. The state evaluator's rating was made prior to the cerebrovascular accident, before independent mobility became impossible. Thus, while the ratings are identical they do not reflect similar assessments.

On the self-identification item the raters disagree. The state evaluator rated the elderly subject as able to accurately identify herself but without adjustment to the situation. The investigator found the subject aphasic, unable to verbally communicate in any meaningful fashion. The difference in assessments is easily explained by the cerebrovascular accident which occurred between the two interviews. The 3 point difference in raw PIB score produced a point difference in weighted PIB score.

The final item, managing medications, also produced discrepant ratings. The raters agreed that the patient was unable to manage her medications. The state evaluator's rating reflects a less than daily need to take medications while the investigator found a need for daily medications. The investigator's rating was based on the daughter's report of the elderly individual being on Orinase and Digoxin daily for many years. The 1 point difference in raw PIB score resulted in a 6 point difference in weighted PIB score.

Subject i received identical ratings on three items: social activities, emotional control items, and managing medications. She was involved in regular activities initiated by her family. She was unable to manage her own medications and her emotional states restricted the type of living arrangement available to her. The elderly individual has had personality conflicts and instances of physical aggression for the past four years. At times the nursing

home personnel felt she was becoming more than they could handle.

The raters' assessments of the elderly person's ability to identify herself are widely discrepant. The state evaluator rated the subject as able to identify herself accurately and appropriately, adjusting the information to the situation. The investigator found the subject completely unable to identify herself. When asked her name, the elderly individual smiled at the investigator blankly. The family stated she was too confused to even know who they were most of the time. The family described a gradual deterioration in orientation over the past four years. There were no intervening variables between the two ratings sufficient to explain the discrepancy. The 4 point difference in raw PIB score produced a 1 point weighted PIB score difference.

On the orientation for living alone item, both raters agreed that the elderly person was confused and needed assistance with activities of daily living. The state evaluator rated the subject as not physically wandering off while the investigator found that she did wander. The investigator's assessment was based on the observation that the elderly individual required posey restraints both in and out of bed to prevent wandering and falling. The family reported that wandering had been a problem for four years now. The 1 point difference in raw PIB score resulted in a 3 point difference in weighted PIB score.

Subject j received concordant ratings on only one item, managing medications. She was totally unable to manage her own medications.

The self-identification item produced discrepant ratings. The state evaluator stated that the individual could accurately and appropriately identify herself. The investigator found that the subject knew her name but not her whereabouts or the decade. She would respond to her name but did not offer it. The granddaughter who had lived with the elderly subject prior to her nursing home admission stated her grandmother had not been aware of her surroundings and had not recognized family members for about 6 months. The 3 point difference in raw PIB scores resulted in a 1 point weighted PIB score difference.

On the social activities item, the state evaluator rated the elderly subject as regularly involved in activities with at least one group. The investigator found that the elderly person would participate in a group if she was reminded and assisted to do so. If taken to a nursing home activity, the subject would participate, but she could not anticipate activities or remember them once they occurred because of her severe memory deficits. The 1 point difference in raw PIB scores resulted in a 1 point difference in weighted PIB scores.

The emotional control item also produced discrepant ratings. The state evaluator rated the subject's emotional control sufficient to not restrict placement options. The

investigator found that her emotional states did restrict the options available to her but the situation was satisfactory in the nursing home. During the assessment visit, the elderly person was observed to cry without any apparent precipitant and without apparent sadness. The crying started and stopped abruptly. The granddaughter stated this had been a frequent occurrence for the past 6 years. The 1 point difference in raw PIB scores did not result in a weighted PIB score difference.

The final item, orientation for living alone, found the raters agreeing that the elderly person was confused and needed assistance with activities of daily living. The state evaluator rated the subject as not prone to physically wander away while the investigator found that she did wander. The investigator's rating was based on a statement by the nursing home personnel regarding the need for posey restraints to keep the elderly subject from vacating her wheelchair and either falling or getting lost or both. The 1 point difference in raw PIB scores produced a 3 point weighted PIB score difference.

Subject k received identical ratings in three items: social activities, emotional control and managing medications. She would participate in a group activity if reminded and assisted to do so. Her emotional states, while restricting the placement options available to her, were not a problem in the nursing home. The elderly subject was not able to manage her medications.

In the self-identification area, the raters agreed a deficit was present but the magnitude of the difficulty was rated higher by the investigator. The state evaluator placed the subject's ability at "identifies self sometimes, or only partly." The investigator's rating was "does not state name/address/phone number information accurately and appropriately, does not use ID for these purposes." The investigator's rating was based on several pieces of data. Her wheelchair contained a written reminder for her of her name and room number. The charge nurse and the elderly subject's caregivers all stated she often forgets her name as well as where she is. The elderly subject could not tell me where she was or what year it was. Despite the 2 point difference in raw PIB scores, the weighted PIB scores were identical.

Orientation for living alone, the final item, produced discrepant ratings. The raters agreed that the elderly person was confused and needed assistance with activities of daily living. The discrepancy was whether the subject physically wandered off: the state evaluator stated that she did not wander while the investigator found that she did. The investigator's rating was based on the ease with which the subject physically moved and the son and daughter-in-law's report of frequent nighttime wanderings. The 1 point difference in raw PIB scores resulted in a 3 point weighted PIB score difference.

Subject 1 received identical ratings on three items: social activities, orientation for living alone and managing medications. She would participate in a group activity if reminded and assisted to do so. The elderly person was unable to manage her medications and she was frequently confused, needing assistance with activities of daily living. She could not physically wander off when the investigator saw her because of mobility deficits secondary to several recent cerebrovascular accidents. Prior to these cerebrovascular accidents the daughter reported frequent wanderings, both daytime and nighttime, precipitating the subject's admission to the nursing home. The cerebrovascular accidents occurred between the raters interviews. Thus, while the scores are identical, the data bases from which they were drawn were very different.

On the self-identification item, the state evaluator found that the subject could identify herself only sometimes or only partly. The investigator found the subject to be completely disoriented to person, place and time. She stated to the investigator that she was born in Iowa, then changed her answer to "right here". The investigator probed this response with "You were born in this nursing home?", to which the subject replied in the affirmative. The daughter noted a decline in orientation and mental status 2 to 3 months ago. This was the time frame within which a series of small strokes occurred. Since the two interviews were almost 7 months apart, this is the most likely explanation

for the discrepant ratings. Despite a 2 point difference in raw PIB scores, no difference in weighted PIB score resulted.

The final item, emotional control demonstrated discrepant assessments. The state evaluator rated the subject as in sufficient control of her emotional states to permit unrestricted living arrangements. The investigator found that the elderly person's emotional states and disturbances did restrict the type of living arrangements available to her, but that the situation was manageable in the nursing home setting. The investigator's rating was based on the daughter's report of the subject's personality conflicts, neighborhood disturbances and recent instances of hitting people. The 1 point difference in raw PIB scores did not produce a weighted PIB score difference.

