THESIS

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OPERATIONALIZATION OF A CONCEPT

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ROLE AMBIGUITY IN THE ILL:
OPERATIONALIZATION OF A CONCEPT

By

Lila Coulter

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ABSTRACT

ROLE AMBIGUITY IN THE ILL: OPERATIONALIZATION OF A CONCEPT

By

Lila Coulter

Difficult relationships in families of the ill or disabled are anecdotally reported in the literature, and the difficulty is often related to the patient incompletely or ambiguously taking on the role of a sick person. This study proposed to operationalize the concept of role ambiguity, defining it as the observed difference between a patient's best ability in activities of daily living (ADL) and his usual performance in those activities. Subjects were 26 male patients receiving services of the Hospital Based Home Care (HBHC) program through the Veterans Administration Medical Center. The patients were rated on the Ambiguity in Activities of Daily Living (AADL) by both a significant other and a member of the HBHC team. Results revealed no role ambiguity as operationalized by this instrument. Performance and Ability subscales were significantly related for both groups of raters. Interrater and test-retest reliability was high for both the Performance and Ability subscales. This suggests that raters view these patients as consistent in their behaviors and as reliably performing at a level equal to their best ability. It is suggested that future studies with this instrument focus on more acute and homogeneous populations in terms of etiology of illness.

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There were many people involved in this project whom I wish to thank. Al Aniskiewicz, my committee chairperson, has been the soul of patience throughout the many changes and delays of this work. His thoughtful approach and calm demeanor often were saving graces, and meetings with him have consistently been times of discovery and re-energizing. Lucy Ferguson and Elaine Donelson as committee members have also been generous in their insightful comments throughout my work. Both helped to clarify issues early in the study and have remained on despite even cross-country communications!

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To my family I send special thanks. Though separated by many miles, I can always count on them to listen when I am discouraged and to share my pleasure when milestones are reached. Len Paauwe and Jeanne Newton, too, I count as members of my family and thank each of them for their unique support with special love and affection.

Lastly, I want to thank the families and patients who were the subjects of this study. I was often awed and humbled by their strength and faith in tremendously adverse conditions. They allowed me into their homes, and for a brief time into their lives. I am richer for it.

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INTRODUCTION

> "Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick." (Sontag, 1979)

A person's self-concept is deeply affected by the perception of the roles s/he should and does play (Goffman, 1959). A debilitating illness or acutely acquired disability upsets one's established role as a member of the world of the "well".

The perception of the newly sick person by the "well" others in his/her world will necessarily be incongruent with perceptions prior to the crisis. This normal incongruence will be increased in the situation in which the appropriateness of the patient's "sick role" and the extent to which s/he accepts it is more ambiguous.

Parsons and Fox (1952) discussed the rights and obligations of the sick. The sick person is not expected to behave the same way as when s/he is healthy. S/he has the right to deviate from usual activities, be dependent on others, and is not expected to fulfill normal responsibilities. S/he is obligated to want to get well and to cooperate with those who can help him/her get well. These rights and obligations comprise what Parsons and Fox call the "sick role."

Twaddle (1969) in a self-report study of adult outpatients reporting a medical condition, reported that those patients who viewed themselves as sick were more likely than those conceiving of themselves as not sick to seek exemption from responsibility, providing support for the Parsons and Fox paradigm.

Zahn (1973) interviewed applicants for disability benefits who were not in rehabilitation treatment. Sixty percent of her subjects were between 45 and 59 years of age and all were under 64 years old. She reported that those found "not fit to work" had better relationships with their spouses and other family members than did the employable. They are clearly disabled and are therefore allowed to take the "sick role". Zahn concluded that the ambiguity of status of those who are disabled and yet fit to work had the most negative impact on family relationships. The lack of clear role definition prevented the disabled member from having clear claim to citizenship in either the kingdom of the well or kingdom of the sick. This role ambiguity upset family homeostasis, and smooth family functioning was compromised.

The exception to this finding was that loss in communication skills is disabling in all types of interpersonal relationships, as such skills are necessary for effective interactions. The more impaired the subject's communication skills were (as rated by an Occupational Therapist), the more his relationships with friends and family members were disrupted. This was only sightly less true for familial relationships, and Zahn hypothesized that the small difference was due to the nonverbal communications that families develop.

The problem of ambiguity of disability and how it affects marital satisfaction was addressed by Fink, Skipper, and Hallenbeck (1968). Their subjects were 36 severely disabled wives and their husbands between 21 and 60 years of age. In all cases the disability had occurred after the couple was married, but type of disability and time since onset were not reported by the authors. Both partners were rated by interviewers on need satisfaction using an instrument derived from Maslow's heirarchy. Marriage satisfaction was rated on items measuring companionship, social status, power, understanding, affection, marital esteem and sex. Evaluation of the women's mobility was made by the physical therapist or attending physician.

