A RAND NOTE

PREDICTING THE COURSE OF NURSING HOME PATIENTS: A PROGRESS REPORT

Robert Kane, Sandra Riegler, Robert Bell, Roslyn Potter, Gail Koshland

January 1982

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Prepared For

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PREFACE

This Note summarizes Rand efforts to date in developing an instrument suitable for assessing the multidimensional functioning of nursing home patients. It represents the first step in a program to develop a method for predicting outcomes of such patients. This instrument will form the basis for a payment system reflecting the extent to which possible outcomes are actually achieved.

SUMMARY

This Note summarizes Rand progress in developing an evaluation instrument that can capture the multidimensional functioning of nursing home patients. It traces the several steps through which the questionnaire has evolved. The final product is a fieldable instrument with levels of reliability adequate to define outcomes in several domains: Activities of Daily Living, Affect, Cognition, Social Activity, Pain/Discomfort, and Satisfaction. Inter-interviewer (test/retest) reliabilities are generally 0.8 or greater. This instrument is the basis for an ongoing study in predicting the course of nursing home patients. The goal is to offer a new system of payment for long-term care based on rewarding the achievement of predicted outcomes.
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I. PROGRESS ON PROGNOSIS

The nursing home symbolizes the failure of the American society (Vladeck, 1980). We seem to be spending more to buy less. It is an institution shunned by both patients (U.S. Comptroller General, 1979) and physicians (U.S. Congress, 1975). But the problem is too big to ignore. In 1979 we spent almost $18 billion on nursing home care, more than half of that from public funds (Fox and Clauser, 1980). Demographic predictions indicate that this level of expenditure will accelerate as the population ages.

In contrast to the long-term care (LTC) system in other western countries, the U.S. nursing home industry is largely proprietary (Kane and Kane, 1976). Despite scandals and disclosures of fraud and abuse, there is no sign of a change in ownership status. The increasing amounts of public dollars spent in proprietary settings has led inexorably to regulation.

Efforts to improve the quality of nursing home care have met with limited success. Despite protestations about the need to consider quality of life concepts, most regulatory effort has addressed the nursing home as a miniature hospital (Kane and Kane, 1979). Part of the dilemma has been due to the difficulty in establishing a clear link between the process of care and its results. Compared with acute care, long-term care is a low technology endeavor where substitutability of personnel and technique seems possible. Nor is it easy to apply traditional quality of care approaches to the nursing home setting (Kane et al., 1979). Meaningful criteria that
monitor important dimensions are difficult to create and apply. Moreover, efforts to improve care by education or consultation are short-lived at best (Penchansky and Taubenhaus, 1965).

Having looked at the situation in this country and abroad, we became convinced that a fundamental change was required in the way nursing home care is financed. The overall goals of such a reform would be:

1. To provide an incentive for high-quality care, defined in broad terms to include social and psychologic health as well as physical health.

2. To discourage market skimming whereby certain patients (usually those needing the least care in a category) are admitted, while others with greater care needs are not.

3. To overcome the general tendency toward assuming that more is necessarily better and especially the perverse incentive of cost reimbursement that rewards the development of increased dependency.

4. To minimize regulation—i.e., to avoid both the record-keeping burden and the constraints on creativity.

5. To use the free market as much as possible to increase the expansion of good homes and the closure of poor ones.

The core of our proposed approach is to link payment for care to the outcomes of that care, but we seek to achieve that linkage in a way that will not reward patient selection. The general thrust of the proposal is shown in the basic payment formula: Nursing Home Payment = (Cost x Prognostic Adjustment Factor).
In this approach, a nursing home is paid the sum of the payments for each patient. These individual payments are based on the product of the average cost of caring for such a patient times the prognostic adjustment factor (PAF). This PAF reflects the extent to which the actual outcome of care exceeds or falls short of an expected level. In its simplest form, one might assign a PAF value of 1.5 if the actual outcome is better than expected, 1.0 if it is as good as expected, and 0.5 if worse than expected. In practice, the PAF can be used as a continuous variable directly tied to the ratio of observed/expected outcomes.

To appreciate how the predicted values are generated, refer to Fig. 1, which offers a general model of the concept. At Time 1, an independent group (or individual) not part of the caregiving team (e.g., the utilization review team) gathers data on the patient. These data are used to generate a predicted course for that patient based on the experience of similar patients: The patient gets better (A), stays the same (B); or gets worse (C). Each of these can be pictured as a vector with confidence intervals.

The same data gatherer returns after a suitable period of time (perhaps six months) and again assesses the patient. Comparing the actual status of the patient with the predicted course gives the PAF for that patient over that interval of time. It is crucial to appreciate that we are primarily interested not in the outcome (i.e., the status at Time 2) but in how that state compares with the predicted state. The same outcome could yield a better, worse, or the same PAF, depending on what had been predicted.
Fig. 1--Diagrammatic representation of serial outcome assessments for a nursing home patient

At time 1, the patient's prognosis for the subsequent period is projected. (The grey areas indicate confidence intervals.) Basically one may look for some degree of improvement (here represented by line A), or maintenance (line B), or a worsening state (line C). When the patient is reassessed at time 2, his actual outcome (shown as a point) is then compared with that expected by prognosis; if the prognosis had been along line C, the patient would be recorded as a positive outcome. However, if the prognosis had been along lines A or B, the outcome would be less than adequate. The actual outcome at time 2 serves as the basis for a new prognosis, shown as A', B', or C'. These are in turn compared with actuality at time 3 and so on.
The process is itself iterative in several respects. The data gathered at Time 2 are used to predict Time 3 as well as to reward Time 2. The prediction equation for Time 3 can also incorporate terms that reflect the changes from Time 1 to Time 2, providing a measure of self-correction for the system.

One must appreciate that the example shown in Fig. 1 assumes a single point of data at each time. In fact, the data are a profile covering a variety of domains. We must reduce this profile to a point by applying appropriate weights to the several outcome measures. Such a step requires knowledge of the value preferences on utility weights of the relevant groups. Ascertaining these becomes an essential component of the research. The overall system involves several steps:

1. Measuring multidomain functioning of each nursing home patient.
2. Measuring associated attributes that might be used to predict the future status of the patient.
3. Using data from earlier (Time 0) and current (Time 1) measurements to predict future (Time 2) status in each of several important domains.
4. Comparing actual status at Time 2 with expected (predicted) status in each domain.
5. Combining multidomain results into a single determination of whether the outcome was better or worse than expected.
6. Paying nursing homes for care of that patient using a formula that adjusts payment upward for better outcomes (actual/expected) and downward for poorer ones.
Especially when the cost of long-term care is likely to make most policymakers shudder, it is critical to appreciate that this system need not increase the cost of care. Indeed, one of its virtues is its adaptability to different constraints and reimbursement schemes. It is a means of improving quality by redistributing resources from those with worse to those with better outcomes.

In our original formulation, we proposed a system of reimbursement that would set the PAF at 0.5 for outcomes worse than expected, 1.0 for those equal to predicted, and 1.5 for those better than predicted. With the experience from this study and subsequent practice, the PAF can be set so that the outcome adjustments will average out. The system will then have no direct effect on total costs.

In the short run, one can control costs by substituting whatever share of true costs the payor is willing to pay in lieu of true costs (perhaps measured as average current expenditures plus inflation). In the long run, costs should fall to the extent that a less structurally regulated environment reveals more efficient ways of providing quality care.

The "costs" to be adjusted could come from any reimbursement scheme. They could be a flat fee based on level of care (as is now the case), prospective fees based on a finer determination of the case mix need for both quantity and level of service (the equivalent of diagnostically related groups in hospitals), or fee for service. Some examples of case-mix adjustments have been developed (Cavaiola, 1975; Costa and Bice, 1980). The outcome adjustments, like other quality-inducing schemes, make more sense for prospective reimbursement (where the inherent problem
is ensuring that patients get the quality we pay for) than for cost-reimbursement (where the problem is controlling costs). Moreover, the same data used to determine a finer gradation of prospective fees can be used to measure progress for the PAF.

Modifications of the prognostic factors can reflect decisions about how much we want to change the nursing home industry status quo. If we want to avoid disruption to the industry, even at a cost in long run inefficiency, we can tie the adjustment of reimbursement to variable costs, make the adjustment factors small, and pay everyone, including the homes with inefficient plants, their fixed costs. Risks of unlikely outcomes can be reduced by making the adjustment factors continuous, by having the size of the factors depend on the size of the home, and other methods discussed by Keeler and Kane (in press). If we want to induce substantial changes, we can base "costs" on average total costs and make the adjustments substantial. This approach is an iterative system; the baseline (i.e., expectations) will rise as the system has a positive effect on the market. In aggregate, it will produce a distribution around that rising mean.

This note recounts our efforts to devise an assessment strategy capable of predicting the status of nursing home patients at one point from information gathered at an earlier point. Such a system would provide the means to achieve a number of purposes:

1. It could serve as the basis for comparing actual with expected outcomes in expectation that a later reimbursement system might be geared to achieving predicted outcomes.
2. It could provide a basis for comparing various forms of long-term care in the absence of more formal randomized trials.

3. It could offer a rare set of longitudinal data on a corps of nursing home patients, yielding useful information about what types of changes over time one might realistically expect.

To accomplish this productive goal, several steps are required: measuring outcomes, predicting outcomes, and assigning value weights to outcomes.

Measuring outcomes means assessing the results of care, regardless of the treatment process used. Thus, one nursing home may emphasize a medical model of treatment while another emphasizes a social model; some homes may use more professional staff and others emphasize nonprofessionals. For our purposes, we ignore the differences in the process of treatment among the various models and focus on the outcomes.

To measure outcomes, we must select meaningful, quantifiable indicators. For example, the presence or absence of decubiti is a meaningful and quantifiable nursing home outcome. Another important outcome may be satisfaction with nursing home care, but satisfaction does not lend itself to quantification as easily as do the indicators of decubiti. This report details our criteria for measures and our work toward producing a useful prediction model for examining nursing home care.
The model for this prediction uses measures at two levels of aggregation. Although a number of individual variables can be used as predictor variables gathered at one time to predict the status of a patient at some later point, the measures used to identify that status must be reasonably few. Thus, a substantial amount of aggregation is needed to describe patient outcomes. We are seeking a single aggregated measure for each of the major outcome domains we have identified. These outcomes must be further aggregated by a second process if we are going to be able to compare them, either with each other or with some set of norms. The goal of this project is to develop a means of predicting the expected course of a nursing home patient to compare the patient's actual status with that predicted. A single term is thus needed.

We will reduce the multiple outcome measures for each of the domains to a single summary outcome by applying weights derived from relative value preferences (or utility weights).

The assignment of value weights to health outcomes is another area of research in this study. In a climate of diminishing resources, such issues as which outcomes of care are important, to whom, and at what cost are critical for both the recipients and the financiers of care. Two components are involved in a valuation of health status: the resources needed to attain or maintain a certain health status and the preferences of the patient and his or her family concerning different health states. The resource need can be estimated directly on a time/cost basis. However, the estimation of value preferences for
different health states is much more complex. The progress in health status measurement and value preference measurement in the context of long-term care was reviewed at a conference held at Rand. The results of that conference are reported in a separate volume (Kane and Kane, in press).

The research to date in developing the techniques for measuring outcomes of nursing home patients was funded by the National Center for Health Services Research. Section II describes our basic methodological concerns, the format of the instrument, the chronology of testing, and the domains chosen. Section III describes the problems that emerged during testing and our responses to them. Section IV describes our progress in developing scales for the outcome measures.

We found that the methodology and measurement tools previously developed to gather data were inadequate for our task. (For a review of measurement in geriatrics and gerontology, see Kane and Kane, 1981.) Most studies do not deal with the spectrum of nursing home patients. The problems that make the interviewing and assessment of this population a unique challenge are poorly documented. Our attempts to focus clearly on these problems (e.g., the uneveness of patient performance), the permutations of the instruments, and our conclusions will be relevant to those interested in the assessment and evaluation of health status in the elderly. Practitioners, clinicians, and researchers alike will recognize the context and problems with which we are grappling.
II: INSTRUMENT DEVELOPMENT

METHODOLOGICAL CONCERNS

The goal of the nursing home project is to develop and test a strategy to use patient data gathered at one time to predict the status of that patient at a later time. The system designed to achieve this purpose must be based on sound measurement principles. The area of measurement became a major focus of our initial efforts. Although we had begun the project with the expectation that previous gerontological research and the methodologic advances of Rand’s Health Insurance Study would provide a substantial body of readily and directly applicable instruments for our nursing home study population, we quickly realized that much work remained before we would be ready to field a workable instrument appropriate for the patient group we sought to study.

Closer attention to the problems of instrumentation for LTC and, more specifically, for this project have led to the development of a set of criteria for the measures:

1. They must cover a variety of domains appropriate to the broad mandate of LTC. These include at least:

   - physical (a term used to imply the basic parameters generally considered in medical assessment—e.g., blood pressure, decubiti, edema)

   - functional (including ability to perform both basic self-care functions and Activities of Daily Living—ADL)

   - cognitive performance

   - affect (emotional state)

   - social activity

   - satisfaction with care and living environment
2. They must be obtained independently of the care providers. If the system is to be used for reimbursement or evaluative purposes, data supplied by those being reimbursed or evaluated would not be credible. This decision does not totally preclude the use of records. Although suspect on the more general grounds of poor quality, incompleteness, and lack of standardization, some basic information, including diagnoses is gathered from them. (However, we have cause to question the completeness and accuracy of many recorded diagnoses.) Nevertheless, the nursing home patient is the principal source of information—including what we can observe about the patients and what they report.

3. The data must be reliable (reproducible and stable over short intervals) if we are to detect real changes over longer periods. Here we must be concerned with both inter-interviewer and intra-interviewer reliability. Inter-interviewer reliability refers to the most stringent case in which two interviewers independently interview the same resident at different times in a one-to-three day period. We did not use other, less rigorous types of inter-rater reliability assessment (such as two ratings of the same interview or ratings of a theoretical scenario) except in training interviewers. Intra-interviewer testing refers to one interviewer interviewing the same resident twice.
4. The measures must be capable of registering meaningful changes in patient status. This requirement seems to directly threaten the previous one. The more sensitive the measure, the less it may be with patients whose status varies slightly from day to day. The tradeoff between sensitivity and stability is well illustrated by the problem of choosing the appropriate time window for ADL. Most of the work to date with these measures has relied on the reports of caregivers who are asked to assess functioning over a period of time (e.g., the past month). If directly observable task performance is substituted for caregiver judgment, the data gatherers are limited to observations at a single time rather than a summation over a longer period. The same type of problem is raised when patients with suspected poor time perception are asked to describe their present state or feelings rather than to recall their feelings over time.

5. The measures should be direct and important reflections of the parameter being assessed. Indirect indicators might become dysfunctional if the system were a basis for reward. Efforts might be misdirected toward improving indicator performance itself rather than the trait it represents. The more closely an indicator is tied directly to the domain of concern, the less chance there is for such corruption.

6. The measure must be broad enough to cover the full range of performance levels represented by the LTC population. For some patients, we might look for a change within the range of a single mental status test. Some might not be capable of even
one correct response, while others would find it too easy. A series of measures may thus require a Guttman-type scale, (where an orderly accomplishment is implied) with appropriate branching in the interview schedule.

7. Data collectors without extraordinary professional backgrounds should be able to administer the instrument. Items that require a high level of special training (e.g., extensive physical assessment) should be avoided if a widely useful tool is sought.

8. The instrument should be quickly administered. We have set a goal of no more than one hour.

9. In addition to personnel and time, the measures should not be costly. Items with a high unit cost, such as laboratory tests, were discarded.

10. The measures should not be embarrassing (e.g., tasks that are too hard or too easy, questions that are too personal).

These criteria for measures have been systematically applied to a review of the gerontologic literature. Although we have uncovered scores of measures, few have been used in projects like the present one, and they have rarely been used for longitudinal studies. We have talked with the developers of many of the established scales and scores to be certain that important experience was not overlooked. In summary, the state of previous work in this area did not justify our enthusiastic expectation of directly transferring materials to the study at hand. Our assessment of the gerontologic measurement literature (Kane and Kane, 1981) indicates that:

1. There is a dearth of longitudinal studies on LTC patients.

The best scales have been most commonly used in cross-sectional
research. Direct contacts with researchers and developers of scales confirm the shortage of historical information on the use of these measures in longitudinal work. A major contribution of the current effort will therefore lie in filling this void.

2. Many of the instruments widely used have had only limited reliability testing for use with nursing home populations or comparable groups. Few reports of reliability measurements specify whether agreement is based on direct test-retest data collection by a single interviewer or by different interviewers (Cutler and Chiraboga, 1976; Folstein, Folstein, and McHugh, 1975; Lawton, 1972; Linn, 1967; Ridley, Bachrach and Dawson, 1979). Some reports on reliability refer to the observer-rater measures in which one person collects and interprets data and a second person observes and interprets the same data (Copeland et al., 1976; Farina, Arenberg, and Guskin, 1957; Kuriansky and Gurland, 1976). Still other reports are based on an indirect rater-rater measurement in which rater interpretations of data presented in a description or scenario are compared (Smyer, 1980).

3. Patient willingness and ability to participate may substantially limit research efforts. Although the prevailing stereotype of the nursing home patient features an individual bored with the environment and eager to be involved in a study as a source of new diversion, many patients are reluctant to get involved in an actual interview situation. Where documented, previous
research indicates a 25 to 40 percent rate of subject loss (Ridley, Bachrach and Dawson, 1979; Smyer, 1980; Zemore and Ames, 1979). This proportion of nonparticipants may produce an important selection bias. They may be composed of the very ill—either debilitated or confused—or, conversely, those who are maximally functional and too busy to participate. The glimpses of experience reported in the literature suggest that nonrespondents come primarily from the former group, and thus the full range of potential bias is still unexplored. Nor has extensive work been reported on developing strategies to encourage participation of nursing home patients in studies of this kind.  

4. The cognitive ability or inability of a patient to respond in the interview situation is unexplored. Problems arising during the interview may lead to a lack of confidence in the quality of the data. New techniques are needed to acquire data from such individuals.

With these considerations in mind, we devoted considerable effort to the development of appropriate measures that could be successfully fielded in a nursing home setting.

FORMAT OF THE INSTRUMENT

Scant information exists about interviewing with an elderly population, much less a nursing home population. From techniques discussed in the general literature (Hyman et al., 1954), we chose to combine several data-gathering techniques in our instrument: chart review (e.g., demographics), observable data (e.g., physical examination), demonstrable tasks (e.g., ADL), and self-reported items
(e.g., satisfaction). In addition, interviewer ratings have been developed as important adjuncts to the interview itself.