Summary

Overall in Group III, out of 25 items, there were 12 instances of rater disagreement resulting in a 21 point raw PIB score difference and a 19 point weighted PIB score difference. All of the differences in weighted PIB score points resulted in a higher score for the investigator. In two instances a cerebrovascular accident occurred between the two ratings. This accounted for the wide differences in self-identification scores but it did not account for why the orientation for living alone scores were identical. Had the cerebrovascular accidents not occurred, the scores would still have been discrepant.

Impact of Cognitive Functioning on Nursing Home Placement

The reasons given for placing an elderly person in a nursing home fell into two groups. Those elderly individuals whose cognitive functioning was not impaired had mobility problems that precluded them from living alone. They also lacked a primary caregiver who was available and physically able to assist with mobility activities. One elderly woman's only child married and moved to Alaska with her new husband. One elderly spouse could no longer effectively assist her 200 pound husband with transferring activities. This couple's three children lived 350 miles away. The final cognitively intact elderly subject had severe personality conflicts with all of the female members of his family rendering their homes unavailable to him except as a visitor. He was placed in a nursing home after three instances of hospitalization with pulmonary crisis in 6 weeks because of diet and medication mismanagement.

The caregivers of the elderly individuals whose cognitive functioning was impaired all reported a similar cluster of reasons for deciding to utilize the nursing home. All of the elderly subjects had been confused prior to admission. The length of time from the onset of confusion to the decision to utilize the nursing home ranged from 2 years to 17 years with a mean of 6.9 years. According to the primary caregivers, they did not consider nursing home placement until the confusion became coupled with some sort of dangerous behavior such as falling or wandering. All of

the cognitively impaired elderly subject had a recent history of falling with five of the nine subjects breaking bones. All of them also had no sense of daytime or nighttime resulting in their frequently being up at night. Wandering was a problem for eight of the elderly individuals. Families typically were able to cope with confusion, wandering and/or falling behaviors until their elderly members lost their sense of time. Once the elderly person required monitoring 24 hours a day for dangerous behavior, the family sought outside placement. Deficits in mobility, continence and other activities of daily living were not mentioned as reasons for deciding that nursing home placement was necessary. All of the cognitively impaired elderly subjects had a female caregiver available and able to assist with activities of daily living.

Summary

Intact cognitive functioning did not preclude nursing home placement. The lack of an available primary caregiver who was physically able to assist with mobility activities resulted in two nursing home admission. Personality conflicts with available caregivers precipitated the final admission.

Cognitive impairment alone was not a sufficient condition to precipitate nursing home admission. Only when the elderly person's level of care required monitoring for dangerous behavior and was coupled with a disorientation to time was a nursing home considered.

CHAPTER IV

DISCUSSION, SUMMARY AND CONCLUSIONS

This final chapter discusses the study results. For each of the three research questions the findings will be examined and related to the literature review. The study will conclude with a discussion of the implications of the findings and suggestions for future research.

Discussion of Findings for Research Question One

Research question one was concerned with the comparison of the investigator's and a state evaluator's ratings on the PIB items that assess cognitive functioning (See Table 2). The results revealed the highest level of agreement between the two raters on the emotional control item (58%) and the least agreement on the orientation for living alone item (33%). The remaining items had a 50% agreement rate between the raters.

The emotional control item is constructed to screen for harmful or disruptive behaviors such as angry outbursts, hitting others, or suicidal and homocidal tendencies. A score of 3 or higher indicates the need for psychiatric hospitalization. The elderly individuals in nursing homes generally scored 1 or 2 on this item. The limited range of options on this item undoubtedly contributed to the higher concurrence between the raters.

The high rate of disagreement (67%) on the orientation for living alone item usually centered around whether or not the subject had a propensity to wander. It is interesting

to note that in two of the instances of rater agreement on this item a cerebrovascular accident had occurred between the evaluations. Had the physical illness not occurred, these ratings would also have been discrepant, producing an 83% disagreement rate. The propensity to wander cannot be assessed directly with any accuracy. This finding is consistent with the study by Reifler, et al. (1981), who reported that cognitively impaired persons saw themselves as suffering no significant problems in activities of daily living when professional persons and family caregivers saw major difficulties. The investigator had the advantage of multiple sources of data. The state evaluator may not have had the time or the opportunity to confer with other data sources.

The social activities item and the managing medications item both had 50% agreement rates between the two evaluators. Generally, the more cognitively impaired the elderly person was, the more the raters agreed. On the self-identification item which also had a 50% agreement rate, the opposite is true; the more cognitively impaired the elderly individual was, the less the raters scores were in agreement. A small portion of the difference on the self-identification item was explained by an intervening physical illness between ratings, but the overall magnitude of the differences is great.

The reasons for scoring differences between the raters may be explained by the different purposes for which the

instrument was used (Kane, et al., 1981a). The state evaluator's score carried clinical implications for the elderly individual. Because the scores had implications for placement and service decisions, the state evaluator may have manipulated the scoring to secure needed services for the client. The investigator's ratings had no direct clinical implications for the elderly person. Because the scores were part of a research assessment, accuracy was given highest priority. The investigator also had the advantages of multiple sources of information and few time constraints. The fact that this was an exploratory study freed the investigator from the bias of attempting to prove or disprove an hypothesis. The differences in rater background and orientation to cognitive dysfunction may also explain some of the variability in scoring.

Thus, the comparison of the investigator's and the state evaluator's ratings on the PIB items that assess cognitive functioning demonstrated poor interrater reliability. The most likely explanations of this phenomenon are differing implications of the scores, differing time constraints and differing backgrounds and orientation of the raters.

Discussion of Findings for Research Question Two

Research question two addressed the sensitivity of the PIB to cognitive impairment in the elderly subjects. The investigator's weighted score totals presented in Table 2 demonstrated a sensitivity in the PIB to the presence of

cognitive impairment. The state evaluator's scores did not reflect any difference among the three groups. The investigator's weighted score totals reflect a major difference between the cognitively intact elderly in Group I (4.3) and the cognitively impaired elderly in Groups II and III (12.25 and 13.00, respectively). The minute difference between Group II and Group III suggests that while the PIB is sensitive to the presence of cognitive impairment, it is not sensitive to the degree of impairment.

The group means on the self-identification and social activities items demonstrated graduated differences among the groups. With the exception of one elderly individual's score, the emotional control item did not discriminate among any of the groups. The orientation for living alone item differentiated the cognitively intact from the cognitively impaired. While it also distinguished between the two cognitively impaired groups, Group II, the least impaired group scored higher than Group III because of a better physical ability to wander. The final item, managing medications was able to differentiate between the cognitively intact Group I and the cognitively impaired Groups II and III. It did not distinguish between the levels of impairment present in Groups II and III. Thus, relative to distinguishing cognitive functioning, the emotion control item had no value; the orientation for living alone and managing medications items could discriminate only between the presence or absence of cognitive impairment; and the

self-identification and social activities items demonstrated an ability to differentiate among the three levels of cognitive functioning.

