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DEVELOPMENT AND TESTING OF A
QUALITY OF LIFE ASSESSMENT
PACKAGE

by

A. Kirsten Woodend

Thesis submitted to
the School of Graduate Studies and Research
in partial fulfilment of the requirements for the
M.Sc. degree in Epidemiology

University of Ottawa



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ABSTRACT

The purpose of this study was to develop and test a measure of quality of life meant for use in an outpatient cardiac population. Quality of life measurements can be used to describe the quality of daily living of patients and therefore indicate possible areas of benefits from treatment as well as to evaluate the impact of treatment. There are many quality of life measures available but none has been developed specifically for use for this population, and none is adequately responsive to detect clinically important changes in a relatively well cardiac population.

This study was conducted in three phases. In the first, the aspects (elements) of daily living which should be included in a measure of life quality were determined. A total of 114 subjects were asked to indicate every item in a list of elements to be important or not important to the quality of daily living of cardiac outpatients. The subjects were comprised of: a) clinic patients in whom permanent cardiac pacemakers had been implanted, b) clients attending exercise classes at the cardiac rehabilitation and prevention centre, c) staff of the University of Ottawa Heart Institute working in the pacemaker clinic and the rehabilitation and prevention centre, and d) family members of the patients/clients. A list of twenty-two elements with highest mean scores, using the patient/client data only, were chosen, such that the final questionnaire would take thirty to sixty minutes to complete.

In the second phase a review, of existing quality of life questionnaires, was done to find questions which related to the twenty-two elements considered by the

patients/clients to make important contributions to the quality of their daily living. The questionnaire, called the Quality of Life Assessment Package (QLAP), consists of the Duke Activity Status Index, in its entirety, and sections from a number of other questionnaires. The QLAP is made up of 90 questions. Four subscores (physical, psychological, social, activity) were developed using the ratings of importance of each element determined by patients and clients in Phase I. A total score was developed using a weighted sum of the four subscores.

The reliability and validity of the QLAP was tested in the third and final phase of the study. Two hundred and twenty-two subjects completed a demographic profile, the QLAP, and a modified version of Spitzer's Quality of Life Uniscale. The sample was comprised of: a) clinic patients in whom permanent cardiac pacemakers had been implanted, b) clients attending exercise classes at the cardiac rehabilitation and prevention unit, c) inpatients at the University of Ottawa Heart Institute and d) subjects with no known acute or chronic illnesses. Subjects reported that it took between 15 and 45 minutes to complete the QLAP. The QLAP is reliable with respect to internal consistency (Cronbach's $\alpha = 0.93$). Correlation between the QLAP and the Quality of Life Uniscale was 0.69 for the total score. Construct validity was evaluated using the known groups approach. An analysis of variance, and post-hoc testing showed that total scores on the QLAP differed significantly between chronically ill, acutely ill and healthy subjects. Scores for healthy subjects were the highest and scores for acutely ill subjects were the lowest, as expected.

Linear regression analyses done for the entire subject population and for the

rehabilitation group demonstrated that activity level and number of medications per day are related to QLAP scores. This supports the biologic validity of the measure. Marital status and education were also significantly related to QLAP score. Subjects who were married had higher scores than those who were single, divorced, or widowed.

In conclusion:

- a) the QLAP is internally consistent (reliable),
 - b) the QLAP has content validity,
 - c) the criterion related validity has been supported, and
 - d) evidence has been provided to support the construct validity of the QLAP.
- Further study is required to assess the stability and responsiveness of this measure.

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CHAPTER I

INTRODUCTION

Quality of life measurement is an important part of an evaluation of a medical intervention and has increasingly become a part of clinical trials of medical therapy. The goal of therapy in most patients with heart disease is improvement in function through reduction of symptoms, or limitation of disease progression rather than cure. Traditionally the measures of effectiveness of medical or surgical treatment have been limited to biomedical measures. Over the past 10 years an increasing number of studies have included a measure of quality of life to assess effectiveness of therapy.

There are many quality of life measures available but none has been developed specifically for use in relatively well cardiac populations such as patients in whom pacemakers have been implanted. Some scales used have been developed solely for a particular study and often adequate validation of these scales is not performed. Content validity has not been evaluated for many of the existing scales and many of the scales being used to measure quality of life may actually be measuring something else (such as the impact of sickness). The problem of primary import in measuring quality of life in this population is the lack of measures which are responsive to clinically important changes in this relatively well population.

The aim of this study was to compile a quality of life assessment package for use in the cardiac outpatient population. The word element will be used throughout this text to denote any aspect of daily living which might contribute to the quality of life. Other definitions related to the study can be found in Appendix A (Definition

of Terms).

CHAPTER II

LITERATURE REVIEW

Quality of life - General

Interest in quality of life (QL) began in the 1960's when a number of sociological studies was done investigating life satisfaction in the United States¹. In the mid seventies investigators became interested in looking at the impact of various health states on the population and from there a preoccupation with QL developed among medical researchers. Quality of life has been measured for many different reasons: a) to defend or dispute forms of therapy, b) to choose between therapies, and c) to identify reductions in life quality resulting from disease or treatment².

No one definition of quality of life, appropriate for both practice and research, has become standard. Harland³ defines QL as "the totality of those goods, services, situations and states of affairs which are delineated as constituting the basic nature of human life and which are articulated as needed and wanted". Szalai⁴ defines it as a global evaluation of the good or satisfactory character of people's life.

Hornquist⁵ has defined quality of life as the degree of need satisfaction within the physical, psychological, social, activity, material and structural areas. He describes a model in the shape of a spiral expressing the complicated interaction which takes place when considering these needs and their satisfaction. He states that there is no hierarchical order of needs and that needs within the six spheres are given different priority depending on under what circumstances and for what purpose QL is being measured. I chose to use Hornquist's conceptualization of quality of life as the

framework for this research because it provides a very comprehensive view of QL. It is not specifically a definition of health related QL. It was anticipated that when the content was developed, using this framework in a patient population, the resulting measure would be weighted by the health concerns of those patients.

The lack of one accepted definition and theory of quality of life has prompted many different operationalizations of the concept. This in turn has led to the development of a profusion of Quality of Life measures (Appendix H). The use of different measures has resulted in a lack of comparability of the results of studies of QL. It has also slowed the accumulation of knowledge about the concept itself.

There are a number of issues to consider when choosing or developing a measure of life quality. Should objective indicators, subjective indicators or a combination of the two be used? Should an outside observer, or the patient themselves evaluate the quality of their daily living. Should the approach to measurement be global or specific and should it include all aspects of life which contribute to its quality? What attributes should one look for in a measure of life quality?

Objective measures or indicators are those that include quantifiable aspects of QL such as income, employment, marital status, social class and education. There is no evidence to suggest that physiological parameters are good indicators of QL. Wants vary among individuals, therefore the correlation between the subjective and objective indicators of life satisfaction may be minimal⁶. An implicit assumption of the objective indicators approach is that one's health, physical environment, quality

of housing, and other material circumstances are valid indicators of the quality of one's life⁷. A number of authors have suggested that accurate description of QL requires the use of both subjective and objective indicators.

Should an outside observer, or the patient themselves evaluate the quality of their daily living? Slevin et al⁸ found that patient and physician scores on a number of quality of life measures correlated poorly. They concluded that physicians could not accurately determine what patients felt and that QL measures must come from the patients themselves. Epstein et al⁹ found that patient and proxy (family member/caregiver) scores for overall health, functional status, social activity, and emotional health were strongly correlated. They were only moderately correlated for satisfaction. Proxies reported lower emotional health and satisfaction than did patients. Campbell¹⁰ emphasizes that the individuals themselves must be the source of information about life quality. There are times when a patient is unable to give a response and if a measure of quality of life is desired a proxy will have to be used.

There are two approaches to the measuring of life quality; global and specific. The global approach involves the assessment of many dimensions of quality of life. At the other extreme, the specific approach restricts evaluation to symptoms related to a specific treatment or disease. There are a number of global health-related quality of life measures, such as the Nottingham Health Profile¹¹ and the Sickness Impact Profile¹², in use at the present time. The global approach possesses the advantage that it reflects overall satisfaction of needs. This may be at the expense of being able to assess some dominant symptom of a particular illness or

treatment¹³ and which may be responsive to intervention. The specific approach may fail to effectively assess the impact of a disease and/or treatment on a patient's whole life¹⁴.

Is it necessary to measure all of the aspects of life which contribute to its quality? Some researchers^{15 16 17} support specifying quality of life dimensions, and giving dimensions different priorities, depending on the purpose for which quality of life is being measured. Spitzer disagrees, saying that we are not measuring quality of life unless we include: physical function, social function, mental status, burden of symptoms and perception of well-being. One of the bases for this argument is the differing applications of measures of quality of life. The types of application of indices can be classified as: discriminative, predictive or evaluative¹⁸. Discriminative measures are used to distinguish between individuals and groups. Predictive measures are measures such as screening tests which predict health status. Evaluative measures are used to assess longitudinal changes. The type of application most appropriate for a quality of life index is evaluative.

Current literature supports a different approach to content selection for discriminative and evaluative measures^{18 19}. Item selection for discriminative measures involves including all of the aspects of daily living that are important to quality of life. Item selection for an evaluative measure involves including only those aspects of QL which are responsive to clinically significant change. If only aspects of QL which are responsive to change are included in a measure of QL there is a chance that the measure will no longer be of QL but of some narrower aspect of QL

such as activity. I would argue that this then would be a measure of activity and not QL.

There are two other concerns about an approach to measurement that does not include all aspects of daily living and where different aspects of quality of life are measured and given different priority from study to study. The first is a lack of comparability between the results of studies^{20 21}. The second is that it encourages the development of a multitude of different quality of life measurement tools which are not well validated through repeated testing. We need to concentrate on a few measures so that a few well validated tools result. It is occasionally necessary to develop new tools for the reasons which will be presented at the end of this chapter.

Quality of life is a global concept and measures should include all aspects of life which might affect the subject's perception of its quality. There are some practical limitations to this in that the measure must be of reasonable length. Wenger and associates²² advise the use of a battery of measures with separate subscales for each dimension. This parallels the biomedical concept that no aggregate measure reflects the results of a variety of physiological tests. Although the measure being developed is meant as an evaluative tool, an attempt will be made to include all aspects of daily living which contribute to the QL.

The measure used to assess quality of life should have three psychometric properties. It should actually be measuring life quality (validity). Secondly, it should be reliable. This means that it should yield the same results when used multiple times under unchanging conditions (stability) and responses to individual questions

should be consistent (internal consistency)^{23 24}. Finally, the measure should detect even small, but clinically important, differences^{25 26 27 28} in life quality (responsiveness).

The three major types of validation are: content, criterion-related, and construct validation²⁹ (Appendix A). The content of QL measures for the large part has been derived through review of the literature and solicitation of information from health professionals^{30 31}. The views of the patients have been considered in the development of some quality of life measures^{32 33 34 35}. Content validity of many of the existing measures has not been evaluated (Appendix H). Criterion-related validation can only be done when there is some "gold-standard" against which to compare the measure. No "gold-standard" for the measure of QL exists. There is some confusion in the literature as to the definitions of the types of validation that make up construct validation. Validating a scale is a process of determining the degree of confidence we can place on inferences about people based on their scores from that scale³⁶. It is, simply, a process of hypothesis testing.

Two types of reliability must be taken into consideration; internal consistency, and stability (test-retest). Nunnally³⁷ considers a reliability of 0.70 as moderate and 0.80 adequate.

The usefulness of an instrument designed to measure change over time (evaluative) is dependent not only on its validity and reliability but also on its ability to detect even small, but clinically important, differences³⁸ (responsiveness). The Sickness Impact Profile has been shown to be relatively insensitive to clinically

discernible changes in patient status³⁹. A review of 55 trials in which QL measurement was considered an important part of the trial found that measurements with established validity and responsiveness were used in only ten⁴⁰.

Although the QLAP will be used, in clinical trials, to assess longitudinal changes, item selection will not be based on the responsiveness of individual items. The priority in developing this tool, is that it be a measure of QL, in the broad sense. This may be at odds with producing a measure which is also responsive. It is anticipated that the measure will be responsive because it includes aspects of QL considered important to patients and because it will have subscales such as activity which may by themselves be responsive.

Quality of life - Cardiovascular Disease

The use of quality of life measures in cardiovascular research has increased rapidly over the past 13 years. Most of the early studies were searching for differences in life quality for patients treated by coronary artery bypass grafting as opposed to medically treated^{41 42 43 44 45}. Quality of life issues in studies of medical versus surgical treatment of coronary heart disease became important because of the comparable mortality between the two treatments. The measures of life quality used in these studies were, for the most part, objective. Information about angina status, hospitalization, employment status and exercise performance were considered to be indicators of life quality. The questionnaires used were developed for these studies.

The majority of cardiovascular research purporting to use quality of life as an

outcome measure is now being done on the medical treatment of hypertension^{46 47 48 49 50 51 52 53 54 55 56 57 58}. Half of these studies were measuring only symptoms or side effects of hypertension^{46 48 54 56 57 58}. Four^{49 51 53 55} used a global approach to assessing quality of life including measures of the physical, activity, psychological, and social aspects of living.

Another area in which quality of life measurement is being increasingly used is in evaluating the effect of cardiac transplantation on the quality of life. The majority of these studies are case series describing patient's life quality before and after transplant^{59 60 61 62}. Lough and her colleagues⁵⁹ used the Quality of Life Scale, developed by Young and Longman⁶³ in cancer patients, in addition to a list of symptoms related to the immunosuppressive drug side effects. The validity of the Quality of Life scale, used in a cardiac population, has not been assessed. The symptom list was developed for the study and neither the reliability or validity of this measure have been evaluated. Packa⁶¹ used the McMaster Health Index Questionnaire⁶⁴ which has questions relating to physical, social and emotional functioning. Its validity has been evaluated but its responsiveness to clinical changes in this population has not been measured. The other two studies used a number of psychological and social measures. O'Brien et al⁶⁵ used the Nottingham Health Profile (NHP)¹¹ to measure life quality. They combined the subscores of the NHP to produce estimates of quality adjusted life years. The authors of the NHP have consistently argued against the combining of its profile of scores.

Cardiac pacemakers have been in use for the past two decades. There have

been rapid advances in electronic technology resulting in artificial pacemakers which more closely emulate the physiological pacemaker. Although the primary objective of implanting a permanent pacemaker is still the alleviation of fatal or nonfatal symptoms, the modern day pacemaker is striving to achieve near normal hemodynamic physiology. These advancements include pacing in response to atrial activity, and in response to various physiological sensors such as muscle activity, body temperature, respiration, and evoke potential^{66 67 68}. In patients with chronotropic incompetence in whom atrioventricular synchronous pacing is not able to achieve satisfactory heart rate response for demand, rate responsiveness should produce further improvement in pacemaker capability as well as in the patient's performance and acceptance^{69 70}. The benefits of these newer modalities of pacing have been assessed by physiological testing including: exercise testing, metabolic studies, echo doppler studies and/or radionuclide ventriculography.

There have been few studies evaluating the patient's assessment of the pacemaker's performance. In addition to the expense, time involved and accessibility of these sophisticated physiological measures, some of the patients with implanted pacemakers are unable to undergo exercise testing. There is considerable interest in a more global and accessible method of determining the optimal settings of these pacemakers for individuals. A method of assessment which is sensitive enough to pick up changes in quality of life at different pacing modalities is required.

There is no published disease-specific measure of quality of life for use in patients in whom permanent pacemakers have been implanted. The existing quality

of life measures have not been responsive to changes in quality of life resulting from changes in pacemaker setting and/or modes^{71 72 73}. In studies incorporating quality of life as an outcome measure in the evaluation of cardiac pacing^{74 75 76}, the patients have high quality of life scores even before treatment or at the least optimal pacing modes. It is very difficult to improve on these high scores and in fact these studies have documented that with treatment and improvement of pacing mode physiologically, there were no significant changes in quality of life scores. Some of the measures used in these studies (Nottingham Health Profile⁷⁷, McMaster Health Index, Psychological General Well Being Index) were developed and tested in populations that were less well than outpatients with cardiac pacemakers and so there is little room for improvement in scores.

There is also a need for a quality of life assessment tool in the Cardiac Rehabilitation programme. Patients enrolled in the cardiac rehabilitation programme usually have had a major cardiac event e.g. myocardial infarction, heart failure management or have undergone coronary bypass surgery. They may need physical, emotional, and/or physiological help to return to their previous state of health⁷⁸. The use of measures of morbidity and mortality to evaluate programme efficacy or effectiveness requires large study populations^{79 80 81 82} and the efficacy of exercise in reducing morbidity and mortality has not clearly been shown. In addition this approach does not take into account many other potentially important benefits of a cardiac rehabilitation programme⁸³.

Very little has been done using quality of life as an outcome measure in

evaluating the effectiveness of cardiac rehabilitation programmes. Mayou and his colleagues⁸⁴ allocated post myocardial infarction (MI) patients to control, exercise, and advice groups. Quality of life in each treatment arm was assessed at the end of twelve weeks. A semistructured interview was used along with measures assessing psychological state and social adjustment. They found only modest evidence that cardiac rehabilitation improved the quality of everyday living. The validity of the semistructured questionnaire was not assessed although test-retest reliability was shown to be greater than 80 percent. Since the responsiveness of the measure had not been measured, it is not possible to determine whether the lack of substantial difference in QL in the treatment arms was because no change in QL occurred with rehabilitation or the measure was not responsive enough to detect changes which had occurred.