The instrument consists of a structured interview with branching that allows appropriate assessment to be quickly reached. As an example, the interviewer initially observes whether the patient is alert, semi-alert, or comatose. Upon this discrimination, the data collector proceeds with the interview if the patient is alert or semi-alert but takes only the physical measurements that do not require active cooperation if the patient is comatose. Standardized probes were developed to elicit responses in areas subject to varying interpretations; this permits consistent question administration and contributes to inter-interviewer reliability.

A structured interview allows easy comparison of data from different interviewers, the ascertaining of reliability, easy replication of the interview, and comprehensive and economical assessment. One disadvantage is that it may be difficult to determine and adequately code certain types of affective information; individualized, personalized data are sacrificed for data that can be aggregated for group information. In addition, the quality and accuracy of answers given in such self-report interviews may be questionable. Elderly respondents may be prone to deny problems or present themselves and their situation in a positive light (Carp and Carp, 1981).

Wherever possible, we use demonstrations of functioning in lieu of self-report for several reasons: (1) they minimize the subjective aspects of the patient's condition that interfere with the measurement of capacity; (2) this type of data collection requires minimal verbal
instruction, lessening communication problems with impaired or confused elderly; (3) older people with psychiatric problems tend to understate their health and ability to function. Further, the etiology of an inability to complete a functional task (comprehension, volition, or physical limitation) is not directly addressed in this study, which emphasizes outcomes.

In the realm of actual data collection and interviewing, much emphasis has been placed on the interactive nature of the process (Freitag and Barry, 1974) and resultant need for training (Hyman et al., 1954). Because our data collectors are skilled health professionals (nurses), training focused least on awareness of patient reactions (fatigue, stress, mood, etc.) and instead emphasized the need for reliability, complete reporting, minimum accurate coding, and maintenance of confidentiality. Interviewers worked with each other and with a third person to standardize the administration of the entire instrument.

THE CHRONOLOGY OF TESTING

Many rounds of testing, analysis, and revision have been undertaken during this project. A brief summary is presented here to acquaint the reader with the various phases.

Winter 1979: Literature search/choice of domains and instruments.

Development of the pilot test instrument and early field trials.

Spring 1980: Pilot testing, analysis, and revisions.

The questionnaire for pilot testing contained 207 questions. Because most of the items had been previously tested and their use documented by others, we reasoned
that we could risk combining a test of inter-interviewer
and intra-interviewer reliability. Accordingly, the two
interviewers separately administered the instrument to
25 patients in a nursing home that was not included in
the actual study. For each patient, the two administra-
tions were separated by one to three days; each administra-
tion required one to two hours. The order of the inter-
views was random, with no attempt to get a representa-
tive sample at this time.

The results of the pilot test were disappointing. Two
types of reliability tests were used initially: kappa
correlation coefficients and Pearson product-moment
correlation coefficients. Acceptable levels of
reliability were set at .85 and .90, respectively.
(Because the kappa offered little more useful informa-
tion than did the less expensive Pearson r in this case,
we relied on the latter for most of our analyses.)
Reliability levels ranged from .16 to .95. Only six
items or scales met the stringent .9 criterion; four others
approached the .9 level. Revisions of the questionnaire
at this point focused on improving correlation coeffi-
cients by decreasing respondent burden and improving
question construction. We shortened the overall length of
the questionnaire, simplified question and response
wording, and converted abstract concepts into concrete
eamples wherever possible. Interviewers were carefully
trained to increase the standardization levels of
administering this newly revised questionnaire.
Summer 1980: Pre-testing, analysis, and revision.
The pre-test questionnaire contained 163 questions.
Fifty pairs of interviews were done at a facility
not in the actual study. Inter-interviewer reliability
levels improved in areas amenable to greater standardi-
zation--e.g., physical assessment. In general, however,
levels were not dramatically different. Each interviewer
tested the same respondent twice in 25 intra-interviewer
tests. These results were similar to the inter-interviewer
correlations and yielded no concrete clues to the source
of the unreliability problem.

After the questionnaire was further refined and
simplified, two inter-interviewer comparisons were run on
areas that had been extensively reworked. The first
trial was done with Rand staff, using a sample of 25 for
a total of 50 interviews. We used this group of intellec-
tually active, younger respondents to determine how high
an inter-interviewer reliability was possible on the
affective and self-perceived health items. We reasoned
that, if reliabilities were high, the questions and
administration could be considered adequate for testing
a highly functional population. We could then consider
these reliability levels as the highest possible for these
items. When using these items with a nursing home
population, low reliability could then be attributed to
some characteristic in the resident rather than to
non-standardized administration or poor item construction. Reliabilities in this test ranged from .63 to 1.00. The .63 item was dropped from the questionnaire; all others were above .69 and deemed reliable in this domain. Using a sample of 25, a second inter-interviewer test was run with elderly residents of a board-and-care facility. This population was used because it is closer to the nursing home population in its general cohort characteristics but does not have as severe cognitive or physical problems. We posited that reliability levels would be lower for this population than for the Rand group but higher than for the nursing home population. The reliability of the same affect items ranged from .35 to .82. The dilemma of respondent reliability was becoming clearer. Pain and activity batteries were also tested, with reliabilities ranging from .65 to .70. At this point we decided that the measurement error could be more profitably assessed in predicting future status and therefore initiated our data collection in the targeted nursing homes.

Fall 1980 to Winter 1981

Wave I Data Collection, Analysis and Revision

Wave I data collection consisted of 212 interviews in four nursing homes. We required approximately three weeks to complete interviewing in each nursing home. A day or two in mid-cycle was required to include people admitted between cycles. These data are currently being analyzed.
After Wave I data collection, no changes were made in the interview. However, because the reliability of residents' responses is a major problem (see Sec. III), we expanded the Interviewer Observations to include interviewer ratings of confidence in the data given by each resident. We also added proxy observations, which are coded if a resident does not respond or if response accuracy is questioned by the interviewer. General observations of all residents were also expanded to provide a more complete assessment of the resident.

DOMAINS COVERED

The instrument envisioned was intended to meet the criteria outlined previously. A primary concern was that it meaningfully measure the multiple domains already outlined. Fig. 2 summarizes these domains.

Questions from the various domains are interspersed with each other to lessen fatigue and increase interest for both participant and interviewer. Thus, cognitive status questions or batteries are interspersed with physical and affective questions. For purposes of this Note, however, each domain is discussed as an intact unit.

Administrative Data

The instrument begins with administrative data collection, including standard demographic information, admissions, releases, and diagnoses. Branching occurs with an observation of "Consciousness Level." The introductory statement is read and the interview proper commences. Fig. 3 traces the changes made from the questionnaire first used in the pilot test through the items in use today.
Fig. 2—Domains selected
Fig. 3--Changes in the administrative data
Physical Domain

We began by selecting many possible areas for testing with the view that the less critical ones would be eliminated or altered as the process evolved. Several criteria were defined for indicators in the physical area. Measures had to be outcomes of care rather than indicators of process of care. For example, the presence of decubiti is an outcome of poor care (not being turned often enough), while participation in physical therapy is an indicator of the process of care. Some measures can be both and could be included (e.g., blood pressure). As an outcome, sensitivity to small increments of change was important. Measures also had to be non-intrusive and not add to the cost of data collection. Thus, we eliminated laboratory tests of any type. In addition, measures had to be easy to learn and possible to administer reliably by a variety of interviewers without medical backgrounds. With these constraints in mind, the first draft included measures of blood pressure, pulse, height, weight, respiratory rate and effort, presence and location of decubiti and edema, vision and hearing, contractures, tremors, and dentition. A variety of other physical measures were added and deleted in the course of testing as experience how well they conformed to our criteria. These changes are illustrated in Fig. 4.

The well-known domain, Activities of Daily Living, assesses a person's functional status. From the several available, we chose to build on the Barthel-Granger scale rather than the Katz scale because Barthel scales into four categories, allowing a discrimination between levels of functioning from total dependence to total independence (Granger and Greer, 1976). This scale covers the major ADL groups: grooming, toileting, washing, feeding, walking, and wheelchair
Fig. 4—Changes in the physical data
mobility. We chose to emphasize performance over capacity in our outcome measures. The former is more likely to be sensitive to the environment; someone with a capacity to do a task may not be allowed to use it. However, designing our measures to provide the opportunity whenever feasible removed some of the distinction between performance and capacity. Because some of the Barthel questions do not require a demonstration and we felt this was extremely important to accuracy, we incorporated part of the Performance Test of ADL demonstration battery (Kuriansky and Gurland, 1976) to strengthen our measures in this area. A few items were initially eliminated from the Barthel-Granger scale because they are not applicable to this institutionalized population (e.g., climbing stairs). Missing from any ADL battery is an assessment of the functioning of bedridden patients; we developed a battery of five questions to fill this gap and scaled it in the Barthel format. Deletions were generally made in this area if questions proved too time-consuming, were demeaning in some way, or if the skill level assessed was already incorporated in another question. Refinements in questions were aimed at unambiguous phrasing. This process is also illustrated in Fig. 4.

Although pain and discomfort might be important outcome measurements for nursing home residents, the literature offers little in the field of pain measurement. Some analog scales attempt to objectify this subjective perception (Hunt, et al., 1977), but none seem adequate for a population that appears to comprehend concrete concepts more easily than abstract concepts. We therefore developed a battery of questions that addressed the existence of pain and related symptoms of discomfort, their location, frequency, severity, alleviation, and consequences. These were streamlined to include only location and
frequency along with a general severity item. We found that an estimation of severity by location was too difficult a concept for most residents. Alleviation and consequences were deleted in the interest of parsimony. These changes are illustrated in Fig. 4.

Straddling the physical and psychosocial areas is the battery of self-reported health adapted from Lawton's Philadelphia Geriatric Center (PGC) Scale (Sherwood et al., 1977) and Ware's General Well-Being Scale (Ware et al., 1979). This dimension was included because research had indicated that self-reported health is a strong prognosticator of mortality—the ultimate outcome. Question and response wording were simplified and made consistent with each other. Fig. 4 illustrates these changes.

Psychological Domain

This domain includes two major subsections: cognitive functioning and affective status. Cognitive functioning measures assess orientation, memory, and brain damage as outcomes. We also expected the measures to serve as a screening or branching device to identify those residents who would not be expected to answer other items on the questionnaire reliably.

Cognitive Functioning Measures. Among the plethora of orientation scales that assess cognitive functioning, we narrowed the possibilities to tests of proven reliability and validity that have been used in an interview format with an elderly population. The VIRO Orientation Scale (Kastenbaum and Sherwood, 1972) has proven reliability but not validity; nor does it assess long-term memory. The Mental Status Questionnaire (MSQ) (Kahn et al., 1960) has proven reliability and validity and has been used extensively in geriatric research and practice. It is similar
to VIRO but does tap a dimension of long-term memory; however, it is questionable whether its content is relevant to old people residing in institutions. Pfeiffer's Short Portable MSQ (1975), part of the OARS multidimensional assessment technique for use with community elderly, is similar to the MSQ in its reliability and validity but also probes long-term memory with an item more likely to be known—mother's maiden name. Because the SPMSQ has been used with institutionalized elderly and has the unique added feature of norms that adjust for race and education, we chose this instrument for use. We opted to substitute street name for telephone number as more applicable to a nursing home population. We also made minor word changes in three of the ten questions.

Two general orientation questions assessing knowledge of the type of place and duration of time in the facility have been included to give more information concerning this aspect of a patient's cognitive functioning.

As indicators of brain damage, we reviewed the Visual Counting Test (Fishback, 1977); the Hooper Visual Test, Trailmaking A and B, the Speed of Crossing Off Test (Botwinick and Storandt, 1974); and the Face-Hand Test (Bender, Fink, and Green, 1951). The last has been used with patients at all levels of functioning. It correlates with clinical diagnoses of organic brain syndrome and is known to be highly reliable. Because it is not a timed test like the Speed of Crossing-Off Test, it is more appropriate for dysfunctional elderly participants. In addition, it fits our preference for demonstrable behavior and was therefore incorporated into the questionnaire. The Set Test was initially included as another cognitive measure because it is
easily administered, does not require the use of complex skills, and has norms that distinguish between demented and nondemented patients on the basis of categorical fluency (Isaacs and Kennie, 1973). It was later deleted because it correlated highly with the SPMSQ.

Another cognitive assessment area is memory. Many instruments have been developed to measure short-term recall, recognition, and long-term memory. Because we have no way of knowing what material respondents had learned, we chose not to request a demonstration of original learning or long-term memory. Instead we elected to test the patient's recall of specific material presented during the interview. Both the Babcock (1930) and Wechsler (1945) tests involve recall of information in a paragraph read to the resident, but both require complicated interpreting and scoring procedures and are lengthy to administer. We therefore selected the Repeat Digits Test from the Wechsler Memory Scale (Wechsler, 1945). It is brief, reliable, and uncomplicated to administer and score.

Because many nursing home residents function at the middle-to-low cognitive level, we chose to increase assessment in this area. We added a time-telling item that distinguishes people at very low levels of functioning. A coin recognition and use question, derived from Gurland and his colleagues (1977), distinguishes those at the upper and lower ends of the cognitive functioning continuum. These developments are traced in Fig. 5.

Affective Status. The other major component of psychological health is emotional or affective status. Because the objective of the questionnaire is to assess changes in health over time, we needed instruments that would measure present affective status rather
Fig. 5--Changes in the psychological data
than personality traits. Recognizing that many emotions are candidates for measurement, we chose those that research had identified as important possible outcomes of care: depression, personal well-being, and anxiety. Other scales of morale, satisfaction, and happiness were rejected as measures because they overlapped with each other, lacked sensitivity, or had conflicting definitions that raised issues of construct validity.

Loneliness, futurity, and paranoia were originally included as areas of assessment. The loneliness and future-orientation questions were adapted from Lawton's PGC instrument (Sherwood et al., 1977), but response categories were altered to fit our format of three responses. The paranoia questions were adopted from Gurland's Full Assessment Instrument (Gurland et al., 1977). However, they were deleted in subsequent trials when question length and respondent burden emerged as critical issues.

Zung's (1965) Depression Scale and the Beck Depression Inventory (Beck et al., 1961) are the two major batteries for measuring depression. Although the Zung scale has been used with elderly populations more than the Beck Scale, it lacks reliability documentation. We chose the Beck scale because it has high reported reliability and can be scaled into two sections: somatic and psychological symptoms. This distinction is especially appropriate for an older person whose natural physical aging process may mimic symptoms indicative of depression in a younger person but not necessarily indicate depression for the elderly person. We used Gallagher's revised version of Beck's
Inventory, which lessened the number of response categories and used more concise questions and responses (Gallagher, Thompson, and Levy, 1981).

As part of the Health Insurance Study done at Rand (Ware et al., 1979), Ware developed a General Well-Being Scale that included two subtests identified as relevant for our use: the Anxiety Scale and the Personal Well-Being Scale. Both have been rigorously tested for reliability and validity on younger, noninstitutionalized subjects. During the course of testing, we found that both the Beck and Ware items, which were designed to be self-administered, were very difficult to administer orally. The statements are long and contain several constructs within each item. Confusion resulted about what we were assessing. These items were therefore rewritten to eliminate redundancy and to assess one construct per item; consistent response options for all items were used. These changes are shown in Fig. 5.

Social Health

Social functioning is reflected in activities and interaction patterns and is influenced by one's place in and perception of the environment. We adapted Gurland's list of typical nursing home activities, which includes solitary and group activities (Gurland et al., 1977). We classified the frequency of participation among seven categories and gathered qualitative information about interest in each of the activities.

Experience has shown that many residents were unable to report activity levels reliably in terms of frequency per day, week, or month.
However, they did have subjective perceptions in terms of participation in an activity or not at all. Therefore we altered response categories to reflect a perceived frequency of participation: a lot, some, very little, none. Reasons for nonparticipation were also explored. However, no variance for nonparticipation reasons appeared, and this item was dropped.

Because activity outside the nursing home was not assessed adequately, we added an outdoor activity frequency matrix. This scale used seven items, two of which allowed assessment of the upper end of the social activity continuum. These were eventually collapsed into two questions.

To determine the amount of interaction between resident and family or friends, we began with a frequency-of-contact battery using seven response categories, later collapsed to four. Preference for more or less contact was incorporated. Once again, the time conceptualization or memory required to respond reliably to this battery proved a problem for residents. The battery was altered to simple subjective perceptions of contact experience.

The presence or absence of a confidante has been hypothesized as important to morale (Lowenthal and Haven, 1968). We inquired about this area in two components—a confidante within and outside the facility. Illustrations of changes in Social Health indicators are found in Fig. 6.

Satisfaction

The final area, satisfaction with care and with the living environment, has elicited a great deal of interest among researchers but
Fig. 6--Changes in the social data
few conclusive results. The constructs are not well developed and
measurement has suffered. We deemed such scales as Neugarten's Life
Satisfaction Index (Neugarten, Havighurst, and Tobin, 1961)
inappropriate for our purposes because we wanted to tap satisfaction
issues directly affecting nursing home living. Therefore we tested both
global satisfaction and opinion items. The global items were broad
indicators of satisfaction with the environment; the opinion battery
related to more specific elements in nursing home living such as food,
staff, surroundings, and physical care. These were all combined with a
modified version of McCaffree and Harkins' Satisfaction Battery (1976)
worded as simply and unambiguously as possible. One global summative
question was retained and the satisfaction battery was pared down to 14
items.

The satisfaction questions were originally asked in two versions.
The first approach asked the resident to indicate how satisfied he or
she was with each of a series of items. The second approach asked the
extent to which he or she would agree or disagree with a series of state-
ments. The former approach proved much less useful with the nursing
home population and was abandoned. Different techniques for getting
information using the latter approach were tried.

We asked the resident to determine if, in his or her opinion,
statements read were mostly true or mostly false for him or her. These
items were then more strongly phrased as statements with which the
resident was asked to agree or disagree. We hoped that strong, clear,
relevant statements would elicit more reliable data. The neutral
category was not given as an option in order to encourage a decision,
but it was used as a code category if the interviewer determined it to be applicable.

Because satisfaction with care can be a sensitive topic, it can be difficult to elicit meaningful data using the formal question format. However, indications of satisfaction may be given informally during the course of the interview. So as not to lose these data, we included response categories to allow the interviewer to record contradictory information given by the resident in reference to specific items. The development of this domain is illustrated in Fig. 7.