Discussion of Findings for Research Question Three

Research question three was concerned with the comparison of the cognitively impaired and the non-cognitively impaired elderly subjects with respect to the factors which impacted on nursing home placement decisions. All of the elderly subjects had mobility deficits ranging from infrequent falling to total inability to maneuver without the constant assistance of another person. This supports the literature reports of mobility and transferring activities being troublesome for the elderly in nursing homes (Kane, et al, 1981b; Smallegan, 1981). The cognitively intact group cited mobility deficits as a primary reason for nursing home placement. Other physical problems were also mentioned, supporting the finding that health status can be critical in deciding to utilize a nursing home (Foley, et al., 1980; Kraus, et al., 1976a). However, with the exception of falling, mobility deficits and health status were not mentioned by any of the caregivers of the cognitively impaired elderly as a reason for nursing home placement. The difference between the two groups was the availability and physical ability of a female caregiver to compensate for the health and mobility deficits of the elderly person. The cognitively intact elderly had no such person available while the cognitively impaired subjects all had an able

female caregiver. This finding strongly supports the literature report of the importance of social support as a buffer between community residence and institutionalization (Barney, 1977; Brody, 1966; Callahan, et al., 1980; Kraus, et al, 1976b; Lawton, 1981; Lefroy, 1978; McAuley, et al., 1981; Smallegan, 1981; Stoller, et al., 1977).

The families of the cognitively impaired elderly consistently tolerated confusion, wandering and/or falling behaviors until the elderly person lost his/her sense of time. Once the elderly individual required monitoring 24 hours a day for dangerous behavior, the family sought outside placement. Potentially harmful behaviors such as wandering are reflected in the literature as difficult for families to manage (Haley, 1983; Reifler, et al., 1981; Ross, Kedwood, 1977). The notion that the magnitude of the difficulty may be linked to the elderly person's orientation to time has not been reported.

Thus, the factors which impact on the decision to utilize a nursing home were different for the cognitively intact elderly than the cognitively impaired elderly. Without an able female caregiver, mobility deficits and health problems led to nursing home placement regardless of cognitive functioning. When a female caregiver was present, the precipitant to nursing home admission was confusion coupled with dangerous behavior such as falling or wandering and a disorientation to time.

Summary and Conclusions

This study has examined the sensitivity of the PIB to cognitive impairment and the impact of cognitive functioning on the decision to utilize nursing home placement. While the PIB was shown to be somewhat sensitive to the presence of cognitive impairment, it was not able to discriminate levels of impairment. Intact cognitive functioning did not preclude nursing home placement in this study. It was shown that the lack of an available female caregiver who was physically able to assist with mobility activities was the main factor in these nursing home admissions. Cognitive impairment alone was not a sufficient condition to precipitate nursing home admission. Only when the elderly person's level of care required monitoring for dangerous behavior and was coupled with a disorientation to time was a nursing home considered.

Implications for Practice

This study suggests that while the PIB is somewhat sensitive to cognitive impairment it is unable to discriminate the degree of impairment sufficiently to be used with confidence in functional assessments. It also suggests that the instrument should be revised to include an item which reflects the presence of dangerous behavior such as wandering, in conjunction with a disorientation to time. Since this symptom cluster was identified as the primary precipitant to nursing home admission in families actively involved in home caregiving, the new item should be weighted heavily.

The presence of mobility deficits in cognitively intact elderly individuals without an able primary caregiver should alert clinicians to the possible request for nursing home admissions. Since these elderly individuals do not require 24 hour monitoring, community alternatives such as family foster care and homes for the aged might be more appropriate placements.

Suggestions for Future Research

The directions for further research derived from this study are aimed at improving the ability of the PIB to assess cognitive functioning and at identifying those factors predictive of the need for nursing home placement.

1) Revise the PIB to include an assessment of dangerous behaviors associated with a disorientation to time. Retest the PIB's sensitivity to cognitive impairment.

2) Compare the ability of the PIB to screen for cognitive impairment with an instrument that directly assesses cognitive functioning such as Grauer and Birnbom's Geriatric Functional Rating Scale (1975).

3) Compare the ability of the PIB to reflect the need for nursing home placement with the Geriatric Functional Rating Scale.

4) Test the ability of the symptom cluster, dangerous behavior and disorientation to time, to predict nursing home admission using both community and nursing home samples.

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APPENDIX A

PLACEMENT INFORMATION BASE (PIB)

Oregon Department of Human Resources FIG/Waiver Project PLACEMENT INFORMATION BASE (PIB) 6/15/79

Person Code: Observer Code: Date:

INSTRUCTIONS: For each scale, choose and write in the answer space that one level which, from your observation and knowledge of the person, and/or conversation with him or her, best describes how the person is usually functioning these days. When you are not sure which of several levels to choose, because the wordings of two or more levels seem to fit the person's usual function about equally well, or because the person regularly varies among levels, select the higher numbered level. If you cannot make a reasonable choice after attempting to get the information, write a zero (0) in the answer space.

Cluster One: Communication

1. ( ) SELF-IDENTIFICATION
   1. Individual states name, address, phone number, time, and place accurately and appropriately, and communicates information fluently and with detail appropriate to the situation.
   2. States name, address, phone number, accurately and appropriately, but without adjustment to the situation, or uses I.D. for these purposes.
   3. Identifies self only sometimes or only partly.
   4. Hardly ever identifies self, even with I.D., or does so inaccurately at least some of the time.
   5. Does not state name/address/phone number information accurately and appropriately, does not use I.D. for these purposes.
2. ( ) VISION (with glasses, if used – if the person is confused, make the best estimate you can)
   1. Normal or minimal loss, without glasses, or with old prescription. Sees adequately in most situations; can see newsprint, public notices, television, medication labels.
   2. Normal or minimal loss, with glasses prescribed within the last year.
   3. Moderate loss, can read large print, see simple pictures, and see obstacles, but not details, usually can count fingers at arm's length.
   4. Severe loss, cannot find way around without feeling or using cane, cannot locate objects without hearing or touching them; can tell light from dark.
   5. Total blindness. No vision at all. Cannot tell light from dark.
3. ( ) HEARING (with hearing aid, if used – if the person is confused, make the best estimate you can)
   1. Normal or minimal loss, without hearing aid or with old prescription. Hears adequately in most situations, can carry on an unrestricted conversation or otherwise responds appropriately to being addressed without speaker raising voice or altering normal pace and style of diction in groups as well as one-to-one; TV or radio; addressed from behind; etc.
   2. Normal or minimal loss, with hearing aid prescribed or with correction rechecked within the last three years.
   3. Moderate loss, hears adequately only in special situations, i.e., one-to-one, with firm, clear diction, raised volume of radio, etc.
   4. Severe loss, hears with difficulty even in special situations, i.e. conversation restricted, many misunderstandings, or frequently fails to respond, etc.
   5. Total deafness, no hearing at all useful for communication.