The Sickness Impact Profile (SIP) has been used in a randomized study of cardiac rehabilitation⁸⁵. Patients were randomly allocated to a control group, an exercise group, or an exercise plus teaching and counselling group. Ott and his colleagues found that the scores for all groups on the SIP were very near zero (lowest impact of sickness). The quality of life of 51 elderly patients enrolled in cardiac rehabilitation was described by Packa et al⁸⁶. They used the McMaster Health Index Questionnaire and the Cantril Self Anchoring Ladder to measure life quality.

The problem of the use of many different measures and the lack of responsiveness of some of the measures used is occurring in the study of cardiac rehabilitation patients as well as in pacemakers. Many of the measures which have

been used have undergone little or no assessment of their validity. The content of some of the measures is broad (SIP, NHP) but many of the measures used assess the quality of only a few of the aspects of daily living (symptom profiles, Psychological General Well Being Index). The major problem with the measures that have been used to date is a lack of responsiveness in this relatively well population.

In conclusion, there are a number of qualities that I would consider essential in a measure of life quality. It should:

- 1) be comprehensive in content, and consist mainly of subjective indicators and have content validity;
- 2) be useable in a broad range of patients with cardiac diagnoses;
- 3) be valid and reliable; and
- 4) be responsive to clinically significant changes in QL.

From a practical perspective the measure should also:

- 1) be self administered, and easy to read;
- 2) take 30-60 minutes to complete; and
- 3) be relatively easy to score.

Currently available measures of quality of life have been reviewed (Appendix H) and no measure has been identified which meets all of these criteria.

Since both of the groups of interest consist of outpatients recovering from myocardial infarctions or various cardiac surgical procedures, it is anticipated that the elements identified as contributing to quality of life will be similar for the two groups.

CHAPTER III

RESEARCH DESIGN

Objectives

The aim of this study was to compile and test a quality of life assessment package for use in the cardiac outpatient population. The specific objectives of this study were:

1. To identify the elements (constructs) which contribute to the quality of life in patients in the Cardiac Rehabilitation programme and in patients in whom permanent pacemakers had been implanted.
2. To select existing tools which measure the above constructs.
3. To determine the optimal method of scoring the resulting battery to reflect the "weight" of each of the contributing elements and to give subscores for physical, psychological, social, activity, material and structural quality of life.
4. To test the validity, reliability, and ease of administration of the selected tools in these two groups of patients.

Overview

Phase I of the present study was designed to ensure that the final measure contained all aspects of daily living which were considered to influence life quality (content validity). Patients, family members and staff were asked to identify elements which they considered to have an influence on the quality of the patient's/client's life.

In Phase II a review of the literature was done to identify measures of the elements of daily living identified in Phase I. These measures, or portions of these measures, were consolidated to produce one questionnaire (the Quality of Life Assessment Package). The weight assigned to each question and subscale was determined using the patient's rating of the importance of each aspect to his/her quality of life.

In Phase III, the questionnaire was given to clients in the cardiac rehabilitation programme, patients in the pacemaker clinic, healthy adults, and cardiac inpatients to complete. This was done in order to assess the construct validity, internal consistency, and ease of administration of the questionnaire.

Phase I

Design

A Medline search, using the keyword quality of life, was done for the period from 1975 to 1989. This keyword does not exist in Medline prior to 1975. From this list all empirical studies, which included a measure of life quality, were selected and reviewed. A list of elements measured in each study was made, by the investigator. Duplications were removed and the list was divided into six sections according to Hornquist's definition of life quality. This list of the elements, in the form of a survey (Appendices A and B), was given to physicians, allied health professionals, patients and families of patients associated with the cardiac rehabilitation programme and with the pacemaker clinic. Each group was asked to identify which elements

contribute either positively or negatively to the quality of life of these patients. Space was provided for the appending of elements not included in the list.

The survey tools which were used in this phase were different for staff and patients. The staff survey was done first and many respondents expressed difficulty in dichotomizing the importance of an element to the quality of life. The staff felt that all of the elements were important to some degree. The survey form was revised to allow a continuous response using a linear analogue scale which was anchored at one end by "not important" and at the other by "important". The survey form given to family members was similar to that used for the patients/clients except that they were asked to rate the importance to their family member, not to themselves.

Subjects and Sample size

All personnel in the two areas (pacemaker clinic, Cardiac Rehabilitation and Prevention Programme) were asked to complete the survey form. Cardiac rehabilitation patients were selected randomly from the five levels of classes held each week, with an equal number coming from each level. A list of all patients attending exercise class was available. The patients were stratified by level of class and a random number table was used to select subjects from each class. Pacemaker patients were selected randomly from the pacemaker clinics over a two week period with approximately equal numbers coming from each clinic. Clinic lists were available one week in advance and a random number table was used to select subjects from each clinic day in the two week period. All patients were asked to have a family

member, who met the inclusion and exclusion criteria, complete the questionnaire.

The following inclusion and exclusion criteria were used:

Inclusion criteria:

- i. Persons (and spouses of persons) attending the exercise portion of the cardiac rehabilitation programme at the University of Ottawa Heart Institute.
- ii. Outpatients attending the pacemaker clinic at the University of Ottawa Heart Institute.
- iii. Medical and paramedical personnel in the Cardiac Rehabilitation programme and Cardiac Pacemaker clinic.

Exclusion criteria:

- i. Non English speaking.
- ii. Unable to read and write well enough to complete the questionnaires with minimal assistance.
- iii. Inability to give informed consent.

Sample size calculations, for the patient/client sample, were based on the method outlined by Hulley and Cummings⁸⁷ for descriptive techniques using continuous variables. The parameter of interest was the importance score and the sample size was determined to achieve a 95 percent confidence interval of ± 1.5 cm. The estimated standard deviation, based on the highest anticipated standard deviation, was 4.00cm on the visual analogue scale. This yielded a required sample size of approximately 25 from each area.

Statistical Analysis

Staff:

The data for staff were collected using a different questionnaire than for the other subjects; therefore a separate analysis was required. The staff ranked most of the elements in the survey as important contributors to the quality of daily living. It was therefore impossible to rank the elements using the frequency at which they were identified as important. The staff group had also been asked to list the five most important elements in each section in order of importance. In order to rank elements, within each of the subsections (activity, physical, psychological, social, material and structural), these elements were scored by their rank in the list. Elements listed first were assigned 5 points and elements listed fifth were assigned 1 point. This score was multiplied by the number of staff that assigned that rank to the element. In this way the elements were assigned a relative order of importance.

Patient and family:

Elements were assigned scores, to the half centimetre, based on the position of the mark put on the 18 centimetre scale. Not important was assigned a score of zero and important a score of 18. Mean, median, and log mean scores were calculated as were standard deviations. These were plotted to determine a "natural" cut-off point above which the elements would be included in the final measure. The cutoff point was chosen based on the following considerations:

- 1) No more elements than could be assessed in 30 to 60 minutes be included.
- 2) That it include enough elements to be valid and reliable.

Phase II

Design

This phase consisted of the review and selection of tools which measure the elements identified as important by the patient/client group in Phase I. The following criteria were used, in the following order, in the selection process:

- a) It should be a self-assessment tool (that is completed by the patient without input by health professionals).
- b) It should contain the elements (or some of the elements) identified in phase one.
- c) It had been demonstrated to have construct validity and a high internal consistency.
- d) It had been tested and/or used in similar populations.

The method of scoring was generated in this phase based on the relative weight of Phase I importance scores for included elements. The mean of the scores for each element were summed within each of the four categories. The contribution of each category to the total score of 100 was determined by dividing each category score by the total score and multiplying by 100. The resulting measure is called the Quality of Life Assessment Package (QLAP) (Appendix C).

Phase III

Design

In the final phase of this study the reliability and validity of the QLAP was

evaluated. Four groups of patients completed a demographic questionnaire, the QLAP, and the QL Uniscale⁸⁸. The QL Uniscale consists of a single visual analogue scale on which the subject is asked to rate his quality of life from lowest to highest. It has been used in a broad range of subjects and its content and construct validity have been supported. There is no data available on its reliability or responsiveness.

A number of hypotheses were tested to begin amassing evidence to support the construct validity of the QLAP. These hypotheses were:

- a) Scores on the QLAP and the QL Uniscale will correlate moderately and positively.
- b) There will be a gradient of diminishing mean QLAP scores from the "healthy" neighbours to those with chronic illness to the acutely ill.
- c) Scores on the QLAP will be higher in subjects with higher levels of physical functioning.
- d) The QLAP is assessing four areas of life quality (factors): activity, physical, psychological, social.

Subjects and Sample Size

The QLAP and the QL uniscale⁸⁸ were administered to the following groups:

1. Cardiac rehabilitation programme patients,
2. Pacemaker patients from the outpatient pacemaker clinic,
3. Hospitalized cardiology patients,
4. Subjects with no known chronic diseases.

The following inclusion and exclusion criteria were followed:

Inclusion criteria:

- i. Patients participating in the exercise component of the cardiac rehabilitation programme at the University of Ottawa Heart Institute.
- ii. Outpatients attending the pacemaker clinic at the University of Ottawa Heart Institute.
- iii. Hospitalized post-myocardial infarction and post-coronary artery bypass patients at the University of Ottawa Heart Institute.
- iv. Neighbours of i. & ii. without any known chronic disease.

Exclusion criteria:

- i. Non English speaking.
- ii. Unable to read and write well enough to complete the questionnaires with minimal assistance.
- iii. Inability to give informed consent.
- iv. Patients/clients who participated in Phase I.

The group with no chronic disease was originally going to be made up of neighbours of the same sex and age as the cardiac rehabilitation and pacemaker clinic patients. The rehabilitation unit did not wish its clients to be asked to give the name of a neighbour. Only 23 names were volunteered by the 68 patients in the pacemaker clinic. As a result of the low numbers in the original group and in order to get subjects with the same range of ages as in the chronically ill group, subjects were recruited from personnel and post-RN classes from the university and from

volunteers at the Queensway-Carleton Hospital.

Sample sizes were estimates because many of the required parameters were estimated using the results of tests on similar instruments. Sample sizes were calculated for each test and the largest sample size required was chosen (correlation between scores on the QLAP and the QL Uniscale for each subject group). A correlation coefficient of at least 0.40 was expected for the correlation of the score on the QL Uniscale and the total score on the QLAP. The following formula was used⁸⁷:

$$N = [(z_{\alpha} + z_{\beta}) \div C]^2 + 3.$$

1. $\alpha = .05$, $\beta = .10$ therefore $z_{\alpha} = 1.645$, and $z_{\beta} = 1.282$;
2. $C = 0.5 * \ln[(1 + r)/(1 - r)] = 0.424$

The required sample size was 51 people per group. A minimum of 70 subjects in the rehabilitation and pacer group were approached to ensure that an adequate sample was obtained.

Statistical Analysis

Internal consistency, was determined by calculating Chronbach's Alpha for each of the subscores and for the total score.

To test the first hypothesis, Pearson correlation coefficients for the results of the QLAP package and the QL Uniscale were calculated.

To test the second hypothesis, analyses of variance were done to determine whether the scores for the three groups (healthy, chronic, acutely ill) differed significantly. The distributions of the total score and subscores were not normal. A

log transformation of the scores does not normalize the distribution. However, Monte Carlo studies⁸⁹ have shown that: a) violations of the normality assumption do not contribute a serious problem unless those violations are especially severe, and b) even sizeable differences among variances do not appear to distort the F distribution seriously. For this analysis, the combined pacemaker and rehabilitation subjects were considered to be the chronically ill population.

Linear regression analysis was done to test whether scores on the QLAP were higher in subjects with higher levels of physical functioning. The rehabilitation class, in which the subject was enrolled, was used as a measure of their physical functioning. The activity level of the rehabilitation clients, usually assessed by bicycle ergometry, is used to place clients in the various classes. Those able to exercise at the lowest level are placed in the Low Impact Class (LIC) and those able to exercise at the highest level in the IIIB class. Age, education and the number of medications taken per day were also included as independent variables in this analysis. To further explore the relationship between some of the variables and scores on the QLAP, linear regression analyses were done for the entire study sample. The independent variables included in the regression were: age, sex, education, marital status, illness, medication. The variable illness was a response 'yes' or 'no' to a question about whether the subject considered that they had any chronic illnesses.

A factor analysis with varimax rotation was performed, through BMDP4M⁹⁰, to determine whether the QLAP was assessing four areas of life quality (factors): activity, physical, psychological, and social. Since at least 5 subjects are required for

each question (element)⁹¹ included in the analysis, the individual questions were not used. Instead, the analysis was done using a score for each of the 21 elements included in the questionnaire.

CHAPTER IV

RESULTS

Phase I

Subject Profiles

Staff

Twenty two staff members, out of a possible 24, completed and returned the survey form. Eighteen worked in the Cardiac Rehabilitation and Prevention Unit, two in the pacemaker clinic. Two were cardiologists with large numbers of pacemaker patients in their practice. The cardiac rehabilitation staff consisted of one physician, nurses, one psychologist, physiotherapists, occupational therapists, dieticians, and social workers. The two from the pacemaker clinic were a nurse and a respiratory technologist who managed the clinic.

Patient

Forty clients attending exercise classes in the Cardiac Rehabilitation Centre were randomly chosen from the exercise class lists with the same proportion coming from each class level. Four of these were excluded for the following reasons: did not read/write English (2), no longer participating in the exercise portion of the cardiac rehabilitation programme (2). Of the 36 clients contacted by phone, 1 refused to participate and one's phone number was no longer in service. Thirty four questionnaires were given out and of these 27 (79%) were returned.

The mean age of the rehabilitation clients returning questionnaires was 59.6 years (Table 1). Eighty-one percent were male. The mean length of time the clients

Table 1. Subject Profile; Patient/Client Group

VARIABLE	REHABILITATION CLIENT	PACER CLINIC PATIENT	TOTAL
N	27	31	58
AGE mean±SD (yrs) range	59.6±10.5 39 TO 79	69.6±16.6 11 TO 97	65.2±14.4
TIME mean±SD SINCE range ONSET	30.1±68.4 3 TO 336 Mo.	94.4±66.5 2 TO 216 Mo.	65.2±74.1
# MEDS mean±SD /DAY range	2.6±2.1 0 TO 9	2.3±1.7 0 TO 5	2.4±1.9
SEX	81% male	58% male	69% male
MI	52%	27%	39%
CABG	37%	28%	32%
VALVE REPLACEMENT	22%	11%	16%
ANGINA	33%	31%	32%

had had cardiac disease was 2.5 years. Fifty-two percent had had previous myocardial infarctions and thirty-seven percent had had coronary artery bypasses. Four percent of this group had had cardiac pacemakers implanted.

Among the pacemaker clinic patients, fifty patient names were randomly selected from clinic lists for nine clinics (two per week). Four patients were unable to participate because they did not read english, three had some form of senile dementia and three refused. Of the 40 questionnaires given out while the patients were in the clinic, 31 (77.5%) were returned. The mean age of the pacemaker clinic

patients who returned the questionnaire was 69.6 years (Table 1). The mean length of time the respondents had had cardiac disease was 8 years. Twenty-seven percent had had previous myocardial infarctions and twenty-eight percent had had coronary artery bypasses.

The mean age of the rehabilitation clients was significantly lower than the mean age of the pacemaker patients ($t=2.58$, $p=0.013$). The mean length of time since the first diagnosis of cardiac disease was significantly lower among the rehabilitation clients than among the pacemaker patients ($t=3.52$, $p=0.001$). The mean number of different medications taken per day was not significantly different for the two groups ($t=0.64$, $p=0.523$).

Family

Of the 27 rehabilitation patients who completed questionnaires, only 19 had family members who could complete the questionnaire. In some cases there was no close family member, some did not read or write english well enough to complete it, and a small number refused.

Of the 31 pacemaker clinic patients who completed the questionnaire, only 15 had family members who did so. Twelve of the pacemaker clinic patients did not take questionnaires home for family members. Seven, of these, had no family member sharing living quarters, 4 had family members who were not able to complete the survey, and 1 family member refused. Four questionnaires sent to the family members of pacemaker clinic patients were not returned. A total of 34 family survey forms were returned by both groups of subjects. The mean age of the family

members was 57.1 ± 16.6 years and 73.5 percent were female.

Survey Results

Most of the elements were identified by the staff as important to a client's/patient's quality of life (Appendix E). Within each section of the survey the staff were asked to list those elements which they felt were the most important, in order of importance. Scores were assigned to these elements with the first in the category assigned a value of five and the fifth assigned a value of one. In this way I established the five most important elements in the physical, psychological, social, and activity categories (Table 2).

Family members rated each element as 'important' to 'not important' on a linear analogue scale that was 18 centimetres long. The mean scores and standard deviations for each element are listed in Appendix F.

Patients and family members agreed on the two most important elements in the physical category (mobility and general health status). Patients perceived symptom relief, diet and time spent in hospital to be more important than did family members. Staff rated exercise tolerance, general health status, symptom relief, chest pain and perceived benefits of treatment as the most important physical elements. Patients ranked chest pain as seventeenth out of the 26 physical elements. Family members ranked it only slightly higher than did patients.