The results showed that while need satisfaction and marriage satisfaction were highly correlated as expected, the physical condition of the woman was not a useful predictor of need or marriage satisfaction in either member of the couple. The authors suggest that the lack of correlation may be explained by the ambiguity of the role of the disabled but not immobile patient; the woman is not "sick" but neither is she entirely well, and therefore her rights and obligations are unclear. By the same token, the rights and obligations of her husband toward her are equally murky. "It would be an error to assume that the completely paralyzed woman will automatically have marriage and family problems. Greater mobility may cause greater role ambiguity. Neither she nor her family knows exactly what she can do or how close to her former self she is" (p. 73).

Although these authors argue strongly for the salience of the ambiguity of status of many of their subjects, they did not compare results from those couples in whom the woman was completely immobile with those couples in whom the woman had greater freedom of movement. Nor did they analyze their data by time since onset of disability, which may be assumed to have an effect on comfort with current roles.

During the initial period of return home, one may expect greater strain due to role adjustment. Deutsch (1960) studied family factors in home adjustment of the physically disabled using interview and observation techniques. She found that adult patients' own actions and degree and manner to which they assume former responsibilities are very important in determining the adjustment of the whole family. Immediately after the patient returns home, the spouses of the disabled speak of a "rather difficult" relationship which is apparently resolved by adjustment on both sides, and by assumptions of family responsibilities by the disabled member. This study suggests that ambiguity is at its highest level immediately after return home by the disabled member, and that as the appropriate rights and obligations are worked out, this "ambiguity" resolves into clearer role definitions. Homeostasis in the family relationships can again be attained.

Carpenter (1974) studied spousal agreement on the roles taken by disabled husbands two to five years after onset of physical disability. He found no significant differences in agreement on the husbands' household role performance. In discussing this result, he noted that the data were obtained at a time by which the families had had time to adjust to the impact and meaning of the husband's disability and suggested that greater disagreement would have been observed if the data had been collected at an earlier stage following onset of disability. Presumably, the incongruence between pre- and post-disability roles had been resolved by two years post-onset.

In a report on her work with wives of brain-damaged men, Lezak (1978) reports that in the first few months post-onset, "the family is cheerfully solicitous and indulgent while the patient gains strength" (p. 594). This is the time when the family presumably is comfortable with the patient taking the "sick" role. However, this "can turn into impatience, exasperation and...anger as discrete capabilities improve, but...the patient makes little or no effort to resume ordinary responsibilities" (p. 594). Here again, the ambiguity of role may be invoked to help explain the spouse's reactions to her husband's behavior. It would appear that these wives believe that their husbands are able to do activities that they simply choose not to. Whether or not the men are capable of the activities is unclear to the women.

Statement of Purpose

This rather sparse literature on the ambiguity of role in the ill and how it may affect family relationships raises several interesting questions and implications that have not been thoroughly examined, and it is the purpose of this study to delineate and address these areas.

First, it would appear that ambiguity of role is most often reported as a factor when other variables studied do not appear to be contributory. Thus, ambiguity has never been well operationalized or carefully defined as a variable in its own right. It appears that ambiguity of role might be defined as the difference between the level of performance that the patient is attributed as being capable of and the level at which s/he is currently performing. When there is evidence of congruence between these two attributed variables, relationships in the family seem to be less impaired than when there is perceived incongruence. Apparently, the incongruity is due to the inappropriate attribution of normal capabilities to the disabled person. Neither s/he nor others in his/her environment are perceiving his/her current status clearly, and have not yet accepted the fact of his/her disability. For the purposes of this study, role ambiguity will be operationalized as the difference between the level of independence in activities of daily living of which a patient is believed capable and the level of his/her daily performance of these activities.

Second, there is disagreement regarding the time during which the patient's role ambiguity will be at its highest level. Deutsch (1960) and Carpenter (1974) suggest that ambiguity will be at its peak early in the period following return home, while Lezak (1978) reports greater dissatisfaction and distress in wives after the early period is over and the husband is expected to take on more of the responsibilities of the well person.

The third area of interest concerns similarities or differences in view of the patient by the family member versus a more objective member of the medical establishment responsible for the patient's care. Physical and Occupational therapists are often asked to rate patients on their ability to perform Activities of Daily Living. These activities include the simple activities of dressing, toiletting, eating and so forth. Although it is generally accepted among rehabilitation professionals that many patients do not regularly perform at their best level, a search of the rehabilitation literature revealed no study in which the therapist was asked to rate and compare the patient on his/her everyday versus optimal performance in these activities. In addition, no study was found in which a spouse and medical worker both rated the same subject, although several reported that either one <u>or</u> the other was used as a rater (e.g., Carey and Posabac, 1978). In these reports, interrater reliability is generally good.

To summarize, the major purpose of this work is to provide an operational definition of role ambiguity and an instrument by which role ambiguity may be measured.

Hypotheses

1. Ratings of patient role ambiguity by the same rater one week apart will be reliably similar.

   This test-retest approach will measure the stability and reliability of this construct over a brief period of time.

2. Family members will report greater perceived role ambiguity than will those members of the medical team treating the patient at home.

   The medical personnel generally have had little contact with the patient prior to onset of illness or disability and therefore will not be bound or influenced by previous knowledge of the patient in his/her role as a well person.