Cluster Two: Mobility

4. ( ) TRAVEL (by those means which are available and accessible)
   1. Uses private and public transportation properly and appropriately, on own. Can drive safely.
   2. Uses public transportation properly and appropriately, with a little help. Cannot or should not drive.
   3. Uses public transportation for both short and long trips with a moderate amount of help.
   4. Manages short trips with moderate assistance, but totally dependent on others for long or unusual trips.
   5. Totally dependent on help from others when any travel is necessary.
5. ( ) MOBILITY, WITHOUT AIDS (the extent to which the individual gets around alone, without aids: walker, cane, wheelchair).
   1. Has no difficulty and takes regular outside walks for exercise.
   2. Walks or gets around without difficulty both inside and outside.
   3. Walks or gets around easily inside, can get to various rooms alone, but needs some help outside.
   4. Gets around in own room, but needs assistance beyond that.
   5. Does not get around, even in room, without continuous assistance by another person.
6. ( ) MOBILITY WITH AIDS (the extent to which the individual gets around alone, using whatever aids (walker, cane, wheelchair) he/she has).
   1. Walks or gets around without difficulty both inside and outside.
   2. Walks or gets around easily inside, can get to various rooms alone, but needs some help.
   3. Gets around in own room, but needs assistance beyond that.
   4. Gets around in room, but uses wheelchair and needs help to transfer; may or may not need assistance to go further.
   5. Does not get around, even in room, without continuous assistance by another person.

Cluster Three: Household and Food Management

7. ( ) HOUSEKEEPING
   1. Takes complete care of his/her living space and that of others in living situation.
   2. Takes care of his/her own living space, both light and heavy work.
   3. Consistently manages own light housekeeping, but not heavy work.
   4. Does light housekeeping, but inconsistently or inadequately.
   5. Does not take care of own living space.
8. ( ) PERSONAL SHOPPING (gets such items as newspapers, toilet articles, snack foods, within physical limitations and any other restrictions)
   1. Does personal shopping regularly and properly without assistance or reminding.
   2. Does personal shopping without help, but must be reminded from time to time.
   3. Does personal shopping without help, but must always be reminded.
   4. Needs assistance from another person to get some items.
   5. Another person gets all items.
9. ( ) SHOPPING FOR AND PREPARING FOOD
   1. Does food shopping and preparation of meals.
   2. Shops with help; usually prepares meals.
   3. Does not shop, but usually prepares meals.
   4. Does not shop; prepares meals about half the time.
   5. Does not shop or prepare meals, or needs special diet, does not prepare it.
10. ( ) NUTRITIONAL HABITS
   1. Eats three meals a day; daily, eats at least two servings of each of (a) fruits, (b)vegetables, (c) whole grain products, (d)fish, poultry, or meat, and (e) dairy products.
   2. Eats three meals a day; daily, eats at least one serving of each of (a) fruits, (b) vegetables, (c)whole grain products, (d) fish, poultry, or mean, each day, and (e) dairy products.
   3. Eats three meals,a day; but usually omits at least one of (a) fruits, (b) vegetables, (c) whole grain products, (d) fish, poultry or meat, each day, and (e) dairy products.

11.( ) EATING (with special equipment if regularly used)

1. Feeds self, chews and swallows solid foods without difficulty.
2. Feeds self, chews and swallows solid foods which have been cut or pureed.
3. Needs assistance with feeding, but chews and swallows solid foods (which may have to be cut or pureed)
4. Needs assistance with feeding and has difficulty with chewing or swallowing, even with food cut or pureed. May need to be fed by tube.
5. Must be fed intravenously.

Cluster Four: Social and Emotional

12.( ) SOCIAL ACTIVITIES

1. Involved regularly in activities with (a) family, (b) neighbors, and (c) church/fraternal/occupational/social/political organization(s). Extensive and satisfying social relationships.
2. Involved regularly in activities with at least one of these three kinds of groups.
3. Will participate in activities with at least one of these three kinds of groups if reminded and/or assisted to do so; only some of the relationships may be satisfying.
4. Will go to or be present at activities of at least one of these three kinds of groups if reminded and/or assisted to, but needs prompting and encouragement to actually participate; or is responsive when visited by one of only a limited number of people.
5. Not willing to go to activities of any of these kinds of groups, nor to be involved if present at them. Is not responsive to visitors, no social relationships.

13.( ) PERSONAL INDEPENDENCE

1. Accepts change: actively adapts, makes plans, handles crises well, is confident.
2. Accepting, but needs some help in adapting and making plans and decisions.
3. Actively resistive; refuses to make decisions; consistently negative or hostile.
4. Neutral or passive. Requires regular assurance and/or guidance.
5. Withdrawn, afraid, or insecure; needs near constant support.

14.( ) EMOTIONAL CONTROL

1. Personal problems, disturbances, emotional states do not particularly restrict the individual's type of living arrangement and companions.
2. Personal problems, disturbances, emotional states restrict individual's type of living arrangement and companions, but things work out O.K. in present set-up.
3. Personal problems, disturbances, emotional states restrict the type of living arrangement and companions, and things are not working out O.K. in present set-up.
4. Person is dangerous or violently abusive to self or others, but is controllable with medications.
5. Person is dangerous or violently abusive to self or others, not controllable with medications, requires physical restraints.

15.( ) TELEPHONE

1. Makes and takes calls appropriately, fluently, with normal frequency.
2. Makes and takes calls appropriately, but infrequently.
3. Makes few calls, but takes calls and handles most of them appropriately.
4. Makes few or no calls, but takes some calls and handles at least some appropriately.
5. Neither makes nor takes calls appropriately.

16.( ) ORIENTATION FOR LIVING ALONE (Oriented means: explains details of care, if any; reasons for it; how long it will be needed. Responsible means actually does the tasks he or she is supposed to do as part of the care).

1. Fully oriented and responsible for care of self, if needed.
2. Fully oriented but needs to be checked up on one or twice a day.
3. Fully oriented but needs help with activities of daily living.
4. Is sometimes confused, needs reminders and/or help for activities of daily living, but does not physically wander off.
5. Is sometimes or frequently confused, needs reminders and/or help for activities of daily living, and physically wanders off regularly.

17.( ) NATURAL SUPPORT (friends/family/neighbors/volunteers)

1. One or more persons available to give care indefinitely.
2. One or more persons available to give care regularly for several months.
3. One or more persons available to give care from time to time for several months.
4. Several persons available to help out, one at a time or in rotation, from time to time, but there is no one to take overall responsibility for helping on a regular basis.
5. No person available to help except perhaps under extreme circumstances.

18.( ) PERSONAL ACTIVITIES

1. Spends most of the time each day in a variety of personal activities, including reading, hobbies, crafts, occupations (not including passive entertainment.)
2. Spends most of the time each day in a limited set of personal activities (other than passive entertainment).
3. Spends mornings, afternoons, or evenings each day in personal activities (other than passive entertainment).
4. Spends 1 to 2 hours a day in personal activities (other than passive entertainment).
5. Spends less than an hour a day in personal activities (other than passive entertainment).

