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A Telephone Interview Compared to a Face-to-Face Interview in Determining Health Status of Patients Discharged Home from a Rehabilitation Hospital

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements of the degree of Doctor of Philosophy.

Nicol Korner-Bitensky

School of Physical and Occupational Therapy
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January, 1993

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Telephone interviewing to determine health status

ABSTRACT

This study examined the comparability of estimates of health status elicited through a telephone interview and a face-to-face interview. Standardized measures of cognition, mood, functional performance, and community reintegration were administered, over the telephone and then again in the home, to 366 individuals up to five years after their discharge from a rehabilitation hospital. Information on illness, hospitalizations, falls, and medication use was also elicited. Half of the telephone interviews were performed by health professionals, the other half by trained lay interviewers: all of the home interviews were performed by health professionals. Proxy respondents provided information for those unable to respond for themselves. The prevalence and degree of disability reported were similar for the telephone and face-to-face interviews. The reliability coefficients indicated moderate to substantial agreement between the modes on the majority of indices and health related questions. Discord between modes, when present, was greatest for individuals with *moderate* and *severe* disability, with less frequent reporting of disability on the telephone. The results support the use of lay persons to administer a structured telephone interview and the use of proxy respondents when the patient is unable to participate. This study has shown the telephone assessment of health status to be a valuable means of determining health status of individuals in the community who are potentially at high risk for morbidity and functional decline.

RÉSUMÉ

Cette étude visait à comparer des évaluations d'états de santé faites à partir d'entretiens téléphoniques avec d'autres évaluations découlant d'entrevues réalisées en personne. A l'aide de critères standard, on a mesuré, par téléphone et ensuite à domicile, la connaissance, l'humeur, le rendement fonctionnel et la réinsertion sociale de 366 personnes, dans les cinq années suivant leur sortie d'un hôpital de réadaptation. On a également recueilli des renseignements sur les maladies, les hospitalisations, les chutes et l'utilisation de médicaments. La moitié des entretiens téléphoniques ont été réalisés par des professionnels de la santé, l'autre moitié par des non-spécialistes ayant reçu une formation; toutes les entrevues à domiciles ont été menées par des professionnels de la santé. Le cas échéant, des mandataires répondaient à la place des personnes incapables de le faire elles-mêmes. Les entretiens téléphoniques et les entrevues à domicile ont fait ressortir une prévalence et un degré d'incapacité similaires. Les coefficients de fiabilité ont révélé une concordance de moyenne à grande entre les modes d'évaluation, et ce, pour la plupart des indices et des questions liées à la santé. L'écart, quand il y en avait un, était plus grand lorsqu'il s'agissait de personnes atteintes d'une invalidité moyenne ou grave, moins de cas d'invalidité étant signalés par téléphone. Les résultats soutiennent l'utilisation de non-spécialistes pour effectuer des entrevues téléphoniques structurées et celle de mandataires pour répondre à la place des patients qui ne peuvent le faire eux-mêmes. Cette étude a montré la validité de l'entretien téléphonique comme moyen d'évaluer l'état de santé de personnes à domicile qui représentent un risque élevé de morbidité et de déclin fonctionnel.

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This thesis is dedicated to the memory of a very special lady, my mother Else Korner.

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CHAPTER 1: INTRODUCTION

Life expectancy has increased in Canada (Health and Welfare Canada, 1985). This increase adds potential years of life with a disability and a concomitant burden on emergency, acute, and long-term care services (Colvez & Blanchet, 1983; Brody, Brocks & Williams, 1987; Wilkins & Adams, 1987). Rehabilitation is designed to offset this burden by providing patients the opportunity to learn the skills necessary to live in the community. Accordingly, the success of a rehabilitation program is measured not only by the individual's improvement while in hospital but also by the individual's ability to flourish in the community after discharge (Jongbloed & Crichton, 1990). Although some patients who return home will be re-hospitalized because of an unavoidable exacerbation of a disease process, many others could enjoy a good quality of life in the community if problems in physical and emotional functioning and community reintegration could be detected and acted upon.

Traditionally, when follow-up of patients is performed to ascertain health status, it is either in the form of a clinic visit, or, more rarely, a home visit. Clinics may be troubled by poor attendance, especially in the elderly who find it difficult to return to the hospital setting. Home visits are expensive and the health professionals needed to conduct them are scarce.

As an alternative to traditional follow-up, this study proposes a method of assessing health status using a structured health status assessment administered over the phone. The health status assessment includes indices measuring functional abilities, mood state, reintegration to the community, and cognition, along with questions on health and health events. To determine the feasibility of using lay persons to elicit information on health status, the study design includes the use of non-professional interviewers to perform some of the telephone interviews. In addition, this study examines the use of proxy respondents for those patients who are unable to respond for themselves because of cognitive or physical impairments.

Ultimately, if a telephone interview can be shown to be effective in ascertaining health status of elderly and disabled individuals discharged home from a rehabilitation hospital, then the use of the telephone interview to measure health status and to detect early signs of deterioration will have immediate implications for follow-up and community reintegration programs.

1.1 IMPETUS FOR THE STUDY

The impetus for this study arose from the evaluation of a clinical follow-up program that was initiated in the early 1980's at the Jewish Rehabilitation Hospital (JRH), a 120 bed institution that provides in-patient rehabilitation for patients from Montreal and surrounding regions. In 1986-87, as part of my research activities, I had the opportunity of reviewing information from the program. The audit revealed that, from the more than 900 patients discharged per year, less than 20% were receiving follow-up services. Discussions with the Follow-up Program team members and the hospital Director indicated that this low rate of follow-up was partly due to limitations in funding but was also associated with poor patient compliance to the clinic visit. A major concern raised by the team was that patients who were most in need of follow-up might be those very patients who were not able, because of a lack of a family network or poor physical or mental health, to return to the hospital. A chart review and further discussion with the individual team members (consisting of physical, occupational, and speech therapists, and a psychologist, social worker and nurse) suggested that many individuals who were thought to be at risk because of advanced age, multiple co-morbid conditions, or a limited kinship support system, were not returning to the hospital for their scheduled follow-up even after repeated attempts by the program Coordinator to schedule a visit. To address these concerns a system of home visits by a health professional was implemented in 1987-88. The goal was to follow patients who were considered, based on the clinical decision of the in-hospital treatment team, to require assessment but who had not returned for their scheduled appointments.

This new mandate was implemented for a trial period of one year with a decision to re-evaluate the program at that time. After a number of months the feedback from the team was that many home visits were being performed for patients who required no interventions or recommendations. It was decided that a more cost-effective manner of identifying patients in need of the expensive home visit be considered. Simultaneously, telephone interviews were being considered as a cost-effective way of contacting large numbers of patients and of identifying patients that required additional follow-up. The feedback from the professionals conducting the home visits encouraged us to advocate the use of a telephone interview as an initial screening tool for patients discharged home.

By 1989 we had assembled a telephone questionnaire that covered various components of health status including mood, physical and functional ability, cognitive status, and community reintegration along with questions on service utilization. This questionnaire was pilot tested on more than 100 patients, with varying medical diagnoses, who had been discharged home.

The most important finding from this initial phase was that it was feasible to obtain responses to questions on health status using the telephone. What remained to be evaluated was the accuracy of the information obtained. Towards this goal, a formal research proposal was submitted to the Fonds de la recherche en santé du Québec (FRSQ) and to the National Health Research and Development Program (NHRDP) in November of 1989. The project was favorably reviewed by both agencies and received funding from FRSQ in April 1990, at which time the study was launched.

1.2 THESIS CONTENT

To acquaint the reader with the content of this thesis a brief synopsis of its content is presented. Chapter 1 includes a broad spectrum of literature that is relevant to the conduct of this study. Section 1 includes a definition and an overview of health status assessment and provides the reader with information on some of the tools commonly used to assess health status. In addition, the first section summarizes measurement qualities that are desirable when choosing scales and indices. Section 2 justifies the use of a health status assessment in patients discharged home from rehabilitation hospitals. Emphasis is on the outcome of stroke and orthopedic conditions (notably, hip fracture) because these two conditions are prevalent in rehabilitation hospitals that treat adults and it is individuals with these two conditions who constitute our cohort. As this study searches out individuals who might be at risk for deterioration, it was also crucial to provide evidence that interventions are available for individuals identified to require them. Towards this end, Section 2 also covers the literature on intervention programs. Section 3 shifts somewhat to literature in the social sciences. This section covers the methodological issues pertinent to the conduct of this study including a critique of the telephone as a mode to ascertain health status, a review of survey methodology and finally, a section devoted to the use of proxy respondents to ascertain health.

Chapter 2 defines the objectives of the study. Chapter 3 includes an outline of the study design and an overview of the content of the health status assessment. It proceeds with information on the setting, the target population, the criteria of eligibility and a justification of the sample size. The procedures for training interviewers and for tracing and recruiting subjects are explained, as is the randomization schedule for subject allocation.

The steps taken in collecting and entering the data are outlined. This is followed by a detailed description of each component of the health status assessment. The final section of Chapter 3 describes the statistical analyses used in the study.

Chapter 4 presents the results of the study in 5 sections. Section 1 includes information on the cohort from which the subjects were recruited, details on the tracing, and a description of those who were eligible and those who participated. Sections 2, 3 and 4 include information on the indices and health related questions used to assess individuals during a telephone and a home interview. Section 2 presents contrasts between interviews performed by lay interviewers and by health professionals. These contrasts were performed to determine if the prevalence of the conditions under study would be similar when reported, by lay interviewers and by health professionals, using a telephone assessment of health. Section 3 compares the distribution of scores on the telephone interview to that on the home interview. The information provided by these distributions is an important first step in identifying the prevalence of the conditions under study and identifying any striking variations in prevalence based on the type of interviewer, the type of respondent (patient or proxy) and the mode of interview (telephone or home). Section 4 provides the main bulk of the analyses on the reliability and validity of the telephone interview. Section 5 presents information on the differences in scores between the telephone and home interviews and Section 6 gives the results of a series of logistic regression analyses performed to explore variables associated with discordant responses between the telephone and home interview.

Finally, in Chapter 5, there is a discussion of the findings of the study. The limitations of the study are explored as are the implications of the findings on clinical practice.

The appendices include the French and English versions of the interview questionnaire (Appendix A), data collection sheets and consent forms (Appendices B,C,F,G,H), additional tables and figures referred to in the Results section (Appendices E, I, J, K) and a glossary of terms (Appendix L). Appendix M contains the distribution of raw scores on the indices.

CHAPTER 2: LITERATURE REVIEW

2.1 HEALTH STATUS

2.1.1 Defining Health Status

"the absence of death is not all there is to life" (Branch et al. 1985)

Health is a complex and abstract concept (McDowell & Newell, 1987). Traditionally it has been considered to be the antithesis of illness, and is often measured by the number, or severity of illness as evidenced by longevity or the findings on laboratory tests. Stedman's Medical Dictionary (1977) refers to health as the state of the organism when it is functioning optimally, without evidence of disease or abnormality. In contrast, Webster's Dictionary (1986) defines health in a positive manner as the condition of being of sound body, mind and spirit. Similarly, the World Health Organization (1980), in recognition of the limitations of mortality and morbidity data to describe overall health, has expanded the definition to include physical, mental, and social well-being and not only the absence of disease and infirmity.

While the broader definition of health has been criticized as being unmeasurable (Williams & Aspin, 1981), in recent decades there has been increased attention to the development of tools that measure constructs such as social well-being and physical performance. The impetus for the creation of these additional measures has been accentuated by a number of trends. With the increased use of clinical trials in the 1970's came a recognition that there were few well designed global assessments of health to measure the impact of an intervention in areas other than survival and rate of recurrence, infection or re-hospitalization (Katz, 1987; Spitzer, 1987a). In addition, the marked increase in the number of elderly individuals, and, the advent of geriatric medicine created a demand for alternative measures of health because we have come to recognize that while some interventions may not extend life, they may improve quality of life and functional autonomy (Bergner & Rothman, 1987). This especially holds true in rehabilitation, where success of an intervention must be measured by outcomes such as the individual's ability to return to a productive life in the community, and not, solely, by survival.

2.1.2 Determinants of Health

The health of a population is influenced by many factors both inherent and acquired (Evans, 1984). The most commonly studied innate variables are age, sex, race and ethnic origin. Acquired characteristics include those of a biological nature such as nutritional state, muscular development and specific immunities as well as those of a behavioral nature such as dietary choice, physical and recreational activities, sleeping habits, smoking and personality traits. Social or economic attributes including level of education, occupation, income and marital status have also been associated with the occurrence, severity and outcome of disease (Fox, Hall & Elveback, 1970). Health of the population is more strongly linked to sanitation, diet and shelter than to advances in health care (Evans, 1984).

Comparisons of the health systems across various countries are often performed using measures such as life expectancy and infant mortality (Raffel, 1985). Increased life expectancy has been attributed, largely, to the drastic reduction in infant, particularly neonatal mortality, and to the control of acute, infectious diseases (Fries, 1980). Individuals now live to an age where chronic illness such as arteriosclerosis, cancer, arthritis and cardio-pulmonary diseases are the major health problems. Chronic illness are usually characterized by a slow and insidious onset and by a lengthy period of disability (Colvez & Blanchet 1983). Thus, as increased life expectancy is achieved, there is a concern that we are seeing a concomitant increase in the total number of years that individuals spend in poor health and with disability (Fries, 1980; Wilkins & Adams 1987).

While the more traditional outcome measures of health such as hospitalization rates and mortality have been used extensively in the past, the current increase in chronic diseases and disability have necessitated the addition of more global measures of health status.

2.1.3 Measuring Health

The measurement of the physical and emotional well-being of the individual has traditionally been considered too *soft* an outcome for use in rigorous studies. In contrast, laboratory measures have been considered to be *hard*, and thus, synonymous with being objective. Proof of a laboratory measure's objective qualities is classically provided by its preservability and its ability to demonstrate test-retest reliability and because *gold standards* such as death certificates and autopsy or biopsy reports are available against which to measure sensitivity and specificity (Feinstein, 1987). When it comes to tools that attempt to measure parameters such as activities of daily living (ADL) or mood there are few *gold standards* against which to compare the properties of these instruments.

In the past decades, the seemingly *hard* information such as x-ray and blood pressure readings has been scrutinized and reports have been published suggesting that these tools are less reliable than previously believed (Koran 1975a & b; Goldberg, Poitras, Mayo, et al 1988; Coats, 1990). The qualities of laboratory instruments and assessors have improved with calibration of the instruments, standardized instruction, and vigorous training. These same principles should also improve the quality of the *softer* tools (Kirshner & Guyatt, 1985).

2.1.4 Properties of Health Indicators

The value of an instrument is evaluated by the degree of standardization of the procedure for its use, the validity and reliability, and, its responsiveness to change. A brief definition of these four terms follows below.

Standardized instruments are those designed with explicit criteria for scoring the items thereby improving the objectivity, and, with a format for quantifying the results so that information can be reported in finer detail and more routinely than with the use of personal judgements (Nunnally, 1978).

The *validity* of an instrument is the degree to which it measures what it purports to (Last, 1988). There are a number of types of validity that are considered during the development of a measurement tool.

Face validity is the extent to which an instrument *looks like* it measures what it is intended to measure (Nunnally, 1978).

Content validity is defined as the extent to which the items chosen for inclusion in the instrument represent the domain they are measuring. Content validity is affected by the rigor by which the items have been assembled. Typically, a group of individuals with varying expertise is brought together. The group is then requested to contribute items, or is given a predetermined list of items, and asked to rate the importance of these to the domain being described. The degree of rigor taken in choosing who is to be surveyed, and the amount of structure built into the way in which the responses are elicited is then used to judge the content validity, in the absence of statistical testing (Nunnally, 1978).

Construct validity refers to the extent to which the items of the measure group together to represent an abstract variable or construct. For example, physical functioning is an abstract concept that cannot be measured directly. Rather, it is necessary to identify observable manifestations of the abstract construct such as the ability to perform everyday tasks (Nunnally, 1978; Carmines & Zeller, 1979). Construct validation requires a theoretical basis for including items in a measurement. It is necessary to identify other concepts with which the construct is thought to be related. The relationship between the constucts is then tested (Carmines & Zeller, 1979). For example, if it is believed that the greater the physical impairment, the poorer the performance on measures of physical functioning, then there should be a correlation between the patient's degree of impairment and his physical functioning.

Criterion validity refers to the extent to which a measure correlates with another measure that is known to be the "gold standard" for the evaluation of the domain in question. In rehabilitation there are few "gold standards" but a previously validated instrument is frequently used as the best approximation. There are two forms of criterion validity: *concurrent* validity refers to the extent to which a measure correlates with another measure used at the same point in time; *predictive* validity refers to the ability of the measure to predict an event or health state in the future.

The *reliability* of a measure is demonstrated if it behaves consistently under different testing circumstances. Three types of reliability have been identified.

Test-retest reliability assesses the stability of the measure over time. This type of reliability is demonstrated when the results on two separate administrations of the test are similar. The testing situations should be designed to ensure that as many factors as possible are kept consistent so that common sources of variability (such as patient fatigue or improvement over time) are minimized, or, addressed in a consistent manner. *Inter-rater reliability* is defined as the degree to which different observers, independently assessing traits, classify subjects in a similar manner (McDowell & Newell, 1987).

Intra-rater reliability is tested by assessing whether a rater, scoring an identical situation or performance on more than one occasion, would achieve similar results. The use of video tapes, showing subjects performing the activities to be measured, improves consistency between the testing situations, but does not necessarily reflect clinical reality.

Internal consistency refers to the extent to which items of a test correlate with one another (Streiner & Norman, 1989). There are a number of ways to test internal consistency, one of the most common being Cronbach's alpha (Cronbach, 1971). It should be noted that an instrument may demonstrate a high degree of test-retest reliability and inter-rater agreement, without necessarily demonstrating a high degree of internal consistency.

All forms of reliability are strengthened by the use of an instrument with a well-documented protocol for administration, test items that are clearly phrased, a scoring system that is mutually exclusive and by extensive training of raters (Kane & Kane, 1984).

The reliability of a measurement tool is affected by random error but not by systematic error. For example, the scoring performed by two raters may be virtually identical, yielding high reliability coefficients, but both raters may have incorrectly assessed the individual's responses or performance. In contrast, validity is influenced by both systematic and random error. Systematic error is likely to occur in situations where socially desirable answers are given more often, if there is a tendency to a response set that occurs when individuals are more likely to respond with the first or last response on a Likert scale; or, when the wording of a scale creates an inherent bias in the responses given. Ultimately, the *accuracy* of a measure will be the degree to which the measurement is both valid and reliable.

Responsiveness of an instrument to change in performance or in health status has been the focus of increasing attention in the measurement literature over the past years (Deyo & Centor, 1986; MacKenzie 1986; Chambers, Haight, Norman et al, 1987; Guyatt, Townsend, Berman, et al, 1987; Guyatt, 1987; Guyatt, 1989). Choosing a scale that is sensitive to small increments or decrements in patient performance or well-being is understandably important in longitudinal studies where the goal is to identify or monitor change in health status. Often, however, it is difficult to interpret change scores. For instance, is a five point increment on a functional scale indicative of clinical improvement. Some authors have suggested that testing the responsiveness of a scale is similar to assessing the discriminatory ability of a diagnostic test (Deyo and Centor, 1986). There is no specific condition that is being diagnosed but rather one tries to diagnose whether a clinically important change has occurred. In this situation, the *gold standard* becomes a set of criteria such as the therapist's judgement of whether the person has improved, or, deteriorated. The scale's responsiveness to change is then described in terms of sensitivity and specificity in detecting improvement or deterioration.

2.1.5 Existing Scales to Measure Health

Scales to measure health can be loosely categorized by whether they are designed (1) to survey the health of large groups, for example, through a national or provincial census, or to identify the health of an individual (2) to measure the outcome of a specific condition or disease versus various conditions (3) for use with a specific age group or a wide range of ages (4) to measure one aspect of health such as emotional status or global health status including physical, social and mental functioning and (5) to measure impairment, disability or handicap.

2.1.5a Surveys versus screening and case finding

It has been suggested that scales that measure the health of the individual differ, in a number of areas, from scales that measure the health of a group (Kane & Kane, 1984). Although both must be reliable across raters and over time and both must be valid, it is recognized that when measuring large groups it is necessary to use a minimum of time and money for each interview and, if possible, to use a self-administered mode or to employ non-professional interviewers. Large scale studies are typically undertaken to identify the incidence or prevalence of a disease, condition, or trait, and are useful for policy making and cost analysis. These studies seldom include any treatment or intervention strategies directed at the individual. In contrast, measures designed to assess the health of an individual are most often used to detect a specific condition, to evaluate the need for health services, and to identify small changes in the outcomes being measured (Kane and Kane, 1984). It has been noted that the acceptable level of reliability differs, depending on the proposed use of a scale, be it to measure groups, or to identify the needs of an individual. For example, when estimating the prevalence of depression in the community to determine the need for services, reliability coefficients of .80 to .85 may be acceptable: the same tool may require coefficients of greater than .90 to be acceptable in a clinical screening of depression, where a failure to detect the problem may result in a failure to provide important treatment to an individual (for a review, see Streiner & Norman, 1989).

2.1.5a.i *Surveys*

In the past two decades there has been growing interest in conducting studies that examine the health of the population. In Canada, the first health related survey of the non-institutionalized population was the Canadian Sickness Survey in the early 1950's (Health Reports, 1989). It documented the incidence and prevalence of illness, health care use and personal expenditures on health care services. In the 1970's and 1980's a number of large scale Canadian surveys were launched including the Nutrition Canada Survey, the Health Survey, the Fitness Survey, the Health and Disability Survey, the Health Promotion Survey, the more recent Health Activity Limitation Survey and the General Social Survey (summarized in Health Reports, 1989). The combined contribution of these surveys has been the identification of the nutritional habits of the population, the level of physical activity, the extent of disability, the social and community participation in work and leisure activities, and the social support exchanges between seniors and their relatives and friends.

In the United States, the National Health Interview Survey was initiated in 1957 and is now conducted on an ongoing basis to address major current health issues in non-institutionalized civilians (reviewed by Moss & Parsons, 1986). By performing repeated measures on the same group it is possible to ascertain trends in the health of the population. A number of health assessment scales have been developed with the specific intent of measuring the physical, social and emotional well-being. The Medical Outcomes Study used an evaluation of functioning and well-being in more than 9,000 adults at the time of a physician visit to evaluate the extent and impact of chronic illness on physical, social, mental health, pain and health perception (Stewart, Greenfield, Hays et al, 1989).

2.1.5a.ii *Screening and case finding*

Screening is the identification of an unrecognized disease or defect by applying a test or procedure that is administered fairly rapidly (Last, 1988). Case finding refers to the identification of individuals with symptoms or disabilities in the hope of intervening prior to a decline in current status (Williamson, Smith & Burley, 1987). The Older Americans Resources and Services (OARS) Multidimensional Functional Assessment Questionnaire, was developed as a screening tool to identify social and economic resources, mental and physical health, and activities of daily living, along with the services being received and needed by elderly individuals living at home (Pfeiffer, 1975; Fillenbaum & Smyer, 1981). One of the best respected measures of health, and one that has undergone rigorous testing is the Sickness Impact Profile (Bergner, Bobbitt, Kressel et al, 1976; Bergner, Bobbitt, Carter et al, 1981). This scale was designed to identify changes in an individual's behavior resulting from illness. The McMaster Health Index Questionnaire (Sackett, Chambers, MacPherson et al, 1977), the Nottingham Health Profile (Hunt, McEwen & McKenna, 1985), the Quality of Well-being Index (Kaplan & Bush, 1982) which was originally called the Health Status Index (Fanshel & Bush, 1970) and later the Index of Well-being (Kaplan, Bush & Berry, 1976), and the General Health Questionnaire (Goldberg, 1972) that focuses on psychological distress, are other well known assessments of health. A review of many of these scales is available in McDowell and Newell (1987).

2.1.5b Condition specific versus general use scales

Condition specific indices are used to measure the health of individuals within a specific diagnostic group or with a particular disease. In contrast, generic health status measures such as the Sickness Impact Profile serve across types and severities of illness and are often used in comparisons of outcomes across different populations and interventions (Patrick & Deyo, 1989). Both have particular strengths and weakness. In the case of a randomized clinical trial looking at two different treatments for rheumatoid arthritis, a condition specific index such as the Arthritis Impact Measurement Scale (Meenan, Gertman & Mason, 1980) may be appropriate as it is likely to be the most sensitive in identifying changes related to the particular problems of patients with arthritis. However, such a tool may also pose a disadvantage if the items are so specific that they fail to identify possible complications of a treatment intervention in areas other than those that are anticipated. For example, a medication may effect other than the expected physiological systems or may effect the emotional well-being of the individual: these occurrences may go undetected if the questionnaire items cover too narrow a range.

2.1.5c Age specific scales

Many scales have been created for use with specific age groups such as the old and very old (for a review see Kane & Kane, 1984). For example, Katz's Index of ADL was developed in the late 1950's to assess the effects of treatment on the elderly and those with chronic illness (Katz, Ford, Moskowitz et al, 1963). Scales designed specifically for the elderly serve limited use in studies where individuals of varying ages are recruited. Conversely, scales used to assess individuals of differing age ranges, without taking into consideration that often the norms for the scale are based on a much younger age group, raise concerns. The study of depression in the elderly poses such a problem. The Zung Scale (Zung, 1965), a widely used assessment of mood, originally, had norms for the definition of depression established on a relatively young age group (for a review, see Hedlund & Vieweg, 1979). In those of more advanced ages it was suggested that the cut-offs for identifying the presence of depression be adjusted to reflect the increased prevalence of somatic complaints that might falsely appear to indicate depression (Zung, 1967). Subsequently, the Zung Scale was tested and norms established for its use in older individuals (Steuer, Bank, Olsen et al, 1980).

2.1.5d Scales to measure one or many aspects of health

Many multi-dimensional scales are available such as the Patient Evaluation Conference System (PECS) developed by Harvey and Jellinek (1981), the OARS Multidimensional Functional Assessment Questionnaire (Pfeiffer, 1975), and the Sickness Impact Profile (Bergner, Bobbitt, Kressel et al, 1976; Bergner, Bobbitt, Carter et al, 1981). The use of multi-dimensional or aggregate scales introduce some problems in that overall scores do not indicate ability in any single domain unless subsections of the scale are specifically designed to provide subscores. Conversely, a major advantage of a multi-dimensional scale is that it permits many aspects of the individual's health to be rated, often using the same scaling, and, frequently, with the added benefit of an aggregate score. Where team care is a priority, multi-dimensional scales such as the PECS (Harvey & Jellinek, 1981) permit each discipline to evaluate the patient in their own area of expertise, but on a scoring system that is common and therefore understood across disciplines.

Of the many scales developed to assess only one aspect of health such as physical status, functional status, mood, cognitive functioning, or quality of life, those measuring activities of daily living has been most prolific. The PULSES Profile (Moskowitz & McCann, 1957) was derived primarily as an indicator of impairment in physical and emotional status of the chronically ill and elderly, institutionalized population. The Kenny Self-Care Evaluation (Schoening, Anderegg, Bergstrom et al, 1965; Iversen, Silberberg, Stever et al, 1973) is a detailed assessment of activities of daily living and is useful for detecting small increments in patient performance during the course of clinical treatment. The Barthel Index (Mahoney & Barthel, 1965) is one of the most widely used assessments of function as it can be administered quite easily and quickly to large numbers of individuals and has been tested extensively in various patient groups for reliability and validity (Granger, Dewis, Peters et al, 1979; Risteen Hasselkus, 1982; Roy, Togneri, Hay et al, 1988). The Katz Index (Katz, Ford, Moskowitz et al, 1963), although originally designed to measure physical functioning in the elderly and chronically ill, is now used extensively with various age groups. One negative aspect of the Katz Index is that it is less sensitive to change in functioning then the Barthel Index or the Kenny Self-Care Evaluation (Gresham, Philips & Labi, 1980).

2.1.5e Impairment, disability, or handicap

Most scales that exist to measure an aspect of health can be identified as focusing on *impairment, disability,* or *handicap.* Simply defined, impairment is a decrease in physical or mental functions at the organic or systemic level (World Health Organization, 1980). A disability is a restriction in a person's ability to perform an activity, that is considered *normal* for an individual of that age, because of the impairment. Handicaps are the disadvantages that the disability produces on the individual's ability to lead his usual lifestyle (World Health Organization, 1980). Scales that assess *impairment* include those measuring balance, sensory abilities, visual acuity, muscle strength or range of motion. Scales developed to measure *disability* focus on identifying restrictions in a person's ability to perform an activity and include the assessment of functional activities, mood, mobility and quality of life, to name a few. More recently, scales have been developed to focus on the degree of disruption of the person's lifestyle produced as a result of a disability or impairment, that is, to measure the handicap. The degree of handicap that a condition poses is reflected in scales such as the Reintegration to Normal Living Index (Wood-Dauphinee, Opzoomer, Williams et al, 1988) and the Quality of Life Systemic Inventory (Dupuis, Perrault, Lambany et al, 1989). These scales ask questions, not exclusively on the performance of daily activities, but on the satisfaction or happiness that the individual feels with the way his personal and social needs are being met.

2.1.6 Choosing Appropriate Scales

It has been noted that, although we already have an abundance of scales to choose from, clinicians and researchers continue to develop new ones rather than using and improving upon those that are currently available (Spitzer, 1987b). Dissatisfaction with a scale may arise because of a lack of forethought regarding the proposed purpose, or, because a scale is attempting to meet too many purposes. Commonly, tools are chosen to discriminate between groups, to plan treatment, to predict outcomes, to monitor change in status or to document general trends in large groups (Kirshner & Guyatt, 1985; Feinstein, 1987). Most scales currently in existence do not satisfy all of these needs simultaneously. Thus, a researcher may choose a scale that is satisfactory for documenting changes in functioning when used with large groups of individuals but that is frustrating for the clinician because it does not permit the identification of small increments in patient performance. For example, the Kenny Self-Care Evaluation allows for the documenting of very specific ADL skills. However, it is lengthy to administer and is impractical for use in large follow-up studies or when in-person interviews are not convenient. Conversely, the Barthel Index (Mahoney & Barthel, 1965) has been used successfully for research purposes but does not document specific skills such as the ability to put on, or take off, a sweater.

It is evident that the choice of an appropriate scale is a complex decision. The perfect scale is unlikely to be available and, thus, compromise is necessary. The alternative is that no quantifiable measure is used. This is a poor solution to a pressing problem of trying to objectively measure the physical, functional, social and emotional well-being of the individuals we treat.

2.2 EVIDENCE THAT REHABILITATION PATIENTS ARE AT HIGH RISK

In 1977 the Expert Group (World Health Organization, 1977) identified seven risk factors for increased morbidity and mortality in the elderly. These included being older than 80 years of age, being recently widowed, having never married, living alone, being socially isolated, being childless, and being in poor economic circumstances. A prospective study (Taylor & Ford, 1983) confirmed that age, gender, functional capacity and recent hospitalization are major predictors of mortality in the elderly. Another report (Branch, 1984) indicated that old age, living alone, requiring assistance in self care, or in activities such as cooking and shopping, using ambulatory aids, and being mentally disoriented were predictive of institutionalization. In addition, life events such as physical illness, a recent move, and social difficulties have been reported to be major precipitators of depression, which in turn, may affect physical, cognitive, and social functioning (Murphy, 1982; Robinson & Price 1982; Robinson, Starr, Kubos et al, 1983; Robinson, Starr, Lipsey et al, 1984; Sinyor, Amato, Kaloupek et al, 1986; Wade, Legh-Smith, Hewer, 1987; Wells, Stewart, Hays et al, 1989). Multiple drug use in older individuals has also been associated with impairments in activities of daily living (Vinet & Vezina, 1988; Magaziner, Cadigan, Fedder et al, 1989) and the occurrence of falls has been associated with an increased risk of institutionalization (Tinetti, Speechley, & Ginter, 1988).

Patients who return home from rehabilitation hospitals usually have some or many of the risk factors just described and are, therefore, at risk to suffer additional morbidity and mortality. Further evidence that elderly individuals, after discharge from hospital, are at an increased risk for extended periods of functional disability, re-hospitalization, and mortality, has recently been presented (Jones, Densen & Brown 1989; Roberts, 1990; Rosenfeld, Fahey, Price et al, 1990). Rosenfeld's group (1990) reported that 30 of 90 elderly patients discharged from the accident and emergency department of an Australian teaching hospital suffered a negative outcome by three months post-discharge, 27 had been readmitted to hospital and 3 had died.

All of the reviewed studies reinforce the notion that patients discharged from rehabilitation hospitals are at a high risk. In addition, those who make substantial use of rehabilitation beds such as patients with stroke or orthopedic conditions, are subject to further health events after returning home.

2.2.1 Hip Fracture and Stroke

Hip fracture and stroke are associated with a lengthy acute-care hospital stay, with long term residual deficits and with an increased risk of morbidity and mortality in the post-acute period. What follows is a brief review of the impact of these two conditions on the health of the individual and on the health care system.

A *stroke* has been defined as a focal or global neurological impairment of sudden onset, that lasts more than 24 hours (or leads to death) and is of presumed vascular etiology (Aho, 1980). Few diseases impact as heavily on society as stroke. It is the fourth most frequent physical cause of acute-care hospitalization (Statistics Med-Echo, Quebec, Canada, 1988), estimated to newly affect more than 50,000 Canadians each year.

Stroke occurs more commonly among the aged: between the ages of 65 and 74 years the annual incidence of stroke is approximately 12 per 1000 and doubles to approximately 25 per 1000 for persons 80 years and over (Shah & Bain, 1989; Mayo, Goldberg, Levy, et al, 1991). The prevalence of stroke among non-institutionalized persons over the age of 55 years now approaches 5% (Verbrugge, Lepkowski, Imanaka, 1989). Owing to the changing incidence, improved survival, the high rate of recurrence, and the increasing proportion of elderly people in the community, stroke is a growing problem.

The literature on the outcome of stroke indicates in-hospital case-fatality rates range from 18% to 37% (Wood-Dauphinee, Shapiro, Bass et al, 1984; Gillum, Gomez-Martin, Kottke et al, 1985; Bonita, Anderson, North, 1987). For those who survive the acute period, stroke is one of the most disabling of chronic conditions (Verbrugge, Lepkowski, Imanaka, 1989) with a broad spectrum of sequela that encompasses perceptual-cognitive, sensory, and motor deficits. Changes in mood are frequently reported, with depression estimated to range from 30% to 60% (Robinson and Price, 1982; Parikh, Lipsey, Robinson, et al, 1987; Bacher, Korner-Bitensky, Mayo et al, 1990). Cognitive disorders have been estimated to range from 12% to 60% averaging around 33% (Robinson, Starr, Lipsey et al, 1984; Wade, Legh-Smith & Hewer, 1987). Disorders of speech and comprehension are often present following lesions of the left hemisphere and more subtle communication disorders are now recognized to follow lesions of the right hemisphere.

Information on the rate of recovery after stroke is varying and complex. The time taken to reach a specific functional stage has been evaluated by several authors (Prescott, Garraway & Akhtar 1982; Wade, Wood & Hewer 1985; Chen & Ling, 1985). Prescott, Garraway and Akhtar (1982) showed that patients gained steadily in functional ability over a 16 week period following a stroke but the rate was influenced by motor ability at six weeks. Wade, Wood and Hewer (1985) used functional outcomes to indicate recovery and evaluated the number of days after stroke needed to achieve each functional skill. For many of the skills (feeding, dressing, and toileting), the majority of subjects achieved some degree of independence during the first 30 days. Patients were still regaining the ability to walk up to 60 days post-onset, however, the majority of those eventually able to walk alone did so 10 to 20 days after their stroke. Demeurisse and colleagues (1980) evaluated the time-to-recovery of speech and related skills and found that patients with severe aphasia showed little improvement in speech after six months of follow-up. Patients with either expressive or receptive aphasia showed the most improvement in the first three months. Bonita and Beaglehole (1988) found that almost two-thirds of patients had persisting motor deficits at six months post-onset, while Bacher and colleagues (1990) found that the prevalence of post-stroke depression increased during the first year.

Of those who survive a stroke, two-thirds (Mayo, Hendlisz, Goldberg et al, 1989) or more (Bonita, Anderson & North, 1987) go directly home. Many of these individuals continue to require care because of the persistence of post-stroke sequala. There is some suggestion that those who do return home have a difficult time remaining in the community: stroke is the third leading primary admission diagnosis for skilled nursing facility placement preceded only by heart disease and chronic brain disease (Larrey, 1980).

Hip fracture is the term used to describe fractures of the proximal femur corresponding to the following anatomical sites: transcervical region (including fractures from the sub-capital area to the basi-cervical area) and pertrochanteric region (including fractures of the greater and lesser trochanters, and fractures of the intertrochanteric and subtrochanteric areas). The occurrence of hip fracture rises rapidly with age and is more common among women than among men (Gallagher, Melton, Riggs et al, 1980). The cost of treating hip fracture is astonishing: by the year 2040, hip fracture in the United States is expected to cost $16 billion annually (Cummings, Rubin & Black, 1990). According to these estimates, the cost of treating this condition in Quebec will soon approach $400 million dollars annually.

The literature on the outcome of hip fracture focuses primarily on the events around the time of discharge, including the length of acute-care hospitalization (Lewis, 1981; Rodrigues, Sattin & Waxweiler, 1989; Boereboom, de Groot, Raymakers et al, 1991), in-hospital mortality (Raunest, Kaschner & Derra, 1990), discharge destination (Miller, 1978; Stott & Gray, 1980; Harris & Eastwood, 1991) and the ability to return to pre-fracture levels of ambulation (Miller 1978). Rates of mortality during acute-care hospitalization have been reported to range from 4% to 18% (Miller 1978; Stott & Gray, 1980; Lewis, 1981; Holmberg & Thorngren, 1987; Larsson, Friberg & Hansson, 1990; Quint & Wahl, 1991). Much of this variability is probably explained by the differences in design such that some studies included only those under the age of 65 while others included individuals of all ages.

The proportion of persons discharged home directly from the acute-care hospital also differs greatly from one study to another with reports ranging from a low of 16% to 64% (Foubister & Hughes, 1989; Bonar, Tinetti, Speechley et al, 1990). Again, it is probable that inclusion criteria played a large part in this discrepancy. For example, some studies included *all* patients with hip fracture while others investigated only those who were community dwelling at the time of the fracture. A wide variability has been also reported in the rate of discharge to facilities providing rehabilitation (8% to 47%) and in the rate of discharge (41% to 60%) to long-term care settings (Lewis, 1981; Palmer, Saywell, Zollinger, et al, 1989; Fitzgerald & Dittus, 1990). Some of the inconsistency was undoubtedly due to differences in the organization of, and the accessibility to, health care services and to the lack of a clear distinction between true long-term care facilities and those that, although referred to as long-term care, provided rehabilitation services.

While most of the studies that looked at the period of hospitalization investigated mortality, discharge destination, and surgical outcome, there was one that investigated the well-being of the individual. Billig (1986) found that depression was surprisingly high amongst patients with hip fracture; almost one-third were depressed while in hospital. These rates are similar to those previously reported for stroke (Bacher, Korner-Bitensky, Mayo et al, 1990). Although post-stroke depression has received a tremendous amount of attention (Robinson & Price, 1982; Robinson, Starr, Price, 1984; Parikh, Lipsey, Robinson, et al, 1987) it was interesting to find that information on depression after hip fracture was sparse.

