Measuring Health Status of Persons With Chronic Illness: Use of the Duke-UNC Health Profile

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Abstract

Measuring Health Status of Persons with Chronic Illness: Use of the Duke-UNC Health Profile

This study explored the appropriateness of the Duke-UNC Health Profile (DUHP) for measuring health status changes in chronically ill individuals who were in a rehabilitation program. The five chronic illness groups selected for study were patients with cancer, post myocardial infarction or coronary artery bypass graft, obesity, stroke due to arterial thrombosis, and diabetes mellitus (Type I and II). This volunteer convenience sample (n=81) was tested with the DUHP three times at three week intervals.

A general trend toward improvement as measured by the DUHP subscales was found in the sample as a whole and in each diagnostic group although the improvement was not statistically significant.

The DUHP was found to be reliable, with internal consistency values and test-retest reliabilities equal to or higher than those obtained by the developers of the DUHP. This study also demonstrated evidence for construct validity through moderate correlations between DUHP subscale scores and a self-anchoring Health Perception Scale, with the

strongest correlation being that between the Health Perception Scale and the symptom subscale of the DUHP. The DUHP was also found to be brief and easy to administer in a variety of settings.

Measuring Health Status of Persons With Chronic Illness: Use of the Duke-UNC Health Profile

Health status has generally been defined in terms of disease processes and the physiological changes in the body produced by disease (Parkerson, Gehlbach, Wagner, James, Clapp & Muhlbaier, 1981). Recently, more global definitions of health have broadened both attitudes and approaches to assessment of health status. For example, The World Health Organization (WHO) states, "health is a state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity" (1958).

Concurrent with the changing definition of health, health status measurement has moved from focusing on disease to measuring positive indicators of health status. Increasingly, these measures consider elements of human functioning such as role performance, social interaction, and psychological or emotional functioning.

Health in persons with chronic illness is increasingly being conceptualized as a phenomena that can coexist with, yet be different from illness. This conceptualization suggests that a person may have an illness and yet be able to maintain social role performance, functional activities, and a high level of self-esteem; in other words, still be healthy. An individual with chronic illness has the same basic concerns as a person without a chronic illness, that is, "to manage personal, social, and occupational activities as well as he can" (Reif, 1973).

In an individual experiencing a chronic illness, rehabilitation efforts tend to focus on improving physical, emotional and social functioning in the presence of disease. The ability to detect subtle changes in health status is important to the health care provider, providing for objective evaluation of prescribed treatment/rehabilitation plans. The purpose of this study was to test the usefulness of a health status instrument, which includes multiple parameters, in the assessment of individuals experiencing chronic illness.

Historical Development of Health Status Indicators

The early measures of health indicators were used to describe the total health status of groups and focused on mortality and morbidity rates and disease incidence and prevalence (Jette, 1980). These measures were useful for evaluating the health or more realistically, the illness of

populations but were not descriptive of the experiences of individuals.

As the definitions of health have moved toward a focus on the individual, subjective health ratings, symptom or illness inventories, and measures of physical functional status have become more common (George & Bearon, 1980). Evolving multidimensional measures of health status now include such factors as mental health status, quality of interpersonal relationships, and social and economic resources. The theoretical background for these measures acknowledges the matrix of biological, psychological, and social factors that all contribute to general health status (George & Bearon, 1980). This comprehensive view of health is particularly applicable to the chronically ill because the onset of a chronic illness is a major life crisis that requires continuous adaptation to ongoing alterations in all areas of human functioning.

Health Assessment in Chronic Illness

When there is no cure for a chronic disease, attention must be focused on reducing the level of disability (Charlton, Patrick & Peach, 1983). Until recently, evaluation of functional impairment associated with any particular chronic illness often used measures which "assessed only a small portion of the spectrum of functional impairments" (Deyo, Inui, Leininger & Overman, 1982). This portion was usually the obvious physical disabilities. However, psychological and

social functioning in the context of chronic illness may be as important as physical function in judging a patient's response to therapy and the need for and utilization of health services (Hunt, McKenna, McEwen, Backett, Williams & Papp, 1980).

Although change may vary from illness to illness, measurement of change in functioning over time is quantifiable. Social and physical function as a result of rehabilitation programs can be measured. Abrahams, Wallach, and Divens (1979), in a study of long term geriatric patients, were able to evaluate the effectiveness of a psychosocial rehabilitation program by measuring an increase in social interaction, reduction in daytime sleeping, and increase in mobility. Seventy-two patients in a post myocardial infarction rehabilitation program (Ott, et al, 1983) showed improvement in mood and ability to undertake physical activity without anginal pain as a result of the program. Carey and Posavac (1982), were also able to detect changes in a population of stroke patients as a result of a structured rehabilitation program by evaluating activities of daily living, mobility, and communication skills. One problem with these studies is that they all use different measures of health status, so that comparability across chronic illness groups has been difficult to measure.

Several questionnaire instruments have recently been devised which attempt to assess health status in terms of both physical and psychological function across patient groups

(Carey & Posavac, 1982: Charlton, Patrick & Peach, 1983). Of these instruments, the Sickness Impact Profile (SIP), developed by Bergner, Bobbitt, Carter, and Gilson (1981) has been cited in the largest number of published studies. The SIP was first tested on a random sample of prepaid group practice enrollees and with smaller trials on samples of patients with hyperthyroidism, rheumatoid arthritis (Deyo & Inui, 1984; Deyo, Inui, Leininger & Overman, 1982; Deyo, Inui, Leininger & Overman, 1983), back pain (Deyo & Diehl, 1983), patients who were post-myocardial infarction (Ott et al, 1983), and in an age-integrated psychosocial rehabilitation program for the elderly (Abrahams, et al, 1979). The sensitivity of the SIP to clinical changes was variable among different populations.

While Deyo and Diehl (1983) found the SIP to be sensitive to clinical changes in back pain patients, Deyo and Inui (1984) indicated that for individual rheumatoid arthritis patients, a patient self-rating scale, the American Rheumatism Association functional classification, and the SIP were all relatively insensitive and poor predictors for clinically estimated change. Charlton, Patrick, and Peach (1983) also found the SIP lacked measurement sensitivity in a sample of disabled individuals living in the community. These authors felt the lack of discrimination was due to several activities being evaluated in the same question. An individual could perform adequately in one activity and poorly in another with

the answer to the question resulting in ambiquity. On the other hand, Johnson, King and Murray (1983) found the SIP to be an acceptable measure of quality of life in a variety of cancer patients undergoing radiation therapy. Thus, overall, the sensitivity of the SIP appears to be variable among chronic illness populations.

The Duke-University of North Carolina Health Profile (DUHP), is a non disease-specific, multidimensional assessment instrument (Parkerson et al, 1981). Like the SIP, it addresses several areas of functional status. Unlike the SIP, the DUHP focuses on ability versus disability, exhibits greater discrimination in social function, is briefer, and is less emotionally intrusive. Although the DUHP was developed on a primary care sample of patients, the authors of the DUHP suggest that further research using the instrument should include:

(1) Populations of patients who are sicker than ambulatory primary care patients, i.e., elderly and/or chronically ill.

(2) Studies that test the clinical applicability by correlating scores with other medical evaluations and/or instruments.

(3) The DUHP administered at intervals to demonstrate associations between self-reported and provider reported health status as their condition fluctuates over time.

The present study addresses these suggestions. Three questions were asked:

(1) Is the Duke University Health Status Profile (DUHP) sensitive enough to measure change over time resulting from rehabilitation programs?

(2) Do changes in health status, as measured by the DUHP, correspond with physiological/functional indicators of chronic disease status?

(3) Is the reliability and validity of the DUHP, when used in chronic illness samples, comparable to that in the original report?

Method

Sample

Five chronic illness groups selected for study were: persons with cancer, post myocardial infarction or coronary artery bypass graft (CABG), obesity, stroke due to arterial thrombosis, and diabetes mellitus (Type I & II). These particular chronic diseases were chosen because heart disease, cancer, stroke, and diabetes mellitus are the leading causes of death due to chronic illness (Department of Health, Education and Welfare, 1973), and obesity is not only a chronic entity in itself, but can be a precursor to the development and progression of the above chronic diseases. Each group was a volunteer convenience sample of 15-20 subjects involved in a treatment, rehabilitation, and/or educational program for their illness. Criteria for inclusion

in the study were: 18 years and older, English speaking, absence of severe acute illness, absence of any major receptive communication deficits, and informed written consent.

Those individuals with cancer and stroke were participants in rehabilitation programs at a large metropolitan medical center. The individuals with diabetes and obesity were recruited from treatment/education programs in a health sciences university. Post myocardial infarction and post CABG subjects were enrolled in one of three community based outpatient rehabilitation programs. Of these diagnostic groups, subjects enrolled in the stroke rehabilitation program represented the only hospital population. The remaining four subsamples were outpatient, ambulatory subjects.