Cluster Five: Finances

19.( ) MONEY MANAGEMENT

1. Writes checks, pays bills without any help. Keeps expenses within income.
2. Writes checks, pays bills without any help, but needs some advice or help each month to balance checkbook or perform similar tasks.
3. Manages day-to-day buying, but needs help with writing checks and/or paying bills.
4. Can handle purchasing of some personal items, but cannot handle all day-to-day buying.
5. Completely unable to handle money.

Cluster Six: Health

20.( ) HEALTH CONDITION

1. Excellent or good physical health; no significant illnesses or disabilities; only routine health care such as annual checkups.
2. Mild health problems needing short-term attention or corrective measures (wounds requiring dressing changes, bed sores, etc.)
3. Has one or more moderate medical problems which may be painful or which require medical attention periodically (gets dizzy on movement, etc.)
4. Highly impaired, confined to bed, requires full time medical assistance or nursing care to maintain certain vital bodily functions (for example, turning for pressure relief and repositioning because of stroke, paralysis, weakness, or other reason)
5. Unconscious, unable to respond, needs total care for all bodily functions.

21.( ) MANAGING MEDICATIONS (Consider the person's currently prescribed oral, topical, and injectable medications. Select the one category which fits best).

1. Needs no medications; or if needs them, manages medications alone. Knows what to take, takes them at correct times, keeps them properly.
2. Medications must be laid out for him/her each week, but no problems taking correct ones at correct times.
3. Must be given direct daily reminders, but follows them.
4. Does not manage own medications, needs to have some medication administered to him/her by someone else regularly but less than daily.
5. Does not manage own medications, needs to have some medication admisistered to him/her by someone else regularly, and daily or more frequently.

Cluster Seven: Self-Care

22.( ) GROOMING AND DRESSING

1. Grooms and dresses self without any help. Combs hair, does nails, manages buttons, ties shoes, etc.
2. Grooms and dresses self without any help, but must be reminded to do so on some days.
3. Grooms and dresses self without any help, but must always be reminded to.
4. Needs help from another person to do some parts of grooming, or some parts of dressing, such as managing buttons or tying shoes; may or may not need reminding.
5. Needs help from another person to do all of grooming, or all of dressing, or both, and or may not need reminding.

23.( ) BATHING OR SHOWERING

1 1. Bathes or showers self regularly, without reminders and without help for any task including turning the water on and off.
2. Bathes or showers self without any help, but must be reminded at least some of the time.
3. Bathes or showers self, but must have help for turning the water on and off.
4. Bathes or showers self, but must have help for more than turning the water on and off.
5. Does not do any part of bathing or showering, requires another person to do everything.

24.( ) USING TOILET

1. Gets to and from toilet, adjusts clothes, cleans self, etc., without help.
2. Needs help getting to toilet, but needs no other help.
3. Gets to toilet, but needs some help once there.
4. Gets to toilet, but needs total help.
5. Does not use toilet, Neither gets there, nor handles function without at least some help.

25.( ) CONTINENCE (To what extent are the individual's natural excretory functions under personal control, day and night, whether naturally or with ostomy, catheter, etc; aid means having another person give an enema, insert a suppository, clean an appliance, etc.)

1. No accidents, or infrequent accidents; no problesm, needs no help or aid.
2. Accidents one or twice a week, or needs help or aid once or twice a week.
3. Accidents three to five times a week, or needs help or aid three to five times a week.
4. Needs assistance regularly (daily or more frequently) with specific parts of activity.
5. Needs moderate to great assistance. Someone must be present every time to assist with all, or nearly all, parts of the activity.

APPENDIX B

GUIDELINES FOR WEIGHTING PIB SCORES

A=0
B=1
C=2
D=4
E=8

	Personal and Social Functions Relevant to Long-term Care Assessment Instrument	Levels of Function 1	2	3	4
Communication	1. Can identify self (or use I.D.)	A	A	B	B
	2. Vision (with glasses, if used)	A	A	B	B
	3. Hearing (with hearing aid, if used)	A	A	B	B
Mobility	4. Travel (by public or private means)	A	A	B	B
	5. Mobility (without walker, cane, wheelchair)	A	A	B	B
	6. Mobility, with aids (walker, cane, wheelchair, do not respond if aids not needed)	A	B	B	B
Household & Food Management	7. Housekeeping (vacuums, dusts, dishes, chores)	A	A	B	B
	8. Personal shopping (newspapers, toilet articles, snack foods)	A	B	B	B
	9. Shopping for and preparing food	A	B	B	B
	10. Nutritional habits (food selection, balance, amount)	A	B	B	B
	11. Eating (with special equipment if regularly used)	A	B	B	B
Social & Emotional	12. Social activities (family, neighbors, church/ fraternal/occupational/social/political groups)	A	A	B	B
	13. Personal independence (acceptance of changes, handling crises and decisions positively)	A	A	B	B
	14. Emotional control (personal problems, disturbances, emotional states do not restrict living arrangements and relationships with others; not dangerous to self or others).	A	A	C	C
	15. Use of telephone (making and taking calls)	A	A	A	C
	16. Orientation for living alone (can explain details of self-care needed, reasons, duration; and is responsible for following regime without reminding)	A	B	B	B
	17. Natural support (regular availability of reliable help from family, friends, neighbors or volunteers)	A	A	B	B
	18. Personal activities (spends substantial part of each day on reading, hobbies, crafts, occupations, etc., not including passive entertainment	A	A	A	B
Finances	19. Money management (writing checks, paying bills, keeping expenses within income)	A	B	B	B
Health	20. Health condition (general physical status, absence of significant illness or disability)	A	C	C	C
	21. Managing medications (knows what to take, takes at correct times, keeps medications properly, needs no help or reminding. Do not respond if medication not needed)	A	B	B	C
Self-Care	22. Grooming and dressing (clothes, buttons, shoes, hair and nails)	A	B	B	B
	23. Bathing or showering (can do without help from others)	A	B	B	B
	24. Using toilet (can do without help from others)	A	B	B	D
	25. Continence (no accidents, whether naturally or with ostomy, catheter, etc., if present; no need for help from others for enema, suppository, etc.)	A	B	D	D

APPENDIX C

FOCUSED IN-DEPTH INTERVIEW

WITH ELDERLY INDIVIDUAL

OREGON HEALTH SCIENCES UNIVERSITY
SCHOOL OF NURSING

INTERVIEW WITH ELDERLY INDIVIDUAL

1. Subject Number_____

2. Subject's Address_____
   Street and Number City State

3. Subject's Phone ( )_____

4. Date of Interview_____

5. Time Interview Began_____

6. Interviewer's Name_____

7. Name of family member or friend_____

8. Place of Interview (specify home or type of institution)

   _____

9. Subject' Residence if not the place of interview

   _____

10. Subgroup A - Home

    B - Foster care-family

    C - Foster care-non family

    D - Home for aged

    E - Nursing home

11. Description of Interview Setting (include observations of physical environment, water, heat, etc.)

12. Description of Interviewee

*13. Sex of Subject

1 Male
2 Female

*14. Race of Subject

1 White (Caucasian)
2 Black (Negro)
3 Oriental
4 Spanish American (Spanish surname)
5 American Indian
6 Other
- Not answered

*15. Age of subject

a. When were you born?_____
(Month) (Day) (Year)

b. How old are you?_____

1 65-69
2 70-74
3 75-79
4 80-84
5 85-89
6 90-94
7 95-99
8 100+

*16. How far did you go (have you gone) in school?