There have been a number of studies that followed patients up to one year after injury. Mortality rates in the first year ranged from 13% to 45% and a strong relationship between age and mortality was observed (Miller, 1978; Grimley Evans, Prudham et al, 1979; Jensen, Tondevold, Sorenson, 1980; Lagoe & Lauko, 1985; Foubister & Hughes, 1989). Miller (1978) showed a number of negative consequences following hip fracture in a retrospective analysis of 360 patients one year after injury. While the post-operative death rate was below 10%, of those who survived the early period almost one-quarter remained non-ambulatory and for the first eight months after injury, the death rate was significantly higher in this group than for the population at large (Miller, 1978). Jensen and colleagues (1980), while finding rates of in-hospital mortality of under 6%, revealed negative outcomes in the follow-up period. At six months post-injury, even those individuals who functioned well in their pre-injury state, had deteriorated: 17% who survived were now residents of a nursing home and 41% had reduced social functioning, as defined by the amount of help needed to accomplish self care and household tasks.

For the most part, studies suggest that about two-thirds of patients do return home during the first year following hip fracture (Bonar, Tinetti, Speechley et al, 1990; Larsson, Friberg & Hansson, 1990). The proportion of persons returning to their pre-injury level of ambulation varies amongst studies. Larsson and colleagues (1990) found that 20% of patients remained unable to ambulate one year after fracture: Miller (1978) reported that 50% had not returned to their pre-injury ambulatory status.

The few studies that were available on the long term outcome of fracture present a bleak picture: by six years post-fracture, half of patients had died (Holmberg & Thorngren, 1987), increasing to two-thirds by 10 years (Doi, 1989; Borquist, Ceder et al, 1990; Larsson, Friberg & Hansson, 1990). The literature has shown that the death rate in the years following hip fracture is higher than for the general population (Sexson & Lehner, 1988). Exactly which factors contribute to this increased mortality remains largely unknown. This rather negative portrait may, in part, be attributable to an overall, poorer, state of health in these individuals prior to fracture; indeed, hip fracture may have been the culminating event in a generally downhill course. The opportunity to examine this question has arisen as an extension to a funded study on falls, as yet unpublished, that was conducted at the JRH. Fallers who fractured were compared with those who did not fracture. Surprisingly, fallers who fractured a hip were similar to, if not better than, fallers who did not fracture, in terms of ambulatory status, complaints of illness or symptoms, and nature and prevalence of concurrent medical conditions. Based on these limited findings, it is questionable if all of the problems experienced by hip fracture patients can be explained by their pre-morbid status.

The studies on the outcome of hip fracture and stroke indicate that individuals with these conditions are at high risk for functional deterioration and additional morbidity. In particular, those who come to rehabilitation hospitals to recuperate are often frail, elderly, individuals who are at an increased risk for morbidity and mortality after discharge (Thomas & Stevens 1974; Miller, 1978; Grimley Evans, Prudham & Wandless, 1979; Jensen & Tondevold, 1980). Stroke patients and those who fracture a hip are particularly vulnerable (Verbrugge, 1984) because both conditions have a relatively acute onset that leaves little time for the individual and the family to adjust to drastic changes in functional autonomy.

2.2.2 Unmet Needs

It might be argued that elderly, disabled individuals, especially those with chronic conditions, are already substantial users of the health care system and, therefore, seeking these individuals out is neither necessary, nor desirable, but will add an additional burden to an already overloaded system. As well, it might be assumed that those in need of services will seek them out. Unfortunately, there is mounting evidence (Lowther, MacLeod & Williamson, 1970; Barber, 1976; Barber & Wallis, 1976; Barber, 1981; Hendriksen, Lund & Stomgard 1984; Vetter, Jones & Victor, 1984; Williams, 1984; Williams & Barley, 1985; Rubenstein, Josephson, Nichol-Seamons et al, 1986; Williamson, 1987; Miller, Morley, Rubenstein et al, 1990), although not without controversy (Ford & Taylor, 1985), that a system of self-referral is insufficient in elderly individuals. It appears that when elderly individuals visit a physician often only the most obvious or important problems are identified, and other areas of concern that impact heavily on functional autonomy are overlooked (Barber, 1984; Goldsmith & Brodwick, 1989). This problem is likely to be exacerbated in those with chronic disabling disease where it is not necessarily the acute illness that will go undetected but the more gradual deterioration in overall functioning.

Medical needs are not the only concern for these individuals: health care includes the global continuum of care that allows the individual with a disability to remain in the community. Findings from the Commonwealth Fund Commission on Elderly People Living Alone, based on the National Health Interview Survey, 1984 Supplement on Aging (reviewed by Rowland, 1989) estimated that almost 30% of elderly people who have restrictions in activities of daily living are living alone. One out of every five impaired individuals receives no assistance with their daily care or sustenance.

All is not disheartening, for there is an increasing body of literature suggesting that programs of community intervention can be effective in altering or slowing the course of negative events in individuals who are identified as being at high risk.

2.2.3 Effectiveness of Community Intervention Programs

The impetus for the formation of various home intervention programs has come largely from the growing field of geriatric medicine. A randomized controlled trial of the effectiveness of a combined inpatient geriatric assessment and follow-up program (Rubenstein, Wieland, Josephson et al, 1988) found that patients receiving this form of care had better survival, were less likely be in a nursing home, and were more likely to have improved functional status at one and two years post-hospitalization, than patients receiving the usual hospital and out-patient care. A number of other randomized controlled trials of community intervention and surveillance have reported similar results (Tulloch & Moore, 1979; Hendriksen, Lund, Stomgard et al, 1984; Victor & Vetter, 1985). Infante-Rivard and colleagues (1988) found that a telephone support system consisting of regular phone calls from a community health nurse reduced ambulatory physician visits, however, their findings were not statistically significant. A long term study looking at the impact of home care found that the treatment group had better cognitive functioning and fewer unmet needs at nine months as compared with the control group and better cognitive functioning at 48 months (Hughes, Conrad, Manheim et al, 1988). The limitations of this study include the lack of a randomized procedure for allocation to groups and the small number of individuals available for the four year follow-up (n=42).

Vetter and associates (1984) found that a health visitor in an urban setting significantly reduced mortality, but not morbidity, during the two year study period. Using a health visitor in a rural setting did not have the same results. The findings of the study are weakened because only one visitor was used in each setting.

Hendriksen and colleagues (1984) conducted a randomized controlled trial where a physician and nurse assessed medical and social status to identify problems and to make suitable arrangements for older individuals, living at home. The experimental group was followed by a home visitor every three months over a three year period. When compared with the control group, the treatment group showed decreased hospital use and fewer emergency medical visits, nursing home admissions, and deaths (Hendriksen, Lund, Stomgard et al, 1984). Gerety and colleagues (1989) found that patients with hip fracture, when discharged to a rehabilitation oriented nursing home rather than to a convalescent setting, were more likely to be ambulatory and living at home at one year post-injury.

The review of the literature strongly supports our supposition that individuals discharged home from a rehabilitation hospital are at high risk for further deterioration. When interventions have been implemented in those thought to be at high risk there have been reductions in morbidity, mortality, and, medical care utilization.

Our current system of health care for those discharged from hospital with chronic conditions typically consists of treatment for specific medical conditions and of crisis intervention. Rehabilitation services and subsequent follow-up services are limited (Neysmith, 1989; Fox, 1989; Mayo, Hendlisz, Goldberg, et al, 1989) and when follow-up is available, it often implies the need for the patient to return to the hospital setting for a clinic visit.

Although performing health status assessment of individuals discharged from a rehabilitation hospital is a costly proposition, such a program may be justifiable if the assessment is used as a *case finding* tool (Williamson, Smith & Burley, 1987) to identify individuals who are getting into difficulty before they are in a crisis situation. In order for such a system of screening to be beneficial there must be some mechanism in place, in the community, to provide interventions.

Currently, in Quebec, there is a system of community based interventions known as the *centre local de service communautaire* (CLSC) whose mandate it is to bring health and social services to individuals living in the community. Although plagued by staff shortages and long waiting lists, the services are available. Other areas of Canada also offer home care programs with self care assistance and therapy (for a discussion see Sutherland & Fulton, 1988). Therefore, in Canada it is feasible to contemplate a provision of services for persons identified, through a screening process, to be in need of health care and supportive services once they return home.

2.3 METHODOLOGICAL ISSUES IN SURVEYS

2.3.1 Methods for Obtaining Information

Survey interviewing is increasingly used to ascertain previously unavailable information on large numbers of individuals. Today, most North Americans have access to telephones (Catlin & Shields, 1988) making the telephone interview an economical way of ascertaining knowledge on a variety of health related topics.

A number of studies have focused on comparing responses based on the mode of presentation (Hochstim, 1967; Colombotos, 1969; Henson, Cannell & Roth, 1978; Siemiatycki, 1979; Jordan, Marcus & Reeder, 1980; Aneshensel, Frerichs, Clark et al, 1982; Groves & Kahn, 1979; Frey, 1983; Weeks, Kulka, Lessler et al, 1983; Siemiatycki, Campbell, Richardson et al, 1984; Helzer, Robins, McEvoy et al, 1985; Shinar, Gross, Bronstein et al, 1987; Wells, Burnam, Leake et al, 1988). In general, responses ascertained through a telephone contact are similar to those attained from an in-person interview, with some notable exceptions.

Aneshensel and colleagues (1982) interviewed a total of 546 individuals residing in Los Angeles, 238 by the in-person method and 308 over the telephone. The rate of non-response did not differ by mode. While answers to health status, illness, and hospitalization were comparable between the telephone and in-person interviews, more restricted activity days were reported with the in-person interview. Considering the multiple comparisons that were made it is likely that this one difference can be attributable to chance or to true group differences, rather than to an effect of mode.

Siemiatycki and associates (1984) reported that the mail questionnaire strategy, when compared to the telephone strategy, was more likely to result in the reporting of illness and medical care use. Henson, Cannell and Roth (1978) noted that individuals answering a telephone interview expressed fewer health symptoms than did individuals answering an in-person interview, while Miller (1984), in contrast, reported that telephone interviews produced higher reporting of health care utilization and morbidity than did in-person interviews. Hochstim (1967) also reported that the telephone and mail strategy resulted in a higher proportion of individuals rating their health as *fair* as compared to the in-person strategy.

Wells and colleagues (1988) tested the concordance between a face-to-face and telephone administered version of a depression interview. The subjects were 230 English speaking individuals. All received a face-to-face interview followed, after an average delay of three months, by a telephone interview. The sensitivity of the telephone version to identifying a depressive disorder was moderate 71%, the corresponding specificity was 89%. The long delay between interviews and the failure to randomize the order of presentation of the two modes of interview may have contributed to the differences between the modes.

Health care indices such as the McMaster Health Index Questionnaire (Sackett, Chambers, MacPherson et al, 1977) have been administered by the telephone, in-person and through the self-administration mode with no appreciable differences in reporting of health status based on mode (Chambers, Haight, Norman, et al, 1987). Weeks and associates (1983) found differences in the rate of reporting of dental visits and self care limitations between the two modes; but the two groups of individuals interviewed differed on other important variables such as socioeconomic status and age and, thus, it is questionable if the differences found between the groups were related to the mode of interview.

There has been considerable discussion as to the best mode of eliciting answers to sensitive questions (Hochstim, 1967; Bradburn & Sudman, 1980) or those addressing issues of social acceptability (Hochstim, 1967; Colombotos, 1969). Henson, Roth & Cannell (1977) found that individuals gave more *cheerful* responses on the telephone than in the personal interview. Bradburn and Sudman (1980) reported that when questions were considered threatening, the telephone mode was more accurate. Similarly, Hochstim (1967) found more frequent reporting of alcohol consumption on the telephone, than with a mail questionnaire or in-person interview. In contrast, Mangione and colleagues (1982) reported that individuals were more likely to admit to drinking problems during a personal interview or self-administered procedure. Others have found minimal differences between the two modes for the reporting of embarrassing events such as arrests for drunken driving or personal bankruptcy (Locander, Sudman & Bradburn, 1974). Siemiatycki and co-workers (1984) reported higher rates of non-response to information on family income with the telephone mode than with the mail mode (19% versus 9% respectively) while Colombotos (1969), found no differences in responses to socially acceptable responses between the telephone and in-person modes in a group of physicians.

There is no clear indication, from the literature reviewed above, that the home interview is the superior mode for eliciting information on sensitive issues. The conflicting reports are probably due, in part, to the variety of topics studied. In addition, because the majority of studies were conducted on two different groups of people, it is possible that inconsistencies were due, in part, to true differences. Rogers (1976) presents one of the few studies that re-interviewed the same group (although only a small number of subjects) and found no differences between the modes on reporting of income, education and voting practices. Coombs and Freedman (1964) also used a repeat interview and found that data on family planning and pregnancy could be elicited as well through the telephone interview as through the in-person interview.

De Leeuw and van der Zouwen (1988) performed meta-analysis using the results of 25 studies that compared face-to-face and telephone interviews conducted from 1952 to 1986. The analysis suggests that the two modes are similar for accuracy of responses, but that the face-to-face interview produced more answers considered to be socially desirable. In addition, they found that the telephone interview resulted in higher refusal rates and more missing data particularly in response to open-ended questions. However, the analysis also revealed that the differences between modes are decreasing, possibly because researchers are becoming more experienced in designing questionnaires that are appropriate for use in telephone interviews.

There may be apprehension in using the telephone mode with the elderly because of a concern that they do not have access to a telephone, are incompetent to communicate through this mode, and are unable to provide accurate health status information on the telephone. Although there has been some suggestion of a higher refusal rate as a function of age (Herzog & Rodgers, 1988), other published reports suggest that the elderly are agreeable to participating in surveys (for a review see Hoinville, 1983). Negative opinion on the ability of older individuals to reply to questions on the telephone is not strongly supported by empirical data. To the contrary, recent evidence from population surveys such as Health and Welfare Canada's Health and Social Support Survey (1987) suggests that most older individuals living in the community are active and productive.

In summary, although there is a large body of literature on the use of the telephone mode to elicit information, the study results often conflict with one another or are not comparable because of differences in the design, the group of participants, the data collected or the sophistication of the analyses. It is therefore difficult to come to a final decision regarding the utility of a telephone survey in ascertaining health status. Ideally the comparison of the two modes should be done with identical questions, equivalently well trained interviewers for both modes, and a strong study design that includes a random assignment of the order in which the modes of interview are presented. Although few studies presented here meet all of these criteria, the literature is encouraging enough to warrant a further investigation of the telephone mode as a method of ascertaining health status.

2.3.2 Methods of Insuring High Response Rates in Telephone Studies

The *Total Design Method* (Dillman, 1978) is often cited or expanded upon (Moser & Kalton, 1972; Cannell, Oksenberg & Converse 1977b; DeMaio, 1980; Bradburn & Sudman 1980; Weeks & Moore, 1981; Sudman & Bradburn, 1982; Frey, 1983; Fowler, 1988) as a guideline for achieving high rates of participation. Generally, this method stresses attention to detail including the choice of mode of administration, the format in which the questions are asked, the optimal timing of contacts, the importance of introductory statements and personalized contacts, and the rigorous training of interviewers. What follows is a brief review of some of the more pertinent methodological issues.

Questionnaire content: A now classic text was published by Payne in 1951 (reviewed in Fowler, 1988), that provided guidelines for the writing of clear questions that could be administered as worded. A number of authors have published information on the structuring of questionnaires (Bradburn & Sudman, 1980; Sudman & Bradburn, 1982; Frey, 1983; Streiner & Norman, 1989). Cannell and colleagues (1977a) showed marked differences in the rate at which physician visits, health conditions and hospitalizations were reported based on how questions were phrased. Open-ended questions have been found to elicit less information. For example, reading a checklist of medical conditions to an interviewee resulted in the reporting of more conditions than an open-ended question that requested this information (Belson & Duncan, 1962).

Refusals: Extensive material has been published on ways of increasing participation in surveys (Moser & Kalton, 1972; Dillman, Gallegos, Frey, 1976; Cannell, Oksenberg, Converse, 1977b; Sudman & Bradburn, 1982; Frey, 1983; Lavrakas, 1987; Fowler, 1988). The recommendations include the use of a brief but personalized introductory statement to develop a rapport with the interviewee, the identification of a respected agency conducting the interview, the training of the interviewers to respond to questions and difficult situations, and, the sequencing of questions such that those that are easy to answer come early on.

The use of an introductory letter to give notice of the upcoming telephone contact is somewhat controversial. On the one hand, it may increase the refusal rate (Brunner & Carroll, 1958) but, others have found that it may increase participation if the letter is sent from a respected agency or individual (Dillman, Gallegos & Frey, 1976). Sending a preliminary letter permits the individual to consider his or her willingness to participate and, thus, may improve the quality of responses at the time of the interview as he or she is aware of what is expected.

Completion rates: The vast amount of literature on survey methodology allows one to glean some general concepts on conducting successful surveys. Suggestions include the use of transitional statements to assist the respondent in changing from one topic to another, placement of certain components of the questionnaire early, or late, in the interview depending on how receptive individuals are to a particular series of questions, and the preparation of standard responses to commonly asked questions so that the interviewers are adequately prepared to deal with a variety of circumstances.

Timing of Interviews: A number of studies have examined the optimal day of the week or time of day for finding respondents at home (Dillman, 1978; Jordan, Marcus & Reeder, 1980; Weeks, Jones, Folsom et al, 1980; Vigderhous, 1981). Weekday supper hour or early evening yields good results and requires the fewest number of callbacks. However, as telephone studies have commonly included individuals in young age groups (Dillman, 1978; Jordan, Marcus & Reeder, 1980; Weeks, Jones, Folsom et al, 1980), it is conceivable that the optimal time of day for individuals who are elderly or disabled and non-working may be different from that previously reported.

Interview duration: The total time to complete the interview has been found to play a role in respondent participation (Bradburn & Sudman, 1980). Generally, questionnaires of 20-30 minutes have been well tolerated in the general population with little attrition once the actual interview is underway.

Characteristics of interviewer: Intensive training of interviewers and monitoring of performance throughout the study have also been found to yield more complete questionnaires and fewer refusals (Loosveldt, 1986). In the early 1950's Hyman and colleagues (as reviewed in Fowler, 1988) introduced the importance of interviewer training by demonstrating how bias could be introduced by changing the wording of the questions. Groves and Magilavy (1986) investigated interviewer effects from nine telephone surveys and found that older respondents were more susceptible than other age groups. Bradburn and Sudman (1980) also reported that interviewers' feedback, prompting, and reading errors increased with the age of the interviewee. Oksenber and colleagues (reviewed in Molenaar, 1991) investigated voice quality and found lower refusal rates when the interviewer was judged to have good voice quality. Weeks and Moore (1981) investigated the effects of race on response with no clear answers as to whether an ethnicity effect exists. Dillman, Gallegos and Frey (1976) did not find an effect of interviewer gender on participation rate. One interesting difference has been the higher non-response rate to questions on income when the interviewer found these questions inappropriate (Bailar, Bailey & Stevens, 1977). Although the literature on interviewer characteristics is quite extensive, only one study was found that compared the use of health professionals and lay individuals to ascertain information on health (Wells, Helzer, Robins, McEvoy et al, 1985). Helzer and colleagues (1985) found that lay interviewers, using a standardized assessment, concurred well with psychiatrists' clinical impressions (kappa scores were all greater than .60).

The literature reviewed in the preceding paragraphs indicates that the manner in which a survey is planned and executed is crucial to the quality of the survey results. Questionnaire design is complex, interviewer training is needed and the approach taken to the recruiting of subjects will impact on the success of the study.

2.3.3 Use of Proxy Respondents

There are many instances when a self respondent is not available for questioning or, if available, is not able because of physical or cognitive limitations to provide his or her own information. As the study of those with very advanced age or with neurological conditions escalates, so will the difficulty of ascertaining pertinent health related information for these groups. The options are limited, either exclude these individuals from studies, or, attempt to use proxy respondents to attain information.

The first option, of using only those individuals who are able to respond to a questionnaire, is likely to present a false picture of the outcome or exposure being measured as there will be an overrepresentation of those with good health status. Yet, the introduction of proxy respondents into the study design will result in increased concern over the quality of the responses attained.

Numerous studies have been published investigating the use of proxy respondents (Kaufert, Green, Dunt et al, 1979; Williams Pickle, Morris-Brown, Blot, 1983; Siemiatycki, Campbell, Richardson et al, 1984; Humble, Samet & Skipper 1984; Rubenstein, Schairer, Wieland et al, 1984; Herrmann, 1985a & 1985b; Lerchen & Samet, 1986; Farrow & Samet, 1990) to ascertain completeness and reliability of responses, and, to determine the type of proxy who provides the most accurate information. These studies cover a variety of topics including dietary habits (Humble, Samet & Skipper 1984; Herrmann, 1985a; Lerchen & Samet, 1986), smoking habits (Williams Pickle, Morris-Brown, Blot, 1983; Lerchen & Samet, 1986), medical histories (Hermann, 1985a), mental health (Spear Bassett, Magaziner, Hebel, 1990) and health care utilization (Siemiatycki, Campbell, Richardson et al, 1984). A selected review of the literature most relevant to this study is presented.

Williams Pickle and colleagues (1983) looked at the completeness of proxy responses using information from three case-control studies that investigated respiratory cancer in south-eastern United States. Surrogates were sought with the following preferred order: spouse, child, sibling or *other*, this latter category including distant relatives and friends. Information was collected on the lifetime history of tobacco use, occupation, residence, history of other cancer and chronic lung diseases, and, a number of other demographic variables. There was great variability in the percentage of complete responses achieved, based on the type of questions being asked. For example, 95% of proxies were able to provide information on the subject's level of education and the country of residence at birth, but only 31% could provide answers on the cancer history of the grandparents. While gender of the study subject had little effect, gender of the respondent had some effect on responses with males having lower non-response rates. This male/female difference is probably explained, in part, by the difficulty female proxy respondents had in responding to specific questions on asbestos and shipbuilding exposure in males, while male proxies, when asked about a spouse's or mother's exposure to these variables almost always reported that such exposure had not occurred. Striking differences were also reported according to the type of surrogate. Spouses and offspring were best able to respond to questions about events during adult life, while the *other* category of respondents provided the poorest information on key variables such as smoking history.

Using the telephone mode, Siemiatycki and colleagues (1984) found that proxy respondents were more likely to under-report physician visits and underestimate morbidity as compared to self respondents. Spear Bassett, Magaziner and Hebel (1990) investigated the concordance between responses provided by self respondents and proxy respondents on mental health questionnaires and found a trend towards the proxies reporting poorer psychological well-being, than did the respondents themselves. In contrast, proxies rated cognitive status higher than the actual ability of the respondent.

Kaufert and colleagues (1979) explored the concordance of responses between older individuals recruited from a group general practice and their health care providers on functional activities. The discrepancies were highest for the items assessing outdoor walking and stairs and instrumental activities of daily living while the concordance for items related to feeding, dressing, transferring and walking indoors were better.

Humble, Samet and Skipper (1984) investigated the reporting of dietary information and found that there were differences between males and females in the reporting of food intake, with husbands under-reporting the total intake of vitamin A in their wives, while the wives were more accurate in their reporting of husband's intake. In a case-control study of patients with colon cancer (Hermann, 1985a), agreement for medical history and cigarette smoking was high, with husbands and wives giving equally reliable responses. However, when both the subject and the proxy received interviewer-administered questions, concordance was higher than when the proxy received a self-administered questionnaire.

Recently, Farrow and Samet (1990) compared the responses of proxies and patients for health and functional status, social network, and life events using in-person interviews and a standardized assessment of functional status, the modified Katz Index. Patients were all older than 65 years of age and had recently been diagnosed with cancer of selected sites. Proxies included spouses, children and friends. Spouses were least likely to report that they *did not know* the response to a question followed by children, and then by friends. Agreement about health status, as measured by the existence of 19 medical conditions, was generally highest when attained from a spouse, then a child, and, finally, a friend, with the kappa values being .67, .52, and .44, respectively. The kappa values for the performance of activities of daily living such as bathing, dressing, cooking and shopping ranged from .67 to .33 (Farrow & Samet,1990). Although these kappas ranged from only fair to quite good, information provided by the authors on the percentage of patients and proxies reporting functional limitations was very similar for all eight functional areas described. This possible contradiction may have resulted from the very low prevalence of functional impairment in the group under study, for example, only 1.8% of subjects reported that they required help going to the bathroom. With the prevalence of the trait under investigation being this low it would have been difficult to achieve higher values of kappa. Agreement of surrogates for depression, a condition that only 4% of subjects reported as being present, was indicated to be poor by the authors but was in fact quite good if the respondent was a spouse (*k* = .60), and was only less satisfactory when the proxy was a friend (*k*=.36), or a child (*k*=.22).

Rubenstein and colleagues (1984) investigated the effects of different data sources on the reporting of functional status of hospitalized patients. For the items on a functional index the agreement between patients and proxies was exact at least 60% of the time. Telephone interviews were used when proxies were not available for in-person interviews. When overall differences in reporting of function occurred it was almost always in the direction of the patient rating his or her function level significantly higher than the functional status reported by nurses, family and friends. Proxies having more contacts with the patient scored them lower in function, than did proxies who visited fewer times. The lowest scores of function were those derived from spouses. The authors suggest that the spouses may have wanted to stress the burden of care that would be required if the patient was discharged from hospital. In addition, the possibility of discrepant findings because of the use of the telephone mode for a sub-group of proxies is also postulated.

In a study by Magaziner and colleagues (1988) the crude agreement between proxy and self respondent on activities of daily living and instrumental activities of daily living such as shopping, meal preparation and housework was quite high whereas the kappa statistics indicated that the reliability was only *poor* to *good* for most items. The discrepancy may have been due in part to the difficulty in arriving at consensus when using a four-point scale. In addition, some of the discrepancy may have been associated with the instability of the Kappa statistic, because the prevalence of the characteristics under study were generally low. The trend again was for proxies to score the patient as more disabled than did the patient himself. Those proxies with the more frequent contact with the patient responded most similarly to the patient.

Two of the studies cited above (Rubenstein, Schairer, Wieland et al, 1984; Magaziner, Simonsick, Kashner et al, 1988) reported that the individual's ability to perform activities of daily living was scored lower by relatives than by the individual himself. In contrast, Farrow and Samet (1990) reported no trends towards over- or under- reporting of events by surrogates. However, examination of the tables presented by Farrow and Samet, for the eight items on function, suggest a consistent, albeit small, trend towards the reporting of greater functional impairment by the proxy than by the self respondent.

Epstein and colleagues (1989) investigated responses to overall health, functional status, social activity, and satisfaction with medical care, in patients and proxies. Individuals were 60 subjects and 60 proxies selected from persons over the age of 65 who were eligible to receive health care at a university health service. Generally, correlation on social activity, emotional status, overall health and functional status was good, ranging from r=.62 to r=.73, with stronger subject-proxy correlations evidenced for those pairs who saw each other more often. When there were discrepancies in the reporting of functional status, health, and social activity, the proxy consistently rated the subject to be more impaired than did the subject. The one notable exception was that subjects who had the poorest health tended to rate themselves lower than did the proxies. It is to be noted that the authors used tests for trend such as Pearson Product Moment Correlations and comparisons of means, rather than the more appropriate measures of concordance. Thus, if there were consistent differences between the raters, the correlation coefficients may have been higher than the corresponding kappa scores.

In the absence of a gold standard for comparison, when answers provided by proxy respondents conflict with those offered by self respondents, it is difficult to determine which of the respondents is more accurate. McLaughlin's group (1990), in an attempt to address this question, investigated the concordance of a 1980 interview and a 1984 interview for both self respondents and proxy respondents. Next-of-kin responders were as reliable as self responders in recalling smoking status after four years. Overall, spouses were more accurate in reporting cigarettes smoked per day and packs smoked per year compared with self respondents, but, were less accurate on the reporting of alcohol consumption.

A methodological issue when assessing all of the literature on proxy-patient comparisons of responses is that some of the lack of concordance between the two responses would have occurred even in a test-retest of the same individual and, therefore, poor concordance cannot be explained simply by the use of the proxy. Rather, it may be a result of other factors such as the quality of the questions being asked. For example, it has been our experience that when a patient is asked if he or she is able to bathe, eat, or walk, he may respond differently from when the question is asked in a very specific format such as *if there was no one to help you with the following functional activity could you do it alone or would you need someone's help*. In all of the studies comparing patient-proxy responses on function (Rubenstein, Schairer, Weiland et al, 1984; Magaziner, Simonsick, Kashner et al, 1988; Farrow & Samet, 1990) there was no information provided on how the interviewers were instructed to ask the questions. Yet, the phrasing of questions is crucial to the quality of the responses.

Using information provided by proxy respondents warrants prudence as the results may be influenced in a number of ways. If misclassification of patients by proxies is random there will be a loss of precision (Nelson, Longstreth, Koepsell, et al, 1990) which, although disturbing, may be less serious then systematic bias. Systematic bias will arise if self respondents consistently report their status as higher, or lower, than that reported by the proxy. Depending on the purpose of the assessment this may, or may not, have serious implications. For example, if health status is being ascertained for the purpose of providing some form of intervention, then the bias introduced by the consistent over-reporting of symptoms or dysfunction by proxies might result in more frequent or intense intervention for the patient group assessed through a proxy. Although this is not a desirable scenario and may be wasteful of limited health care resources, the alternative, that is the under-reporting of impairment or disability by proxies would have more serious implications because of the possible lack of necessary intervention.

In case-control studies, the use of proxy respondents is a reason for concern, assuming that proxies are more likely to be needed for the cases and assuming that this unbalanced representation by proxy respondents distorts effect estimates if the probability of misclassification is greater in the proxy group (Walker, Velema & Robins, 1988). For example, if the outcome variable of interest was functional ability and if more proxy respondents were used to respond for the cases than the controls, a consistent tendency for proxies to score patients lower then the patients would score themselves would result in the cases appearing to be more impaired in function than the controls when, in reality, no such difference existed. In spite of these concerns the alternative, to exclude those cases that are unable to answer for themselves, is likely to distort truth to an even greater extent.

Overall, the review of the literature on the use of proxy respondents suggests some value to their use. However, it has been noted that there is considerable variability in the quality of responses based on the type of proxy being interviewed and the types of questions being asked. These issues have received strong consideration in the design of the present study.

2.4 SUMMARY OF THE LITERATURE

The literature strongly suggests that those who leave a rehabilitation hospital continue to experience health related problems after their discharge. A review of the health status assessment literature indicates that tools have been created to measure the health constructs of interest.

A review of the extensive literature on survey methodology reveals that the quality of the responses ascertained from a telephone administered interview is influenced by the quality of the questionnaire design, the approach taken when recruiting subjects and the intensity of interviewer training. Response rates on telephone administered interviews have been good, and are getting better. Thus, the telephone interview is a feasible means of ascertaining information. Although the literature points to differences in the quality of responses based on the type of proxy, be it a close family friend, spouse, or child, it appears that proxy respondents are potentially useful.

The final evidence needed before launching a health status assessment program relates to the effectiveness and availability of health related resources. Clearly, there is no benefit to a program that cannot take action based on its findings. The literature provides evidence that implementing interventions in those thought to be at high risk has resulted in reduced morbidity, mortality and medical care utilization. In addition, investigation of the health care resources available in Quebec indicates that needed services are available and expanding.

CHAPTER 3: OBJECTIVES

The primary objective of this study was to assess the comparability of estimates of health status elicited through a telephone interview with estimates of health status elicited through a face-to-face interview.

The secondary objectives were:

1. to assess the comparability between the modes of interview (telephone and in-person) according to the type of interviewer, health professional or lay individual,

2. to assess the comparability between the telephone and in-person interview according to the type of respondent, self respondent or proxy respondent.

The ultimate goal was to determine the usefulness of a telephone administered health status questionnaire in identifying conditions such as depression, functional impairment and negative health events in the individual.

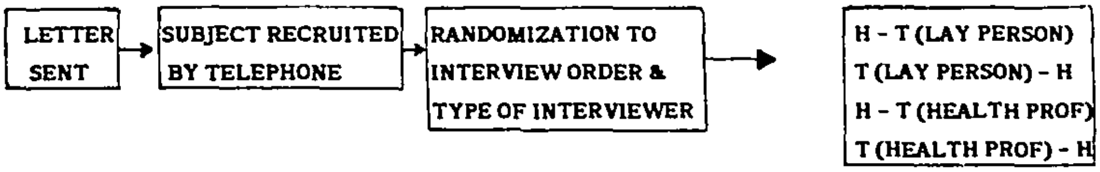
CHAPTER 4: MATERIALS AND METHODS

4.1 OUTLINE OF STUDY DESIGN AND ANALYSES

A cross sectional, analytical study was conducted to compare a telephone interview and an in-person interview in assessing health status. The health status assessment included measures of mood, functional performance, community reintegration and cognitive status and questions on illness, hospitalization, falls, and medication use. The questionnaire was administered twice to each patient, once on the telephone and, again, in a face-to-face interview in the home. Half of the patients were randomized to receive the phone interview followed by the home interview (order T-H) and half were randomized to receive the home interview followed by the telephone interview (order H-T). The interviews were normally scheduled three days apart. For patients unable to be interviewed because of language barriers, aphasia, severe hearing loss or cognitive dysfunction, we chose a close relative or friend to act as a *proxy* respondent. The telephone interviews were conducted by either trained lay interviewers or occupational therapists: the assessments in the home were performed by occupational therapists. All interviewers received three days of training and each interviewer participated in a minimum of eight practice sessions.

The comparisons of the telephone/home interviews were based on two statistical concepts, agreement and accuracy. Agreement is commonly used when two measures are thought to provide approximately equivalent quality of information. Alternatively, measures such as sensitivity/specificity and positive and negative predictive value are commonly used when one of the measures is considered to be superior. In this study the home assessment, conducted by well qualified therapists who underwent intensive training on the use of the questionnaire, could be argued to be a close approximation to a *gold standard*. Yet, the telephone and home interview questionnaires are virtually identical and there is no body of literature that suggests that the home interview mode is superior to the telephone mode. Thus, it was deemed justifiable to perform the comparisons of the telephone/home information using both groups of measures. These analyses were performed for the group as a whole, and according to type of respondent (patient or proxy) and type of interviewer (lay or professional). For the assessment of sensitivity/specificity and positive and negative predictive validity, the face-to-face home interview was considered to be the *gold standard* against which the telephone interview was compared.

VISUALIZATION OF THE STUDY DESIGN



4.2 OVERVIEW OF THE COMPILATION OF THE HEALTH STATUS ASSESSMENT

The goal was to assemble a generic health status battery that consisted of reliable and valid tools, that could be administered either on the telephone or in-person and that required only a short time to complete. To be suitable for administration on the telephone, we required instruments that did not demand written responses or the viewing of visual stimuli, had a limited number of response options, were simply worded, and, would be sensitive to changes in health status. As a first step in deciding what should go into a health status assessment, a meeting was held with the multi-disciplinary team conducting follow-up of patients after their discharge from hospital. Representatives from each discipline, including physical therapy, occupational therapy, nursing, psychology, social service and nutrition were asked to choose key areas that they considered pertinent in the evaluation of patients once they returned home. After much discussion, the following areas of health status were identified as being important to assess: *physical functioning, mood status, extent of reintegration into the community, cognitive status, medication use, illness, hospitalizations and occurrence of falls.* An extensive review of available questionnaires was conducted to identify those that would be suitable for use in the proposed study and in future clinical practice and research. One instrument was chosen for each component based on its content, reports on validity and reliability and on the practicality of its administration on the telephone and in the home.

The Barthel Index (Mahoney & Barthel, 1965) was selected to measure physical functioning, the Zung Scale (Zung & Durham, 1965) to measure mood, the Pfeiffer Short Portable Mental Status Questionnaire (Pfeiffer, 1975) to assess cognition and the Reintegration to Normal Living Index (Wood-Dauphinee, Opzoomer, Williams et al, 1988) to assess instrumental activities of daily living, social activities and the individual's satisfaction with his level of functioning. All of the components, except the cognitive status assessment, were piloted in both French and English over a seven month period in 1989 by the follow-up team of the JRH. Detailed information on each component of the questionnaire can be found later in the section on Components. Copies of the assessments can be found in Appendix A.

4.3 SETTING

This study targeted patients discharged from the Jewish Rehabilitation Hospital (JRH), a 120-bed rehabilitation facility that provides in-patient adult physical rehabilitation for individuals living in Montreal, Quebec and surrounding regions. More than 900 patients are admitted to this hospital each year; 60% are female and 40% are male; one-third are French speaking and two-thirds are English speaking. Forty percent of patients are of the Jewish faith, 40% are Roman Catholic and the remaining are of various religions. Seventy percent of all patients admitted are over the age of 65 years; nearly one half are 75 years of age and over. Approximately 20% of patients are admitted for rehabilitation following a stroke and 40% of patients are admitted for treatment of orthopaedic conditions. The remaining 40% consist of those with other neurological conditions, musculoskeletal conditions or those who are receiving post-operative convalescent care. The average length of stay for stroke patients is 70 days while for orthopaedic patients it is 48 days. Approximately 80% of patients are discharged directly home.

4.4 TARGET POPULATION

We sought to accrue a representative cohort of individuals with conditions that should not manifest fluctuating health status over the three to four day period between interviews. To expedite the identification of eligible individuals, a cohort admitted to the JRH from April 1, 1986 to March 30, 1989, was chosen. It consisted of two prevalent patient groups seen for rehabilitation, those with an orthopaedic condition (most often a hip fracture) and those with a stroke.

4.5 ELIGIBILITY CRITERIA

The following criteria were used for inclusion in the study:

1. a primary diagnosis of stroke or orthopaedic condition at time of admission;
2. living at home; for the purposes of this investigation a patient was considered to reside at *home* if he or she lived either alone, or with friends or

family in a private dwelling, apartment, or senior citizen's residence. Those in acute-care hospitals, foster homes or long-term care facilities for the duration of the project were considered to live in an environment other than home and were therefore not eligible.

The following exclusion criteria were applied:

1. living outside of a 30 mile radius of the hospital;
2. a co-morbid condition characterized by frequent fluctuations such as Parkinson's Disease, or a progressive malignancy;
3. expected absence of the patient or proxy from the Montreal area for the duration of the project;
4. grave illness or death;
5. a language barrier in both patient and proxy;
6. no suitable proxy when one was indicated.

Patients admitted to the JRH more than once during the study period for a stroke, or an orthopaedic condition, were eligible for inclusion only once, based on the most recent admission.

4.6 SAMPLE SIZE CONSIDERATIONS

We required a sample size sufficiently large for the formation of the separate strata consisting of type of respondent (patient or proxy) and type of interviewer (lay or professional). As it was anticipated that receiver operating characteristic (ROC) curves would be plotted as part of the statistical analyses, Hanley and McNeil's (1982) calculation of sample size for the area under a curve formula was considered in the determination of the necessary sample size. In addition, sample size calculations for reliability coefficients were calculated. As ROC curves were not utilized in analyzing the results of this study, we present here only the sample size formula for reliability coefficients. However, the two formulas provided similar sample size requirements.

The goal in a reliability study is to have reliability coefficients that are close to the *true* reliability coefficients. When the confidence interval around the coefficient is narrow, there is some assurance that this is so. Confidence intervals are influenced by the sample size such that $N= (Z_{a/2}/CI)^2 +3$, using $Z_{a/2} = 1.96$ (for a 95% confidence interval). Using this formula, we would require 387 subjects to estimate a reliability coefficient with a 95% CI of width 0.1 (Streiner & Norman, 1989). For example, with a reliability coefficient of 0.75 a confidence interval would range from 0.70 to 0.80. Alternatively, a sample size of 174 individuals would result in a 95% CI of ±0.15. Thus, it was our goal to have group sizes with a minimum of 174 individuals to explore the effect of interviewer type and respondent type.