Both patients and family members agreed that, of the psychological elements, self esteem, satisfaction with life, and confidence were the most important aspects of

Table 2. Five most important elements within each category as identified by the staff.

PHYSICAL

exercise tolerance
 general health status
 chest pain
 symptom relief
 perceived benefits of treatment

PSYCHOLOGICAL

depression
 anxiety regarding health
 confidence
 self image
 fear of recurrence and death

SOCIAL

interpersonal relationships
 changes in marriage
 family life
 internal control over personal life
 recreational activities

ACTIVITY

activities of daily living
 energy
 ability to live normally
 employment status
 perception of limitations to
 activity

life quality. The staff felt that depression, and anxiety regarding health were the most important aspects. They also ranked fear of recurrence and death among the five most important psychological elements. Neither patients nor family members ranked fear of recurrence or death highly although scores for both these elements were higher for family members than for patients.

The five most important social elements according to the patient group were: internal control over social life, family life, interpersonal relationships, changes in marriage and changes in family. Family member and staff rankings were similar to the patient rankings for the 4 most important elements.

Patients ranked the ability to live normally, activities of daily living, energy, home management and perceptions of limitations to activity as the most important activity elements to their quality of daily living. Family member rankings were similar

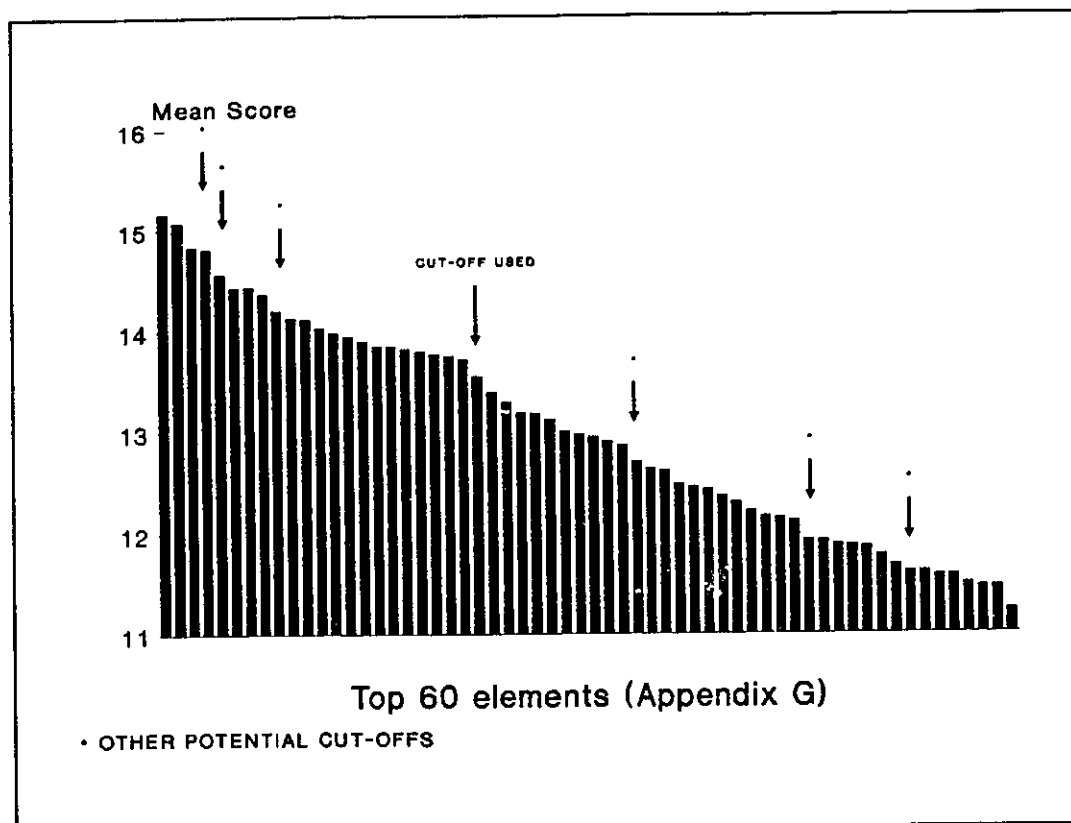


Figure 1. Mean patient scores for elements in descending order.

although the average scores were lower. Staff rated employment status among the first five elements. Patients and family members gave both employment status and working capacity a much lower ranking. Family member scores for these two elements were even lower than the patient scores. All material and structural elements were given relatively low scores by both patients and families. Material and structural aspects of life are rarely included in measures of life quality.

There was little difference in scoring between patients from the pacemaker clinic and those from the cardiac rehabilitation programme.

Patient scores were, like family scores, measured on an 18 cm scale. It was necessary to determine a cutoff point where elements with a higher mean score

would be included in the questionnaire. The mean scores were calculated both with blanks as missing and with blanks as zero assuming that a subject who did not complete a question did not consider the element important. The mean scores, median scores, modal scores, mean log scores, and standard deviations were imported into a spread sheet (Appendix G). All of these scores were sorted in descending order and plotted. The plot of the mean score with blanks as zero was used to determine the cutoff point (Figure 1). There was little difference between the order of the elements with blanks as zero and with blanks as missing. A cutoff point 13.70 (mean score) met the criteria. All elements with mean scores above 13.70 were included in the final questionnaire (22 elements). All groups did list elements not included in the original survey but not with enough frequency to include them in the final questionnaire.

Phase II

Existing questionnaires were reviewed to find ones which met the criteria outlined in the methodology. A list of questionnaires used can be found in Table 3. Only one questionnaire, the Duke Activity Status Index⁹², was used in its entirety. The final questionnaire includes 90 questions (Appendix B). There were no other questionnaires that met the criteria of containing the elements identified in Phase I with a minimum of other aspects of life quality. For this reason questions relating to the remaining elements were chosen from a number of questionnaires. Two questions, relating to general health status, were taken from the General Well Being Schedule⁹³. The two questions on visual perception were taken from the OECD

Table 3. Questionnaires contributing to the Quality of Life Assessment Package.

<u>ELEMENTS QUESTIONS)</u>	<u>QUESTIONNAIRE (# OF</u>
Activities of daily living (actadl) energy (actenerg) ability to live normally (actnorm)	Duke Activity Status Index (12)
perceived benefits of treatment (phsperc) relief in symptoms (phsrel, phssymr)	questions developed for QLAP (6)
general health status (phsgh)	General Well being Schedule (2)
visual perception (phsvis)	The OECD Long-Term Disability Questionnaire (2)
range of movement (phsrom) mobility (phsmob)	Nottingham Health Profile (8)
satisfaction with life (pssatis)	Life satisfaction Index (20)
internal control over emotions (psintern)	General Well-being Adjustment Scale (3)
psychological general well being (psps1) self image (psimage) self esteem (psesteem) confidence (pscomf)	Affect balance scale (10)
intellectual performance (psintell) alertness (psalert)	modified from Multilevel Assessment Instrument (2)
changes in marriage (socchann) family life (socfam)	The Social Adjustment Scale (17)
social role performance (socper)	The General Health Questionnaire (7)
internal control over personal life (socint)	question written(1)

Long-Term Disability Questionnaire⁹⁴. Eight questions relating to range of movement and mobility were taken from the Nottingham Health Profile⁹⁵. Appropriate, existing questions were not found for 'relief in symptoms', or 'perceived benefits of treatment' and 'internal control over personal life'. Questions on

satisfaction with life were from the Life Satisfaction Index⁹⁶. This was the measure from which the largest number of questions was used (20). Three questions relating to internal control over emotions were from the General Well being Index⁹⁷. Ten questions from the Affect Balance Scale⁹⁸ pertained to: psychological general well-being, self image, self esteem and confidence. The Social Adjustment Scale⁹⁹ had 17 questions relating to changes in marriage and to family life. The General Health Questionnaire contained seven questions relating to social role performance. No appropriate questions were found for perceived benefits of treatment, relief in symptoms, or internal control over personal life. Questions, modified from cancer questionnaires, were written for these. Seven questions were developed for these elements based on similar questions in cancer quality of life measures.

Weights for each section were determined using the mean, patient, importance score from Phase I. The first step in the process of determining the weighting of each section was to determine what percentage of the total score should be contributed by each section of the QLAP. The mean importance scores for each element within a section (activity, physical, psychological, social) were summed. The scores for each section (Table 4) were then summed to give an overall total of mean importance scores. The percent contribution of each section to the total score was determined by dividing the total importance score for a section by the total score (Formula 1).

$$\% \text{ Contribution} = (\sum I_{ia} / \sum I_i) * 100 \quad \text{Formula 1.}$$

Note: I_{ia} = the mean importance score for each element comprising an activity,

I_i = the mean importance score for each element making up the QLAP.

For simplicity, it was decided that the total score on the QLAP should range from 0

to 100. Therefore activity would account for 16 percent of that score, physical 29 percent, psychological 35 percent, and social 20 percent (Table 4).

The second step in determining the weights was to apply the percentages, determined in the previous step, to the actual scores for the questions and determine the weight by which each section score would be multiplied. The numbers of questions used to gather information about each element did not equal the number of elements. When question responses are summed, in each section, each section has a Total Score (Table 4). In order for each section to contribute the percentage calculated in the first step a weight by which the score is multiplied is determined using formula 2.

$$\text{Weight} = \frac{\% \text{ Contribution (from step 1)}}{\text{Total score for each section (Table 4)}} \quad \text{Formula 2.}$$

Table 4. QLAP: Scoring and weighting of subscales.

	NUMBER OF ELEMENTS	TOTAL SCORE	% CONTRIBUTION TO TOTAL SCORE	WEIGHT
ACTIVITY	3	58.2	16	0.27
PHYSICAL	6	48.0	29	0.60
PSYCHOLOGICAL	8	140.0	35	0.25
SOCIAL	4	100.0	20	0.20
TOTAL		21	100.0*	100

* The maximal total score for the QLAP has be set at 100 and so this is not a sum of the total scores but of the weighted total scores.

For example: 1) using the importance scores for the elements, it was

determined that questions relating to activity would account for 16 percent of the total QLAP score, 2) the highest attainable score on the Duke Activity Status Index, which was used for this section, is 58.20, 3) in order for activity to account for 16 percent of the total QLAP score (100) the activity score is multiplied by 0.27 (Table 4), 4) the highest number of points which the activity section can contribute to the total QLAP score is therefore 16.

The questions making up the final questionnaire are scored from zero to five when a Likert-type scale is used, or zero to one when dichotomous response set was used. Positive responses were given the highest score (Table 5). The only questions that are weighted individually are those which relate to activity. The weights used by the authors of the Duke Activity Status Index are used here. Not all respondents will

ACTIVITY =	$(QS1 * 2.75) + (QS2 * 1.75) + (QS3 * 2.75) +$ $(QS4 * 5.50) + (QS5 * 8.00) + (QS6 * 2.70) +$ $(QS7 * 3.50) + (QS8 * 8.00) + (QS9 * 4.50) +$ $(QS10 * 5.25) + (QS11 * 6.00) + (QS12 * 7.50)$
PHYSICAL =	Sum of questions 13 through 30
PSYCHOLOGICAL =	Sum of questions 31 through 35
SOCIAL =	(Sum of questions 66 through 90) (divided by the number of questions which were answered in that section) and (multiplied by 25)†
TOTAL SCORE =	$(ACTIVITY * 0.27) + (PHYSICAL * 0.60) +$ $(PSYCHOLOGICAL * 0.25) + (SOCIAL * 0.20)$
note: QS# refers to the question of that number	
† some questions in the social category could only be completed if a partner or children existed	

Table 5. Scoring and weighting of the QLAP subscores and total score.

be able to answer all questions within the social section. To preclude penalizing for questions not answered, the questions which have been answered are summed and divided by the number which are answered. The score is then multiplied by 25 resulting in scores ranging from 0 to 100 for the social section of the QLAP.

The reading level of the final questionnaire was assessed using the Flesch-Kincaid¹⁰⁰ formula. This formula takes into account the average sentence length and the average number of syllables per word. The overall reading grade level for the QLAP is between grades 4 and 5.

Phase III

The QLAP and Uniscale were administered to 222 subjects in four groups.

Subject Profile

Pacemaker Group

Eighty-nine patients, in whom pacemakers had been implanted, were selected over 14 pacemaker clinic days. Patients who were ineligible due to confusion or inability to speak english were identified by the clinic staff and were not included in the list. Eighty-two (92%) of the eligible patients were reached by phone prior to the clinic visit and 3 (4%) refused to participate. Seventy-nine QLAPs were given to patients in the clinic. Sixty-eight (86%) were returned. Three of these were incomplete (1 unable to complete because of confusion, 1 French speaking, 1 refusal). Therefore a total of 65 questionnaires were completed.

The average age of the subjects from the pacemaker clinic was 66 years (Table 6). Fifty-one (78%) were married and 37 (57 %) were male. Nineteen (29%) had

Table 6. Phase III: Subject Profile

	<u>Pacer</u>	<u>Rehabilitation</u>	<u>Acute</u>	<u>Neighbour</u>
N	65	57	40	60
AGE(MEAN)	66.4±12.1	53.3±11.1	57.1±13.7	53.4±16.0
AGE(RANGE)	28-83 yo	28-77 yo	24-81 yo	24-76 yo
EDUCATION 14.9±3.7 (years)	13.0±4.4	13.9±4.2	12.6±3.8	
MEDS/DAY	2.5±2.1	3.0±1.6	3.0±1.6	0.7±0.9
SEX(%male)	57	74	88	33
MARITAL STATUS (% married)	78	81	68	77
MI(%)	29	47	55	0
CABG(%)	15	54	28	0
VLVE SURG	11	11	5	0
ANGINA(%)	18	60	53	0
CHF(%)	23	5	13	0
PACEMAKER(%)	100	2	8	0

had myocardial infarctions and eight (15 %) had had coronary artery bypass grafts.

Rehabilitation Group

Subjects were chosen from each of the exercise classes in the Cardiac Prevention and Rehabilitation Programme. Approximately 75 percent of the subjects were reached by phone. The others were: not reached after numerous calls, phones were not in service or the subject was in hospital. Seventy-two forms were left at the exercise class for the subjects, two of which were not picked up. Of the forms picked up, 57 (81%) were completed and returned.

The average age of the rehabilitation subjects was 53 years (Table 6). Forty-two (74%) were male and 46 (81 %) were married.

Acute Group

Consent was obtained, from the three cardiologists with the most patients on the wards, to approach inpatients. Sixty questionnaires were left with inpatients to complete. Seven inpatients refused, two were primarily french speaking and found it too difficult to complete, and 12 were discharged prior to completing or returning the form. Forty of the 60 (67 percent) questionnaires were returned completed.

The average age of the acutely ill subjects was 57 years. Eighty-eight percent were male and 68 percent were married. Fifty-five percent had had a myocardial infarction, 53 percent had had angina, and 28 percent had had coronary artery bypass grafts.

Neighbour Group

Neighbour forms were given along with the QLAP to 45 patients in the pacemaker clinic. Twenty-four names of neighbours of approximately the same age as the subject accompanied the returned questionnaire. The QLAP was sent to all of these neighbours and 16 returned it complete. Four refused and returned a blank questionnaire. In order to obtain more healthy subjects the QLAP was given to a class composed of support staff at the University (n=13) and a class of post-RN nursing students (n=8). The mean age was lower and education level higher for the latter groups than for the pacer and rehabilitation subjects (Table 6). The QLAP was given to 29 volunteers at the Queensway Carleton Hospital, a population which was likely closer in age and education. Twenty-three volunteers returned completed questionnaires. A total of 60 questionnaires were completed by subjects with no chronic known diseases.

The average age of the healthy subjects was 53 years and 33 percent were

male. Seventy-seven percent were married and they had an average of 15 years of education. Unfortunately, all of the subjects were not asked to record how long it took them to complete the QLAP. Subjects who were questioned responded that it took anywhere between 15 and 45 minutes.

Chronbach's alpha was used as a measure of the internal consistency¹⁰¹ of the questionnaire. This was calculated for the total score and for each of the subsections. The alpha's for each were: total score (0.934), activity (0.870), physical (0.817), psychological (0.930), and social (0.865).

Hypothesis 1: Scores on the QLAP and the QL Uniscale will correlate moderately and positively.

The Pearson correlation coefficient for the score on the uniscale with each of the total and subscores was computed. The results are tabulated in Table 7. The

Table 7. Correlations of total and subscores of the QLAP with the score on the Uniscale.

	Uniscale	Activity	Physical	Psychological	Social	Total
Uniscale	1.00					
Activity	0.34	1.00				
Physical	0.55	0.52	1.00			
Psychological	0.66	0.26	0.46	1.00		
Social	0.45	0.14	0.35	0.53	1.00	
Total	0.69	0.69	0.82	0.79	0.58	1.00

correlation coefficient for the total QLAP score and the QL Uniscale was 0.69. This

is higher than the correlations between the subscales of the QLAP and the QL Uniscale.

Hypothesis 2: There will be a gradient of diminishing QLAP scores from the "healthy" neighbours to those with chronic illness to the acutely ill.

The range of possible scores which could be obtained on the QLAP and its subscales are:

- 1) 0 to 100 for the total score;
- 2) 0 to 58.20 for the activity subscore;
- 3) 0 to 48 for the physical subscore;
- 4) 0 to 140 for the psychological subscore; and

Table 8. Total scores and subscores for each group on the QLAP.