Interviewer Observations

This section of the questionnaire was originally intended as a supplement to record a variety of interviewer observations about the resident. Adaptations of Gurland's INCARE Screening Schedule (Gurland et al., 1977) were combined with our own observation list. These observations initially were used as a basis for overall interviewer prediction of a resident's future status in each major domain--cognitive, affective, medical, ADL, social, satisfaction--at the time of the next interview three months later. If these subjective clinical prognoses provide more accurate predictions than statistical, data-based model(s), the interviewer ratings may provide clues about what additional information needs to be included in the model(s). If the subjective prognoses do not prove more successful as predictors, we can assume that the data-based model(s) accurately include the critical predictors.
Fig. 7--Changes in the satisfaction data
However, this section has evolved beyond the original intent. As respondent-related problems surfaced (see Sec.III), we made two important additions to the questionnaire: ratings and proxies. Ratings of interviewer confidence in the data from each domain were coupled with a bevy of codable reasons for any lack of confidence. This allows the interviewer to assess lower or marginally functional residents and record her own perceptions of that person's functioning. These ratings may also be an accurate way to screen patients concerning the reliability of their responses. Because each domain is rated separately, the ratings have flexibility that allows inconsistent functioning to be identified, albeit subjectively, and recorded. Seven areas are rated on the basis of complete, some, or no confidence in the data given by the resident. If an interviewer lacks confidence in the data, the reasons for this are coded, along with a proxy, if applicable.

Four proxy observations have been added to tap those domains in which the interviewer lacks confidence in the data obtained. They are also coded if the interviewer was unable to administer that section to a resident.

General observations made for all residents are intended to capture observations of the resident elicited during the interview; these observations include demonstration of abstract thought processes, humor, or the degree and target of anger. The ratings, along with the reasons for lack of confidence, the proxies, and the general observations make possible a more complete assessment of the resident. Figure 8 illustrates the changes made in this area.
Fig. 8--Changes in the interviewer data
III: PROBLEMS ENCOUNTERED

During all of the testing periods, certain problem areas recurred. They can be defined in several broad groups:

1. Interviewing techniques
2. Questionnaire construction
3. Facility-related problems
4. Respondent-related problems.

After the pilot test, we reviewed these four problem groups in an effort to define and lessen the influence of the factors that yielded unreliable data. This process has continued through all testing phases to the present. For each problem area, we will describe our responses to these problems as they emerged during the course of the project.

INTERVIEWING TECHNIQUES

The pilot test dramatically pointed to a number of areas where we needed greater precision in delineating steps in the administration, interpretation, and coding of the data. Although it was not possible to definitively separate the sources of unreliability, some clues were offered when we found a systematic difference between the two interviewers. Such a difference pointed to problems of inter-interviewer reliability—an area more generally amenable to correction than intra-interviewer reliability, which might reflect real changes in the patient from day to day.

In order to increase inter-interviewer reliability, we undertook a multipronged approach, which included the following:
1. The interviewers wrote explicit guidelines for each procedure, question, and administrative technique. Interpretations of questions, probing styles, and techniques were discussed and agreed upon as the basis for standardization. As the questionnaire itself changed, guidelines were reworked and documented. A detailed manual is now available.

2. An intensive review of the literature on interviewing techniques revealed little concerning specific interviews with the elderly, but much information about general interviewing applicable to this project (Fletcher, 1972; U.S. DHEW, 1977). Special attention was given to possible sources of bias due to roles and expectations, the effects of voice intonation, body language, listening skills, and reinforcement techniques. The effects of interviewer stress as a potential generator of coding errors in a situation with a hostile or difficult patient were reviewed, and techniques for field recording were modified.

3. Interviewers went back into the field to test inter-interviewer differences. One person interviewed and coded and a second person observed and coded the same subject independently. After the interview, comparisons of the two coded questionnaires brought differences to light.

4. After this test was completed, a third person was brought in to observe both interviewers separately and to note any differences in technique or question administration. This
technique was used several times in the interim period with observers from different backgrounds (e.g., medicine, gerontology).

5. After the pretest, the interviewers met with an interviewing specialist to determine whether they could further develop their skills. The specialist could not identify any consistent differences between the raters that would be likely to introduce systematic bias. However, he did note areas that are amenable to increased standardization such as "drift" away from probing rules and adjustments in question administration to fit the needs of the respondent. The basic implication was that we define, agree upon, and adhere to a level of standardization in these areas. In order to standardize our probing techniques, we agreed upon particular ways of probing—e.g., repeating part of a question or response or nondirective clarification. We also strictly limited the number of probes asked to minimize variation in how deeply an interviewer probes to obtain a codable response. It was also noted that evaluative feedback, which might lead the respondent to socially desirable responses, was sometimes given.

6. We adapted the taping/monitoring technique from Cannell and his colleagues (1975) to use for training and monitoring during the data collection effort. The interviewers have remained close to the guidelines set.
QUESTIONNAIRE CONSTRUCTION

Because we could not directly decrease the level of respondent unreliability due to deficiencies inherent in a nursing home population, we tried to reduce the effect of those decrements by manipulating the questionnaire to tap domains in the most effective manner. When the data collectors fielded the instrument after early question development, it was evident that the questionnaire was too long and involved. Both the respondents and interviewers were exhausted by the administration, which often lasted two hours. The fatigue and possible alienation induced by the length of the instrument was shown by some refusals to participate in the interview a second time. Because such burdens threatened both inter-temporal reliability and participation, we sought to decrease the number and length of the questions. From that point to the present, the principle of deleting any redundant, demeaning, tiring, or difficult-to-administer items (e.g., weighing a bed-ridden patient) has been applied.

We re-examined each item to delete long sentence structures, complex wordings, and unnatural syntax in both questions and response options. We did not delete items solely on the basis of low variance when such events were rare but potentially important. Because there is a general lack of knowledge about the factors that are good health predictors in the aged, a great deal of trial and error must occur before practical, significant variables are clearly identified. We became sensitized to problems of question administration with the hearing impaired, who constitute a major part of the nursing home population. Those who are completely deaf but cognitively intact could
participate by reading the questions. However, we recognized that a larger group was hearing most speech but was having difficulty distinguishing certain words in the questionnaire. As a result, we modified confusing words. For example, "anxious," which was heard as "ancient," became "tense." "The staff shows a personal interest in the residents" (heard as "residence") became "The staff shows a personal interest in you."

Certain types of questions seemed particularly difficult for nursing home residents to answer. We observed that abstractions such as satisfaction or importance of events caused difficulty. Such concepts were altered to become concrete statements, which elicited better results, e.g.:

Abstract: How satisfied are you with your chance to be alone?

Concrete: You can be alone as much as you like (agree/disagree).

We also experimented with time and frequency of events items that caused some residents difficulty and had low reliabilities. For example, frequency of contact response categories were changed from objective, recalled data to subjective, perceived data:

Objective response categories: daily, weekly, monthly, yearly

Subjective response categories: a lot, sometimes, a little, never

We found that respondents might be unable to remember a time or frequency level but did have clear feelings about whether an event occurred a lot, sometimes, a little, or never.

Question consistency became the focus for our next round of alterations in pursuit of reliability. Some strict criteria for items were applied to our questions:
1. Each item should address only one construct. Synonyms should not be used because one cannot assume that all people are equating the same meaning to the synonym as to the original construct. Using the same word also eliminates the possibility of multi-dimensionality within an item and subsequently varying interpretations.

2. All item stems should be couched in the same time frame to eliminate the necessity for the respondent to switch from one time frame to another. This simple principle seems particularly appropriate for a cognitively frail population. Using these criteria, we revised items on the Beck scale that use both synonyms and varying time frames. As an example, the construct to be measured in the following set of statements is confounded:

I don't feel I am worse than anyone else.
I am critical of myself for my weaknesses or mistakes.
I blame myself all the time for my faults.
I blame myself for everything bad that happens.

An example of varying time frames occurs in this set of statements:

I make decisions as well as I ever could.
I put off making decisions more than I used to.
I have greater difficulty making decisions than before.
I can't make decisions at all any more.

3. The final criterion concerns response categories. Like item stems, response categories should be free of synonyms or varying time frames. In fact, they should reflect the language of the stem question and require a response to one construct. In addition, response options should be mutually exclusive.
Thus a decision was required about whether we wanted to know how much of the time something occurred, how much of something existed, or to what degree something existed (duration, quantity, quality).

An example of an item in the Beck Scale and the results of applying these three criteria are:

**Beck Scale Item:**

I do not feel sad.
I feel sad.
I am sad all the time, and I can't snap out of it.
I am so sad or unhappy that I can't stand it.

**Our revision:**

During the past month, how much of the time have you felt sad:
most of the time, some of the time, very little of the time, or none of the time?

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<th>most of the time</th>
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<td>some of the time</td>
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<td>very little of the time</td>
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<tr>
<td>none of the time</td>
</tr>
<tr>
<td>I don't know</td>
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<td>no response</td>
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Throughout the process of questionnaire construction, we made formatting changes to simplify the coding process and to decrease the level of error from this source; for example, decubiti and contracture items were formatted into matrices. The two original groups of satisfaction items were combined; those items requiring a response indicating an abstract level of satisfaction were altered to fit the more concrete agree/disagree format. We found that residents were able to understand and reply to the concrete question more easily than to the more abstract type.
FACILITY-RELATED PROBLEMS

Facility-related problems are mentioned because they do cause stress for the resident and interviewer in the interview situation. This may be a contributing factor influencing reliabilities.

Privacy is a problem for several reasons. Because participants often resist being interviewed in a private place and prefer a hallway, dining room, or their own semi-private room, confidentiality was compromised. As a result, questions concerning others who might be in the immediate vicinity (e.g., staff or roommates) have to be omitted. We do not know how this affects respondent answers to questions. In one instance, a cadre of nonparticipant onlookers, who perceived parts of the questionnaire negatively, voiced their critical opinions quite openly.

Environmental noise levels sometimes make it difficult to hear, with resulting confusion. Patients with marginal capabilities are easily distracted by the activity of residents and visitors to the home. Working under these difficult conditions is also draining for the interviewing staff.

We also became sensitive to questions that were not appropriately asked in an institutional setting. Depending on the rules or routines of an institution, certain activities might be prohibited. Examples of such items are the use of the telephone and making all preparations to wash face and hands. (One might legitimately argue here that such imposed restrictions do not detract from their usefulness as outcome measures.)
RESPONDENT-RELATED PROBLEMS

Refusal Rates

Securing written consent and participation in the interview initially proved to be unexpectedly difficult. Patients were of three persuasions: one small group was interested in participation in the study and willing to sign the consent forms. A second group absolutely refused to participate. A third, sizable group was interested in participating but refused to sign a consent form. These residents seemed reluctant to sign anything that appeared to be legal, regardless of content. It was not clear whether this reticence was the result of a sense of vulnerability due to poor eyesight or hearing, a more general fear of exploitation, or a fear of endangering their position within the facility. Whatever the cause, we secured approval from the Rand Institutional Review Board to obtain only oral consent, allowing us to reach this important segment of the population. Nevertheless, the pilot testing phase required more time than we had anticipated. We found that the stereotype of willingness to talk to anyone or participate in any activity to challenge the boredom of an institution certainly did not apply to many patients. Much time was spent convincing people to participate in the study.

In some cases, we found that residents were resistant to interviewer approaches because they were in pain, were simply not feeling well, were depressed, or saw no benefit in such an interaction. Others might view the data collectors incorrectly as advocates for their plight; in such an instance, interviewers had to be sensitive "teachers" of how to help the patient become his own advocate. Paths for giving feedback were discussed with the facility administrators before testing in order to avoid politically embarrassing situations.
The literature on refusal rates for studies of the elderly is thin. Rates range from 10 percent (Zemore and Ames, 1979) to 37 percent (Ridley, Bachrach, and Dawson, 1979), with the higher rate for community elderly. During our pretesting phase, residents were asked to do the interview twice; the initial refusal rate was 42 percent. An additional 19 percent completed the interview but refused the second interview. When Wave I data collection was complete, refusal rates had dropped to about 30 percent. During Wave II testing, we approached those who had refused in the past; some agreed to participate during this wave. As a result, refusal rates were again lowered, ranging from 12 to 20 percent. Our increased credibility and familiarity to residents may be the reason for this lessening of refusals. Of the four nursing homes, 34 people who refused the first time agreed to be interviewed the the second time; 42 who refused the first time also refused the second; and 17 who agreed the first time refused to be interviewed the second time.

Limitations of Respondents

Our design calls for interviewing all patients in the nursing home. Information from the literature using similar populations (i.e., all impairment levels) is vague. Most studies do not report selection criteria. Those studies that do report using selection criteria of "stable" mental characteristics (Cutler and Chiraboga, 1976) or an MSQ to screen for those with only "mild organicity" (Nelson and Paluck, 1980). Subjective attitudes questions were not asked of the "demented" (Spasoff et al., 1978). Mishara (1979) found he could not administer tests of neurophysiological functioning (except for Face-Hand Test) to elderly mental hospital residents because they could not complete the measures. McCaffree and Harkins
(1976), whose study has some close parallels with this one, do not specifically report problems with the lower-functioning group, but they admit that there was selection bias because those least able to function mentally could not give their consent, nor could it be secured for them from the state. Thus, few definitive data are available, and we are aware of no theoretical treatise about working with confused or impaired elderly in the interview context.

Once the obstacles to participation were overcome, the limitations of the population became apparent. The length of the interview was a concern. Fatigue was a frequent problem, regardless of the physical or emotional status of the resident. Sometimes the interview had to be divided into several sessions. Emotional limitations (e.g., lability, depression), distractibility, and the short attention spans of many residents required adept interviewing skills. Physical decrements presented barriers to testing—branching points were introduced into the questionnaire to accommodate varying levels of mobility. However, the unreliability of the respondent population was emerging as a major issue.

After our experience with the pilot test, we made changes and ran a pretest during the summer of 1980. The reliability of inter-interviewer data was generally improved in the pretest, but it did not reach the levels we had hoped for. Intra-interviewer reliabilities were done on troublesome portions of the instrument, and they were not significantly higher than the inter-interviewer reliability correlations. This supported the contention that the interviewers
were reliable with each other and that the performances of certain respondents contributed to the lack of higher correlations.

We had hypothesized that reliabilities would be significantly higher between interviewers because of the changes we had made and the training they had undergone. However, we were aware that reliable and consistent data were not being elicited from marginally or lower-functioning people. We were also aware that this group of people does not necessarily perform unreliably in the same domains; they may also be unreliable in one area of the questionnaire and highly reliable in another. This unevenness is the crucial characteristic that hampers the identification of members of this group and subsequent meaningful data analysis.

Because we cannot affect respondent reliability, we sought to use a cognitively based screening procedure to identify members of the unevenly reliable group. We began with the score achieved on the MSQ. A score below four was used as the cutoff point. We also devised a series of questions about recent relevant events (e.g., watching television, taking a shower) asked at the onset of the interview and again after the physical examination. Inconsistent answers were taken as signs of unreliability. Analysis of pretest data showed that neither of these methods could be used to predict unreliable performance, as reflected in inter-interviewer reliability scores. Therefore we looked at other variables to locate possible screening items: correlations with physical variables such as vision, hearing, and frequency of pain and discomfort; cognitive variables such as the
digit-span test, the face-hand test, the clock and coin tests. We even examined patterns of interviewer probing, "no response," and the number of interruptions to the interview. None of these were useful as predictors of unreliability in the respondent.

Our conclusion was that the questionnaire, even with attempts at screening, could not be used for all residents. If it is used this way without qualification, several problems occur:

1. **Confidence in the data.** For one group of residents, confidence in the quality of the data is high. For a second group, confidence is mixed, with some areas possibly appearing to be more credibly reported than others. For a third group, confidence in the reported data is low. Other than a general rating of overall confidence, however, there was no provision in the questionnaire for these distinctions to be recorded in detail by the interviewers.

2. **Absence of data.** In some situations, portions of the interview are not done--residents may be unable or unwilling to complete a section. A portion of the questionnaire might be done one day and the patient discharged the next; such interruptions result in lost data.

3. **Elements not addressed.** As the questionnaire is constructed, it does not distinguish higher cognitive functioning. Subtle nuances of intellectual levels such as irony, humor, and active interest in the world around are not tapped.
To overcome these shortcomings without increasing the respondent burden, we developed a set of ratings that parallel the domains assessed in the interview. We opted to use the analytical and observational skills of our interviewers to rate confidence in the responses given for each domain; reasons for any lack of confidence are documented. These changes allow finer distinctions in rated confidence levels to be made.

In addition, if there is an absence of data or if the interviewer lacks confidence in the data or perceives evidence that conflicts with the responses given, proxy items are coded. For example, a resident replies to the pain questions that he or she experiences no pain. However, during the course of the interview, the resident mentions the pain that he or she feels. This is an often-noted case of the information given at the time of the question conflicting with information relayed less formally. Such contradictory statements are often made in the area of satisfaction. We therefore added response categories that allow both the response and an observation of contradictory comments to be recorded.

We also added observations of behaviors for all residents, including observations of higher cognitive function such as humor. These observations are intended to capture interviewer perceptions of the resident; these perceptions may prove important in identifying unreliable residents or in predicting outcomes.
IV: SUMMARY OF SCALE DEVELOPMENT

The Nursing Home Resident Questionnaire collects information in the following domains:

1. Cognitive
2. Satisfaction with care and environment
3. Affective
4. Social activities
   - Inside and outside activities
   - Social contact
5. Activities of daily living (ADL)
6. Physical

Each domain is covered by a series of questions designed to measure the resident's condition in the domain. Analysis of the first wave of 212 interviews has emphasized greatly reducing the set of outcome measures. The magnitude of the reduction depends on the validity and internal consistency of the resulting scales. For example, in the satisfaction domain, items covering a variety of aspects of satisfaction (validity) relate in a way suggesting that satisfaction forms a single dimension (consistency). In contrast, the notion of validity requires that individual items within the physical domain be treated separately, because specific problems have importance in their own right.

Except in the physical domain, one or two scales have been developed to summarize the information from each domain. In the physical domain, scales have been developed for particular items. Of these, we report the results for a pain and discomfort scale. In some cases, alternative scales measure similar attributes. Future work, based
on reliability data being collected currently and validation of Wave 1 scale development, may help us to choose among similar scales.