Given that approximately 100 stroke patients and 200 orthopaedic patients are discharged home from the JRH each year, we anticipated achieving the desired sample size by drawing from patients discharged over a three year period. Based on estimates from a longitudinal study of stroke patients (Bacher, Korner-Bitensky, Mayo et al, 1990) we projected that approximately 80% (240) of patients discharged home would still be living at home after one year and would continue to meet the other criteria for inclusion: by the second and third year we expected a drop to 75% (225) and 65% (195), respectively. From pilot work on this questionnaire (where participation was greater than 90%) we projected a consent rate of 80% in the 660 eligible individuals. Thus, we calculated 528 potential participants. The number of anticipated proxy respondents was based on identifying those who had severe hearing loss, aphasia, cognitive impairments, or, who were documented to be very frail. We estimated that 40% of potential participants would be proxy respondents - sufficient numbers to study the proxy responders and self-responders separately. By randomizing an equal number of proxies, and, an equal number of self-responders to be interviewed by either a lay or professional interviewer, we expected sufficient numbers in these strata to study the effect of interviewer type. If sufficient sample size could not be achieved using the three years of patients, we had access to hospital records for patients discharged from previous years. In fact, when it became evident, midway through the study, that we were not recruiting sufficient numbers of individuals in the proxy category, charts of patients with stroke admitted from the years 1984 and 1985 were also scrutinized in an attempt to increase the numbers of proxy respondents.

4.7 PROCEDURES

4.7.1 Recruitment of Participants

A letter explaining the purpose of the study and requesting participation (Appendix B) was sent to each eligible patient. Letters were sent approximately three to five days prior to the anticipated day of contact by the project Coordinator. There were 16 mailings, sent out in batches of approximately 40 each. A final mailing of 180 letters was sent with the specific purpose of recruiting proxy respondents (Appendix B). This last mailing was directed only at proxy respondents as by this time the targeted number of self respondents had been obtained and it would have been costly to continue to include self respondents when only proxy respondents were required.

4.7.2 Telephone Tracing Procedure

A trained research assistant was responsible for reviewing the charts of eligible patients to identify the patient's address, home telephone number, the telephone numbers of family members and friends, and other contacts such as the family physician. The following protocol for telephoning patients was implemented. A telephone call was defined as reaching an active number allowing for a maximum of 12 rings or reaching a number with a busy signal. For busy signals, the Coordinator redialed the number at approximately five minute intervals until they were successful in reaching the patient or proxy or at longer intervals until the end of the work day. Renewed attempts to contact the patient continued the following day or, if it was a Friday, on the following Monday.

The procedure for phone calls with no answer was as follows. The first three phone calls were made, at varying times of day, within a two day period, to the patient's last known number. If the patient or proxy was not reached on the second day, the Coordinator called the other recorded numbers to ascertain if the number called was correct, to determine the current address and to identify the patient's current eligibility. Patients or other contacts who were not reached within the two day period were added to the list to be phoned the following week. If after two weeks an individual had not been contacted, telephoning attempts continued in the evening, or on the week-end. Attempts to contact individuals continued on a weekly basis until the end of the study.

These telephoning procedures were implemented to permit each participant an optimal opportunity of being contacted thereby reducing possible bias from the over-representation of easy to contact individuals. The total number of telephone calls made and the time taken to contact and interview each subject was documented on a telephone call sheet (Appendix C). A maximum of 25 phone calls (including no answer, busy signals etc.) were made in attempting to reach each patient. A limit was placed on the number of phone calls because of time and cost.

When a patient or proxy was contacted, the Coordinator ascertained the current eligibility status. After determining that the individual was eligible for inclusion, she explained the purpose of the study, obtained verbal consent, and arranged the time of the home and the telephone interviews. Written consent was obtained at the time of the home visit by the occupational therapist (Appendix D).

For individuals who were hard to trace, the procedures were as follows. Attempts were made to contact the family, friends and physician identified on the medical charts or from the temporary discharge form. The hospital's follow-up records, including information from the social service department and the multi-disciplinary follow-up team, were reviewed to identify any additional information on the patient. Telephone operator assistance was used to trace patients or their next of kin but this form of tracing was found to be less productive than the telephone directory. Using the directory it was possible to trace many of the patients who were difficult to find, by identifying family members having the same surname or maiden name.

In an effort to trace hard-to-contact individuals a directory indexed by address was used to identify former neighbors who might know the whereabouts of the patient. In addition, a list of names of the untraced individuals was submitted to the *Ministère de Justice, régistre de référence, l'état civile* of Quebec, who identified those who were deceased.

4.7.3 Identifying Type of Respondent

From the review of the medical charts we had pre-categorized individuals according to anticipated type of respondent, self or proxy. The need for a proxy respondent was anticipated if the patient was noted to have any of the following: severe hearing impairment, dementia, a severe comprehension or expressive disorder, decreased alertness, confusion, lack of concentration or a language barrier.

At the time of the initial telephone contact we first asked to speak with the patient. When the ability of the patient to be a self respondent was doubtful, the Coordinator asked the patient a few structured preliminary questions to evaluate the individual's ability to respond to questions regarding current health status.

If the individual answering stated that the patient could not communicate on the telephone, the reason was documented and, if appropriate, the patient was considered to require a proxy respondent. Ability to act as a proxy was based on two criteria: that the proxy be able to speak either English or French and that the individual have face-to-face contact with the patient a minimum of three times a week. If such an individual was available, then the purpose of the study was explained and the potential proxy was requested to participate.

4.7.4 Allocation of Subjects

Once the Coordinator had ascertained the type of respondent to be interviewed and the individual had agreed to participate, he or she was given a study assignment based on a pre-determined randomization schedule. Randomization was performed within the strata formed by type of respondent (self or proxy). Subjects were randomized to one of four possible interview strategies according to the type of interviewer performing the telephone assessment and according to the order of the telephone/home interviews. The four strategies were:

	I	II	III	IV
FIRST INTERVIEW	HOME	TELEPHONE	HOME	TELEPHONE
SECOND INTERVIEW	TELEPHONE	HOME	TELEPHONE	HOME
TELEPHONE INTERVIEWER	LAY	LAY	PROFESSIONAL	PROFESSIONAL
SHORT TITLE	H-T(LAY)	T(LAY)-H	H-T(PROFESSIONAL)	T(PROFESSIONAL)-H

For the self respondents the sequence of randomization was prepared using a Table of Random Numbers with permutations of 16 (Cochran & Cox, 1957). Within each block of 16 there were four assignments to each group.

The entire randomization procedure was repeated for the proxy respondents, using another set of envelopes numbered from 1 to 250 and again using permutations of 16, and a different set of Random Numbers.

The process of assignment was followed without replacement such that on the rare occasion when the randomization had been made and the individual was unable to participate at the time of the interview, the allocation for that individual was not given to another. This randomization procedure was prepared by the biostatistician on the project (S.S.) and was rigidly followed throughout the study.

4.7.5 Scheduling of Interviews

Both the telephone and the home interview were scheduled by the project coordinator at the time of her initial telephone contact with the respondent. The goal was to conduct interviews three days apart, as we considered this time span to be a reasonable balance, long enough to permit forgetting the exact response given on any one item, yet short enough to avoid changes in the health status of the individual. As there was some concern that those being interviewed would assume that only additional information was desired at the time of the second interview, the patient or proxy was told that they were to provide information in full during the second interview and not only to provide additional information. Interviewers were told to ascertain that any events such as falls, reported to have occurred from the time of the first interview to the second interview, be indicated so that the patient's responses could be adjusted accordingly. For example, if the patient fell in the interim between interviews then that fall would be subtracted from the total number of falls reported to have occurred in the past month.

4.7.6 Partial Interviews and Refusals

During the study, interviewees who expressed fatigue or a desire to discontinue the telephone interview were asked if the interviewer might call back at another convenient time. Based on the outcome of the re-phoning effort, those interviewed were to be considered complete responders if they completed the entire interview, partial responders if they completed some sections of the questionnaire, or refusers, if they completed no component of the questionnaire. For the home visit the criteria was slightly different: because of the additional cost that would have resulted from the revisiting of partial responders the decision was made to conduct only one visit for each individual. Our experience in the pilot phase had suggested that partial responses and refusals during the home visit would be extremely rare.

4.7.7 Choice of Interviewers

Telephone interviews were conducted by four trained lay interviewers and by three trained occupational therapists: home visits were conducted by five occupational therapists. Lay interviewers were individuals who had no specific training in any health care field and no previous experience in interviewing. All interviewers were female. All spoke both French and English and received training in administering the health status questionnaire in both languages during the preliminary stage of the study.

The home assessment was considered to be the closest approximation to a *gold standard* mode of eliciting health status. Therefore, it was deemed necessary to use professional interviewers for all home interviews. The home visit was conducted by occupational therapists for a number of reasons. During the pilot phase nurses, physical therapists and occupational therapists performed the assessments. The general impression of the follow-up team was that the occupational therapists were well suited to the global assessment of health status, in persons discharged from a rehabilitation hospital. For example, in completing the functional assessments in the home it was sometimes necessary to have a stroke patient demonstrate his or her ability to climb stairs, or to do bath transfers independently. The occupational therapist had the knowledge to judge the ability and safety of the individual.

The occupational therapists were all registered, certified and had, at minimum, a Bachelors Degree in Science. Each of the five occupational therapists chosen to perform the home interviews had at least five years of experience in the treatment of adults with physically disabling diseases. The three occupational therapists who performed the telephone interviews had similar credentials. One occupational therapist began the study performing the telephone visits and then became a home interviewer. Thus, there were a total of seven occupational therapists who participated in the study. All therapists administered the health status questionnaire in either French or English: one therapist felt more comfortable performing interviews in English and thus only performed one French interview.

4.7.8 Training of Interviewers

All interviewers participated in intensive training and their performance was monitored throughout the study. Each was given a global orientation session during which the various components of the health status questionnaire were reviewed and unclear questions or instructions identified. The interviewers were then given one week to review the questionnaires and were asked to practice on family members or friends. After this interval we began practice sessions that were carried out on a convenience sample of hospitalized patients with stroke and orthopaedic conditions and their families.

Interviewers were trained to conduct interviews only in the mode that they were assigned to administer during the study. Patients were chosen who represented varying levels of function so that the interviewers would have experience with assessing patients at differing levels. After each interview, discrepancies between raters were identified, discussions held, and guidelines established to reduce the potential for inconsistent recording of patient responses. Further information on these guidelines can be found in Section 4.9.4. A total of 22 practice interviews were conducted, 8 for the face-to-face interview mode and 14 for the telephone interview mode: 18 were performed on self respondents and 4 on proxy respondents.

4.7.8a Face-to-face interviewer training

For the face-to-face interview training sessions patients were interviewed, in a quiet room in the hospital, by one of the occupational therapists designated to perform the face-to-face interviews in the home. Each interviewer had the opportunity to perform some of the practice interviews while the other face-to-face interviewers observed and completed the questionnaire independently. A total of eight patients with varying degrees of disability were assessed. After each interview discordance was discussed and rules and guidelines established to clarify scoring. For the last four patients there was perfect agreement amongst all of the therapists on all the components of the questionnaire. At that point we considered the training complete. Figure E-1 in Appendix E presents the numbers of errors and omissions on each of the face-to-face practice sessions (trials), for each component of the questionnaire. A summary of the problems and the guidelines established to optimize agreement can be found in Section 4.9.4.

4.7.8b Telephone interviewer training

The telephone interview training sessions were conducted by phoning patients in their rooms from a hospital telephone equipped with a voice projection apparatus. Each telephone interview was conducted by one of the interviewers while the others listened to the dialogue and completed the health status questionnaire independently. Training sessions were to continue until patients with a range of disabilities had been assessed and until there was total group agreement on the scoring of the components of the questionnaire for three consecutive patients. Four practice sessions were held with three to four patients interviewed at each session. There were more practice sessions necessary for the telephone interviews because of the complexity of working out the telephone system, of getting lay interviews accustomed to speaking with patients and of having therapists and lay interviewers working together. During the first session the logistics of using the telephone mode, and differences between the way the lay and professional interviewers would answer specific items, were discussed. During the next three sessions the questionnaire responses for each interviewer were recorded. After each interview, discordance was discussed and rules and guidelines were established. Care was taken to maintain consistency between the rules and guidelines established for the home and for the telephone interviews. By the fourth session there was perfect agreement on the scoring for the last three patients. Thus, we considered the training complete based on our apriori decision to discontinue the practice sessions when there was unanimity on three consecutive patient assessments. Figure E-2 in Appendix E presents the numbers of errors and omissions, on each patient assessment (trial), for each component of the telephone administered questionnaire.

4.7.9 Ongoing Surveillance of the Interview Process

Two months after the study had started, a meeting was held with all team members to discuss any problems that the telephone and home interviewers might be having, to identify inconsistencies in reporting, and, to reiterate the importance of following the study protocol. A number of specific concerns, based on the ongoing input of the interviewers, were raised. The resulting actions, based on the feedback received, are reported below:

(1) Participants at times appeared to have forgotten a number of pieces of information presented to them at the time of the first telephone contact. These included the purpose of the study, the fact that there were two interviews being performed, and that they needed their medications in front of them at the time of the telephone contact. The interviewers were therefore instructed, before initiating the assessment, to verify that the interviewee understood the exact nature of the study, had the medications ready and was aware that the study consisted of two interviews.

(2) The interviewers expressed difficulty in coming to decisions on how to complete a number of sections of the questionnaire. The first was in completing the item that identified how much confidence the interviewer had in the interviewee's replies for a particular component of the assessment. This item required the interviewer to state, with a *yes* or *no* response, whether they felt the respondent had given accurate information. An example of such a situation might be a patient reporting that he or she was not depressed while seeming to be very depressed. After much discussion, it was decided that any doubts about the interviewee's replies constituted non-confidence and should, therefore, be marked as a *no* on that section of the questionnaire.

Another concern was the final item on the questionnaire that required a judgement about the patient's need for intervention. Some interviewers documented a need for intervention for relatively minor concerns such as the participant wishing to have more contact with his or her family. The interviewers discussed needs that constituted intervention and came up with a satisfactory list of examples, such as a patient requiring assistance with bathing and not having anyone available to assist him, no food in the house, patient appearing confused about medications, to name a few.

General reminders were given by the researchers including the need for completed questionnaires. For example, if the patient had not fallen, the question on falls was sometimes left blank rather than the interviewer noting that no falls had occurred. The researchers also reiterated the need for the home interviewers to request that the patient perform a functional activity such as walking if it was felt that there was a discrepancy between the verbal report, and the appearance or behavior of the patient.

During the pilot phase the Zung Scale was identified as being unpopular with some respondents. The proxy respondents found it especially difficult to report on the patient's mood status with the patient in the room. Although no specific solutions were presented, the discussion highlighted the need for eliciting this information, when possible. We also reaffirmed that the interviewer should discontinue if the respondent appeared extremely uncomfortable.

4.7.10 Data Collection

There were five main data collection and data entry phases in this study:

1. Computerized hospital records were reviewed to identify all patients discharged home with a primary diagnosis of stroke or an orthopaedic condition during the defined period. The name and chart number of each of these individuals was entered into a computerized data base management system.

2. Medical charts of all individuals identified from the hospital records to meet initial eligibility criteria were reviewed and pertinent medical and socio-demographic information was recorded on the data entry form (Appendix F).

3. Information from the introductory telephone contact was also collected on the data entry form (Appendix F) and on the telephone call sheet (Appendix C) and included information on the current status of eligibility of the patient, the total time and number of calls required to trace the patient or proxy and the time taken to explain the study and obtain consent.

4. The information from the telephone administered health status questionnaire was entered into the database (Appendix G).

5. The information from the face-to-face interview in the home was entered into the database (Appendix H).

4.8 QUALITY OF THE DATA

The research assistants responsible for abstracting the basic medical and socio-demographic information from the medical charts had participated in research projects before and had undergone both informal and formal inter-rater training on the variables being collected.

During the initial period of the study the telephone interviewers were supervised by the principal investigator to ascertain that the questions were being asked as per the study protocol. The therapists and lay interviewers who conducted the interviews submitted the completed questionnaires to the project coordinator either at the end of the day or within a few days of the interview. Each questionnaire was then reviewed by the coordinator for its completeness. For questionnaires that were incomplete, the interviewer was contacted to provide the missing information, or, if uncertain of the correct response, was asked to re-contact the patient to verify the response to a particular question.

The following steps were taken to insure that the information was accurately recorded. First, the information was routinely entered into a computerized data base system along with other information on the patient. The research assistant, after entering the information from each questionnaire verified her entries against the questionnaire. The project coordinator then compared a printout of the patient's record with the data on the questionnaire. To further verify that the information on the computer database was identical to the information on the questionnaire a five member team, including the principle investigator, re-verified all of the questionnaires against the computer printouts. At that time additional errors were identified and changes were made in the computer database.

4.9 THE HEALTH STATUS ASSESSMENT

4.9.1 Selecting Scales

The identification of the tools used in the present study began with a broad search through the health status literature. The review of the literature suggested that there were scales in existence to measure each aspect of health including functional status, cognitive and emotional status, quality of life and social reintegration into the community. As there was such an abundance of work to choose from, the process of elimination had to be performed in some logical manner. Aggregate scales were first reviewed, but, no one scale covered all of the areas that we wished to include or they were too extensive to be practical for use over the telephone. Unidimensional assessment tools were reviewed to identify those that were usable on the telephone and that would serve well with individuals of differing ages who had multiple and varying health conditions. Scales were also critiqued according to their proven reliability, validity and simplicity of administration. Following an extensive review of the literature, we chose the following assessments: the Barthel Index (Mahoney & Barthel, 1965) for the measurement of functional ability, the Zung Scale (Zung & Durham, 1965) for the assessment of mood, the Pfeiffer Short Portable Mental Status Questionnaire (Pfeiffer, 1975) to assess cognition and the Reintegration to Normal Living Index (Wood-Dauphinee, Opzoomer, Williams et al, 1988) for the assessment of quality of life and social reintegration into the community.

4.9.2 Piloting the Questionnaire

The health status battery includes the components mentioned above, as well as questions on health and health events including medication use, illness, hospitalizations and falls. French and English versions of the scales were piloted, over a seven month period, on more than 100 patients who had been discharged from hospital. As noted previously, the telephone interviews and home visits were initially conducted by nurses, physical therapists, and occupational therapists. After much discussion, occupational therapists were chosen by the clinical follow-up team as being the most suitable to perform a general health assessment of patients discharged home from a rehabilitation hospital. Weekly meetings were held to document the feedback from the interviewers and to make revisions to the questionnaire as necessary. Revisions included shortening the questionnaire, eliminating repetitive questions and simplifying or rephrasing instructions or questions that the patients found difficult to understand.

Revisions were made on both the English and French versions of the indices. French speaking individuals and English speaking individuals translated and then back-translated these revisions. These individuals were not professional translators. To identify any gross discrepancies between the English and French versions, in 83 patients with complete data, the frequency distribution and mean scores on each scale were investigated by language of presentation. There were no striking differences on any of the three scales according to language of presentation and we, therefore, felt reasonably confident that the two versions were comparable.

The following section describes, in detail, each component of the assessment used in this study and includes a description of the revisions made as a result of the pilot work. The same questionnaire forms were used for both the telephone and face-to-face interview with minimal differences in administration based on mode. For example, in the home there was the option of requesting clarification by demonstration, or, of restating the question if the patient's responses were judged to be inconsistent with the therapist's observations.

If a proxy respondent was used, the questions were asked with minor rephrasing to refer to the patient. The proxy was asked questions from each component of the assessment except the one relating to cognition. For the assessment of cognition we attempted to have the patient respond even when a proxy was being used for the other components of the assessment.

4.9.3 Components of the Questionnaire (Appendix A)

4.9.3a Physical function

Physical function was measured using the Barthel Index (Mahoney & Barthel, 1965). This Index contains 10 items evaluated on a three-point scale. The Index has both a self-care and a mobility component. Self-care includes items related to eating, grooming and toileting; the mobility component contains items related to transfers and ambulation. Scores range from 0 to 100 with higher scores signifying better functioning. The Index has been shown to have high inter-rater reliability: Shinar and colleagues (1987) investigated the inter-rater reliability on stroke patients and found high correlation (r=0.99) using Pearson and Spearman correlations. In a group of 20 neurological patients, Roy and associates (1988) reported an inter-rater reliability of 0.88. Wylie and White (1964) looked at predictive ability of the Barthel Index against 6 month mortality in 486 stroke patients and found it to be predictive. Another study (Granger, Dewis, Peters et al, 1979) examined initial Barthel scores of 110 patients against length of stay and place of discharge. A Barthel score lower than 40 was predictive of fewer discharges home and scores higher than 60 were predictive of a shorter length of stay. The Barthel Index has been used in a variety of settings (Granger, Dewis, Peters et al, 1979; Risteen Hasselkus, 1982; Shinar, Gross, Bronstein et al, 1987) and a modified version of the Index has been used in a telephone interview of stroke patients (Shinar, Gross, Bronstein et al, 1987).

In our study, the individuals conducting the telephone interviews had only the verbal responses of the patient on which to base their answers. The face-to-face interviewers had the added advantage of requesting that the patient perform one or more of the functional activities if there appeared to be a discrepancy between the patient's self report and his or her apparent physical capabilities. The interviewers involved in the pilot phase reported one specific inconsistency regarding the administration of this component. Some respondents would specify that they required assistance with a functional activity, yet, in the face-to-face interview it was evident that the patient was independent. The differences arose because of discrepancies in how the questions were asked so that some patients were reporting on what they were capable of doing rather than on their actual performance. We phrased the questions in the following manner *If there was no one to help you with the following functional activity could you do it alone or would you need someone's help?* If help was required then the amount of help was ascertained so that the three level scale of the Index could be completed.

4.9.3b Mood

We chose to use the short version of the Zung Self-Rating Depression Scale (Tucker, Ogle, Davidson et al, 1987). This scale comprises 10-items taken directly from the 20-item scale (Zung & Durham, 1965). Scores on the Scale range from 25 to 100. Higher scores signify more severe levels of depression. During the pilot phase we initially used the long form of the scale because it has acceptable levels of test-retest reliability (for a review see Hedlund & Vieweg, 1979), because it includes more of the characteristics common of depression in the elderly than some other scales (Weiss, Nagel & Aronson, 1986) and because it has been used with populations similar to the one under study (Robinson & Price, 1982; Robinson, Starr, Kubos et al, 1983; Robinson, Starr, Lipsey et al, 1984; Parikh, Lipsey, Robinson et al, 1987, Wade, Legh-Smith, Hewer, 1987). A recent publication (Agrell & Dehline, 1989) comparing six measures of depression in elderly stroke patients reiterated that the Zung Scale has high sensitivity, specificity and predictive value when compared to a clinical evaluation of depression. The 20-item questionnaire was not well tolerated by patients during the pilot phase: some criticized its length and some simply refused to continue to the end of the scale. The interviewers had difficulty asking questions they felt covered emotional, sensitive matters. This in turn led to high non-response on the depression items, a problem reported to occur if the interviewer is uncomfortable with the question he or she is asking (Bailar, Bailey & Stevens, 1977). Numerous group discussions and training sessions were conducted to improve the administration of the scale. Prior to changing to the short form of the Zung Scale we compared its sensitivity in detecting depression, in a group of 48 stroke patients, against that of the original Zung Scale. Based on using a cut-off score of 55 on both scales, the sensitivity of the short form to detecting depression was 100% with a specificity of 96%.

4.9.3c Community reintegration

We used the Reintegration to Normal Living (RNL) Index as a measure of community functioning (Wood-Dauphinee, Opzoomer, Williams et al, 1988). This 11-item scale covers areas such as participation in recreational and social activities, movement within the community and how comfortable the individual is in his or her role in the family and with other relationships. It has been shown to be a valid and reliable measure of physical, social and psychological performance and it has a high correlation with the Spitzer Quality of Life Index (Spitzer, Dobson, Hall et al, 1981). The RNL Index has been used with stroke and cancer patients, proxies, and with patients from acute care and rehabilitation settings (Wood-Dauphinee, Opzoomer, Williams et al, 1988). During the development of the RNL Index three forms of scoring were tested. These included a visual analogue scale, a three-point scoring system, and a four-point scoring system. Based on our piloting of the RNL the three-point scale was chosen because patients found the four levels of response too difficult to attend to and retain. The eleven items are each scored *0*, *1*, or *2*, for a total score of 22, which is then transformed to a score out of 100. Lower scores signify less disability.

4.9.3d Cognitive status

Pfeiffer's 10-item Short Portable Mental Status Questionnaire (SPMSQ) was used to measure cognitive status (Pfeiffer, 1975). This questionnaire can be administered by telephone as it does not require the use of visual demonstration or written responses. For each item the patient receives a dichotomized score of *0* or *1*. Five to seven errors signify moderate intellectual impairment and 8-10 errors, severe intellectual impairment. The scoring system is out of 100 with low scores signifying poor performance. The Questionnaire has been shown to have good agreement with a dichotomous clinical classification of organic brain syndrome in community residents (Pfeiffer, 1975). As mentioned earlier, this component of the questionnaire was answered only by the patient, even when a proxy was used for the other components of the assessment. However, there were circumstances, for example when the patient was aphasic, that prohibited the use of the assessment.

4.9.3e Illness

The following question from the Canada Health Survey (1987) was asked to ascertain illness. *In the past month how many days were you in bed for most of the day because of sickness, injury or other health problems? None, 1-4, 5-7, greater than seven.* The individual was also asked a question to detect general deterioration *Compared to last month would you say you are functioning better, the same, worse, or don't know.*

4.9.3f Hospitalizations

The number of hospitalizations and the total number of days in an acute-care or rehabilitation hospital in the six months prior to contact were elicited from the respondents during the interview.

4.9.3g Medication use

Medication use and frequency of use were elicited by asking patients to assemble their medications and to read the label from each bottle to the interviewer. This method has been used with good success by one of the co-investigators (R.B.) in a geriatric clinic telephone contact. The interviewers recorded the names of the medications used, and the frequency of use for the 24 hour period from 6:00 a.m. the day prior to the interview, to 6:00 a.m on the day of the interview. Medications taken periodically were also identified, as were the frequencies of their use.

4.9.3h Occurrence of falls

Patients were asked the question *Have you fallen in the past month?* For those who answered *yes* the circumstances surrounding the fall, the location of the fall or falls, and the injuries sustained, were also documented.

4.9.3i Patient's recall of events

It is difficult to ascertain the correctness of answers, especially for constructs such as mood. To permit an overall impression of the patient's accuracy in reporting events we asked questions for which we had accurate information based on the medical chart. This included the name of the acute care hospital to which he or she had been admitted prior to coming to the rehabilitation setting, the date of admission and the length of stay. Patients or proxies who could not state the exact date, or number of days, were asked to give an approximation.

4.9.3j Confidence in patient's responses, interviewer's general impressions and comments by respondent

For each component of the questionnaire, the interviewer had the opportunity to subjectively express her degree of confidence in the patient's responses and to add any comments she might have. In addition, interviewers coded their overall impression on a three point scale; *patient appears fine no intervention suggested, some concern regarding status and intervention suggested, emergency situation requiring immediate action*. At the end of the interview the following open-ended question was asked *Is there anything else you think we should know about your health or functional status*? This question permitted the patients to express concerns they felt were not elicited during the interview.

4.9.4 Additional Guidelines For Administering the Questionnaire

During the 22 practice interviews conducted prior to the initiation of the study a number of additional guidelines were established for the administration of the questionnaire.

4.9.4a Barthel Index

On the Barthel Index (Mahoney & Barthel, 1965) there were often disagreements amongst the raters regarding whether a patient was independent or required assistance based on his need for an aid or adaptation. The established criterion was to consider a patient to be independent in an activity of daily living, even when an aid or adaptation was required, if the patient was able to use the equipment without any human assistance.

4.9.4b Zung Scale

Answering of questions on the Zung Scale (Zung & Durham, 1965) was found to be difficult for some respondents because of the four possible choices for each item. Interviewers reported that it was possible to know the direction of the response but that individuals had difficulty finalizing between two response choices for example, *a good part of the time* and *most of the time*. To help respondents who were having difficulty choosing one of the four answers, the interviewers were asked to establish the direction of the response and to then allow the individual to choose from the closest two or three responses.

4.9.4c Reintegration to Normal Living Index

On the Reintegration to Normal Living Index (Wood-Dauphinee, Opzoomer, Williams et al, 1988), a number of changes were necessary. A global change was made so that the questions were rephrased to be asked in the second person rather than in the first person such that *I move around my living quarters as I feel is necessary* was asked in the following manner *Do you move around your living quarters as you feel is necessary?*. We also changed the possible responses for each question from *fully describes my situation, partially describes my situation* and *does not describe my situation* to *yes, partially*, or *no* as the patients and proxies found the former categories to be too arduous. Question #8 on the RNL which asks *are you assuming a role in your family which meets your needs and those of other family members* was incomprehensible to many interviewees. The interviewers began this question with the following statement *now I am going to ask you about the role that you assume in your family, by this I mean your role, for example, as a grandmother, parent or wife/husband.*

One additional problem was found when using the RNL Index. Question #5 asks *do you spend most of your days occupied in an activity that is necessary or important to you?* and begins with examples such as work and school, followed by housework and volunteer work. After hearing the first two examples the respondents often interjected that they (or the person for whom they were responding) were not working, before the interviewer had an opportunity to present the other examples. Considering the large number of elderly individuals in the study we wanted to stress that employment was not the only necessary or important activity. Therefore, we switched the order of the listed activities to begin with housework and volunteer work.

We also added a non-applicable column for the scoring of the RNL Index as patients sometimes felt that some of the questions did not apply to them. However, we stressed that the interviewers should not use this option unless the respondent absolutely insisted that the question was non-applicable.

4.9.4d Medications

The documenting of medications posed a problem during the practice sessions. When patients gave their medications over the telephone, the interviewers were often unfamiliar with the names and, therefore, had difficulty spelling them. This created problems for the research assistants when they entered the data into the computerized data base system. To simplify identification, each interviewer was provided with an alphabetized list of commonly used medications.

4.10 STATISTICAL ANALYSES

4.10.1 Analyses Performed on the Data

Initial scrutiny of the data was performed using descriptive statistics to examine the characteristics of those who were eligible and those who participated.

To answer the major question of interest regarding the telephone/home comparisons, a series of steps were taken. The distribution of responses on the various indices and questionnaire items were examined according to mode of interview. Analyses of agreement between the telephone and the home interview were performed on selected indices and items, followed by the analyses of sensitivity/specificity and the predictive validity of the telephone interview. Finally, logistic regression was performed to investigate the contribution of a number of explanatory variables on the probability of discord between the telephone and the home interview. The statistical analyses used are detailed below.

4.10.1a Analyses of concordance

To provide an overall indication of the consistency of the responses between the telephone and home interview on the Barthel Index, Zung Scale and RNL Index, we used the intra-class correlation coefficient (ICC). The ICC describes agreement using the full range of available scores (Landis & Koch, 1975; Streiner & Norman, 1989). For comparing two methods of interview the ICC is considered preferable to the commonly reported Pearson Correlation Coefficient because unlike the Pearson Coefficient, the ICC will be reduced if one method of interview results in systematically higher, or lower, responses (Fleiss, 1986).

The intra-class correlation coefficient was derived from a repeated measures analysis of variance model that allows the partitioning of the variance due to subjects, to mode and to error (Fleiss, 1986). In this study we explored the effect of the mode of interview using a *fixed* effect model of the following form:

$$\text{ICC} = \frac{\sigma^2 T}{\sigma^2 T + \frac{1}{K} \Sigma \rho_j^2 + \sigma_e^2}$$

where σ_e^2 represents the variance due to random error, *k* represents the number of modes, $\rho^2 j$ is the observation for one subject based on mode of interview and $\sigma^2 T$ represents the error-free variability.

The following formula was used as an estimator of the ICC:

$$\text{ICC} = \frac{\text{N(msS - msE)}}{\text{N * msS} + (k\text{-1})\text{msM} + (\text{N-1})(k\text{-1})\text{msE}}$$

where msS = mean square due to differences among subjects; msM = mean square due to differences among methods (telephone and face-to-face); msE = mean square due to residual (error) variance; N = number of subjects; and *k* = number of modes (Fleiss, 1986).

In this study, a high ICC would signify that the difference among subjects accounts for a large proportion of the variance relative to the mode or error variance (Fleiss, 1986).

To further depict the agreement between the telephone and the home interview on the indices of function, mood, and community reintegration, descriptive statistics were calculated by taking the *total score* on the home interview *minus* the *total score* on the telephone interview. The agreement was investigated according to the degree of dysfunction evidenced on the home interview categorized as *no*, *mild to moderate* and *severe* dysfunction. Categorization was considered important because it has been suggested that agreement may vary depending on the severity of impairment (Jette & Deniston, 1978). For the Barthel Index agreement of the telephone interview score with the home interview score was explored for four functional levels as indicated by the following home interview scores: a perfect score of 100 on the home interview indicating *no* disability, a score of 81-99 indicating *mild* disability, 61-80 indicating *moderate* disability and 60 or less indicating *severe* disability. On the Zung Scale the categories were as follows: scores less than 50 indicating *no* depression, greater than 60 indicating *severe* depression, and 50-60 indicating *mild-to-moderate* depression. For the RNL Index the scores were categorized as follows: greater than 50 for *severe* disability, 26-50 for *moderate* disability, 1-25 for *mild* disability and a perfect score of 0.

While the ICC and descriptive statistics provided an overall indication of agreement, it was also important to explore the consistency of responses between the modes when specified cut-off scores were used to indicate the presence or absence of impairment. This information is especially important in clinical practice where the decision to intervene, or to not intervene, is often based on the use of a specified cut-off score.

Crude agreement (percent agreement) and Cohen's Kappa (K) statistic (Cohen, 1960) were calculated for each of the items on selected components of the questionnaire and for the total scores on the Barthel Index, Zung Scale and RNL Index using specified cut-off points. Crude agreement was used to identify the numbers of patients for whom the telephone and home assessment gave the same classification. Cohen's Kappa statistic was used to express the degree to which the agreement between the two interviews differed from chance (Cohen, 1960) with;

$$K = \frac{P_0 - P_e}{1 - P_e}$$

where P_0 is the proportion of units in which the responses are in agreement and P_e is the proportion expected by chance.

The method presented by Fleiss (1986) was used for comparisons of three or more categories: ninety-five percent confidence intervals were calculated using the standard error from the formula of Fleiss (1986). Although kappa has been criticized as being difficult to interpret (Maclure & Willett, 1987; Umesh, Peterson, Sauber, 1989), Landis & Koch (1975) suggest that values of K below 0.40 indicate only slight to fair agreement, values ranging from 0.41 to 0.60 are considered moderate, values from 0.61 to 0.80 are substantial and those over 0.80 are considered almost perfect.

4.10.1b Accuracy of the telephone interview

As discussed earlier, an additional form of analyses of the telephone/home data identified the sensitivity, specificity, positive and negative predictive value of the telephone interview, vis-a-vis the potentially *gold standard* face-to-face interview. Sensitivity was computed as the proportion of individuals identified as having the trait at the time of the face-to-face interview who were also identified as having the trait when interviewed on the telephone. Specificity was computed as the proportion of individuals free of the trait at the time of the face-to-face interview who were identified as free of the trait on the telephone. Taking the home assessment as *truth*, the positive predictive value is the probability of the trait in those with a positive test as indicated by disability during the telephone interview: the negative predictive value is the probability that the trait is *not* present in those with a negative test as indicated on the telephone. The formulas are:

		Home Interview	
		Trait present (+)	Trait absent (-)
		(+)	(-)
Telephone	(+)	A	B
Interview	(-)	C	D

Sensitivity = A/A+C; specificity = D/B+D; positive predictive value A/A+B; negative predictive value D/C+D.

The specified cut-off scores for classifying presence or absence of the trait under study were identified from previously published literature on the Barthel Index (Risteen Hasselkus, 1982; Shinar, Gross, Bronstein et al, 1987; Granger, Dewis, Peters et al, 1979) and the Zung Scale (Zung, 1965; Steuer, Bank, Olsen et al, 1980). For the Barthel Index, common cut-off scores are 60 or 80 out of a possible 100, depending on the population under study (Wylie & White, 1964; Granger, Dewis, Peters et al, 1979). On the Zung Scale scores of 50 and 60 out of 100, have been used to identify depression, with a score of 60 thought to be more applicable with older individuals (Steuer, Bank, Olsen et al, 1980). For the Reintegration to Normal Living Index (Wood-Dauphinee, Opzoomer, Williams et al, 1988), a newer scale where information for the type of subjects under study is less readily available, the trait was identified as being present using cut-off scores of 40 and of 60.

4.10.1c McNemar's X^2 statistic

One further examination of the categorical variables was performed using McNemar's X^2 statistic (Kramer & Feinstein, 1981). This statistic identified any tendency towards more frequent reporting of disability based on mode of interview. For example if the telephone interview resulted, consistently, in a higher classification of the subject's status as compared to the home interview, then the McNemar's X^2 test could be used to test whether this trend was statistically significant.

The formula for McNemar's X^2 statistic is:

$$X^2 = \frac{(B - C)^2}{B + C}$$

where B = the number of individuals for whom the telephone assessment indicated the condition (e.g. depression) but the home assessment did not and C = the number of individuals for whom the home assessment indicated the condition but the telephone did not (see 2*2 table above).

The formula used when there were more than two categories of the variable was:

$$X^2 = \frac{(U - L)^2}{U + L}$$

where U = the upper right off-diagonals that is, the number of individuals where the telephone assessment more often indicated the condition and L = the lower left off-diagonals or, the number for whom the telephone assessment less often indicated the condition. Note that the cells signifying U or L differed according to whether higher scores on a scale were indicative of the condition, or, vice versa.

4.10.1d <u>Assessing the influence of interviewer type</u>

Prior to performing the telephone/home comparisons it was first necessary to identify any influence that type of telephone interviewer (lay person or health professional) had on respondents' replies. Descriptive statistics were used to explore the characteristics of the group of respondents interviewed over the telephone by lay persons and the group interviewed over the telephone by health professionals. The distribution of responses to the indices and health status questions were then compared, according to the type of interviewer performing the telephone interview, using Chi-square tests. Next, Cohen's Kappa statistic was used to assess the agreement between the telephone and home interview responses according to type of telephone interviewer. Finally, these agreements were compared to reveal whether concordance between the modes was influenced by the type of telephone interviewer.

The following formula was used to compare the kappa scores:

$$Z = \frac{K_1 - K_2}{SE_{K1} + SE_{K2}}$$

where SE represent the standard errors of the kappas that are being compared (Kramer & Feinstein, 1981).

Fleiss and Cicchetti (1978) have shown this comparison to be acceptable providing that the number of subjects is sufficiently large, that is, the numbe is at least $3g^2$, where *g* indicates the number of measurement categories. In this study acceptable numbers of subjects were available, thus, allowing the use of this formula.

4.10.1e Assessing the contribution of explanatory variables

Additional analyses of the data were performed using unconditional logistic regression to investigate the contribution of a number of explanatory variables on the probability of discord between the telephone and home interview. For each index, a dichotomous outcome variable was created to indicate whether the scores on the two interviews (telephone and home) were in *accord* or *discord*: *discord* was defined as a difference of greater than 10 points between the telephone and the home interview.

The decision on the difference in scores that would constitute *discord* was based on a preliminary investigation of the raw data, on the judgement of the investigators, and on consultation with clinical associates. The Barthel items are given weighted scores of 0, 5, 10 or 15. Thus, a greater than ten point spread on the Barthel Index signifies a difference in scoring on as little as one item, but more commonly on two items, depending on the weight assigned to each. On the Zung Scale, an increment was equal to 2.5 points. A spread of greater than 10 points could occur if one item was scored erroneously at the extreme values and another item was off by one increment. Alternatively, differences between the telephone and the home could occur on as many as four items, with only one increment difference, before a coding of *discord* was made. On the RNL Index, an increment was equal to 4.54 points. A spread of greater than 10 points indicated differences on two or more items.