	ACUTE	REHABILITATION	PACEMAKER	HEALTHY
TOTAL*:				
MEAN±SD	62.49±10.88	68.49±13.64	72.15±11.03	77.3±8.162
RANGE	38.58-82.76	32.79-93.74	43.94-90.52	53.56-90.80
ACTIVITY*:				
MEAN±SD	31.38±18.90	41.93±15.01	36.86±15.82	49.31±13.42
RANGE	0-58.20	0-58.20	0-58.20	0-58.20
PHYSICAL*:				
MEAN±SD	30.05±8.03	37.25±6.72	38.08±7.04	40.40±4.48
RANGE	10-46	20-46	16-46	25-46
PSYCHOLOGICAL*:				
MEAN±SD	86.65±24.40	85.42±25.89	101.98±8.56	102.15±18.10
RANGE	0-127	20-136	55-136	27-131
SOCIAL*:				
MEAN±SD	67.76±10.75	67.30±11.58	69.29±8.56	71.12±7.45
RANGE	38.58-82.76	32.79-93.74	43.94-90.52	53.56-90.80

* p < 0.05

5) 0 to 100 for the social subscore. The mean scores for each of the four groups on the QLAP in this study can be found in Table 8. The acutely ill subject group had the lowest mean score with increasingly higher mean scores in the rehabilitation group, the pacemaker group and the healthy group (Figure 2).

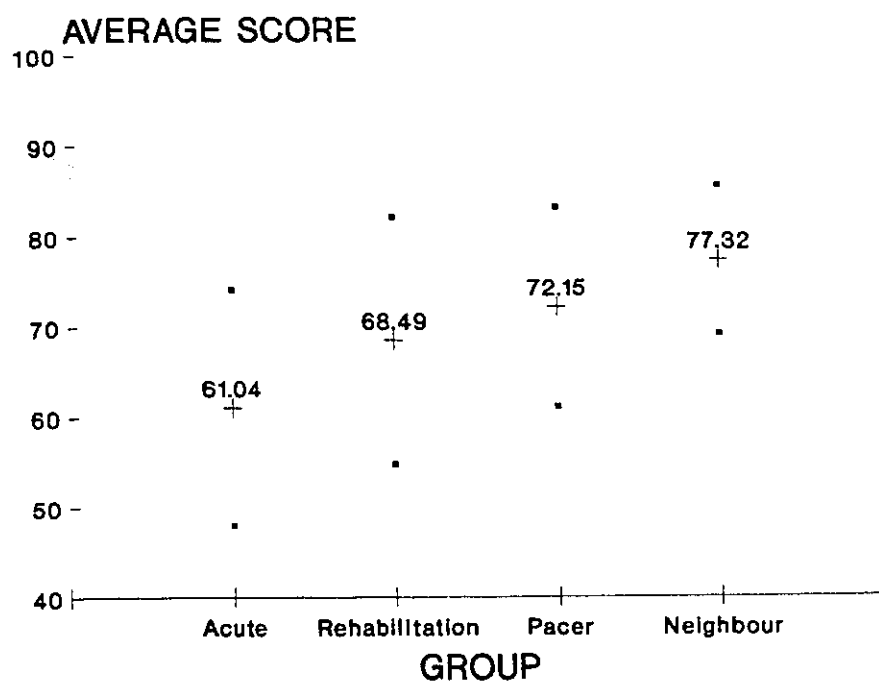


Figure 2: Means and standard deviations of total scores by group.

T-tests were done to compare the mean scores for the rehabilitation and pacemaker groups. This was done in order to determine whether they were similar enough to be combined to produce a chronically ill group for comparison with the healthy group and the acutely ill group. The only significant difference found was for the psychological subscore (Table 9). For further analysis the rehabilitation and pacemaker groups were combined and constitute the chronically ill group. The scores

Table 9. T-tests comparing QLAP scores and subscores for the rehabilitation⁵¹ and pacemaker groups.

	T	p
TOTAL	1.83	0.07
ACTIVITY	1.79	0.07
PHYSICAL	0.70	0.48
PSYCHOLOGICAL	4.40	0.00
SOCIAL	1.15	0.25

and subscores for the three groups (chronically ill, acutely ill, and healthy) were compared by ANOVA using the MGLH procedure in SYSTAT¹⁰². These were found to differ significantly ($p < 0.05$) (Table 10). After applying the correction for multiple testing, post-hoc testing revealed the following:

- 1) **Total score** -all groups scores differed significantly from each other;
- 2) **Activity subscore** -all groups subscores differed significantly from each other;
- 3) **Physical subscore** -all group subscores differed significantly from each other;
- 4) **Psychological subscore** - differences between the chronic and acute subscores were not significant, and differences between the chronic and healthy subscores were not significant, the difference between the acute and healthy subscores was significant;
- 5) **Social subscore** - differences between the chronic and acute subscores were not significant, and differences between the chronic and healthy subscores were not significant, the difference between the acute and healthy subscores was significant.

Table 10. Analysis of variance for total and subscores of the QLAP.

	F VALUE	p
TOTAL	17.09	0.00
ACTIVITY	12.25	0.00
PHYSICAL	20.91	0.00
PSYCHOLOGICAL	10.23	0.00
SOCIAL	3.09	0.03

Hypothesis 3: Scores on the QLAP will be higher in subjects with higher levels of physical functioning.

In order to look at the effect of activity level on the total QLAP score, a linear regression analysis was done. The independent variables were; age, education, number of medications, and rehabilitation class as a proxy to activity level. The

Table 11. Linear regression for rehabilitation subjects, on total score.

	STANDARDIZED REGRESSION COEFFICIENT	SQUARED SEMI-PARTIAL CORRELATION	P
AGE	0.14	0.0167	0.27
EDUCATION	0.25	0.0560	0.04
MEDICATION	-0.42	0.1660	0.00
ACTIVITY LEVEL	0.31	<u>0.0947</u>	0.01
	SUM =	0.3334	
Multiple R ²	= 0.3146		
Shared Variance	= 0.0512		

rehabilitation class to which a subject is assigned depends on the level of METs at which he can exercise as determined by stress test. Classes were numbered one to four with one being the lowest activity level and four being the highest. This information was available for subjects in the rehabilitation programme only. Analysis was performed using BMDP1R. Fifty-two complete cases were available for this analysis. Table 11 displays the standardized regression coefficients, the squared semi-partial correlations, p , multiple R^2 , and the shared variance. Thirty-eight percent of the variation in the total score was explained by the variables included in the analysis. The number of medications was significantly and negatively related to the total score. The activity level (exercise class) was significantly positively related to the total score. Age does not appear to have a significant effect on the total QLAP score in this analysis.

Linear regression analysis was done for the total population (Table 12) using as the dependent variable the total score to further study the relationships between subject attributes and the QLAP score. The independent variables were age, sex, education, marital status, whether the subject indicated that they had a chronic illness, and number of medications. The effect of sex and illness were not significant. Thirty percent of the variation in the total scores was explained by the independent variables used. One-third of this is shared variance. There were moderate correlations between the following variables: age and education; age and number of medications; perception of illness and number of medications. Marital status appears to have the strongest effect on the total score with married persons having higher scores than those who are alone.

Table 12. Linear regression for all subjects with total score as the dependent variable.

	STANDARDIZED REGRESSION COEFFICIENT	p
AGE	0.14	0.04
SEX	0.04	0.57
EDUCATION	0.19	0.00
MARITAL STATUS	-2.38	0.02
ILLNESS	-0.08	0.24
MEDICATION	-0.41	0.00

Hypothesis 4. The QLAP is assessing four areas of life quality (factors): activity, physical, psychological, and social.

Principal factors analysis with varimax rotation was performed through BMDP4M on the 21 elements which constitute the QLAP. When all factors with eigenvalues greater than 1.00 were included, five factors were identified. These have been designated: activity, psychological, physical, social, and performance. Performance is the factor that had not been identified prior to the analysis. Loading of elements on factors, and the amount of variance explained by the factor are shown in Table 13. Variables are ordered and grouped by size of loading to facilitate interpretation. Loadings under 0.250 have been replaced by blanks. In general, the elements have loaded heavily on one factor only. The element, visual perception, loaded only moderately on the first factor. The five factors together account for 65 percent of the variance in the variables. The new factor, performance, accounts for

10 percent of the variance in the variables.

Table 13. Factor loadings of Activity, Psychological, Physical, Social, and Performance among all subjects (varimax rotation).

VARIABLE	FACTORS				
	1	2	3	4	5
ACTIVITY:					
ADL	0.849				
Ability to live normally	0.805				
Energy	0.774		0.255		
Mobility	0.712				
Range of movement	0.685		0.259		0.303
Visual perception	0.280				
PSYCHOLOGICAL:					
Satisfaction with life		0.799	0.301		
Psych. general well-being		0.719	0.333		
Self esteem	0.313	0.707			
Confidence		0.698			
Self image		0.684			
Internal control over emotions		0.547	0.392		
PHYSICAL:					
Perceived benefits of treat			0.797		
General health status	0.282		0.728		
Relief/decrease in symptoms			0.688		
SOCIAL:					
Changes in marriage				0.829	
Control over personal life				0.775	
Family life				0.724	
PERFORMANCE:					
Alertness					0.859
Intellectual performance					0.827
Social role performance		0.285	0.319	0.316	0.515
Variance explained by the factor (SSL/N _v)	0.16	0.16	0.11	0.10	0.10

CHAPTER V

DISCUSSION

Few longitudinal studies of QL have been done in patients with permanent pacemakers or in patients participating in a cardiac rehabilitation programme. Those which have been done have used measures which detected little or no change resulting from interventions^{70 71 76 84 85}. Different pacing modalities and cardiac rehabilitation do seem to result in improved functional capacity and patient reports of "feeling better". My goal is to develop a quality of life measure which would record these changes. The aim of this study was to compile the measure and assess its reliability and validity.

Phase I

Comparison of choice of elements by patients, family and staff:

Overall, patients/clients appear to have chosen elements which represent the more positive aspects of life. These differences are more marked in the physical, psychological and activity sections than in the social section. There are fewer differences between the patient and family ratings than between the patients and staff ratings. Family members usually rated problematic elements such as dizziness and chest pain as more important than did patients. Guyatt et al¹⁰³ in their study of quality of life in patients with chronic airflow limitations made similar findings. Once a patient selected an item as a problem, the relative tended to feel that the problem was more important than the patient did themselves. It is possible that the patients and their family member consulted on the ratings of each of the elements since some of the questionnaires were completed at home. Records, on the site of completion

of the Phase I survey, were not kept. If they had been, and the sample size had been large enough, it would be interesting to compare the ratings of elements by pairs that had the opportunity to consult with each other versus those who did not.

Originally the elements making up the QLAP were to have been derived from the three populations (patients, family, staff). When it became apparent that the priorities for the three groups were fairly different, only the patient/client group was used. If the importance scores from the staff had been used to decide which elements should be included in the QLAP it would have included more of the elements commonly contained in QL measures such as: symptoms, anxiety about health, fear of recurrence and death, depression, employment status, and sexual activity. This would increase the acceptability of the questionnaire to staff since it would appear, to them, to have face validity.

Comparison of findings with those of other studies:

With patient/client importance scores used to determine which elements should be included in the QLAP, desire to work, employment status, hours worked per day and working capacity were not included in the measure. Employment status and/or working capacity have frequently been included in measures of life quality^{104 105 106 107}. In many of the early studies, purporting to measure life quality, employment status was the main indicator used^{108 109}. Studies that have included work/employment status as part of the assessment of life quality have shown little or no differences in employment status when other aspects of life quality have changed^{110 111 112}.

Neither sexual activity nor sexual functioning had a high enough mean

importance score to be included in the final measure. Sexual activity and functioning have frequently been included in studies and measures of quality of life^{113 114 115 116}. They were ranked as more important by staff than by patients but not highly enough to have been included in a measure derived from staff importance scores. This may be accounted for by the difference in populations being studied. In studies of hypertension, for instance, a change in sexual functioning or activity is a potential symptom/side-effect of the use of antihypertensives. Since staff rate symptoms as an important contributor to QL, if the population had been primarily hypertensive, sexual functioning might have been considered more important.

Very few measures of life quality have evolved inductively from patient-generated definitions of the content of quality of life. Two studies have been done wherein cancer patients defined quality of life. In the first¹¹⁷, patients were asked four open ended questions about the meaning of quality of life, what contributes to good or poor quality of life, and how pain influences quality of life. Three areas of content emerged: 1) physical well-being, 2) psychological well-being, and 3) interpersonal well-being (social support and social role functioning). In that study more negative aspects were identified by the patients than positive aspects in contrast to the present study. In the second study¹¹⁸, patients with metastatic breast cancer were asked to rate the relative importance of 28 items concerned with general health or disease. Most general health items, such as mobility, physical activity, and family relationships, were ranked higher than disease or treatment related items. The findings of this second study are consistent with mine. The method this second study used was also more analogous to mine.

Seventy-eight percent of the Phase I survey forms given out to patients/clients were returned. The forms returned represented 64 percent of the patients/clients originally chosen from the rehabilitation classes and the pacemaker clinic to participate. There, therefore, may be some concern about the representativeness of the results of the survey due to these incomplete response rates. The main reason given for not completing the survey was the inability to read or write english or some form of dementia. The elements chosen represent those aspects of QL considered important by literate anglophones with no form of dementia. It is possible that the aspects of life which were considered important by the respondents would not be the same for non-anglophones, illiterates, or persons with some form of dementia. No research has been done on this problem. This limits the use of the QLAP to subjects who can read and write english at the grade 5 level, and who suffer form no forms of dementia.

A more qualitative approach to soliciting information on what patients/clients think contributes to their quality of life would in all likelihood have resulted in a somewhat different list of elements. The use, in the Phase I survey, of only those aspects of QL which had be previously used in measures is somewhat restricting. A broader range of items, might also have resulted if the items suggested by the patients, on the survey form, had been added to the initial survey and the survey repeated in another patient group. No elements suggested by patients were listed by more than 4 or 5 subjects so a repeat survey with these items added may not have changed the results.

Optimally, all of the elements with an importance score other than zero should

have been included in the questionnaire, weighted to reflect their relative importance. Realistically, to make it useable, patients/clients had to be able to complete the final questionnaire in 30 to 60 minutes. It also had to contain enough elements to be reliable and valid. For these reasons only the 22 elements with the highest patient/client scores were included.

Phase II

Discussion of questionnaires from which questions were taken for use in the

QLAP:

A review of the majority of the measures which have been used to assess life quality was done and questions were chosen to make up the final QLAP. It had been hoped that a few questionnaires, in their entirety, could be used. Since this was not possible, questions relating to the elements were selected from a number of existing, self-administered questionnaires. Where there were a number of measures, containing questions relating to the elements, the questionnaires which had been developed and/or tested in relatively healthy populations and which had been shown to be valid and reliable were chosen.

The Duke Activity Status Index⁹¹ (DASI) was the only measure that could be used in its entirety. This is a brief self-administered questionnaire which measures functional capacity, and ability to perform various physical activities. It was developed and tested in patients undergoing exercise testing. Scores on the DASI correlate well with peak oxygen uptake, the Canadian Cardiovascular Society Classification¹¹⁹, and the Specific Activity Scale¹²⁰.

The General Well Being Schedule¹²¹ is a 68 item, self-administered questionnaire, developed, and tested in healthy populations. It is composed of questions assessing: anxiety, depression, general health, positive well-being, self-control, and vitality. Its construct validity, when used in a healthy population, has been supported and it is internally consistent and relatively stable.

The OECD Long-Term Disability¹¹⁴ Questionnaire is a 16 item, self-administered questionnaire meant for assessing disability in population surveys. It contains questions relating to self care, mobility, body movement, and senses. The limited test-retest reliability studies which have been done show it to be somewhat unreliable. Its validity has not been well supported.

The Nottingham Health Profile¹¹⁵ has been tested in populations with chronic illnesses and has been used to measure quality of life in studies of coronary artery bypass grafting, cardiac transplants, and pacemakers. Its reliability and validity for use in a number of populations has been supported but as it stands, it has been shown not to be responsive enough for use in evaluating alternate forms of pacing.

The Life Satisfaction Index¹¹⁶ is a 20 item measure assessing such aspects of life satisfaction as: zest, resolution and fortitude, congruence between desired and achieved goals, self concept, and mood tone. Its validity, when used in healthy populations, has been moderately supported and it is internally consistent.

The General Well-being Adjustment Scale¹¹⁷ is a 22 item, self-administered scale the validity of which has been supported by a number of studies. The Affect Balance Scale¹¹⁸ is a 10 item, self-administered scale which measures the psychological reaction of people to positive and negative events in their lives. Its

validity has been supported and there are Canadian reference standards for this scale. It is stable but does not have high internal consistency.

The Social Adjustment Scale¹¹⁹ consists of 42 questions in two versions: interview, and self-administered. Its validity has been tested and moderately supported in a number of different populations including community residents.

The General Health Questionnaire¹²¹ was developed as a screening instrument for psychiatric disorders. It is self administered and consists of 60 items. Its validity has been well tested in a number of different populations and countries, it has been shown to be stable, and to have a high internal consistency.