1 0-4 years
2 5-8 years
3 High school incomplete
4 High school completed
5 Post high school, business or trade school
6 1-3 years' college
7 4 years' college completed
8 Post graduate college
- Not answered

*17. Are you single(never married), widowed, divorced, or separated

1 Single (never married)
2 Married
3 Widowed
4 Divorced
5 Separated
- Not answered

*18. Who lives with you? (include relationship to person)

*19. Please tell me how well you think you (and your family) are doing financially as compared to other people your own age?

2 Better
1 Same
0 Worse
- Not answered

Explain:

*20. How well does the amount of money you have take care of your needs?

2 Very well
1 Fairly well
0 Poorly
- Not answered

Probe: Would you say you:

3 ___ do without many needed things
2 ___ have the things I need but none of the extras
1 ___ have the things I need and a few of the extras

*21. Do you feel that you will have enough for your needs in the future?

2 Yes
0 No
- Not answered

Explain:

*22. What is it like for you being an older person living in this area?

Probe: What does it mean to you to be living in your (own home? a foster home? home for aged? nursing home?)

*23. a. How would you rate your overall health at the present time?

3 Excellent
2 Good
1 Fair
0 Poor
- Not answered

Explain:

b. What health or medical problems do you have?

c. How do you manage these problems? What do you do for them? (Meds, hearing aides, canes etc.)

*24. Is your health now better, about the same, or worse than it was five years ago?

3 Better
2 About the same
0 Worse
- Not answered

Explain:

*25. How much do your health problems stand in the way of your doing the things you want to do?

3 Not at all
2 A little
0 A great deal
- Not answered

Explain:

26. What kinds of activities do you usually do during a day?

27. Tell me about a recent typical day.

28. Tell me what you usually eat during the day.

a. How many meals do you eat each day?

29. Assistance patterns.
(Ask general questions first and record response and perceptions. Then probe for each of the following II areas if not covered)

General?: a. What kinds of activities do you need help with?
b. Who helps you and how much time is involved?
c. What does it mean to you to receive their help?
d. How satisfactory is their help? Satisfying to you?

Area probes:
(1) Personal care: (bathing, dressing, toilet, eating, mobility)

(2) managing medical regimes (taking meds, dressings, etc)

(3) home keeping

(4) home maintainance

(5) meal preparation

(6) shopping

(7) transportation

(8) money management

(9) contact with outside world

(10) negotiation of health and social service systems

(11) other

30. In what way has the kind of assistance you receive changed over the last year?

*31. How many people do you know well enough to visit withing their homes?

3 Five or more
2 Three to four
1 One to two
0 None
- Not answered

*32. a. About how many times did you talk to someone--friends, relatives, or others on the telephone in the past week (either you called them or they called you)?

(IF SUBJECT HAS NO PHONE, QUESTION STILL APPLIES)

3 Once a day or more
2 2-6 times
1 Once
0 Not at all
- Not answered

b. Probe: Who were the people you talked with and how satisfied were you with the contact?

*33. a. How many times during the past week did you spend some time with someone who does not live with you, i.e., went to see them, or they came to visit you, or you went out to do things together?

3 Once a day or more
2 2-6 times
1 Once
0 Not at all
- Not answered

b. Who were the people? What did you do together? How satisfactory was the contact?

34. How happy are you with the amount of contact you have with your friends and relatives?

1 happy
2 somewhat happy/unhappy
3 unhappy
- not answered

Explain:

*35. Do you have someone you can trust and confide in?

2 Yes
0 No
- Not answered

Probe: Who is it? How often do you see them, etc.

*36. Do you find yourself feeling lonely quite often, sometimes, or almost never?

0 Quite often
1 Sometimes
2 Almost never
- Not answered

Probe: What do you do if you feel lonely?

*37. Is there someone who could give you any help at all if you were sick or disabled, for example, your husband/wife, a member of your family or a friend? (PIB 17 - natural support)?

1 Yes
0 No one able to help
- Not answered

(IF "YES", ASK a. through c.)

a. Is there someone who could take care of you indefinitely (as long as needed)? who?

b. Is there someone who could take care of you for a short time (a few weeks to six months)? who?

c. Is there someone who could help you now and then (taking him to the doctor or fixing lunch, etc.)? who?

- Not answered

Probe: Is this person willing to help you?

*38. Taking everything into consideration, how would you describe your satisfaction with life at the present time?

2 Good
1 Fair
0 Poor
- Not answered

Probe: What would make life more satisfying?

39. Has there been a time in the past when the family needed to rally around a member? Explain

40. Have you (or your spouse) ever been ill? If so, what arrangements were made? Who helped you?

41. If you are having trouble making ends meet (financial problems), could you call on your family or relations? If so, what can you expect?

42. Some people feel that in time of trouble, it is better to let off steam and show their emotions. Others prefer to keep their feelings to themselves. Which describes you?

43. In general, how do your family members react in times of trouble?

44. If something happened to you that you had trouble handling yourself, who is your family likely to turn to?

_____ the family
_____ relatives
_____ friends
_____ professionals
_____ others (identify)

45. How often do you worry about things?

0 Very often
1 Fairly often
2 Hardly ever
- Not answered

Probe: What kinds of things do you worry about most?

46. How would you rate your ability to cope with life or every day events at the present time-- excellent, good, fair or poor

3 Excellent
2 Good
1 Fair
0 Poor
- Not answered

Explain:

47. Is your coping ability better, about the same, or worse than it was five years ago?

3 Better
2 About the same
1 Worse
- Not answered

Expalin:

48. What services do you think communities should provide for older persons?

49. What services do you know of in the community?

Probe: How did you find out about them?

50. Which do you receive? Did you receive?

51. Here is a list of services that may be offered in the community. Have you received any of these services (hand card to subject)?

52. Which would you like to recieve? (Would have been useful to you when you were in your home? For example, visiting nurse, house-keeping, meals on wheels, etc.)

53. What benefits have you gotten from having X service? What problems have X service caused for you?

54. What would it mean to you to no longer receive X service?

55. How do you feel about relying on services (e.g. homemaker) provided by your community? County? State?

56. If (when) you could no longer stay in your home, what alternatives would (did) you consider? Describe them.

    Probe: Here is a list of supervised residential settings that may be found in some communities. Did you consider any of these?