Instruments

The Duke-UNC Health Profile (DUHP) developed by Parkerson, Gehlbach, Wagner, Sherman, Clapp, and Muhlbaier (1981), is a 63 item instrument that measures health status on four dimensions: symptom status (26 items), physical function (9 items), emotional function (23 items), and social function (5 items). The original purpose of this instrument was to assess the effect of primary medical care on the self-reported functional status and feelings of patients. Because its focus is on ability rather than disability, it parallels elements of human functioning such as role performance, social interaction, psychological or emotional functioning, as well

as the physical symptom status. The DUHP was developed and tested in a primary care setting using 395 adults, most of whom were experiencing acute episodic illnesses such as pneumonia, influenza, urinary tract infections, etc. Forty-five subjects had some form of chronic illness, such as osteoarthritis and diabetes. Reliability was established using internal consistency, temporal stability, and scalogram analysis. The overall internal consistency for the emotional function subscale was 0.85 using Cronbach's alpha. Guttman scalogram analysis applied to the physical function subscale revealed high coefficients for reproducibility (0.98) and scalability (0.89). For the social function subscale, scalogram analysis produced Guttman coefficients of 0.93 for reproducibility and 0.71 for scalability. Temporal stability analysis for the symptom subscale was indicated by a reliability coefficient of 0.68.

Content validity was established by comparison with other health status instruments, review of the literature, and the professional experience of the investigators. Convergent and discriminant validity were evaluated by the multi-trait multi-method proposed by Campbell and Fiske (1959). Subjects completed one of three comparison instruments in addition to the DUHP: the Sickness Impact Profile (Bergner, et al, 1981),Tennessee Self-Concept Scale (Fitts, 1964), or the Zung Self-Rating Depression Scale (Zung, 1965). Validity was supported for all portions of the emotional and social

function dimensions, all but two items of physical function, and half of the symptom status items. The authors explained that physical function validity was difficult to obtain in the subscale because very few subjects in their pilot population had upper extremity dysfunction. Lack of support for validity for some of the symptom status items occurred because none of the three comparison measures provided items or groups of items which could be correlated with eyesight, hearing, breathing, urination, headache, itching, fever, fainting, weakness, weight gain, and bleeding. These symptoms, however, are characteristic of the chronic illnesses included in this study providing support for the use of the DUHP.

The DUHP can be self or interviewer administered and usually can be completed in 10 minutes or less. The score for each of the four dimensions, symptom status, physical, social and emotional function, is a proportion from 0 to 1 and is obtained by summing the raw item values within each dimension and dividing by the maximum sum for that dimension. Higher scores indicate better function; lower scores, poorer function (Parkerson et al, 1981).

Comparative Physiological/Functional Measures

Physiological/functional measures specific to each of the five chronic illness samples were selected for comparison with DUHP scores. In the stroke sample, an institution-specific interdisciplinary team rating of functional gain was employed. Scores from individuals with cancer were compared

to those obtained from their response on the Karnofsky Performance Status instrument (Karnofsky, Abelmann, Craver, & Burchenal, 1949). In the diabetes sample, blood glucose scores were used. Weight loss was used in the obesity sample. Heart rate and anginal signs/symptoms during monitored exercise periods were the comparative measures in the sample of individuals with cardiac disease.

In addition to answering questions on each of the DUHP subscales, individuals were asked to make a subjective estimate of their health on a self anchoring health perception (HP) scale modeled after the Cantril ladder (Cantril, 1965) with values ranging from one to ten. The question posed was "on a scale from one to ten, with one being the least healthy you have ever felt, and ten the most healthy, how healthy would you rate yourself today?"

Procedures

All subjects gave informed consent to participate in this study. The instruments were self-administered whenever possible and when interviewer administered, read verbatim. The first administration of the DUHP occurred upon initiation of the rehabilitation/educational program. Initially, 81 subjects were taken into the study. Three dropped from the study by choice and two died before the second administration of the DUHP. Two additional administrations at three week intervals were completed on each subject. These time intervals were held constant across sample groups. Subjects completed the instruments in the health care setting or in their homes.

Results

Demographic characteristics of the study population re listed in Table 1. The mean age was 54 years. The majority of subjects was female (56 per cent), married (67 per cent), working (60 per cent), and educated at least to the high school graduation level (75 per cent).

Table 1.

Demographic Characteristics of Study Sample
(N=81, First Administration)

CHARACTERISTIC	%
Sex	
Male	44
Female	56
Educational Level	
Graduate School	7.4
College	24.7
Technical School	9.9
High School	49.4
Grammar School	8.6
Occupational Status	
Working	60.2
Not Working	39.8
Marital Status	
Married/Partnered	66.7
Divorced/Separated	17.3
Widowed	9.8
Never Married	6.2
Diagnosis	
Cardiac	25.9
Cancer	21.0
Obesity	18.5
CVA	17.3
Diabetes	17.3

Scores

The first research question asked whether the DUHP was sensitive enough to measure the changes resulting from rehabilitation programs. The mean subscale scores for the sample as a whole showed a consistent trend toward improvement over time (Table 2). Scores on the two subscales for physical ability and social functioning were lower than scores on the subscales for symptom status and emotional status. Standard deviations were largest on the social functioning and physical functioning scales. Health Perception scale scores also showed improvement from time one to time three.

Table 2

SUBSCALE MEANS AND STANDARD DEVIATION
FOR TOTAL GROUP BY ADMINISTRATION

SUBSCALES	TIME 1	TIME 2	TIME 3
SYMPTOM TOTAL			
Mean	0.77	0.78	0.81
Stan. Dev.	0.13	0.13	0.12
PHYSICAL TOTAL			
Mean	0.53	0.56	0.58
Stan. Dev.	0.24	0.22	0.22
SOCIAL TOTAL			
Mean	0.60	0.62	0.66
Stan. Dev.	0.29	0.26	0.24
EMOTIONAL TOTAL			
Mean	0.69	0.69	0.72
Stan. Dev.	0.13	0.14	0.14
HEALTH PERCEPTION SCALE			
Mean	5.49	5.73	6.20
Stan. Dev.	0.14	0.13	0.14

The second question in this study related to the association between physiological or functional variables and the DUHP scores. There were no significant correlations between any of the physiological/functional variables and the DUHP scores.

Reliability

A comparison of the reliability and validity of the DUHP between this study and the original study was made using three different types of reliability estimation (Table 3). Guttman analysis revealed 0.99 for reproducibility and 0.98 for scalability on the physical function dimension; 0.94 for reproducibility and 0.77 for scalability on the social subscales at time one. These scores compared favorably to those reported by Parkerson et al (1981). Alpha coefficients for internal consistency reliability were: symptoms (0.85) and emotional (0.78). While the emotional coefficient was close to the original DUHP study, the authors did not report a statistic for the symptom subscale. Repeated measures analysis of variance revealed that the four subscales each had a high degree of temporal stability.

Table 3

RELIABILITY OF SUBSCALES AT THREE TIMES*

	TIME 1	TIME 2	TIME 3
SYMPTOM TOTAL			
Cronbach's Alpha	.85	.85	.82
EMOTIONAL TOTAL			
Cronbach's Alpha	.78 (.85)	.84	.84
PHYSICAL TOTAL			
Reproducibility	.99 (.98)	.97	.99
Scalability	.98 (.89)	.87	.98
SOCIAL TOTAL			
Reproducibility	.94 (.93)	.92	.85
Scalability	.77 (.71)	.65	.16

*Reproducibility and scalability on the DUHP in the original report by Parkerson et al 1981, are shown in parentheses

The original Parkerson study had a variable test-retest interval of one to eight weeks while this study held the intervals constant at three weeks. Table 4 presents the test-retest correlation coefficients of the subscales for Time 1 and Time 3 at the six week interval. These test-retest reliability scores compare favorably with the Spearman's Rho correlations in the original study on all but the social subscale.

Table 4

TEST-RETEST RELIABILITY SCORES ON EACH SUBSCALE BETWEEN TIME 1 & TIME 3*

	SOCIAL	PHYSICAL	EMOTIONAL	SYMPTOM	HP SCALE
r (r_S)	.77(.52)*	.84(.82)	.74(.72)	.68(.68)	.60
P Value	P=.000	P=.000	P=.000	P=.000	P=.000

*Values in parentheses represent Spearman's Rho correlation coefficients from the original study.

Validity

Validity testing of the DUHP in the present study was guided by the original Parkerson study. This was evaluated in two ways. First, Pearson correlations were run between the subscales. Second, Spearman correlations among the subscales in the study provided evidence that all four subscales are measuring a different, but related, dimension of health status. The correlations are comparable to those found by Parkerson and his associates. (Table 5).

Table 5

SPEARMAN RANK ORDER COEFFICIENTS AMONG DUHP HEALTH DIMENSION SCORES

	SYMTOT	PHYTOT	EMOTOT	SOCTOT
SYMTOT		.68(.46)	.49(.30)	.46(.36)
PHYTOT			.28(.17)	.64(.29)
EMOTOT				.21(.27)
SOCTOT				

*Values in parentheses represent original DUHP Spearman Rank-Order Correlation Coefficients p=<.03.

Spearman rank order correlations were calculated between the subscales and the Health Perception Scale. Overall there were positive correlations between the DUHP subscale scores and the Health Perception Scale. Strongest correlations occurred between the Health Perception Scale and the DUHP symptom subscale (.47). The remaining three subscale correlations ranged from .40 to .43.

Discussion

There was a general trend toward improvement as m asured by the DUHP subscales in the sample as a whole and in each diagnostic group although the improvement was not statistically significant. This trend is not surprising as improvement could be expected with all subjects involved in a treatment or rehabilitation program during the study. It is possible that further studies in chronic illness populations using longer time intervals would obtain statistically significant changes in perceived health status as measured by the DUHP subscale scores over time. Longer time intervals would more closely parallel the course of chronic illness and could apply to both improvement or decline in health status.

The DUHP was shown to be reliable in this sample of individuals with chronic illness. Internal consistency values (Cronbach's Alpha and Guttman) were equal to or higher than those obtained by the original authors. In addition, test-retest reliabilities were higher than those reported by Parkerson et al. They had speculated that test-retest would be higher in a more dysfunctional sample, which was found to be the case in this study.