Since it is the questionnaires themselves and not the individual questions to which measures of reliability and validity apply, the choice of questions did not ensure that the QLAP would be either valid or reliable. Using this approach does give some insurance that the questions are well written and interpretable by the person completing the questionnaire. It is hoped that choosing questions from measures which had been developed or tested in healthy population would result in a more responsive questionnaire. This is because there would be a range of answer options at the healthy end of the continuum rather than one option indicating function above a certain level.

The QLAP was weighted by the importance scores of each subsection instead of by the importance scores for each element. Although it would have been more scientifically justifiable to weight each of the elements contributing to the final score, the resulting calculation would have been very complex. This measure is meant for use in the clinical setting and so the more practical approach was to weight it by the

subsection importance score for each subsection. A number of researchers have studied the relative merits of weighting items over merely summing them^{122 123}¹²⁴. The majority concluded that weighting contributes relatively little except added complexity. There may be some benefit to weighting when there are fewer than 20 to 40 items^{125 126}. The QLAP is implicitly weighted because the number of questions relating to each element differs. For example, the QLAP includes 6 physical elements, and 8 psychological elements. Scored directly, the physical elements would only account for 14 percent of the final score whereas the psychological elements would account for 40 percent. Some form of weighting was required to compensate for this imbalance.

Phase III

It was felt that using neighbours for the group with no chronic disease would control to some extent for age and socioeconomic status. These factors have been shown to have a very small influence on QL scores in some studies. There was, however, a problem recruiting neighbours of chronically ill patients. The rehabilitation department would not allow a form requesting the patient to identify a neighbour to be included in the questionnaire. Not all of the patients from the pacemaker clinic were able to submit the name of a neighbour. A similar problem was experienced by Shaw¹²⁷ in his study of cancer patients. Fewer than 50 percent of the cases volunteered the name of a friend. The group with no chronic illness was younger than the pacemaker patients but did not differ in age from the rehabilitation patients. Their level of education was also similar to that of the rehabilitation patients. They did differ markedly in the proportion of men, 33 percent male as

opposed to 57 percent male in the pacemaker group and 74 percent male in the rehabilitation group. The regression analysis showed a minimal effect of age and no significant effect of sex on the final QLAP score and so the differences in this group were not considered serious.

As indicated, some methodological and implementation problems occurred during the study. Among these were:

- 1) relatively poor return rate (67 to 86 percent in phase 3);
- 2) inability to get enough subjects free of chronic diseases using the method proposed in the study.

It might appear that the returns would have been higher if subjects had been asked to complete the questionnaires while they were at the Heart Institute. Instead, it would probably have increased the refusals because subjects would not stay for the time it would take to complete the questionnaire. More reminder phone calls or cards with repeat questionnaires would also have increased returns. Only one reminder phone call was made if questionnaires had not been returned within two weeks. Obviously, the subjects that did not return completed questionnaires may differ from those that completed them. There is not adequate information available on the refusers, or non-returners to further explore this.

Reliability

The Quality of Life Assessment Package and its subscores are internally consistent. This means that the questions making up the QLAP are tapping different aspects of the same attribute. A very high Chronbach's alpha for the total score

might not have been expected because the QLAP is intentionally multidimensional¹²⁸. The high internal consistency is compatible with Hornquist's theory that there is a high degree of interaction within and between various life domains¹²⁹. The stability of the QLAP was not assessed in this study. It is important that it be assessed in further testing of the measure since the responsiveness and validity of a measure are related to its reproducibility.

Validity.

The tests done in this study have provided support for the validity of the QLAP. Validation is a process of hypothesis testing¹²⁶. A number of hypotheses were proposed and tested in this study. It was proposed that if the QLAP were a valid measure of quality of life, the following would be true:

- 1) Scores on the QLAP and the QL Uniscale would correlate moderately and positively (>0.40);
- 2) There would be a gradient of diminishing mean QLAP scores from the "healthy" neighbours to those with chronic illness, to the acutely ill;
- 3) Scores on the QLAP would be higher in subjects with higher levels of physical functioning;
- 4) The QLAP would be assessing four areas of life quality (factors): activity, physical, psychological, and social.

Hypothesis 1:

The QLAP total scores correlated positively ($r=0.69$) with scores on the QL Uniscale. The QL Uniscale is a reflection of overall satisfaction with life¹³⁰ as is

the total QLAP score. The two scales are only moderately correlated. Had a high correlation been obtained there would be no need for the QLAP since it would be a repeat of the QL Uniscale. As expected, the correlation for the total score and the QL Uniscale was higher than between the QLAP subscores and the QL Uniscale.

Hypothesis 2:

The healthy subject group had the highest scores on the QLAP for the total and for the four subscores. The acutely ill subject group had the lowest scores. All three group's (healthy, acute, chronic) scores differed significantly. Many studies of QL measures have been unable to clearly demonstrate differences in scores between groups of cancer patients¹³¹. The fact that this measure can discriminate between these three groups encourages one to believe that it may also be responsive to changes resulting from treatment. It is important to keep in mind that this measure is meant to be used as an evaluative one and the purpose of testing this second hypothesis was not to assess its ability to discriminate between groups. The purpose was to test a prediction about the QLAP based on the present understanding of QL. Further validation studies should be done to assess whether longitudinal within-subject changes in scores with an intervention have the expected relationship to other variables measured.

Notwithstanding the differences in age and gender composition of the rehabilitation group and the pacemaker group, it was expected that their scores would not differ significantly and this was supported.

Hypothesis 3:

Rehabilitation clients are assigned to exercise class by the level at which they

can exercise (in METS). Where possible, this is assessed prior to entry into the programme using a bicycle stress test. As anticipated, there was a positive correlation between the exercise class to which the subject was assigned and the score on the QLAP. It was also shown for both the rehabilitation group and for the whole group that QLAP scores became lower as the number of medications taken per day increased. The effect of age on the QLAP score was found to be insignificant in the linear regression analyses done using rehabilitation patients only. There was a moderate effect of age when all subjects were included in the regression. This may have been because the ages of the rehabilitation population were more homogeneous. The effect of sex on the QLAP score was insignificant in both analyses. These results are consistent with the findings of Abbey and Andrews¹³². They found that standard demographic or social classification variables such as age, sex, education, and income showed only modest relationships, if any, to self-assessments of life quality. In testing the construct validity of a measure, we are not only testing the measure but the theory as well. The linear regression analysis done on the whole sample was done primarily to learn more about the relationship of QL and the QLAP to objective indicators.

Hypothesis 4:

The factor analysis indicated a fifth factor (performance) which was not included as a separate subscale of the QLAP. Social role performance loads most heavily under the performance factor but also loads under social as originally placed. The second highest loading for Intellectual performance and alertness is under psychological where they were originally placed. The activity subscore has two of the

physical variables (mobility and ROM) loading most heavily under it. They also load, but more weakly, under the physical and performance factors. The remainder of the elements load where they were expected to. The question arises whether one should revise the scoring of the QLAP to include five subscales (activity, physical, social, psychological, and performance) instead of four. Further analysis, allowing only four factors, is warranted. I have decided to remain with the four subscales for now because: 1) all of the elements which are loading under factors other than those proposed are also loading, but more weakly, under the original factors, and 2) Hornquist's framework does not include a separate performance factor.

CHAPTER VI

CONCLUSIONS

The Quality of Life Assessment package has the following characteristics:

- 1) it is easily completed by subjects able to read english at the grade 5 level;
- 2) it takes between 30 and 60 minutes to complete;
- 3) it is moderately easy to score by hand;
- 4) it has content validity;
- 5) it is internally consistent; and
- 6) it has had its validity supported by the hypotheses tested in this study.

Further study of this measure is required to assess the following:

- 1) test-retest reliability;
- 2) responsiveness; and
- 3) further tests of construct validity.

The following two-phase study is proposed as the next step in assessing the QLAP. In Phase I, the validity would be appraised by administering the QLAP along with other health assessment questionnaires. It would be determined whether the QLAP shows the expected correlation with other measures and whether it correlates more strongly with measures more closely related to the construct than with measures bearing a looser relationship (Multitrait-multi-method matrix¹³³). The internal consistency of the questionnaire will be reassessed by calculating the Chronbach's alpha for these test scores.

In Phase II (Figure 3), patients in whom ventricular rate-responsive pacemakers have been inserted, on giving consent, would twice undergo treadmill

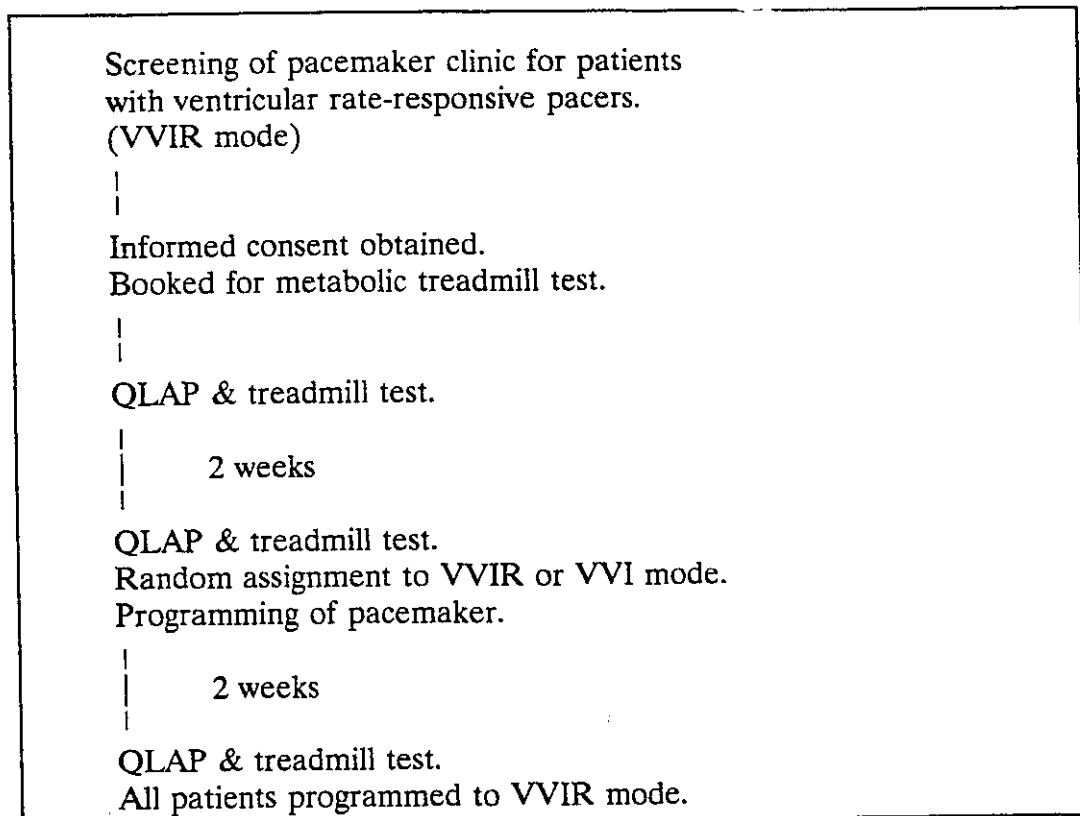


Figure 3. Phase II of proposed study.

testing and complete the QLAP. After half of the patients have had their pacemaker mode changed, they will again undergo exercise testing and complete the QLAP. To assess the test-retest reliability the QLAP scores will be compared. In order to assess the responsiveness of the measure, QLAP and treadmill test scores, before and after the mode changes, will be compared. An Index of Responsiveness will be calculated¹³⁴.

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APPENDICES

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APPENDIX A

Definition of Terms

- Construct:** an abstraction or concept inferred from situations, events or behaviours which is deliberately invented for a specific purpose (ie Quality of Life).
- Construct validity:** the extent to which a measure relates to other measures consistent with theoretically derived hypotheses concerning the constructs which are being measured (there are different types of evidence for construct validation; convergent evidence, discriminant evidence, factorial evidence).
- Content validity:** the extent to which the items of an instrument adequately represent the domain they are supposed to measure.
- Convergent evidence:** when the direction and level of correlation between a single existing measure and the proposed measure is that suggested by knowledge of the construct (confirmation by independent measurement procedures).
- Criterion related validity:** comes the closest to the definition of validity itself but cannot be appraised since there is no gold standard for measurement of quality of life.
- Discriminant evidence:** when the proposed measure correlates better with a second measure accepted as more closely related to the construct than it does to a third more distantly related measure.
- Factorial validity:** examination of how far the various items in an index accord in measuring one or more common themes
- Internal consistency:** an estimate of reliability based on both the average correlation among items and numbers of items

Operationalization:	delineation of the procedures and tools required to make the measurements.
Reliability:	the extent to which a measure will yield the same results in repeated measures of an unchanging characteristic
Responsiveness:	the ability of a measure to detect minimal clinically important differences
Validity:	the extent to which a measurement method measures what it is supposed to

APPENDIX B
PHASE I: Staff Survey Form

PHYSICAL

Please indicate, by putting an "X" in the appropriate box, whether you feel each item is an important or an unimportant contributor to the Quality of Life of Cardiac Rehabilitation Patients.

	IMPORTANT	NOT IMPORTANT
appetite		
body satisfaction		
chest pain		
diet		
dizziness		
exercise tolerance		
fainting		
fatigue		
general health status		
medical complications		
mobility		
motor perception		
need for medications		
number of incapacitated days per month		
perceived benefits of treatment		
percentage of time hospitalized (number of rehospitalizations)		
range of movement		
relief of, or decrease in, symptoms		

shortness of breath

sleep/rest

symptoms due to medications (side effects)

symptom duration

symptom frequency

symptom relief

symptom severity

visual perception

IMPORTANT	NOT IMPORTANT

Please add any items which you consider contribute to QUALITY OF LIFE in the physical area but which have not been included in this list.

Please list the five items from the above list that you consider the most important contributors to the QUALITY OF LIFE in the physical area.

PSYCHOLOGICAL

Please indicate, by putting an "X" in the appropriate box, whether you feel each item is an important or an unimportant contributor to the Quality of Life of Cardiac Rehabilitation Patients.

	IMPORTANT	NOT IMPORTANT
academic performance		
alertness		
anxiety regarding health		
confidence		
control by others over one's emotions		
depression		
emotional difficulties		
fear of recurrence and death		
general anxiety		
intellectual performance		
internal control over one's emotions		
learning disabilities		
mood		
personality type (A or B)		
psychological general well-being		
psychological affect		
psychotic symptoms		
satisfaction with life		
self esteem		
self image		
stress		

IMPORTANT

NOT
IMPORTANT

temper

--	--

Please add any items you consider contribute to QUALITY OF LIFE in the psychological area but which have not been included in this list.

Please list the five items from the above list that you consider the most important contributors to the QUALITY OF LIFE in the psychological area.

SOCIAL

Please indicate, by putting an "X" in the appropriate box, whether you feel each item is an important or an unimportant contributor to the Quality of Life of Cardiac Rehabilitation Patients.

	IMPORTANT	NOT IMPORTANT
changes in marriage		
changes in family		
control by others over one's personal life		
critical life events		
family life		
internal control over one's personal life		
interpersonal relationships		
number of social relationships		
recreational activities		
social activities		
social dependency		
social integration		
social isolation		
social performance		
social role functioning		
social support		

Please add any items you consider contribute to QUALITY OF LIFE in the social area but which have not been included in this list.

Please list the five items from the above list that you consider the most important contributors to the QUALITY OF LIFE in the social area.

ACTIVITY

Please indicate, by putting an "X" in the appropriate box, whether you feel each item is an important or an unimportant contributor to the Quality of Life of Cardiac Rehabilitation Patients.

	IMPORTANT	NOT IMPORTANT
ability to live normally		
activities of daily living		
desire to work		
employment status		
energy		
home management		
hours worked per day		
leisure time activity		
perception of limitations to activity		
previous education		
sexual activity		
sexual functioning		
working capacity		

Please add any items you consider contribute to QUALITY OF LIFE in the activity area but which have not been included in this list.

Please list the five items from the above list that you consider the most important contributors to the QUALITY OF LIFE in the activity area.

MATERIAL

Please indicate, by putting an "X" in the appropriate box, whether you feel each item is an important or an unimportant contributor to the Quality of Life of Cardiac Rehabilitation Patients.

	IMPORTANT	NOT IMPORTANT
financial burden		
need for clothing		
need for food		
need for shelter		
socioeconomic status		

Please add any items you consider contribute to QUALITY OF LIFE in the activity area but which have not been included in this list.

STRUCTURAL

Please indicate, by putting an "X" in the appropriate box, whether you feel each item is an important or an unimportant contributor to the Quality of Life of Cardiac Rehabilitation Patients.

	IMPORTANT	NOT IMPORTANT
contacts with authorities		
political participation		

Please add any items you consider contribute to QUALITY OF LIFE in the activity area but which have not been included in this list.

APPENDIX C
PHASE I: Patient Survey Form

Compilation and Testing of a Quality of Life
Assessment Package

Investigators: Kirsten Woodend (787-6420)
Dr. A. Tang
Dr. R. Nair

PURPOSE OF STUDY: To compile a questionnaire which will measure the **QUALITY OF LIFE** of patients in the Cardiac Rehabilitation programme or who have had pacemakers inserted.

REASON FOR SELECTION: Patients who are participating in the Cardiac Rehabilitation programme or who have had pacemakers implanted have been selected, at random, to participate.

PROCEDURE: You are asked to follow the directions for completing the attached questionnaire. It should take between a half an hour and an hour to complete.