Except in the cognitive domain, nonresponse to a question has been generally treated as missing data. In certain cases (determined on an item-by-item basis), nonresponse or such answers as "I don't know" are recoded to a particular response (e.g., incorrect on cognitive items). When just a few items making up a scale are missing, we use one of several methods to complete the scale, thus avoiding the loss of substantial information about the resident. Most commonly, the mean score for other residents is substituted in forming the scale score. However, if more than half the items forming the scale are missing, the scale score is treated as missing also. Except for the cognitive domain, for which items are spread throughout the questionnaire rather than grouped, very few residents require substitutions on more than one or two items in any domain. The list of domain scales and the percent of residents with missing scores on each are

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<th>Scales</th>
<th>Percent Missing</th>
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<tr>
<td>NSQ</td>
<td>11</td>
</tr>
<tr>
<td>Comprehensive cognitive</td>
<td>8</td>
</tr>
<tr>
<td>Satisfaction with care</td>
<td>30</td>
</tr>
<tr>
<td>Affective (factor 1)</td>
<td>32</td>
</tr>
<tr>
<td>Affective (factor 2)</td>
<td>32</td>
</tr>
<tr>
<td>Inside activities</td>
<td>11</td>
</tr>
<tr>
<td>Inside and outside activities</td>
<td>22</td>
</tr>
<tr>
<td>Social contact</td>
<td>23</td>
</tr>
<tr>
<td>Activities of daily living</td>
<td>14</td>
</tr>
<tr>
<td>Pain and discomfort</td>
<td>23</td>
</tr>
</tbody>
</table>

In almost all cases, missing scale scores are due to discontinuation of the interview.
COGNITIVE DOMAIN

The cognitive domain is dominated by the ten-item Mental Status Questionnaire (MSQ) but also includes several single item scales: digit repetition, telling time, face-hand test, general orientation, and coin test. Because of the MSQ's past performance in terms of reliability and consistency, two cognitive scales will be used for future testing: the MSQ itself and a comprehensive cognitive scale combining the MSQ score with scores from the other cognitive items. The latter scale was developed using factor analysis. The comprehensive cognitive scale helps to differentiate better among residents, especially those at the lower end of the MSQ scale.

The MSQ (Pfeiffer, 1975) contains ten items that are scored on a full or no credit basis.[1] Answers of "I don't know" and no response are treated as incorrect and thus receive no credit. The items and percent of the residents with correct scores are listed in Table 1. For residents who were asked all ten questions, the MSQ score is the number of correct answers. Those who were asked from five to nine of the questions are assigned a prorated score based on the proportion of correct answers on the questions they were asked.[2] The distribution of MSQ scores appears in Table 2. These scores exhibit a mild concentration toward the lower end of the scale. This concentration would increase if

---

[1] Although partial credit is recorded on the questionnaire for three of the items (present date, subtraction, and birthdate), it is not given in the MSQ score.

[2] Mainly because the MSQ items are spread throughout the questionnaire, 41 of the scores required prorating.
Table 1
PERCENT OF RESIDENTS WITH CORRECT ANSWER ON EACH MSQ ITEM

<table>
<thead>
<tr>
<th>Item a</th>
<th>Percent Correct b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Today's complete date</td>
<td>21</td>
</tr>
<tr>
<td>Day of week</td>
<td>41</td>
</tr>
<tr>
<td>Name of President</td>
<td>47</td>
</tr>
<tr>
<td>Name of previous President</td>
<td>24</td>
</tr>
<tr>
<td>Repeated subtraction</td>
<td>26</td>
</tr>
<tr>
<td>Name of nursing home</td>
<td>37</td>
</tr>
<tr>
<td>Street name of nursing home</td>
<td>31</td>
</tr>
<tr>
<td>Mother's maiden name</td>
<td>74</td>
</tr>
<tr>
<td>Resident's age (within one year)</td>
<td>41</td>
</tr>
<tr>
<td>Resident's birthdate (exact)</td>
<td>42</td>
</tr>
</tbody>
</table>

a The items appear on the questionnaire in the above order.

b Residents who did not reach a particular question are not included for purposes of computing the percent correct.
Table 2
DISTRIBUTION OF SCORES ON THE MSQ AND COGNITIVE SCALES

<table>
<thead>
<tr>
<th>MSQ Score</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>34</td>
</tr>
<tr>
<td>1 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>28</td>
</tr>
<tr>
<td>2 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>28</td>
</tr>
<tr>
<td>3 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>13</td>
</tr>
<tr>
<td>4 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>14</td>
</tr>
<tr>
<td>5 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>10</td>
</tr>
<tr>
<td>6 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>17</td>
</tr>
<tr>
<td>7 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>7</td>
</tr>
<tr>
<td>8 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>19</td>
</tr>
<tr>
<td>9 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>10</td>
</tr>
<tr>
<td>10 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cognitive Score</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>-8 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>5</td>
</tr>
<tr>
<td>-7 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>7</td>
</tr>
<tr>
<td>-6 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>7</td>
</tr>
<tr>
<td>-5 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>10</td>
</tr>
<tr>
<td>-4 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>19</td>
</tr>
<tr>
<td>-3 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>19</td>
</tr>
<tr>
<td>-2 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>13</td>
</tr>
<tr>
<td>-1 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>10</td>
</tr>
<tr>
<td>0 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>18</td>
</tr>
<tr>
<td>1 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>12</td>
</tr>
<tr>
<td>2 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>29</td>
</tr>
<tr>
<td>3 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>18</td>
</tr>
<tr>
<td>4 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>15</td>
</tr>
<tr>
<td>5 * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *</td>
<td>12</td>
</tr>
</tbody>
</table>

\(a\) The MSQ score is missing for 23 residents who were asked four or fewer questions. Most of these residents gave no correct answers to the items that they were asked.

\(b\) Each * represents one nursing home resident.

\(c\) The cognitive scale score is missing for 18 residents who received less than one-half the tests.
the distribution included residents whose interviews were discontinued (usually for consistent nonresponse) before half of the MSQ items had been administered.

Pair correlations among the MSQ items indicate good consistency among most of the items. [3] The two exceptions are the subtraction and mother's maiden name items. The former is substantially less consistent (internally) than the rest; the latter is marginally less consistent.

A comprehensive cognitive scale including the MSQ score and scores from each of the other five cognitive tests has been developed using factor analysis. The first factor, which accounts for 61 percent of the variance in scores on the six items, is the scale score. The MSQ score contributes the most to the factor; telling time and general orientation contribute the least. The distribution of this factor also appears in Table 2. Probably because the digit repetition, face-hand test, and coin test scores allow partial credit, the comprehensive cognitive scale spreads out the scores at the lower end of cognitive functioning. This hypothesis is supported by Guttman scale analysis, which indicates that scoring high on the MSQ and successfully completing the digit repetition generally imply doing well on the other cognitive tests. A second factor does not account for a sizable proportion of variance.

[3] Because the item scores are two-point distributions with substantially different success probabilities (see Table 1), Pearson correlations can provide a distorted sense of pair relationships, especially between the hardest and easiest items. Thus gamma coefficients have been used for this investigation.
SATISFACTION DOMAIN

The questionnaire contains 14 items measuring the resident's satisfaction with various aspects of the care provided by the nursing home. Each item is a statement read aloud by the interviewer to which the resident is asked to agree or disagree.[4] The distributions of responses to the items appear in Table 3. An additional item asks how much of the time the resident enjoys living in the nursing home. The scale for the satisfaction domain is the first factor from a factor analysis of these 15 items.

The 14 main satisfaction items are scored on a 2-1-0 scale. For positive statements, the resident scores two points for agreeing, one point for a neutral answer, and zero points for disagreeing. For negative statements, the scale is reversed. For the frequency-of-satisfaction item, scores are: most of the time=6, some=3, very little=1, and none=0.[5] Correlations among the satisfaction items are generally small but positive. A factor analysis of the 15 satisfaction items indicates the presence of one fairly weak factor on which all the items load positively. This first factor accounts for 36 percent of the variance. No other factor appears to be important; the second factor accounts for only 14 percent of the remaining variance. The factor scores are shown in Table 4 in order of decreasing importance. There is a tendency for items that load most strongly on

[4] Although agree and disagree are the only responses suggested to the resident, a neutral response is recorded if one is volunteered. The neutral response is also recorded if the response is "I don't know."

[5] Because a factor analysis is used to derive the scale score, the different ranges for the two types of questions are immaterial.
Table 3

DISTRIBUTIONS OF RESPONSES TO SATISFACTION ITEMS\textsuperscript{a}

<table>
<thead>
<tr>
<th>Item</th>
<th>Agree</th>
<th>Neutral\textsuperscript{b}</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Positive Statements</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The food is good</td>
<td>85</td>
<td>21</td>
<td>41</td>
</tr>
<tr>
<td>Room and surroundings are clean</td>
<td>132</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Can keep personal possessions</td>
<td>95</td>
<td>9</td>
<td>39</td>
</tr>
<tr>
<td>See doctor when needed</td>
<td>106</td>
<td>9</td>
<td>32</td>
</tr>
<tr>
<td>Nursing staff cares about you</td>
<td>98</td>
<td>21</td>
<td>30</td>
</tr>
<tr>
<td>Choice of bedtime</td>
<td>121</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Help comes within a reasonable time</td>
<td>108</td>
<td>12</td>
<td>27</td>
</tr>
<tr>
<td>Have enough privacy</td>
<td>108</td>
<td>10</td>
<td>27</td>
</tr>
<tr>
<td>This is a cheerful place</td>
<td>98</td>
<td>13</td>
<td>34</td>
</tr>
<tr>
<td>Something is done about complaints</td>
<td>94</td>
<td>18</td>
<td>30</td>
</tr>
<tr>
<td>Staff shows a personal interest</td>
<td>95</td>
<td>21</td>
<td>23</td>
</tr>
<tr>
<td><strong>Negative Statements</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount of noise bothers you</td>
<td>35</td>
<td>8</td>
<td>104</td>
</tr>
<tr>
<td>Life is boring here</td>
<td>59</td>
<td>9</td>
<td>71</td>
</tr>
<tr>
<td>Personal belongings have disappeared</td>
<td>71</td>
<td>9</td>
<td>65</td>
</tr>
</tbody>
</table>

Responses to: How often do you like living here?

- Most of the time 53
- Some of the time 36
- Very little of the time 21
- None of the time 34

\textsuperscript{a} 61 residents did not respond to any of the satisfaction questions. Depending on the question, responses are missing from 2 to 12 additional residents.

\textsuperscript{b} The neutral category includes responses of "I don't know."
Table 4
FACTOR SCORES FOR THE SATISFACTION FACTOR

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff shows a personal interest</td>
<td>0.75</td>
</tr>
<tr>
<td>Something is done about complaints</td>
<td>0.74</td>
</tr>
<tr>
<td>Overall satisfaction</td>
<td>0.73</td>
</tr>
<tr>
<td>Nursing staff cares about you</td>
<td>0.71</td>
</tr>
<tr>
<td>Help comes within a reasonable time</td>
<td>0.71</td>
</tr>
<tr>
<td>This is a cheerful place</td>
<td>0.69</td>
</tr>
<tr>
<td>Can keep personal possessions</td>
<td>0.59</td>
</tr>
<tr>
<td>Life is boring here</td>
<td>0.59</td>
</tr>
<tr>
<td>The food is good</td>
<td>0.56</td>
</tr>
<tr>
<td>See doctor when needed</td>
<td>0.56</td>
</tr>
<tr>
<td>Room and surroundings are clean</td>
<td>0.54</td>
</tr>
<tr>
<td>Have enough privacy</td>
<td>0.53</td>
</tr>
<tr>
<td>Choice of bedtime</td>
<td>0.46</td>
</tr>
<tr>
<td>Personal belongings have disappeared</td>
<td>0.24</td>
</tr>
<tr>
<td>Amount of noise bothers you</td>
<td>0.17</td>
</tr>
</tbody>
</table>
this factor to relate to the dedication and interest of the nursing home staff while items further from the control of the staff have the smallest factor scores.

Table 5 shows the distribution of scores on the satisfaction scale derived from the first factor of the factor analysis. The scores are definitely skewed because many of the residents have expressed a high level of satisfaction. Consequently those who express substantial dissatisfaction stand out from the crowd.

AFFECTIVE DOMAIN

The affective domain contains 12 questions asking the resident how often during the past month he has felt a particular emotion. The possible responses to each item are: most, some, very little, and none of the time. The distribution of responses to each item appears in Table 6. After each item had been scored, a factor analysis was used to produce two distinct scales for the affective domain. Each item is scored on a 6-3-1-0 point scale (most of the time=6, some=3, very little=1, and none=0).

The factor analysis dramatically divides the affective items into two groups: those addressing positive emotions and those addressing negative ones. Fig. 9 offers a plot of the factor scores from the two factors. As one might expect, the first factor (vertical axis) loads all items according to the type of emotion—i.e., most of the time in response to positive emotions and none of the time in response to negative emotions receive the highest scores on this factor. Thus the first factor is a clear measure of affective well-being. In contrast, the second factor measures the resident's tendency to report frequency of
Table 5

DISTRIBUTION OF SCORES ON THE SATISFACTION SCALE

<table>
<thead>
<tr>
<th>Satisfaction Score</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>-13 **</td>
<td>2</td>
</tr>
<tr>
<td>-12 ***</td>
<td>3</td>
</tr>
<tr>
<td>-11 **</td>
<td>2</td>
</tr>
<tr>
<td>-10 **</td>
<td>2</td>
</tr>
<tr>
<td>-9 **</td>
<td>2</td>
</tr>
<tr>
<td>-8 ******</td>
<td>6</td>
</tr>
<tr>
<td>-7 ****</td>
<td>3</td>
</tr>
<tr>
<td>-6 *****</td>
<td>5</td>
</tr>
<tr>
<td>-5 *</td>
<td>1</td>
</tr>
<tr>
<td>-4 **********</td>
<td>9</td>
</tr>
<tr>
<td>-3 ****</td>
<td>4</td>
</tr>
<tr>
<td>-2 **********</td>
<td>6</td>
</tr>
<tr>
<td>-1 ****************</td>
<td>15</td>
</tr>
<tr>
<td>0 *****</td>
<td>5</td>
</tr>
<tr>
<td>1 ****************</td>
<td>14</td>
</tr>
<tr>
<td>2 **********</td>
<td>10</td>
</tr>
<tr>
<td>3 ****************</td>
<td>13</td>
</tr>
<tr>
<td>4 ****************</td>
<td>15</td>
</tr>
<tr>
<td>5 *****************</td>
<td>20</td>
</tr>
<tr>
<td>6 *****************</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 6

DISTRIBUTIONS OF RESPONSES TO AFFECTIVE ITEMS

<table>
<thead>
<tr>
<th>Item</th>
<th>Most</th>
<th>Some</th>
<th>Very Little</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Positive Emotions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Happy</td>
<td>60</td>
<td>33</td>
<td>26</td>
<td>25</td>
</tr>
<tr>
<td>Life is interesting</td>
<td>48</td>
<td>28</td>
<td>25</td>
<td>34</td>
</tr>
<tr>
<td>Wakeup fresh and rested</td>
<td>58</td>
<td>31</td>
<td>29</td>
<td>22</td>
</tr>
<tr>
<td>Something to look forward to</td>
<td>42</td>
<td>28</td>
<td>31</td>
<td>38</td>
</tr>
<tr>
<td>Cheerful</td>
<td>58</td>
<td>31</td>
<td>31</td>
<td>22</td>
</tr>
<tr>
<td><strong>Negative Emotions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bothered by nerves</td>
<td>29</td>
<td>31</td>
<td>31</td>
<td>58</td>
</tr>
<tr>
<td>Sad</td>
<td>28</td>
<td>42</td>
<td>33</td>
<td>40</td>
</tr>
<tr>
<td>Depressed</td>
<td>39</td>
<td>34</td>
<td>35</td>
<td>34</td>
</tr>
<tr>
<td>Worried</td>
<td>30</td>
<td>33</td>
<td>25</td>
<td>53</td>
</tr>
<tr>
<td>Anxious</td>
<td>25</td>
<td>39</td>
<td>26</td>
<td>41</td>
</tr>
<tr>
<td>Thought about suicide</td>
<td>6</td>
<td>10</td>
<td>4</td>
<td>120</td>
</tr>
<tr>
<td>Felt lonely</td>
<td>43</td>
<td>38</td>
<td>23</td>
<td>39</td>
</tr>
</tbody>
</table>
FACTOR1

1

.9

.8

K  H  .7  C

G  A  .6  D  F

L  .5

.4

B  .3  I

.2

.1

1.0  .9  .8  .7  .6  .5  .4  .3  .2  .1  0  .1  .2  .3  .4  .5  .6  .7  .8  .9  1.0

FACTOR2

.1

.2

.3

.4

.5

.6

.7

.8

.9

1

NERVES =A  ANXIOUS =B  HAPPY =C  LIFE =D  WAKEUP =E

CHEER =F  LONELY =G  SAD =H  LOOKFWD =I  DEPRESS =J

WORRIED =K  SUICIDE =L

Fig. 9--Plot of factor 1 with factor 2
emotions of either type (positive and negative). A large score on
the second factor is obtained by "most of the time" and "some of the
time" to almost all the items; answering "very little" or "none of the
time" lowers the score on this factor. Except for two items (anxious
and something to look forward to, which load weakly on the first
factor), the positive and negative items cluster into two very tight
groups.[6]

ACTIVITIES AND SOCIAL CONTACT

Three social activities scales have been developed: one measuring
participation in activities within the nursing home, another combining
the first scale with measures of outside activity, and one measuring
social interaction both inside and outside the nursing home.

The second affective factor differs from the other outcome scales
in an important respect because there are no obvious good or bad scores.
However, there may be predictive power in the scale because certain
other scales correlate more highly with the second factor than with the
first factor.

[6] Interpretation of the second factor is somewhat difficult. A
priori, one might expect related emotions such as happy/sad/cheerful or
nervous/wakeful-fresh-and-rested/anxious to form a second factor. How-
ever, correlations are almost uniformly higher within the positive and
negative groups than across groups. This raises the possibility of
response bias—a tendency to give the same answer regardless of the
question being asked. The patterns of responses for a small percentage
of residents indicates that this is a real possibility. Several
residents either responded "most of the time" or "none of the time" to a
majority of each emotion type. Although a preponderance of "none of the
time" answers might simply indicate a dulling of emotion, the
preponderance of "most of the time" answers by some residents appears
contradictory. However, the same second factor remains fairly clear
when the five least consistent cases are dropped from the factor
analysis.
Inside Activities

The measure of inside activities is based on the frequencies of participation during the past month in eight activities available at each nursing home. Table 7 lists the activities and frequency distributions for each. For each item, a score is assigned according to the frequency of participation (a lot=6, sometimes=3, very little=1, none of the time=0). Because we have no reason to value some activities over others, the inside activities scale is an unweighted sum of scores on the eight items. The distribution of scores on the inside activities scale appears in Table 8. The distribution is positively skewed because of a few residents who report frequent participation in most of the inside activities.