In general, internal consistency estimates were stable over time except for scalability in the social dimension for time 3. However, when the most dysfunctional group (CVA) was removed from the analysis, scalability of the social subscale rose from .16 to .51. These relatively strong reliabilities

may be a combination of the reliability of the instrument and greater homogeneity of the sample populations in terms of diagnosis. In this study all subjects were experiencing chronic illness and only five diagnostic categories were included.

Evidence for construct validity in this study was demonstrated in the correlations between DUHP subscale scores and the self-anchoring Health Perception Scale. The finding that the strongest correlation was found with the symptom subscale suggests that symptoms may be the least subjective indicator of health status and therefore would be expected to correlate most closely with perceptions of health.

There are several possible explanations for the lack of significant findings between the physiological/functional variables and DUHP scores. First, all of the comparison measures with the exception of the functional rating scales used in the stroke and cancer samples were physiological indicators rather than performance evaluations. This provides evidence that the clients' perceptions of their health or physical well-being may not be dependent upon those indicators health professionals use to judge health status. Secondly, while small changes on some of the measures were enough to classify the subjects as "improved" (i.e. blood glucose drop from 180 to 150), this may not have been enough change to produce any difference in the person's response to DUHP subscales over the three week time period. Third, measurement

error in the improvement variable could not be excluded. Some of the data was self-reported (heart rate, angina, blood glucose) and there may have been random fluctuation in all variables over this short time period.

This study has provided initial evidence that the Duke-UNC Health Profile is a reliable instrument for assessing health status and evaluation of health care outcomes in chronic illness. Although statistical significance was not achieved, it is possible that the use of longer time intervals which correlate more closely with the course of chronic illness would yield significant results. Consequently, recommendations for further study include longer time intervals between administrations, larger samples, and additional diagnostic groups.

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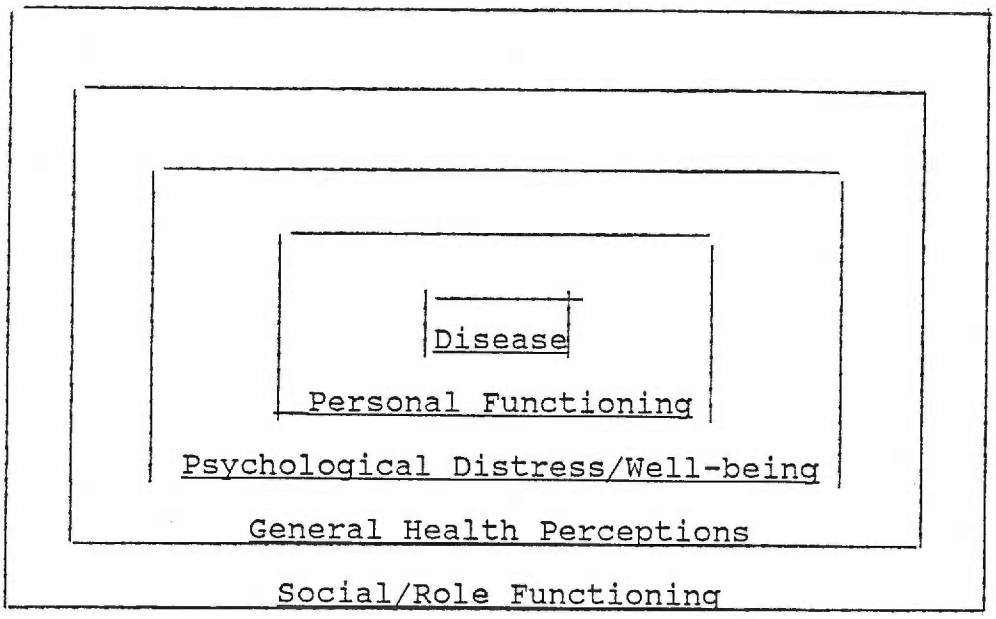
Appendix A

Conceptual Framework

In caring for individuals with a chronic illness, the interrelationship between the physiological and psychosocial mechanisms must be addressed. Ware (1984) has proposed a model for assessment of disease and its impact on the individual.



At the center of the model is the disease itself which encompasses symptoms and the underlying physiological or metabolic abnormalities. Assessment of disease, then, must consider signs recognizable by the individual as well as those that can be detected by various tests and procedures performed by the client or health care professional. The presence of underlying physiological abnormalities with their resultant symptoms may directly affect the person's personal

functioning, that is, the ability to perform everyday tasks such as self-care, physical activities, and mobility. Assessment of this dimension of physical functioning may be carried out by asking the person what he/she can do such as walking stairs or combing hair.

Ware (1984) and Parkerson and associates (1981) have acknowledged that physical function alone however, is not an adequate description of the impact of disease on the individual. Clinicians caring for people with chronic illness note that physical/personal function activities often continue despite severe symptoms. Thus, another dimension of the model is psychological distress/well-being. This dimension addresses the individual's feeling state or self-esteem. An individual living with a chronic illness may show no alteration in ability to perform self-care or usual daily activities but report dramatic impact on her/his emotional reactions as a result of the illness.

General health perceptions relate to the individual's estimation of the quality of her/his health. This dimension is proposed to encompass the first three dimensions in that people evaluate the status of their health on the basis of symptoms, personal functioning, and emotional well-being. The General Health Rating Index (Davies & Ware, 1981), demonstrated that the majority of individuals scoring in the lower 10% of the instrument showed one or more serious chronic disease, a functional limitation, and/or psychological

impairment. However, many individuals with chronic disease also demonstrated little correlation between perceived health status and severity of their chronic illness. This indicates perhaps, that the individual's perception of health status should receive greater attention by health care providers.

Social/Role functioning refers to the ability to perform usual role activities such as formal employment or family role. Regimens designed to treat chronic illnesses often require enormous investment in time, energy, and expense (Glaser & Stauss, 1975). The impact of these regimens, such as those required of people with diabetes may be dramatic in terms of the person's ability to meet the demands of a job or family role. Because treatment of chronic illness is directed at enabling the individual to continue with usual activities and her/his desired life style, evaluation of ability to perform social role is important.

In summary, assessment of health status, particularly in chronic illness, must consider not only the obvious physical signs and symptoms but also the individual's emotional well-being and social function. An individual with a chronic illness has the same basic concerns as a healthy person "to manage personal, social, and occupational activities as well as he can... much depends on altering the conditions under which he functions and in revising his expectations of the amount and type of activity he can perform" (Reif, 1973).

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Appendix B

Description of Cardiac Subsample

Those people in the cardiac sample (n=21) were all beginning a Phase II cardiac rehabilitation program and were either post-myocardial infarction or post-coronary artery bypass graft surgery. The sample was a volunteer sample selected from three programs - two community-based programs and one hospital-based program in two states (Washington and Oregon).

The mean values on the emotional subscale for this group did not differ significantly from those on the emotional subscale for the other groups. The mean values on the symptom subscale for the cardiac group were significantly higher (0.05, Scheffe Test) than those for the other groups at Time 1 and Time 2. However, by Time 3, the other groups had improved on the symptom subscale so there were no significant differences between the cardiac group and the other groups.

Changes in mean subscale scores over time for the cardiac sample followed a pattern similar to those of the other groups, with most showing slight improvement from Time 1 to Time 2 to Time 3. The social subscale was the exception, with a mean score of 0.76 at Time 1, 0.70 at Time 2, and again 0.76 at Time 3. This could be explained by a number of factors, including very cold, snowy weather during the week the Time 2 results were obtained. The weather could have reduced the social

interactions of this sample during that time.

There were no significant correlations between the Health Perception scale and any of the subscale scores for this group. In addition, there were no significant correlations between the physiological/functional variables and the DUHP subscale scores. The physiological variables used for this group were heart rate; pre-exercise, during exercise, and post-exercise. The heart rates were self-reported. In each program, the participants took their own pulse and recorded it on a card. The heart rates remained almost the same throughout the program - even post-exercise, and so did recovery to their resting heart rate. Also, participants in the cardiac rehabilitation programs reported any angina they experienced while exercising. No angina was reported by any of the participants. Two patients who reported angina in the first exercise session were referred for coronary artery bypass graft surgery and dropped from the study.

Appendix C

Description of Cancer Subsample

Advances in treatment have resulted in increased numbers of persons living with cancer. Cancer has become one of the most prevalent chronic illnesses whose course may span months or years. Problems related to cancer and its treatment may affect all aspects of living, necessitating the need for quantification and evaluation of that impact on the person's life. The cancer sample was included in this study to evaluate the usefulness of the DUHP in this subsample of persons with chronic illness.

The cancer sample was obtained from Good Samaritan Hospital and Medical Center. These were persons diagnosed with cancer who met the general entry requirements of the study. In addition, they were involved in the cancer rehabilitation portion of Good Samaritan's cancer program and were receiving a minimum of two services from the Cancer Rehabilitation Team.

This sample consisted of 17 persons ranging in age from 39 to 70 with a mean age of 57. There were 12 females and five males. Diagnoses ranged from breast cancer (n=7), lung cancer (n=2), bladder cancer (n=1), endometrial (n=1), colon (n=1), multiple myeloma (n=1), adenocarcinoma of the stomach (n=1), osteogenic sarcoma (n=1), liver cancer (n=1), and brain cancer (n=1).