Information from this questionnaire will remain confidential and you will never be identified in any report or publication. You are free to refuse to complete this questionnaire and your decision will not adversely affect your care (or your family members care) at this institution.

I _____ certify that I have read the preceding, or that it has been read to me and that I understand its contents, and that any questions I have pertaining to the research have been or will be answered by Kirsten Woodend and that my permission is given freely.

DATE

SIGNATURE

COMPILATION AND TESTING OF A QUALITY OF LIFE ASSESSMENT PACKAGE
INFORMATION SHEET

AGE: _____

SEX: MALE / FEMALE

LENGTH OF TIME SINCE FIRST CARDIAC EVENT (HEART ATTACK / HEART SURGERY /
 PACEMAKER):

_____ (DAYS / MONTHS / YEARS)

LENGTH OF TIME SINCE LAST CARDIAC EVENT (HEART ATTACK / HEART SURGERY /
 PACEMAKER):

_____ (DAYS / MONTHS / YEARS)

HOW MANY DIFFERENT MEDICATIONS ARE YOU TAKING A DAY?

HAVE YOU HAD THE FOLLOWING? (CIRCLE ALL THAT APPLY):

HEART ATTACK?	Y / N
CORONARY ARTERY BYPASS GRAFTS?	Y / N
HEART VALVE SURGERY?	Y / N
HEART TRANSPLANT?	Y / N
ANGINA?	Y / N
HEART FAILURE?	Y / N
PACEMAKER INSERTION?	Y / N

PACEMAKER CLINIC / REHABILITATION

LIC/II/IIIA/IIIB

COMPILATION AND TESTING OF A QUALITY OF LIFE ASSESSMENT PACKAGE

Dear _____

I am attempting to compile a Quality of Life Assessment Package which can be used to assess the effectiveness of various programmes and modes of treatment on the Quality of Life of cardiac rehabilitation programme participants and patients who have received permanent pacemakers. A definition of quality of life is the degree of need satisfaction within the physical, psychological, social, activity, material and structural areas of life.

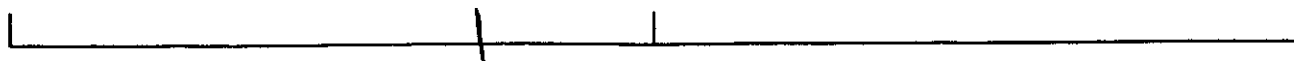
A list of the constructs (elements) has been compiled from the quality of life research done since 1977. I have used the above definition to divide this list under six headings. Please put a mark across the scale under each element to indicate how important the element is to your quality of life.

EXAMPLE:

READING A GOOD BOOK:

important

not important



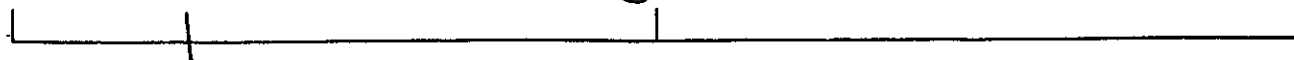
At the end of each section, space has been provided for you to add any items which you feel are important but which have not been listed. You are also asked to mark a scale for each of these items.

EXAMPLE:

1. having time to relax each day

important

not important



If you have any questions or comments please feel free to call me at 787-6480 (University of Ottawa) or 822-1179 (home).

Kirsten Woodend
 Student (MSc, Epidemiology)
 University of Ottawa
 Department of Epidemiology and Community Medicine

PHYSICAL

Please indicate, by putting a mark across the line, how important a contribution each item makes the quality of your life. Please keep in mind that this is not a list of problems you might have. It is a list of elements the importance of the presence or absence of which, we would like you to rate.

APPETITE:		
important	_____	not important
BODY SATISFACTION:		
important	_____	not important
CHEST PAIN:		
important	_____	not important
DIET:		
important	_____	not important
DIZZINESS:		
important	_____	not important
EXERCISE TOLERANCE:		
important	_____	not important
FAINING:		
important	_____	not important
FATIGUE:		
important	_____	not important
GENERAL HEALTH STATUS:		
important.	_____	not important
MEDICAL COMPLICATIONS:		
important	_____	not important
MOBILITY:		
important	_____	not important

MOTOR PERCEPTION: important	not important

NEED FOR MEDICATIONS: important	not important

NUMBER OF INCAPACITATED DAYS PER MONTH: important	not important

PERCEIVED BENEFITS OF TREATMENT: important	not important

PERCENTAGE OF TIME HOSPITALIZED (NUMBER OF REHOSPITALIZATIONS): important	not important

RANGE OF MOVEMENT: important	not important

RELIEF OF, OR DECREASE IN, SYMPTOMS: important	not important

SHORTNESS OF BREATH: important	not important

SLEEP/REST: important	not important

SYMPTOMS DUE TO MEDICATIONS (SIDE EFFECTS): important	not important

SYMPTOM DURATION: important	not important

SYMPTOM FREQUENCY: important	not important

SYMPTOM RELIEF: important	not important

SYMPTOM SEVERITY:

important

not important

VISUAL PERCEPTION:

important

not important

Please add any items which you consider contribute to QUALITY OF LIFE in the physical area but which have not been included in this list and rate them as you did the above items.

1. _____
important not important

2. _____
important not important

3. _____
important not important

4. _____
important not important

5. _____
important not important

PSYCHOLOGICAL

Please indicate, by putting a mark across the line, how important a contribution each item makes the quality of your life.

ACADEMIC PERFORMANCE:

important not important

ALERTNESS:

important not important

ANXIETY REGARDING HEALTH:

important not important

CONFIDENCE:

important not important

CONTROL BY OTHERS OVER ONE'S EMOTIONS (CONTROL OTHER PEOPLE HAVE OVER HOW YOU FEEL):

important not important

DEPRESSION:

important not important

EMOTIONAL DIFFICULTIES:

important not important

FEAR OF RECURRENCE (HAVING ANOTHER HEART ATTACK, HEART SURGERY OR PROBLEMS WITH YOUR HEART RHYTHM) AND DEATH:

important not important

GENERAL ANXIETY:

important not important

INTELLECTUAL PERFORMANCE:

important not important

INTERNAL CONTROL OVER ONE'S EMOTIONS (CONTROL BY YOURSELF OVER YOUR EMOTIONS):

important not important

LEARNING DISABILITIES (PROBLEMS WITH LEARNING SUCH AS MEMORY PROBLEMS, VISION PROBLEMS OR DIFFICULTY WITH CONCENTRATING):

important not important

MOOD:

important not important

PERSONALITY TYPE (A OR B) (A TYPE A PERSON IS IN A HURRY AND ALWAYS TRYING TO DO MORE IN LESS TIME, A TYPE B PERSON IS THE OPPOSITE):

important not important

PSYCHOLOGICAL GENERAL WELL-BEING:

important not important

PSYCHOLOGICAL AFFECT (HOW YOU APPEAR TO BE PSYCHOLOGICALLY, FOR EXAMPLE LOOKING CHEERFUL WHEN YOU FEEL DEPRESSED):

important not important

PSYCHOTIC SYMPTOMS (SYMPTOMS OF HAVING LOST CONTACT WITH REALITY):

important not important

SATISFACTION WITH LIFE:

important not important

SELF ESTEEM (RESPECT FOR YOURSELF):

important not important

SELF IMAGE (THE IMPRESSION YOU HAVE OF YOURSELF):

important not important

STRESS:

important not important

TEMPER:

important not important

Please add any items which you consider contribute to QUALITY OF LIFE in the psychological area but which have not been included in this list and rate them as you did the above items.

1. _____ important _____ not important
|-----|
2. _____ important _____ not important
|-----|
3. _____ important _____ not important
|-----|
4. _____ important _____ not important
|-----|
5. _____ important _____ not important
|-----|

SOCIAL

Please indicate, by putting a mark across the line, how important a contribution each item makes the quality of your life. Please keep in mind that this is not a list of problems you might have. It is a list of elements the importance of the presence or absence of which, we would like you to rate.

CHANGES IN MARRIAGE:

important not important

CHANGES IN FAMILY:

important not important

CONTROL BY OTHERS OVER ONE'S PERSONAL LIFE (THE EXTENT TO WHICH YOU FEEL THAT OTHER PEOPLE DETERMINE WHAT HAPPENS IN YOUR LIFE) :

important not important

FAMILY LIFE:

important not important

INTERNAL CONTROL OVER ONE'S PERSONAL LIFE (THE EXTENT TO WHICH YOU FEEL THAT YOU, PERSONALLY, DETERMINE WHAT HAPPENS IN YOUR LIFE):

important not important

INTERPERSONAL RELATIONSHIPS (QUALITY OF PERSONAL RELATIONSHIPS WITH OTHERS):

important not important

NUMBER OF SOCIAL RELATIONSHIPS:

important not important

RECREATIONAL ACTIVITIES:

important not important

SOCIAL ACTIVITIES:

important not important

SOCIAL DEPENDENCY (HAVING ONE'S SOCIAL LIFE CONTINGENT UPON SOMEONE ELSE):

important not important

SOCIAL INTEGRATION ('FITTING IN' SOCIALLY):

important not important

SOCIAL ISOLATION:

important

not important

SOCIAL PERFORMANCE (HOW SUCCESSFUL YOU FEEL YOU ARE IN FULFILLING SOCIAL ROLE DEMANDS):

important

not important

SOCIAL ROLE FUNCTIONING (HOW WELL YOU FUNCTION IN YOUR SOCIAL ROLES):

important

not important

SOCIAL SUPPORT (EXTENT TO WHICH SIGNIFICANT OTHERS EXPRESS POSITIVE REGARD, AFFECTION AND ENCOURAGEMENT):

important

not important

Please add any items which you consider contribute to **QUALITY OF LIFE** in the social area but which have not been included in this list and rate them as you did the above items.

1. _____
important not important

2. _____
important not important

3. _____
important not important

4. _____
important not important

5. _____
important not important

ACTIVITY

Please indicate, by putting a mark across the line, how important a contribution each item makes the quality of your life.

ABILITY TO LIVE NORMALLY:

important

not important

ACTIVITIES OF DAILY LIVING (SELF RELIANCE):

important

not important

DESIRE TO WORK:

important

not important

EMPLOYMENT STATUS:

important

not important

ENERGY:

important

not important

HOME MANAGEMENT:

important

not important

HOURS WORKED PER DAY:

important

not important

LEISURE TIME ACTIVITY:

important

not important

PERCEPTION OF LIMITATIONS TO ACTIVITY:

important

not important

PREVIOUS EDUCATION:

important

not important

SEXUAL ACTIVITY:

important

not important

SEXUAL FUNCTIONING:

important

not important

WORKING CAPACITY:

important

not important

Please add any items which you consider contribute to QUALITY OF LIFE in the activity area but which have not been included in this list and rate them as you did the above items.

1. _____

important

not important

2. _____

important

not important

3. _____

important

not important

4. _____

important

not important

5. _____

important

not important

MATERIAL

Please indicate, by putting a mark across the line, how important a contribution each item makes the quality of your life.

FINANCIAL BURDEN:

important _____ not important

NEED FOR CLOTHING:

important _____ not important

NEED FOR FOOD:

important _____ not important

NEED FOR SHELTER:

important _____ not important

SOCIOECONOMIC STATUS:

important _____ not important

Please add any items which you consider contribute to QUALITY OF LIFE in the activity area but which have not been included in this list and rate them as you did the above items.

1. _____
important _____ not important

2. _____
important _____ not important

3. _____
important _____ not important

4. _____
important _____ not important

5. _____
important _____ not important

STRUCTURAL

Please indicate, by putting a mark across the line, how important a contribution each item makes the quality of your life.

CONTACTS WITH AUTHORITIES (HELP FROM AUTHORITIES):

important _____ not important

POLITICAL PARTICIPATION (POSSIBILITY OF INFLUENCING SOCIETY):

important _____ not important

Please add any items which you consider contribute to QUALITY OF LIFE in the activity area but which have not been included in this list and rate them as you did the above items.

1. _____ not important
important

2. _____ not important
important

3. _____ not important
important

4. _____ not important
important

5. _____ not important
important

APPENDIX D
PHASE III: Quality of Life Assessment Package

**QUALITY OF LIFE
ASSESSMENT PACKAGE**

DIRECTIONS FOR COMPLETING THE QUESTIONNAIRE

There are a number of different types of questions in this questionnaire.

For the following type of question, you will be asked to put an X in the box under the appropriate answer.

for example.....

Can You...

- 1) chew gum while walking?
2) read and watch TV at the same time?

	Yes		No
			X
	X		

For the following type of question, you will be asked to put an X in the appropriate box. There are labels in capital letters at each end of the box which indicate the extremes and your X will go into a box which is closest to the answer you feel is correct. If your opinion is somewhere in the middle, then your X will go in the middle.

for example.....

- 3) Can you read and watch TV at the same time?

	X			
--	---	--	--	--

EASILY

NOT AT ALL

The final type of question is a multiple choice with 5 possible answers. Please put an X in the box next to the answer which is closest to the way you feel.

for example.....

- 4) Can you read and watch TV at the same time?

- [] 1. Very easily.
 2. Easily.
 [] 3. Somewhat.
 [] 4. With difficulty.
 [] 5. Not at all.

Questionnaire #: _____

The Duke Activity Status Index*

Please put an X in the box under the correct answer:

Can You...

	Yes	No
1) take care of yourself, that is, eating, dressing, bathing or using the toilet?		
2) walk indoors, such as around the house?		
3) walk a block or two on level ground?		
4) climb a flight of stairs or walk up a hill?		
5) run a short distance?		
6) do light housework around the house like dusting or washing the dishes		
7) do moderate work around the house like vacuuming, sweeping floors, or carrying in the groceries?		
8) do heavy work around the house like scrubbing floors, or lifting or moving heavy furniture?		
9) do yardwork like raking leaves, weeding or pushing a power mower?		
10) have sexual relations?		
11) participate in moderate recreational activities like golf, bowling, dancing, doubles tennis, or throwing a baseball or football?		
12) participate in strenuous sports like swimming, singles, tennis, football, basketball, or skiing?		

* Hlatky et al, Am J Cardiol:1989;63:651-54

Please put an X in the box under the correct answer:

13) Have you had dizzy spells in the last two weeks?

- 1. Not applicable (I've never had dizzy spells).
- 2. Much fewer than before.
- 3. Fewer than before.
- 4. Same as usual.
- 5. More than before.
- 6. Much more than before.

14) Have you had fainting spells (episodes of syncope) in the past two weeks?

- 1. Not applicable (I've never had fainting spells).
- 2. Much fewer than before.
- 3. Fewer than before.
- 4. Same as usual.
- 5. More than before.
- 6. Much more than before.

15) Have you experienced shortness of breath on exertion in the last two weeks

- 1. Not applicable (I've never experienced shortness of breath).
- 2. Much fewer than before.
- 3. Less than before.
- 4. Same as usual.
- 5. More than before.
- 6. Much more than before.

16) Have you experienced "palpitations" in the last two weeks?

- 1. Not applicable (I've never had palpitations).
- 2. Much fewer than before.
- 3. Fewer than before.
- 4. Same as usual.
- 5. More than before.
- 6. Much more than before.

17) Have you experienced angina (chest pain) on exertion in the last two weeks?

- 1. Not applicable (I've never had angina).
- 2. Much less than before.
- 3. Less than before.
- 4. Same as usual.
- 5. More than before.
- 6. Much more than before.

18) Have you experience fatigue and tiredness in the last two weeks?

- 1. Not applicable (I've never had fatigue & tiredness).
- 2. Much fewer than before.
- 3. Less than before.
- 4. Same as usual.
- 5. More than before.
- 6. Much more than before.

19) Is your eyesight good enough to read ordinary newspaper print? (with glasses if usually worn).

--	--	--	--	--

EASILY READ
NEWSPRINT

CANNOT READ
NEWSPRINT

20) Is your eyesight good enough to see the face of someone from 4 metres (12 feet)? (with glasses if usually worn).

--	--	--	--	--

EASILY SEE
FACE

CANNOT SEE
FACE

21) Have you been bothered by any illness, bodily disorders, pains, or fears about your health during the past two weeks?

- 1. All the time
- 2. Most of the time
- 3. Some of the time
- 4. A little of the time
- 5. None of the time

22) How concerned or worried about your HEALTH have you been?
 For the following scale, note that the words at each end of scale describe opposite feelings. Please put an X in the box which is closest to how you have generally felt during the past two weeks.

--	--	--	--	--

NOT AT ALL
 CONCERNED

VERY
 CONCERNED

Please put an X in the box under the correct answer:

	YES	NO
23) I can walk about only indoors.		
24) I find it hard to bend.		
25) I'm unable to walk.		
26) I have trouble getting up and down stairs or steps.		
27) I find it hard to reach for things.		
28) I find it hard to dress myself.		
29) I find it hard to stand for long (e.g. at the sink, waiting for a bus).		
30) I need help to walk about outside (e.g. a walking aid or someone to support me)		

Here are some statements about life in general that people feel differently about. Would you read each statement put an X in the box which is closest to how you have generally felt during the past two weeks. For the following scale, note that the words at each end of scale describe opposite feelings. "DISAGREE".

31) As I grow older, things seem better than I thought they would be.

--	--	--	--	--

AGREE

DISAGREE

32) I have got more breaks in my life than most of the people I know.

--	--	--	--	--

AGREE

DISAGREE

33) This is the dreariest time of my life.