Outside Activities

Two questions inquire about the frequency of outside activities during the previous month. The first asks about going outside to people's homes, restaurants, entertainment, etc.; the second is limited to staying overnight at someone's home. The sum of the scores on these two items provides an outside activities scale. By itself the scale provides very little discrimination among residents because only 40 percent of the residents went outside at all. The combined activities scale is the sum of the inside activities scale and 1.5 times the outside activities scale.[7] The distribution of this scale is shown in

[7] The factor 1.5 times the outside activities is used because there are eight inside activities and only two outside activities.
Table 7
PARTICIPATION IN INSIDE ACTIVITIES

<table>
<thead>
<tr>
<th>Activity</th>
<th>A Lot</th>
<th>Sometimes</th>
<th>Very Little</th>
<th>Not at All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading</td>
<td>43</td>
<td>45</td>
<td>22</td>
<td>90</td>
</tr>
<tr>
<td>Crafts or handwork</td>
<td>12</td>
<td>17</td>
<td>8</td>
<td>158</td>
</tr>
<tr>
<td>Bingo</td>
<td>19</td>
<td>28</td>
<td>17</td>
<td>128</td>
</tr>
<tr>
<td>Exercise class</td>
<td>35</td>
<td>25</td>
<td>12</td>
<td>114</td>
</tr>
<tr>
<td>Attend parties</td>
<td>32</td>
<td>35</td>
<td>41</td>
<td>78</td>
</tr>
<tr>
<td>Talk on telephone</td>
<td>6</td>
<td>11</td>
<td>12</td>
<td>155</td>
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<td>Play cards</td>
<td>71</td>
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<td>Item</td>
<td>Frequency</td>
<td></td>
<td></td>
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<tr>
<td>----------</td>
<td>-----------</td>
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<td></td>
</tr>
<tr>
<td><strong>Inside Activity Scores</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-1</td>
<td>15</td>
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<td>2-4</td>
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<tr>
<td>5-7</td>
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<td>8-10</td>
<td>28</td>
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<td></td>
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<tr>
<td>11-13</td>
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<td>14-16</td>
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<td>17-19</td>
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<td>29-31</td>
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<td></td>
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<tr>
<td>32-34</td>
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<td>35-37</td>
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<tr>
<td>41-43</td>
<td>1</td>
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<td></td>
</tr>
<tr>
<td><strong>Combined Activity Scores</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>0-1</td>
<td>10</td>
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<td></td>
<td></td>
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<tr>
<td>2-4</td>
<td>16</td>
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<td></td>
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<td>5-7</td>
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<td></td>
<td></td>
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<tr>
<td>8-10</td>
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<td></td>
<td></td>
<td></td>
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<td>35-37</td>
<td>3</td>
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<tr>
<td>38-40</td>
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<td>50-52</td>
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<tr>
<td>53-55</td>
<td>1</td>
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</tr>
</tbody>
</table>
Table 8. Although the combined scale should be more comprehensive, the outside activities may be too dependent on physical condition. Both scales will be tested in the future for reliability and sensitivity to real changes.

Social Contact

Social contact is measured by a series of questions addressing both the frequency of contact with others and the resident's assessment of the closeness of these interactions. The possible contacts include other residents in the nursing home, friends outside the nursing home, and family members outside the home. Correlations between scores measuring different types of social contact (e.g., family versus within the nursing home) are generally low, about 0.20. This suggests that, to some extent, one source of contact may serve to substitute for another. Because each source of social support is theoretically useful, we have developed a social contact scale that gives fairly equal weights to each. The distribution of this scale score appears in Table 9.

ACTIVITIES OF DAILY LIVING

The ADL domain combines direct observations and self-reported information on the ability to perform the following basic daily activities: bathing, toileting, transferring, dressing, feeding, remaining continent, moving within bed. Katz (1963) and his colleagues found that the first six activities are modeled well by a Guttman scale; a resident who can perform a particular function without assistance can generally also perform all lower ones in the list.
Table 9

DISTRIBUTION OF SCORES ON THE SOCIAL CONTACT SCALE

<table>
<thead>
<tr>
<th>Social Contact Scores</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-1</td>
<td>10</td>
</tr>
<tr>
<td>2-3</td>
<td>6</td>
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<tr>
<td>4-5</td>
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<td>6-7</td>
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<td>8-9</td>
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<td>18-19</td>
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<td>24-25</td>
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<td>26-27</td>
<td>6</td>
</tr>
<tr>
<td>28-29</td>
<td>2</td>
</tr>
</tbody>
</table>
We have added a short series of observations testing the movement of bedridden patients, and we have developed a single ADL scale including all seven functions mentioned above.

In this study, it is infeasible to observe bathing and toileting directly or to reliably observe the resident's ability to remain continent; we therefore collect information on these functions through self-reports. Analysis of patterns of answers (using Guttman analysis), and the interviewers' assessments cause us to trust the self-reported data less than the demonstrations.

Where we have direct observations rather than only self-reports, our analysis substantiates Katz's finding of Guttman scalability. The best results occur for a scale of four direct observations, which follow Katz's order: walking ten feet without assistance, buttoning a shirt, using a spoon, and remaining continent throughout the interview. The coefficient of reproducibility for this scale is 0.93 (the coefficient of scalability is 0.74). Attempts to complete the scale by introducing bathing and toileting items are hindered by inconsistencies between demonstrations and self-reports. A substantial number of residents who report the ability to bathe or use the toilet by themselves are unable to demonstrate one or more presumably easier tasks. Thus the coefficient of reproducibility for the six-item scale is only 0.87. Using the self-reported measure of continence reduces the coefficient of reproducibility still further (to 0.83) because a surprisingly large number of residents were willing to admit some form of incontinence during the previous month.
A single ADL scale has been developed that includes all seven activities. To increase sensitivity of the scale, partial credit is provided on certain items using the scale (completed intact=3, with limited assistance=2, with a helper=1, and unable=0). The ADL scale score (see Table 10) is the sum of the scores on the seven items. Future analysis will investigate the feasibility of using two ADL scales—one based on observations only, the other on self-reports only. In that case, the latter might be used only when no intertemporal change occurs in the former scale.

PHYSICAL

The questionnaire contains numerous direct observations of physical condition and a few self-reported items. The observations were chosen to limit respondent burden and to avoid the need for highly skilled medical personnel as interviewers. In contrast to other domains, no overall scale is planned for use in the physical domain because specific conditions will be important outcome measures. To focus on a general health scale might mask important changes over time. Certain sets of items have been combined into scales measuring such conditions as vision, flexibility of joints, and pain and discomfort. As an example, the pain and discomfort scale is described below.

Pain and Discomfort Scale

The residents are asked to report the frequency with which they experience each of six types of pain and discomfort (see Table 11). The scale score, shown in Table 12, is the sum of scores from the six items (every day=2, less than daily=1, no pain and discomfort=0), so that a high score implies the greatest amount of pain and discomfort.
Table 10
DISTRIBUTION OF ADL SCALE SCORES

<table>
<thead>
<tr>
<th>ADL Scores</th>
<th>Frequency</th>
</tr>
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<tbody>
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<td>0   **</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
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<tr>
<td>3   ***</td>
<td>3</td>
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<td>4</td>
<td>0</td>
</tr>
<tr>
<td>5   *****</td>
<td>4</td>
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<td>6   *********</td>
<td>10</td>
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<tr>
<td>7   *****</td>
<td>4</td>
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<td>8   *********</td>
<td>10</td>
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<td>9   *********</td>
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<td>11  *********</td>
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<td>16  **********</td>
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<td>17  **********</td>
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<td>18  **********</td>
<td>14</td>
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<tr>
<td>19  *****</td>
<td>6</td>
</tr>
<tr>
<td>20  **********</td>
<td>17</td>
</tr>
<tr>
<td>21  **********</td>
<td>15</td>
</tr>
</tbody>
</table>

Table 11
FREQUENCY OF PAIN AND DISCOMFORT

<table>
<thead>
<tr>
<th>Pain Item</th>
<th>Every Day</th>
<th>Less than Daily</th>
<th>No Pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aches</td>
<td>35</td>
<td>49</td>
<td>89</td>
</tr>
<tr>
<td>Chest pain</td>
<td>5</td>
<td>30</td>
<td>138</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>13</td>
<td>35</td>
<td>121</td>
</tr>
<tr>
<td>Dizziness</td>
<td>7</td>
<td>37</td>
<td>118</td>
</tr>
<tr>
<td>Itching</td>
<td>25</td>
<td>39</td>
<td>95</td>
</tr>
<tr>
<td>Headaches</td>
<td>9</td>
<td>41</td>
<td>109</td>
</tr>
</tbody>
</table>
Table 12
DISTRIBUTION OF PAIN AND DISCOMFORT SCALE SCORES

<table>
<thead>
<tr>
<th>Scores</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
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<td>47</td>
</tr>
<tr>
<td>1</td>
<td>22</td>
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<tr>
<td>2</td>
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<td>1</td>
</tr>
<tr>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>11</td>
<td>1</td>
</tr>
</tbody>
</table>
RELATIONSHIP AMONG SCALES

The scales described above are designed to measure different dimensions of nursing home residents' conditions. Thus, for example, the questionnaire avoids asking about activities that a majority of the residents are physically unable to do. Similarly, the questions are phrased in simple language to avoid penalizing residents with low cognitive abilities.

Table 13 displays correlations among the scale scores. With certain exceptions, there are positive correlations among most of the scales. Two exceptions are the negative correlations of MSQ with satisfaction and overall affect. Because high scores on the pain and discomfort scale imply frequent pain and discomfort, the large negative correlation between affect and pain and discomfort might be expected.

SCALE AND ITEM RELIABILITY

Data collected during the early summer of 1981 indicate that the efforts described in Secs. II and III to revise the questionnaire have improved reliability. A vital step in the evolution of the questionnaire was the collection of reliability data during the 1980 pretest. The results at that time suggested several changes. These included: rewording many questions and response categories, eliminating unreliable or repetitious items to shorten the interview, and standardizing interviewing techniques.

Test/retest data for the revised questionnaire were collected on 111 residents at four nursing homes not previously in the study. To
Table 13
CORRELATIONS OF SCALE SCORES

<table>
<thead>
<tr>
<th></th>
<th>MSQ</th>
<th>COG</th>
<th>SAT</th>
<th>AFF1</th>
<th>AFF2</th>
<th>INSDE</th>
<th>COMB</th>
<th>SOC</th>
<th>ADL</th>
<th>PAIN</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSQ</td>
<td>1.00</td>
<td>.88</td>
<td>-.21</td>
<td>-.11</td>
<td>.01</td>
<td>.27</td>
<td>.25</td>
<td>.42</td>
<td>.20</td>
<td>.19</td>
</tr>
<tr>
<td>COGNIT</td>
<td>.88</td>
<td>1.00</td>
<td>-.10</td>
<td>.00</td>
<td>-.02</td>
<td>.27</td>
<td>.23</td>
<td>.38</td>
<td>.28</td>
<td>.09</td>
</tr>
<tr>
<td>SATIS</td>
<td>-.21</td>
<td>-.10</td>
<td>1.00</td>
<td>.49</td>
<td>.21</td>
<td>.25</td>
<td>.25</td>
<td>.08</td>
<td>.14</td>
<td>-.19</td>
</tr>
<tr>
<td>AFFECT1</td>
<td>-.11</td>
<td>.00</td>
<td>.49</td>
<td>1.00</td>
<td>-.01</td>
<td>.29</td>
<td>.28</td>
<td>.12</td>
<td>.05</td>
<td>-.50</td>
</tr>
<tr>
<td>AFFECT2</td>
<td>.01</td>
<td>-.02</td>
<td>.21</td>
<td>-.01</td>
<td>1.00</td>
<td>.29</td>
<td>.29</td>
<td>.36</td>
<td>.14</td>
<td>.26</td>
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<tr>
<td>INSIDE</td>
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<td>.27</td>
<td>.25</td>
<td>.29</td>
<td>.29</td>
<td>1.00</td>
<td>.96</td>
<td>.46</td>
<td>.16</td>
<td>.04</td>
</tr>
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<td>COMBINE</td>
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<td>.23</td>
<td>.25</td>
<td>.28</td>
<td>.29</td>
<td>.96</td>
<td>1.00</td>
<td>.46</td>
<td>.19</td>
<td>.03</td>
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<tr>
<td>SOCIAL</td>
<td>.42</td>
<td>.38</td>
<td>.08</td>
<td>.12</td>
<td>.36</td>
<td>.46</td>
<td>.46</td>
<td>1.00</td>
<td>.10</td>
<td>.15</td>
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<tr>
<td>ADL</td>
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<td>.26</td>
<td>.04</td>
<td>.03</td>
<td>.15</td>
<td>.03</td>
<td>1.00</td>
</tr>
</tbody>
</table>

*aStandard errors of the correlations are approximately 0.08 or less.*
minimize respondent burden, only one-half the questionnaire was administered to most of these residents (although seven did receive the entire questionnaire). Two to five days later, another interviewer readministered the same half of the questionnaire. These data provided up to 60 pairs of responses for each item. Because of the number of items in the questionnaire and the general memory deficiencies of this population, we judge that the residents are unlikely to remember more than isolated responses over the time between interviews.

The residents in the reliability sample exhibited significantly higher cognitive functioning than those in the regular sample. This was apparent both in higher scores on the cognitive items and in their ability to complete half the questionnaire. (Scores on other domains seemed to be comparable.) To the extent that good reliability is associated with cognitive functioning, these results may overestimate the reliability of the questionnaire in the full nursing home population.

The type of reliability reported here, inter-interviewer reliability over a few days, is a more stringent criterion than either intra-interviewer or inter-rater (same interview, different coders) reliabilities. The distinction is important because our reliability measure includes variation from several sources: questioning or probing styles, assessment of responses and demonstrations, short term fluctuation in resident attitudes and abilities, and randomness in resident responses. Including short-term fluctuation is important because responses that change from day to day do not provide reliable information about long-term progress. The reliability coefficient
equals the proportion of variance in scores that is due to difference between residents rather than the other sources of variation mentioned above.

**Empirical Results**

Table 14 contains reliability (Pearson correlation) coefficients for the scales described in the previous sections. An additional column shows the range of observed coefficients for the items forming each scale. The standard errors for the scale reliabilities are approximately 0.10.

Because the scales combine information from related items, their reliabilities are consistently higher than those for the individual items. Most of these scale reliability coefficients exceed 0.80. The exceptions are the social activity and interaction scales and the second affect factor, which is not intended to be an outcome measure. The reliability coefficients are generally higher than those obtained in the pretest for similar scales.

The reliability coefficients for individual items can help us spot potentially poor questions if, for example, an item's reliability is substantially lower than that of others in the domain. With a few exceptions, the results are consistent with the hypothesis that all individual item reliabilities are approximately 0.60.

**NEXT STEPS**

The gratifying results on the reliability of the revised questionnaire have allowed us to move forward with the project. Several waves of data on individual nursing home residents have now been collected.
Table 14

RELIABILITY COEFFICIENTS FOR SCALES AND ITEMS FORMING SCALES

<table>
<thead>
<tr>
<th>Scale</th>
<th>Reliability</th>
<th>Range for Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>0.84</td>
<td>0.53 to 0.89&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>MSQ</td>
<td>0.89</td>
<td>0.46 to 0.83&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>0.88</td>
<td>0.31 to 0.80&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Affect (factor 1)</td>
<td>0.85</td>
<td>0.40 to 0.78</td>
</tr>
<tr>
<td>Affect (factor 2)</td>
<td>0.62</td>
<td>--</td>
</tr>
<tr>
<td>Inside Activities</td>
<td>0.70</td>
<td>0.54 to 0.76&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Social Interaction</td>
<td>0.59</td>
<td>0.30 to 0.71</td>
</tr>
<tr>
<td>ADL</td>
<td>0.80</td>
<td>0.52 to 0.74</td>
</tr>
<tr>
<td>Pain and Discomfort</td>
<td>0.82</td>
<td>0.54 to 0.80</td>
</tr>
</tbody>
</table>

<sup>a</sup>The observed reliability for telling time correctly was only 0.08.

<sup>b</sup>The reliability for one satisfaction item was only 0.09.

<sup>c</sup>The reliability for the item measuring the frequency of attending parties was only 0.23.
Preliminary modeling results from the first two waves of data suggest that the original goal of developing a predictive model is indeed feasible.

We have trained a new generation of data collectors, thereby establishing the transferability of this aspect of the project. We have been especially gratified to note that many of the nursing home patients in our study greet the interviewers warmly on their return for a new round of data collection. For them, the data collection is not an imposition but an opportunity to converse.

We have elected to continue our efforts to gather data from as many respondents as possible, despite communication barriers. We have created a large-type version of our questions for the visually impaired. With as complete a range of respondents as possible, we will then be in a position to analyze the results to determine which limitations make the data unusable; at that point, we will offer empirically derived decision rules on who should be excluded from future attempts to collect such data. Except for a very few limited respondents, the data collection time is within our initial goal of one hour; often it is considerably less. Some patients tire easily and must be covered in more than one session.

The next phase of our work will emphasize three areas: (1) improving the accuracy of the prediction equations, including a comparison of interviewer predictions with those of our regression models, (2) assessing value preferences of several respondent groups to develop utility weights for the several outcome measures, and (3) simulating the effect of our reimbursement system on nursing home performance. Future Notes will describe our progress in these areas.
ASSESSMENT INSTRUMENT

QUESTIONNAIRE 6

1. PATIENT IDENTIFICATION

2. WAVE NUMBER

3. TRIAL DATE

4. INTERVIEWER NUMBER

THE FOLLOWING INFORMATION SHOULD BE GATHERED FROM THE PATIENT'S RECORD. QUESTIONS 5-14 ARE GATHERED ONLY AT THE FIRST TRIAL. FOR SUBSEQUENT TRIALS, SKIP TO QUESTION 15.