The comparison measure used for the cancer sample was the Karnofsky Performance Status Scale (KPS) (Karnofsky, Abelman, Craver, & Burchenal, 1948). The KPS is widely used to quantify

the functional status of cancer patients, to stratify subjects exposed to various treatment interventions (chemotherapy, surgery, radiation, nutritional), and as an outcome measure to compare differences in the functional abilities of the subject before and after the intervention. The KPS has also been used as a comparison measure in the development of other instruments (Padilla, Presant, Grant, Metter, Lipsett, & Heide, 1985; McMurray & Levitt, 1984). The KPS has also shown use as a predictor for the length of survival of terminal cancer patients (Mor, Laliberte, Morris, & Wiemann, 1984; Yates, Chalmer, & McKegney, 1980).

The KPS rates physical activity on a scale from 0 to 100% in increments of 10. It has been shown to be a reliable and valid measure of perfomance/functional status in persons with cancer. Mor and colleagues (1984) achieved an interrater reliability of 0.97, while Yates et al (1980) obtained a value of 0.69. In a study conducted by Schag and colleagues (1984), an interrater reliability of 0.89 was achieved.

Construct validity with other measures (Katz ADL Index, Melzack's Pain Questionnaire, Cancer Inventory of Problem Situations, specific variables related to physical function and psychological status, etc.) was shown to exist in the previously mentioned studies. Mor (1984) constructed a severity index from specific functional variables. The chi-square test indicated significant differences among categories ($p<0.001$) and a very strong relationship between increasing KPS scores and higher

functional status (contingency coefficient = 0.49). Over 50% of the cases in the two worst KPS levels were in the worst severity category, while 40% of the patients with a KPS of 50 were in the "most functional" severity category. In this same study, a relationship between the KPS and the physical Quality of Life (QL) was demonstrated. There were significant differences ($p<0.001$) between the KPS levels in the proportion of persons with low physical QL values--the lower the KPS values, the higher the proportion of persons with poor physical QL (Kendall's tau statistic of 0.35 between the two measures, indicating a strong relationship). In addition, the degree of pain reported by patients at various KPS scores was measured using a modified version of Melzack's pain questionnaire. No significant relationship to the patient's KPS rating was found. There was also no significant relationship between the KPS score and other physical symptoms reported by the patients.

In a study conducted by Yates and associates (1980), the KPS was strongly correlated with variables most closely related to physical functioning (especially difficulty with balance and difficulty on stairs; 0.61 and 0.63, respectively) and less strongly (but still significantly; ranging from 0.24 to 0.54) with most of the variables related to psychological status. Of interest is the lack of significant correlations with the variables: pain level (-0.37), negative affect (-0.09), and happiness (0.12).

Schag and colleagues (1984) evaluated the construct validity

of the KPS with correlations with 18 variables previously selected. All of the 18 variables were significantly correlated at the 0.05 level or less with the physician's KPS; however, eight of the variables had the greatest correlations (problems with eating and grooming; difficulty walking, doing physical activity, and driving; difficulty working part time; weight loss, pain, and a reduction in energy). These studies demonstrate that the KPS has considerable validity as an overall indicator of the functional status of patients with cancer.

In this present research project, the KPS was used as an objective measure (i.e., health care provider rated). The subject was given a score at the time of the three separate DUHP administrations. To determine interrater reliability, the first KPS score assigned by the investigator was compared with the score assigned by another health care provider who was familiar with the subject. Interrater reliability was found to be 0.80.

The KPS scores ranged from 40% to 100% with an overall mean of 77%. The means of the KPS, as with the DUHP subscale means and the Health Perception Scale (HPS) means, showed a trend toward improvement over time (KPS Time 1 - 74.12, Time 2 - 77.72, and Time 3 - 78.75) (HPS Time 1 - 5.20, Time 2 - 5.29, Time 3 - 5.63). On the HPS, a score of eight and nine occured more frequently with KPS scores of 80% to 100% (12/27, or 44%). Of interest also is the occurence of self-assigned scores of two and three on the HPS which corresponded with rater-assigned KPS scores of 80% and 90% (5/27, or 19%). These findings may

indicate the difference between overall perceived health status as viewed by the patient and the patient's health as perceived by the health care provider.

Correlations between the HPS scores for this sample at Time 1 correlated most closely with the physical subscale of the DUHP (Pearson's r=0.58, p=0.02). At Time 2 there were no significant correlations between the DUHP subscales and the HPS. Time 3 showed correlations most closely with the symptom subscale (Pearson's r=0.60, p=0.007) and the physical subscale (Pearson's r=0.55, p=0.014). Correlations of the DUHP subscale scores and the KPS were not obtained. However, correlations between the improvement variable (extrapolated from decline, unchanged, or improvement of the functional/physiological measures) and the DUHP for the total group showed a lack of significant correlation (Pearson's r Time 2 = 0.065; Time 3 = -0.015). The original intention of the improvement variable was to allow for total group comparison of the functional/physiological measures and the HPS and DUHP. Although the improvement variable scores were obtained from changes in scores of these measures, the data was most likely collapsed to to great an extent to prove meaningful.

The use of the KPS in this study seems to bear out previous findings indicating it's usefulness as an overall functional status measure, while emphasizing that it may not address those psychological, emotional, and social components of perceived health status. Further statistical analysis would be necessary

to determine more closely the associations between the DUHP and the KPS.

Recommendations for future research on the KPS and the DUHP include: 1) further comparisons of the KPS with the DUHP symptom and physical subscales, and 2) comparison of the KPS as an objective (health care provider) and subjective subject-rated) measure.

KARNOFSKY PERFORMANCE STATUS SCALE

	Percent	
Able to carry on normal no activity; no special care is needed	100	Normal; no complaints, evidence of disease
	90	Able to carry on normal activity;minor signs or symptoms of disease
	80	Normal activity with effort; some signs or symptoms of disease
Unable to work; able to live at home; cares for most personal needs; a varying amount of assistance is needed	70	Cares for self; unable to carry on normal activity or do active work
	60	Requires occasional assistance but is able to care for most needs
	50	Requires considerable assistance and frequent medical care
Unable to care for self; equivalent of institutional or hospital care; disease may be progressing rapidly	40	Disabled, requires special care and assistance
	30	Severly disabled; hospitalization is indicated though death not imminent
	20	Very sick; hospitalization is necessary
	10	Moribund; fatal processes progressing rapidly
	0	Dead

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Appendix D

Description of Obesity Subsample

Obesity is one of the more prevalent chronic health problems in the United States today. Fourteen percent of adult men and twenty-four percent of adult women are at least twenty percent overweight (Bray, 1980). This figure continues to rise (White, 1982). Obesity can be a contributing factor to many other diseases including cancer, diabetes, heart disease, and atherosclerosis (Stewart & Brook, 1983; & Stunkard, 1984). The obesity sample was included in this study to evaluate the usefulness of the Duke University of North Carolina Health Profile (DUHP) in evaluating a treatment program designed to intervene in this chronic illness.

The sample was obtained from an obesity treatment clinic affiliated with Oregon Health Sciences University Hospital. All of the subjects were enrolled in the rehabilitation treatment program designed by the OHSU clinic.

The sample consisted of eighteen subjects originally; two dropped out of the study leaving a final n of 16. All were daignosed as having an obese condition prior to acceptance in the treatment setting. The program entails a modified fast or low calorie diet accompanied by weekly group sessions designed to discuss different aspects of weight loss and maintenance.

In this research project, weight was used as an objective

comparison measure to the DUHP. Weight was monitored along with the administration of the DUHP at three week intervals . All subjects lost weight during the study. Improvement on all subscales of the DUHP except the symptom subscale was noted at Time 2, and on all subscales but the physical at Time 3 (Table 1).

Table 1

Subscale Means for Obesity Sample by Administration

	Time 1	Time 2	Time 3
Symptom	.79	.79	.84
Physical	.64	.68	.68
Social	.72	.78	.79
Emotional	.68	.71	.75

The use of the DUHP in this sample seems to correlate fairly well with weight loss. The relatively small number of subjects and short time intervals between administrations renders it difficult to make any stronger statements related to the usefulness of the DUHP. Recommendations for further study include: (1) longer time intervals between administrations, (2) a greater number of administrations, and (3) use of another comparison measure in addition to weight loss.

References

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Appendix E

Description of Diabetes Subsample

Diabetes is a prevalent incurable chronic disease affecting more than 11 million Americans (American Diabetes Association Fact Sheet, 1984). In addition, diabetes, with its complications, is the third leading cause of death by disease in the United States. Complications associated with diabetes occur as a result of the derangement in glucose metabolism with the resultant prolonged exposure to hyperglycemia (Ross, Bernstein & Rifkin, 1983).

Because diabetes is not curable, treatment has historically focused on the control of blood glucose levels in an effort to prevent or delay complications such as renal deterioration, retinal hemorrhages, and neuropathy. However, the impact of a chronic disease such as diabetes not only affects the way the individual feels physically, but also interferes with social function and psychological well-being. "The intrusion of a significant illness, especially of a chronic and disabling nature, is a major life crisis posing a formidable challenge to what was previously a workable adaptation to life" (Feldman, 1974).

Clinicians involved in the care of individuals with diabetes are concerned not only with correction of the underlying physiological derangement, but also the impact of the disease on other areas of human functioning such as social role and emotional state. Treatment and education programs

are increasingly adopting a more holistic approach to diabetes management. To evaluate the effect of such programs on the physical, emotional, and social health status of individuals, instruments which are multidimensional in nature should be used in conjunction with physiological indicators of disease status.