--	--	--	--	--

AGREE

DISAGREE

34) I am just as happy as when I was younger.

--	--	--	--	--

AGREE

DISAGREE

35) My life could be happier than it is now.

--	--	--	--	--

AGREE

DISAGREE

36) These are the best years of my life.

--	--	--	--	--

AGREE

DISAGREE

37) Most of the things I do are boring or monotonous.

--	--	--	--	--

AGREE

DISAGREE

38) I expect some interesting and pleasant things to happen to me in the future.

--	--	--	--	--

AGREE

DISAGREE

39) The things I do are as interesting to me as they ever were.

--	--	--	--	--

AGREE

DISAGREE

40) I feel old and somewhat tired.

--	--	--	--	--

AGREE

DISAGREE

41) I feel my age, but it does not bother me.

--	--	--	--	--

AGREE

DISAGREE

42) As I look back on my life, I am fairly well satisfied.

--	--	--	--	--

AGREE

DISAGREE

43) I would not change my past life even if I could.

--	--	--	--	--

AGREE

DISAGREE

44) Compared to other people my age, I've made a lot of foolish decisions in my life.

--	--	--	--	--

AGREE

DISAGREE

45) Compared to other people my age, I make a good appearance.

--	--	--	--	--

AGREE

DISAGREE

46) I have plans for things I'll be doing a month or a year from now.

--	--	--	--	--

AGREE

DISAGREE

47) When I think back over my life, I didn't get most of the important things I wanted.

--	--	--	--	--

AGREE

DISAGREE

48) Compared to other people, I get down in the dumps too often.

--	--	--	--	--

AGREE

DISAGREE

49) I've got pretty much what I expected out of life.

--	--	--	--	--

AGREE

DISAGREE

50) In spite of what people say, the lot of the average man is getting worse, not better.

--	--	--	--	--

AGREE

DISAGREE

51) Have you been in firm control of your behaviour, thoughts emotions or feelings during the past two weeks?

- [] 1. Yes, definitely so.
- [] 2. Yes, for the most part.
- [] 3. Not too well.
- [] 4. No, and I am somewhat disturbed.
- [] 5. No, and I am very disturbed.

52) Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory (during the past two weeks)?

1. Not at all.
 2. Some -- but not enough to be concerned or worried about.
 3. Some and I have been a little concerned.
 4. Some and I am quite concerned.
 5. Yes, very much so and I am very concerned.

53) Have you been feeling emotionally stable and sure of yourself during the past two weeks?

1. All of the time.
 2. Most of the time.
 3. Some of the time.
 4. A little of the time.
 5. None of the time.

During the past few weeks did you ever feel.....

54) Particularly excited or interested in something?

--	--	--	--	--

OFTEN

NOT AT ALL

55) Did you ever feel so restless that you could not sit long in a chair?

--	--	--	--	--

OFTEN

NEVER

56) Proud because someone had complemented you on something you had done?

--	--	--	--	--

OFTEN

NEVER

57) Very lonely or remote from other people?

--	--	--	--	--

OFTEN

NEVER

58) Pleased about having accomplished something?

--	--	--	--	--

OFTEN

NEVER

59) Bored?

--	--	--	--	--

OFTEN

NEVER

60) On top of the world?

--	--	--	--	--

OFTEN

NEVER

61) Depressed or very unhappy?

--	--	--	--	--

OFTEN

NEVER

62) That things were going your way?

--	--	--	--	--

OFTEN

NEVER

63) Upset because someone criticized you?

--	--	--	--	--

OFTEN

NEVER

- 64) How has your memory been, the last two weeks?
- 1. Much better than it has been.
 - 2. Better than it has been.
 - 3. Same as it has been.
 - 4. Worse than it has been.
 - 5. Much worse than it has been.
- 65) How has your ability to understand and solve everyday problems been, during the last two weeks?
- 1. Much better than it has been.
 - 2. Better than it has been.
 - 3. Same as it has been.
 - 4. Worse than it has been.
 - 5. Much worse than it has been.
- 66) During the last two weeks, have you been thinking that you have let any of your relatives down or have been unfair to any of them?
- 1. I did not feel that I let them down at all.
 - 2. I usually is not feel that I let them down.
 - 3. About half the time, I felt that I let them down.
 - 4. Most of the time I have felt that I let them down.
 - 5. I always felt that I let them down.
- 67) During the last two weeks, have you been thinking that any of your relatives have let you down or have been unfair to you at any time?
- 1. I never felt that they let me down
 - 2. I felt that they usually did not let me down.
 - 3. About half the time, I felt that they let me down.
 - 4. I usually felt that they let me down.
 - 5. I am very bitter that they let me down.
- 68) Are you living with your spouse or have been living with a person of the opposite sex in a permanent relationship?
- If yes, answer the next 9 questions.
 - If no, skip to question #75.

- 69) Have you had open arguments with your partner in the last 2 weeks?
- 1. We have had no arguments and we got along well.
 - 2. We usually got along well but had minor arguments.
 - 3. We had more than one argument.
 - 4. We had many arguments.
 - 5. We were constantly in arguments.
- 70) Have you been able to talk about your feelings and problems with your partner during the last 2 weeks?
- 1. I could usually talk freely about my feelings
 - 2. I usually could talk about my feelings.
 - 3. About half the time I felt able to talk about my feelings.
 - 4. I usually was not able to talk about my feelings.
 - 5. I was never able to talk about my feelings.
- 71) Have you been demanding to have your own way at home during the last 2 weeks?
- 1. I have not insisted on always having my own way.
 - 2. I have usually not insisted on always having my own way.
 - 3. About half the time I insisted on having my own way.
 - 4. I usually insisted on having my own way.
 - 5. I always insisted on having my own way.
- 72) Have you been bossed around by your partner these last 2 weeks?
- 1. Almost never.
 - 2. Once in a while.
 - 3. About half the time.
 - 4. Most of the time.
 - 5. Always.
- 73) How much have you felt dependant on your partner these last two weeks?
- 1. I was independent.
 - 2. I was usually independent.
 - 3. I was somewhat dependant.
 - 4. I was usually dependant.
 - 5. I depended on my partner for everything.

- 74) How have you felt about your partner during the last 2 weeks?
- 1. I always felt affection.
 - 2. I usually felt affection.
 - 3. About half the time I felt dislike and half the time affection.
 - 4. I usually felt dislike.
 - 5. I always felt dislike.
- 75) Have you had unmarried children, stepchildren or foster children living at home during the last two weeks?
- If yes, answer the next 4 questions.
 - If no, skip to question #79.
- 76) Have you been interested in what your children are doing - school, play or hobbies, during the last 2 weeks?
- 1. I was always interested and actively involved.
 - 2. I usually was interested and actively involved.
 - 3. About half the time interested and half the time not interested.
 - 4. I usually was disinterested.
 - 5. I was always disinterested.
- 77) Have you been getting along with the children the last two weeks?
- 1. I had no arguments and got along very well.
 - 2. I usually got along but had minor arguments.
 - 3. I had more than one argument.
 - 4. I had many arguments.
 - 5. I was constantly in arguments.
- 78) How have you felt toward your children these last 2 weeks?
- 1. I always felt affection.
 - 2. I mostly felt affection.
 - 3. About half the time I felt affection.
 - 4. Most of the time I did not feel affection.
 - 5. I never felt affection toward them.
- 79) Have you ever been married, ever lived with a person of the opposite sex, or ever had children?
- If yes, answer the next 4 questions.
 - If no, skip to question #83.

- 80) Have you worried about your partner or any of your children without any reason during the last 2 weeks, even if you are not living together now?
- 1. I never worried.
 - 2. Once or twice I worried.
 - 3. About half the time I worried.
 - 4. I always worried.
 - 5. I always worried.
 - 8. Not applicable, partner or children not living.
- 81) During the last two weeks have you been thinking that you have let down your partner or any of your children at any time?
- 1. I did not feel that I let them down at all.
 - 2. I usually did not feel that I let them down.
 - 3. About half the time I felt I let them down.
 - 4. Most of the time I have felt that I let them down.
 - 5. I let them down completely.
- 82) During the last two weeks have you been thinking that your partner or any of your children have let you down at any time?
- 1. I never felt that they let me down.
 - 2. I felt that they usually did not let me down.
 - 3. About half the time I felt they let me down.
 - 4. I usually felt they let me down. I let them down.
 - 5. I feel bitter that they have let me down.
- 83) Have you recently been managing to keep yourself busy and occupied?
- 1. More so than usual.
 - 2. Somewhat more than usual.
 - 3. Same as usual.
 - 4. Rather less than usual.
 - 5. Much less than usual.
- 84) Have you recently been taking longer over things you do?
- 1. Much more quickly than usual.
 - 2. More quickly than usual.
 - 3. Same as usual.
 - 4. Longer than usual.
 - 5. Much longer than usual.

- 85) Have you recently felt on the whole you were doing things well?
- 1. Much better than usual.
 - 2. Better than usual.
 - 3. About the same.
 - 4. Less well than usual.
 - 5. Much less well.
- 86) Have you recently been satisfied with the way you've carried out your task?
- 1. Much more satisfied.
 - 2. More satisfied.
 - 3. About the same as usual.
 - 4. Less satisfied than usual.
 - 5. Much less satisfied.
- 87) Have you recently felt that you are playing a useful part in things?
- 1. Much more so than usual.
 - 2. More so than usual.
 - 3. Same as usual.
 - 4. Less useful than usual.
 - 5. Much less useful.
- 88) Have you recently felt capable about making decisions about things?
- 1. Much more so than usual.
 - 2. More so than usual.
 - 3. Same as usual.
 - 4. Less so than usual.
 - 5. Much less capable.
- 89) Have you recently been able to enjoy your normal day-to-day activities?
- 1. Much more so than usual.
 - 2. More so than usual.
 - 3. Same as usual.
 - 4. Less so than usual.
 - 5. Much less than usual.
- 90) Have you recently felt you had control over your personal life?
- 1. Much more so than usual.
 - 2. More so than usual.
 - 3. Same as usual.
 - 4. Less so than usual.
 - 5. Much less than usual.

APPENDIX E
PHASE I: Staff Responses to survey (n=22)

	IMPORTANT	NOT IMPORTANT
<u>PHYSICAL</u>		
appetite	16(73%)	06
body satisfaction	22(100%)	00
chest pain	21(95%)	01
diet	17(81%)	04
dizziness	21(95%)	01
exercise tolerance	22(100%)	00
fainting	16(73%)	06
fatigue	22(100%)	00
general health status	22(100%)	00
medical complication	20(100%)	00
mobility	22(100%)	00
motor perception	14(74%)	05
need for medications	21(95%)	01
number of incapacitated days per month	21(95%)	01
perceived benefits of treatment	22(100%)	00
percentage of time hospitalized	20(91%)	02
range of movement	13(59%)	09
relief of, or decrease in, symptoms	22(100%)	00
shortness of breath	22(100%)	00
sleep/rest	22(100%)	00
symptoms due to medications	21(95%)	01
symptom duration	20(91%)	02
symptom frequency	22(100%)	00
symptom relief	22(100%)	00
symptom severity	21(100%)	00
visual perception	12(57%)	09
<u>PSYCHOLOGICAL</u>		
academic performance	07(33%)	14
alertness	17(81%)	05
anxiety regarding health	22(100%)	00
confidence	22(100%)	00
control by others over one's emotions	11(58%)	09
depression	22(100%)	00
emotional difficulties	21(100%)	00
fear of recurrence and death	22(100%)	00
general anxiety	22(100%)	00

	IMPORTANT	NOT IMPORTANT
intellectual performance	13(59%)	09
internal control over one's emotions	20(95%)	01
learning disabilities	10(48%)	11
mood	20(91%)	02
personality type	14(67%)	07
psychological general well-being	22(100%)	00
psychological affect	21(95%)	01
psychotic symptoms	12(55%)	10
satisfaction with life	22(100%)	00
self esteem	22(100%)	00
self image	22(100%)	22
stress	21(95%)	01
temper	12(60%)	08
<u>SOCIAL</u>		
changes in marriage	20(95%)	01
changes in family	19(95%)	01
control by others over one's personal life	20(95%)	01
family life	21(100%)	00
internal control over one's personal life	21(100%)	00
interpersonal relationships	21(100%)	00
number of social relationships	13(62%)	08
recreational activities	20(95%)	01
social activities	21(100%)	00
social dependency	19(90%)	02
social integration	20(95%)	01
social isolation	20(95%)	01
social performance	18(86%)	03
social role functioning	20(95%)	01
social support	20(95%)	01
<u>ACTIVITY</u>		
ability to live normally	21(100%)	00
activities of daily living	21(100%)	00
desire to work	19(90%)	02
employment status	21(100%)	00
energy	21(100%)	00
home management	20(95%)	01
hours worked per day	17(81%)	04
leisure time activity	21(100%)	00
perception of limitations to activity	21(100%)	00

	IMPORTANT	NOT IMPORTANT
previous education	10(48%)	11
sexual activity	21(100%)	00
sexual functioning	21(100%)	00
working capacity	21(100%)	00
<u>MATERIAL</u>		
financial burden	20(95%)	01
need for clothing	15(75%)	05
need for food	16(80%)	04
need for shelter	17(81%)	04
socioeconomic status	19(90%)	02
<u>STRUCTURAL</u>		
contacts with authorities	08(38%)	13
political participation	01(5%)	20

APPENDIX F
PHASE I: Family Responses to Survey

	MEAN	STANDARD DEV.
<u>PHYSICAL</u>		
appetite	11.69	4.62
body satisfaction	11.88	4.81
chest pain	13.01	4.90
diet	12.60	3.46
dizziness	12.28	5.51
exercise tolerance	12.18	4.14
fainting	11.47	5.85
fatigue	13.25	3.83
general health status	13.96	3.16
medical complication	13.75	3.62
mobility	14.41	3.11
motor perception	12.26	4.19
need for medications	11.57	4.75
number of incapacitated days per month	11.24	5.03
perceived benefits of treatment	13.03	3.99
percentage of time hospitalized	12.16	4.50
range of movement	13.56	3.96
relief of, or decrease in, symptoms	14.56	2.72
shortness of breath	12.96	4.39
sleep/rest	14.04	3.18
symptoms due to medications	12.53	4.37
symptom duration	12.87	4.09
symptom frequency	12.43	4.82
symptom relief	13.09	4.64
symptom severity	13.74	4.49
visual perception	13.56	3.67
<u>PSYCHOLOGICAL</u>		
academic performance	10.32	5.32
alertness	13.62	3.47
anxiety regarding health	13.38	3.95
confidence	14.60	2.78
control by others over one's emotions	10.46	5.42
depression	12.04	4.43
emotional difficulties	11.78	4.49
fear of recurrence and death	13.37	3.80
general anxiety	12.96	3.84
intellectual performance	12.72	3.86

	MEAN	STANDARD DEV.
internal control over one's emotions	13.46	2.97
learning disabilities	12.85	2.97
mood	13.25	3.56
personality type	9.72	5.27
psychological general well-being	13.63	2.63
psychological affect	11.21	3.97
psychotic symptoms	10.60	5.21
satisfaction with life	14.16	2.82
self esteem	13.34	4.04
self image	12.44	4.25
stress	12.85	4.13
temper	12.03	4.14
<u>SOCIAL</u>		
changes in marriage	10.43	5.79
changes in family	12.24	4.07
control by others over one's personal life	10.26	4.47
family life	13.88	3.26
internal control over one's personal life	14.22	2.94
interpersonal relationships	13.43	3.19
number of social relationships	9.75	4.63
recreational activities	10.74	4.63
social activities	9.97	4.17
social dependency	8.25	4.30
social integration	9.50	4.48
social isolation	9.94	4.46
social performance	10.85	3.96
social role functioning	11.06	3.95
social support	12.10	3.91
<u>ACTIVITY</u>		
ability to live normally	13.96	4.36
activities of daily living	13.43	4.38
desire to work	11.29	5.01
employment status	7.90	5.61
energy	12.44	4.47
home management	11.79	4.96
hours worked per day	8.87	5.05
leisure time activity	9.99	5.35
perception of limitations to activity	10.47	5.08

	MEAN	STANDARD DEV.
previous education	10.04	5.36
sexual activity	8.94	5.40
sexual functioning	8.43	5.27
working capacity	7.13	6.76
<u>MATERIAL</u>		
financial burden	9.91	5.25
need for clothing	8.59	4.48
need for food	9.38	4.57
need for shelter	10.12	4.82
socioeconomic status	9.44	4.62
<u>STRUCTURAL</u>		
contacts with authorities	9.00	4.76
political participation	6.97	3.82

APPENDIX G
PHASE I: Patient responses / Ranking of elements within
each of the four categories (sorted on mean).