57. Evaluate respondent's behavior during the interview on a 3-point scale, ranging from low, medium, to high.

ITEM	LOW				HIGH
Attention & concentration	Mind wanders frequently	3	2	1	Attended entire interview
Interaction with interviewer	No contact	3	2	1	Very responsive
Interest	Very casual	3	2	1	Intense interest
Cooperativeness	Barely civil	3	2	1	Went out of way to be helpful
Comfort	Tense	3	2	1	Relaxed
Openness	Guarded	3	2	1	Frank
Understanding	Confused	3	2	1	Comprehending
Mood	Sad	3	2	1	Happy

APPENDIX D

FOCUSED IN-DEPTH INTERVIEW

WITH FAMILY MEMBER

OREGON HEALTH SCIENCES UNIVERSITY
SCHOOL OF NURSING

INTERVIEW WITH FAMILY MEMBER

1. Subject number_____

2. Subject's address_____
   Street and Number City State

3. Subject's phone ( )_____

4. Date of interview_____

5. Time interview began_____

6. Interviewer's name_____

7. Relationship to elderly family member_____

8. Place of interview

   _____

9. Subject's residence if not the place of interview

   _____

10. Subgroup A - Home

    B - Foster-care family

    C - Foster care - non family

    D - Home for aged

    E - Nursing Home

11. Description of interview setting (include observations of physical environment: water, heat, etc.)

12. Description of interviewee

*13. Sex of Subject

1 Male
2 Female

*14. Race of Subject

1 White (Caucasian)
2 Black (Negro)
3 Oriental
4 Spanish American (Spanish surname)
5 American Indian
6 Other
- Not answered

*15. Age of subject

a. When were you born?_____
(Month) (Day) (Year)

b. How old are you?_____

1 65-69
2 70-74
3 75-79
4 80-84
5 85-89
6 90-94
7 95-99
8 100+

*16. How far did you go (have you gone) in school?

1 0-4 years
2 5-8 years
3 High school incomplete
4 High school completed
5 Post high school, business or trade school
6 1-3 years' college
7 4 years' college completed
8 Post graduate college
- Not answered

*17. Are you single(never married), widowed, divorced, or separated

1 Single (never married)
2 Married
3 Widowed
4 Divorced
5 Separated
- Not answered

18. Who lives with you? (include relationship to person)

19. Tell me about your older family member. (Include nature of relationship (historical and current) and description of physical and mental health).

Probe: How much guidance does x need to make decisions?
How adaptable is x to change?

Probe: Overall, how would you rate your ralationship with x?

Five years ago: _____Excellent _____Good _____Fair _____Poor

Current: _____Excellent _____Good _____Fair _____Poor

20. Assistance patterns

A. What kinds of help does x need?
B. What does x expect from you?
C. What kinds of help do you provide and how much time is involved?
D. What does it mean to you/is it like for you to give the help?

Ask general question first, record response.

Probe with

1. Personal care (bathing, dressing, mobility, toliet, eating)

(2) managing medical regimes (taking meds, dressings, etc)

(3) home keeping

(4) home maintainance

(5) meal preparation

(6) shopping

(7) transportation

(8) money management

(9) contact with outside world

(10) negotiation of health and social service systems

(11) other

21. SANFORD'S TOLERANCE OF DISABILITY

Does your older family member have any of the following problems? If so, how difficult is it for you to live with?

Problem	Occur.	No Problem	Management	Difficult	Intol.
Sleep disturbance					
Incontinence - F					
Incontinence - U					
Inability to get out of bed					
Inability to get off commode					
Dangerous behavior					
Inability to walk					
Personality conflict					
Physically aggressive					
Inability to dress					
Inability to wash					
Inability to commu.					
Daytime wandering					
Inability to climb stairs					
Inability to feed self					

22. How do you manage these problems? What advice would you give others experiencing the same problem?

23. What does it mean to you to care for your older family member?

Probe: What are the benefits to you?

Probe: What are the costs to you?

24. What changes have you made in your life since the assumption of caregiving activities? What do you feel abou these changes?

a. Leisure activities

b. Income and expenditures

c. Community activities

d. Employment status

e. Social/family relationships

f. Other

25. Have you any health problems limiting your own ability to provide care for your older family member?

Problem
Anxiety/depression
Personality conflict
Insufficient physical strength
Arthritis
Back strain
Bronchitis
Embarrassment
Other (explain)

26. What services do you think communities should provide for older persons?

27. What services do you know of in the community?

28. What help do your receive in providing care for your older family member?

a. From family and friends?

b. From community providers?

Probe: Here is a list of services that may be offered in the community. Have you or your older family member received any of these?

29. How did you find out about x community services? (Describe the process of obtaining services)

Probe: What was the experience of getting and maintaining the service like for you?

30. What would it mean to you to no longer have x service?

31. What help, if any, do you think your older family member needs, but is not receiving?

Who should provide the help?

Why do you think it is not available?

32. Who actually participated in making decisions about the kind of help (services) your older family member receives?

33. How do (did) you feel about your older family member living in his/her own home?

34. What alternative living arrangements would you/did you consider for your older family member?

1. Long term care facilities _____
2. Board and Care homes _____
3. Senior citizens housing _____
4. Present residence with supportive community services and family _____
5. New, more efficient residence _____
6. Residence with family member _____
7. Other, explain _____
_____

(Describe in detail the informant's evaluation of these alternatives and what role the respondent and other family members will play.)

35. Who participated (would participate) in decision making about an appropriate residence for 'X' your older family member?

36. How would you/did you feel about your older family member going into the alternative living situation?

37. Please tell me how well you think you (and your family) are doing financially as compared to other people your own age?

2 Better
1 Same
0 Worse
- No answer

Explain:

38. How well does the amount of money you have take care of your needs?

2 Very well
1 Fairly well
0 Poorly
- No answer

Explain:

Probe: Would you say you:

3 do without many needed things
2 have the things you need but none of the extras
1 have the things you need and a few of the extras

39. Do you feel that you will have enough for your need in the future?

2 Yes
1 No
0 No answer

Explain:

40. How would you rate your overall health at the present time?

3 Excellent
2 Good
1 Fair
0 Poor
- No answer

Explain:

41. Is your health now better, about the same, or worse than it was five years ago?

3 Better
2 About the same
0 Worse
- No answer

Explain:

42. How much do your health problems stand in the way of your doing the things you want to do?

3 Not at all
2 A little
0 A great deal
- No answer

Explain:

43. Taking everything into consideration, how would you describe your satisfaction with life at the present time?

2 Good
1 Fair
0 Poor
- No answer

Probe: What would make life more satisfying?

44. How often do your worry about things?

0 Very often
1 Fairly often
2 Hardly ever
- No answer

45. What kind of things do you worry about most?

46. Has there been a time in the past when the family needed to rally around a member? Explain.

47. Have you or your husband ever been ill? If so, what arrangements were made? Who helped you?

48. If you are having trouble making ends meet (financial problems), could you call on your family or relations? If so, what can you expect?