A subsample of individuals with diabetes was appropriate to include in this study testing the reliability, validity, and usefulness of a multi-dimensional health status measure (DUHP). Subjects for this subsample were obtained from the Oregon Health Sciences University Diabetes outpatient treatment and education/self-management program. This subsample consisted of 14 individuals with Type I or Type II diabetes mellitus. The mean age was 46 years.

As with the other four diagnostic groups in the study, subjects with diabetes showed a consistent trend toward inprovement over the three time periods. This indication of improvement over time is not surprising as the individuals were involved in a program designed to improve their physical well-being and assist them in acquiring essential self-management skills for control of the disease. Longer time intervals between administrations of the DUHP would probably result in statistically significant differences in scores particularly on the symptom and physical subscales. The rationale for this hypothesis lies in the nature of diabetes. Initial normalization of blood glucose levels often

takes longer than six weeks and because most symptoms relate to abnormal glucose levels, measures of symptoms and physical function would be reflective of this time period. This, of course, is a generalization which has exceptions. There is no specific blood glucose level at which symptoms appear or disappear and occasionally individuals report essentially no symptoms even with marked elevations.

Despite the fact that blood glucose levels are not necessarily predictive of physical symptoms or dysfunction, these levels are an important evaluation measure in the management of diabetes. Blood glucose levels were converted into the improvement variable for the purposes of this study. In this conversion, even small changes in blood glucose (30-50 mg./dl.) were considered as "improved" or "not improved". These changes may not have been of sufficient magnitude to influence scores on the DUHP subscales. This is the most plausible explanation for the finding of no correlation between DUHP subscale scores and the improvement variable.

In summary, the conclusions drawn from this study can be echoed in this subsample. The Duke-UNC Health Profile was clinically feasible to use because of its brevity and concise format and it demonstrated sensitivity to change over the relatively short time period.

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Appendix F

Description of Stroke Subsample

The subsample of persons rehabilitating following a stroke due to cerebral thrombosis represented the only hospital bound group. The individuals with stroke were spending six to twelve weeks at the Rehabilitation Institute of Oregon (RIO). This setting was selected because patients had been screened for having a good prognosis for rehabilitation to higher functional levels. In other words, these patients were expected to improve their health status as a result of the intervention.

The CVA subsample was older than the larger group, the average age being 67 (Table 1) and the most debilitated, most experiencing upper extremity diysfunction. While other subjects in the study were capable of carrying out activities of daily living, the stroke patients were unable to accomplish simple tasks without assistance. Table 2 lists the subscale score means of all diagnostic groups for Times 1 through 3. While the CVA subsample demonstrated a similar trend toward gradual improvement, the scores on the physical and social subscales are significantly lower than the other diagnostic groups. The social subscale asked questions such as, "How many days in the last week were you in bed due to illness?" This subscale was the least applicable to the CVA subsample.

It is interesting to note that persons with stroke did not differ significantly on either the symptom or the emotional subscales. In spite of the fact that these individuals were physically incapable of performing ADL's unassisted, their perceived health status, as measured by the Health Perception Scale, their symptom report, and their self-esteem, as measured by the emotional subscale of the DUHP, paralleled scores of ambulatory, functional individuals (Table 3).

This seemingly optimistic self-report of health status could have several explanations. First, the environmental "mindset " of positive reinforcement for even minor functional improvements could have had an effect on subjects' responses to the instrument items (Forsyth, Delaney, and Gresham, 1984). Second, many subjects answered according to how they viewed themselves and their functional ability prior to the stroke. In other words, subjects' responses were more reflective of their "traits" rather than their "states". A third explanation was explored statistically during the study in that generally, there was little correlation between an individual's physical capabilities and their perceived state of health or self-esteem.

As with the other subsamples, there was essentially no correlation between any of the subscales and the improvement variable. This comparison measure of a multidisciplinary team rating of improvement, while clinically valuable, was not a tested reliable measure. Essentially, the study attempted to correlate subscale score means of perceived health with a subjective "change" score, and encountered the methodological difficulties typical of measuring change over time.

References

Forsyth, G.L., Delaney, K.D. & Gresham, M.L. (1984). Vying for a winning position: Management style of the chronically ill. Research in Nursing and Health, 7, 181-188.

Informed Consent

I _____ agree to participate in an investigation about health status in chronic disease conducted by Tamara Schuman, Susan King, Susan Holt, Maryanne Bletscher, and Karen Benson. The researchers are registered nurses enrolled in the Oregon Health Sciences University School of Nursing, Department of Adult Health and Illness.

I understand that I will be asked to complete a three page questionaire on three occasions, three weeks apart. The questionaire will take approximately 10-30 minutes of my time on each occasion.

I understand that all information about myself or my participation in this study will remain confidential. Code numbers will be assigned to me to protect my privacy and any identifying information will be destroyed when the project is completed.

My questions about the project have been answered. If I have any further questions I may contact _____ or Carol Burckhardt R.N. PH.D. at (503) 225-7796.

The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions please call Dr. Michael Baird, M.D. at (503) 225-8014.

I understand that I may refuse to participate or withdraw from the study at any time without in any way affecting my relationship with, or care at, the Oregon Health Sciences University.

I have read the foregoing and agree to participate in this study.

Date:_____ Signature:_____

Witness: _____

Date: _____

ID Number: _____

Date of Birth: _____

Method of Administration:

- ☐ Self-administered
- ☐ Interviewer-administered (_____)
  Interviewer

Duke-UNC Health Profile

Duke-UNC Health Profile

Instructions:

Here are a number of questions about your health and feelings. Please read each question carefully and check (✓) your best answer. You should answer the questions in your own way. There are no right or wrong answers.

DURING THE PAST WEEK: How much trouble have you had with:

	None	Some	A Lot
1) Eyesight			
2) Hearing			
3) Talking			
4) Tasting food			
5) Appetite			
6) Chewing food			
7) Swallowing			
8) Breathing			
9) Sleeping			
10) Moving your bowels			
11) Passing water/urinating			
12) Headache			
13) Hurting or aching in any part of your body			
14) Itching in any part of your body			
15) Indigestion			
16) Fever			
17) Getting tired easily			
18) Fainting			
19) Poor memory			
20) Weakness in any part of your body			
21) Feeling depressed or sad			
22) Nervousness			

DURING THE PAST MONTH how much trouble have you had with:

	None	Some	A Lot
23) Undesired weight loss			
24) Undesired weight gain			
25) Unusual bleeding			
26) Sexual performance (Having sex)			

DURING THE PAST WEEK how often did you:

	Not at All	1-4 Days	5-7 Days
27) Do your usual work (either inside or outside the home)	_____	_____	_____
28) Get your work done as carefully and accurately as usual ...	_____	_____	_____
29) Socialize with other people (talk or visit with friends or relatives)	_____	_____	_____
30) Take part in social, religious or recreation activities (meetings, church, movies, sports, parties)	_____	_____	_____
31) Care for yourself (bathe, dress, feed yourself)	_____	_____	_____

DURING THE PAST WEEK:

	None	1-4 Days	5-7 Days
32) How many days did you stay *in your home* because of sickness, injury or health problems?	_____	_____	_____
33) How many days were you *in bed* most of the day because of sickness, injury or health problems?	_____	_____	_____

TODAY would you have any physical trouble or difficulty:

	None	Some	A Lot
34) Peeling an apple	_____	_____	_____
35) Combing your hair	_____	_____	_____
36) Walking to the bathroom	_____	_____	_____
37) Walking up a flight of stairs	_____	_____	_____
38) Running the length of a football field	_____	_____	_____
39) Running a mile	_____	_____	_____
40) Running 5 miles	_____	_____	_____

Instructions:

Here are some statements you could use to describe how you feel about yourself. Please read each statement carefully and place a check (✓) in the blank that best fits how the statement describes you.

Here is an example:

	Yes, describes me exactly	Somewhat describes me	No, doesn't describe me at all
I like T.V. soap operas		✓	

(If you put a check where we have, it means that liking T.V. soap operas describes you more than "somewhat" but not "exactly".)

Answer each item as best you can. There are NO right or wrong answers.

	Yes, describes me exactly	Somewhat describes me	No, doesn't describe me at all
41) I am a pleasant person			
42) I don't feel useful			
43) I get on well with people of the opposite sex ..			
44) My family doesn't understand me			
45) I like who I am			
46) I feel hopeful about the future			
47) I try to look my best			
48) I am a clumsy person			
49) I have difficulty making decisions			
50) I like meeting new people			
51) I'm not an easy person to get along with			
52) I'm a failure at everything I try to do			
53) I'm basically a healthy person			
54) I wish I had more sex appeal			
55) I give up too easily			
56) I like the way I look			
57) I'm not as smart as most people			
58) I have difficulty concentrating			
59) I'm satisfied with my sexual relationships			
60) I am happy with my family relationships			
61) I don't treat other people well			
62) I am comfortable being around people			
63) I can take care of myself in most situations			

Purpose and Nature of the Instrument

The measurement of health is important in studying human response to physical and psychosocial environmental factors and in assessing the impact of medical care interventions. While other measures of health status exist and have had limited use among health care researchers, there has been a need for an instrument suitable both for research and for ongoing clinical assessment which is brief, simply administered, and easily comprehended by a broad cross section of patients in the primary care setting. The Duke-UNC Health Profile (DUHP) was developed to meet this need. It is intended for adults aged 18 years or older, is self-administered for those with at least a ninth grade education or otherwise easily interviewer-administered, and can be scored by hand or machine.