The logistic model is in the form of $\log (p/1-p) = (\beta_o + \beta_1 x_1 + \beta_2 x_2 + \ldots + \beta_i x_i)$, where *p* is the probability of *discord*. The regression coefficients can be interpreted as follows. If the regression coefficient (β_i) for cognition (x_i) is 0.2 then the effect of a one point change in cognition is to multiply the odds of *discord* by a factor of *exp*(0.2) or 1.22, assuming a multiplicative model (Schlesselman, 1982).

For each outcome of interest three separate collections of logistic analyses were performed, one including all participants, another for self respondents and one for the group consisting of proxy respondents. The potential co-variates differed for each group and included respondent related and interview or interviewer related variables.

For the group as a whole, the influence of the following variables was considered:

- type of respondent (self or proxy);
- diagnosis (stroke or orthopaedic condition);
- respondent's accuracy on responses to known information;

- patient's cognitive status;
- number of medications used;
- type of interviewer (health professional or lay person);
- language of interview;
- interviewer's confidence in the respondent's reply.

For the analysis of the group of self respondents, the variables *age* and *sex* of the patient were added to the model. For the analysis of the group of proxy respondents, the type of proxy (spouse, child, or *other*), was included. The categorical variables signifying cognitive status and relationship of the proxy to the patient, were factored. When a variable is factored, a dummy variable is created for each level of the variable. The level of interest is then compared to the first level of the variable, commonly referred to as the referent.

Variables were chosen for inclusion as co-variates based on our clinical judgement regarding their potential contribution to explaining discord and on their univariate significance. Schlesselman (1982) reviews the potential for deleting important variables if inclusion in a model is based solely on their significance level. This problem is accentuated in studies where the sample size is small, as was the case for the analyses for the group formed by proxies.

For each model, regression was performed using backward elimination, a procedure in which all of the variables in the particular model were first included and then excluded one-by-one (Hosmer & Lemeshow, 1989). The adequacy of the fit of each logistic model was assessed using the Chi Square likelihood ratio test. This test assesses whether the currently fitted model is better than the previously fitted, using the difference between the maximized log likelihood statistics for the two models (Breslow and Day, 1980).

Logistic regression was run on the EGRET version of PECAN (1985-90). Many of the other analyses including the analysis of variance for the ICC's and the descriptive statistics were performed on SAS version 6 (1990). The measures of reliability and validity were calculated by entering the appropriate formulas into the spreadsheet program Quatro-Pro (1990).

4.10.2 Definition of Variables and Their Coding

The outcome variables on which the concordance of the telephone and the home interview were judged are summarized in Table 1. Table 2 presents the potential explanatory variables. A variable considered as an outcome in one analysis might, at another point, be used as an explanatory variable. For example, cognitive status was investigated during the preliminary analysis of response distributions, but not for the analyses of agreement. Rather, it was used as an explanatory variable for the analyses of discord. Detailed information on the variables has been presented in Section 4.9.3.

Table 1: Outcome Variables used in the Statistical Analyses

Outcome	Specific Measure	Categories/ Units	Scale	Analysis
Function				
item reliability	Barthel Index	dep/indep	discrete	% agreement, kappa
scale reliability	Barthel Index	(0-100)	continuous (0-100)	ICC
scale validity	Barthel Index	(0-100)	dichotomized at 60/60	sensitivity, specificity
discord	Barthel Index	(0-100)	>10 score difference home/tele	logistic regression
Mood				
item reliability	Zung Scale	(1-4)	discrete	% agreement, kappa
scale reliability	Zung Scale	(0-100)	continuous	ICC
scale validity	Zung Scale	(0-100)	dichotomized at 50/60	sensitivity, specificity
discord	Zung Scale	(0-100)	>10 score difference home/tele	logistic regression
Community Reintegration				
item reliability	RNL Index	(0-2)	discrete	% agreement, kappa
scale reliability	RNL Index	(0-100)	continuous	ICC
scale validity	RNL Index	(0-100)	dichotomized at 40/60	sensitivity, specificity
discord	RNL Index	(0-100)	>10 score difference home/tele	logistic regression
Falls				
item reliability	number in 1 month	0, >0	yes/no dichotomy	% agreement, kappa
item sensitivity	number in 1 month	0, >0	yes/no dichotomy	sensitivity, specificity
Hospitalizations				
item reliability	number in 6 months	0, >0	yes/no dichotomy	% agreement, kappa
item sensitivity	number in 6 months	0, >0	yes/no dichotomy	sensitivity, specificity

Table 1: con't. Outcome Variables used in Statistical Analysis

Outcome	Specific Measure	Categories/ Units	Scale	Analysis
Medications Use				
item reliability	number	0-1, 2-4, 5-7, >7	discrete	% agreement, kappa
Illness Days				
item reliability	number of days	0, 1-4, 5-7, >7	discrete	% agreement, kappa
Overall functioning				
item reliability	Canada Health Survey	better, same, worse, unsure	discrete	% agreement, kappa

Table 2. Explanatory Variables used in Statistical Analysis

Variable	Specific Measure	Categories/Units
Age	of the patient (date of interview-date of birth)	years
Sex	of the patient, not of the proxy	male=1, female=2
Respondent	self or proxy	self=1, proxy=2
Diagnosis	stroke, orthopaedic condition	stroke=1, orthopaedic condition=2
Medication use	number of regular and occasional medications	continuous or 0-2, 3-6, 7-15
Type of proxy	spouse, child or *other* (e.g. friend)	spouse=1, child=2, other=3 or spouse=1, all other=2
Cognitive status	Pfeiffer Short Portable Mental Status	category 1=(0-4), 2=(5-8) 3=(9-10) higher signifies better function)
Depression	Zung Index score >60 on telephone	not depressed=0, depressed=1
Accuracy of responses	number of correct answers to length of stay and name of admitting acute-care hospital	0-6 (3 telephone + 3 home).
Language of interview	French, English	English=1, French=2
Interviewer's confidence	confidence in respondent's reply	no confidence=0, confidence in one=1, confidence in both=2.
Type of interviewer	health professional, lay person	lay=1, professional=2

CHAPTER 5: RESULTS

Section 1 of this chapter includes information on the cohort from which the subjects were recruited, details on the tracing, a description of those who were eligible and those who participated, the characteristics of self respondents and those who required proxy respondents and finally a comparison of the characteristics of subjects interviewed by lay interviewers and health professionals.

Sections 2, 3 and 4 all include information on the indices and health related questions, but each with a distinct focus. Section 2 presents contrasts between telephone interviews performed by the lay interviewers and by the health professionals. These contrasts were performed, as mentioned earlier, to determine if the prevalence of the conditions under study would be similar when reported on the telephone, for the two types of interviewers, and to determine if the data from the two types of interviewers could be combined for the analysis of the telephone versus the home mode. Section 3 compares the distribution of scores on the telephone interview to that on the home interview. These comparisons are an important first step in identifying the prevalence of impairment in this group of subjects, and in identifying any striking variations in prevalence based on mode of interview. Sections 4 and 5 provide the analyses of agreement between the modes. Section 6 presents the results of the logistic regression analyses used to identify variables associated with discord between the modes. Appendix M presents a distribution of the raw scores on the major indices of interest according to the type of interview.

5.1 THE STUDY POPULATION

The charts of stroke patients admitted from April 1, 1984 to March 31, 1989, and the charts of orthopaedic patients admitted from April 1, 1986 to March 31, 1989 were reviewed during the spring and summer of 1990. Eligibility was ascertained in three phases. First, based on a review of the discharge data of the JRH a total of 1602 admissions were identified where the primary diagnosis was stroke (n=816) or an orthopaedic condition (n=786). Of these, 1098 had been discharged home and were thus considered eligible. Based on a chart review, a further 191 were excluded the reasons being: the home greater than 30 miles from the hospital (n=80); discharge from hospital to a foster home (n=26); a co-morbid condition characterized by frequent fluctuations including Parkinson's Disease, a progressive malignancy, or end stage heart, kidney or lung disease (n=16); death (n=13); an error in the diagnosis such that the patient was neither a stroke, nor an orthopaedic patient (n=8); and a repeat admission during the study period in those already identified to be eligible by reason of an earlier admission (n=48).

At the time of the initial telephone contact the project coordinator ascertained additional exclusions for the 907 possible participants: patient or proxy expected to be away from home for the duration of the project (n=5), a move out of the 30 mile study radius (n=40) or to a destination other than home (n=111), no suitable proxy when one was required (n=10), grave illness (n=30), and death (n=164). One patient was inadvertently excluded. Two additional reasons for exclusion included not requiring a proxy respondent (n=105), and, an inability to trace the individual (n=11). These two reasons are discussed in the following paragraphs.

5.1.1 Recruiting Respondents

During the study it became evident that, although we would not have problems recruiting a sufficiently large number of self respondents, there were fewer than expected proxy respondents. Some patients identified from the chart to require a proxy were, at the time of the first telephone contact, able to act as self respondents. For example, of the 194 individuals indicated by the medical chart to have expressive aphasia, 87 were eligible for inclusion at the time of the study. At the initial telephone contact 32 (36%) were found to be capable of acting as self respondents. Some patients indicated as having a severe hearing loss were able, with or without telephone adaptations, to respond to questions on the phone and thus became self respondents (n=9). Additional losses resulted from a higher than expected number of deaths, grave illness and long term care placements in the potential proxy group (37%) as compared with those initially designated as potential self respondents (23%). In addition, few patients with orthopaedic conditions required proxy respondents.

A number of actions were taken to increase the number of proxy respondents. First, we extended the recruitment period to include stroke patients from two additional years, 1984 and 1985, and by doing so recruited 14 additional proxies. In addition, a revised recruitment letter was sent to 164 individuals with an orthopaedic condition requesting participation of *only* those individuals who required a proxy respondent. This procedure was undertaken as we had already surpassed the desired number of self respondents and did not wish to recruit additional ones. Another 16 individuals who were previously excluded because their language was neither English, nor French, and because they lived alone, were approached to participate through a proxy respondent. These two final strategies resulted in an additional 9 proxies being recruited.

5.1.2 Tracing of Patients

A total of 3,231 telephone calls were made in order to trace the 907 individuals who received letters requesting participation. The mean number of calls necessary to contact individuals was 3.56 (S.D.=3.66; range 0 to 23 calls). For 8% of individuals it was necessary to make 10 or more calls to ascertain final study status. There were 74 individuals who required no calls as they contacted the project coordinator after receiving the introductory letter. The average time necessary for contacting the appropriate individual, that is either the patient or the proxy, and explaining the study to them was 7.73 minutes (S.D.=7.70). This did not include additional time spent perusing telephone directories and medical records, nor did it include the time taken to reschedule appointments or to speak with subjects who called requesting information or clarification.

All but 16 individuals were traced using information from social service, known telephone numbers, the obituary columns, or the telephone directory. Five of these individuals were deceased according to information provided from the *Ministère de Justice, régistre de référence, l'état civile,* of Quebec. We attempted to trace the remaining 11 individuals using a directory indexed by address, to identify former neighbors. Early on it became apparent that this last step in tracing was to be a lengthy and costly procedure and considering that the numbers of untraced individuals was less than 1%, this procedure was abandoned.

Table 3 provides a summary of the reasons for exclusion based on the chart review and on the telephone contact. Note that the 105 individuals who did not require a proxy respondent are those who received the letter, in the later part of the study, requesting participation of only proxies. At the time of the telephone contact the project coordinator reiterated that only those requiring proxy respondents were being recruited. This procedure was undertaken purely for financial and logistic reasons: having surpassed the expected sample size, we saw limited benefit in applying for additional funds to recruit more self respondents. There is no reason to believe that those who were considered ineligible, at this stage, differed from self respondents who participated.

Table 3: Eligibility and Reasons for Exclusion

	n	
Potential participants	**1098**	
Eligible for inclusion	**430**	
Ineligible	**668**	
not living at home at follow-up		137
living greater than 30 km from hospital		120
dead		177
fluctuating medical conditions, grave illness		46
more than one admission during study		48
no suitable proxy		10
diagnosis neither stroke nor orthopaedic		8
away for duration of study		5
inadvertently excluded		1
untraced		11
Not requiring a proxy*		105

* towards the end of the study only those requiring a proxy were recruited as the targeted number of self respondents had been obtained

Thirty-nine individuals (9% of those who were eligible) refused to participate: 33 at the time of the initial contact and 6 at the time of the interview. Table 4 summarizes the reasons for refusal. Almost one-third of those who refused gave very specific reasons such as a fear of having someone visit the house, or anger about some aspect of their hospital stay.

Table 4: Reasons for Refusal

	n	
Refusal to Participate	**39**	
patient unwilling/uninterested		17
proxy unwilling/uninterested		10
unhappy about care received in hospital		6
fearful of having someone visit at home		5
too depressed over recent death of spouse		1

5.1.3 Characteristics of Study Group

Baseline characteristics of the 430 potential participants are presented in Table 5 according to their final status. Those who participated were similar to those who were eligible for all variables studied. The small group who refused to participate were slightly older, more often of the female gender and more likely to have been hospitalized for an orthopaedic condition. They also spent a shorter period of time in hospital and were more often living alone, than those who participated.

Of the 391 individuals who participated, sixteen followed a specific protocol looking at the concordance between their responses and that of a close family member or friend. The analysis for this sub-group is not presented within this thesis. Eleven individuals failed to complete one of the two interviews, including two that followed the special protocol. Thus these analyses are based on the data from 366 individuals.

Figure 1 provides a summary of the numbers of individuals who were eligible for inclusion and who were randomized into the study. Losses due to refusal and due to incomplete interviews are also indicated at the point in time at which they occurred; some before and others after randomization into the study.

FIGURE 1: STROKE/ORTHOPEDIC PATIENTS DISCHARGED HOME 1984-89

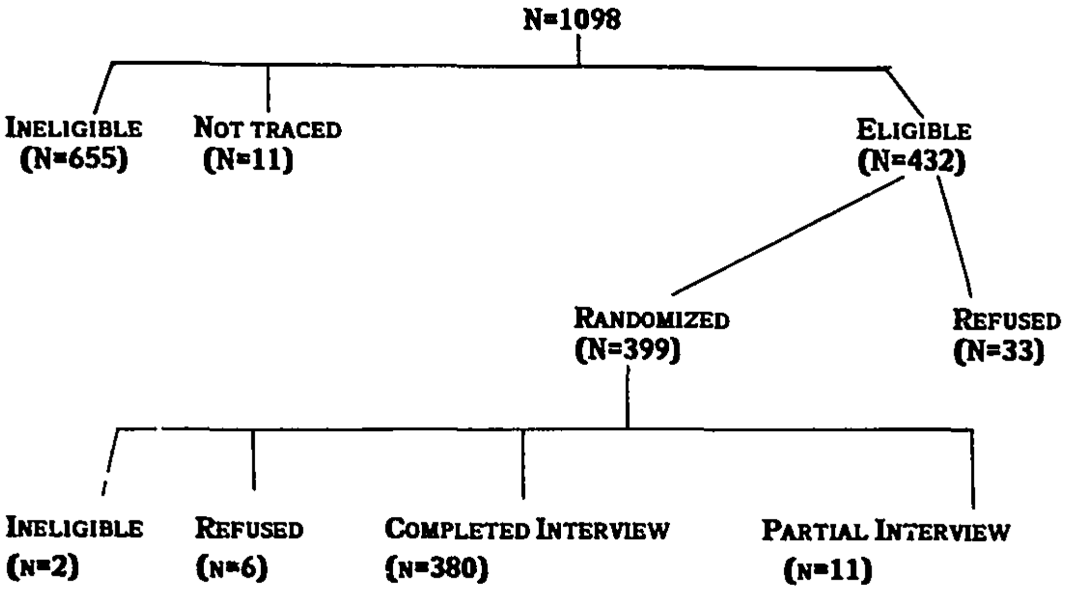


Table 5: Characteristics of Those Who were Eligible, Refused and Participated

	Eligible (n=430)		Refused (n=39)		Participated (n=391)	
Age (years)						
mean (SD)	68.8	(12.1)	73.7	(11.8)	68.3	(12.1)
range	22-97		40-93		25-97	
Age category						
<55	51	(12%)	2	(5%)	49	(13%)
55-64	91	(21%)	7	(18%)	84	(22%)
65-74	136	(32%)	12	(31%)	124	(32%)
75-84	118	(27%)	11	(28%)	107	(27%)
>85	34	(8%)	7	(18%)	27	(7%)
Sex [N (%)]						
women	243	(57%)	31	(79%)	212	(54%)
men	187	(43%)	8	(21%)	179	(46%)
Language [N (%)]						
English	209	(49%)	29	(74%)	180	(46%)
French	146	(34%)	8	(21%)	138	(35%)
both	49	(11%)	1	(3%)	48	(12%)
neither	26	(6%)	1	(3%)	25	(6%)
Length of hospital stay [N (%)]						
mean in days (SD)	63.2	(41.4)	53.7	(35.9)	64.1	(41.8)
median in days	54		43		55	
Diagnosis [N (%)]						
stroke	233	(54%)	11	(28%)	222	(57%)
orthopaedic	197	(46%)	28	(72%)	169	(43%)
Living arrangement at admission [N (%)]						
alone	121	(28%)	18	(46%)	104	(27%)
spouse/family/friends	305	(71%)	20	(51%)	284	(73%)
paid help/residence	3	(1%)	0	(0%)	3	(1%)
alone with young children	1	(0%)	1	(3%)	0	(0%)
unknown	0	(0%)	0	(0%)	0	(0%)

5.1.3a Characteristics of self respondents and respondents requiring proxies

Of the 366 individuals, 259 were self respondents and 107 were proxy respondents. Those requiring proxy respondents were more often males and, as anticipated, tended to be slightly older and were more often stroke patients than those who acted as self respondents (Table 6).

Table 6: Characteristics of Study Subjects According to Type of Respondent

	Self (n=259)	Proxy (n=107)	Overall (n=366*)
Age (years)			
mean ±SD	70.3 (11.6)	73.1 (11.8)	71.1 (11.7)
range	25-93	39-98	25-98
Sex (N (%))			
women	148 (57%)	49 (46%)	197 (54%)
men	111 (43%)	58 (54%)	169 (46%)
Diagnosis (N (%))			
stroke	140 (54%)	74 (69%)	214 (58%)
orthopaedic	119 (46%)	33 (31%)	152 (42%)

* completed both the telephone and the home interview

A proxy respondent was most commonly needed when the patient was aphasic or unable to communicate in French or English (questionnaires were only available in these two languages). A small number of individuals expressed a desire for someone such as a spouse to answer for them, while others were too confused to answer for themselves. Table 7 provides a summary of the reasons for using a proxy respondent.

Table 7: Reason for Patient Requiring Proxy Respondent

	n
Proxy Respondents	**107**
patient aphasic	39
patient speaks neither English nor French	27
patient fatigues easily, or is too frail	18
patient confused or asked to have *other* answer	15
patient hard of hearing	8

5.1.3b Patient characteristics according to type of telephone interviewer

Study subjects were randomly allocated to be interviewed by a lay interviewer or a health professional on the telephone. Of the 366 respondents, 188 were interviewed by lay interviewers and 178 were interviewed by professional interviewers. A comparison was made of baseline characteristics of the study subjects according to type of interviewer. While slightly more of the subjects interviewed by the health professionals had a diagnosis of stroke, were men, or were interviewed in English, all of these differences were compatible with appropriate conduct of the randomization process (Table 8).

Table 8: Characteristics of Patients According to Type of Interviewer Performing the Telephone Interview

	Type of Interviewer	
	Lay Interviewer (n=188)	Health Professional (n=178)
Age (years)		
mean (SD)	72.0 (11.0)	70.0 (11.8)
median	72	70
range	25-98	37-95
Sex [N (%)]		
women	108 (57%)	89 (50%)
men	80 (43%)	89 (50%)
Diagnosis [N (%)]		
stroke	106 (56%)	108 (61%)
orthopaedic	82 (44%)	70 (39%)
Language of interview		
English	114 (61%)	117 (66%)
French	74 (40%)	61 (34%)
Type of respondent		
self	135 (72%)	124 (70%)
proxy	53 (28%)	54 (30%)
Order of interviews		
home then telephone	93 (50%)	85 (48%)
telephone then home	95 (50%)	93 (52%)

5.2 SEVERITY OF IMPAIRMENT ACCORDING TO THE TYPE OF INTERVIEWER

This section compares the results of telephone interviews performed by the lay interviewers and by the health professionals. These contrasts were done to determine if the prevalence of the conditions under study would be similar when the lay persons and the health professionals conducted the telephone interviews and, thus, determine if the data from the two types of interviewers could be combined for the analysis of the telephone versus the home mode.

Table 9a-c presents the distribution of scores on the Barthel Index, Zung Scale and RNL Index according to the type of interviewer performing the telephone interview. As two individuals did not complete the RNL Index and one did not complete the Zung Scale, the number of individuals for which we had data varied slightly from index to index. On the Barthel Index, regardless of interviewer type, 45% of patients were reported to have *no* functional disability (Table 9a). For approximately half of subjects there was an indication of *mild-to-moderate* disability and for relatively few (7% or less), *severe* functional disability was reported (Table 9a). The distribution of scores on the Zung Scale of mood (Table 9b) was such that about half of the respondents' replies were indicative of depression, regardless of type of interviewer.

On the RNL Index there was a significant difference ($p<.05$, X^2 test with 2 degrees of freedom; Table 9c) in the reported prevalence of dysfunction, with more frequent reporting of *severe* disability for those interviewed on the telephone by health professionals than for those interviewed on the telephone by lay interviewers (15% versus 9%).

Table 9d to 9h presents information on health status and health events including general well-being, bed days due to illness, hospitalization, falls and medication use, according to type of telephone interviewer. For the item eliciting information on the number of bed days due to illness, the distribution of responses was virtually identical for the two groups: 87% of individuals reported no days in bed because of illness; only 4% reported more than seven days in bed because of illness. Functioning as compared to last month was significantly different ($p<.05$) with those interviewed by the lay interviewer more often indicating that they were *better*. The information on hospitalization in the six months prior to interview revealed significantly higher reports of hospitalization in the past six months ($p<.05$) in those interviewed by lay interviewers (25%) than in those interviewed by professionals (17%). The information on falls suggested virtually identical incidence in the two groups. There were no significant differences in the numbers of medications taken or in the ability to elicit information on medication use.

Table 9i compares cognition scores on the SPMSQ according to type of telephone interviewer. Those interviewed by the health professionals were significantly more likely ($p<.05$) to have scores indicative of cognitive impairment than those interviewed by the lay persons. The more serious cognitive problems and poorer RNL Index scores in those interviewed by health professionals are likely to be attributable to the greater proportion of stroke patients in the group interviewed by health professionals as compared to the group interviewed by lay persons.

In summary, the comparison of response distributions according to type of interviewer performing the telephone interview, while indicative of some differences, does not suggest a consistent trend towards the reporting of greater or lesser impairment according to type of interviewer. It was therefore possible to proceed with the comparison of the telephone interview versus the home interview using the information from both the lay persons and the health professionals.

Table 9: Level of Impairment by Type of Telephone Interviewer on Indices and on Questions Related to Illness, Falls, Medication Use and Hospitalization

	Type of Telephone Interviewer			
	Lay Interviewer		Health Professional	
	n*	%	n	%
a. Barthel Index				
no disability (100)	84	(45%)	80	(45%)
mild/moderate disability (61-99)	90	(48%)	88	(49%)
severe disability (≤60)	14	(7%)	10	(6%)
b. Zung Scale				
no impairment (<50)	93	(49%)	78	(44%)
mild/moderate impairment (50-60)	37	(20%)	39	(22%)
severe impairment (>60)	58	(31%)	60	(34%)
c. Reintegration to Normal Living Index[a]				
no disability (0)	29	(16%)	15	(8%)
mild/moderate disability (1-50)	140	(75%)	136	(77%)
severe disability (>50)	17	(9%)	27	(15%)
d. Bed days in past month[c]				
none	163	(87)	154	(87)
one to four	16	(9)	14	(8)
five to seven	1	(1)	3	(2)
greater than seven	8	(4)	7	(4)
e. Functioning as compared to last month[a,c]				
better	55	(29)	31	(17)
same	101	(54)	118	(66)
worse	29	(15)	29	(16)
don't know	3	(2)	0	(0)
f. Hospitalization in past 6 months[a]				
no	141	(75)	147	(83)
yes	47	(25)	31	(17)
g. Falls in past month[b]				
none	168	(89)	158	(89)
one	13	(7)	18	(10)
two to four	5	(3)	2	(1)
not ascertained	2	(1)	0	(0)
h. Number of medications used				
none	8	(4)	15	(8)
one to two	44	(23)	47	(26)
three to four	60	(32)	51	(29)
five to nine	59	(31)	54	(30)
ten or more	6	(3)	4	(2)
not ascertained	11	(6)	7	(4)

* n's vary slightly due to missing data on some indices; [a] significant differences, $p < .05$ (X^2 test); [b] variable dichotomized for X^2 test; [c] item collapsed to 3 levels, X^2 test with 2 degrees of freedom).

Table 9 continued: Level of Impairment by Type of Telephone Interviewer on Indices and on Questions Related to Illness, Falls, Medication Use and Hospitalization

	Type of Telephone Interviewer			
	Lay Interviewer		Health Professional	
	n*	%	n	%
i. Cognition Index (SPMSQ)[a]				
no impairment (9-10)	125	(74%)	98	(60%)
mild/moderate impairment (5-8)	35	(21%)	47	(29%)
severe impairment (<5)	10	(6%)	18	(11%)

[*] n's vary slightly due to missing data when self-respondents could not respond as proxy responses were not accepted on this component of the questionnaire; [a] significant differences, $p<.05$ (X^2 test);

5.3 SEVERITY OF IMPAIRMENT ACCORDING TO THE MODE OF INTERVIEW

Information on prevalence of disability and health events is presented in Table 10, according to mode of interview, for the 366 individuals who completed both the telephone and the home interview. The numbers of individuals included in the analyses vary slightly because, as previously mentioned, there were three individuals with incomplete information on the telephone interview. The protocol stipulated that these two interviews be conducted three days apart: 79% of interviews were performed within that time span.

On the Barthel Index, the Zung Scale and the RNL Index, the percentage of patients indicated to have no disability was similar between the modes (Table 10a-c). For example, on the Barthel Index 45% of respondents, when interviewed on the telephone indicated no disability: at the time of the home visit 46% indicated no disability. There was a slight tendency towards higher reporting of severe dysfunction on the indices of function, mood and community reintegration during the home interview.

The telephone/home comparisons revealed only minor differences in the distribution of responses to questions on general health status and health events (Table 10d-h): there was more frequent reporting of bed days during the telephone interview. It was possible to elicit information on medication use for 100% of individuals during the home visit and 95% of individuals over the telephone. The comparison of responses on the cognition index revealed virtually identical distributions for the two modes (Table 10i). More cognition questionnaires were completed during the home visit than during the telephone interview (346 versus 333). This difference arose because of a misunderstanding of the appropriate protocol for administering the SPMSQ over the telephone: some interviewers failed to elicit information on cognition from the patient when a proxy was answering the other components. This discrepancy was identified in the first week of the study and the interviewers were directed to elicit cognitive status from the patient, even when a proxy respondent was answering all other components of the questionnaire.

Overall the findings presented in Table 10 suggest that the prevalence of disability and health events were reported with approximately the same frequency on the telephone and in the face-to-face interview. For only one category did the proportion between the telephone and the home differ by greater than five percent: mild to moderate disability on the RNL Index was more frequently reported during the telephone interview.

Table 10: Level of Impairment by Type of Interview on the Indices and on Questions Related to Illness, Falls, Medication Use and Hospitalization

	Type of Interview			
	Telephone		Home	
	n*	%	n	%
a. Barthel Index				
no disability (100)	164	(45%)	169	(46%)
mild/moderate disability (61-99)	178	(48%)	167	(46%)
severe disability (≤60)	24	(7%)	30	(8%)
b. Zung Scale				
no impairment (<50)	171	(47%)	161	(44%)
mild/moderate impairment (50-60)	76	(21%)	78	(21%)
severe impairment (>60)	118	(32%)	127	(35%)
c. Reintegration to Normal Living Index				
no disability (0)	44	(12%)	58	(16%)
mild/moderate disability (1-50)	276	(76%)	256	(70%)
severe disability (>50)	44	(12%)	52	(14%)
d. Bed days in past month				
none	317	(87)	337	(92)
one to four	30	(8)	14	(4)
five to seven	4	(1)	3	(1)
greater than seven	15	(4)	12	(3)
e. Functioning as compared to last month				
better	86	(24)	75	(21)
same	219	(60)	239	(65)
worse	58	(16)	51	(14)
don't know	3	(1)	1	(0)
f. Hospitalization in past 6 months				
no	288	(79)	299	(82)
yes	78	(21)	67	(18)
g. Falls in past month				
none	326	(89)	335	(92)
one	31	(7)	22	(6)
two to four	7	(3)	9	(2)
not ascertained	2	(1)	0	(0)
h. Number of medications used				
none	23	(6)	31	(9)
one to two	91	(25)	86	(23)
three to four	111	(30)	121	(33)
five to nine	113	(31)	121	(33)
ten or more	10	(3)	7	(2)
not ascertained	18	(5)	0	(0)

*n's vary slightly due to missing data on some indices or questions

Table 10 continued: Level of Impairment by Type of Interview on the Indices and on Questions Related to Illness, Falls, Medication Use and Hospitalization

	Type of Interview			
	Telephone		Home	
	n*	%	n	%
i. Cognitive Status (SPMSQ)				
no disability (9-10)	223	(67%)	237	(68%)
mild/moderate disability (5-8)	82	(25%)	89	(26%)
severe disability (≤ 5)	28	(8%)	20	(6%)

* n's vary slightly due to missing data when self-respondents could not respond as proxy responses were not accepted on this component of the questionnaire;

5.4 CONCORDANCE BETWEEN THE TELEPHONE AND HOME INTERVIEW

The analyses of agreement were performed for the Barthel Index, Zung Scale and the Reintegration to Normal Living Index in their entirety and for the questions relating to falls and hospitalization, on the study group as a whole, and for the subgroups formed by type of interviewer and type of respondent (Tables 11-14). The reliability and validity of each *item* on the Indices was investigated. These more detailed tables can be found in Appendices I, J and K. The analyses of agreement were performed on these specific areas, rather then on all questionnaire items, to keep the length of the presentation reasonable. Information regarding the additional items is available upon request from the authors.

5.4.1 Barthel Index

On the Barthel Index the intraclass correlation coefficient for the telephone/home comparison was 0.89, suggesting good comparability between the modes. Table 11 presents information on agreement between the two modes using cut-off scores of 60 and of 80 to classify dysfunction. Using a cut-off of 60 the kappa was 0.68, which represents good to substantial reliability between the modes (Seigel, Podgor & Remaley, 1992). The overall sensitivity of the telephone assessment to detecting functional disability was low (63%) while the corresponding specificity was excellent (98%). At a cut-off of 60, the negative predictive validity of the telephone interview was high at 0.97, the positive predictive value was 0.79. While at a cut-off of 60 the kappa scores achieved by the health professionals were higher than those of the lay persons (0.71 versus 0.66; Table 11) these differences were not statistically significant (Z=0.13). Using a cut-off score of 80 the two types of interviewers performed equally well (0.76 and 0.75, respectively).

Using a cut-off score of 80 the overall kappa (0.76) was higher than that evidenced at the cut-off of 60 and was more consistent across the subgroups, ranging from 0.71-0.76. The sensitivity of the telephone interview was 73%, the specificity 98% (Table 11). The positive predictive value of the telephone interview was 0.92: the negative predictive value was 0.91. McNemar's test revealed significantly less reporting of disability over the telephone, a tendency that was seen regardless of type of respondent or type of interviewer (Table 11).

Table 11: Agreement on Barthel Index Between the Telephone (Tel) and Home Interview Using a Cnt-off Score of 60 and 80

		Home							
		+	-						
	Tel + -	A C	B D	Sensitivity (%)	Specificity (%)	McNemar Bias	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)
Barthel 60									
all		19 11	5 331	63	98	2.25	95	0.68	0.60 - 0.79
lay interviewer		11 7	3 167	61	98	1.60	94	0.66	0.52 - 0.80
health professional		8 4	2 164	66	98	0.67	96	0.71	0.57 - 0.86
self		5 6	2 246	45	99	2.00	96	0.54	0.42 - 0.65
proxy		14 5	3 85	73	96	0.50	92	0.73	0.54 - 0.92
Barthel 80									
all		66 25	6 269	72	97	$11.65^{\&}$	91	0.76	0.66 - 0.86
lay interviewer		36 13	4 135	73	97	$4.76^{\wedge}$	90	0.75	0.61 - 0.89
health professional		30 12	2 134	71	98	$7.14^{@}$	92	0.76	0.62 - 0.91
self		27 14	4 214	65	98	$5.56^{\wedge}$	93	0.71	0.59 - 0.83
proxy		39 11	2 55	78	96	$6.23^{\wedge}$	87	0.75	0.56 - 0.94

$^{\wedge}$p<.05, $^{@}$p<.01, $^{\#}$p<.005, $^{\&}$p<.001

Tables I-1 to I-5 (in Appendix I) present the agreement and sensitivity/specificity of the individual Barthel items, for the group as a whole, and the sub-groups formed by type of participant and type of interviewer.

The calculations were performed using a dichotomous classification of function on each item, *independent* or *dependent*, which included the categories *needs assistance* and *dependent*. Only a brief synopsis of the findings from Tables I1 - I5 is presented here. There were significant differences on the items measuring feeding, dressing and walking with the telephone assessment resulting in less frequent reports of disability. For ambulation, this was especially pronounced (Table I-5) when proxies responded: for 20 of the 107 patients assessed through a proxy there was a report of independence on the telephone, whereas, at the time of the home visit the patient was found to need assistance for ambulation. For self respondents (Table I-4), this trend also held but failed to reach significance.

Kappa scores for the items measuring bowel and bladder control were only fair to moderate. When reporting on these two items self respondents often provided inconsistent responses between the two interviews, but the inconsistencies appeared to be random.

5.4.2 Zung Scale

The intraclass correlation coefficient for the Zung Scale was 0.83. When the Zung scores based on the telephone and home interviews (dichotomized at 50) were compared for the group as a whole, the kappa was in the range of moderate to substantial (0.62). The sensitivity of the telephone assessment to identifying depression was 81% with a corresponding specificity of 82% (Table 12). The negative predictive value was 0.77, while the positive predictive value was 0.85. A comparison of the kappa scores by type of interviewer revealed a higher kappa, at a cut-off of 50, when the telephone lay interviewers performed the Zung assessment as compared to when the health professionals performed the interview (0.69 versus 0.55; Table 12). However, the differences were not statistically significant and the 95% confidence intervals around the kappa's were wide and overlapped (Table 12). With a cut-off of 60 again no significant differences were found based on type of interviewer (Z=0.18).

Using a cut-off of 60 on the Zung Scale the sensitivity was 74%, slightly lower than at a cut-off of 50 (Table 12). The positive predictive value was 0.79 and the negative predictive value 0.87. Proxy respondents, when providing telephone information that was inconsistent with the home interview, were more likely to provide responses indicative of less *severe* depression with the telephone mode than indicated by the home interview (McNemar's statistic =7.18, p<.01; Table 12). In contrast, the group consisting of self respondents, when providing telephone responses that were inconsistent with the home interview, sometimes indicated more and sometimes indicated less impairment when questioned over the telephone (Table 12).

Kappa scores for the individual Zung items, when the whole group was studied, were mostly fair, ranging from 0.28 to 0.43, with few reaching the range of moderate agreement (Tables J-1 to J-5, Appendix J). Similar levels of agreement were found regardless of interviewer type or respondent type. McNemar's statistic revealed significant differences on three of the 10 items when the interviewer was a professional, but none when the interviewer was a lay person. McNemar's statistic also indicated significant differences on four of the ten items when the respondent was a proxy (Table J-5 in Appendix J), three of which were in the direction of less frequent reporting of disability on the telephone. In contrast, as already indicated above, self respondents did not demonstrate significant directional differences in their reporting.

5.4.3 Reintegration to Normal Living Index

Table 13 presents the sensitivity, specificity, percent agreement, and kappa statistic of reliability for the RNL Index using the entire group of respondents. The ICC for the RNL Index was 0.80. When the overall RNL score (dichotomized at 40), was compared for the group as a whole, the kappa was 0.61: the sensitivity was 65% with a specificity of 93%. The positive predictive value was .80, the negative predictive value was .85.

Using a dichotomy at 60 (that of more severe disability), the kappa was 0.52: the sensitivity was 48% with a specificity of 97%. The predictive validity of the telephone interview to identifying dysfunction was poor, .56: the negative predictive value was high, .96. The sensitivity of the telephone assessment was low across all sub-groups, ranging from 42% to 53%. with corresponding specificities all exceeding 90%. Again, this demonstrates, as with the Barthel Index, that the sensitivity to detecting dysfunction dropped for those with greater problems. Comparisons of the kappa's achieved by lay interviewers and health professionals revealed some variation based on the cut-off used: at a cut-off of 40 the health professionals achieved a kappa of 0.67, the lay persons a kappa of 0.54 (Table 13). At a cut-off of 60, it was the lay interviewers who had more consistent responses between the modes k=0.56 versus k=0.42. None of these differences were statistically significant.

McNemar's statistic (at a cut-off score of 40) indicated a trend towards less frequent reporting of disability on the telephone. The same trend was evident using a cut-off of 60 (Table 13), but it did not reach statistical significance.

When the whole group was studied, kappa scores for the individual RNL items were fair to moderate (0.20 to 0.56; Table K-1 in Appendix K). Wide ranges of agreement were also found for the sub-groups (Tables K-2 to K-5).

5.4.4 Falls and Hospitalizations

Table 14 presents the reliability and validity of two important health related events, hospitalizations and falls. For falls, the overall kappa was 0.73: kappas for the sub-groups were substantial (Table 14). For all subjects the sensitivity of the telephone assessment to identifying falls was 84% with a specificity of 96%. McNemar's statistic indicated a significant difference when the patient was the interviewee, with a higher reporting of falls on the telephone, than in the home.

The telephone interviewers were able to elicit information on hospitalizations in the past six months that were in concordance with the information provided at the time of the home visit. The kappa scores were all substantial, 0.71 or greater (Table 14).