49. Some people feel that in time of stress, it is better to let off steam and show their emotions. Others prefer to keep their feelings to themselves. Which describes you?

50. In general, how do your family members react in times of trouble?

51. If something happened to you that you had trouble handling yourself, who is your family likely to turn to?

_____ The family
_____ Relatives
_____ Friends
_____ Professionals
_____ Others (identify)

52. Do you have someone you can trust and confide in?

2 Yes
0 No
- Not answered

Probe: Who is it? How often do you see them/talk with them?

53. How would you rate your ability to cope with life or every day events at the present time?

3 Excellent
2 Good
1 Fair
0 Poor
- No answer

Explain:

54. Is your coping ability better, about the same, or worse than it was five years ago?

3 Better
2 About the same
1 Worse
- No answer

Explain:

APPENDIX E

CONSENT FORM

UNIVERSITY OF OREGON HEALTH SCIENCES CENTER
SCHOOL OF NURSING

STUDY:* USE OF NURSING HOMES AND COMMUNITY-BASED SERVICES BY OLDER PERSONS IN A RURAL AREA

INTERVIEWERS:** PATRICIA ARCHBOLD, RN., DNSc
BEVERLY HOEFFER, RN., DNSc

PATRICIA ARCHBOLD AND BEVERLY HOEFFER, NURSES AND FACULTY MEMBERS AT THE SCHOOL OF NURSING, UNIVERSITY OF OREGON HEALTH SCIENCES CENTER, ARE DOING A STUDY OF THE USE OF NURSING HOMES OR COMMUNITY-BASED SERVICES BY OLDER PERSONS IN A RURAL AREA IN COLLABORATION WITH THE DEPARTMENT OF HUMAN RESOURCES.

IF I AGREE TO BE IN THIS STUDY, THE FOLLOWING WILL HAPPEN: I WILL ANSWER QUESTIONS IN ONE INTERVIEW SESSION REQUIRING APPROXIMATELY TWO HOURS. I ALSO UNDERSTAND THAT A MEMBER OF MY FAMILY, OR A FRIEND, _____, WILL BE INTERVIEWED IN ONE SESSION REQUIRING APPROXIMATELY TWO HOURS. I UNDERSTAND THAT WHAT I SAY WILL BE WRITTEN DOWN BUT THAT THE INFORMATION WILL BE KEPT CONFIDENTIAL.

SHARING MY THOUGHTS AND EXPERIENCES WITH DR. ARCHBOLD OR DR. HOEFFER MAY NOT HELP ME PERSONALLY, BUT MAY HELP OTHERS IN THE FUTURE.

IF I HAVE COMMENTS OR QUESTIONS ABOUT THE STUDY, I SHOULD TALK WITH DR. ARCHBOLD OR DR. HOEFFER. THEY WILL ANSWER MY QUESTIONS. I MAY DECIDE NOT TO ANSWER CERTAIN QUESTIONS OR MAY STOP THE DISCUSSION AT ANY TIME. DOING SO WILL NOT AFFECT MY RELATIONSHIP WITH, OR TREATMENT AT, THE UNIVERSITY OF OREGON HEALTH SCIENCES CENTER, OR THE DEPARTMENT OF HUMAN RESOURCES.

WHEN THE STUDY IS FINISHED, DR. ARCHBOLD AND DR. HOEFFER WILL SEND ME A SUMMARY OF THE FINDINGS.

I HAVE READ WHAT IS WRITTEN ABOVE AND AGREE TO BE IN THE STUDY.

I HAVE HAD READ TO ME WHAT IS WRITTEN ABOVE AND AGREE TO BE IN THE STUDY.

DATE	SIGNATURE OF OLDER PERSON
DATE	SIGNATURE OF FAMILY MEMBER OR FRIEND

* UTILIZATION OF INSTITUTIONAL OR COMMUNITY-BASED SERVICES BY FRAIL ELDERLY IN RURAL AREAS.

** PATRICIA ARCHBOLD, RN., DNSc
ASSOCIATE PROFESSOR
PROJECT DIRECTOR, GERONTOLOGY PROJECT
SCHOOL OF NURSING, 225-8839

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DEPARTMENT OF PSYCHIATRIC/MENTAL HEALTH NURSING, 225-7827

APPENDIX F

COMPARISON OF INVESTIGATOR'S AND STATE EVALUATOR'S WEIGHTED PIB SCORES

COMPARISON OF INVESTIGATOR'S AND STATE EVALUATOR'S WEIGHTED PIB SCORES

SUBJECT	INVESTIGATOR	STATE EVALUATOR
Group I		
a	18.00	30.00
b	32.00	25.00
c	16.00	28.00
Mean	22.00	27.67
Group II		
d	29.00	23.00
e	30.00	24.00
f	39.00	17.00
g	33.00	28.00
Mean	32.75	23.00
Group III		
h	39.00	17.00
i	44.00	25.00
j	47.00	22.00
k	38.00	26.00
l	42.00	23.00
Mean	42.00	22.60

AN ABSTRACT OF THE THESIS OF

PATRICIA TONER DINGMAN

FOR THE MASTERS OF NURSING

DATE OF RECEIVING THIS DEGREE: June 10, 1983

TITLE: ASSESSING COGNITIVE IMPAIRMENT AND ITS IMPACT ON NURSING HOME PLACEMENT OF FRAIL ELDERLY

APPROVED: _____

BEVERLY HOEFFER, R.N., D.N.Sc THESIS ADVISOR

Cognitive impairment in an elderly member has been reported as one of the most difficult deficits for families to manage. The PIB (Placement Information Base), a functional assessment tool used to guide nursing home placement decisions, does not directly assess cognitive functioning. The purpose of this study was: 1) to examine and describe the ability of the PIB to screen for cognitive impairment; and 2) to examine the impact of cognitive functioning on the decisions made regarding nursing home placement.

Subjects for this exploratory study were drawn from clients participating in a study of utilization of institutional and community-based services by frail elderly in rural areas (Archbold & Hoeffer, 1981). A state service agency provided the researchers with the names, placements and a quantified assessment of Medicaid-eligible elderly 65 years and over in four rural counties. Twelve residents of

six nursing homes and fourteen people identified as their primary caregivers participated.

The data were collected using the PIB, focused, in-depth interview and participant observation. The investigator's ratings on the PIB were compared with those reported by the state evaluator.

The major findings revealed little agreement between the ratings of the investigator and the state evaluator. The ratings of the investigator demonstrated some sensitivity to cognitive impairment in the PIB while those of the state evaluator did not. The factors which impacted on the decision to utilize a nursing home were different for the cognitively intact and the cognitively impaired elderly: The cognitively intact elderly had mobility deficits, health problems and lacked an able female caregiver; the cognitively impaired elderly had confusion coupled with dangerous behavior such as falling or wandering, and a disorientation to time as precipitants to nursing home admission. This study suggests that the PIB should be revised to include an item which reflects the presence of dangerous behavior in conjunction with a disorientation to time.