Its 63 self-descriptive items cover the following major dimensions of health: symptom status (26 items); physical function measured by disability days, ambulation and use of upper extremities (9 items); emotional self-esteem including personal, physical and social self (23 items); and social role performance comprising self-care, ability to function in the work place or at home, interactions with people and participation in community and social events (5 items). Completion time is 10 minutes (self-administered) or 20 to 30 minutes (interviewer-administered).*

Guidelines for Administration

Self-administration:

1. The questionnaire should be completed within a stated encounter or doctor visit.
2. There should be no discussion of any of the items with anyone, including family members.
3. To ensure completeness of data, reinforce the importance of responding to every item and check for any missing items when the respondent has finished the questionnaire.

Interviewer-administration:

1. Administration by interviewer is indicated for those participants with less than ninth grade education, and/or with a writing or visual impairment.
2. The entire questionnaire, including instructions and items, must be read exactly as written.

A standardized explanation of the instrument by the administrator to the respondent should be developed by each investigator or provider using the DUHP. It should be appropriate for the particular setting in which it is being used.

Calculation of Dimension Scores

Each item has a range of values from 0 to 2 or 0 to 4 depending on the length of its scale. Each of the four dimension scores, i.e., symptom status, physical, emotional, and social function, is a proportion from 0 to 1 and is calculated by summing the raw item values within each dimension and dividing by the maximum sum for that dimension. Higher scores indicate better function; lower scores, poorer function.

> **Example:** If 5 symptoms are checked as "some trouble" and the remaining 21 are "no trouble," the raw symptom sum is $(5 \times 1) + (21 \times 2)$ or 47; the symptom status dimension score is 47 divided by the maximum symptom sum, 52, or 0.90.

Missing data: Despite precautions to ensure that all the items are answered, respondents may still omit items. The scoring procedure to follow for missing items is to use a substitute value for each item omitted. This substitute value is a dimension-specific mean, a whole number, which is computed by summing the values of the items checked within a given dimension and dividing by the number of items checked. If the tenth decimal place is greater than or equal to 5, the mean is rounded to the next whole number.

> **Example:** Two of the 26 symptom status items were not checked by the respondent. The sum of the values for the remaining 24 items which were checked equals 36. The mean substitute value then would be $36 \div 24 = 1.5$. When this value, rounded to 2, is substituted for each of the missing values, the raw score for the dimension becomes $36 + 2 + 2 = 40$. This is divided by the maximum sum for the symptom status dimension to give the final score, 0.77 ($40 \div 52 = 0.77$).

See the following pages for the values assigned for scoring. (Transparent overlays are furnished to facilitate scoring.)

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*For development of the instrument and its psychometric properties, see: Parkerson G R Jr, Gehlbach S H, Wagner E H, James S A, Clapp N E, Muhlbaier L H: The Duke—UNC Health Profile: An Adult Health Status Instrument for Primary Care. *Medical Care* 19:806-828, 1981.

Duke-UNC Health Profile

Instructions:

Here are a number of questions about your health and feelings. Please read each question carefully and check (✓) your best answer. You should answer the questions in your own way. There are no right or wrong answers.

SYMPTOMS—TOTAL SUM: 52

DURING THE PAST WEEK: How much trouble have you had with:

	None	Some	A Lot
1) Eyesight	2	1	0
2) Hearing	2	1	0
3) Talking	2	1	0
4) Tasting food	2	1	0
5) Appetite	2	1	0
6) Chewing food	2	1	0
7) Swallowing	2	1	0
8) Breathing	2	1	0
9) Sleeping	2	1	0
10) Moving your bowels	2	1	0
11) Passing water/urinating	2	1	0
12) Headache	2	1	0
13) Hurting or aching in any part of your body	2	1	0
14) Itching in any part of your body	2	1	0
15) Indigestion	2	1	0
16) Fever	2	1	0
17) Getting tired easily	2	1	0
18) Fainting	2	1	0
19) Poor memory	2	1	0
20) Weakness in any part of your body	2	1	0
21) Feeling depressed or sad	2	1	0
22) Nervousness	2	1	0

DURING THE PAST MONTH how much trouble have you had with:

	None	Some	A Lot
23) Undesired weight loss	2	1	0
24) Undesired weight gain	2	1	0
25) Unusual bleeding	2	1	0
26) Sexual performance (Having sex)	2	1	0

SOCIAL—TOTAL SUM: 10

DURING THE PAST WEEK how often did you:

	Not at All	1-4 Days	5-7 Days
27) Do your usual work (either inside or outside the home)	0	1	2
28) Get your work done as carefully and accurately as usual ...	0	1	2
29) Socialize with other people (talk or visit with friends or relatives)	0	1	2
30) Take part in social, religious or recreation activities (meetings, church, movies, sports, parties)	0	1	2
31) Care for yourself (bathe, dress, feed yourself)	0	1	2

PHYSICAL—TOTAL SUM: 18

DURING THE PAST WEEK:

	None	1-4 Days	5-7 Days
32) How many days did you stay *in your home* because of sickness, injury or health problems?	2	1	0
33) How many days were you *in bed* most of the day because of sickness, injury or health problems?	2	1	0

TODAY would you have any physical trouble or difficulty:

	None	Some	A Lot
34) Peeling an apple	2	1	0
35) Combing your hair	2	1	0
36) Walking to the bathroom	2	1	0
37) Walking up a flight of stairs	2	1	0
38) Running the length of a football field	2	1	0
39) Running a mile	2	1	0
40) Running 5 miles	2	1	0

Instructions:

Here are some statements you could use to describe how you feel about yourself. Please read each statement carefully and place a check (✓) in the blank that best fits how the statement describes you.

Here is an example:

	Yes, describes me exactly	Somewhat describes me	No, doesn't describe me at all
I like T.V. soap operas		✓	

(If you put a check where we have, it means that liking T.V. soap operas describes you more than "somewhat" but not "exactly".)

Answer each item as best you can. There are NO right or wrong answers.

EMOTIONAL—TOTAL SUM: 92

	Yes, describes me exactly		Somewhat describes me		No, doesn't describe me at all
41) I am a pleasant person	4	3	2	1	0
42) I don't feel useful	0	1	2	3	4
43) I get on well with people of the opposite sex ..	4	3	2	1	0
44) My family doesn't understand me	0	1	2	3	4
45) I like who I am	4	3	2	1	0
46) I feel hopeful about the future	4	3	2	1	0
47) I try to look my best	4	3	2	1	0
48) I am a clumsy person	0	1	2	3	4
49) I have difficulty making decisions	0	1	2	3	4
50) I like meeting new people	4	3	2	1	0
51) I'm not an easy person to get along with	0	1	2	3	4
52) I'm a failure at everything I try to do	0	1	2	3	4
53) I'm basically a healthy person	4	3	2	1	0
54) I wish I had more sex appeal	0	1	2	3	4
55) I give up too easily	0	1	2	3	4
56) I like the way I look	4	3	2	1	0
57) I'm not as smart as most people	0	1	2	3	4
58) I have difficulty concentrating	0	1	2	3	4
59) I'm satisfied with my sexual relationships	4	3	2	1	0
60) I am happy with my family relationships	4	3	2	1	0
61) I don't treat other people well	0	1	2	3	4
62) I am comfortable being around people	4	3	2	1	0
63) I can take care of myself in most situations	4	3	2	1	0

APPENDIX I

DEMOGRAPHIC INFORMATION

ID#_____

AGE_____

SEX_____

MARITAL STATUS

_____Married/Partnered

_____Widowed

_____Divorced/Separated

_____Never Married

EDUCATION

_____Grammar School

_____High School

_____Technical School

_____College

_____Graduate School

PRESENT OCCUPATIONAL STATUS
Example: Salesman/ Lawyer/ Retired

_____

MEDICAL DIAGNOSIS

_____

_____

_____

LENGTH OF TIME SINCE FIRST DIAGNOSED
Example: 2 years, 6 months

_____years _____months _____weeks

LIST THE PERSONS IN YOUR HOME, NOT INCLUDING YOURSELF.
Example: Wife, son, daughter

_____ _____ _____

_____ _____ _____

THE OREGON HEALTH SCIENCES UNIVERSITY

MEMO

Date: August 7, 1985

To: Carol S. Burckhardt, Ph.D/RN MacHall 4123

From: Donna Buker, Administrative Assistant
Committee on Human Research

Subject: "Evaluation of the Duke-UNC Health Profile in Chronic Illness Populations

Your above entitled study falls under category # 3 and is considered to be exempt from the requirement for Committee on Human Research. Therefore, I have put your study into our exempt files and you will receive no further communication from our Committee concerning this study.

If the involvement of human subjects changes in this study you should contact the Committee on Human Research to find out whether or not these changes should be reviewed.

If you have any questions regarding the status of this study, please contact Donna Buker at X7887.

Sincerely,

Donna Buker

Donna Buker, Admin. Asst.
Committee on Human Research

APPENDIX K

May 23, 1985

George R. Parkerson,Jr., M.D.
Department of Community and Family Medicine
Box 3886
Duke University Medical Center
Durham, N.C., 27710

Dear Dr. Parkerson;

We are graduate nursing students at the Oregon Health Sciences University in Portland, Oregon. The focus of our research is the assessment of health status in chronic illness populations. Although the Duke-UNC Health Profile was originally developed for a primarily healthy population, we would like to apply it to our practice situations. The groups to be tested are patients with post myocardial infarction, chronic obesity, diabetes mellitus, breast cancer, and stroke due to cerebral thrombosis.