5. DATE OF MOST RECENT ADMISSION TO FACILITY

6. DATE OF FIRST ADMISSION TO FACILITY

7. BIRTHDATE

8. SEX

MALE

FEMALE

1 46/

2
9. ETHNIC BACKGROUND

WHITE (NON-HISPANIC) ............... 1 47/
BLACK .................................. 2
HISPANIC .............................. 3
ASIAN .................................. 4
INDIAN OR OTHER AMERICAN NATIVE .. 5
OTHER (SPECIFY) ...................... 6
MISSING DATA .......................... M

10. MARITAL STATUS:

NEVER MARRIED .......................... 1 48/
MARRIED .................................. 2
WIDOWED ................................. 3
DIVORCED ................................. 4
LEGALLY SEPARATED ...................... 5
MISSING DATA ........................... M

11. LEGAL STATUS

LEGALLY COMPETENT ..................... 1 49/
GUARDIAN ................................. 2
MISSING DATA ........................... M

12. SOURCE OF PAYMENT
(CIRCLE ALL THAT APPLY)

PRIVATE FUNDS .......................... 1 50/
MEDICARE ............................... 1 51/
MEDI-CAL ............................... 1 52/
OTHER (SPECIFY) ....................... 1 53/
13. PATIENT ADMITTED FROM:

OWN HOME............................. (GO TO Q15) ... 1
HOME OF RELATIVE/FRIEND........... (GO TO Q15) ... 2
BOARD & CARE FACILITY.............. (GO TO Q15) ... 3
LODGING/HOTEL.......................... (GO TO Q15) ... 4
OTHER NURSING HOME............... (GO TO Q15) ... 5
REHABILITATION HOSPITAL............. (GO TO Q15) ... 6
MENTAL HOSPITAL...................... (GO TO Q15) ... 7
ACUTE HOSPITAL....................... (GO TO Q14) ... 8
OTHER (SPECIFY)____________________ (GO TO Q15) ... 9
MISSING DATA........................... (GO TO Q15) ... M

14. BEFORE ENTERING ACUTE HOSPITAL, PATIENT LIVED IN:

OWN HOME............................................. 1 55/
HOME OF RELATIVE/FRIEND............... 2
BOARD AND CARE FACILITY............... 3
LODGING/HOTEL............................... 4
OTHER NURSING HOME.................... 5
SAME NURSING HOME...................... 6
REHABILITATION HOSPITAL............... 7
MENTAL HOSPITAL......................... 8
OTHER (SPECIFY)_____________________ 9
MISSING DATA................................. M
15. DIAGNOSIS:  

| A. ____________________________ | CODE: | 56-59/ |
| B. ____________________________ | 60-63/ |
| C. ____________________________ | 64-67/ |
| D. ____________________________ | 68-71/ |
| E. ____________________________ | 72-75/ |
| F. ____________________________ | 76-79/ | (CARD 0.3) |
| G. ____________________________ | 13-16/ |
| H. ____________________________ | 17-20/ |

16. CURRENT STATUS OF PATIENT:  

- ACTIVE PATIENT....(GO TO Q21)........... 1 21/
- DISCHARGED, DEAD....(GO TO Q17)........... 2
- DISCHARGED, ALIVE....(GO TO Q18)........... 3

17. DATE OF DEATH....(END OF INTERVIEW)........... [00] / [00] / [00] 22-27/

18. DISCHARGE DATE....................... [00] / [00] / [00] 28-33/

19. PLACE DISCHARGED TO:  

- HOSPITAL................................. 1 34/
- COMMUNITY............................... 2
- OTHER NURSING HOME.................... 3
- OTHER INSTITUTION...................... 4
- MISSING DATA............................ M

20. REASON FOR DISCHARGE:  

- IMPROVED CONDITION.................... 1 35/
- DETERIORATED CONDITION................ 2
- OTHER (SPECIFY)____________________ 3
- MISSING DATA............................ M
21. HOW MANY TIMES WAS THE PATIENT HOSPITALIZED IN INTERIM BETWEEN TRIALS?
   YES...(GO TO Q22) ENTER NUMBER 36/
   NONE...(GO TO Q25)......................... 0
   MISSING DATA...(GO TO Q25)................... M

22. DATE OF HOSPITAL ADMISSION.................. □□ / □□ / □□ 37-42/

23. DATE OF RETURN TO FACILITY.................. □□ / □□ / □□ 43-48/

24. REASON(S) FOR HOSPITALIZATION:
   CODE:
   A. _____________________________ 49-52/
   B. _____________________________ 53-56/

25. NOTE INDICATIONS IN THE CHART OF THE FOLLOWING CHANGES IN THE INTERIM BETWEEN TRIALS.

   A. PAYMENT STATUS:
      NO CHANGE...................... 1 57/
      CHANGE TO PRIVATE FUNDS........ 2
      CHANGE TO MEDICARE............... 3
      CHANGE TO MEDI-CAL................. 4
      OTHER.................................. 5

   B. RESPONSIBLE PERSON:
      NO CHANGE.......................... 1 58/
      CHANGE TO________________________ 2

   C. LEGAL STATUS:
      NO CHANGE............................ 1 59/
      CHANGE TO GUARDIANSHIP.............. 2

   D. OTHER (TRAUMA):
      NONE.................................... 1 60/
      SPECIFY__________________________ 2
BEFORE STARTING INTERVIEW, OBTAIN RESIDENT'Sambulation STATUS FROM STAFF.

INTERVIEW

26. TIME OF INTERVIEW..........................10/10 61-64/

27. OBSERVED CONSCIOUSNESS LEVEL

<table>
<thead>
<tr>
<th>TEST:</th>
<th>ALERT.......................... 1 65/</th>
</tr>
</thead>
<tbody>
<tr>
<td>[A] GREETING OR</td>
<td>Semi-Alert.......................... 2</td>
</tr>
<tr>
<td>[B] TOUCH ARM OR</td>
<td>Comatose.......................... 3</td>
</tr>
<tr>
<td>[C] PINCH UPPER TRUNK</td>
<td></td>
</tr>
</tbody>
</table>

Now I'd like to start the interview.

28. What is the date today including the day, month and year? _______________________

| IF ONLY DAY, MONTH, OR YEAR IS GIVEN, PROBE FOR MISSING DATA | CORRECT DAY, MONTH, AND YEAR.......................... 1 66/ |
|---------------------------------------------------------------|
| INCORRECT IN ANY ONE CATEGORY................................. 2 |
| INCORRECT IN ANY TWO CATEGORIES.............................. 3 |
| INCORRECT IN ALL THREE CATEGORIES/IDK......................... 4 |
| NR.................................................... 9 |

29. What day of the week is it? _______________________

| CORRECT DAY........................................ 1 67/ |
| INCORRECT ANSWER/IDK.................................. 2 |
| NR.................................................... 9 |

IF THIS IS THE FIRST TRIAL, CONTINUE. IF NOT, GO TO Q36.
Since this is the first time we've met, I'd like to ask you a few questions about your family background before you came here.

30. Are you married, widowed, divorced, or have you never been married?

- MARRIED (ASK Q31) 1 68/
- DIVORCED, WIDOWED, SEPARATED (GO TO Q31) 2
- NEVER MARRIED (GO TO Q32) 3
- IDK (GO TO Q31) 8
- NR (GO TO Q31) 9

31. How many living children do you have? 69-70/

32. How many living brothers and/or sisters do you have? 71-72/

33. I'd like to know about your education. Did you finish grammar school?
   IF YES: Did you finish high school?
   IF YES: Did you finish college?

- NO FORMAL EDUCATION 0 73/
- GRAMMAR SCHOOL 1
- HIGH SCHOOL 2
- COLLEGE 3
- IDK 8
- NR 9
34. Who would you say actually made the decision for you to come to this nursing home, yourself or others?

<table>
<thead>
<tr>
<th>Option</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>SELF (OR SELF &amp; OTHERS)</td>
<td>1</td>
</tr>
<tr>
<td>OTHERS</td>
<td>2</td>
</tr>
<tr>
<td>IDK</td>
<td>8</td>
</tr>
<tr>
<td>NR</td>
<td>9</td>
</tr>
</tbody>
</table>

35. I'm interested in knowing how much you wanted to come to this nursing home. Would you say you wanted to come here a lot, a little, or not at all?

<table>
<thead>
<tr>
<th>Option</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>A LOT</td>
<td>1</td>
</tr>
<tr>
<td>A LITTLE (OR SOMewhat)</td>
<td>2</td>
</tr>
<tr>
<td>NOT AT ALL</td>
<td>3</td>
</tr>
<tr>
<td>IDK</td>
<td>8</td>
</tr>
<tr>
<td>NR</td>
<td>9</td>
</tr>
</tbody>
</table>

I'm going to ask you some questions about your health.

36. How would you rate your overall health at the present time — excellent, good, fair or poor?

<table>
<thead>
<tr>
<th>Option</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXCELLENT</td>
<td>1</td>
</tr>
<tr>
<td>GOOD</td>
<td>2</td>
</tr>
<tr>
<td>FAIR</td>
<td>3</td>
</tr>
<tr>
<td>POOR</td>
<td>4</td>
</tr>
<tr>
<td>IDK</td>
<td>8</td>
</tr>
<tr>
<td>NR</td>
<td>9</td>
</tr>
</tbody>
</table>
37. At the present time, is your health better, about the same, or worse than it was 1 month ago?

    BETTER.............................................. 1 77/
    THE SAME........................................... 2
    WORSE.............................................. 3
    IDK.................................................. 8
    NR.................................................. 9

38. During the past month, how much of the time did your health problems stop you from doing the things you wanted to do: most of the time, some of the time, very little of the time or none of the time?

    MOST OF THE TIME................................. 1 78/
    SOME OF THE TIME................................ 2
    VERY LITTLE OF THE TIME....................... 3
    NONE OF THE TIME................................ 4
    IDK.................................................. 8
    NR.................................................. 9
The next questions are about activities that you may have done here in the nursing home in the past month. I will read the list of activities to you. For each one, I would like you to tell me if you have done that particular activity or not.

39. During the past month, have you (A - H) ________________?

IF YES: Have you done ______ a lot, sometimes or very little?
IF NO: CODE "NOT AT ALL"

<table>
<thead>
<tr>
<th>Activity</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
<th>H</th>
</tr>
</thead>
<tbody>
<tr>
<td>Done any reading?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>9</td>
<td>13/</td>
<td></td>
</tr>
<tr>
<td>Done handiwork, e.g., knitting/sewing or arts &amp; crafts?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>9</td>
<td>14/</td>
<td></td>
</tr>
<tr>
<td>Played bingo or other games?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>9</td>
<td>15/</td>
<td></td>
</tr>
<tr>
<td>Gone to exercise class?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>9</td>
<td>16/</td>
<td></td>
</tr>
<tr>
<td>Gone to birthday parties or special concerts?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>9</td>
<td>17/</td>
<td></td>
</tr>
<tr>
<td>Spoken on telephone (made &amp; received calls)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>9</td>
<td>18/</td>
<td></td>
</tr>
<tr>
<td>Played cards?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>9</td>
<td>19/</td>
<td></td>
</tr>
<tr>
<td>Watched or listened to TV or the radio?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>9</td>
<td>20/</td>
<td></td>
</tr>
</tbody>
</table>

40. Who is President of the United States now?

CORRECT ANSWER..............(ASK Q41)............. 1 21/

INCORRECT ANSWER/IDK............(GO TO Q42)........... 2

NR..............................(GO TO Q42)............. 9
41. Who was the President just before him?

CORRECT ANSWER................................. 1 22/
INCORRECT ANSWER/IDK.......................... 2
NR.................................................. 9

42. I am going to read some numbers to you. Please listen carefully and repeat them back to me.

5 2
6 8

SECOND LINE OF EACH SET IS READ TO RESIDENT ONLY IF HE INCORRECTLY REPEATS THE FIRST LINE
6 1 7
5 9 1
7 2 8 6
6 4 3 9

4 2 7 3 1
7 5 8 3 6

6 1 9 4 7 3
3 9 2 4 8 7

5 9 1 7 4 2 3
4 1 7 9 3 8 6

5 8 1 9 2 4 7 6
3 8 2 9 5 1 7 4

ENTER HIGHEST NUMBER CORRECTLY REPEATED ON EITHER TRIAL [ ] [ ] 23-24/

STATES UNABLE.................................... 77
NR.................................................. 99
NOT ADMINISTERED (NOTE REASON)............... 88
Next, I'm going to ask you to identify some coins. I'll place each coin in your hand and you tell me what coin it is.

43. INTERVIEWER SHOULD INDIVIDUALLY PLACE EACH TYPE OF COIN (PENNY, NICKEL, DIME, QUARTER) IN RESIDENT'S HAND.

I'd like you please to tell me what this coin is?

STEP 1: Correct identification of all coins.

INTERVIEWER SHOULD RANDOMLY PLACE ALL COINS ON TABLE IN FRONT OF RESIDENT.

STEP 2: I'd like you to please tell me or show me which coins would make 7 cents?

CONTINUE WITH NEXT STEP ONLY IF RESIDENT CORRECTLY PERFORMS STEP 2.

STEP 3: I'd like you to tell me or show me which coins would make 32 cents?

STEP 4: Now, I'd like you to subtract 32 cents from a dollar and tell me or show me how much money you would have left?

5: INCORRECT PERFORMANCE OF STEP 1.

ENTER HIGHEST STEP CORRECTLY PERFORMED [____] 25/

UNABLE TO DETERMINE [____] 8

NR. [____] 9

Now, I'm going to ask you to do a subtraction task without coins. Let me give you an example. I will subtract 2 from 10 and keep subtracting 2 from each new number all the way down. 10, 8, 6, 4, 2, 0.

44. Would you subtract 3 from 20 and keep subtracting 3 from each new number all the way down?

ALL CORRECT (20, 17, 14, 11, 8, 5, 2). [____] 26/

ONLY ONE MISTAKE IN SERIES [____] 2

MORE THAN ONE MISTAKE [____] 3

UNABLE TO DETERMINE [____] 8

NR. [____] 9
45. According to this clock, what time is it?

CORRECT................................................. 1 27/
INCORRECT............................................. 2
UNABLE TO DETERMINE................................. 3
IDK....................................................... 8
NR....................................................... 9

I am going to ask you to do some tasks for me. Some of the things I ask may seem silly, too easy, or too hard, but I ask everyone to do the same things. I need to see you actually do the tasks.

CODING TERMS FOR Q46-65

1. INTACT INDEPENDENT.
2. LIMITED WITH EQUIPMENT ONLY.
3. HELPER ANOTHER PERSON NEEDED FOR SUPERVISION OR FOR PHYSICAL HELP; I.E., HALF THE TASK OR LESS.
4. UNABLE ANOTHER PERSON NEEDED TO PERFORM THE TASK; I.E., MORE THAN HALF THE TASK.
5. STATES UNABLE RESIDENT STATES HIS/HER INABILITY TO DO A TASK.
8. UNABLE TO DETERMINE CIRCUMSTANCES DO NOT ALLOW A DEMONSTRATION.
9. NO RESPONSE DOES NOT INITIATE OR RESPOND IN ANY WAY.

46. Would you write your first name on this paper as clearly as you can?

INTACT/LEGIBLE................................. 1 28/
LIMITED/ILLEGIBLE OR NEEDS PAPER HELD...... 2
UNABLE................................................. 4
STATES UNABLE........................................ 5
UNABLE TO DETERMINE............................. 8
NR....................................................... 9
47. Please pick up the spoon. (INTERVIEWER FILLS SPOON). Now, show me how you lift the spoon to your mouth without spilling the raisins.

<table>
<thead>
<tr>
<th>Intact</th>
<th>Unable</th>
<th>States Unable</th>
<th>Unable to Determine</th>
<th>NR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>29/4</td>
<td>5</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>

48. I would like to get an idea of how you prepare your food. I'm going to ask you to perform a task similar to buttering bread. Here is a knife and a piece of cardboard (PLACE KNIFE AND CARDBOARD ON TABLE IN FRONT OF RESIDENT) Please show me how you would spread butter on this piece of cardboard.

<table>
<thead>
<tr>
<th>Intact</th>
<th>Unable</th>
<th>States Unable</th>
<th>Unable to Determine</th>
<th>NR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>30/4</td>
<td>5</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>

49. Please show me how you would put on and take off this shirt. Please try to do as much as you can on your own. (If you need help, let me know.)

<table>
<thead>
<tr>
<th>Intact</th>
<th>Helper</th>
<th>Unable</th>
<th>States Unable</th>
<th>Unable to Determine</th>
<th>NR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>31/3</td>
<td>4</td>
<td>5</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>

50. Would you show me how you put on and take off one of your socks? (Please try to do as much as you can on your own. If you need help, let me know.)

<table>
<thead>
<tr>
<th>Intact</th>
<th>Helper</th>
<th>Unable</th>
<th>States Unable</th>
<th>Unable to Determine</th>
<th>NR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>32/3</td>
<td>4</td>
<td>5</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>
51. When you take a bath or shower, do you wash your chest, arms and legs without any help?

IF NO, does a nurse help you but you do some of the washing?
IF NO, does a nurse do all the washing?

INTACT (DONE BY SELF) ....................... 1 33/
HELPER (DONE BY SELF WITH HELP) .......... 3
UNABLE (DONE BY ANOTHER) .................. 4
IDK ........................................... 8
NR ........................................... 9

52. When you go to the bathroom, do you take down and pull up your underpants all by yourself?

IF NO, do you do most of the task while the nurse gives you a little help?
IF NO, do you need someone to do most of the task?

INTACT .................................... 1 34/
HELPER ..................................... 3
UNABLE ..................................... 4
UNABLE TO DETERMINE ...................... 8
NR ........................................... 9

53. During the past month, have you had any urinary accidents when you wet yourself, your bed, or your chair?

NO (INTACT) .................................... 1 35/
YES (UNABLE) .................................. 4
N/A PATIENT HAS CATHETER .................. 8
NR ........................................... 9
54. During the past month, have you had any bowel accidents when you soiled yourself, your bed or your chair?

NO (INTACT) ........................................ 1 36/
YES (UNABLE) ................................. 4
N/A PATIENT HAS OSTOMY ................. 8
NR .............................................. 9

55. DURING THE INTERVIEW PERIOD, THE INTERVIEWER NOTICED ONE OF THE FOLLOWING:

NO EVIDENCE OF INCONTINENCE ............ 1 37/
URINARY INCONTINENCE ONLY ............. 2
BOWEL INCONTINENCE ONLY ................. 3
BOTH URINARY & BOWEL INCONTINENCE .... 4
RESIDENT WEARING DIAPER ................. 5

56. WHAT IS THE HIGHEST LEVEL OF MOBILITY OBSERVED IMMEDIATELY BEFORE OR DURING THE INTERVIEW?

A. RESIDENT WALKS

INTACT .......................... 1 38/
LIMITED .......................... 2
HELPER ........................... 3

B. RESIDENT USES W/C

INTACT .......................... 4
LIMITED .......................... 5
HELPER ........................... 6

C. RESIDENT IS IN STATIONARY CHAIR ....... 7

D. RESIDENT IS IN BED ................... 8

E. OTHER...(SPECIFY__________________) .... 9
57. Are you able to walk at all?

YES...(ASK Q58)........................................... 1 39/

NO: Are you able to use a w/c?