3. Ratings by family members will covary with time since return home from the hospital, with greater ambiguity being attributed to those patients more recently returned home.

   This hypothesis is supported by the work of Deutsch (1960) and Carpenter (1974) who suggest that the change in the homeostasis of the family structure is a large factor in attribution of ambiguity of role. The time immediately subsequent to return home is marked by uncertainty of roles and re-adjustment to interactions that have been markedly changed by the patient's disability or illness. Lezak's (1978) work with wives of aphasic patients would suggest the contrary hypothesis: that role ambiguity increases with time since return home in those patients who have suffered a stroke.

4. Ratings by members of the medical team will not covary with time since return home from the hospital.

The medical personnel will have had previous experience with recuperation patterns, and expectations for recovery of role will likely be lower, thus allowing for greater objectivity.

5. Patients who are rated as having high motivation to put forth their best effort will receive lower ambiguity scores than will those with lower motivation ratings.

A sick/disabled person who does not fulfill the obligation to try hard to recover will have only incompletely taken on the role of the sick person. This will lead to confusion in the perceiver regarding the patient's true role, and result in greater attributed role ambiguity.

METHOD

Subjects

Subjects were recruited from the population of male patients receiving services from the Veterans Administration Medical Center (VAMC) Hospital Based Home Care (HBHC) program in Allen Park, Michigan. HBHC is provided by the VAMC for patients with a variety of illnesses of disabilities. The purpose of the program is to provide health care for the patient whose daily needs for care can largely be provided by a non-professional, but who requires the occasional regular (weekly to monthly) services of professional care. The HBHC professional may provide training for the home caretaker and/or provide other health care services such as assistance in activities of daily living (e.g., bathing) that do not require a hospital visit or a physician's direct attention. The program allows patients a smoother transition in their return home from the hospital, and allows very ill patients to remain home rather than to be housed in a hospital setting. Participation in the program requires the commitment of a significant other (usually a spouse or other family member) who will agree to be the patient's primary caretaker. At the time of this investigation, the staff responsible for home visits consisted of one registered nurse and three health technicians.

Of the 69 patients in this program who were contacted over a three month period, 26 agreed to participate. Due to procedures protecting the privacy of those patients contacted but who chose not to participate, we are unable to address the primary reasons for nonparticipation. Of those who did not choose to take part, two died within a month, and four were re-hospitalized. This indicates the level of severity of illness present in this population, and we surmise that this may have been an important factor in the low response rate. There were a variety of medical diagnoses in the subject population, and many had more than one contributing factor. Table 1 provides a listing of the primary cause for each patient being enrolled in the HBHC program. Tables 2 and 3 illustrate that although a majority of the patients have been ill for over two years, recent hospitalizations were quite common to this group. Interviews with the patients and significant others (SO) revealed that numerous and repeated brief hospitalizations were the norm for this population. Complete data was obtained on 22 of the subjects. Four of the SOs did not return the second rating on AADL.

The age range of the 26 subjects was 31 to 96 years, with a mean age of 65.15 years and median age of 61.5 years. Nineteen had less than a high-school education, two had completed high-school, and the remainder had up to three years of college. While none of the subjects were currently employed, the majority of these men had worked at skilled or unskilled labor jobs previously. Fourteen were black and twelve were white. Mean annual family income was between 10,000 and 15,000 dollars. The picture thus emerges of an elderly, generally low socio-economic group.

TABLE 1

Description of Subjects by Primary Diagnosis

Primary Diagnosis	Number of Patients
Cerebrovascular Accident (stroke)	8
Cancer	5
Multiple Sclerosis	4
Chronic Obstructive Pulmonary Disease	3
Dementia	1
Seizure Disorder	1
Renal Failure	1
Bone Fracture	1
Bone Infection	1
Blind, Hard of Hearing, "Frail"	1
	N = 26

TABLE 2

Time Since Onset of Illness

1 month	0
1-6 months	2 (7.5%)
6-12 months	4 (15.5%)
1-2 years	4 (15.5%)
over 2 years	16 (61.5%)
	N=26 (100%)

TABLE 3

Time Since Return Home from Recent Hospitalization

1 month	6 (23%)
1-6 months	11 (42.5%)
6-12 months	4 (15.5%)
1-2 years	2 (7.5%)
over 2 years	3 (11.5%)
	N=26 (100%)

Of the SO raters, 17 were wives to the patients, 2 were mothers, 6 were other female relatives, and one was a live-in companion. All were female. The HBHC raters consisted of 2 males and 2 females.

Measurement Instrument: Ambiguity in Activities of Daily Living (AADL)

The AADL is an instrument developed by the investigator in an attempt to operationalize the concept of role ambiguity in the sick and/or disabled (see Appendix A).