We found the research instrument easy to administer, efficient and comprehensive and would appreciate your permission to use it in our study. We will be careful to cite proper authorship, reliability, and validity issues and to keep you posted on our progress.

Thank you for your time and consideration.

Sincerely,

Karen Benson, RN, PhD. Susan King, RN, BSN

Susan Holt, RN, BSN Mary Ann Bletscher, RN, BSN

Tamara A.Schuman, RN, BSN
1185 Forest Meadows Way
Lake Oswego, Or. 97034
503-635-4986

DUKE UNIVERSITY MEDICAL CENTER

Division of Family Medicine
Department of
Community and Family Medicine

June 3, 1985

Tamara Schuman
1185 Forest Meadows Way
Lake Oswego, OR 97034

Dear Ms. Schuman:

Thank you for your interest in the Duke-UNC Health Profile. We are most anxious for investigators to further test the instrument and gladly give you permission to use the profile. I am enclosing an order form which you can use to obtain the copies you need. I am also sending a sample copy and scoring directions, along with the list of other people who have obtained permission to use the instrument.

I hope that the instrument will serve the purpose that you envision. We would ask that you keep us informed of your findings and use the customary citations if any work is published.

If there is any way I can help please let me know.

Sincerely,

George R. Parkerson, Jr., M.D., M.P.H.
Associate Professor

GRP/kbb
Enclosures

Box 3886 • Durham, North Carolina 27710 • Telephone (919) 471-2571

Introduction

Health status has generally been defined in terms of the disease process and the physiological changes in the body produced by disease (Parkerson, Gehlbach, Wagner, James, Clapp & Muhlbaier, 1981). Recently, more global definitions of health have broadened both attitudes and approaches in the assessment of the impact of advances in health care technology. The World Health Organization (WHO) states, "Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity." (World Health Organization, 1958). The recognition of the importance of including all areas of human functioning as criteria for evaluation has had a major influence in the movement from a strict medical model to a more holistic definition of health. Holism refers to the concept that health is a multifaceted phenomenon which encompasses social, economic, behavioral and physical influences (Feldman, 1974).

This comprehensive view of health is particularly applicable to the chronically ill population. Although the onset of a chronic illness is a major life crisis that requires continuous adaptation to ongoing alterations in physical functioning, in many ways the chronically ill individual remains healthy in other areas of human functioning.

Statement of the problem

The holistic view of health allows for consideration of all areas of human functioning. Health needs to be conceptualized as a phenomena coexisting with, yet different from illness. This suggests that a person may have an illness and yet at the same time, consider himself to be relatively healthy (Lamberton, 1983). An individual with chronic disease has the same basic concerns as a healthy person, "to manage personal, social, and occupational activities as well as he can...much depends on altering the conditions under which he functions and in revising his expectations of the amount and type of activity he can perform." (Reif, 1973). Nursing intervention is directed toward assisting the individual to manage resources and achieve an optimal level of functioning. In order to develop a plan of care and evaluate the specific ways in which social, occupational, and psychological aspects of the chronic illness and its treatment impact the person, assessment and quantification are necessary. An individual health status measurement instrument which is efficient and sensitive to the subtle changes in function experienced by persons with a chronic illness, would enable the nurse to obtain accurate data about the impact of illness and treatment. Further, information obtained by this method can be combined with physiological measures to yield a comprehensive evaluation of the status of the individual.

This study will examine the applicability of a specific health status measurement tool in five chronic illness populations. The overall question to be researched is whether

the instrument is sensitive enough to detect change in health, as perceived by the client, during a time period in which the underlying disease process is being subjected to treatment.

Review of the Literature

Historical Development of Health Status Indicators

The early forms of health indicators were used to describe the total health status of groups and focused on mortality and morbidity rates and disease incidence and prevalence (Jette, 1980). Until the early 1960's, death rates provided the only relevant and sensitive measure of the health of populations (Moriyana, 1968). However, Moriyana (1968) pointed out in his now classic article that death rates were unlikely to change unless major medical breakthroughs occurred which would increase life expectancy. At about this same time, as the problems associated with mortality as a measure of health status were realized, assessment of health relied increasingly on measures of morbidity (Bergner, 1985), and aggregate measures of health were described which would measure the physical health of the nation as a whole as the Gross National Product described its economic health (Linder, 1966). While these measures were useful from a community perspective in evaluating the health of populations, they were not particularly useful when attempting to focus on the health status of the individual (Jette, 1980).

As the definition of health moved toward a focus on the individual, subjective health ratings, symptom or illness inventories, and measures of physical function status became more common (George & Bearon, 1980). Early efforts focused on

one or more of these areas. The earliest work was in the specific area of mental health. Surveys and questionnaires were developed to measure the mental health of population groups. Examples of these measures are Norman Bradburn's measure of psychologic well-being (Bradburn, 1969), and Harold Dupuy's Index of General Well-Being (Fazio, 1977) in addition to others (Bergner, 1977; Stewart, Ware, & Brook, 1977). Also, instruments were developed to measure social functioning, social support and social networks (Greenblatt, 1975; Leighton, 1959; Lerner, 1973; Renne, K., 1974; & Stewart, Ware, & Brook, 1977).

With increasing awareness of the limitations of measuring single aspects of functional status came the development of multidimensional measures of functional status. These include the assessment of physical functional status but also include such factors as mental health status, quality of interpersonal relationships and social and economic resources. The theoretical background for such measures acknowledges the matrix of biological, psychological, and social factors that contribute to general health status (George & Bearon, 1980).

As this more holistic definition of health has evolved, health status measures have also moved from a negative perspective of disease to measuring health in a more positive, health-focused view (Bergner, 1985). Increasing recognition has been given in these measures to all the elements of human functioning. Quality of life measures are being used increasingly as an outcome measure of medical care services. The measuring of the "nonbiochemical and nonphysiologic aspects

of health as quality of life ... seems an attempt to separate the aspects of health that are manipulated directly by the clinician from those that may be indirect effects of disease or treatment." (Bergner, 1985). As quality of life is defined largely in terms of personal preferences, the life quality of aggregate members of society reflects the quality of its individual members (Dimond & Jones).

This comprehensive view of health is particularly applicable to the chronically ill population. The onset of a chronic illness can be a major life crisis that requires continuous adaptation to ongoing alterations in all areas of human functioning. Dimond and Jones (1983) suggest that the major sources of disability in those with chronic illness can be found in the interaction of clinical, personal, and social definitional systems. The interactive components of these systems and the function of each system alone makes it difficult, and yet, very important to accurately assess all areas of health status in chronic illness.

Health Assessment in Chronic Illness

When there is no cure for a chronic disease, attention is focused on reducing the level of disability (Charlton, Patrick & Peach, 1983). Until recently, evaluation of functional impairment associated with any particular chronic illness often used measures which "assesed only a small portion of the spectrum of functional impairments" (Deyo, Inui, Leininger, & Overman, 1982). This portion was usually the obvious physical disabilities. Psychosocial function, however, may be as important as physical function in judging a patient's response

to therapy and the need for and utilization of health services (Hunt, McKenna, McEwen, Backett, Williams & Papp, 1980).

Measurement of change in function over time is quantifiable, although change may vary from illness to illness. Changes in social and physical function as a result of rehabilitation programs can be measured. Abrahams, Wallach and Divens (1979), in a study of twelve long term geriatric patients, were able to evaluate the effectiveness of a psychosocial rehabilitation program by measuring an increase in social interaction, reduction in daytime sleeping, and increase in mobility. Seventy-two patients in a post myocardial infaction rehabilitation program (Ott, et al., 1983) showed improvement in mood and ability to undertake physical activity without anginal pain as a result of the program. Carey and Posovac (1982) were also able to detect changes in a population of stroke patients as a result of a structured rehabilitation program by evaluating activities of daily living (n=167), mobility (n=160), and communication skills (n=90). In a non-intervention study, Smyer, Hofland, and Jonas (1979) were able to evaluate intellectual functioning in 181 subjects from seven intermediate care facilities and nine home care agencies.

Self-report and subjective measures of health status are based on the idea that the "real world of an individual is what that individual perceives it to be: no more and no less." (Gill, 1984). If health is related to the state of "well-being", then it is the individual's perception of health that is likely to provide the most valid indication of what that state may be. In 1984, Margaret and Bernard Linn

described a short, comprehensive self-report of health which they designed for elderly adults. The scale was developed from two studies of 826 persons. The Linns found the factors in the scale to be stable and reliable and they were able to discriminate between various groups in the expected direction. Gill (1984) designed an instrument to measure subjective well-being. The instrument consisted of an adjective checklist, and was found to have a test-retest reliability coefficient of 0.99, internal consistency of 0.96, was sensitive to changes in health status as perceived by the individuals, and was also found to be valid. It seems, then, that it is possible to develop a subjective measure of health which has acceptable reliability and validity. In addition, self-assessment of health status correlates well with the objective situation. Maddox (1964), in a longitudinal study of 176 elderly subjects found that two of three of these subjects displayed a reality orientation in their subjective evaluatins of health status. Among the one subject in three who did not agree with the objective measures of the physician's assessment of his health, a pattern of social and attitudinal factors was found to distinguish between subjects with seemingly incongruous subjective assessments who were predisposed to be either optimistic or pessimistic.