YES...(GO TO Q.59)........................................... 2

NO, BEDRIDDEN...(GO TO Q.60)............................ 3

NO, RESIDENT IN STATIONARY CHAIR...(GO TO Q.65)... 4

NR...(GO TO Q.60)............................................. 9

58. Do you need someone to help you walk? Do you need to use a cane, walker or w/c to walk? (GO TO Q.60)

INTACT..................................................... 1 40/

LIMITED E.G., CANE................................. 2

HELPER..................................................... 3

NR......................................................... 9

59. Are you able to move your wheelchair by yourself?

INTACT..................................................... 1 41/

LIMITED (ELECTRIC).............................. 2

HELPER..................................................... 3

UNABLE................................................. 4

NR......................................................... 9
60. The goal of this question is to record the highest level of function demonstrated by the resident. However, since it is not always possible to have the most functional level demonstrated, the resident should be observed demonstrating the most appropriate function under the circumstances.

Choose A, B or C

A. Walking Demonstration:

Please walk to ___ (an object 10' away) and back.

- Intact: 1 42/
- Limited (uses equipment, supports or takes over one minute): 2
- Helper: 3
- Unable: 4

- Unable to determine: 8
- NR: 9

B. Wheelchair Demonstration:

Please go from here to ___ (an object 10' away) and back.

- Intact: 1 43/
- Limited: 2
- Helper: 3
- Unable: 4

- Unable to determine: 8
- NR: 9
C. BEDRIDDEN DEMONSTRATION:

Can you show me how you lift your head?

INTACT (i.e., CAN SEE A SPACE BETWEEN HEAD AND PILLOW) ......................... 1 44/

UNABLE ................................................. 4

STATES UNABLE ........................................ 5

UNABLE TO DETERMINE ................................. 8

NO RESPONSE ............................................ 9

Can you show me how you lift your arm(s)?

INTACT ................................................. 1 45/

UNABLE ................................................. 4

STATES UNABLE ........................................ 5

UNABLE TO DETERMINE ................................. 8

NO RESPONSE ............................................ 9

Can you show me how you roll over onto your side?

INTACT ................................................. 1 46/

LIMITED (e.g., USES BED RAILS) ..................... 2

HELPER .................................................. 3

UNABLE ................................................. 4

STATES UNABLE ........................................ 5

UNABLE TO DETERMINE ................................. 8

NO RESPONSE ............................................ 9

Can you show me how you lift your hips when using a bed pan?

INTACT (i.e., CAN SEE SPACE BETWEEN HIPS AND BED) ......................... 1 47/

UNABLE ................................................. 4

STATES UNABLE ........................................ 5

UNABLE TO DETERMINE ................................. 8

NO RESPONSE ............................................ 9
65. What kind of a place is this? Is it a school, a convalescent hospital or a store?

CORRECT........................................... 1 48/
INCORRECT/IDK................................. 2
NR.................................................. 9

66. What is the complete name of this place? ____________________________

CORRECT FORMAL NAME........................ 1 49/
INCORRECT/IDK................................. 2
NR.................................................. 9

67. What street is this place on? ____________________________

CORRECT STREET NAME......................... 1 50/
INCORRECT/IDK................................. 2
NR.................................................. 9

68. How long have you been in this nursing home? _______________________

ACCURATE........................................... 1 51/
INACCURATE...................................... 2
IDK.................................................. 8
NR.................................................. 9

69. During the past month, have you gone outside the nursing home to people's homes, to restaurants, to plays, movies, or something like that?

IF YES: Have you gone a lot, sometimes or very little?
IF NO: CODE "NEVER"

ALOT.............................................. 1 52/
SOMETIMES....................................... 2
VERY LITTLE..................................... 3
NEVER............................................ 4
N/A............................................... 8
NR.................................................. 9
70. During the past month, have you stayed overnight at someone's house:
   IF YES: Have you stayed overnight a lot, sometimes or very little?
   IF NO: CODE "NEVER"

A LOT......................................... 1
SOMETIMES................................... 2
VERY LITTLE.................................. 3
NEVER......................................... 4
N/A............................................. 8
NR.............................................. 9

71. During the past month, how often have your children or other relatives come to visit you: a lot, sometimes, very little or never?

A LOT......................................... 1
SOMETIMES................................... 2
VERY LITTLE.................................. 3
NEVER......................................... 4
IDK............................................ 8
NR.............................................. 9

72. During the past month, how often have your friends from outside the nursing home come to visit you: a lot, sometimes, very little, or never?

A LOT......................................... 1
SOMETIMES................................... 2
VERY LITTLE.................................. 3
NEVER......................................... 4
N/A............................................. 8
NR.............................................. 9

73. What was your mother's maiden name? ________________________________

CORRECT...................................... 1
INCORRECT/IDK............................... 2
UNABLE TO DETERMINE...................... 8
NR.............................................. 9
74. During the past month, how often have you sat and talked with other people who live here in the nursing home: a lot, sometimes, very little, or never?

A LOT........................................ 1 57/
SOMETIMES.................................. 2
VERY LITTLE................................ 3
NEVER....................................... 4
N/A......................................... 8
NR.......................................... 9

75. Is there any one person outside the home that you feel especially close to? Think about relatives and friends.

YES...(ASK Q76)............................ 1 58/
NO...(GO TO Q77).......................... 2
IDK...(GO TO Q77)......................... 8
NR...(GO TO Q77).......................... 9

76. During the past month, how often did you talk with this person: a lot, sometimes, very little or never?

A LOT........................................ 1 59/
SOMETIMES.................................. 2
VERY LITTLE................................ 3
NEVER....................................... 4
N/A......................................... 8
NR.......................................... 9

77. Is there anyone in this nursing home that you feel especially close to?

YES........................................... 1 60/
NO............................................. 2
IDK.......................................... 8
NR.......................................... 9
78. I am going to touch you and, each time, would you please tell me (or point to) where I touched you.

INTERVIEWER TOUCHES RESIDENT AT LOCATIONS A-J AND AT EACH LOCATION ASKS:

Where did I touch you?

IF RESIDENT ONLY NAMES 1 OF THE 2 LOCATIONS, ASK:

Did I touch you anywhere else?

| A. LEFT HAND, RIGHT CHEEK | 1 | 2 | 9 61/ |
| B. RIGHT HAND, LEFT CHEEK | 1 | 2 | 9 62/ |
| C. RIGHT HAND, RIGHT CHEEK | 1 | 2 | 9 63/ |
| D. LEFT HAND, LEFT CHEEK | 1 | 2 | 9 64/ |
| E. RIGHT CHEEK, LEFT CHEEK | 1 | 2 | 9 65/ |
| F. RIGHT CHEEK, LEFT HAND | 1 | 2 | 9 66/ |
| G. RIGHT CHEEK, LEFT HAND | 1 | 2 | 9 67/ |
| H. LEFT CHEEK, RIGHT HAND | 1 | 2 | 9 68/ |
| I. RIGHT CHEEK, RIGHT HAND | 1 | 2 | 9 69/ |
| J. LEFT CHEEK, LEFT HAND | 1 | 2 | 9 70/ |

ENTER ACTUAL READINGS FOR THE FOLLOWING

79. BLOOD PRESSURE..............................[000]/[000] 71-76/

NOTE ARM USED: RIGHT_____ / LEFT_____
I am going to listen to your chest now.

80. APICAL PULSE.......REGULAR (FOR 30 SEC. x 2).................

[Blank] 13-15/

OR

IRREGULAR (FOR 60 SEC.)..................

[Blank] 16-18/

81. RESPIRATION RATE (15 SEC. x 4)..................................

[Blank] 19-21/

82. How old are you?

CORRECT WITHIN ONE YEAR................. 1 22/

MUST REPORT YEARS OF AGE

INCORRECT AGE GIVEN/IDK .................. 2

NR.............................................. 9

83. What is your birthdate, including the day, month and year?

CORRECT DAY, MONTH, YEAR................. 1 23/

IF ONLY MONTH, DAY OR YEAR IS GIVEN, PROBE FOR MISSING DATA

INCORRECT IN ONE CATEGORY.................. 2

INCORRECT IN TWO CATEGORIES.............. 3

INCORRECT IN ALL CATEGORIES/IDK ........... 4

NR.............................................. 9

INSURE ADEQUATE LIGHTING FOR VISION TESTS

84. CAN RESIDENT IDENTIFY DIRECTION OF "E" SYMBOLS AT ARM'S LENGTH?

YES, WITH GLASSES..................... 1 24/

YES, WITHOUT GLASSES................... 2

NO, WITH GLASSES....................... 3

MUST IDENTIFY ANY 5 FIGURES ON BOTTOM LINE FOR "YES" SCORE

NO, WITHOUT GLASSES................... 4

NO, GROSS VISUAL IMPAIRMENT............. 5

UNABLE TO DETERMINE..................... 8

NOTE REASON:__________________________
85. CAN RESIDENT IDENTIFY DIRECTION OF "E" SYMBOLS AT 10 FEET?

<table>
<thead>
<tr>
<th>Option</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES, WITH GLASSES</td>
<td>1</td>
</tr>
<tr>
<td>YES, WITHOUT GLASSES</td>
<td>2</td>
</tr>
<tr>
<td>NO, WITH GLASSES</td>
<td>3</td>
</tr>
<tr>
<td>NO, WITHOUT GLASSES</td>
<td>4</td>
</tr>
<tr>
<td>NO, GROSS VISUAL IMPAIRMENT</td>
<td>5</td>
</tr>
<tr>
<td>UNABLE TO DETERMINE</td>
<td>8</td>
</tr>
</tbody>
</table>

NOTE REASON: ____________________________

86. IS HEARING AID WORN?

<table>
<thead>
<tr>
<th>Option</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>1</td>
</tr>
<tr>
<td>NO</td>
<td>2</td>
</tr>
<tr>
<td>UNABLE TO DETERMINE</td>
<td>8</td>
</tr>
</tbody>
</table>

87. THROUGHOUT THE INTERVIEW, RESIDENT HEARS ONLY WHEN INTERVIEWER SHOUTS.

<table>
<thead>
<tr>
<th>Option</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO, SHOUTING NOT NEEDED</td>
<td>1</td>
</tr>
</tbody>
</table>

IF YES, RESIDENT HEARS:

<table>
<thead>
<tr>
<th>Option</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>MOST OF WHAT THE INTERVIEWER SAYS</td>
<td>2</td>
</tr>
<tr>
<td>SOME OF WHAT THE INTERVIEWER SAYS</td>
<td>3</td>
</tr>
<tr>
<td>NONE OF WHAT THE INTERVIEWER SAYS</td>
<td>4</td>
</tr>
<tr>
<td>N/A</td>
<td>8</td>
</tr>
</tbody>
</table>

88. IS RESIDENT EMACIATED?

<table>
<thead>
<tr>
<th>Option</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>1</td>
</tr>
<tr>
<td>NO</td>
<td>2</td>
</tr>
</tbody>
</table>

89. I'd like to know about your teeth: do you have any trouble chewing?

<table>
<thead>
<tr>
<th>Option</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>1</td>
</tr>
<tr>
<td>NO</td>
<td>2</td>
</tr>
<tr>
<td>NR</td>
<td>9</td>
</tr>
</tbody>
</table>
EXAMINE FOR DECUBITI IF RESIDENT IS BEDRIDDEN OR IS A WHEELCHAIR PATIENT BUT IN BED.

EXAMINE PATIENT FOR DECUBITUS ULCERS IN THE LOCATION GIVEN. IF NONE EXIST, ASK QUESTION 91. IF DECUBITI ARE FOUND, RECORD MEASUREMENTS, COLOR AND DRAINAGE.  (Q90)

RECORD DATA FOR THE LARGEST ULCER

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>UNABLE TO DETERMINE</th>
<th>DIAMETER (IN MM.)</th>
<th>DEPTH (IN MM.)</th>
<th>COLOR (RECORD BLACK IF ANY AREA IS BLACK)</th>
<th>DRAINAGE</th>
<th>YES NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>RT. ARM</td>
<td>1 2 8</td>
<td></td>
<td></td>
<td>1 2</td>
<td>1 2</td>
<td>30-37/</td>
</tr>
<tr>
<td>RT. LEG</td>
<td>1 2 8</td>
<td></td>
<td></td>
<td>1 2</td>
<td>1 2</td>
<td>38-45/</td>
</tr>
<tr>
<td>RT. HIP</td>
<td>1 2 8</td>
<td></td>
<td></td>
<td>1 2</td>
<td>1 2</td>
<td>46-53/</td>
</tr>
<tr>
<td>LT. ARM</td>
<td>1 2 8</td>
<td></td>
<td></td>
<td>1 2</td>
<td>1 2</td>
<td>54-61/</td>
</tr>
<tr>
<td>LT. LEG</td>
<td>1 2 8</td>
<td></td>
<td></td>
<td>1 2</td>
<td>1 2</td>
<td>62-69/</td>
</tr>
<tr>
<td>LT. HIP</td>
<td>1 2 8</td>
<td></td>
<td></td>
<td>1 2</td>
<td>1 2</td>
<td>70-77/</td>
</tr>
<tr>
<td>SACRUM</td>
<td>1 2 8</td>
<td></td>
<td></td>
<td>1 2</td>
<td>1 2</td>
<td>13-20/</td>
</tr>
</tbody>
</table>

I'd like to look at your joints now.

91. IS EDEMA PRESENT?

<table>
<thead>
<tr>
<th>LOWER LEGS &amp; SACRUM MUST BE ASSESSED ACCORDING TO THE PROCEDURES</th>
<th>YES, PITTING ONLY</th>
<th>YES, PITTING, SHINY AND TAUT</th>
<th>NO</th>
<th>UNABLE TO DETERMINE</th>
<th>NOTE REASON: ____________________________</th>
</tr>
</thead>
</table>
92. IS THERE A SIGNIFICANT TEMPERATURE DIFFERENCE (TO TOUCH) BETWEEN THE RIGHT LEG & LEFT LEG (NOTE ONLY A SIGNIFICANT DIFFERENCE)?

YES, RIGHT LEG COLDER ..................... 1 22/
YES, LEFT LEG COLDER ..................... 2
NO ............................................. 3
UNABLE TO DETERMINE ..................... 8

NOTE REASON: __________________________

93. IS EITHER LOWER EXTREMIT Y CYANOTIC?

YES, ONE EXTREMITY ..................... 1 23/
YES, BOTH EXTREMIT IES ..................... 2
NO ............................................. 3
UNABLE TO DETERM I N E ..................... 8

NOTE REASON: __________________________

94. DOES EITHER EXTREMIT Y SHOW MOTTLE NG?

YES, ONE EXTREMITY ..................... 1 24/
YES, BOTH EXTREMIT I E S ..................... 2
NO ............................................. 3
UNABLE TO DETERM I N E ..................... 8

NOTE REASON: __________________________
95. ARTICULATIONS: CIRCLE THE MOST APPROPRIATE CATEGORY FOR EACH JOINT LISTED BELOW.

<table>
<thead>
<tr>
<th></th>
<th>IMMOVABLE BLOCKED</th>
<th>MAINTAINED IN FLEXED OR EXTENDED POSITION</th>
<th>PAINFUL/ DIFFICULT MVT (NOT MAINTAINED)</th>
<th>FREELY MOVABLE</th>
<th>UNABLE TO DETERMINE</th>
</tr>
</thead>
<tbody>
<tr>
<td>R HAND</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>R ELBOW</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>L HAND</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>L ELBOW</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>R HIP</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>R KNEE</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>L HIP</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>L KNEE</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

96. AMPUTATED LIMBS: CIRCLE ONE CATEGORY FOR EACH JOINT.

<table>
<thead>
<tr>
<th></th>
<th>NO</th>
<th>YES ONE</th>
<th>YES BOTH</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. BELOW SHOULDER</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>B. BELOW KNEE</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>C. ABOVE KNEE</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

97. IS THERE A TRACHEOTOMY PRESENT?

YES................................. 1 36/

NO................................. 2
The next set of questions is about pain or discomfort you may have had in the past month.

98. During the past month, have you had any (ASK A - F)?

IF YES, Did you have ______ every day?

IF NO, INTERVIEWER CODES "NOT AT ALL."

<table>
<thead>
<tr>
<th></th>
<th>LESS EVERY THAN</th>
<th>NOT AT</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DAY</td>
<td>DAILY</td>
<td>ALL</td>
<td>IDK</td>
<td>NR</td>
<td></td>
</tr>
<tr>
<td>A. Aches/pains in joints or muscles</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
<td>9</td>
<td>37/</td>
</tr>
<tr>
<td>B. Chest pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
<td>9</td>
<td>38/</td>
</tr>
<tr>
<td>C. Shortness of breath</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
<td>9</td>
<td>39/</td>
</tr>
<tr>
<td>D. Dizziness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
<td>9</td>
<td>40/</td>
</tr>
<tr>
<td>E. Itching/burning</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
<td>9</td>
<td>41/</td>
</tr>
<tr>
<td>F. Headaches</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
<td>9</td>
<td>42/</td>
</tr>
</tbody>
</table>

99. During the past month, have you had any severe pain?
IF YES, have you had severe pain most of the time, some of the time, or very little of the time?

MOST OF THE TIME.......................... 1 43/
SOME OF THE TIME.......................... 2
VERY LITTLE OF THE TIME.................. 3
NONE OF THE TIME.......................... 4
IDK........................................... 8
NR............................................. 9
For the next set of questions, please think about how you have felt in general during the past month. When you answer the questions, please choose one of the following answers: most of the time, some of the time, very little of the time or none of the time. Here is a card that will remind you of the categories.

100. During the past month, how much of the time have you been bothered by your nerves: most of the time, some of the time, very little of the time, or none of the time?

   MOST OF THE TIME.................... 1 44/
   SOME OF THE TIME.................... 2
   VERY LITTLE OF THE TIME............. 3
   NONE OF THE TIME.................... 4
   IDK..................................... 8
   NR..................................... 9

101. During the past month, how much of the time have you felt happy: most of the time, some of the time, very little of the time or none of the time?

   MOST OF THE TIME.................... 1 45/
   SOME OF THE TIME.................... 2
   VERY LITTLE OF THE TIME............. 3
   NONE OF THE TIME.................... 4
   IDK..................................... 8
   NR..................................... 9

102. During the past month, how much of the time have you felt that your life was interesting: most of the time, some of the time, very little of the time or none of the time?

   MOST OF THE TIME.................... 1 46/
   SOME OF THE TIME.................... 2
   VERY LITTLE OF THE TIME............. 3
   NONE OF THE TIME.................... 4
   IDK..................................... 8
   NR..................................... 9
103. During the past month, how much of the time did you wake up fresh and rested in the morning: most of the time, some of the time, very little of the time or none of the time?

MOST OF THE TIME.............................. 1 47/

SOME OF THE TIME............................. 2

VERY LITTLE OF THE TIME..................... 3

NONE OF THE TIME.............................. 4

IDK............................................... 8

NR................................................ 9

104. During the past month, how much of the time have you felt sad: most of the time, some of the time, very little of the time or none of the time?