Table 12: Agreement on Zung Scale Between the Telephone (Tel) and Home Interview Using a Cut-off Score of 50 and 60

	Home +	 -	Sensitivity (%)	Specificity (%)	McNemar Bias	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)
Tel +	A	B						
-	C	D						
Zung 50								
all	165 39	29 132	81	82	1.47	81	0.62	0.52 - 0.73
lay interviewer	83 17	12 76	83	86	0.86	85	0.69	0.55 - 0.83
health professional	82 22	17 56	79	77	0.64	78	0.55	0.40 - 0.70
self	99 26	24 109	79	82	0.08	81	0.61	0.49 - 0.73
proxy	66 13	5 23	84	82	3.56	83	0.60	0.42 - 0.79
Zung 60								
all	93 33	25 214	74	90	1.10	84	0.64	0.54 - 0.75
lay interviewer	44 18	14 112	71	89	0.50	83	0.61	0.47 - 0.75
health professional	49 15	11 102	77	90	0.62	85	0.68	0.53 - 0.82
self	53 19	22 164	74	88	0.22	84	0.61	0.49 - 0.75
proxy	40 14	3 50	74	94	7.18$^{@}$	84	0.68	0.50 - 0.87

$^{*}p<.05$, $^{@}p<.01$, $^{\#}p<.005$

Table 13: Agreement on Reintegration to Normal Living (RNL) Index Between the Telephone (Tel) and Home Interview Using a Cut-off Score of 40 and 60

	Tel	Home +	 -	Sensitivity (%)	Specificity (%)	McNemar Bias	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)
	+	A	B						
	-	C	D						
R.N.L.40									
all		73	18	65	93	8.34$^{\#}$	84	0.61	0.51 - 0.71
		40	233						
lay interviewer		31	8	55	94	8.76$^{\#}$	82	0.54	0.40 - 0.68
		25	122						
health professional		42	10	74	92	1.00	86	0.67	0.52 - 0.82
		15	111						
self		33	7	52	96	14.30$^{\&}$	86	0.56	0.44 ·· 0.67
		30	187						
proxy		40	11	80	31	0.05	80	0.61	0.42 - 0.80
		10	46						
R.N.L. 60									
all		14	11	48	97	0.62	93	0.52	0.42 - 0.61
		15	324						
lay interviewer		7	3	50	98	1.60	95	0.56	0.41 - 0.69
		7	169						
health professional		7	8	47	95	0.00	91	0.42	0.27 - 0.56
		8	155						
self		5	4	42	98	0.82	96	0.45	0.33 - 0.57
		7	241						
proxy		9	7	53	92	0.07	86	0.46	0.27 - 0.65
		8	83						

$^{\wedge}p<.05$, $^{@}p<.01$, $^{\#}p<.005$, $^{\&}p<.001$

Table 14: Agreement for Falls and for Hospitalizations Between the Telephone (Tel) and Home Interview Dichotomized as Event (+) or No Event (-)

Event	Tel	Home + +A -C	 - B D	Sensitivity (%)	Specificity (%)	McNemar Bias	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)
Falls									
all		26	12	84	96	2.88	95	0.73	0.62 - 0.83
		5	321						
self		15	10	88	96	5.33^	95	0.69	0.57 - 0.81
		2	230						
proxy		11	2	79	98	0.20	95	0.79	0.60 - 0.98
		3	91						
lay		11	7	73	96	0.82	94	0.63	0.48 - 0.77
		4	164						
professional		15	5	94	97	2.67	97	0.81	0.67 - 0.96
		1	157						
Hospitalization									
all		56	18	85	94	2.29	92	0.75	0.65 - 0.86
		10	282						
self		34	11	81	95	0.47	93	0.74	0.62 - 0.86
		8	206						
proxy		22	7	92	92	2.78	92	0.77	0.59 - 0.96
		2	76						
lay		33	13	85	91	2.58	90	0.71	0.57 - 0.85
		6	136						
professional		23	5	85	97	0.11	95	0.81	0.66 - 0.96
		4	146						

*p<.05. @p<.01. #p<.005

5.5 DIFFERENCES IN SCORES BETWEEN THE TELEPHONE AND HOME INTERVIEW

The results presented above suggest poorer agreement between the modes for those with more disability. To further explore and illustrate these findings, the scores on the home interview were used to categorize an individual's dysfunction as *no, mild, moderate or severe* (as detailed in section 4.10.1a). Then, for each individual the difference in the scores on the two interviews was calculated by taking the *total score* on the home interview *minus* the *total score* on the telephone interview.

Figures 2 a-d, 3 a-c and 4 a-d depict the differences between the telephone and the home interview scores, by level of dysfunction, for the Barthel Index, the Zung Scale and the RNL Index.

On the Barthel Index 87% of individuals who received a perfect score of 100 at the time of the home interview received the same score at the time of the telephone interview (Figure 2a). For those who were classified to be mildly disabled (scores of 81-99) at the time of the home interview (Figure 2b), all but 2% of telephone/home disagreements were within 10 points. As can be seen in Figures 2c and d, the major disagreements were for those in the two most impaired categories, where only about 15% of scores were in complete accord.

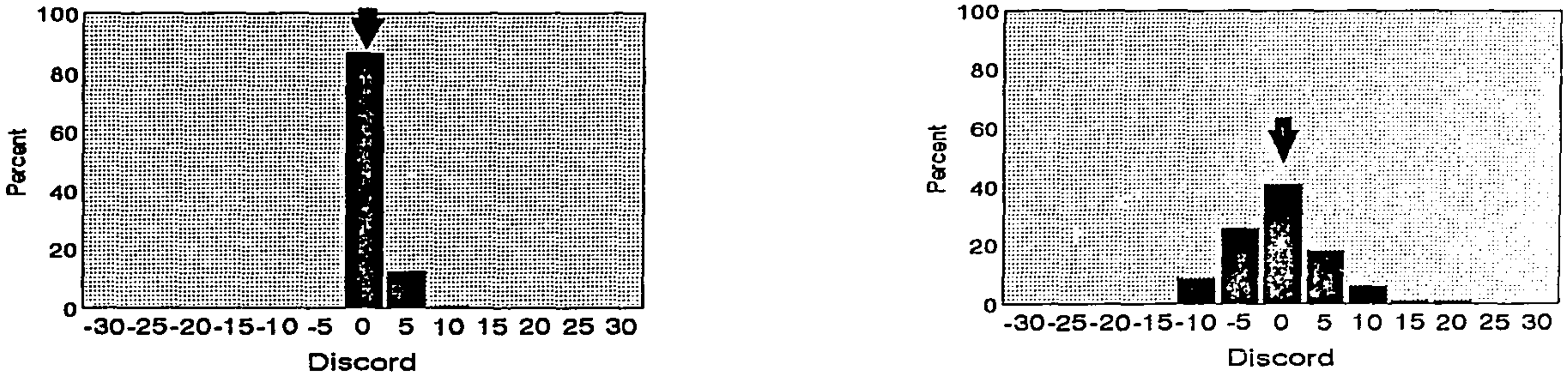
On the Zung Scale perfect accord between the telephone and home interview was rare (less than 14%) for all three categories (Figure 3a-c). However, for the three categories the scores on the telephone were within 10 points of the home interview about two-thirds of the time (Figure 3a-c).

On the RNL Index (Figure 4a-d), 57% of those reporting *no* disability during the home interview reported *no* disability on the telephone: 93% of scores were within 10 points (Figure 4a). The accord dropped dramatically with severity of dysfunction: for those classified as *mildly* disabled, the telephone/home scores were within 10 points 75% of the time and for the *moderate* and *severe* groups, less than 50% of the time (Figure 4c & d).

Figure 2: Discord on Barthel Index (Home Score - Telephone Score)

a) No Disability (n=169)

b) Mild Disability (n=106)



c) Moderate Disability (n=61)

d) Severe Disability (n=30)

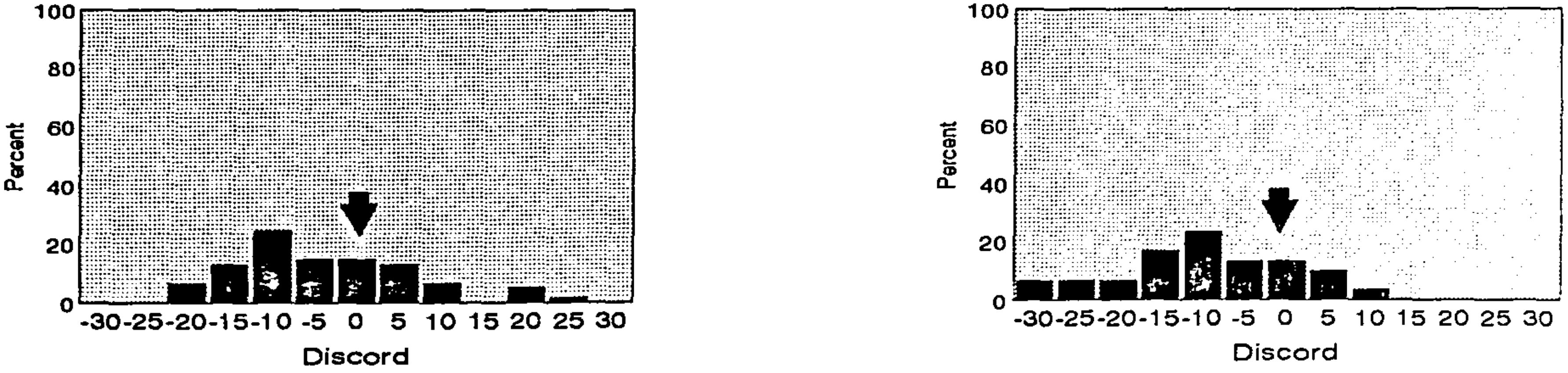
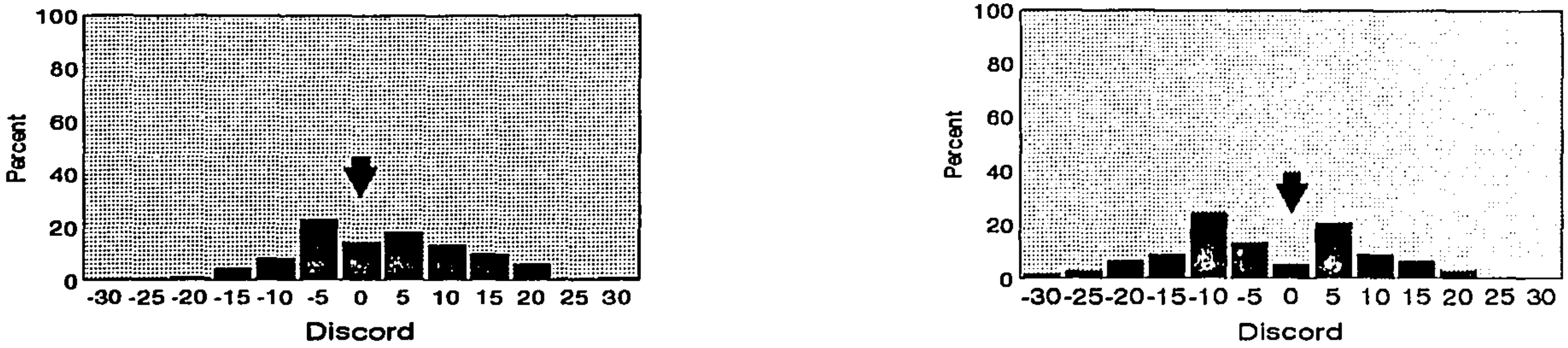


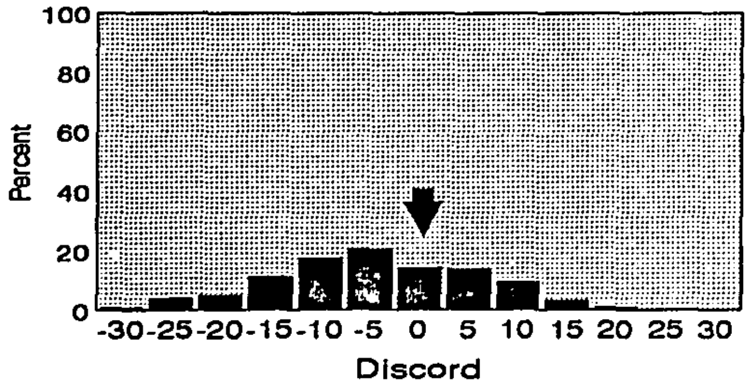
Figure 3: Discord on Zung Scale*
(home score - telephone score)



a) No Impairment (n=161)
(scores <50)

b) Mild-Moderate Impairment (n=78)
(scores 50-60)

c) Severe Impairment (n=126)
(scores >60)

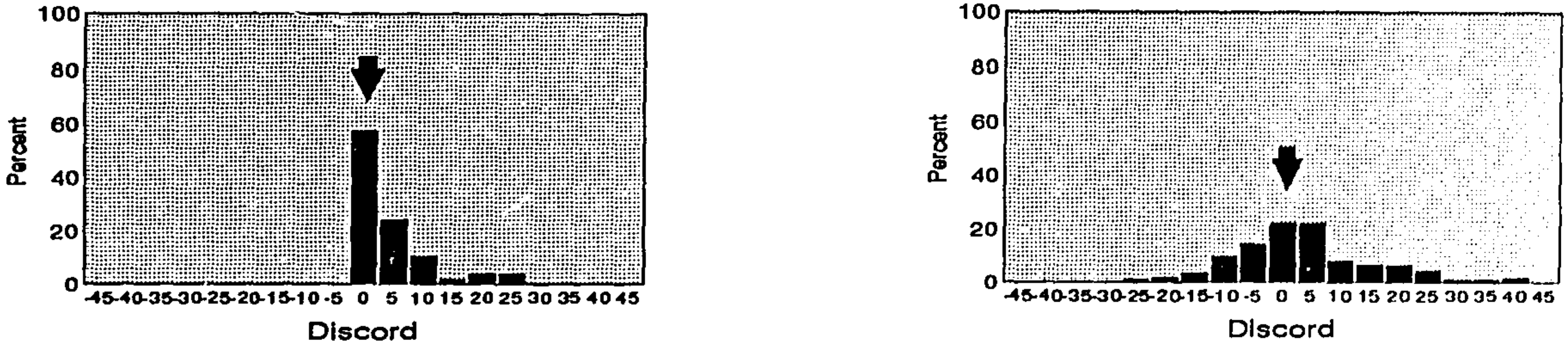


* negative values signify less impairment on telephone

Figure 4: Discord on RNL Index*
(home score - telephone score)

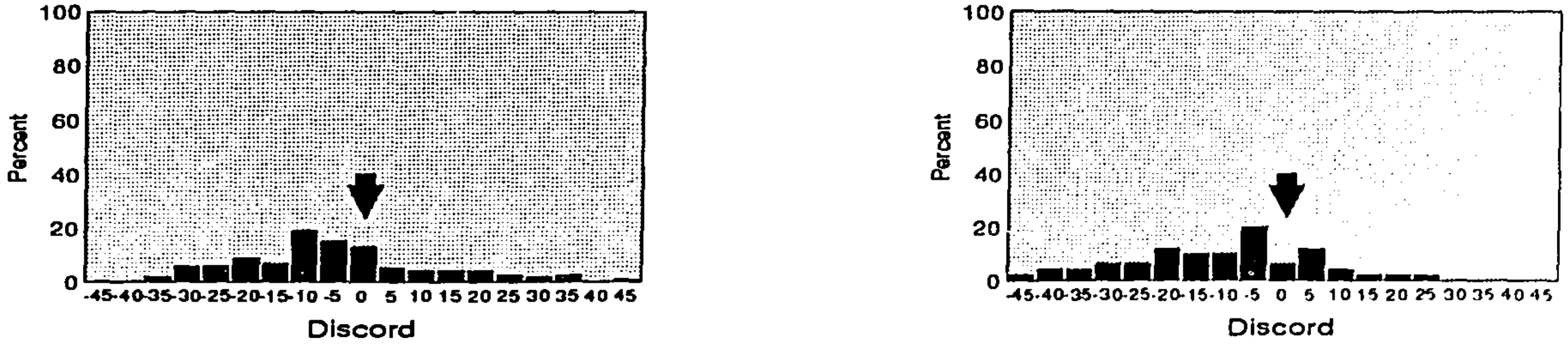
a) No Disability (n=58)
(score = 0)

b) Mild Disability (n=128)
(scores 1-25)



c) Moderate Disability (n=127)
(scores 26-50)

d) Severe Disability (n=51)
(scores >50)



*negative values signify less impairment on telephone

5.6 DETERMINANTS OF DISCREPANT REPORTING

As described in Section 4.10.1e, for the logistic regression analyses *discord* was defined by a difference of greater than 10 points between the telephone and the home interview. Table 15 presents a summary of the numbers of individuals for whom there was discord based on this definition.

Table 15: Numbers of Individuals with Discordant* Replies on the Barthel Index, the Zung Scale and the Reintegration to Normal Living Index

	Level of Discord	
	>10	
	n	(%)
Barthel Index		
all respondents	29	(8)
self respondents	16	(6)
proxy respondents	13	(12)
Zung Scale		
all respondents	92	(25)
self respondents	70	(27)
proxy respondents	22	(21)
RNL Index		
all respondents	119	(33)
self respondents	76	(30)
proxy respondents	43	(40)

* calculated by taking the absolute value of the difference between the telephone and home interview score out of a possible 100.

Using a cut-off of 10 points, only 29 (8%) of respondents had discordant Barthel scores between the telephone and home interview. On the Zung Scale, about one-fourth of responses were discordant. The RNL Index exhibited the greatest discord of the three indices, one-third or more of responses differed by greater than 10 points (Table 15).

Discord on the Barthel Index and on the RNL Index was less frequently encountered when the patients responded for themselves (Table 15). On the Zung Scale, this trend was not evidenced.

Tables 16 and 17 present information on the co-variates of interest for the analysis of discord. These tables are presented as a preliminary exploration of the variables considered for use in the logistic models.

On the Barthel Index, self respondents with a diagnosis of stroke had greater discord in scores than those with an orthopaedic condition (Table 16). Further exploration of the data to examine proxy accord by diagnosis of the patient, found no greater discord when the patient for whom they were responding had a diagnosis of stroke. Discord by proxy respondents occurred for 11% of stroke patients and 15% of orthopaedic patients. Age and sex of the patient were not associated with discord, nor was the language of presentation (Table 16). Those with discordant scores had, on average, higher depression scores and used more medications (Table 16).

Table 17 combines information for both proxy and self respondents. Interviewers seldom reported that they lacked confidence in the replies given by the respondents. However, on the rare occasion when they did report it was most often in those who provide discordant replies (1% for those with accord versus 10% for those with discord).

There was some information for which we had accurate information such as the name of the hospital to which the patient had been admitted and the length of stay in the rehabilitation hospital. Those who did not or who rarely provide accurate information on these questions were more likely to provide discordant responses between the modes: 13% of those with accord answered two or less answers correctly, versus 31% of those with discord (Table 17).

On the Zung Scale, the group providing discordant scores had higher depression scores, poorer cognitive scores and fewer correct responses to questions with known responses (Table 16). Discord was more often evidenced on the French version of the scale (Table 17).

On the RNL Index (Tables 16 & 17), comparisons indicated a few differences. Discord was more frequent in those with a greater number of medications and for those in whom the interviewers were less confident. Females were somewhat more likely to provide discordant replies, as were proxy respondents.

Table 16: Characteristics of Self Respondents According to Discord of >10 points between the Telephone and Home Interview on the Barthel Index, the Zung Scale and the Reintegration to Normal Living Index (RNL)

	Barthel Index		Zung Scale		RNL Index	
	Discord		Discord		Discord	
	no	yes	no	yes	no	yes
Age (mean S.D.)	67.4 ±11.9	67.6 ±8.9	67.4 ±11.9	67.8 ±11.0	67.9 ±12.2	67.6 ±11.8
Sex						
female	139 (57%)	9 (56%)	107 (57%)	41 (59%)	98 (54%)	48 (63%)
male	104 (43%)	7 (44%)	81 (43%)	29 (41%)	83 (46%)	28 (37%)
Diagnosis						
stroke	127 (52%)	13 (81%)	97 (52%)	42 (60%)	97 (54%)	42 (55%)
orthopedic condition	116 (48%)	3 (19%)	91 (48%)	28 (40%)	84 (46%)	34 (45%)
Cognition* (mean S.D.)	9.1 ±1.1	8.9 ±1.3	9.2 ±0.9	8.8 ±1.5	9.1 ±1.1	9.1 ±1.0
0-4	2 (1%)	0 (0%)	0 (0%)	2 (3%)	2 (1%)	0 (0%)
5-8	45 (19%)	4 (25%)	31 (16%)	17 (24%)	33 (18%)	15 (20%)
9-10	196 (81%)	12 (75%)	157 (84%)	51 (73%)	146 (81%)	61 (80%)
Depression (mean S.D.)	50.3 ±16.5	57.1 ±18.2	49.6 ±16.9	53.5 ±15.7	47.1 ±15.5	58.7 ±16.2
yes	48 (20%)	5 (31%)	45 (24%)	8 (11%)	29 (16%)	22 (29%)
no	195 (80%)	11 (69%)	143 (76%)	62 (89%)	152 (84%)	54 (71%)
Medication use**						
mean (S.D.)	4.1 ±2.5	5.4 ±3.0	4.1 ±2.5	4.5 ±2.7	4.0 ±2.5	4.6 ±2.7
0-2	77 (32%)	1 (6%)	60 (32%)	18 (26%)	60 (33%)	18 (24%)
3-6	120 (50%)	11 (69%)	94 (51%)	36 (51%)	91 (51%)	39 (51%)
7-15	44 (18%)	4 (25%)	32 (17%)	16 (23%)	28 (16%)	19 (25%)

* out of a possible score of 10 with higher scores signifying better function

** included medications used regularly and occasionally, maximum of 15

Table 17: Characteristics of All Respondents according to Discord of >10 points between the Telephone and Home Interview on the Barthel Index, the Zung Index and the Reintegration to Normal Living (RNL) Index

	Barthel Index		Zung Index		RNL Index	
	Discord		Discord		Discord	
	no	yes	no	yes	no	yes
Language of interview						
English	213 (63%)	18 (62%)	179 (66%)	51 (55%)	158 (64%)	72 (61%)
French	124 (37%)	11 (38%)	94 (34%)	41 (45%)	87 (36%)	47 (39%)
Interviewer confident in replies						
no on telephone and home	1 (0%)	0 (0%)	3 (1%)	2 (2%)	1 (0%)	1 (1%)
no on either telephone or home	3 (1%)	3 (10%)	19 (7%)	6 (7%)	12 (5%)	9 (8%)
yes on telephone and home	333 (99%)	26 (90%)	251 (92%)	84 (91%)	232 (95%)	109 (92%)
Number of accurate responses						
0-2	45 (13%)	9 (31%)	37 (14%)	17 (18%)	36 (15%)	17 (14%)
3-4	129 (38%)	9 (31%)	99 (36%)	39 (42%)	90 (37%)	47 (40%)
5-6	163 (48%)	11 (38%)	137 (50%)	36 (39%)	119 (49%)	55 (46%)
Type of Proxy						
spouse	40 (43%)	7 (54%)	36 (42%)	11 (50%)	26 (41%)	21 (49%)
child or other	54 (57%)	6 (46%)	49 (58%)	11 (50%)	38 (60%)	22 (51%)
Type of participant						
self	243 (72%)	16 (55%)	188 (69%)	70 (76%)	181 (74%)	76 (64%)
proxy	94 (28%)	13 (45%)	85 (31%)	22 (24%)	64 (26%)	43 (36%)
Type of interviewer						
lay	172 (51%)	16 (55%)	142 (52%)	46 (50%)	129 (53%)	57 (48%)
professional	165 (49%)	13 (45%)	131 (48%)	46 (50%)	116 (47%)	62 (52%)

5.6.1 Results of Logistic Regression Analyses

Multiple logistic regression was used to identify the contribution of the co-variates of interest on the dichotomous outcome variable defined as *discord*. For each of the three indices analyzed, *discord* was said to be present if the absolute difference between the telephone and the home interview score was greater than 10 points. For a complete description of the variables used in the logistic regression analyses, the reader is referred to Section 4.10.2 and Table 2. Briefly, for each index three separate collections of logistic analyses were performed, one including all participants, another for the group consisting of self respondents and one for proxy respondents. An apriori decision had been made to analyze the groups separately because the potential co-variates differed. For the purpose of these analyses the cognitive status of the individual is used as an explanatory variable and not as an outcome variable.

5.6.1a Barthel Index analyses

Model I: This model used all 366 participants, the outcome variable Barthel *discord* and the following covariates *accuracy of responses, cognitive status, confidence in the respondent's replies, depression (yes, no), interviewer type, participant type, diagnosis, language of interview* and *numbers of medications* used.

The variable *number of medications used* was associated with discord, such that for each increment in medication use, there was a 1.19 increase in the odds of discordant responses: the corresponding confidence interval was 1.03 - 1.37. The variable measuring *confidence in the respondent's replies* was also associated with an increase odds of discordance (O.R. = 4.06). However, the numbers were small, and the resulting CI was wide (.93-17.6) and included 1. A model including an interaction term for these two variables showed no effect. The variable *diagnosis* approached, but was not significant, with a trend towards more frequent discord when there was a diagnosis of stroke.

Models II and III: Model II included only self respondents. The variables were similar to those in Model I, but with the addition of age and sex of the patient, and with the variable *participant type* excluded. Model III included only proxy respondents, the variables in Model I and the additional variable *type of proxy* (spouse, child or *other*). Again, the variable *participant type* was excluded

While the variables *confidence in the patient's replies* and a *diagnosis* of stroke, increased the odds of discord, the estimates were unstable and the confidence intervals wide. For the proxy group no variables were identified that helped explain discord between the modes.

5.6.1b Zung Scale analyses

Model IV: This model used all 366 participants, the outcome variable *Zung discord* and the covariates *accuracy of responses, cognitive status, confidence in the respondent's replies, depression (yes, no), interviewer type, participant type, diagnosis, language of interview* and *numbers of medications used.*

The only variable that approached significance was *language of interview* with interviews performed using English less likely to be associated with discordant replies.

Models V and VI: Model V used the group consisting only of patient respondents and adding the variables *age* and *sex* to Model I. Model VI included only proxy respondents, the variables in Model IV and the additional variable *type of proxy* (spouse, child or *other*).

Two variable were significantly associated with discord. *Medication* use was important (O.R.=1.19, C.I.=1.01 - 1.27). In addition, *cognitive status* of the patient was associated with discord such that for each one category decrement in *cognitive status* (based on a three category, non-factored variable) there was an increased odds of discordant responses (O.R.=2.10, CI=1.13 - 3.88). A model including the interaction term failed to explain discord better than the two variables individually. The analyses for the group consisting only of proxy respondents including the variables in Model I and the variable *type of proxy* (spouse, child or *other*) failed to reveal any significant coefficients.

5.6.1c RNL Index analyses

Model VII used all 366 participants, the outcome variable *RNL discord* and the following covariates: *accuracy of responses, cognitive status, confidence in the respondent's replies, depression (yes, no), interviewer type, participant type, diagnosis, language of interview* and *numbers of medications used.*

The only variable that was significantly associated with an increased odds of discord was *medication* use (O.R.=1.11, C.I.=1.02 - 1.21). While *cognitive status* was associated with discord (O.R. = 1.351), the confidence interval was relatively wide (0.91 - 1.99) and included 1.

Models VIII and IX: Regression analyses for the group identified as patient respondents, again, revealed the variable *medication* use (O.R.=1.14, C.I.=1.02-1.27). For the group consisting of proxy respondents, the factored variable indicating *cognitive status* was associated with a high odds ratio, of 2.57 and 3.50 against the referent category but with confidence intervals including 1. A diagnosis of stroke, approached, but did not reach significance.

5.6.2 Summary of Findings from Logistic Regression

A summary of the findings for the logistic regression models is presented in Table 18. The number of medications used was repeatedly associated with an increased odds of discord, both when entered as a continuous variable and when used as a categorical, factored variable. The cognitive status of the patient was also associated with an increased odds of discord on two of the indices, the Zung Scale and the RNL Index.

Table 18: Logistic Regression Analysis of Discord* for the Barthel Index, the Zung Scale and the Reintegration to Normal Living (RNL) Index

	Discord		
	Variable	Odds Ratio	Confidence Interval
All respondents			
Barthel Index	medication use	1.19	1.03 - 1.37
	confidence in replies	4.06	0.93 - 17.60
Zung Scale	-------		
RNL Index	medication use	1.11	1.02 - 1.21
Self respondents			
Barthel Index	-------		
Zung Scale	medication use	1.19	1.01 - 1.27
	cognitive impairment	2.10	1.13 - 3.88
RNL Index	medication use	1.14	1.02 - 1.27
Proxy respondents			
Barthel Index	-------		
Zung Scale	-------		
RNL Index	cognitive status[a]	2.58	0.75 - 8.80
		3.50	0.92 - 13.31

* calculated by taking the absolute value of the difference between the telephone and home interview score out of a possible 100. Differences greater than 10 points were indicated to be discordant. --- signifies that no covariates were identified to influence *discord*. [a] based on a three-level factored variable.

CHAPTER 6: DISCUSSION

6.1 INTRODUCTION AND OVERVIEW

This study was designed to investigate the comparability of a telephone and a face-to-face health status assessment in individuals with physically disabling conditions. The primary question of interest was whether a telephone administered questionnaire could be used to elicit accurate information on physical functioning, mood, reintegration into the community and health related events. Of additional interest was the performance of trained lay interviewers and the usefulness of proxy respondents to elicit health related information for those who were unable to respond for themselves.

The findings of this study indicate that the telephone interview provides information on the prevalence of disability and health events that is, for many components of the questionnaire, virtually identical to that identified by a home visit. The telephone interview is also a reasonably reliable means of determining functional state and the occurrence of health events in the individual: the kappa scores were moderate to substantial for most comparisons. However, ideally coefficients of greater than .90 are optimal if the telephone interview is to be used for *case finding*, where a failure to detect a problem may result in a failure to provide important treatment to an individual (for a review of this issue see Streiner & Norman, 1989). There is, however, some concern regarding the use of the telephone interview to identify an individual's status based on a specified cut-off score. The sensitivities of the individual indices to detecting dysfunction were only good to moderate.

One consistent finding and one that warrants concern was that discord between the telephone/home interview was greatest for those with severe disability. The tendency was for less frequent reporting of disability on the telephone which suggests that the telephone interview may fail to identify a small sub-group of individuals who are in need of surveillance or intervention.

The findings regarding the use of lay interviewers are generally encouraging. The results suggest that using trained lay persons to estimate the prevalence of disability in community dwelling individuals would provide similar estimates to those elicited by health professionals. Overall, on the telephone lay interviewers performed as well as health professionals.

The findings on the use of proxy respondents suggest a willingness to respond to questions related to the overall health status of friends and family members. The results also indicate that proxy respondents were generally as consistent in their replies as were self respondents.

6.2 DETAILED INFORMATION ON THE HEALTH STATUS MEASURES

6.2.1 Information on the Use of the Barthel Index

The results of this study suggest that, with a few exceptions, functional status, as identified using the Barthel Index, can be elicited reliably over the telephone. For the group as a whole, and for the sub-groups, the percent agreement was always greater than 90%. In a previous study comparing answers on a telephone administered Barthel Index with those from an in-person assessment, Shinar and colleagues (1987) found correlations for the individual items ranging from .80 to 1.00 with the lowest coefficients were those measuring walking and grooming. Although our results suggest slightly lower coefficients the two studies are difficult to compare because the authors used measures of trend rather than reliability and a somewhat smaller sample size of 36 self and 36 proxy respondents.

As previously indicated, only 29 (8%) individuals had scores differing by more than 10 points between the telephone and the home interview. Unfortunately, the differences were always in those considered to have *moderate* to *severe* impairment, and were most often (23 of 29 times) in the direction of higher scores, indicative of less disability, on the telephone. This would suggest that, in a small sub-group of patients, a telephone interview may fail to detect those with moderate and severe functional problems.

An important finding is that the telephone assessment worked well in identifying those who did *not* have functional disabilities: the negative predictive values were .97 at a cut-off score of 60 and .91 at a cut-off of 80. All individuals who scored 100 on the home interview, scored 95 or better on the telephone. Theoretically, these are the same individuals who might receive an unnecessary home visit, to assess bathing and other self care activities, when a telephone assessment could indicate that this type of intervention is not needed. Considering that a large number of participants scored a perfect 100 on both the telephone and the home interview (40%), this finding has important implications for clinical practice.

It is noteworthy that responses between the modes of interview, when provided by proxies, were twice as likely to differ by greater than 10 points, than responses provided by self respondents (12% discordance versus 6%). Another point of interest is that only 19 of the perfect scores were reported by proxy respondents. As anticipated, those who required proxies were rarely functioning well in their daily activities. It appeared that one reason for the proxies providing discordant responses was the difficulty in achieving agreement for those with serious problems. Whereas at a cut-off of 60 on the Barthel Index the kappa score for patients was higher than that for proxies, at a cut-off of 80 there were no differences in the reliability coefficients for the two groups. However, when the variable identifying type of participant was included in the logistic regression model it did not help to explain the discord between the modes.

One serious *item* discord between the modes bears discussion. For 20 (19%) of the 107 patients assessed through a proxy, there was a report of independence in ambulation on the telephone whereas the home visit revealed a need for assistance (Table I-5, in Appendix I). Patients, to a lesser degree, also tended to report better ambulation on the telephone as compared to that observed during the home interview (Table I-4, in Appendix I). We postulate that a proxy, accustomed to the gait pattern of the patient, may have indicated independence on the telephone while the visiting therapist considered the patient unsafe. This same scenario probably held true for patients who may have felt that they were safe walkers but were considered unsteady by the therapist. In conversation with the therapists who conducted the telephone interviews they stressed that they asked the question on ambulation in a direct manner, as stated in the protocol, and did not attempt to elaborate during their questioning. In future use of a telephone questionnaire, the introduction of a number of items dealing with mobility, that focus on safety and balance and not solely one's ability to walk a defined distance, should provide a more accurate picture of ambulatory status.

It is plausible that the discord noted for ambulation exemplifies a much greater problem, that is, a trend towards under-reporting of all functional disabilities when a verbal report, rather than visual demonstration, is used. Ambulatory status was observed for most individuals at the time of the home visit. For example, many patients walked to the door to greet the therapist. Other areas such as bathing and washing, although by protocol viewable at the request of the therapist, were rarely observed. Therefore, had the therapists made more requests to observe functional behavior, the discrepancies between the telephone and the home might have been accentuated to an even greater extent. This issue of the validity of verbal reporting as compared to actual demonstration has, occasionally, been brought to light in the literature. Harris and colleagues (1986) and Collin and colleagues (1988) compared the self-report of patients with actual performance using a functional assessment scale and found that agreement between the verbal report and visual demonstration was, in general, similar. In contrast, McGinnis and colleagues (1986) found significant differences between patient reports and performance based scores using the Barthel Index, whereas Roy and associates (1988) did not. The inconsistency of the findings are likely due in part to small sample sizes (often 20 individuals or less) and the use of a number of different statistical measures, often inappropriate, to compare the modes. The question of performance based evaluation versus the verbal report remains an interesting one which, although not answerable within the current protocol, justifies further investigation.

Attempts to identify characteristics of those for whom discord was likely to occur on the Barthel Index revealed two variables, the *number of medications used* and the *confidence* that the interviewer had in the replies given by the respondent. Unfortunately, the variable *confidence in replies* would potentially earmark only a small number of individuals, based on four reports of non-confidence in replies over the telephone. One interesting point is that, of the 7 respondents in whom therapists reported a lack of *confidence* only 1 was a proxy. Yet, as mentioned above 12% of responses from proxies led to discord. We speculate that the *number of medications used* may be serving as a proxy variable indicating the overall health status of the individual. Alternatively, a specific medication, or combination of medications such as those affecting awareness, memory and concentration may have been associated with an increased likelihood of discord. The analysis necessary to answer this question was not carried out but is of interest for further study.

For the sub-group consisting of only patients, the logistic regression analysis revealed an effect of diagnosis and, not unexpectedly, the variable identifying *confidence*. Those with a diagnosis of stroke and those in whom the therapists did not have confidence, were more likely to provide discordant answers. We speculated that a diagnosis of stroke might be acting as a proxy for severity, in that those with greater dysfunction were more difficult to classify correctly. When proxy respondents provided answers the analyses did not reveal a higher discord for stroke patients than for orthopaedic patients.

6.2.2 Information on the Use of the Zung Scale

The assessment of mood presented one of our biggest dilemmas. Many of the clinicians when consulted for opinions regarding the choice of a depression scale, were dissatisfied with the available tools. Some respondents clearly disliked this portion of the questionnaire. Anecdotally, older male participants were particularly antagonized by this aspect of the interview. The interviewers found the Zung Scale difficult to administer. They sometimes expressed concern that they were accentuating a sad state of affairs and then offering nothing other than a few consoling words. The switch to the short version of the Zung Index for the main study, as compared to the 20 item version for the pilot phase appeared to make the assessment of mood, if not a cheerful event, at least more tolerable.

Despite our concerns the Zung Scale performed quite well. When the Zung score (dichotomized at 60), was compared for the group as a whole, the kappa was substantial (k= 0.64). The sensitivity of the telephone assessment to identifying severe depression was only fair at 74%, but the specificity was respectable at 90%. The negative predictive value was .87, suggesting that the telephone interview did a moderate job of identifying those who were not depressed.

A comparison of the kappa scores for responses elicited by lay interviewers and by health professionals revealed, as had the Barthel Index, no trend towards more consistent reporting by one or the other group.

For the sub-groups formed by patients and by proxies, higher kappa scores were evidenced between proxy responses than between patient responses (Table 12). Discord, based on a greater than ten point difference between the modes, occurred in 21% of proxy responses versus 27% of patient responses. However, McNemar's statistic indicated that proxies were significantly less likely to report depression when interviewed on the telephone, as compared to in the home. No such trend was evidenced for patient respondents. These findings appeared to present conflicting information that was clarified with further inspection of the data. Although the discord in the scores of patient respondents was greater, the discord was random, that is, sometimes scores were higher on the telephone; sometimes they were higher on the home interview. In contrast, discordant responses by proxies were almost always based on a reporting of a lower score on the telephone interview, hence a significant McNemar's test, but a better kappa.

Logistic regression analyses, for the entire group of participants, failed to reveal variables to help explain discord. For the subgroup formed by patients, poor cognitive functioning, and multiple drug use increased discordance. For the subgroup formed by proxies, with the additional covariate indicating relationship to the patient, be it a spouse, child or *other*, there were no variables identified that helped explain discord.

There is much controversy surrounding the appropriate cut-off for defining depression on the Zung Scale. Using a cut-off score of 50, almost half of the respondents' replies were indicative of depression, whereas, for a cut-off of 60, the prevalence of depression was about 30%. This latter finding concurs with previous reports of prevalence of depression following stroke (Robinson and Price, 1982; Parikh, Lipsey, Robinson, et al, 1987; Bacher, Korner-Bitensky, Mayo et al, 1990) and, although infrequently reported, following hip fracture (Billig, 1986). In those of more advanced age it has been suggested that a cut-off at 60 is more appropriate for identifying depression, as it reflects the increased prevalence of somatic complaints associated with age (Zung, 1967; Steuer, Bank, Olsen et al, 1980). If this scale was used for *case finding* in clinical practice, a cut-off of 60 would be more reasonable for it is difficult to contemplate the usefulness of the Zung Scale, for our proposed purposes, if it identifies half of the population as being in need of intervention.

The Zung Scale was the only scale on which language of presentation, specifically the French version, was associated with a tendency, although not statistically significant, towards greater discord. The Zung Scale was translated, for the purposes of other studies in our center, by a French speaking individual and back-translated by an English speaking individual. However, there may remain some discrepancies or vagaries in the French questionnaire format that will require further examination. Perhaps simple translation is not sufficient. Possibly, cultural differences are accounting for some of the discrepancies.

Recently, Stewart and Ware (1992) have presented the results of testing on a measure that focuses on psychological distress and well-being. This battery, which is part of the Medical Outcomes Study framework of health indicators, examines feelings such as happiness, anxiety, depression and feeling blue. Rather than attempting to diagnose depression, it focuses on the perceived well-being of the individual. This battery, which has been adapted for use on the telephone, may prove an interesting alternative to the Zung Scale in future studies.

6.2.3 Information on the Use of the RNL Index

The Reintegration to Normal Living Index (Wood-Dauphinee, Opzoomer, Williams et al, 1988), is a relatively new tool. While it has been used to assess individuals with myocardial infarct, cancer and, to a lesser extent, patients with neurological conditions, the group interviewed here was older and more disabled. It was also the first time that the Index was used over the telephone and administered by an interviewer, rather than being self-administered. Our pilot work revealed that respondents had problems understanding some of the questions. This in turn led to a number of slight changes in the phrasing of the questions and the response choices, in both English and French. The interviewers also reported that the RNL was asked in the least standardized manner because of the need to paraphrase some of the questions. It was therefore not surprising that the respondents showed a greater tendency towards discord between the modes with this measure, than with the others: 33% of responses differed by more than 10 points.