Several questionnaire instruments have recently been devised which attempt to assess health status in pterms of both physical and psychologic function. Of these instruments, the Sickness Impact Profile (SIP), developed by Bergner, Bobbitt, Carter & Gilson (1981) has been cited in the largest number of

published studies.

The SIP was first tested on a random sample of prepaid group practice enrollees and with smaller trials on samples of patients with hyperthyroidism, rheumatoid arthritis, and hip replacements. This assessment tool has since been used in populations with rheumatoid arthritis (Deyo & Inui, 1984; Deyo, Inui, Leininger & Overman, 1982; Deyo, Inui, Leininger & Overman, 1983) back pain (Deyo & Diehl, 1983), patients who were post-myocardial infarction (Ott et al, 1983), and in an age-integrated psychosocial rehabilitation program for the elderly (Abrahams, Wallach & Divens, 1979). The sensitivity of the SIP to clinical changes was variable among different populations.

While Deyo and Diehl found the SIP to be sensitive to clinical changes in back pain patients, Deyo & Inui (1984) indicate that for individual rheumatoid arthritis patients, a patient self-rating scale, the American Rheumatism Association functional classification, and the SIP were all relatively insensitive and poor predictors for clinically estimated change. Charlton, Patrick & Peach (1983) also found the SIP lacked measurement sensitivity. These authors felt the lack of discrimination was due to several activities being evaluated in the same question. An individual could perform adequately in one activity and poorly in another. Johnson, King and Murray (1983) found the SIP to be an acceptable measure of quality of life in a variety of cancer patients undergoing radiation therapy.

The Duke-University of North Carolina (DUHP) Health Profile is a non disease-specific, multidimensional assessment instrument (Parkerson et al, 1981). Like the SIP, it addresses several areas of functional status. This instrument is discussed in detail in the instrument section of this paper. The authors of the DUHP suggest that further research using the instrument should include:

--Populations of patients who are sicker than ambulatory primary care patients, i.e. elderly and/or chronically ill.

--Studies that test clinical applicability by correlating scores with other medical evaluations and/or instruments.

--The DUHP administered at intervals to demonstrate associations between self-reported and medically reported health status as their condition fluctuates over time.

The utility of the DUHP for measurement of changes in function and symptom status over time has not been evaluated in a chronically ill population. However, the four health parameters measured; social, emotional, physical function and symptom states suggest applicability in this population.

Instrument

The Duke-University of North Carolina (Duke-UNC) Health Profile (DUHP) measures health status along four dimensions: symptom states, physical function, emotional function and social function. Although designed to measure functional status and symptoms in a relatively healthy population with acute episodic illness, the authors (Parkerson, et al., 1981) acknowledge the importance of measuring variability "among people and within the same person over time."

The DUHP was developed as a discriminating measure of health and as an assessment aid for the impact of medical care interventions. It also maintains a functional perspective. The authors of the DUHP wanted to develop a brief measure of health status and had as a further objective to develop a health oriented tool rather than one focusing on disease or dysfunction. The study setting was a Family Medicine Center. A random block design of 395 patients ranging in ages from 18 to 65 was used (Parkerson et al, 1981). Temporal stability for the assessment tool was established with a longitudinal study in which the DUHP was readministered to all study participants within one to eight weeks of the initial test administration, with the finding that 60 of 63 items showed positive test-retest score correlations ranging from 0.15 to 0.87. Reliability was established using internal consistency, temporal stability and scalogram analysis. The overall internal consistency for the 23 items measuring emotional function was 0.85 as measured by Cronbach's alpha. Guttman scalogram analysis applied to the ambulation items as a measure of physical function revealed high coefficients for reproducibility (0.98) and scalability (0.89). In the social function dimension, scalogram analysis produced Guttman coefficients of 0.93 for reproducibility and 0.71 for scalability.

Content validity was based on the study of other health status instruments, review of the literature and the professional experience of the investigators. Spearman correlations were used from the analysis of observed

associations following three Delphi rounds to reach consensus. Convergent and discriminant validity was determined by the multi-trait multi-method and was supported for all portions of the emotional and social function dimensions, all but two items of physical function and half of the symptom status items.

Symptom status and physical functioning are scored on a scale of one to three, one indicating no difficulty and three indicating a great deal of difficulty. The emotional and social functioning are scored on a five item Likert-type scale with one indicating "doesn't describe me at all" and five indicating "describes me exactly."

The DUHP is intended for use as an outcome measure in the primary care setting--the individual person serves as the basic unit of study and his perceptions of health provide the data. It is sensitive to the various levels of health, has clinical content validity and is health rather than sickness focused. The DUHP can be self-administered in less than 10 minutes. These characteristics, along with the dimensions of physical, emotional, functional and symptom status make the DUHP applicable to use with chronically ill populations.

The first section of the DUHP contains physical symptoms which may be present in each of the five chronic illness populations in this study. Further, it is expected that as the underlying physiological abnormality is treated, changes in symptom status will be noted. For example, individuals beginning treatment for diabetes commonly report feeling fatigue, blurred vision, and frequent urination --three symptoms which are addressed in this section of the instrument

and which usually improve as blood glucose abnormalities are corrected.

Research Question

The Duke-UNC Health Profile was developed for use in a primarily healthy population experiencing acute episodic illness. This study explores the appropriateness of its use in populations of patients experiencing chronic illness. Specifically, in all five populations, do changes in perceived health status, as measured by the DUHP, correspond with physiological indicators of disease status?
Further, this study will examine whether or not the DUHP is sensitive enough to measure the subtle changes characteristic of chronic disease over time.

Design and Methods

Several methods are available for calculating the length of a longitudinal study. Of these methods, a parametric test which computes the study length required to assure a desired statistical power for any given significance level, hazard ratio, accrual rate, loss to follow-up rate and length of the period of observation (Rubenstein, Gail & Santner, 1981) considers the most variables. In one controlled randomized study of 258 patients in cardiac rehabilitation (Ott et al, 1983), frequent (at least monthly) measurements over three months from the baseline assessment (done in the hospital) proved to show the largest change. After three months, most patients had recuperated to their subsequent functional level.

Sample

The five chronic illness populations to be studied are: cancer, post myocardial infarction, morbid obesity, stroke due to arterial thrombosis, and diabetes mellitus. Each disease group will be a convenience sample of 16-20 subjects measured at three three-week time intervals commencing with the initiation of the treatment plan. The criteria for inclusion in the study will be; 18 years and older, absence of severe acute illness, English-speaking, absence of any major receptive communication deficits.

A sample of stroke patients will be selected from newly admitted rehabilitation candidates at the Rehabilitation Institute of Oregon. The first administration of the DUHP will take place on admission, the second, three weeks later, and the third, three weeks later. This final administration will likely occur in the client's home, as the average period of inpatient rehabilitation is less than sixty days. Clinical significance of changes on the DUHP will be evaluated by comparing scores with health professionals ratings of functional gain.

The cancer subjects will be a convenience volunteer sample undergoing rehabilitation at Good Samaritan Hospital and Medical Center. The DUHP will be self-administered within the first week of rehabilitation therapy, three weeks following initial administration and three weeks following that. Clinical significance of changes on the DUHP will be evaluated by comparing scores with Karnofsky Scale ratings assessed by the health care providers in this setting.

Measurement of the effectiveness of treatment of diabetes mellitus is usually dependent upon physiological parameters such as blood glucose levels. Although nursing's role in diabetes management encompasses more than this parameter, attempts will be made during the course of this study to demonstrate the relationship between scores on the DUHP and capillary blood glucose levels.

Successful management of morbidly obese persons focuses primarily on weight loss. This will be the criteria used to determine clinical significance of changes in the DUHP.

Cardiac rehabilitation programs generally use intermittent ECG monitoring, resting heart rate pre and post exercise or ability to exercise without anginal pain as a criteria for evaluating activity tolerance and myocardial status. This procedure will also be used to demonstrate clinical significance in relationship to scores on the DUHP.

Setting

The Duke-UNC Health Profile will be administered in an ambulatory or home setting depending on the nature of the disease, the intervention, client's health status, and preference.

Protection of Human Subjects

There is no experimental intervention in the study, the subject sample will be voluntary. Informed written consent will be obtained. All information collected will be confidential. Subject anonymity will be protected by use of a code number system.

Data Collection Procedures

All data collection methods will follow the same procedure set by developers of the DUHP.

The Duke-UNC Health Profile will be self-administered whenever possible. The questionnaire will be completed within an encounter. There will be no discussion of any of the items with the client or family members. To ensure completeness of data, the administrator will reinforce the importance of responding to every item and will check for any missing items when the respondent has finished the questionnaire. For those persons who are unable to self-administer the questionnaire on the basis of physical disability, the entire questionnaire, including instructions and items, will be read exactly as written by the adminstrator.

Data Analysis

The data will be scored and tabulated using descriptive statistics. Means, frequencies, and standard deviations will be calculated for demographics, each subscale as well as for the instrument as a whole. ANOVA will be used to determine if there are any significant ($p=.05$) differences between groups at any point in time. Interitem correlations will be calculated for each subscale and the instrument as a whole in order to compare them with published reliability findings. Pearson correlations will be calculated to compare the scores on the subscales of the Duke instrument and the designated physiologic measures. In addition, correlations will be drawn between Duke subscale score, total score and responses to the quality of life scale.

Either a Neuman Keuls or a Tukey's W will be used to evaluate what may be contributing to statistical significance. Multiple analysis of covariance of the total Duke score and subscale scores within and between groups will calculate correlations between each of the five groups and how well the subscales correlate with each other.

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