MOST OF THE TIME.............................. 1 48/

SOME OF THE TIME............................. 2

VERY LITTLE OF THE TIME..................... 3

NONE OF THE TIME.............................. 4

IDK............................................... 8

NR................................................ 9

105. During the past month, how much of the time have you had something to look forward to: most of the time, some of the time, very little of the time or none of the time?

MOST OF THE TIME.............................. 1 49/

SOME OF THE TIME............................. 2

VERY LITTLE OF THE TIME..................... 3

NONE OF THE TIME.............................. 4

IDK............................................... 8

NR................................................ 9
106. During the past month, how much of the time have you felt depressed: most of the time, some of the time, very little of the time or none of the time?

MOST OF THE TIME.......................... 1  50/
SOME OF THE TIME.......................... 2
VERY LITTLE OF THE TIME.................. 3
NONE OF THE TIME.......................... 4
IDK......................................... 8
NR........................................... 9

107. During the past month, how much of the time have you been worried: most of the time, some of the time, very little of the time or none of the time?

MOST OF THE TIME.......................... 1  51/
SOME OF THE TIME.......................... 2
VERY LITTLE OF THE TIME.................. 3
NONE OF THE TIME.......................... 4
IDK......................................... 8
NR........................................... 9

108. During the past month, how much of the time have you felt cheerful: most of the time, some of the time, very little of the time or none of the time?

MOST OF THE TIME.......................... 1  52/
SOME OF THE TIME.......................... 2
VERY LITTLE OF THE TIME.................. 3
NONE OF THE TIME.......................... 4
IDK......................................... 8
NR........................................... 9
109. During the past month, how much of the time have you felt tense or on edge: most of the time, some of the time, very little of the time or none of the time?

MOST OF THE TIME.......................... 1 93/
SOME OF THE TIME.......................... 2
VERY LITTLE OF THE TIME..................... 3
NONE OF THE TIME.......................... 4
IDK........................................... 8
NR.............................................. 9

110. During the past month, have you thought about killing yourself? IF YES, how much of the time: most of the time, some of the time, or very little of the time?

MOST OF THE TIME.......................... 1 94/
SOME OF THE TIME.......................... 2
VERY LITTLE OF THE TIME..................... 3
NONE OF THE TIME.......................... 4
IDK........................................... 8
NR.............................................. 9

111. During the past month, how much of the time have you felt lonely: most of the time, some of the time, very little of the time or none of the time?

MOST OF THE TIME.......................... 1 95/
SOME OF THE TIME.......................... 2
VERY LITTLE OF THE TIME..................... 3
NONE OF THE TIME.......................... 4
IDK........................................... 8
NR.............................................. 9

112. Could you tell me once again:

What was your mother's maiden name? ________________________________
113. For the next questions, I'm interested in knowing your impressions about this nursing home. There are no right or wrong answers to the questions. I would just like to know your feelings. I am going to read some statements and I want to know if you agree or disagree.

<table>
<thead>
<tr>
<th>WRITE IN THE RESPONSES VERBATIM THAT YOU DO NOT KNOW HOW TO CODE</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th></th>
<th>AGREE/</th>
<th>DISAGREE/</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CONTRA-</td>
<td>CONTRA-</td>
</tr>
<tr>
<td></td>
<td>STATEMENT</td>
<td>STATEMENT</td>
</tr>
<tr>
<td></td>
<td>AGREE (YES)</td>
<td>AGREE (NO)</td>
</tr>
<tr>
<td></td>
<td>NEUTRAL</td>
<td>IDK</td>
</tr>
<tr>
<td>A. The food is good here.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>B. Your room and surroundings are clean.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>C. You can keep as many personal possessions in your room as you like.</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>D. You can see a doctor as often as you need to.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>E. The nurses and aides care about you.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>F. At night you have a choice of going to bed when you want.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>G. The amount of noise here bothers you.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>AGREE/CONTRA-</td>
<td>AGREE</td>
</tr>
<tr>
<td>-----</td>
<td>---------------</td>
<td>--------</td>
</tr>
<tr>
<td></td>
<td>AGREE/CONTRA-</td>
<td>(YES)</td>
</tr>
<tr>
<td></td>
<td>AGREE/CONTRA-</td>
<td>DICTORY</td>
</tr>
<tr>
<td></td>
<td>AGREE/CONTRA-</td>
<td></td>
</tr>
<tr>
<td></td>
<td>AGREE/CONTRA-</td>
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</tr>
<tr>
<td></td>
<td>AGREE/CONTRA-</td>
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</tr>
<tr>
<td></td>
<td>AGREE/CONTRA-</td>
<td></td>
</tr>
<tr>
<td>H.</td>
<td>When you need help, someone will come within a reasonable time.</td>
<td>1  5  2</td>
</tr>
<tr>
<td>I.</td>
<td>You have enough privacy here.</td>
<td>1  5  2</td>
</tr>
<tr>
<td>J.</td>
<td>This is a cheerful place.</td>
<td>1  5  2</td>
</tr>
<tr>
<td>K.</td>
<td>When you have a complaint, something is done about it.</td>
<td>1  5  2</td>
</tr>
<tr>
<td>L.</td>
<td>Life is boring here.</td>
<td>1  5  2</td>
</tr>
<tr>
<td>M.</td>
<td>Some of your personal belongings have disappeared from your room.</td>
<td>1  5  2</td>
</tr>
<tr>
<td>N.</td>
<td>The staff show a personal interest in you.</td>
<td>1  5  2</td>
</tr>
</tbody>
</table>
114. Summing it all up, how much of the time do you like living here: most of the time, some of the time, very little of the time or none of the time?

- MOST OF THE TIME: 1 70/
- SOME OF THE TIME: 2
- VERY LITTLE OF THE TIME: 3
- NONE OF THE TIME: 4
- IDK: 8
- NR: 9

115. RATING OF CONFIDENCE IN THE DATA

<table>
<thead>
<tr>
<th>AREA RATED</th>
<th>COMPLETE CONFIDENCE</th>
<th>SOME CONFIDENCE</th>
<th>NO CONFIDENCE</th>
<th>N/A</th>
</tr>
</thead>
</table>
| A. ACTIVITIES (IF 2 or 3, CODE Q116A) | 1                   | 2              | 3            | 8   | 71/
| B. ADL (IF 2 or 3, CODE Q116B)      | 1                   | 2              | 3            | 8   | 72/
| C. SOCIAL INTERACTION (IF 2 or 3, CODE Q116C & 117; IF 8, CODE Q117) | 1                   | 2              | 3            | 8   | 73/
| D. FACE-HAND (IF 2 or 3, CODE Q116D) | 1                   | 2              | 3            | 8   | 74/
| E. PAIN (IF 2 or 3, CODE Q116E & 120; IF 8, CODE Q120) | 1                   | 2              | 3            | 8   | 75/
| F. AFFECT (IF 2 or 3, CODE Q116F, 118 & 119; IF 8, CODE Q118 & 119) | 1                   | 2              | 3            | 8   | 76/
| G. SATISFACTION (IF 2 or 3, CODE Q116G) | 1                   | 2              | 3            | 8   | 77/
116. REASONS FOR LACK OF CONFIDENCE (CIRCLE ALL THAT APPLY).

<table>
<thead>
<tr>
<th>AREA RATED</th>
<th>Hearing impaired</th>
<th>Speech impaired</th>
<th>Language impaired</th>
<th>Little comprehension</th>
<th>Deterioration</th>
<th>Memory deficit</th>
<th>Afflict does not want categories given</th>
<th>Other problems resident chooses from categories</th>
<th>Confusing information</th>
<th>Other (specifically)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. ACTIVITIES</td>
<td>01 02 03 04 05 06 07 08 09 10 11</td>
<td>13-23/</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. ADL</td>
<td>01 02 03 04 05 06 07 08 09 10 11</td>
<td>24-34/</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. SOCIAL</td>
<td>01 02 03 04 05 06 07 08 09 10 11</td>
<td>35-45/</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D. FACE-HAND</td>
<td>01 02 03 04 05 06 07 08 09 10 11</td>
<td>46-56/</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E. PAIN</td>
<td>01 02 03 04 05 06 07 08 09 10 11</td>
<td>57-67/</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F. AFFECT</td>
<td>01 02 03 04 05 06 07 08 09 10 11</td>
<td>68-78/</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>G. SATISFACTION</td>
<td>01 02 03 04 05 06 07 08 09 10 11</td>
<td>13-23/</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PROXY OBSERVATIONS**

117. COMMUNICATION:

- TERSE........................................... 1 24/
- NORMAL........................................ 2
- GARRULOUS.................................... 3
- N/A.............................................. 8

118. DEPRESSION:

- DEPRESSED (DEJECTION, DESPONDENCY, INERTIA, HOPELESSNESS).............. 1 25/
- NOT NOTABLE............................... 2
- HAPPY (CHEERFUL, OPTIMISTIC, HOPEFUL)...... 3
- N/A.............................................. 8
119. ANXIETY:
ANXIOUS (PHYSICAL TENSION, FEAR, WORRY ANXIOUS FACIES, APPREHENSION) .......... 1 26/
NOT NOTABLE .................................. 2
N/A ............................................. 8

120. PHYSICAL DISTRESS (PAIN,WINCING, COMPLAINTS OF ACHES, DISCOMFORT):
SEVERE ........................................ 1 27/
MODERATE OR MILD ............................ 2
NONE ............................................. 3
N/A ............................................. 8

GENERAL OBSERVATIONS FOR ALL RESIDENTS

121. SHORTNESS OF BREATH (LABORED, DYSPNEIC):
AT REST ....................................... 1 28/
DURING TASK ................................... 2
NONE ............................................. 3
N/A ............................................. 8

122. ENERGY:
LISTLESS ...................................... 1 29/
PERFORMS WITH EFFORT ....................... 2
ADEQUATE ENERGY .............................. 3
N/A ............................................. 8

123. GROOMING (CLEANLINESS, CLOTHING, HAIR, SKIN):
UNKEMPT .................................... 1 30/
PRESENTABLE ................................... 2
FASTIDIOUS .................................... 3
N/A ............................................. 8
124. ATTITUDE TOWARD FUTURE:

WITHOUT ANY HOPE (BLEAK) ........................................ 1 31/
DISCOURAGED .................................................. 2
NEUTRAL ....................................................... 3
LOOKING FORWARD (POSITIVE, HOPEFUL) ....................... 4
N/A .......................................................... 8

125. ATTITUDE TOWARD PRESENT CIRCUMSTANCES (NURSING HOME, AGE, ILLNESS, ISOLATION, ETC):

NEGATIVE (ANGRY, HOPELESS, GRIEVING, COMPLAINING). 1 32/
NEUTRAL (RESIGNED, ACCEPTING) ............................... 2
POSITIVE (HOPEFUL, HAPPY WITH CIRCUMSTANCES) ........ 3
N/A .......................................................... 8

126. PASSIVITY:

PASSIVE (COMPLAINS OF CIRCUMSTANCES BUT DOES NOT ACT: AGREES TO PERFORM INTERVIEW OR TASKS, BUT OBVIOUSLY DOES NOT WANT TO) ............. 1 33/
NOT NOTABLE .................................................. 2
ASSERTIVE (STATES PROBLEM AND TAKES ACTION;
STATES PREFERENCES CLEARLY; INITIATES DISCUSSION OF PREFERENCES) ................................. 3
N/A ........................................................ 8

127. ABSTRACT THOUGHT (DEMONSTRATION OF ANY OF THE FOLLOWING:
PHILOSOPHICAL THOUGHT, ABILITY TO GENERALIZE FROM SPECIFICS TO GENERAL CONCEPTS):

ABSENT .................................................. 1 34/
PRESENT .................................................. 2
N/A ........................................................ 8
128. ANGER:

<table>
<thead>
<tr>
<th></th>
<th>INTENSE ANGER (HOSTILITY, RAGE)</th>
<th>GRUMBLING (IRRITATION, FRUSTRATION)</th>
<th>NO ANGER</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOWARD SELF AND/OR ILLNESS</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>TOWARD NH OR STAFF</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>TOWARD FAMILY/FRIENDS</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>TOWARD OTHER THAN THOSE LISTED</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
</tbody>
</table>

129. SHOWS INTEREST IN:

- SELF, ILLNESS ......................... 1 39/
- FRIENDS, FAMILY, INTERVIEWER .......... 2
- COMMUNITY AFFAIRS, POLITICS, PROJECT .. 3
- N/A ...................................... 8

130. INITIATES HUMOR (JOKES, PUNS):

- ABSENT .................................. 1 40/
- PRESENT .................................. 2
- N/A ...................................... 8
131. AFFECT/MOOD: DID RESIDENT DEMONSTRATE ANY OF THE FOLLOWING?

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. INAPPROPRIATE BEHAVIOR (SMILES WHEN RELATING UNPLEASANT EXPERIENCE, NOT WHEN RELATING PLEASANT ONE)</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>B. UNPLEASANTNESS (SARCASTIC, HOSTILE, SCOWLING)</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>C. DULL, BLunted AFFECT (RESPONDS PARTIALLY OR NOT AT ALL WITH LITTLE OR NO INTEREST: APPEARS DISTANT: NOT RECEPTIVE OR RESPONSIVE)</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>D. LABILITY (SUDDEn CRYING, LAUGHING, ETC.)</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>E. EUPHORIA</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
</tbody>
</table>

132. HOW MUCH OF THE TIME DID THE RESIDENT ACT ANNOYED, HOSTILE OR SARCASTIC WHEN QUESTIONED?

- MOST OF THE TIME: 1
- SOME OF THE TIME: 2
- VERY LITTLE OF THE TIME: 3
- NONE OF THE TIME: 4
- N/A: 8

133. HOW MUCH OF THE TIME DID THE RESIDENT MAKE THE FOLLOWING TYPES OF STATEMENT DURING THE INTERVIEW: "I AM WAITING TO DIE," OR "I HAVE NOTHING TO LIVE FOR."

- MOST OF THE TIME: 1
- SOME OF THE TIME: 2
- VERY LITTLE OF THE TIME: 3
- NONE OF THE TIME: 4
- N/A: 8
134. How much of the time did the resident demonstrate any one of the following: drumming (fiddling) with objects, wringing hands or difficulty sitting still?

- Most of the time ..................... 1
- Some of the time .................... 2
- Very little of the time ............. 3
- None of the time .................... 4
- N/A ...................................... 8

135. How much of the time did the resident have a short attention span?

- Most of the time ..................... 1
- Some of the time .................... 2
- Very little of the time ............. 3
- None of the time .................... 4
- N/A ...................................... 8

136. How much of the time did the resident refer to the NH, interviewer or family inappropriately?

- Most of the time ..................... 1
- Some of the time .................... 2
- Very little of the time ............. 3
- None of the time .................... 4
- N/A ...................................... 8

137. Did the resident demonstrate suspicious behavior?

- Yes, very suspicious (intense suspicion or incidents) ............ 1
- Yes, somewhat suspicious ................ 2
- No, not at all suspicious ............... 3
- N/A ...................................... 8
138. How much of the time did the resident communicate understandably?

- Most of the time .................. 1  52/
- Some of the time .................. 2
- Very little of the time ............. 3
- None of the time .................. 4
- N/A .................................. 8

139. How much of the time did the resident communicate verbally?

- Most of the time .................. 1  53/
- Some of the time .................. 2
- Very little of the time ............. 3
- None of the time .................. 4
- N/A .................................. 8

140. How much of the time did the resident communicate non-verbally?

- Most of the time .................. 1  54/
- Some of the time .................. 2
- Very little of the time ............. 3
- None of the time .................. 4
- N/A .................................. 8

141. Privacy of interview:

- Private (No one present) ........... 1  55/
- Semi-private (In company of others but some degree of privacy available, e.g., in a hallway) ................. 2
- Not private (In company of others and no privacy available) ..................... 3
- N/A .................................. 8
<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>142. COGNITIVE STATUS</td>
<td>WILL IMPROVE</td>
<td>1</td>
<td>56/</td>
</tr>
<tr>
<td></td>
<td>STAY THE SAME</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>WILL DECLINE</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NOTE</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>REASON</td>
<td></td>
<td></td>
</tr>
<tr>
<td>143. AFFECTIVE STATUS</td>
<td>WILL IMPROVE</td>
<td>1</td>
<td>57/</td>
</tr>
<tr>
<td></td>
<td>STAY THE SAME</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>WILL DECLINE</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NOTE</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>REASON</td>
<td></td>
<td></td>
</tr>
<tr>
<td>144. SOCIAL STATUS</td>
<td>WILL IMPROVE</td>
<td>1</td>
<td>58/</td>
</tr>
<tr>
<td></td>
<td>STAY THE SAME</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>WILL DECLINE</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NOTE</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>REASON</td>
<td></td>
<td></td>
</tr>
<tr>
<td>145. MEDICAL STATUS</td>
<td>WILL IMPROVE</td>
<td>1</td>
<td>59/</td>
</tr>
<tr>
<td></td>
<td>STAY THE SAME</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>WILL DECLINE</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NOTE</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>REASON</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
146. FUNCTIONAL STATUS (ADL)

WILL IMPROVE.......................... 1
STAY THE SAME......................... 2
WILL DECLINE........................... 3

NOTE
REASON

147. IF INTERVIEW NOT COMPLETED OR NOT DONE, NOTE REASON:

RESIDENT'S ILLNESS (GO TO Q.149)........ 1
RESIDENT'S FATIGUE (GO TO Q.149)........ 2
RESIDENT'S UNCOOPERATIVENESS
(SKIP TO Q.149)......................... 3
UNIT (WARD) DEMANDS (GO TO Q.149)....... 4
UNSATISFACTORY INTERVIEW CONDITIONS
(GO TO Q.149)............................ 5

RESIDENT INSULTED BY QUESTION(S)
(GO TO Q.149)............................ 8
OTHER (SPECIFY) (GO TO Q.149).......... 6
INTERVIEW WAS COMPLETED (ASK TO Q.148)... 7

148. RECORD NUMBER OF TIMES INTERVIEW HAD TO BE INTERRUPTED AND BEGUN AGAIN BEFORE COMPLETION:

........................................... 62-63/

149. INCLUDING THIS TRIAL, HOW MANY TIMES HAS THE RESIDENT BEEN INTERVIEWED? CIRCLE ONE.

............................................ 1
............................................ 2
............................................ 3
............................................ 4
............................................ 5
............................................ 6

64/
REFERENCES


Keeler, E.B. and R.L. Kane, "What is Special About Long-Term Care?" in R.L. Kane and R.A. Kane (eds.), Value Preferences and Long-Term Care, D.C. Heath, Lexington, MA (forthcoming).