Functional disability is measured in rehabilitation settings by evaluation of the patient's ability to perform basic Activities of Daily Living (ADL). The patient is generally rated on a four or five point scale ranging from complete inability to perform each activity to normal performance of the activity. Many such instruments have a nearly overwhelming number of activities to be rated by a rehabilitation team member (the current form in use in the VAMCs lists 137 specific activities to be rated). Schoenig, Anderegg, Bergstrom, Fonda, Steinke, and Ulrich (1965) noted the need for a simple and concrete system of measurement that was also relatively comprehensive, and grouped specific self-care activities into six larger, more general categories, each of which contained three to five subcategories. Lehman, Delateur, Fowler, Warren, Arnhold, Schertzer, Hurka, Whitmore, Masock, and Chambers (1975) divided ADL into seven general categories that were specific enough to allow rating with a concrete scoring system.

An adaptation of the Lehman et al. and Schoenig et al. ADL models was developed with the cooperation of the Occupational Therapy service at the VAMC, Allen Park, Michigan. The form uses Lehman et al.'s suggested general categories, but provides other specific activities to be rated within those categories (a la Schoenig et al.) in order to obtain a comprehensive portrait of the patient's level of independence. The five point rating scale is a more specifically explained modification of that used by Carey and Posavac (1978) in which interrater correlations of .82 were achieved when the patient was rated by a nurse and a spouse.

Role ambiguity is here operationally defined as incongruence between the level of independence on ADL of which the patient is believed capable and the level of his assessed actual behavioral performance in ADL. Role ambiguity is therefore an assessment of the difference between ability and performance as viewed by a rater. Small rated differences would suggest that the patient's observed behaviors are consistent with what s/he is presumed to be capable of. Large differences reflect incongruity between ability and performance due to inappropriate attributions of normal capabilities to the disabled person by the rater. In these cases, the patient's role will be inferred to be ambiguous to the rater due to the discrepancy between attributed ability and observed performance.

Using the five point rating scale described above, each rater rated the patient on two dimensions: a) his level of ability to perform the included tasks, and b) his current observed usual level of performance on these tasks. The ambiguity score is equal to the difference between the sums of these two ratings. Two additional items were included to assess the patient's motivation level and emotional lability, both of which are presumed to affect ambiguity.

Procedures

The coordinator of the HBHC program mailed a letter to all currently enrolled patients explaining the purpose of this study, and requested the patient to sign and return a "Release of Medical Information" form if they wished to participate (Appendix B). Those patients who wished to participate and who returned the signed release of information form were telephoned by the investigator. The study was explained in further detail and an appointment time was arranged with the patient and SO. With two exceptions, all appointments were in the patient's homes. Each of the exceptions occurred because the patient had an upcoming outpatient medical appointment at the VAMC where the investigator was employed. In these two cases, arrangements were made to meet at the VAMC on the date of the outpatient appointment. For all subjects, at the prearranged appointment time, the investigator obtained written consent from the patient and SO (Appendix B), collected demographic data (see Appendix A for data collection form), and asked the SO to complete the AADL instrument. It was often necessary to provide assistance to the SO in this task, as the difference between ability and performance was a seemingly difficult concept for some of the respondents. Some SOs also requested definition of some of the vocabulary used on the instrument. Every attempt was made to answer the respondents' questions without completing the form for them. A second, blank copy of the AADL was left with the SO with instructions to complete it again one week from the initial evaluation and to return it to the investigator by mail (a stamped, addressed envelope was provided). If, by 10 days after initial evaluation, the second evaluation was not received via the mails, the investigator made a telephone call to determine if it had been sent and to encourage completion if it had not been done.

Within one week of the first completion of the AADL by the SO, the HBHC professional assigned to the patient completed the AADL. The HBHC professional again completed the AADL within one week of his/her initial evaluation. It should be noted that the HBHC raters received no special training on use of this instrument. It was briefly explained to them at the beginning of the investigation in the same terms used when speaking to the SO raters.

The procedure was completed three times in order to obtain the final number of subjects. The first mailing was to 45 patients. Of those who were contacted, 18 agreed to participate. A second mailing, six weeks later to 15 patients enrolled in HBHC since the first contact resulted in four more agreements to participate. The final mailing, to nine new patients occurred, seven weeks after the second mailing and four more patients were obtained. Thus, approximately 38% of the HBHC patient population was included in the final subject sample.

RESULTS

Except for test-retest data, analyses utilize time-one ratings by all raters. HBHC retest data from one subject were discarded due to a rater-scoring error. Ratings on use of bedpan or urinal were discarded for all subjects as the rating scale was found by all raters to not be applicable to this area of ADL. Due to the extreme difficulty reported by the raters and observed by the investigator in rating emotional lability, no analyses were performed on that portion of the data. Primary analyses were done using the Pearson Product-Moment Correlation.