While the kappa score on the overall RNL score, using a cut-off score of 40, was compared for the group as a whole, the kappa was moderate bordering on substantial: using a cut-off score of 60, a dichotomy designated to identify those with more severe disability, the kappa scored dropped sharply, barely reaching the moderate range. The corresponding sensitivity was low 48%, with a specificity of 97%. This finding demonstrates, as for the Barthel Index, that the reliability and validity dropped for the identification of severe disability. At a cut-off of 60 the negative predictive validity of the Index was excellent, suggesting that the RNL Index proved valuable in detecting those who are not facing serious problems in community integration. McNemar's statistic of bias (at a cut-off score of 40) indicated, as expected from the earlier analyses, a consistent under-reporting of disability on the telephone. Although similar trends were evident at a cut-off of 60 they did not reach statistical significance.

Although sometimes achieving lower reliability, the coefficients for the RNL Index were still in the moderate to substantial range, according to the guidelines provided by Landis and Koch (1977). Poorer reliability may be inherent in instruments such as the RNL Index, because they attempt to measure constructs that are more abstract than those measured by, for example, the Barthel Index. In addition, as previously mentioned, achieving perfect concordance is likely to be easier when no dysfunction is present, which was seldom the case on the RNL Index. While 40% of patients received perfect scores on the

Barthel Index only 9% received comparable scores on the RNL Index. One other potential problem was the positioning of the RNL Index near the end of the questionnaire. Fatigue, or, loss of interest, may have influenced the agreement between the responses, especially because the RNL questions required more concentration and reflection, than some of the earlier questions. It is probable that with some minor changes to the questions and to the response options, and some additional testing, the RNL's reliability over the telephone will be improved.

6.2.4 Illness, Hospitalization and Falls

In this study, we elicited information on overall health status and on health events. Questions included those on general well-being, bed days due to illness, medication use, hospitalization, and falls. There is a body of literature that has explored the best means of eliciting health related information. For example, Aneshensel and colleagues (1982) compared the two modes and found more restricted activity days with the in-person interview. In contrast, we have found more bed days with the telephone interview. Henson, Cannell and Roth (1978) noted that individuals answering a telephone interview expressed fewer health symptoms than did individuals answering an in-person interview, while Miller (1984), reported that telephone interviews produced higher reporting of health care utilization and morbidity. Others have reported no appreciable differences in reporting of health status based on mode (Chambers, Haight, Norman, et al, 1987).

The information on hospitalization in the six months prior to interview revealed that respondents provided comparable answers between the modes. Aneshensel and colleagues (1982) have reported similar findings.

Our group experienced a high rate of falls. On the telephone, 10% of individuals reported the occurrence of a fall, or falls, in the month prior to the study: 8% reported a fall based on the home interview. It is especially alarming that rates of falls were this high among individuals living in the community. Falls in the elderly have received much attention in the health care literature in recent years (Gryfe, Amies, Ashley, 1977; Tinetti, Speechley, & Ginter, 1988; Blake, Morgan, Bendall et al, 1988). Considering the potential mental and physical risks associated with falls in older individuals, it is most encouraging that the sensitivity of the telephone assessment to identifying falls was quite good (84% with a corresponding specificity of 96%). Although McNemar's statistic of bias indicated a significant difference between the modes when the patient was the interviewee, it was towards a higher reporting of falls on the telephone, rather than the less desirable scenario of a higher reporting in the home.

The number of medications used on a regular and occasional basis was ascertained on the telephone and at the time of the home interview. For 5% of individuals it was not possible to ascertain medication use on the telephone. There were three reasons for this: visual impairments that prohibited the reading of the medication labels to the interviewer; the medication being stored in another area of the building such as a nurse's office found in some senior's residences; and because the proxy was not at the patient's residence at the time of the interview. At the time of the home interview, it was possible to obtain information on the name and dosage of medication for 100% of participants. Other than the slight increase in difficulty in eliciting the names of medications on the telephone, the distribution of reported number of medications used was similar on the telephone and in the home interview. This is an important finding as medication errors pose a serious risk in elderly individuals who may use multiple drugs, without a clear understanding of their effects, uses or interactions. Follow-up clinics, especially geriatric services, will benefit from being able to verify the medications the patient is using, without having to do a home visit or having to bring the patient to a clinic. One further point warrants discussion. While ascertaining medications over the telephone, we did not seek information on compliance. However, conversations with the telephone interviewers indicated that respondents asked questions or expressed uncertainty about medication use. These questions, potentially, could have been addressed by a nurse who was knowledgeable about medication use. Thus, in the future, the telephone contact may prove fruitful as a means of providing counselling and verification for those who are at risk for misuse of medications.

The overall impression from the currently presented study and previous works is that the accuracy of information elicited on the telephone will vary depending on the type of information being elicited. Groves and colleagues (1988) have suggested that greater attention to questionnaire design and to telephone interviewing skills have led to a reduction in differences between the modes as compared to earlier studies. Our findings lend support to more recent reports that suggest relatively few differences between the modes for the ascertainment of health related questions. These differences should continue to abate as the sophistication of telephone interviewing techniques increases.

6.3 ACCEPTABILITY OF THE TELEPHONE INTERVIEW

This study has demonstrated that it is possible to use a telephone administered questionnaire to elicit information on health status from community dwelling individuals, many of whom were elderly and disabled, years after their discharge from a rehabilitation hospital. Tracing was successful for all but 11 of 1098 individuals in the cohort. Fewer than 9% of individuals refused to be in the study, and in those who did agree, completion rates were high for both the telephone and the home interview.

The portrait of a refuser was distinctive, most often that of an elderly women living alone. Akhtar (1972) found a similar trend of higher refusal rates in women than in men, based on a survey of the elderly that investigated medical, social, psychiatric and dietary status. It is unlikely that the inclusion of those who refused would have significantly changed the estimates of concordance and, therefore, the concern is not great that these individuals biased the estimates of reliability. Rather, these individuals raise concerns relating to the provision of health care services. An older woman, living alone, who refuses to be included in a follow-up program, may be at high risk of morbidity because of her age and the potential for social isolation. Anecdotally, some individuals who refused to participate, verbalized a fear of having a stranger come to the home, but stated that they would have agreed to the telephone interview. In clinical practice, it would be helpful to introduce a strategy offering those who refuse an interview by a stranger, an interview performed by a health professional who cared for them while they were in hospital. Alternatively, introducing the follow-up interviewer to the patient, prior to his or her discharge from hospital, might dispel some of the individual's fears. The use of only a telephone interview, without the threatening home visit, may also work well with this particular group of individuals.

In general, when discrepancies in reporting occurred between the modes, they were in the direction of a lesser reporting of disability on the telephone. The potential under-reporting of dysfunction raises concerns that those who are in need may be overlooked by the telephone intervention. Although the logistic regression analyses on discordance did highlight some patient characteristics that will help to identify individuals for whom the telephone results should be interpreted with caution, the findings suggest the precautionary use of additional surveillance or a home visit for all individuals scoring low on the indices.

The RNL Index was plagued by the greatest number of problems both during the pilot phase and the main study. This finding raises some general discussion points. Common sense would suggest that by asking very basic, direct questions, there is good potential for high reliability. Trying to measure less tangible constructs, such as the perceived overall well being of an individual, is fraught with problems: instruments attempting to measure constructs such as quality of life are likely to have poorer reliability and validity, even with the most strenuous attempts to reduce error. Yet, it has been shown that the patient's perception of his or her health status is an important predictor of mortality (Kaplan & Camacho, 1983) and thus, warrants consideration.

6.3.1 The Use of Lay Interviewers

This study found strong support for the use of well trained lay interviewers to administer health questionnaires over the telephone. Both lay interviewers and health professionals, at times, elicited discrepant scores between the telephone and home interviews, depending on the item, the index, or the specified cut-off score. Overall, there was no indication that the use of lay interviewers resulted in consistently poorer accord.

Rather, it is probably that the differences that were noted were based on true group differences. For example, those interviewed by the lay persons more often reported being hospitalized in the previous six months and also more often reported that they were functioning better than they had been in the previous month. While these two statements may appear contradictory, it is possible that the group interviewed by the lay persons, having experienced more hospitalization in the previous six months, were indeed functioning better at the time of the telephone contact than in the month prior.

In addition, the greater proportion of individuals with difficulties in reintegration to community living (as assessed by the RNL Index) and with poor cognitive status when interviewed by health professionals may reflect true differences accounted for by the greater number of stroke patients in the group interviewed by health professionals. For example, individuals with stroke did have, on average, poorer scores on the RNL Index than did those with orthopaedic conditions (27.8 ±20.8 versus 22.9 ±20.9).

Anecdotally, the lay interviewers did report some concern regarding their competence to address questions on medication use, health problems or medical services. The occupational therapists were more knowledgeable regarding health problems and medical services but they also expressed a problem responding to questions on medication use.

These reports underscore the importance of distinguishing between an interview that proposes to identify and document health status and one that is used to direct and provide treatment. While it is not suggested that lay interviewers be substituted for professionals when the intention is to provide advice or intervention, lay interviewers may play a valuable role in the *case finding* process. If the practice of using a telephone assessment of health status is instituted using lay interviewers in the clinical settings, it will be important to clarify with the respondent, that the role of the interview is to collect information and not to provide intervention. Appropriate actions can be then be taken based on a review of the assessment, preferably by team members from various disciplines, who are trained to address any needs that might arise.

6.3.2 The Use of Proxy Respondents

When comparing the results of this study to those previously published it is important to clarify that we did not compare the responses given by the proxy to those given by the self respondent. Rather, we explored the consistency of responses between the two different modes of interview.

An interesting finding in this study was that the type of proxy, be it a spouse, a child, or another individual who was close to the subject, did not appear to influence concordance between the telephone and home interview. Sample size was a problem in attempting to look at the effect of type of proxy, therefore, our results are tempered. Other studies have found that the spouse was the most likely to recall events and provide accurate answers (Williams Pickle, Morris-Brown, Blot, 1983; Farrow & Samet, 1990). While for stroke patients it was most often the spouse that acted as a respondent, for orthopedic patients it was most often a child or other individual. While we hypothesized that it may be harder for proxies reporting for stroke patients because of the multiple and severe sequela that are often present, this trend was only evidenced on the RNL Index. On this measure 46% of responses resulted in discord when the proxy was responding for a stroke patient, as compared to 27% when the proxy was responding for an orthopedic patient.

One additional explanation for our finding that there was no significant difference in accord based on type of proxy may be the advanced age of the subjects. Perhaps with older individuals the child is in closer contact and is therefore knowledgeable regarding the parent's health status. This is particularly conceivable in our study group, as there were many elderly individuals with physical limitations who would have been in need of some assistance to carry out their daily activities. Another potential explanation is the stringent criteria used in this study to define a proxy. Proxies must have lived with or had a minimum of three contacts a week with the patient, thus, eliminating those who were not knowledgeable enough to provide accurate information. This hypothesis is probably the most plausible in that, logically, it should be those closest to the patient who can best answer for him or her. If consistency can be taken as a sign of reliability then this finding has important implications for the use of proxy respondents. Rather than choosing the proxy solely by the kinship type, it may be valuable to choose a proxy based on the frequency of contacts with the individual.

Interestingly, most individuals who were approached to participate as proxies agreed to do so willingly. However, there were a number of instances when a potential proxy refused, not because they were averse to being interviewed but, because the individual for whom they were answering was not willing to be discussed, or because the proxy did not want to reply to questions with the patient present. While the protocol in our study stipulated that the patient be present during the home interview it may be advantageous, in clinical practice, to permit the proxy to respond privately. However, instituting such a protocol raises ethical concerns regarding the rights of the patient versus the need to determine health status, especially in those with cognitive or mood disorders.

6.4 LIMITATIONS AND POTENTIAL CONTROVERSIES

A number of limitations and potential controversies need to be discussed. The first series of issues surrounds the use of two interviews on the same individual. A re-interview may result in a number of biases. If the respondent recalls a previously given response he or she may provide the same response in an attempt to be consistent, thereby increasing the similarities between the two interviews. Conversely, information may be lacking on the second interview if the respondent feels that only new information need be provided. In addition, there may be true clinical change from the time of the first interview to the second. The time for reflection between interviews may influence the responses provided on the second interview. Or, the interviewee might be more accustomed to the process by the second interview and, thus, provide, more accurate responses. In this study, attempts were made to control for and limit the impact of these possible influences by randomizing the order of the home and telephone interview, by scheduling the interviews three days apart, and by requesting that the respondent provide complete information during both interviews. The interviewers were also asked to record interim events, such as a fall or change in medication use, that may have had an effect on reporting. A review of the data showed that no interim events were recorded. Scrutiny of the data did not reveal any systematic trend towards more or less frequent reporting of disability or health events with the first interview or the second interview: prevalence of disability on the various indices was reported to be of similar magnitude on the first and second interview, irrespective of mode used. Even for the variable that investigated the number of accurate responses to information on previous hospitalizations and length of stay, information that could quite easily have been verified between the first and second interview, there was no evidence of more accurate reporting at the time of the second interview.

Measures of reliability and of validity were used to investigate the concordance between the telephone and face-to-face interview. While neither was deemed totally applicable, there was some justification for the use of both. Measures of validity were used because the visit to the home by a qualified therapist is thought to elicit responses closer to truth than a telephone interview, where there is a disadvantage posed by not being able to see the individual. However, the literature on the use of telephone interviews suggests that, at times, the telephone interview may actually provide more complete, or better, information. This has been shown to be the case for questions that are considered threatening or of a sensitive nature (Hochstim, 1967; Bradburn & Sudman, 1980). Therefore, as there was no body of research literature that unequivocally supported the home interview as the superior medium, measures of reliability were also considered suitable.

There are a number of additional statistical issues surrounding the comparison of two measures. Until recently, many of the studies reviewed used analyses of trend such as the Pearson Correlation Coefficient, Spearman Correlation Coefficient, or Kendall's Tau, rather than the more appropriate tests of concordance (Kramer & Feinstein, 1981). There have also been proposals for the use of Yule's statistic based on the argument that, at a fixed sensitivity and specificity, kappa scores fall dramatically when prevalence rates are below 20% (Helzer, Robins, McEvoy et al, 1985). Conversely, Sackett (1979) has argued that *K*'s sensitivity to base rates is entirely proper. The *K* statistic measures concordance beyond that attributable to chance. It is more difficult to improve over chance in the general population, where it is likely that the disorders are rare and mild, than it would be, for example, in a hospital based group.

An additional concern with the use of the kappa statistic is that all disagreements are treated equally, that is, there is no credit given for *being close* (Streiner & Norman, 1989;

Maclure & Willett, 1987). A potential alternative was considered for use in this study, that is, the weighted kappa (Maclure & Willett, 1987; Streiner & Norman, 1989). With weighted kappa, weights are assigned according to the degree of discord. Although intuitively, this scheme is appealing, two problems have been pointed out in the literature. First, weighted kappa may be uninterpretable unless different research groups use common weighting schemes with which the reader is familiar (Maclure & Willett, 1987). In addition, weighting may be meaningless for clinical decision-making if the point is to use a dichotomous outcome to decide on clinical practice. In addition, Fleiss and Cohen (1973) have shown that, when there are identical distributions in the margins, weighted kappa approximates the intraclass correlation coefficient.

The use of the ICC statistic poses some potential for controversy when used in comparing scales that are ordinal, rather than continuous. The assumption is made that this is acceptable, if the gaps between the scoring are reasonably narrow and the scores cover a wide range (Kleinbaum & Kupper, 1978). On both the Barthel Index and the RNL Index the range of scores were wide, thereby suggesting that the scores approximated those on a continuous scale.

A potentially debatable decision was the use of a fixed difference of 10 points to indicate discord between the telephone and home interview. The Barthel Index had the most potential for discord based on this criteria. However, intuitively, one would be concerned about discord, even on one item, if it resulted in a failure to identify a serious problem, such as the inability to walk. It may be deemed slightly less serious to misjudge a single item on a mood scale, or on a scale that measures reintegration to the community. If this supposition is accepted, then the fact that the Barthel Index was the most stringently affected by the use a 10 point spread to define discordance seems rational.

When the protocol for this study was originally designed it was anticipated that receiver operating characteristic (ROC) curves would be generated to determine the best cut-offs for the telephone interview. Accordingly, the sample size calculations were made based on the formulas derived by Hanley and McNeil (1982). During the data analysis phase there was opportunity to reconsider the best form of analyses. The measures under study have been used quite extensively, and defined cut-offs for identifying impairment or disability are already established, and are being substantiated in recent publications (Shah, Cooper, Maas, 1991). It was decided that there would be limited benefit to finding that the balance between sensitivity and specificity was best at a score that had no clinically important meaning. Fortunately, a reassessment of the sample size, based on calculations for reliability coefficients, suggested that with the number of individuals available for study we could be reasonably confident that the reliability coefficients attained were close to the *true* reliability coefficients.

One final point concerns the use of multiple statistical comparisons. It is possible that by performing many statistical comparisons on the data we increased the probability of finding a significant difference when none existed. However, in this study we would have been happy to be unable to reject the null hypothesis of no significant differences between the modes or between the interviewer types. Therefore, not performing a correction for multiple comparisons was actually a more conservative approach.

6.5 GENERALIZABILITY OF THE FINDINGS

This study was conducted to determine the feasibility of using a health status questionnaire over the telephone in older individuals with physically disabling conditions, who had experienced a health event requiring rehabilitation. As discussed earlier, the prevalence of a trait or condition in a study group will influence the reliability with which that trait is ascertained. The results of this study should not be extended to the general population, where the prevalences of the traits under study are likely to be lower.

The JRH, the hospital in which this study was performed, accepts patients with a wide range of ages and impairments. The hospital covers a catchment area that includes individuals from many different cultural and ethnic backgrounds. Quebec is a province of mainly French speaking individuals. Thus, we were fortunate in having the opportunity to conduct interviews in two languages, French and English, and with individuals from many ethnic groups. There were no appreciable differences in rates of participation, based on language of interview, nor from what we could observe, based on ethnicity. Participation was high for self respondents, proxy respondents and in those of all ages and ranges of disability. Individuals were receptive to participating even five years after their discharge from hospital. Therefore, the results of this study should be generalizable to other settings that provide in-patient rehabilitation and wish to follow their patients after discharge. It is probable that these results can also be extended to apply to other high risk groups living in the community, such as those discharged from geriatric units of acute care hospitals.

This study used trained lay interviewers and health professionals. Having used a number of lay and professional interviewers we feel confident that the results are applicable, not only to our particular group, but also to other well trained interviewers with and without a background in a health related profession. However, it is doubtful that similar levels of accord between the modes would be achieved without the inclusion of training sessions.

6.6 DIRECTIONS FOR FUTURE RESEARCH

This study has provided a stepping stone for studies using a telephone administered health status questionnaire. We have shown that it is feasible to trace, contact and elicit health status information from physically disabled individuals after they are discharged from rehabilitation services.

It will be important in future work to identify the feasibility of monitoring individuals over time, rather than at only one point in time. Monitoring will require tools that are sensitive to change. Such tools often present multi-leveled Likert type scales that we have found potentially difficult to administer over the telephone. The trade-off between sensitivity and feasibility will pose interesting dilemmas that will benefit from further exploration.

In the three years since this project was undertaken there have been many exciting advances in home communication technology. In the future, these should allow for the installation of visual monitors attached to telephones so that the interviewing process can be performed with the additional benefit of the interviewer and participant being able to see one another. The addition of visual contact with the respondent should provide an opportunity for the use of the telephone interview to monitor status and to provide interventions that are conceptually closer to a home visit. Considering the increasing numbers of elderly and disabled individuals who are socially isolated, especially in the winter months, these technological advances may become important in the follow-up of potentially high risk individuals. While the cost of such a program might be high initially, it is likely to decrease substantially as the technology becomes more widely available.

CONCLUSION

The results of this study indicate that information on the health status of elderly, disabled individuals is generally similar when collected by telephone and through an in-person interview. For individuals with *no* dysfunction or *mild* dysfunction, the telephone interview provided accurate information on health status. However, there is concern that, in those with *moderate* and *severe* disabilities, the telephone mode underestimates morbidity compared with a home interview. Therefore, we suggest that, for those individuals where the telephone interview indicates even mild impairments, continued surveillance or intervention be introduced.

This study provides evidence for the use of well trained lay interviewers in the *case finding* process. These results have important implications for hospital follow-up services and community surveillance programs of elderly or disabled individuals. In a time when health care costs are skyrocketing, when health professionals are in short supply and when the numbers of elderly, disabled individuals living in the community is escalating, there is clearly a need for alternative approaches to monitoring patients. The use of a telephone administered health status assessment as a case finding tool should provide identification of those individuals, in the community, who are *not* in need of scarce professional resources. The use of lay interviewers should also reduce the costs of such a program and permit more time to the health professionals to provide necessary counselling and intervention.

STATEMENT OF ORIGINALITY

To my knowledge, this is the first published study that assessed the agreement between estimates of health status elicited through a telephone interview and a face-to-face interview among disabled and for the most part elderly, individuals discharged from a rehabilitation hospital. The methodology used was distinctive from most previously published reports in that all participants received both a telephone interview and a face-to-face interview in their home, the order of the telephone and the home interview was randomized, and because individuals were randomized to receive the telephone interview by either a lay or a professional interviewer. In contrast to most other published studies comparing the telephone and face-to-face interview, the questionnaire used here encompassed a wide spectrum of health related areas including function, mood, cognition and community reintegration, as well as information on illness, hospitalization, falls and medication use. This study contributes new information on the usefulness of the telephone mode to determine the health status of community dwelling individuals who are potentially at high risk for disability.

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APPENDIX A

NOM DU PARTICIPANT (PARTICIPANTE)________________________________

HOPITAL JUIF DE RÉADAPTATION
QUESTIONNAIRE D'ÉVALUATION DE L'ÉTAT DE SANTÉ

LA PERSONNE QUI EFFECTE L'ENTREVUE DOIT REMPLIR CETTE PAGE.

*** SI INCERTAIN INDIQUER UN POINTAGE INFÉRIEUR ***

ENTREVUE

NUMERO D'IDENTIFICATION PARTICIPANT (PARTICIPANTE)______________

TYPE D'ENTREVUE (TÉLÉPHONIQUE OU DOMICILE)______________________

TYPE DE PARTICIPANT (PATIENT OU MANDATAIRE)______________________

IDENTIFIEZ LE OU LA MANDATAIRE (NOM ET LA RELATION AVEC LE PATIENT). IL EST IMPORTANT DE NOTER QUE LE OU LA MANDATAIRE DOIT HABITER AU MEME DOMICILE QUE LE PATIENT.

____

NOM DE L'INTERVIEWER____

DATE DE L'ENTREVUE____

DÉBUT DE L'ENTREVUE (L'HEURE)_________________________ ______

FIN DE L'ENTREVUE (L'HEURE)______________________________________

L'ENTREVUE FUT COMPLÉTÉE OUI NON

SI NON, POURQUOI ?____

SI L'ENTREVUE NE FUT PAS COMPLETÉE

RAPPEL EFFECTUÉ OUI NON

DATE DU RAPPEL____

Révisé septembre 1990

NOM DU OU DE L PARTICIPANT(E)____

Nous allons commencer par vous poser des questions sur votre fonctionnement dans la vie de tous les jours.

Si vous n'aviez personne pour vous aider, pourriez-vous accomplir les activités suivantes seul ?

Original scoring for the Barthel Index

Item	Incapable d'accomplir la tâche	Besoin d'assistance	Complètement indépendant
Alimentation (peut couper son manger, beurrer son pain)	0	5	10
Se laver, soins des cheveux, barbe, dents, ongles.	0	0	5
Prendre un bain (peut prendre un bain ou douche sans aucune personne présente)	0	0	5
* Habillage (peut mettre ses souliers, bas, pantalons etc).	0	5	10
Aller à la toilette (peut enlever ses vêtements, se nettoyer, s'assoir et se relever de la toilette)	0	5	10
Contrôle fécale (pas d'accidents jour et nuit)	0	5	10
Contrôle urinaire (controle de vessie jour et nuit)	0	5	10
Transferts au fauteuil, au lit (peut transferrer en) sécurité d'une chaise au lit et vice versa	0	5-10	15
** Marche, déplacements (peut marcher 50 mètres sans aide ou supervision mais peut utiliser une canne ou marchette	0	5-10	15
Monter, dèscendre les éscaliers (doit être indépendant)	0	5	10
*** Fauteuil roulant (peut manoeuvrer les coins, se placer près d'un lit ou une toilette etc.)	0	0	5

* *Si le patient porte des aides il ou elle doit se vêtir seul, si non le patient est considéré ayant besion d'assistance*

** *Un patient qui utilise une canne ou une marchette sans aide ou supervision est considéré indépendant*

*** *Compter seulement si le client est incapable de marcher.*

Croyez vous que les réponses du client sont justes et appropriées.

OUI *NON*

*Commentaires*____

NOM DU PARTICIPANT (PARTICIPANTE) ______________________

RAPPEL D'ÉVÉNEMENTS

Quand étiez-vous un patient (une patiente) à l'hôpital Juif de Réadaptation ? *(mois et année approximativement)*

MOIS____________________ANNÉE______________________________

Combien de temps avez-vous été hospitalisé(e) à l'hôpital Juif de Réadaptation? *(journées approximativement)*

JOURNÉES____

Où étiez vous avant d'être admis à l'hôpital Juif de Réadaptation?
(Hôpital/domicile/autre)
SI UN HOPITAL: LE NOM____

Dans les derniers six mois, avez vous été hospilalisé(e) dans un hôpital de soins aigus.

OUI NON

(Si oui) Combien de fois avez vous été hospitalisé(e)? ____________

MALADIE

Au cours du dernier mois, combien de journées avez vous passées au lit à cause de maladie, blessures, ou problèmes de santé?

0

1-4

5-7

>7

Comparé au mois dernier fonctionnez vous

Mieux

Comme avant

Pire (plus mal)

Aucune idée

Croyez vous que les réponses du client sont justes et appropriées?

OUI ***NON***

Commentaires____

____

*NOM DU PARTICIPANT (PARTICIPANTE)*____

Maintenant j'aimerais vous poser des questions de mémoire.

LE PATIENT ET NON LE MANDATAIRE DOIT RÉPONDRE A CETTE PARTIE DU QUESTIONNAIRE

Quelques unes des questions sont un peut simples mais nous les demandons à tout nos anciens patients qui participent à notre étude.

SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE
(Pfeiffer, Canadian Version)

1. Quel est votre nom ? (prénom et nom de famille)	**0**	**1**
SPÉCIFIEZ ____________________		
2. Quelle est votre adresse? (rue et municipalité)	**0**	**1**
SPÉCIFIEZ ____________________		
3. En quelle année sommes-nous ?	**0**	**1**
4. Quel mois sommes-nous ?	**0**	**1**
5. Quel jour sommes-nous ?	**0**	**1**
6. Quel âge avez-vous ?	**0**	**1**
SPÉCIFIEZ ____________________		
7. Quel est le nom du premier ministre du Canada ?	**0**	**1**
8. Quel est la date du commencement de la première guerre mondiale ? (1914)	**0**	**1**
9. Rappelez vous de ces trois articles. Dans quelques minutes, je vous demanderai de me les nommer, lit chaise, fenêtre		
10. Comptez, en descendant, de 20 à 1	**0**	**1**
11. Répétez les trois articles que je vous ai demandé de vous souvenir	**0**	**1**
Total		

Encerclez le chiffre 1 pour chaque question si tous les item sont exacts.

Croyez vous que les réponses du client sont justes et appropriées.

OUI ***NON***

Commentaires____

____

*NOM DU PARTICIPANT (PARTICIPANTE)*____

Cette section concerne vos sentiments ie: comment vous vous sentez ei: "Je remarque que je perds du poids".
Laquelle de ces réponses correspond le mieux à votre situation.

S'IL VOUS PLAIT BIEN NOTEZ QUE L'ÉCHELLE EST DIFFÉRENTE POUR CERTAINES QUESTIONS.

ECHELLE ABREGEE ZUNG

	RAREMENT	QUELQUE-FOIS	SOUVENT	LA PLUPART DU TEMPS
Je suis fatigué(e) sans raison apparente.	1	2	3	4
Je me sens mieux le matin. *	4	3	2	1
Je mange autant qu'avant. **	4	3	2	1
Je suis découragé(e).	1	2	3	4
Mon esprit est aussi clair qu'avant.	4	3	2	1
J'ai de l'espoir pour l'avenir.	4	3	2	1
Il m'est facile de prendre des décisions.	4	3	2	1
Je me sens utile.	4	3	2	1
Ma vie est bien remplie.	4	3	2	1
Je trouve du plaisir dans les mêmes choses qu'avant.	4	3	2	1

* Encerclez 1 si le patient n'a aucun problème.
** L'interviewer peut demander aussi si le poids (du patient) est le même que d'habitude.

Croyez-vous que les réponses du client sont justes et appropriées ?

OUI *NON*

*Commentaires*____

____

*NOM DU PARTICIPANT (PARTICIPANTE)*______________________________

(MÉDICAMENTS)

SI LA PRÉSENTE ENTREVUE EST LA DEUXIEME DEMANDEZ AU PATIENT S'IL Y A DES CHANGEMENTS DEPUIS LA PREMIERE ENTREVUE. INDIQUEZ AVEC UN (A) LES NOUVEAUX MÉDICAMENTS ET UN (D) LES MÉDICAMENTS QUI SONT TERMINÉS

J'aimerais maintenant vous poser quelques questions sur les médicaments que vous avez pris depuis 6 heures hier matin jusqu'à 6 heures ce matin.

Avez vous vos médicaments ?

(Si oui, demandez au patient de lire l'étiquette de chaque bouteille pour la période indiquée ci-haut).
(Si non, demandez au patient d'assembler ses médicaments et de lire l'étiquette de chaque bouteille pour la période indiquée ci-haut)

MÉDICAMENT *1*________________***DOSE***__________ ***FRÉQUENCE*** ________

MÉDICAMENT *2*________________***DOSE***__________ ***FRÉQUENCE*** ________

MÉDICAMENT *3*________________***DOSE***__________ ***FRÉQUENCE*** ________

MÉDICAMENT *4*________________***DOSE***__________ ***FRÉQUENCE*** ________

MÉDICAMENT *5*________________***DOSE***__________ ***FRÉQUENCE*** ________

MÉDICAMENT *6*________________***DOSE***__________ ***FRÉQUENCE*** ________

MÉDICAMENT *7*________________***DOSE***__________ ***FRÉQUENCE*** ________

MÉDICAMENT *8*________________***DOSE***__________***FRÉQUENCE*** ________

MÉDICAMENT *9*________________***DOSE***__________***FRÉQUENCE*** ________

MÉDICAMENT *10*_______________***DOSE***__________ ***FRÉQUENCE*** ________

Avez-vous d'autres médicaments que vous prenez parfois ?

MÉDICAMENT *1*________________***DOSE***__________ ***FRÉQUENCE***________

MÉDICAMENT *2*________________***DOSE***__________ ***FRÉQUENCE***________

MÉDICAMENT *3*________________***DOSE***__________ ***FRÉQUENCE***________

MÉDICAMENT *4*________________***DOSE***__________***FRÉQUENCE*** ________

MÉDICAMENT *5*________________***DOSE***__________ ***FRÉQUENCE***________

Croyer vous que les réponses du client sont appropriées ***OUI*** ***NON***

Commentaires____

____

NOM DU PARTICIPANT (PARTICIPANTE) ______________________________

Maintenant nous sommes à la dernière partie du questionnaire. Quelques unes des questions sont semblables à des questions que nous vous avons déjà posees.

La question sera en forme d'énonciation et vous aurez trois choix. Les trois choix sont oui, partiellement ou non.
Voici la première question.

QUESTIONNAIRE DE REINTEGRATION A LA VIE NORMALE

(Sharon L. Wood-Dauphinee, et al. 1988)

(Fauteuil roulant, autre équipement, ou ressource.)

	Oui	Partiellement	Non	N/A
1. Je me déplace autant que je veux dans mon logement.	0	1	2	___
2. Je me déplace autant que je le veux dans mon entourage (Magasins, banque, etc.)	0	1	2	___
3. Je suis apte a voyager à l'extérieur de la ville autant que je le désire .	0	1	2	___
4. Je suis satisfait(e) de la façon dont mes soins personnels sont accomplis. (m'habiller, me laver, me nourir)	0	1	2	___
5. La plupart de mes journées sont consacrées à une activité qui m'est nécessaire ou importante. (du ménage, du bénévolat, des études, un emploi)	0	1	2	___
6. Je participe aux activités récréatives selon mon désir (passe-temps, sports, artisanat, lectures, télévision, jeux, ordinateurs, etc.)	0	1	2	___
7. Je participe aux activités sociales autant que je le veux. (Avec la famille, des amis ou des relations/amis de travail.)	0	1	2	___
8. Dans le milieu familial, je maintiens un rôle qui répond à mes besoins et les besoins des membres de ma famille. (Famille se rapporte au gens avec qui vous vivez ou n'habitez pas mais que vous voyez de façon régulière.)	0	1	2	___
9. En général, je me sens à l'aise dans mes relations personnelles.	0	1	2	___
10. En général, je me sens à mon aise quand je suis en compagnie des autres.	0	1	2	___
11. Je sens que je peux faire face aux épreuves de la vie quand elles se déclarent.	0	1	2	___

Croyez vous que les réponses du client sont justes et appropriées

OUI ***NO***

Commentaires ______________________________

____

NOM DU PARTICIPANT (PARTICIPANTE) ______________________

J'aimerais maintenant vous posez quelques questions sur vos chutes.

SI LA PRESENTE ENTREVUE EST LA DEUXIEME ENTREVUE IDENTIFIEZ (AVEC UNE ETOILE) LES CHUTES QUI ONT EUT LIEU APRES LA PREMIERE ENTREVUE

(CHUTES)
Avez vous fait des chutes dans le dernier mois ?

OUI NON

(Si non, procédez à la prochaine partie du questionnaire) __________

(Si oui) Nombre de chutes ______________________

(PREMIERE CHUTE)
Circonstances de votre chute ______________________

____

Où étiez vous ? (Lieu de la chute) ______________________

____

Blessures ? OUI NON

(Si oui) Type de biessure ______________________

Partie du corps ______________________

(DEUXIEME CHUTE)
Circonstances de votre chute ______________________

____

Où étiez vous ? (Lieu de la chute) ______________________

____

Blessures ? OUI NON

(Si oui) Type de blessure ______________________

Partie du corps ______________________

(TROISIEME CHUTE)
Circonstances de votre chute ______________________

____

Où étiez vous ? (Lieu de la chute) ______________________

____

Blessures ? OUI NON

(Si oui) Type de blessure ______________________

Partie du corps ______________________

(Si le patient à subi plus que trois chutes inscrivez les particuliers dans l'espace au dessous).

Croyez vous que les réponses du client sont appropriées

OUI *NON*

Commentaires ______________________

____

NOM DU PARTICIPANT (PARTICIPANTE) ______________________________

Y a-t-il autres choses que vous aimeriez a discuter avec nous concernant votre santé et fonctionnement ?

____

____

____

____

____

____

____

RECOMMANDATION GÉNÉRALE

GÉNÉRALEMENT PENSEZ VOUS QUE

1. ***PATIENT SEMBLE BIEN - AUCUNE INTERVENTION***
2. ***INTERVENTION SUGGÉRÉE***
3. ***URGENT - ATTENTION IMMÉDIATE***

COMMENTAIRES

____

____

____

____

PARTICIPANT'S NAME____

JEWISH REHABILITATION HOSPITAL
HEALTH STATUS ASSESSMENT QUESTIONNAIRE

THIS PAGE IS TO BE FILLED IN BY THE PERSON PERFORMING THE INTERVIEW

*** WHEN IN DOUBT GRADE DOWNWARDS ***

INTERVIEW INFORMATION

STUDY NUMBER____

TYPE OF INTERVIEW (telephone or home)______________________

TYPE OF INTERVIEWER (lay or professional)____________________

INTERVIEW ORDER HOME - TELEPHONE

TELEPHONE - HOME

TYPE OF PARTICIPANT (patient or proxy)_____________________

IF PROXY IDENTIFY (name and relationship to patient)
(PROXY MUST LIVE WITH PATIENT)

____

NAME OF INTERVIEWER____________________________________

DATE OF INTERVIEW______________________________________

TIME INTERVIEW STARTED__________________________________

TIME INTERVIEW ENDED____________________________________

INTERVIEW COMPLETED YES NO

IF NO LIST REASON______________________________________

RECALL YES NO

SCHEDULED____

Revised Sept. 90

PARTICIPANT'S NAME____

We will start with questions on (Mrs. or Mr.)___________'s (insert patient's name) functional status.

If there was no one to help (her or him) with the following functional activity could (she or he) do it alone ?

Original scoring for the Barthel Index

Items	Unable to perform task	Needs assistance	Fully independent
Feeding **(Includes cutting, spreading butter)**	0	5	10
Personal hygiene **(Wash hands and face, shave, brush teeth)**	0	0	5
Bathing self **(Must be able to bath or shave without anyone present)**	0	0	5
Dressing * **(Can put on shoes, socks, pants etc. without help)**	0	5	10
Toileting **(Can remove clothes, wipe himself, get on and off toilet)**	0	5	10
Bowel control **(No accidents day or night)**	0	5	10
Bladder control **(Controls bladder day and night)**	0	5	10
Chair/bed transfers **(Can safely transfer from a chair to a bed and back again)**	0	5 - 10	15
Walking ** **(Walks 50 yards without help or supervision but may use aids)**	0	10	15
Stair climbing **(Goes up and down stairs independently)**	0	5	10
Wheelchair *** **(Maneuver corners, position himself near bed, toilet etc.)**	0	0	5

---

* *If patient has special aids that he/she has to wear, he/she must be able to put them on by himself/herself or he/she is classified as needing help.*

** *If the patient is independant with an aid, then patient is independant.*

*** *Score only if unable to walk.*

Do you feel confident in the proxy's responses? *YES* *NO*

*Comments*____

____

*NAME OF PARTICIPANT*________________________________

PATIENT'S RECALL OF EVENTS

When was (Mr. or Mrs.)__________________(insert patient's name) at the Jewish Rehabilitation Hospital? *(month & year approx.)*

MONTH ____________________YEAR__________________________

How long was (she or he) at the JRH ? *(in days approx.)*

DAYS____

Where was (she or he) prior to being admitted to the JRH ? *(Hosp/home/other)*

IF HOSPITAL: NAME____

Has (she or he) been hospitalized in an acute care hospital in the last six months ?

YES NO

(If yes) How many times was (she or he) hospitalized?____________

ILLNESS

In the past month how many days was (she or he) in bed for most of the day because of sickness, injury or other health problems?.

0

1-4

5-7

>7

Compared to last month would you say (she or he) is functioning

Better

Same

Worse

Don't Know

Do you feel confident in the proxy's responses ? YES NO

*Comments*____

____

*PARTICIPANT'S NAME*____

Now we are going to ask you some questions on memory.

Some of the questions are very simple but we are asking them to all patients so that we have complete data.

THIS COMPONENT OF THE QUESTIONNAIRE IS TO BE ANSWERED ONLY BY THE PATIENT EVEN WHEN A PROXY IS BEING USED FOR THE OTHER COMPONENTS OF THE ASSESSMENT. HOWEVER, THERE WILL BE CIRCUMSTANCES, FOR EXAMPLE WHEN THE PATIENT IS APHASIC, THAT PROHIBIT THE USE OF THE ASSESSMENT.

SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE
(Pfeiffer, Canadian Version)

1.	What is your full name ? (correct forename and surname)	0	1
SPECIFY____________________________			
2.	What is your address ? (correct street address and municipality)	0	1
SPECIFY____________________________			
3.	What year is this ? (correct year)	0	1
4.	What month is this ? (correct month)	0	1
5.	What day of the week is this ? (correct day of the week--not date	0	1
6.	How old are you ?	0	1
SPECIFY____________________________			
7.	What is the name of the Prime Minister of Canada ?	0	1
8.	When did the First World War start ? (1914)	0	1
9.	Remember these three items. I will ask you to recall them in a few minutes--bed, chair, window. Have subject repeat them correctly		
10.	Count backwards from 20 to 1	0	1
11.	Repeat the three items I asked you to remember	0	1
	Total		

Score 1 point for each question if all items on that question are correct

Do you feel confident in the patient's responses *YES* *NO*

*Comments*____

____

*PARTICIPANT'S NAME*____

Now I'm going to ask you some questions on how (Mr./Mrs./Miss) ____________________(insert name of patient) feels in general.