Hypothesis One

It was predicted that ambiguity scores would be statistically reliable in test-retest conditions for each rater. Analysis using the Pearson Product Moment Correlation indicated similar levels of reliability of ambiguity scores for the SO ($r = .51$, $p < .025$) and HBHC ($r = .49$, $p < .025$) raters. However, as the ambiguity ratings are derived difference scores (Ability minus Performance = Ambiguity), further analyses were carried out to confirm this reliability rating. Reliability coefficients of the subtests (Ability and Performance) as well as the intercorrelations between subtests were used to predict the reliability of the difference (ambiguity) score. As shown in Tables 4 and 5, the reliability of these subscores was

TABLE 4

Test-Retest Reliability

	Ability	Performance
SO	.93	.96
HBHC	.94	.94

TABLE 5

Correlation Between Ability and Performance

	Time 1	Time 2
SO	.96	.98
HBHC	.99	.98

TABLE 6

Interrater Reliability

	Time 1	Time 2
Ability	.85	.85
Performance	.86	.86

TABLE 7

Mean Motivation Ratings

	Time 1	Time 2
SO	3.38	3.52
HBHC	3.63	3.95

quite high, and the intercorrelation between them even greater. The strength of these interrelationships resulted in a low predicted reliability of ambiguity scores, using the following formula from Cohen and Cohen (1975):

$$r_{(a-b)\ (a-b)} = \frac{(r_a + r_b/2) - r_{ab}}{1-r_{ab}}$$

Thus, the predicted reliability scores (SO: $r = -.375$) (HBHC: $r = -.5$) indicated that the ambiguity ratings by both the SO as well as the HBHC raters were unreliable due to the high intercorrelation between the Ability and Performance ratings, especially as relative to the subscore reliabilities.

Additional Results

As the derived ambiguity ratings had been shown to be unreliable in previous analyses, and since the remaining hypotheses were based on the ambiguity ratings, hypotheses two through five could not be adequately evaluated from these data. Further tests were undertaken to determine agreement between raters on the Ability and Performance subscores. High interrater reliability was found for both subscores, as shown in Table 6.

An additional analysis was performed to compare rated performance levels with rated motivation. HBHC ratings of these areas were related to a significant degree, $r = .55$ ($p < .01$), while SO ratings were not, $r = .34$ (ns). The correlation between HBHC and SO motivations was low, $r = .33$. Test-retest reliability of motivation ratings were .66 ($p < .001$) and .70 ($p < .001$) for SO and HBHC raters respectively. Mean motivation scores are shown in Table 7.

DISCUSSION

The purpose of this study was to examine the reliability of a new instrument proposed to operationalize the concept of role ambiguity in the ill person living at home. Role ambiguity was defined as the perceived difference between the patient's best ability and usual performance in activities of daily living.

The results of the study do not support the presence of role ambiguity as presently conceptualized in this population due primarily to the extremely high correlations between raters' perceptions of the patients' ability and their performance. As there were no perceived differences between ability and performance, no role ambiguity could be inferred. This was true whether the rater was a person closely involved in the patient's life or was a professional with only one to four hours of contact weekly.

Due to the unreliability of the ambiguity scores, secondary hypotheses were not evaluated. This discussion will focus on the primary findings regarding role ambiguity and examine the additional analyses undertaken, as well as observational data, to explicate the issue of role ambiguity.

Observations and anecdotal evidence from the researcher's interactions with the SO raters suggested that the concept of a difference between performance and ability was difficult to grasp. Family members appeared to assume that patients always put forth their best efforts. Many of the SOs suggested that to report otherwise would imply a negative judgment of the patients who were sick and therefore to be guarded from such an accusation. These naive comments supported Parsons and Fox's (1952) conceptualization of the role of the sick person and further offered indications that the patients had taken on the role adequately. That is, the patients were fulfilling their obligation to want to get well and to cooperate with efforts to help them in this pursuit.

If the SO lack of perceived ambiguity could be explained by inability to grasp the concept, we would predict somewhat higher ambiguity ratings by the more sophisticated HBHC raters. However, the HBHC raters also showed exceptionally high agreement between ratings of Performance and Ability, thus again negating the possibility of ambiguity ratings. That neither group of raters reported differences between the patients' Performance and Ability implies that the patients were consistently performing at a level commensurate with their perceived ability. The high interrater reliability in both Performance and Ability ratings also supports the notion that there was a perceived constancy between the patients' prescribed role and their behaviors in that role. This was true whether the rater was a more presumably subjective or objective observer.

Both the SO and HBHC raters also were able to rate the patients reliably on both Ability and Performance in test-retest conditions. This is an interesting and useful finding, especially considering the lack of training provided the SO raters in this instrument. It implies that a simple, well-explained scale can be used reliably by persons with low education levels and with no previous training in use of objective rating scales. This finding, in concert with the high interrater reliability finding has implications for the recruitment of SO raters in monitoring patients' recovery from illness in rehabilitation programs where time-consuming ADL rating by professionals are often utilized as measurements of change or progress. The time generally taken by physical and/or occupational therapists to complete these scales could be devoted to more direct patient care. Additionally, the family members would be allowed to take a meaningful part in monitoring the patients' behavior and recovery curve. They clearly have a great deal of information regarding the home-bound patient's daily behaviors. This recourse is often untapped, and in this population the family members proved to be accurate and consistent observers of behavior. Branson (1977), Borden (1962), and Goodell (1975) reported the importance of including families in rehabilitation efforts. As active and contributing members of the rehabilitation team, family members would be invited to share their knowledge and be validated in their value to the patients' progress. This may also provide a setting in which further conversation and family questions regarding the patient and/or family needs could be addressed.

The findings regarding patient motivation were revealing. While HBHC raters clearly associated motivation with Performance, with better Performance accompanying greater willingness to try difficult tasks, the SOs did not associate these two aspects of behavior. These results suggest that the SO viewed the patients' Performance to be a factor unrelated to inner motivational levels, while the professional raters found one to influence the other. It would appear that the SOs assume that the patient's performance is free of internally motivating factors and should be considered as a behavior that stands on its own. The HBHC raters seem to relate the two in a meaningful way. That is, they seem to report that if the patient tried harder, a better performance resulted. However, due to the correlational nature of the data, we cannot rule out the possibility that higher Performance ratings indicate the inference of a better ability to keep trying when the task is difficult, rather than better Performance resulting from higher motivation to keep trying.

In attributing internal motivation levels via behavioral ratings, both groups of raters showed test-retest reliability that was much lower than that found in Performance and Ability ratings, although the reliabilities were at a level equivalent to many in social research. Many of these patients were very ill, and may have indeed shown fluctuating motivational patterns from time one to time two. In addition, this item requested raters to determine not only the difficulty of items for the patient, but his normative response to them. This "second guessing" may have contributed to the lower reliability. The third factor, which would appear to carry the greatest explanatory power, takes into consideration the composition of the raw data. Performance and Ability reliability scores were derived from ratings on 25 individual ADL items while the motivation scores were derived from only one item. Since reliability increases with test length, we should expect lower reliability with a single-item subtest (motivation) relative to a multiple-item subtest (Performance).

Ratings of emotional lability were not analyzed as all raters reported difficulty interpreting the question which asked them to report affective behaviors which occurred "when there was no apparent reason for that feeling". Both the HBHC and SOs found that they must attribute an environmental cause to affective response. One SO rater reported that her husband seemed sad more than once a day, but that this was because he was sick "and it makes sense that he is sad". Another, whose husband was nonresponsive to most conservational questions was in a room with a television set. When he smiled or laughed, his wife attributed this to the television's stimulus. There were no anecdotal reports of true random responses, as all raters were able to attribute either internal or external "reasons" for the patients' behaviors. In future work, it may be useful to focus on exaggeration rather than randomization of response when seeking ratings of emotional lability.

The results of this study have several implications for both patient care and future research. Clearly, family members are good observers of patient behavior at home and are able to accurately report their observations in the format of a concretely worded rating scale. Further, these observations are reliably similar to those ratings by professional observers. This finding may be put to use in outpatient rehabilitation settings by inviting the family members to participate in formulation of treatment goals and measurement of goal attainment.

The wide variety of illness present in this population, as well as the small sample size prevented analysis by etiology and this avenue may be explored in future research. For instance, it is reported that stroke patients who have suffered injury to the right hemisphere often reveal a laissez-faire attitude toward their disabilities (Diller and Weinberg, 1977), and the concept of role ambiguity may be more applicable to that population than, for instance, a population of cancer patients.

The present study could not address the association between time since return home and ambiguity due to the unreliability of the ambiguity scores. However, we cannot rule out the possibility that the association exists, but is more related to the time since onset. At the time of this study, 77% of these patients had been members of the "kingdom of the sick" or disabled for more than one year. This is the period past which the greatest familial adjustment is presumed to have occurred (Belcher, 1977). Future studies may examine the concept of role ambiguity in the ill beginning with the onset of illness through the first year home in a longitudinal rather than cross-sectional design. The use of a more acute and more homogeneous population may bear out previous observations of the ambiguity factor in familial adjustment to illness.

APPENDICES

APPENDIX A

CHECK ONE: CHECK ONE:

S.O.________ Time 1 ______ NAME:_________________________
HBHC________ Time 2_______ DATE:_________________________

ACTIVITIES OF DAILY LIVING

	ABILITY	USUAL PERFORMANCE
1.	Is not able to do the activity at all.	Usually doesn't do the activity at all.
2.	Is able to do the activity if others help him.	Usually does the activity with the help of others.
3.	Is able to do the activity if others supervise him, but give no physical help.	Usually does the activity with others supervising him, but giving no physical help.
4.	Is able to do the activity with the use of physical aids or changes in the environment (eg: wheelchair, cane, handrails, bar above bed, etc.)	Usually does the activity with the use of physical aids or changes in the environment (eg: wheelchair, cane, handrails, bar above bed, etc.)
5.	Is able to do the activity without any help.	Usually does the activity without any help.

Many people have trouble doing some or all of the activities listed below. Using the scoring key above, please rate the patient on: 1) his ability to do each of the following activities when he really tries, 2) the way he usually accomplishes each of the activities. (Do this for the way you've seen him in the last two weeks.)