FOR EXAMPLE: "(She or he) notices that (she or he) is losing weight" Does this apply to (her or him) rarely, sometimes, often, most or all of the time?

PLEASE NOTE THAT THE SCALE REVERSES FOR SOME QUESTIONS

SHORT ZUNG SCALE

	Rarely	Some-times	Often	Most of the time
(She or he) gets tired for no reason.	1	2	3	4
Morning is when (she or he) feels the best. *	4	3	2	1
(She or he) eats as much as (she or he) used to. **	4	3	2	1
(She or he) feels down-hearted, blue and sad.	1	2	3	4
(Her or his) mind is as clear as it used to be.	4	3	2	1
(She or he) feels hopeful about the future	4	3	2	1
(She or he) finds it easy to make decisions.	4	3	2	1
(She or he) feels that (she or he) is useful and needed.	4	3	2	1
(Her or his) life is pretty full.	4	3	2	1
(She or he) still enjoys the things (she or he) used to do.	4	3	2	1

* Score as "1" if the patient does not have any problems.
** The interviewer can also ask if the patient's weight is still the same.

Do you feel confident in the proxy's responses ? *YES* *NO*

Comments____

____

PARTICIPANT'S NAME____

(MEDICATION)

I'm going to ask questions on medication that (she or he) has used from 6:00 A.M. yesterday morning to 6:00 A.M. this morning.

Do you have the medication assembled?

(If yes, have proxy read the label from each bottle that the patient used in the 24 hr period).
(If no, have proxy assemble the medication and read the label from each bottle that the patient used in the 24 hr period)

IF THIS IS THE SECOND INTERVIEW ASK PROXY IF THERE ARE CHANGES IN MEDICATIONS BETWEEN THE TWO2 INTERVIEWS. IF SO IDENTIFY WITH A STAR THOSE THAT ARE ADDED OR DELETED AND SPECIFY (A) OR (D).

MEDICATION 1 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 2 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 3 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 4 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 5 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 6 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 7 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 8 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 9 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 10 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

Does (she or he) have any other medication that (she or he) uses occasionally?

MEDICATION 1 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 2 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 3 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 4 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

MEDICATION 5 __________________ ***DOSAGE*** ___________ ***FREQUENCY*** __________

(Do you feel confident in the proxy's responses ***YES*** ***NO***

Comments____

____

PARTICIPANT'S NAME________________________________

Now we're coming to the last part of the questionnaire. Some of the questions will be somewhat similar to the questions we've already asked you. The question will be a set statement and you will have three choices. The three choices are yes, partially or no.

REINTEGRATION TO NORMAL LIVING INDEX

(Sharon L. Wood-Dauphinee, et al. 1988)

(Wheelchairs, other equipment or resources may be used)

	YES	PARTIALLY	NO	N/A
1. Does (she or he) move around (her or his) living quarters as (she or he) feels is necessary.	0	1	2	
2. Does (she or he) move around (her or his) community as (she or he) feels is necessary. (Shopping, Banking, etc.)	0	1	2	
3. Is (she or he) able to take trips out of town as (she or he) feels are necessary.	0	1	2	
4. Is (she or he) comfortable with how (her or his) self-care needs are met. (dressing, feeding, toileting, bathing).	0	1	2	
5. Does (she or he) spend most of (her or his) days occupied in a activity that is necessary or important to (her or him). (Activity could be housework, volunteer, school, employment etc.)	0	1	2	
6. Is (she or he) able to participate in recreational activities as (she or he) wants to ? (Hobbies, crafts, sports, reading, television, games, computers, etc.)	0	1	2	
7. Is (she or he) participating in social activities with family, friends, and/or business acquaintances as is necessary or desirable by (her or him).	0	1	2	
8. Is (she or he) assuming a role in (her or his) family which meets (her or his) needs and those of other family members. (Family means people with whom (she or he) lives with and/or relatives with whom (she or he) doesn't live with but sees on a regular basis).	0	1	2	
9. In general, is (she or he) comfortable with (her or his) personal relationships.	0	1	2	
10. In general, is (she or he) comfortable with (herself or himself) when (she or he) is in the company of others.	0	1	2	
11. Does (she or he) feel that (she or he) can deal with life events as they happen.	0	1	2	

Do you feel confident in the proxy's responses *YES* *N*

*Comments*____

____

PARTICIPANT'S NAME ______________________

Now I'm going to ask questions on falls.

(FALLS)

Has (she or he) fallen in the past month? YES NO

(If no, go to next page of the questionnaire)
(If yes) How many times has (she or he) fallen? ______________

*IF THIS IS THE SECOND INTERVIEW IDENTIFY IF ANY FALLS HAVE OCCURRED SINCE THE FIRST INTERVIEW - IDENTIFY BY * (A STAR)*

(FIRST FALL)
What was (she or he) doing when (she or he) fell? ______________

____

Where was (she or he) when (she or he) fell? ______________

____

Did (she or he) have any injuries? YES NO

(If yes) Type of injury ______________________

Site of injury ______________________

(SECOND FALL)
What was (she or he) doing when (she or he) fell? ______________

____

Where was (she or he) when (she or he) fell? ______________

____

Did (she or he) have any injuries? YES NO

(If yes) Type of injury ______________________

Site of injury ______________________

(THIRD FALL)
What was (she or he) doing when (she or he) fell? ______________

____

Where was (she or he) when (she or he) fell? ______________

____

Did (she or he) have any injuries? YES NO

(If yes) Type of injury ______________________

Site of injury ______________________

(If patient has had more than three falls, enter fall data below).

Do you feel confident in the proxy's responses YES NO

Comments ______________________

____

____

*PARTICIPANT'S NAME*________________________________

Is there anything else you think we should know about (her or his) health or functional status ?

____

____

____

____

____

____

____

OVERALL RECOMMENDATION

ON AN OVERALL RECOMMENDATION DO YOU FEEL THAT

1. *PATIENT APPEARS FINE NO INTERVENTION SUGGESTED.*
2. *SOME CONCERN REGARDING STATUS AND INTERVENTION SUGGESTED*
3. *EMERGENCY SITUATION REQUIRING IMMEDIATE ACTION*

INTERVIEWER'S COMMENTS

____

____

____

____

APPENDIX B

«data patedata.doc»
«set date=?enter date»

HÔPITAL JUIF DE RÉADAPTATION
JEWISH REHABILITATION HOSPITAL

3205 PLACE ALTON GOLDBLOOM • LAVAL, QUÉ., H7V 1R2 • TÉLÉPHONE: (514) 688-9550 • FAX: (514) 688-3673

«date»

Dear *«salut» «lname»*,

We are contacting you from the Jewish Rehabilitation Hospital, where you were a patient in 198«yr», to ask for your participation in a research project being conducted in collaboration with McGill University.

The purpose of the study is to find the best way of monitoring how patients are doing once they are back home. We are asking you for your participation on two occasions:

1. On one occasion you will be contacted by telephone and asked some questions, by a trained interviewer, about your current state of health.
2. On another occasion these same questions on your current state of health will be asked during a home visit by an occupational therapist.

Each time we will require your assistance for 20 to 30 minutes. If you are unable to answer the questions you may have someone who lives with you answer the questions for you. All of your responses will be kept strictly confidential.

The knowledge gained from this study will benefit patients who leave a rehabilitation hospital and will help health care professionals to better understand the needs of individuals such as yourself. For this project to be a success, we will need the participation of as many of our former patients as possible. Therefore your participation would be greatly appreciated.

We will be calling you in a few days to formally request your participation, meanwhile if you have any questions about this study, please direct them to: *NICOL KORNER-BITENSKY* or *CLAUDETTE CORRIGAN* at 688-9550 ext. 290. Thank you for taking the time to consider our request.

Yours truly,

Nicol Korner-Bitensky
Co-Chief of Research

Dr. Rubin Becker
Chief of Medicine

Claudette Corrigan
Project Co-ordinator

Dr. Sharon Wood-Dauphinee
Associate Professor
School of Physical and
Occupational Therapy
McGill University

HÔPITAL D'ENSEIGNEMENT
AFFILIÉ DE L'UNIVERSITÉ McGILL

A McGILL UNIVERSITY AFFILIATED
TEACHING HOSPITAL

«data ffptdata.doc»
«set date=?enter date»

HÔPITAL
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RÉADAPTATION

JEWISH
REHABILITATION
HOSPITAL

3205 PLACE ALTON GOLDBLOOM • LAVAL, QUÉ., H7V 1R2 • TÉLÉPHONE: (514) 688-9550 FAX: (514) 688-3673

«date»

Chère *«salut» «lname»*,

Nous vous contactons au nom de l'Hôpital Juif de Réadaptation ou vous étiez une patiente en 198«yr», afin d'obtenir votre participation à un projet de recherche effectué conjointement avec l'Université McGill. L'objectif de notre étude est de trouver la meilleure méthode de suivi des patients qui quittent notre hôpital pour retourner chez eux. Nous solliciterons votre participation à deux reprises:

1. Lors d'un entretien téléphonique, un interviewer qualifié vous interrogera sur votre état de santé actuel.
2. Lors d'une visite à domicile effectuée par une ergothérapeute, au cours de laquelle elle vous interrogera aussi sur votre état de santé.

Nous vous demanderons de nous consacrer de 20 à 30 minutes pour chacun de ces entretiens. Si vous êtes incapable de répondre aux questions, quelqu'un demeurant avec vous pourra le faire. Toutes vos réponses resteront strictement confidentielles.

Grâce aux connaissances acquises à la suite de cette enquête, les patients qui quittent un hôpital de réadaptation, ainsi que les professionnels de la santé, auront une meilleure compréhension des besoins des personnes dans votre cas. Afin que ce projet soit couronné de succès, nous avons besoin de la participation de tous les patients que nous contactons. Nous vous serons très reconnaissants de bien vouloir nous accorder votre consentement à cet égard.

Nous communiquerons prochainement avec vous pour vous demander officiellement votre participation . Pour obtenir de plus amples renseignements concernant cette étude, veuillez téléphoner à *NICOL KORNER-BITENSKY* ou *CLAUDETTE CORRIGAN* au 688-9550, poste 290. Nous vous remercions pour le temps que vous consacrez à la considération de notre demande.

Veuillez accepter nos sincères salutations.

Nicol Korner-Bitensky
Co-directrice de recherche

Dr Rubin Becker
Chef du service médical

Claudette Corrigan
Coordinatrice du projet

Sharon Wood-Dauphinee
Professeur agrégé
École de physio et d'ergothérapie
Université McGill

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3205 PLACE ALTON GOLDBLOOM · LAVAL, QUÉ., H7V 1R2 · TÉLÉPHONE: (514) 688-9550 FAX: (514) 688-3673

July 10, 1991

Dear XXXX,

We are contacting you from the Jewish Rehabilitation Hospital, where you were a patient in 1989, to ask for your participation in a research project being conducted in collaboration with McGill University.

We are interested in finding out about the health and functioning of patients who are unable to respond to questions because of frailness, deafness, aphasia, or a language barrier.

If any of these criteria apply to you *«sal» «name»*, we are asking a family member or friend to assist by providing information on your current health on 2 different occasions:

1. On one occasion they will be contacted by telephone and asked some questions, by a trained interviewer, about your current state of health.
2. On another occasion these same questions on your current state of health will be asked during a visit to your home by an occupational therapist.

Each interview will take about 20 to 30 minutes. All of your responses will be kept strictly confidential.

The knowledge gained from this study will benefit patients who leave a rehabilitation hospital and will help health care professionals to better understand the needs of individuals such as yourself. For this project to be a success, we will need the participation of as many of our former patients as possible. Therefore your participation would be greatly appreciated.

We will be calling you in a few days to formally request your participation, meanwhile if you have any questions about this study, please direct them to: *NICOL KORNER-BITENSKY* or *CLAUDETTE CORRIGAN* at 688-9550 ext. 290. Thank you for taking the time to consider our request.

Yours truly,

Nicol Korner-Bitensky
Co-Chief of Research

Dr. Rubin Becker
Chief of Medicine

Claudette Corrigan
Project Co-ordinator

Dr. Sharon Wood-Dauphinee
Associate Professor
School of Physical and
Occupational Therapy
McGill University

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3205 PLACE ALTON GOLDBLOOM • LAVAL, QUÉ., H7V 1R2 • TÉLÉPHONE: (514) 688-9550 FAX: (514) 688-3673

date

Cher *XXXX*,

Nous vous contactons au nom de l'Hôpital Juif de Réadaptation ou vous étiez un patient en 1989, afin d'obtenir votre participation à un projet de recherche effectué conjointement avec l'Université McGill. Nous désirons obtenir des renseignements concernant l'état de santé et la capacité fonctionnelle des patients qui ne sont pas en mesure de répondre à nos questions en raison de faiblesse, de surdité, d'aphasie ou parce qu'ils ne comprennent pas la langue.

Si l'un de ces critères s'applique à vous, *«sal» «name»* nous demanderons à un membre de votre famille ou à un ami de nous aider en nous fournissant, à deux occasions, des renseignements concernant l'état actuel de votre santé:

1. Lors d'un entretien téléphonique, un interviewer qualifié vous interrogera sur votre état de santé actuel.
2. Lors d'une visite à domicile effectuée par une ergothérapeute, au cours de laquelle elle vous interrogera aussi sur votre état de santé.

Nous vous demanderons de nous consacrer de 20 à 30 minutes pour chacun de ces entretiens. Toutes vos réponses resteront strictement confidentielles.

Grâce aux connaissances acquises à la suite de cette enquête, les patients qui quittent un hôpital de réadaptation, ainsi que les professionnels de la santé, auront une meilleure compréhension des besoins des personnes dans votre cas. Afin que ce projet soit couronné de succès, nous avons besoin de la participation de tous les patients que nous contactons. Nous vous serons très reconnaissants de bien vouloir nous accorder votre consentement à cet égard.

Nous communiquerons prochainement avec vous pour vous demander officiellement votre participation. Pour obtenir de plus amples renseignements concernant cette étude, veuillez téléphoner à *NICOL KORNER-BITENSKY* ou *CLAUDETTE CORRIGAN* au 688-9550, poste 290. Nous vous remercions pour le temps que vous consacrez à la considération de notre demande.

Veuillez accepter nos sincères salutations.

Nicol Korner-Bitensky
Co-directrice de recherche

Dr Rubin Becker
Chef du service médical

Claudette Corrigan
Coordinatrice du projet

Sharon Wood-Dauphinee
Professeur agrégé
École de physio et d'ergothérapie
Université McGill

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APPENDIX C

TELEPHONE-HOME STUDY

BASIC DATA

ADM. NUMBER _______ __   CHART _______
SURNAME _______________   FIRST NAME ____________

PHONE CALL DATA

NO.	DATE	TIME-S	TIME-E	C	DELAY1	DELAY2	# CALLS
1.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	__
2.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
3.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
4.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
5.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
6.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
7.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
8.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
9.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
10.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
11.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
12.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
13.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
14.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
15.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
16.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
17.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
18.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
19.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
20.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
21.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
22.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
23.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
24.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	
25.	__/__/__	__:__:__	__:__:__	__	__:__:__	_____	

1. NO ANSWER
2. DISCONNECTED
3. BUSY (5 MIN)
4. ANSWERED BY OTHER
5. CALL BACK
6. PATIENT CALLED
7. SUCCESS
8. EXCLUDED
9. ANSWERING MACHINE
10. 411
11. DOCTOR'S OFFICE
12. CALLED BY OTHER

TRACING ______________________________   TIME _____
______________________________   _____

TOTAL TRACING TIME _____

APPENDIX D

HÔPITAL
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HOSPITAL

3205 PLACE ALTON GOLDBLOOM • LAVAL, QUÉ., H7V 1R2 • TÉLÉPHONE: (514) 688-9550 • FAX: (514) 688-3673

CONSENT FORM

The researchers at the Jewish Rehabilitation Hospital are working in collaboration with researchers at McGill University to find the best way of monitoring patients once they return home.

We are asking you for your participation on two occasions:

1. On one occasion you will be contacted by telephone and asked some questions, by a trained interviewer, about your current state of health on the telephone.

2. On another occasion these same questions about your current state of health will be asked during a home visit by an occupational therapist.

Each time we will require your assistance for 20 to 30 minutes. If you are unable to answer the questions you may have someone who lives with you answer the questions for you.

CONFIDENTIALITY
All information collected is strictly confidential. This means that your name will never be identified in any publications or presentations of the findings of this research.

CONSENT
Please be assured that no information about this project has been withheld from you. We would like you to participate however, your participation is completely voluntary. If you decide to participate and later change your mind you may withdraw from the project without any negative consequences to you. Also, you are not obliged to fulfill both interviews if you so decide. If you have any further questions about this study please call *NICOL KORNER-BITENSKY* or *CLAUDETTE CORRIGAN* at 688-9550 ext. 290.

Your signature below indicates that you have read this form, or have had it read to you, that you understand the purpose of the research, that you realize that the project may not be of any specific benefit to you, and that you have agreed to participate.

Signature of participant or proxy	Date	Project member	Date
Signature of witness	Date		

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FORMULE D'ASSENTIMENT

Les chercheurs de l'Hôpital Juif de Réadaptation collaborent avec les chercheurs de l'Université McGill pour trouver la meilleure méthode de suivi des patients qui quittent l'hôpital pour retourner chez eux.

Nous vous demandons pour votre participation à deux reprises:
1. Lors d'un entretien téléphonique, un interviewer qualifié vous interrogera sur votre état de santé actuel.
2. Lors d'une visite à domicile effectuée par une ergothérapeute, au cours de laquelle elle vous interrogera aussi sur votre état de santé actuel.

Nous vous demandons de nous consacrer de 20 à 30 minutes pour chacun de ces entretiens. Si vous êtes incapable de répondre aux questions, quelqu'un demeurant avec vous peut le faire.

CARACTERE CONFIDENTIEL
Tous les renseignements recueillis sont strictement confidentiels. Ceci signifie que votre nom ne paraîtra jamais dans une publication quelconque portant sur les résultats de cette recherche.

CONSENTEMENT
Nous désirons vous assurer que nous n'avons omis de vous expliquer aucun aspect du projet. De plus, bien que nous aimerions obtenir votre participation, celle-ci est tout à fait volontaire. Si vous décidez de participer et que, par la suite, vous changez d'avis, vous pouvez retirer votre candidature du projet sans que cette décision n'entraîne aucune conséquence. Aussi, vous avez le droit de refuser la deuxième interview. Pour obtenir de plus amples renseignements concernant notre étude, veuillez communiquer avec *NICOL KORNER-BITENSKY* ou *CLAUDETTE CORRIGAN* au 688-9550 poste 290.

Votre signature apposée ci-dessous indique que vous avez lu cette formule, ou que quelqu'un vous l'a lue, que vous comprenez le but de la recherche, que vous réalisez que ce projet ne vous apportera peut-être aucun avantage personnel, et que vous consentez à y participer

Signature du participant/ de la participante	Date	Représentant de l'Hôpital de réadaptation	Date
Signature du témoin	Date		

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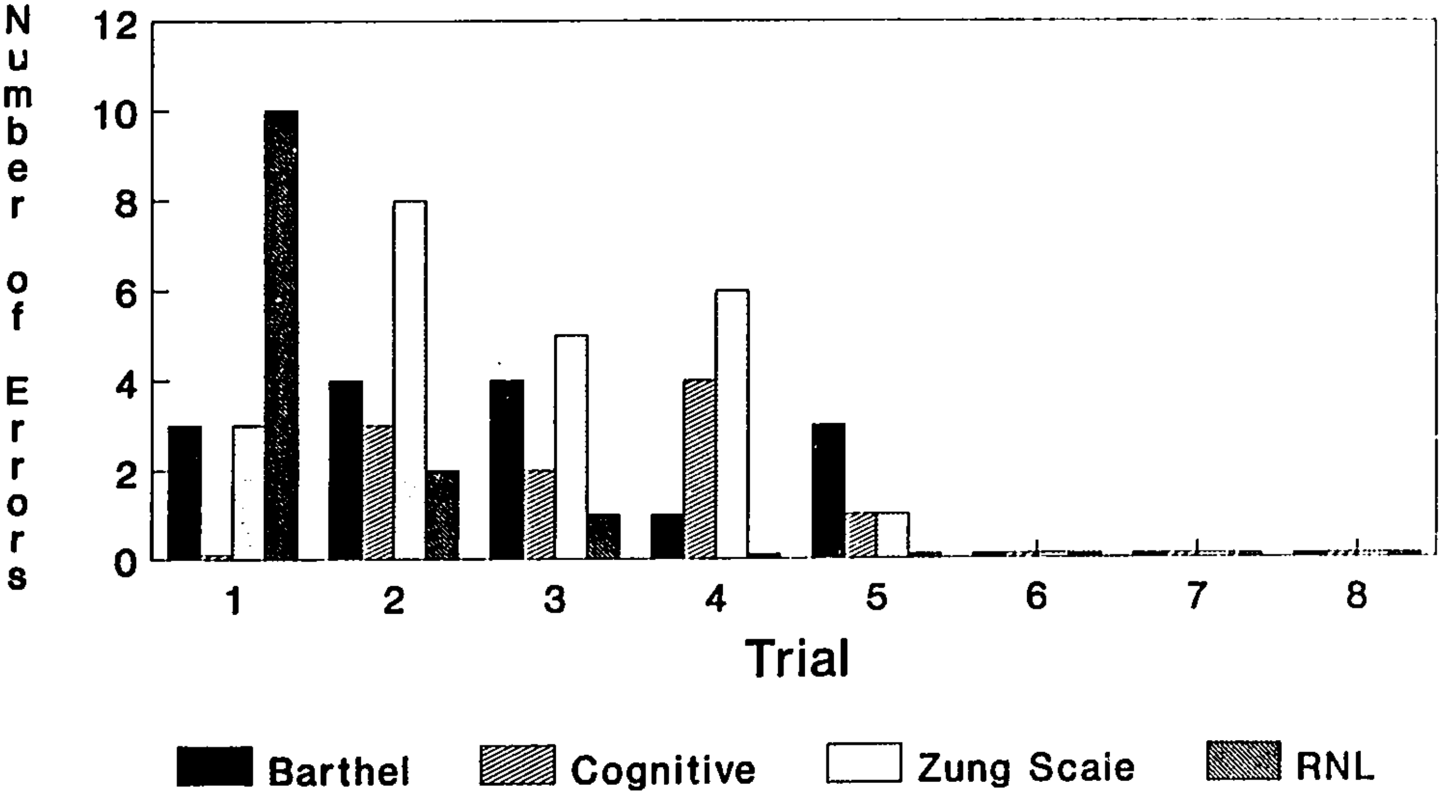
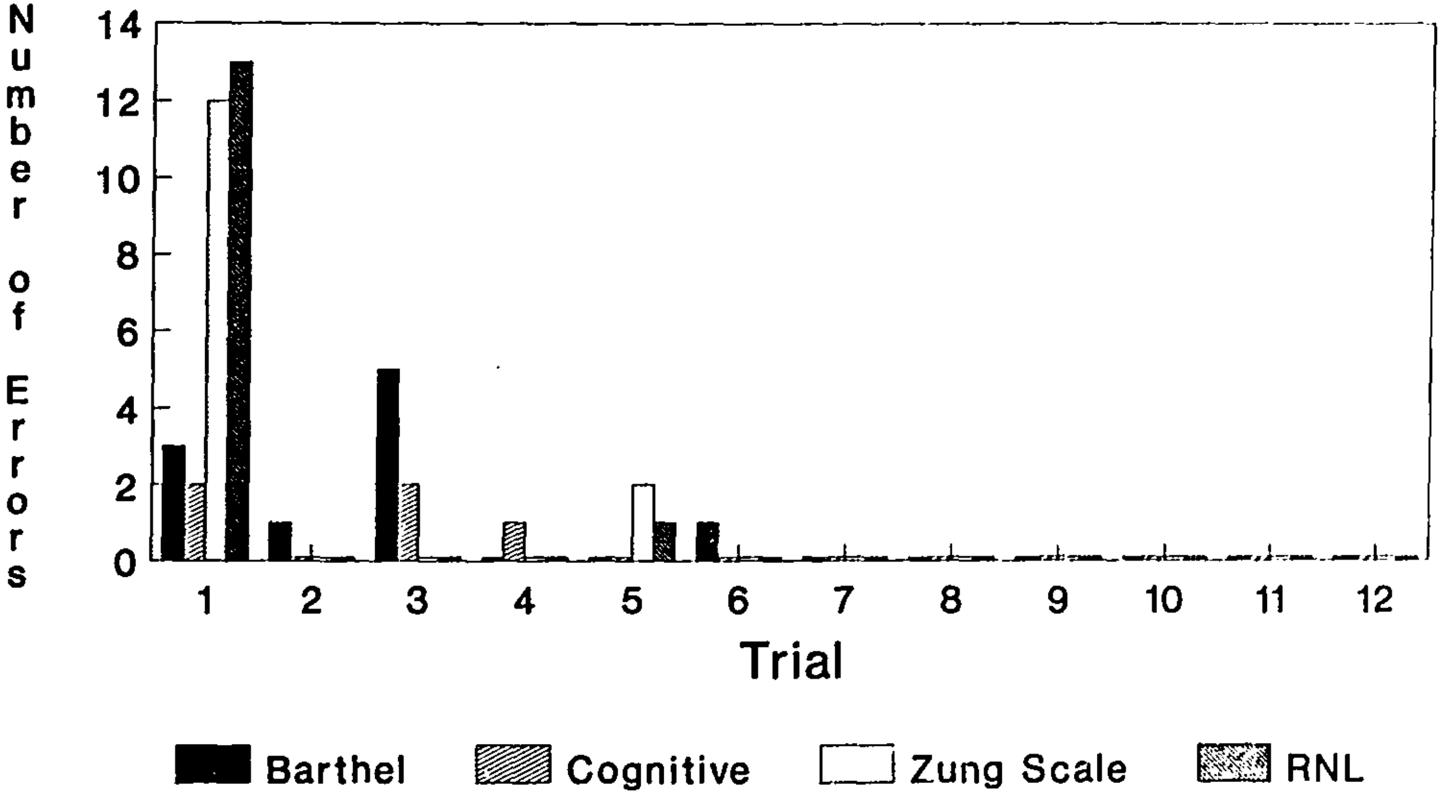
APPENDIX E

Disagreements* Between Home Interviewers** During Training



*includes lack of consensus and omission
** only professionals

Disagreements* Between Telephone Interviewers** During Training



*includes lack of consensus and omission

** both lay-persons and professionals

APPENDIX F

```
ADM.NUMBER  ______ __                  CHART ______     PROXY _
SURNAME    ________________            FIRST NAME  ____________
OUTCOME:  SCHEDULED: _    NUMBER:      ____ ___
HOME COMPLETE _    TEL COMPLETE _      COMPLETE _     PARTIAL _   REASON __ __ __
                 1. PR REFUSED TO CONTNUE      5. PT STATED LEAVING TOWN
                 2. PT MOVED OUT OF AREA       6. PT UNABLE TO COMPREHEND QUESTIONS
                 3. ILLNESS IN PR              7. SECTION MISSING
                 4. ILLNESS IN PT              8. OTHER

EXCLUSION:_  (Y=1,N=0)   EXCLUSION NUMBER: __ ___     REASON: __
1. PT AWAY FOR DURATION OF STUDY  5. DEATH
2. PT MOVED OUT OF AREA           6. NO SUITABLE PROXY
3. PLACEMENT                      7. CE=NOT A PR
4. GRAVE ILLNESS                  8. SECOND LEVEL EXCLUSION
                                  9. EXCLUDED IN ERROR

REFUSAL: _    REFUSAL NUMBER _ __      REASON _
1. ANGRY AT HOSPITAL              5. PT NOT WILLING
2. INTERESTED IN TEL INT ONLY     6. REFUSED AT TIME OF FIRST INT
3. NOT INTERESTED                 7. OTHER
4. PR NOT WILLING

TRACING _     (Y=1,N=0)   TRACING NUMBER _ __

NAME AT BIRTH  ________________       AGE ___
SEX  _   (M/F)    SALUTATION ______
DATE OF ADMISSION   __/__/__  (MM/DD/YY)    _
TELEPHONE NUMBER   (___)-___-___
ADDRESS
STREET:         ________________________________
CITY:           _____________________
PROVINCE:       __
POSTAL CODE:    ______
REFERENCES:   FIRSTLINE:    _____________________________________________________
              SECONDLINE:   _____________________________________________________
              THIRDLINE:    _____________________________________________________
              FOURTHLINE:   _____________________________________________________
DATE OF BIRTH:   __/__/__   (MM/DD/YY)
PROVENANCE:   SHORT __  LONG ________________
GenHospDays ___
SDIAG __    __________
PATIENT _________ (INCLUDED/EXCLUDED)
IF PATIENT IS EXCLUDED FROM STUDY LIST REASON:
           ___________________________________________  __
-------------------------------------------------------------------------------
```

LIVING ARRANGEMENT ______________________
NUM LIVING ARRANGEMENT__
DIAG AT ADMISSION ______________________________
NUMBER OF ADMITS IN THIS STUDY _
FRACTURE _ (Y/N)
IF FRACTURE = "N" ENTER DATE OF ADMISSION TO A GENERAL HOSPITAL
DATE OF FRACTURE __/__/__ DELAY _____
CO-MORBID STATUS OF PATIENT AT DISCHARGE

_________________ _________________ ________
OTHER ________________________________
CO-MORBID 1 __ TOTAL CO-MORBID __
CO-MORBID 2 __
CO-MORBID 3 __
CO-MORBID 4 __
CO-MORBID 5 __
CO-MORBID 6 __
CO-MORBID 7 __
CO-MORBID 8 __
CO-MORBID 9 __
CO-MORBID 10 __

COMPREHENSION OF VERBAL INSTRUCTION __ INTACT = 1; IMPAIRED = 2
VERBAL EXPRESSION __ INTACT = 1; IMPAIRED = 2
ALERT __ INTACT = 1; IMPAIRED = 2
ORIENTED (X3) __ INTACT = 1; IMPAIRED = 2
JUDGEMENT __ INTACT = 1; IMPAIRED = 2
DEPRESSION __ PRESENT = 1; ABSENT = 0
CONFUSED __ PRESENT = 1; ABSENT = 0
LANGUAGE _______
NUMLANG __
FALLS _ (Y/N)
NUMBER OF FALLS __
AMBULATORY STATUS ____________________
NUM AMB __

WAS THIS A PLANNED DISCHARGE _ (Y/N)
IF NO: LIST REASON WHY PATIENT LEFT ________________ __________________
DESTINATION (SHORT) __ ______________
DATE PATIENT LEFT __/__/__
DID PATIENT RETURN _ (Y/N)
IF YES: DATE PATIENT RETURNED __/__/__ DELAY ___ (R-L)
WAS PATIENT READMITTED WITH SAME ADMITTING NUMBER _ (Y/N)
IF NO: NEW ADMITTING NUMBER _______ __
DISCHARGE DATE __/__/__ (MM/DD/YY)
DESTINATION SHORT __ ______________
DAYS IN _____
LIVING ARRANGEMENT _________________________
NUM LIVING ARRANGEMENT __
COMMENTS ____
COMMENTS ____

APPENDIX G

TELEPHONE INTERVIEW

STUDY NUMBER _____ ____
LANGUAGE OF QUESTIONNAIRE _ (ENGLISH = 1; FRENCH = 2)
PARTIAL COMPLETE _ (Y = 1; N= 0)

ADM. NUMBER _______ __ CHART ______
SURNAME _______________ _ FIRST ______________
DATE OF BIRTH __/__/__
DIAG _______________ _

INTERVIEW _ (TELEPHONE = 1; HOME = 2)
INTERVIEWER _ (LAY = 1; PROFESSIONAL = 2)
ORDER OF INTERVIEW _ (H-T = 1; T-H = 2)
PARTICIPANT _ (PATIENT = 1; PROXY = 2)
TYPE OF PARTICIPANT BEFORE INTERVIEW _

RELATIONSHIP TO PATIENT _ REASON FOR PROXY _
PROXY LIVING WITH PT _ (Y = 1; N= 0)
IF NO: SPECIFY ____

NUM INTERVIEWER __ NAME OF INTERVIEWER __________
DATE OF INTERVIEW __/__/__
TIME INTERVIEW STARTED __:__:__ TIME INTERVIEW ENDED __:__:__
INTERVIEW TIME ___
INTERVIEW COMPLETED _ (Y = 1; N= 0)
IF NO: RECALL _ (Y = 1; N= 0)
RECALL: DATE __/__/__ TIME STARTED __:__:__ TIME ENDED __:__:__
DELAY ___ (RECALL - INTERVIEW)
RECALL TIME ___ TOTAL INTERVIEW TIME ______

BARTHEL INDEX

FEEDING __
PERSONAL HYGIENE _
BATHING SELF _
DRESSING __
TOILETING __
BOWEL CONTROL __
BLADDER CONTROL __
CHAIR/BED TRANSFERS __
WALKING __
STAIR CLIMBING __
WHEELCHAIR* _
TOTAL __
CONFIDENCE __ (Y = 1; N= 0)
BARTHEL COMPLETE __ (Y = 1; N= 0) PAGE COMPLETE __ (Y = 1; N= 0)
COMMENTS ____

RECALL OF EVENTS

LAST AT THE JRH: MONTH _______________ YEAR __ RT __ (Y =1; N=0)
LENGTH OF STAY: DAYS _____ RT __ (Y =1; N=0)
WHERE BEFORE JRH: IF HOSPITAL ______________________________

HOSPITALIZED IN ACUTE CARE HOSPITAL __ (Y = 1; N= 0)
IF YES: TIMES HOSPITALIZED __

ILLNESS

DAYS IN BED __ (0 = 1; 1-4 = 2; 5-7 = 3; >7 = 4)
FUNCTIONING __ (BETTER = 1; SAME = 2; WORSE = 3; DON'T KNOW = 4)
CONFIDENCE __ (Y = 1; N= 0)
RECALL COMPLETE __ (Y = 1; N= 0) PAGE COMPLETE __ (Y = 1; N= 0)
COMMENTS ______________________________

MENTAL STATUS QUESTIONNAIRE

NAME __
ADDRESS __ ADDRESS CHANGE _ (Y = 1; N= 0)
YEAR __
MONTH __
DAY __
AGE __ __
PRIME MINISTER __
FIRST WORLD WAR __
COUNT __
REPEAT __
TOTAL __
CONFIDENCE __ (Y = 1; N= 0)
MEMORY COMPLETE __ (Y = 1; N= 0) PAGE COMPLETE __ (Y = 1; N= 0)
COMMENTS ______________________________

SHORT ZUNG SCALE

TIRED __
MORNING BEST __
EAT __
DOWNHEARTED BLUE __
MIND CLEAR __
HOPEFUL FUTURE __
DECISIONS __
USEFUL & NEEDED __
LIFE FULL __
ENJOY THINGS __
TOTAL __
CONFIDENCE __ (Y = 1; N= 0)
ZUNG COMPLETE __ (Y = 1; N= 0) PAGE COMPLETE __ (Y = 1; N= 0)
COMMENTS ______________________________

MEDICATION

MED __ (Y =1; N=0)

MED1	______	N1	_	D1	____	F1	____
MED2	______	N2	_	D2	____	F2	____
MED3	______	N3	_	D3	____	F3	____
MED4	______	N4	_	D4	____	F4	____
MED5	______	N5	_	D5	____	F5	____
MED6	______	N6	_	D6	____	F6	____
MED7	______	N7	_	D7	____	F7	____
MED8	______	N8	_	D8	____	F8	____
MED9	______	N9	_	D9	____	F9	____
MED10	______	N10	_	D10	____	F10	____

TOTAL REGULAR MEDS __

OCCASIONAL MEDS MED __ (Y =1; N=0)

MED1 ____________ N1 _ D1 ______ F1 ______
MED2 ____________ N2 _ D2 ______ F2 ______
MED3 ____________ N3 _ D3 ______ F3 ______
MED4 ____________ N4 _ D4 ______ F4 ______
MED5 ____________ N5 _ D5 ______ F5 ______
TOTAL OCCASIONAL MEDS _ TOTAL REGULAR AND OCCASIONAL MEDS __
CONFIDENCE __ (Y = 1; N= 0)
MEDS COMPLETE __ (Y = 1; N= 0) PAGE COMPLETE __ (Y = 1; N= 0)
COMMENTS ______________________________

REINTEGRATION

LIVING QUARTERS __
COMMUNITY __
TRIPS __
SELF-CARE NEEDS __
ACTIVITY __
RECREATIONAL ACTIVITY __
SOCIAL ACTIVITIES __
ROLE IN FAMILY __
PERSONAL RELATIONSHIPS __
COMFORTABLE WITH YOURSELF __
DEAL WITH LIFE __
TOTAL ___
CONFIDENCE __ (Y = 1; N= 0)
REINTEGRATION COMPLETE __ (Y = 1; N= 0) PAGE COMPLETE __ (Y = 1; N= 0)
COMMENTS ______________________________

FALLS

FALLEN __ (Y = 1; N= 0)
TIMES FALLEN __
FIRST FALL DETAILS ______________________________
WHERE __
INJURIES _ (Y = 1; N= 0)
TYPE __
SITE __
SECOND FALL DETAILS ______________________________
WHERE __
INJURIES _ (Y = 1; N= 0)
TYPE __
SITE __
THIRD FALL DETAILS ______________________________
WHERE __
INJURIES _ (Y = 1; N= 0)
TYPE __
SITE __
CONFIDENCE __ (Y = 1; N= 0)
FALLS COMPLETE __ (Y = 1; N= 0) PAGE COMPLETE __ (Y = 1; N= 0)
COMMENTS ______________________________

APPENDIX H

ILLNESS

DAYS IN BED __ (0 = 1; 1-4 = 2; 5-7 = 3; >7 = 4)
FUNCTIONING __ (BETTER = 1; SAME = 2; WORSE = 3; DON'T KNOW = 4)
CONFIDENCE __ (Y = 1; N= 0)
RECALL COMPLETE __ (Y = 1; N= 0) COMPLETE __ (Y = 1; N= 0)
COMMENTS ______

MENTAL STATUS QUESTIONNAIRE

NAME __
ADDRESS __ ADDRESS CHANGE _ (Y = 1; N= 0)
YEAR __
MONTH __
DAY __
AGE __ __
PRIME MINISTER __
FIRST WORLD WAR __
COUNT __
REPEAT __
TOTAL __
CONFIDENCE __ (Y = 1; N= 0)
MEMORY COMPLETE __ (Y = 1; N= 0) COMPLETE __ (Y = 1; N= 0)
COMMENTS ______

SHORT ZUNG SCALE

TIRED __
MORNING BEST __
EAT __
DOWNHEARTED BLUE __
MIND CLEAR __
HOPEFUL FUTURE __
DECISIONS __
USEFUL & NEEDED __
LIFE FULL __
ENJOY THINGS __
TOTAL __
CONFIDENCE __ (Y = 1; N= 0)
ZUNG COMPLETE __ (Y = 1; N= 0) COMPLETE __ (Y = 1; N= 0)
COMMENTS ______

MEDICATION

MED __ (Y =1; N=0)

MED1	______	N1	_	D1	______	F1	______
MED2	______	N2	_	D2	______	F2	______
MED3	______	N3	_	D3	______	F3	______
MED4	______	N4	_	D4	______	F4	______
MED5	______	N5	_	D5	______	F5	______
MED6	______	N6	_	D6	______	F6	______
MED7	______	N7	_	D7	______	F7	______
MED8	______	N8	_	D8	______	F8	______
MED9	______	N9	_	D9	______	F9	______
MED10	______	N10	_	D10	______	F10	______