	ABILITY	USUAL PERFORMANCE
1. Sitting up from lying down	______	______
2. Standing up from sitting	______	______
3. Moving about the house	______	______
4. Moving from chair to bed	______	______
5. Moving from bed to chair	______	______
6. Shaving with electric razor (already plugged in)	______	______
7. Dressing: Undershirt	______	______
Pants	______	______
Socks	______	______
Shoes	______	______

			ABILITY	USUAL PERFORMANCE
8.	Undressing:	Undershirt	____	____
		Pants	____	____
		Socks	____	____
		Shoes	____	____
9.	Toiletting:	Bowel control	____	____
		Bladder control	____	____
		Uses bedpan/urinal	____	____
		Getting into the bathroom	____	____
		Getting on and off the toilet	____	____
10.	Bathing:	Getting into the shower or bath	____	____
		Bathing self	____	____
11.	Feeding:	Prepares food on plate	____	____
		Feeds self	____	____

Please put a check on the line that best describes the patient's 1) communication <u>ability</u> then he really tries, 2) way he usually communicates.

12. Speaking:

ABILITY	USUAL PERFORMANCE
1._____Is not able to communicate his wants/needs in any way.	1._____Usually doesn't communicate his wants/needs in any way.
2._____Communicates his wants/needs in writing.	2._____Usually communicates his wants/needs in writing.
3._____Communicates his wants/needs with gestures.	3._____Usually communicates his wants/needs with gestures.
4._____Communicates his wants/needs with single words, incomplete sentences.	4._____Usually communicates his wants/needs with single words, incomplete sentences.
5._____Communicates his wants/needs with normal speech (full sentences).	5._____Usually communicates his wants/needs with normal speech (full sentences).

13. Understanding language:

1._____Is not able to understand spoken or written language.	1._____Usually does not appear to understand spoken or written language.
2._____Is able to understand written communications from others.	2._____Usually requires written communication from others to understand.
3._____Needs other aids to understand speech (eg: hearing aid, gestures, etc.).	3._____Usually requires other aids to understand speech (eg: hearing aid, gestures, etc.).
4._____Understands only a few words.	4._____Usually appears to only understand a few words.
5._____Understands "normal" speech (eg: full sentences, normal volume, etc.).	5._____Usually appears to understand "normal" speech (eg: full sentence, normal volume, etc.).

14. When the patient has trouble performing an activity like any of those described above, what does he usually do? Please put a check on the line that <u>best</u> describes his behavior.

_____He keeps trying without encouragement.

_____He tries if given some encouragement.

_____He needs a <u>lot</u> of encouragement to perform the activity.

_____He will only perform the activity if given help (even if it is one he <u>can</u> do alone).

_____He does not try at all, or gives up easily.

_____Other (please describe)____

____

15. How often does the patient seem to feel each of the following emotions when there is no apparent reason for that feeling in the immediate situation?

	More than Once a Day	Once a Day	Almost Every Day	Occasionally	Rarely	Never
Anger:	_____	_____	_____	_____	_____	_____
Frustration:	_____	_____	_____	_____	_____	_____
Sadness:	_____	_____	_____	_____	_____	_____
Irritation:	_____	_____	_____	_____	_____	_____
Happiness:	_____	_____	_____	_____	_____	_____
Amusement:	_____	_____	_____	_____	_____	_____

DATE: ____________________

NAME: ______________________________

ADDRESS: ______________________________

____

PHONE: ______________________________

INTERVIEW AND DEMOGRAPHIC DATA

S.O. NAME: ______________________________

RELATIONSHIP: ______________________________

ADDRESS: ______________________________

____

PHONE: ______________________________

EDUCATION: ______________________________

ETHNIC ORIGIN: ______________________________

OCCUPATION: ______________________________

How long since stopped working: ______________________________

Why stopped working: ______________________________

MARITAL: ______________________________

Persons living in the home: ______________________________

____

Major reason(s) for HBHC treatment: ______________________________

____

____

	1 month	1-6 months	6-12 months	1-2 years	2 years
Time since onset of current disability	_____	_____	_____	_____	_____
Length of most recent hospitalization	_____	_____	_____	_____	_____
How long since return home from hospital	_____	_____	_____	_____	_____

Income level:	under $5,000_____	$15,000-$20,000_____
	$5,000-$10,000_____	$20,000-$30,000_____
	$10,000-$15,000_____	$30,000-or more_____

Changes in living situation since return home: ______________________________

____

APPENDIX B

Medical Center

Southfield and Outer Drive
Allen Park MI 48101

Veterans Administration

In Reply Refer To:

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Dear

Members of the Veterans Administration Medical Center are interested in studying people's reactions and adjustments to long-term illness or disability. I believe that your experiences and the experiences of your family and/or close friends would add to the understanding of these reactions.

As assessment instrument has been developed that we believe measures one important cause of changes in relationships after onset of illness or disability. We hope you will take part in this study. Your cooperation would require that you and a family member or friend that spends a part of each day with you meet with one of the researchers for approximately one hour. This can be either at your home or the Veterans Administration Medical Center, whichever is most convenient for you. During that time, your family member or friend will complete the brief instrument.

Before I release your name to the research team so that you can take part in this study, it is necessary for you to sign the enclosed Release of Information form and return it to me in the preaddressed envelope. Please do this today.

After you return the form, one of the researchers will contact you by telephone to answer any questions you may have concerning the study and to arrange an appointment with you. If you or your family member or friend have any questions about the study before you return the form, please call Lila Coulter at 562-6000 ext. 623. I believe that taking part in this study will be interesting to you, but if you choose not to, your care from the Veterans Administration Medical Center will be in no way affected.

Thank you for your help.

Sincerely,

Joyce Lawrence, R.N.
Coordinator, Home Based Health Care

ENC:2

Form Approved
OMB No. 76-R0138

REQUEST FOR AND CONSENT TO RELEASE OF INFORMATION FROM CLAIMANT'S RECORDS

NOTE: The execution of this form does not authorize the release of information other than that specifically described below. The information requested on this form is solicited under Title 38, United States Code, and will authorize release of the information you specify. The information may also be disclosed outside the VA as permitted by law or as stated in the "Notices of Systems of VA Records" published in the Federal Register in accordance with the Privacy Act of 1974. Disclosure is voluntary. However, if the information is not furnished, we may not be able to comply with your request.

TO	Veterans Administration V.A. Medical Center Southfield & Outer Drive Allen Park, Michigan 48101	NAME OF VETERAN (Type or print)	
		VA FILE NO. (Include prefix)	SOCIAL SECURITY NO. *

NAME AND ADDRESS OF ORGANIZATION, AGENCY, OR INDIVIDUAL TO WHOM INFORMATION IS TO BE RELEASED

VETERAN'S REQUEST

I hereby request and authorize the Veterans Administration to release the following information, from the records identified above to the organization, agency, or individual named hereon:

INFORMATION REQUESTED (Number each item requested and give the dates or approximate dates—period from and to—covered by each.)

() This may include drug or alcohol abuse information or sickle cell.

() Hospital Report - Complaint on admission, condition(s) treated, operations, dates of hospitalization.

(x) Outpatient Report - Period treated, complaint and condition treated.

() Return to work statement.

() Summary of hospital treatment (includes diagnosis, operations and narrative summary of test results, treatment given and results of treatment).

() Other.

* The social security number solicited on this form will be used for identification of records to respond to your request. Although disclosure is voluntary, failure to furnish this number may delay processing.

PURPOSES FOR [illegible]

() For future medical treatment.
() Insurance claim.
() Employment.
(x) Other - Please specify. RESEARCH

NOTE: Additional items of information desired may be listed on the reverse hereof.

DATE	SIGNATURE AND ADDRESS OF CLAIMANT, OR FIDUCIARY IF CLAIMANT IS INCOMPETENT

VA FORM DEC 1975 **60-3288** EXISTING STOCKS OF VA FORM 07-3288, FEB 1974, WILL BE USED.

☆ U.S. Government Printing Office: 1980—311-645/1128

INFORMATION FOR PARTICIPANTS

Ambiguity in Activities of Daily Living

We are asking your help in identifying the different ways that important people in a patient's life view his disabilities/illness.

Should you agree to participate, we will meet with you and the family member or friend who best knows you. We will discuss with you your progress and ask the other person to give his/her view of your current abilities. We will also ask the other person to one week later again complete a brief form to mail to us.

There is no treatment implied in your participation in this study. Nevertheless, it is our belief that you and your family member/friend may find it useful to consider the different ways each of you reward your current physical functioning. Further, we believe that the results of the study will allow us to better understand how different people in the patient's life view his disabilities.

Your confidentiality and identity will be strictly protected and your names will not be mentioned in any reports that may come from this work.

We will be available to answer any of your questions regarding this research at any time, and you are, of course, free to withdraw at any time without affecting your present or future treatment by this hospital. Inquiries should be addressed to:

Lila Coulter
or
Samuel D. Brinkman, Ph.D.
Veterans Administration Medical Center
Allen Park, MI 48101
(313) 562-6000, ext. 623

A copy of the results of the study will be available to you on your request.

Thank you for your interest.

Lila Coulter
Samuel D. Brinkman, Ph.D.

AMBIGUITY IN ACTIVITIES OF DAILY LIVING

Investigators: Lila Coulter
Samuel D. Brinkman, Ph.D.

I have read the attached "Information for Participants".

A detailed explanation of the procedures and their purposes has been given to me and I understand it.

I understand that there will be no direct benefit to me as a result of this project, but that new knowledge may be gained and this knowledge may be of value to me or to others.

I was given the opportunity to ask any questions about the procedures and all were answered to my satisfaction.

I know that I am free to withdraw this consent and to stop participation in the procedures at any time without affecting my access to other services and without generating any prejudice to myself.

I have been assured that my personal identity will not be revealed and will remain confidential in reports and releases of the results of this project. At my request, a summary of the results will be given to me.

Of my own free will, I consent to participate in the procedures.

Date

Participant

Participant

Interviewer-Witness

REFERENCES

REFERENCES

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