TOTAL REGULAR MEDS __

HOME INTERVIEW

STUDY NUMBER ______ ___
LANGUAGE OF QUESTIONNAIRE _ (ENGLISH = 1; FRENCH = 2)
PARTIAL COMPLETE _ (Y = 1; N= 0)

ADM. NUMBER ______ __ CHART ______
SURNAME _______________ _ FIRST _______________
DATE OF BIRTH __/__/__
DIAG _______________ _

INTERVIEW _ (TELEPHONE = 1; HOME = 2)
INTERVIEWER _ (LAY = 1; PROFESSIONAL = 2)
ORDER OF INTERVIEW _ (H-T = 1; T-H = 2)
PARTICIPANT _ (PATIENT = 1; PROXY = 2)
TYPE OF PARTICIPANT BEFORE INTERVIEW _
RELATIONSHIP TO PATIENT _ REASON FOR PROXY _
PROXY LIVING WITH PT _ (Y = 1; N= 0)
IF NO: SPECIFY ________________________________
NUM INTERVIEWER __ NAME OF INTERVIEWER __________
DATE OF INTERVIEW __/__/__
TIME INTERVIEW STARTED __:__:__ TIME INTERVIEW ENDED __:__:__
INTERVIEW TIME ___
INTERVIEW COMPLETED _ (Y = 1; N= 0)
IF NO: RECALL _ (Y = 1; N= 0)
RECALL: DATE __/__/__ TIME STARTED __:__:__ TIME ENDED __:__:__
DELAY ___ (RECALL - INTERVIEW)
RECALL TIME ___ TOTAL INTERVIEW TIME ______

BARTHEL INDEX

FEEDING	__
PERSONAL HYGIENE	_
BATHING SELF	_
DRESSING	__
TOILETING	__
BOWEL CONTROL	__
BLADDER CONTROL	__
CHAIR/BED TRANSFERS	__
WALKING	__
STAIR CLIMBING	__
WHEELCHAIR*	_
TOTAL	__

CONFIDENCE __ (Y = 1; N= 0)
BARTHEL COMPLETE __ (Y = 1; N= 0) COMPLETE __ (Y = 1; N= 0)
COMMENTS ____

RECALL OF EVENTS

LAST AT THE JRH: MONTH _______________ YEAR __ RT __ (Y =1; N=0)
LENGTH OF STAY: DAYS _____ RT __ (Y =1; N=0)
WHERE BEFORE JRH: IF HOSPITAL ______________________________
_____________ _
HOSPITALIZED IN ACUTE CARE HOSPITAL __ (Y = 1; N= 0)
IF YES: TIMES HOSPITALIZED __

OCCASIONAL MEDS MED __ (Y =1; N=0)

MED1	____________	N1	_	D1	____	F1	____
MED2	____________	N2	_	D2	____	F2	____
MED3	____________	N3	_	D3	____	F3	____
MED4	____________	N4	_	D4	____	F4	____
MED5	____________	N5	_	D5	____	F5	____

TOTAL OCCASIONAL MEDS _ TOTAL REGULAR AND OCCASIONAL MEDS __
CONFIDENCE __ (Y = 1; N= 0)
MEDS COMPLETE __ (Y = 1; N= 0) COMPLETE __ (Y = 1; N= 0)
COMMENTS ______________________________

REINTEGRATION

LIVING QUARTERS __
COMMUNITY __
TRIPS __
SELF-CARE NEEDS __
ACTIVITY __
RECREATIONAL ACTIVITY __
SOCIAL ACTIVITIES __
ROLE IN FAMILY __
PERSONAL RELATIONSHIPS __
COMFORTABLE WITH YOURSELF __
DEAL WITH LIFE __
TOTAL __
CONFIDENCE __ (Y = 1; N= 0)
REINTEGRATION COMPLETE __ (Y = 1; N= 0) COMPLETE __ (Y = 1; N= 0)
COMMENTS ______________________________

FALLS

FALLEN __ (Y = 1; N= 0)
TIMES FALLEN __
FIRST FALL DETAILS ______________________________
WHERE __
INJURIES _ (Y = 1; N= 0)
TYPE __
SITE __
SECOND FALL DETAILS ______________________________
WHERE __
INJURIES _ (Y = 1; N= 0)
TYPE __
SITE __
THIRD FALL DETAILS ______________________________
WHERE __
INJURIES _ (Y = 1; N= 0)
TYPE __
SITE __
CONFIDENCE __ (Y = 1; N= 0)
FALLS COMPLETE __ (Y = 1; N= 0) COMPLETE __ (Y = 1; N= 0)
COMMENTS ______________________________

APPENDIX I

Table I-1: Agreement for each Item on the Barthel Index Between the Telephone (Tel) and Home Interview Dichotomized as Independant (-) or Dependant (+) for all Respondents

Abbreviated Barthel Item	Tel	Home +	Home -	Sensitivity (%)	Specificity (%)	McNemar Bias	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)
	+	A	B						
	-	C	D						
Feeding		68	9	74	97	6.82[@]	91	0.75	0.65 - 0.85
		24	265						
Hygiene		32	25	67	92	1.98	89	0.54	0.44 - 0.65
		16	293						
Bathing		136	11	90	95	0.62	93	0.85	0.75 - 0.95
		15	204						
Dressing		62	16	72	94	1.60	89	0.69	0.58 - 0.79
		24	264						
Toileting		23	6	66	98	2.00	95	0.69	0.58 - 0.79
		12	325						
Bowel		9	10	60	97	1.00	96	0.51	0.44 - 0.63
		6	341						
Bladder		26	15	62	95	0.03	92	0.58	0.49 - 0.69
		16	309						
Transfers		22	6	69	98	1.00	96	0.71	0.61 - 0.82
		10	328						
Walking		44	15	53	95	10.67[#]	85	0.53	0.43 - 0.63
		39	268						
Stairs		77	14	80	95	0.76	91	0.76	0.66 - 0.87
		19	256						

[@] $p < .01$, [#] $p < .005$

Table I-3: Agreement for each Item on the Barthel Index Between the Telephone (Tel) and Home Interview Dichotomized as Independant (-) or Dependant (+) When Interviewer was a Health Professional

		Home							
		+	-						
Abbreviated Barthel Item	Tel	+A -C	B D	Sensitivity (%)	Specificity (%)	McNemar Bias	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)
Feeding		39	3	80	98	3.78	93	0.81	0.66 - 0.95
		10	126						
Hygiene		18	12	69	92	0.80	89	0.58	0.44 - 0.73
		8	140						
Bathing		67	6	91	94	0.08	93	0.85	0.70 - 1.00
		7	98						
Dressing		27	6	63	96	4.55*	88	0.64	0.50 - 0.78
		16	129						
Toileting		10	2	59	99	2.78	95	0.66	0.53 - 0.31
		7	159						
Bowel		3	4	50	98	0.14	96	0.44	0.30 - 0.59
		3	168						
Bladder		9	5	56	97	0.33	93	0.56	0.42 - 0.71
		7	157						
Transfers		7	4	64	98	0.00	96	0.61	0.48 - 0.77
		4	163						
Walking		19	6	48	96	8.33#	85	0.50	0.35 - 0.64
		21	132						
Stairs		37	6	86	96	0.00	93	0.82	0.67 - 0.96
		6	129						

*p<.05, #p<.005

Table I-2: Agreement for each Item on the Barthel Index Between the Telephone (Tel) and Home Interview Dichotomized as Independant (-) or Dependant (+) When Interviewer was a Lay Person

Abbreviated Barthel Item	Tel	Home +	Home -	Sensitivity (%)	Specificity (%)	McNemar Bias**	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)
	+	A	B						
	-	C	D						
Feeding		29	6	67	96	3.20	89	0.68	0.54 - 0.82
		14	139						
Hygiene		14	13	64	92	1.19	89	0.51	0.36 - 0.65
		8	153						
Bathing		69	5	90	95	0.69	93	0.86	0.71 - 1.00
		8	106						
Dressing		35	10	81	93	0.22	90	0.73	0.59 - 0.88
		8	135						
Toileting		13	4	72	98	0.11	95	0.72	0.57 - 0.86
		5	166						
Bowel		6	6	67	97	1.00	95	0.55	0.41 - 0.69
		3	173						
Bladder		17	10	65	94	0.05	90	0.58	0.44 - 0.72
		9	152						
Transfers		15	2	71	99	2.00	96	0.77	0.62 - 0.91
		6	165						
Walking		25	9	58	94	3.00	86	0.56	0.42 - 0.70
		18	136						
Stairs		40	8	75	94	1.19	89	0.72	0.57 - 0.86
		13	127						

** McNemar's statistic did not reveal any statistically significant differences

Table I-4: Agreement for each Item on the Barthel Index Between the Telephone (Tel) and Home Interview Dichotomized as Independant (-) or Dependant (+) When Respondent was a Patient

		Home							
		+	-						
Abbreviated Barthel Item	Tel	+A -C	B D	Sensitivity (%)	Specificity (%)	McNemar Bias	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)
Feeding		25	7	60	97	4.17^	91	0.62	0.55 - 0.74
		17	210						
Hygiene		11	13	52	95	0.45	91	0.44	0.32 - 0.56
		10	225						
Bathing		72	7	90	96	0.89	94	0.86	0.74 - 0.99
		8	172						
Dressing		28	10	68	95	0.39	88	0.66	0.53 - 0.78
		13	208						
Toileting		8	3	57	99	1.00	97	0.62	0.50 - 0.74
		6	242						
Bowel		3	5	43	98	0.11	97	0.38	0.27 - 0.52
		4	247						
Bladder		11	12	46	95	0.04	90	0.42	0.30 - 0.54
		13	223						
Transfers		7	4	54	98	0.40	96	0.56	0.46 - 0.70
		6	242						
Walking		21	11	53	95	2.13	88	0.52	0.40 - 0.64
		19	208						
Stairs		34	8	72	96	1.19	92	0.72	0.60 - 0.84
		13	204						

^ $p<.05$

Table I-5: Agreement for each Item on the Barthel Index Between the Telephone (Tel) and Home Interview Dichotomized as Independant (-) or Dependant (+) When Respondent was a Proxy

		Home							
		+	-						
Abbreviated Barthel Item	Tel	+A -C	B D	Sensitivity (%)	Specificity (%)	McNemar Bias	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)
Feeding		43	2	86	96	2.78	92	0.83	0.64 - 1.00
		7	55						
Hygiene		21	12	78	85	2.00	83	0.58	0.42 - 0.75
		6	68						
Bathing		64	4	90	89	0.82	90	0.77	0.59 - 0.96
		7	32						
Dressing		34	6	76	90	1.47	84	0.67	0.48 - 0.86
		11	56						
Toileting		15	3	71	97	1.00	92	0.72	0.53 - 0.91
		6	83						
Bowel		6	5	75	95	1.29	93	0.60	0.40 - 0.79
		2	94						
Bladder		15	3	83	97	0.00	94	0.80	0.61 - 0.99
		3	86						
Transfers		15	2	79	98	0.67	94	0.80	0.61 - 0.99
		4	86						
Walking		23	4	53	94	10.67#	78	0.50	0.33 - 0.68
		20	60						
Stairs		43	6	88	90	0.00	89	0.77	0.58 - 0.90
		6	52						

#p<.005

APPENDIX J

Table J-1: Agreement for each Item* on the Zung Index Between the Telephone and Home Interview for all Participants

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)	McNemar Bias
Always tired	53	0.35	0.29 - 0.41	0.09
Feel best a.m.	67	0.43	0.36 - 0.50	0.00
Appetite same	67	0.40	0.33 - 0.47	7.07$^{@}$
Feel blue	60	0.44	0.37 - 0.50	0.34
Clearheaded	60	0.28	0.21 - 0.35	5.37$^{\wedge}$
Hopeful about future	56	0.37	0.31 - 0.44	0.16
Make decisions easily	59	0.39	0.33 - 0.45	0.06
Feel useful/needed	59	0.41	0.34 - 0.47	5.57$^{\wedge}$
Life pretty full	54	0.34	0.28 - 0.40	6.44$^{\wedge}$
Still enjoy past activities	52	0.33	0.27 - 0.39	0.68

* each item is scored on a four-point scale

$^{\wedge}$p<.05, $^{@}$p<.01, $^{\#}$p<.005

Table J-2: Agreement for each Item* on the Zung Index Between the Telephone and Home Interview When Interviewer was a Lay Person

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)	McNemar's Bias**
Always tired	49	0.30	0.22 - 0.39	0.85
Feel best a.m.	63	0.39	0.30 - 0.48	0.13
Appetite same	66	0.36	0.27 - 0.46	1.29
Feel blue	59	0.41	0.32 - 0.50	0.82
Clearheaded	59	0.27	0.18 - 0.37	0.12
Hopeful about future	54	0.35	0.26 - 0.43	0.42
Make decisions easily	60	0.38	0.30 - 0.47	0.21
Feel useful/needed	62	0.43	0.34 - 0.52	2.00
Life pretty full	56	0.37	0.28 - 0.45	1.22
Still enjoy past activities	51	0.31	0.22 - 0.40	0.87

* each item is scored on a four-point scale

** McNemar's statistic revealed no statistically significant bias

Table J-3: Agreement for each Item* on the Zung Index Between the Telephone and Home Interview When Interviewer was a Health Professional

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)	McNemar's Bias
Always tired	57	0.40	0.31 - 0.49	2.19
Feel best a.m.	70	0.47	0.36 - 0.57	0.17
Appetite same	69	0.44	0.34 - 0.54	$7.14^{@}$
Feel blue	62	0.47	0.38 - 0.56	3.36
Clearheaded	61	0.29	0.19 - 0.39	$9.06^{@}$
Hopeful about future	58	0.40	0.31 - 0.49	0.01
Make decisions easily	58	0.39	0.30 - 0.48	0.01
Feel useful/needed	55	0.38	0.29 - 0.47	3.66
Life pretty full	51	0.31	0.22 - 0.40	$6.08^{\wedge}$
Still enjoy past activities	53	0.35	0.26 - 0.43	0.05

*p<.05, $^{@}$p<.01, $^{\#}$p<.005

* each item is scored on a four-point scale

Table J-4: Agreement for each Item* on the Zung Index Between the Telephone and Home Interview for Self Respondents

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)	McNemar's Bias
Always tired	56	0.38	0.31 - 0.46	0.14
Feel best a.m.	67	0.44	0.36 - 0.53	0.05
Appetite same	63	0.34	0.26 - 0.42	3.04
Feel blue	64	0.47	0.40 - 0.55	0.53
Clearheaded	64	0.29	0.21 - 0.38	1.06
Hopeful about future	56	0.35	0.27 - 0.42	0.08
Make decisions easily	58	0.34	0.27 - 0.42	0.00
Feel useful/needed	58	0.37	0.30 - 0.44	1.11
Life pretty full	55	0.32	0.25 - 0.40	2.79
Still enjoy past activities	49	0.29	0.22 - 0.36	0.48

* each item is scored on a four-point scale

** McNemar's statistic revealed no statistically significant differences

Table J-5: Agreement for each Item[*] on the Zung Index Between the Telephone and Home Interview When Respondent was a Proxy

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)	McNemar's Bias
Always tired	46	0.27	0.16 - 0.38	0.00
Feel best a.m.	66	0.38	0.25 - 0.51	0.11
Appetite same	78	0.56	0.43 - 0.69	6.00[^]
Feel blue	51	0.34	0.23 - 0.45	0.00
Clearheaded	51	0.24	0.12 - 0.36	6.23[^]
Hopeful about future	57	0.40	0.29 - 0.52	0.09
Make decisions easily	60	0.43	0.31 - 0.55	0.21
Feel useful/needed	61	0.46	0.35 - 0.57	7.71[@]
Life pretty full	50	0.33	0.22 - 0.44	4.25[^]
Still enjoy past activities	58	0.39	0.27 - 0.51	7.02[@]

[^] $p<.05$, [@] $p<.01$, [#] $p<.005$;

[*] each item is scored on a four-point scale

APPENDIX K

Table K-1: Agreement for each Item* on the Reintegration to Normal Living Index (R.N.L.) Between the Telephone and Home Interview for all Participants

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)	McNemar's Bias
Move around home	84	0.37	0.28 - 0.45	0.27
Move around community	72	0.56	0.49 - 0.63	10.04$^{\#}$
Take trips out of town	69	0.49	0.41 - 0.57	4.25
Comfortable with self care	82	0.27	0.18 - 0.35	1.56
Occupied with work/school	58	0.35	0.28 - 0.42	0.11
Satisfied with recreational activity	53	0.20	0.13 - 0.27	25.33$^{\#\#}$
Satisfied with social activity	63	0.39	0.31 - 0.46	1.67
Assumes role in family	65	0.32	0.24 - 0.39	0.28
Comfortable with personal relations	71	0.25	0.16 - 0.33	0.00
Comfortable when with others	75	0.40	0.32 - 0.48	1.86
Deal with life events	70	0.47	0.39 - 0.55	0.15

$^{*}p<.05$, $^{@}p<.01$, $^{\#}p<.005$, $^{\#\#}p<.001$

* each item is scored on a three-point scale

Table K-2: Agreement for each Item* on the Reintegration to Normal Living Index (R.N.L.) Between the Telephone and Home Interview When Interviewer was a Lay Person

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)	McNemar's Bias
Move around home	83	0.35	0.23 - 0.47	$4.5^{\wedge}$
Move around community	66	0.46	0.36 - 0.56	$18.06^{\#\#}$
Take trips out of town	66	0.45	0.35 - 0.55	1.29
Comfortable with self care	78	0.17	0.05 - 0.29	1.98
Occupied with work/school	62	0.41	0.30 - 0.51	0.23
Satisfied with recreational activity	50	0.14	0.04 - 0.23	$42.68^{\#\#}$
Satisfied with social activity	67	0.44	0.34 - 0.55	$4.74^{\wedge}$
Assumes role in family	67	0.36	0.25 - 0.46	1.33
Comfortable with personal relations	75	0.28	0.16 - 0.40	0.53
Comfortable when with others	75	0.36	0.23 - 0.48	0.19
Deal with life events	71	0.48	0.37 - 0.59	1.85

$^{*}p<.05$, $^{@}p<.01$, $^{\#}p<.005$; $^{\#\#}p<.001$

* each item is scored on a three-point scale

Table K-3: Agreement for each Item* on the Reintegration to Normal Living Index (R.N.L.) Between the Telephone and Home Interview When Interviewer was a Health Professional

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)	McNemar's Bias
Move around home	84	0.39	0.27 - 0.51	2.29
Move around community	79	0.66	0.56 - 0.77	0.11
Take trips out of town	71	0.53	0.42 - 0.64	3.31
Comfortable with self care	87	0.39	0.27 - 0.52	0.04
Occupied with work/school	54	0.29	0.19 - 0.40	0.00
Satisfied with recreational activity	56	0.28	0.17 - 0.38	0.11
Satisfied with social activity	58	0.33	0.23 - 0.44	0.05
Assumes role in family	62	0.28	0.17 - 0.38	0.13
Comfortable with personal relations	67	0.21	0.10 - 0.33	0.42
Comfortable when with others	75	0.44	0.32 - 0.55	2.27
Deal with life events	70	0.46	0.35 - 0.57	3.63

* each item is scored on a three-point scale

** McNemar's statistic revealed no statistically significant differences

Table K-4: Agreement for each Item* on the Reintegration to Normal Living Index (R.N.L.) Between the Telephone and Home Interview When Respondent was a Patient

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)			McNemar's Bias
Move around home	83	0.28	0.17	-	0.38	1.45
Move around community	71	0.51	0.43	-	0.60	$4.81^{\wedge}$
Take trips out of town	68	0.44	0.35	-	0.53	$4.35^{\wedge}$
Comfortable with self care	85	0.23	0.13	-	0.34	1.26
Occupied with work/school	59	0.32	0.23	-	0.41	0.94
Satisfied with recreational activity	56	0.19	0.10	-	0.27	$14.04^{\#}$
Satisfied with social activity	65	0.41	0.32	-	0.50	2.53
Assumes role in family	70	0.32	0.23	-	0.42	0.21
Comfortable with personal relations	76	0.25	0.15	-	0.36	0.02
Comfortable when with others	81	0.39	0.29	-	0.50	1.33
Deal with life events	73	0.43	0.33	-	0.52	0.00

$^{*}p<.05$, $^{@}p<.01$, $^{\#}p<.005$; $^{\#\#}p<.001$;

* each item is scored on a three-point scale

Table K-5: Agreement for each Item* on the Reintegration to Normal Living Index (R.N.L.) Between the Telephone and Home Interview When Respondent was a Proxy

Abbreviated Zung Item	Percent Agreement	Cohen's Kappa	Confidence Interval for Kappa (95%)	McNemar's Bias
Move around home	85	0.53	0.38 - 0.68	1.00
Move around community	75	0.58	0.44 - 0.71	6.26*
Take trips out of town	71	0.53	0.39 - 0.67	0.29
Comfortable with self care	77	0.29	0.14 - 0.45	0.36
Occupied with work/school	57	0.33	0.19 - 0.46	0.78
Satisfied with recreational activity	46	0.19	0.06 - 0.32	11.66##
Satisfied with social activity	57	0.33	0.20 - 0.47	0.00
Assumes role in family	53	0.25	0.11 - 0.39	0.08
Comfortable with personal relations	58	0.20	0.05 - 0.34	0.02
Comfortable when with others	60	0.32	0.18 - 0.46	0.58
Deal with life events	64	0.46	0.33 - 0.60	0.42

*p<.05, @p<.01, #p<.005; ##p<.001;

* each item is scored on a three-point scale

APPENDIX L

GLOSSARY OF TERMS

COHORT The cohort defined for this study consisted of all patients with stroke admitted to the JRH from April 1, 1984 to June 30 1989 and all patients with orthopaedic conditions admitted from April 1, 1986 to June 30, 1989.

HOME For the purposes of this investigation a patient was considered to reside at *home* if he or she lived either alone, or with friends or family in a private dwelling, apartment, or senior citizen's residence. Those in acute-care hospitals, foster homes or long-term care facilities for the duration of the project were considered to live in an environment other than home and were, therefore, excluded.

LAY INTERVIEWERS Lay interviewers were individuals that had no specific training in any health care field and had no previous experience in interviewing. They were all bilingual individuals who received training in administering the health status questionnaire in both French and English during the preliminary stage of the study.

PROFESSIONAL INTERVIEWERS The professional interviewers were all registered, certified occupational therapists with, a minimum of a Bachelors Degree in Science. Each of the five occupational therapists chosen to perform the home interviews had at least five years of experience in the treatment of adults with physically disabling diseases. The three occupational therapists who performed the telephone interviews had similar credentials. One occupational therapist began the study performing the telephone visits and then became a home interviewer. Thus, there were a total of seven occupational therapists who participated in the study. All but one therapist administered the health status questionnaire in either French or English, the one therapist performed interviews only in English. All received training in administering the health status questionnaire during the preliminary stage of the study.

INTRODUCTORY LETTER The first contact with the potential participant consisted of a letter explaining the purpose of the study and the names and telephone numbers of the investigators. The letter also served to alert the individual of an upcoming telephone call from the project co-ordinator.

FIRST TELEPHONE CONTACT The first telephone contact was performed by the project co-ordinator and consisted of a brief reiteration of the study purpose, a clarification of the type of participant - either patient or proxy, a request for participation, and allocation of those who agreed to participate to a scheduled home interview and telephone interview.

PROXY RESPONDENT A proxy respondent was an individual who answered questions on the health status questionnaire for the patient when the patient was judged to be unable to respond appropriately to questions. The need for a proxy respondent was anticipated if, in the medical chart, the patient was noted to have any of the following: deafness, dementia, a severe comprehension disorder or expressive disorder, decreased alertness, confusion, lack of concentration or a language barrier. A final decision regarding the need for a proxy was made by the project co-ordinator at the time of the first telephone contact. To act as a proxy respondent the individual must have had regular contact with the patient three or more times a week and had to communicate in either French or English.

SELF RESPONDENT A self respondent was an individual who was capable of responding to questions on health status without assistance of another individual.

PATIENT The term patient is used to refer to an individual who was a member of the cohort of patients hospitalized at the JRH. The term is also used to refer to these same individuals after their discharge into the community.

TELEPHONE MODE The telephone mode of interviewing consisted of a telephone call of approximately twenty minutes in duration scheduled at a specified time, and day, and performed by either a lay interviewer or a professional interviewer.

FACE-TO-FACE MODE The face-to-face mode of interviewing, sometimes referred to as the *in-person* interview was conducted in the patient's home, even in instances when a proxy respondent was interviewed. The home interview was scheduled for a specified time, and day, and took approximately 20 minutes to administer.

HEALTH STATUS QUESTIONNAIRE The health status assessment included measures of mood (Zung Scale), functional status (Barthel Index), community reintegration (Reintegration to Normal Living Index) and cognitive status (Pfeiffer Short Portable Mental Status Questionnaire) as well as questions on illness, hospitalization, the occurrence of falls and medication use.

APPENDIX M

```
                                    UNIVARIATE PROCEDURE
         BARTHEL (TELEPHONE)
Variable=BA_TOTT

                                          Moments

                          N                366  Sum Wgts        366
                          Mean        90.50546  Sum           33125
                          Std Dev      13.9305  Variance   194.0589
                          Skewness    -2.02693  Kurtosis   4.645904
                          USS          3068825  CSS        70831.49
                          CV          15.39189  Std Mean   0.728159
                          T:Mean=0    124.2935  Prob>|T|     0.0001
                          Sgn Rank     33580.5  Prob>|S|     0.0001
                          Num ^= 0         366
                          W:Normal     0.71732  Prob<W          0.0


                                      Quantiles(Def=5)

                           100% Max       100        99%       100
                            75% Q3        100        95%       100
                            50% Med        95        90%       100
                            25% Q1         85        10%        70
                             0% Min        10         5%        60
                                                      1%        45

                           Range           90
                           Q3-Q1           15
                           Mode           100


                                          Extremes

                             Lowest    Obs     Highest    Obs
                                10(     138)      100(     357)
                                40(     221)      100(     358)
                                45(     326)      100(     359)
                                45(     160)      100(     363)
                                45(     157)      100(     366)

   SCORE
                        Histogram                          #             Boxplot
    100 +*****************************************        164            +-----+
     95 .******************                                70            *-----*
     90 .*********                                         35            |  +  |
     85 .*******                                           25            +-----+
     80 .*****                                             19               |
     75 .***                                               12               |
     70 .***                                               11               |
     60 .**                                                 6               |
     55 .**                                                 7               0
     50 +**                                                 4               0
     45 .**                                                 7               0
     40 .*                                                  4               0
     35 .*                                                  1               0
     30 .
     25 .
     20 .
     15 .
     10 .
      5 +*                                                  1               *
        ----.----.----.----.----.----.----.--
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                                   SAS      14:10 Thursday, April 29, 1993   2

                               UNIVARIATE PROCEDURE
      BARTHEL (HOME)
Variable=BA_TOTH

                                     Moments

                   N              366  Sum Wgts         366
                   Mean      89.30328  Sum            32685
                   Std Dev   15.65443  Variance    245.0612
                   Skewness  -1.93832  Kurtosis    4.096858
                   USS        3008325  CSS         89447.34
                   CV        17.52951  Std Mean     0.81827
                   T:Mean=0  109.1367  Prob>|T|      0.0001
                   Sgn Rank   33580.5  Prob>|S|      0.0001
                   Num ^= 0       366
                   W:Normal  0.722468  Prob<W        0.0

                                 Quantiles(Def=5)

                    100% Max        100         99%       100
                     75% Q3         100         95%       100
                     50% Med         95         90%       100
                     25% Q1          85         10%        70
                      0% Min          5          5%        55
                                                 1%        40
                    Range            95
                    Q3-Q1            15
                    Mode            100

                                     Extremes

                      Lowest     Obs    Highest     Obs
                          5(     138)      100(     356)
                         25(      10)      100(     357)
                         30(     221)      100(     358)
                         40(     362)      100(     359)
                         40(     187)      100(     363)

SCORE
                    Histogram                                #             Boxplot
  100  .*******************************************        169             +------+
   95  .**************                                      56             *------*
   90  .*********                                           33             |      |
   85  .*****                                               17             +--+--+
   80  .********                                            29                |
   75  .****                                                13                |
   70  .****                                                13                |
   65  .**                                                   6                |
   60  .**                                                   8                0
   55  .**                                                   6                0
   50  .*                                                    4                0
   45  .**                                                   5                0
   40  .*                                                    4                0
   35  .
   30  .*                                                    1                *
   25  .*                                                    1                *
   20  .
   15  .
   10  .
    5  .*                                                    1                *
```

```
                                     SAS     14:10 Thursday, April 29, 1993  12
        ZUNG (TELEPHONE             UNIVARIATE PROCEDURE
Variable=Z_TOTT

                                    Moments

                    N              365  Sum Wgts         365
                    Mean      52.40548  Sum            19128
                    Std Dev   17.02713  Variance     289.923
                    Skewness  0.257253  Kurtosis    -0.79328
                    USS        1107944  CSS           105532
                    CV        32.49112  Std Mean    0.891241
                    T:Mean=0   58.8006  Prob>|T|      0.0001
                    Sgn Rank   33397.5  Prob>|S|      0.0001
                    Num ^= 0       365
                    W:Normal  0.948352  Prob<W        0.0001

                                Quantiles(Def=5)

                     100% Max       98         99%        93
                      75% Q3        65         95%        80
                      50% Med       50         90%        75
                      25% Q1        38         10%        30
                       0% Min       25          5%        25
                                                1%        25
                    Range           73
                    Q3-Q1           27
                    Mode            40

                                    Extremes

                       Lowest    Obs    Highest    Obs
                          25(    322)        90(    366)
                          25(    316)        93(    172)
                          25(    296)        93(    324)
                          25(    295)        95(    113)
                          25(    282)        98(    160)

                             Missing Value        .
                             Count                1
                             % Count/Nobs      0.27
   SCORE
   Stem Leaf                                                #           Boxplot
      9 58                                                  2               |
      9 0033                                                4               |
      8 5555588                                             7               |
      8 00000333                                            8               |
      7 5555555555555588888888                             22               |
      7 0000000000000033333333333333                       28               |
      6 555555555555558888888888888888                     30            +-----+
      6 00000000000000000333333333333333333                35            |     |
      5 555555555555555555588888888888888                  33            |     |
      5 0000000000000033333333333                          25            *--+--*
      4 55555555555555888888888888888888                   32            |     |
      4 00000000000000000000000033333333333333333333333    47            |     |
      3 55555555555555888888888888888888                   32            +-----+
      3 000000000000033333333333333333                     30               |
      2 555555555555555555588888888888                     30               |
```

```
                             UNIVARIATE PROCEDURE
       ZUNG(HOME)
Variable=Z_TOTH

                                   Moments

                    N                366  Sum Wgts        366
                    Mean        53.42077  Sum           19552
                    Std Dev     17.25658  Variance   297.7896
                    Skewness    0.164379  Kurtosis   -0.87068
                    USS          1153176  CSS        108693.2
                    CV          32.30313  Std Mean   0.902016
                    T:Mean=0    59.22375  Prob>|T|     0.0001
                    Sgn Rank     33580.5  Prob>|S|     0.0001
                    Num ^= 0         366
                    W:Normal    0.949219  Prob<W       0.0001

                                Quantiles(Def=5)

                     100% Max          98       99%          90
                      75% Q3           68       95%          80
                      50% Med          53       90%          75
                      25% Q1           40       10%          30
                       0% Min          25        5%          25
                                                 1%          25
                     Range             73
                     Q3-Q1             28
                     Mode              68

                                    Extremes

                       Lowest     Obs     Highest     Obs
                           25(     307)        90(     113)
                           25(     301)        90(     138)
                           25(     296)        93(     172)
                           25(     295)        95(      27)
                           25(     238)        98(     160)
    SCORE
        Stem Leaf                                      #             Boxplot
           9 58                                        2                |
           9 0003                                      4                |
           8 55555888                                  8                |
           8 0000003333                               10                |
           7 55555555555555588888888                  23                |
           7 000000000000000000033333333333333333     36                |
           6 555558888888888888888888888              27             +-----+
           6 00000000000033333333333333333            29             |     |
           5 5555555555555588888888888888888888       34             |     |
           5 00000000000000000033333333333333         32             *--+--*
           4 55555555555555555558888888888888888888   38             |     |
           4 0000000000000033333333333333333333       34             +-----+
           3 55555555555555888888888888888888         32                |
           3 00000000000000333333333333               26                |
           2 5555555555555555555888888888888          31                |
             ----+----+----+----+----+----+----+---
         Multiply Stem.Leaf by 10**+1
```

```
                                      SAS      14:10 Thursday, April 29, 1993   4

                                   UNIVARIATE PROCEDURE
SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE (TELEPHONE)
Variable=C_TOTT

                                         Moments

                    N                333  Sum Wgts       333
                    Mean        8.612613  Sum           2868
                    Std Dev     1.837549  Variance  3.376587
                    Skewness    -1.85235  Kurtosis  3.364428
                    USS            25822  CSS       1121.027
                    CV          21.33556  Std Mean  0.100697
                    T:Mean=0    85.52991  Prob>|T|    0.0001
                    Sgn Rank     27805.5  Prob>|S|    0.0001
                    Num ^= 0         333
                    W:Normal    0.733064  Prob<W         0.0


                                    Quantiles(Def=5)

                     100% Max          10          99%          10
                      75% Q3           10          95%          10
                      50% Med           9          90%          10
                      25% Q1            8          10%           6
                       0% Min           1           5%           4
                                                    1%           2

                     Range              9
                     Q3-Q1              2
                     Mode              10


                                         Extremes

                       Lowest     Obs     Highest     Obs
                            1(     135)        10(     349)
                            1(     111)        10(     354)
                            2(     314)        10(     355)
                            2(     227)        10(     357)
                            2(      68)        10(     358)


                                Missing Value          .
                                Count                 33
                                % Count/Nobs        9.02


                    Histogram                              #             Boxplot
  10   +**********************************************    137             +-----+
   9   .                                                                  |     |
       .*****************************                      86             *-----*
       .                                                                  |  +  |
   8   .********************                               60             +-----+
       .                                                                     |
   7   .**                                                  6                |
       .                                                                     |
   6   .******                                             16                |
       +                                                                     |
   5   .****                                               11                |
       .
   4   .***                                                 7                0
       .
   3    ..                                                  5                *
   2                                                        3
   1                                                        2
```

```
                                  UNIVARIATE PROCEDURE
 SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE (HOME)
Variable=C_TOTH

                                       Moments

                     N                346  Sum Wgts        346
                     Mean        8.624277  Sum            2984
                     Std Dev     1.740528  Variance   3.029438
                     Skewness    -1.99136  Kurtosis   4.369522
                     USS            26780  CSS        1045.156
                     CV          20.18173  Std Mean   0.093571
                     T:Mean=0    92.16791  Prob>|T|     0.0001
                     Sgn Rank     30015.5  Prob>|S|     0.0001
                     Num ^= 0         346
                     W:Normal    0.737805  Prob<W       0.0

                                   Quantiles(Def=5)

                      100% Max          10        99%          10
                       75% Q3           10        95%          10
                       50% Med           9        90%          10
                       25% Q1            8        10%           6
                        0% Min           1         5%           5
                                                   1%           2
                      Range              9
                      Q3-Q1              2
                      Mode              10

                                       Extremes

                        Lowest    Obs     Highest    Obs
                             1(     94)       10(     354)
                             1(     68)       10(     355)
                             2(    195)       10(     356)
                             2(    135)       10(     357)
                             3(    359)       10(     358)

                              Missing Value        .
                              Count               20
                              % Count/Nobs      5.46

 SCORE
                      Histogram                         #             Boxplot
  10   +*******************************************    127            +------+
   9   .                                                               |      |
       .************************************           110            *------*
   8   .                                                               |  +   |
       .****************                                51            +------+
   7   .                                                                  |
       .********                                        23                |
   6   .                                                                  |
       .*****                                           15                |
   5   +                                                                  |
       .**                                               4                |
   4   .
       .*                                                3                0
   3   .
        ***                                              9
   2                                                     2
   1                                                     2
```

```
[illegible]  UNIVARIATE PROCEDURE
Variable=RETOTT          [illegible]
                                 Moments

               N                364  Sum Wgts        364
               Mean        25.76923  Sum            9380
               Std Dev     20.98357  Variance   440.3102
               Skewness    0.811032  Kurtosis   0.129424
               USS           401548  CSS        159832.6
               CV          81.42878  Std Mean   1.099838
               T:Mean=0    23.43003  Prob>|T|     0.0001
               Sgn Rank       25680  Prob>|S|     0.0001
               Num ^= 0         320
               W:Normal    0.910518  Prob<W          0.0

                           Quantiles(Def=5)

                100% Max        100       99%        82
                 75% Q3        38.5       95%        68
                 50% Med         23       90%        55
                 25% Q1           9       10%         0
                  0% Min          0        5%         0
                                           1%         0

                Range           100
                Q3-Q1          29.5
                Mode              0

                                Extremes

                  Lowest    Obs     Highest    Obs
                       0(     353)       82(        8)
                       0(     345)       82(       97)
                       0(     334)       91(      138)
                       0(     313)       91(      160)
                       0(     307)      100(       38)
                        Missing Value          .
                        Count                  2
                        % Count/Nobs        0.55
       SCORE
                        Histogram                       #             Boxplot
     100   +*                                           1                0
           .
           +*                                           2                0
           .
           +*                                           2                |
           .*                                           2                |
           +***                                         5                |
           .****                                        7                |
           +***                                         6                |
           .**********                                 19                |
           +*********                                  18                |
           .******                                     12                |
           +*********                                  17                |
           .************                               23             +-----+
           +************                               23             |     |
           .**********                                 19             |  +  |
           +********************                       40             *-----*
           .**************                             27             |     |
           +*************                              25             |     |
           .************************************       72             +-----+
       0   +**********************                     44                |
            ----+----+----+----+----+----+----+-
```

```
                              UNIVARIATE PROCEDURE
[illegible]
Variable=RETOTH

                                   Moments

                 N               366  Sum Wgts         366
                 Mean       27.39344  Sum            10026
                 Std Dev    22.06499  Variance     486.864
                 Skewness   0.581209  Kurtosis    -0.40361
                 USS          452352  CSS         177705.3
                 CV         80.54845  Std Mean    1.153356
                 T:Mean=0   23.75108  Prob>|T|      0.0001
                 Sgn Rank      23793  Prob>|S|      0.0001
                 Num ^= 0        308
                 W:Normal   0.915984  Prob<W        0.0

                               Quantiles(Def=5)

                  100% Max        95        99%         86
                   75% Q3         41        95%         68
                   50% Med        23        90%         59
                   25% Q1          9        10%          0
                    0% Min         0         5%          0
                                             1%          0

                  Range           95
                  Q3-Q1           32
                  Mode             0

                                   Extremes
                    Lowest    Obs     Highest    Obs
                         0(    353)       82(     226)
                         0(    343)       86(     263)
                         0(    332)       91(      85)
                         0(    313)       91(     324)
                         0(    307)       95(     160)
                    HISTOGRAM
        SCORE
          95  +*                                  1                 0
               .*                                 2                 0
               .*                                 1                 |
               .*                                 2                 |
               .*                                 2                 |
               .***                               6                 |
               .***                               5                 |
               .******                           11                 |
               .***********                      22                 |
               .**********                       20                 |
               .**********                       19                 |
               .************                     24              +-----+
               .*********                        18              |     |
               .**************                   28              |     |
               .**********                       19              |  +  |
               .*************                    25              *-----*
               .**********                       20              |     |
               .**************                   27              |     |
               .****************************     56              +-----+
           0  +*****************************     58                 |
               ----+----+----+----+----+----
```