<u>label</u>	<u>mean</u>	<u>SD</u>	<u>median</u>	<u>mode</u>	<u>rehab</u>	<u>pacer</u>	<u>log mean</u>
actadl	15.16	2.21	16.00	17.00	14.87	14.42	1.18
actnorm	15.08	2.47	15.50	17.00	14.65	15.44	1.17
psesteem	14.84	2.71	15.50	17.50	14.56	15.06	1.16
socint	14.81	2.66	16.00	16.50	14.12	15.39	1.16
pssatis	14.56	3.04	15.50	15.50	14.38	14.71	1.15
actenerg	14.43	2.65	15.00		13.94	14.84	1.15
psalert	14.43	2.63	15.50	16.00	13.98	14.82	1.15
socfam	14.36	3.72	16.00	17.50	13.98	14.68	1.13
phsmob	14.20	3.29	15.50	15.50	13.56	14.74	1.14
phsperc	14.13	2.88	14.75		13.68	14.48	1.14
phsgh	14.12	2.99	15.00		14.12	14.13	1.14
pscomf	14.03	3.17	15.00	16.00	13.34	14.63	1.13
socper	13.98	3.69	15.50	16.00	13.27	14.58	1.12
psintell	13.94	3.22	14.75	16.00	13.64	14.18	1.13
psps1	13.90	2.77	13.75	13.50	13.94	13.85	.96
phsrom	13.85	3.55	15.00	16.00	13.00	14.58	1.12
phsvis	13.84	3.60	15.00	16.00	13.44	14.18	1.12
psintern	13.82	3.23	14.50	15.50	12.87	14.63	1.13
psimage	13.79	3.42	14.50	14.00	13.58	13.97	1.12
phssymr	13.77	4.31	15.00	17.50	13.85	13.71	1.10
phsrel	13.75	3.54	15.00	15.50	13.58	13.89	1.12
socchann	13.71	4.19	15.00	17.00	13.28	14.05	1.09
socchanf	13.54	4.63	15.50	17.50	13.58	13.50	1.08
phssleep	13.38	3.74	14.00	17.50	13.10	13.61	1.09
phssyms	13.28	4.90	15.50	17.50	12.69	13.78	1.06
acthome	13.18	3.91	14.50		12.73	13.85	1.09
actperc	13.17	3.66	13.50	13.00	12.60	13.65	1.10
actleis	13.12	3.66	13.50	13.50	12.90	13.31	1.10
physex	13.00	3.28	13.50	13.50	13.62	12.50	1.09
pslearn	13.00	4.23	14.00	17.50	12.85	13.13	1.08
actwkcap	12.97	3.70	13.75	13.00	13.21	12.65	1.09
physbs	12.94	3.07	13.50	15.50	13.44	12.52	1.10
phssob	12.90	4.82	14.25		11.85	13.82	1.05
psstree	12.86	4.36	14.50	9.00	12.27	13.35	1.06
phsmoper	12.70	4.60	14.00		11.52	13.68	1.09
phsmc	12.63	4.58	14.50	14.50	12.66	12.60	1.05
matfin	12.61	4.74	14.50	14.50	12.32	12.84	1.04

<u>label</u>	<u>mean</u>	<u>SD</u>	<u>median</u>	<u>mode</u>	<u>rehab</u>	<u>pacer</u>	<u>log mean</u>
phsdiet	12.48	4.41	14.00		12.75	12.26	1.05
phssyms	12.45	4.97	14.00	17.00	12.79	12.16	1.03
phssymd	12.42	5.05	14.00	17.50	12.00	12.77	1.02
matshelt	12.36	4.52	12.50	17.50	11.24	13.26	1.04
phssymf	12.30	4.80	13.50	17.50	11.86	12.66	1.02
actprev	12.21	4.41	13.50	16.00	11.42	12.93	1.05
actwork	12.16	4.78	13.50	17.00	12.38	11.97	1.02
socsup	12.14	4.09	13.00	14.00	11.44	12.73	1.05
psmood	12.12	4.22	13.00		12.42	11.85	1.04
phsmed	11.93	4.74	12.50	17.50	12.04	11.84	1.02
phstime	11.92	4.92	13.50	17.50	10.48	13.13	1.01
pstemp	11.88	4.86	13.00	9.00	11.37	12.31	1.02
physfat	11.87	4.22	13.00	14.00	11.13	12.53	1.02
phscp	11.86	5.38	13.00	17.50	12.37	11.44	.99
socrole	11.78	4.00	12.50	12.50	10.46	12.90	1.04
psaced	11.68	4.87	13.00	16.00	11.90	11.48	1.00
soccont	11.61	4.93	13.00	9.00	10.67	12.40	1.00
phyapp	11.61	4.34	12.00	12.00	12.16	11.15	1.02
phsdizz	11.57	5.30	12.50	17.50	11.62	11.53	.99
pspsycot	11.57	5.11	13.00		10.23	12.69	.99
socrec	11.49	4.57	12.50	14.00	11.12	11.83	1.01
psdep	11.46	5.07	13.50		11.46	11.47	.98
socisol	11.46	4.42	12.50	9.00	10.72	12.08	1.01
matfood	11.23	4.81	12.00		10.79	11.62	.99
psgen	11.21	4.50	12.50		11.18	11.23	.99
socact	11.20	4.00	12.00		11.33	11.08	1.01
psanx	11.18	5.01	11.75	15.50	11.65	10.77	.97
pspers	11.05	4.45	10.50	9.00	11.46	10.65	1.00
socperf	11.04	4.04	12.50		9.96	11.94	1.01
phsnum	10.77	5.21	11.50		9.71	11.66	.94
psemot	10.67	5.19	12.50	14.50	11.37	10.08	.95
phsfaint	10.65	5.66	12.00	12.50	11.06	10.29	.94
matses	10.54	4.71	11.00		9.94	11.03	.96
actemplo	10.50	5.61	12.75	15.00	10.92	10.14	.91
psfearec	10.47	5.26	9.50	9.50	11.44	9.63	.94
socin	10.39	4.67	10.00	9.00	8.96	11.54	.95
psps2	10.33	4.62	11.50		9.20	11.24	1.01
socnum	10.28	4.65	9.50	9.00	9.54	10.92	.95
acthours	10.21	4.62	10.50	9.00	9.79	10.57	.95
actsexf	10.18	4.85	9.50	9.00	10.30	10.07	.95

<u>label</u>	<u>mean</u>	<u>SD</u>	<u>median</u>	<u>mode</u>	<u>rehab</u>	<u>pacet</u>	<u>log mean</u>
pscont	9.97	5.06	9.50	9.50	9.21	10.61	.91
actsexa	9.91	4.88	9.50	9.00	9.92	9.89	.94
matclo	9.84	5.05	9.00		9.52	10.11	.91
struct1	9.71	4.79	10.00		9.12	10.27	.90
socdep	8.31	5.01	7.00		7.78	8.73	.81
struct2	7.72	4.55	7.50	3.50	7.44	7.98	.78

APPENDIX H

Measures used to assess quality of life

* note: where categories are left blank, either information was not available, or adequate information had been obtained to exclude the use of the measure.

I.ADDITIVE DAILY ACTIVITIES PROFILE TEST (ADAPT Quality of Life Scale)

- A.SOURCE: Daughton DM, et al. Maximum oxygen consumption and the ADAPT Quality of Life Scale. Arch Phys Med Rehabil 1982;63:620-22.
- B.LENGTH: 105 items
- C.ADMINISTRATION: self
- D.COMPONENTS: consists of a list of activity
- E.VALIDITY: good correlation with max oxygen consumption in pulmonary rehab patients
- F.RELIABILITY:
- G.RESPONSIVENESS:

II.AFFECT BALANCE SCALE

- A.SOURCE:Bradburn NM, The Structure of Psychological Well-being. Chicago: Aldine. 1969.
- B.LENGTH:10 questions
- C.ADMINISTRATION:self
- D.COMPONENTS:indicate psychological reaction of people to positive and negative events in their lives (indicator of happiness or general psychological well-being)
- E.VALIDITY: discriminant, construct, factor analysis
- F.RELIABILITY: test-retest .86-.90, internal consistency .55 - .73
- G.RESPONSIVENESS:
(reference standards exist from the Canadian pop '78-79)

III.ANXIETY SCALE

- A.SOURCE:Lewis FM et al. Clinical tool development for adult chemotherapy patients: process and content. Cancer Nurs 1979;2:99-108.
- B.LENGTH: 9 items (part of a larger multidimensional scale)
- C.ADMINISTRATION: self
- D.COMPONENTS: anxiety
- E.VALIDITY: tested in chemotherapy patients
- F.RELIABILITY: test-retest 0.90, item total correlations 0.51-0.84, split half 0.79
- G.RESPONSIVENESS:

IV.BARTHEL FUNCTION SCALE

- A.SOURCE:Mahoney FI, Barthel DW. Functional Evaluation:the Barthel Index. Md State J. 1965;14;61-65.
- B.LENGTH:10 items

C.ADMINISTRATION:by health practitioner
 D.COMPONENTS:monitor functional independence before and after treatment, has 3 questions on mobility
 E.VALIDITY: predictive, correlational
 F.RELIABILITY: test retest 0.89, inter-rater agreement 0.95
 G.RESPONSIVENESS:basic ADL, unlikely to be responsive in relatively well population

V.BEHAVIOUR MORALE SCALE

A.SOURCE: MacElveen P. The observational measure of patient morale: the Behaviour Morale Scale. Nurs Res Biccinnial Year, 1978;9:88-92.
 B.LENGTH: 17 items
 C.ADMINISTRATION: trained interviewer through observations
 D.COMPONENTS:
 E.VALIDITY:
 F.RELIABILITY: internal consistency 0.95
 G.RESPONSIVENESS:

VI.BRITISH LIFE SATISFACTION SCALE

A.SOURCE: Bigot, The relevance of American life satisfaction indices for research on British subjects before and after treatment. Age Ageing 1974;3:13-121.
 B.LENGTH:
 C.ADMINISTRATION:
 D.COMPONENTS:
 E.VALIDITY:
 F.RELIABILITY:
 G.RESPONSIVENESS:

VII.CANTRIL SELF ANCHORING LADDER

A.SOURCE: Cantril H. The Pattern of Human Concern. Rutgers University Press, New Brunswick, NJ. 1965.
 B.LENGTH: ladder with 9 rungs
 C.ADMINISTRATION: self
 D.COMPONENTS: quality of life
 E.VALIDITY: multitrait-multimethod matrix (0.70) rarely validated
 F.RELIABILITY: test-retest 0.70 (2yr 0.40)
 G.RESPONSIVENESS:

VIII.DOMAIN SATISFACTION SCALE

A.SOURCE: Flanagan JD. A research approach to improving our quality of life. Am Psychol, 1978;31:138-47.
 B.LENGTH:15 items
 C.ADMINISTRATION:
 D.COMPONENTS:financial, leisure, health
 E.VALIDITY:

F.RELIABILITY:
G.RESPONSIVENESS:

IX.DUKE ACTIVITY STATUS INDEX

A.SOURCE: Hlatky MA, Boineau RE, Michael MA. A Brief Self Administered Questionnaire to Determine Functional Capacity (The Duke Activity Status Index). Am J Cardio. 1989;64;651-654.
B.LENGTH: 12 items
C.ADMINISTRATION: self
D.COMPONENTS: functional states -broad range of CV stresses
E.VALIDITY: fair -good correlation with peak oxygen uptake (tested in CV population)
F.RELIABILITY: no testing apparent
G.RESPONSIVENESS: continuous measurement -expect that it will be more responsive to change than the traditional CCS classification

X.DUKE-UNC HEALTH PROFILE

A.SOURCE: Parkerson GL, et al. The Duke-UNC Health Profile: An Adult Health Status Instrument for Primary Care. Med Care. 1981;14(8):806-823.
B.LENGTH: 63 items
C.ADMINISTRATION: self
D.COMPONENTS: symptom status, physical function, emotional function, social function
E.VALIDITY: assessed in general practice outpatients
F.RELIABILITY: test re-test 0.52-0.82 for the for dimensions, internal consistency 0.85
G.RESPONSIVENESS:

XI.GENERAL WELL-BEING SCALE (Schedule)

A.SOURCE: Monk M. Blood pressure awareness and psychological well-being in the Health and Nutrition Examination Survey. Clin Invest Med. 1981;4;183-189.
B.LENGTH: 68 items
C.ADMINISTRATION: self
D.COMPONENTS: anxiety, depression, general health, positive well-being, self-control, vitality
E.VALIDITY: correlational, discriminant, factor analysis
F.RELIABILITY: internal consistency .91-.95, test-retest .68-.85
G.RESPONSIVENESS:

XII.GENERAL WELL-BEING ADJUSTMENT SCALE

A.SOURCE: Ware JE et al. Conceptualization and measurement of health for adults in the Health Insurance study. Model of Health and Methodology Publications. R-1987/3-HEW. Santa Monica. California. The Rand Corp. 1980.
B.LENGTH: 22 items, 8-15 minutes
C.ADMINISTRATION: self

D.COMPONENTS: vitality, positive well-being, anxiety, depression, self control, general health

E.VALIDITY: a number of validation studies done

F.RELIABILITY: internal consistency total-0.94, vitality subscale-0.81

G.RESPONSIVENESS:

XIII.GLASGOW OUTCOME SCALE

A.SOURCE:Jennett B. Assessment of outcome after severe brain damage. Lancet, 1975;1:480.

B.LENGTH: 5 categories

C.ADMINISTRATION: health professional

D.COMPONENTS: rating of degree of disability

E.VALIDITY:

F.RELIABILITY:

G.RESPONSIVENESS: for brain damage assessment

XIV.GROGONO-WOODGATE HEALTH INDEX

A.SOURCE:Grogono AW, Woodgate DJ. Index for Measuring Health. Lancet, 1971;2:1024-26.

B.LENGTH: 10 items

C.ADMINISTRATION: health professional

D.COMPONENTS: work, recreation, physical and mental suffering, communication, sleep, dependency, feeding, excretion, sexual activity

E.VALIDITY:

F.RELIABILITY: interrater 0.884

G.RESPONSIVENESS:

-can be used as a weighting factor in QALY's

XV.HEALTH INDEX QUESTIONNAIRE

A.SOURCE: Sackett DL et al. The development and application of indices of health: general methods and a summary of results. AJPH. 1977;67(5):423-428.

B.LENGTH: 140 questions, 40 minutes

C.ADMINISTRATION: interview

D.COMPONENTS: social functioning, emotional functioning, physical functioning

E.VALIDITY: tested in general practice patients

F.RELIABILITY: not assessed

G.RESPONSIVENESS:

XVI.HEALTH LOCUS OF CONTROL SCALE

A.SOURCE: Wallton KA et al. Development and validation of the Health Locus of Control (HCL) Scale. J Consult Clin Psychol. 1976;44:580-585.

B.LENGTH:

C.ADMINISTRATION:

D.COMPONENTS:
 E.VALIDITY:
 F.RELIABILITY:
 G.RESPONSIVENESS:

XVII.INDEX OF PSYCHOLOGICAL AFFECT

SOURCE: Campbell A, Converse PE. The Quality of American Life: Perceptions, Evaluation, and Satisfaction. Russel Sage Foundation, New York. 1976.

A.LENGTH:
 B.ADMINISTRATION:
 C.COMPONENTS:
 D.VALIDITY:
 E.RELIABILITY:
 F.RESPONSIVENESS:

XVIII.INDEX OF OVERALL LIFE SATISFACTION

A.SOURCE: Campbell A, Converse PE. The Quality of American Life: Perceptions, Evaluation, and Satisfaction. Russel Sage Foundation, New York. 1976.

B.LENGTH:
 C.ADMINISTRATION:
 D.COMPONENTS:
 E.VALIDITY:
 F.RELIABILITY:
 G.RESPONSIVENESS:

XIX.INDEX OF WELL-BEING (now called QUALITY OF WELL-BEING)

A.SOURCE: Kaplan RM, Bush JW, Berry CC. Health Status: type of validity and the Index of Well-Being. Hlth Serv Res. 1976;11:478-507.

B.LENGTH: 50 items, 10-15 min

C.ADMINISTRATION: trained interviewer

D.COMPONENTS: self care, mobility, institutionalization, social activity, activity, symptoms (including psychological)

E.VALIDITY:

1.content validity; includes all levels of function and symptom problem complexes, a clearly defined relation to the death state, and consumer ratings of the relative desirability of the function levels

2.construct validity (convergent evidence); positive correlation with self rated well-being as well as expected negative correlations with other variables (ie physician contacts, dysfunctional status)

3.construct validity (discriminant evidence); demonstrated

F.RELIABILITY: ok

G.RESPONSIVENESS:

XX.KARNOFSKY INDEX OF PERFORMANCE STATUS

A.SOURCE: Karnofsky DA. The clinical evaluation of chemotherapeutic agents in cancer. Cancer. 1948;1:634-656.

- B.LENGTH: 3 conditions
 C.ADMINISTRATION: health professional
 D.COMPONENTS: normal activity performance, ability to work, self care
 E.VALIDITY:
 1.good correlation with other indices measuring emotional well being, social and physical function
 2.concurrent
 3.divergent
 4.predictive
 F.RELIABILITY:
 1.test-retest = 0.66
 2.interrater = 0.69
 G.RESPONSIVENESS:

XXI.KATZ ADL SCALE

- A.SOURCE: Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the Index of ADL. *Gerontologist*. 1970;10:20-30.
 B.LENGTH: 6 items
 C.ADMINISTRATION: health professional
 D.COMPONENTS: measures basic functions of; bathing dressing, toileting, transfer, feeding, continence
 E.VALIDITY:
 1.validated for stroke and senile demential, good face validity
 F.RELIABILITY: little formal testing
 G.RESPONSIVENESS: low sensitivity to change

XXII.LEED'S SELF ASSESSMENT OF DEPRESSION & ANXIETY

- A.SOURCE: Snaith RP et al. The Leeds Scale for self assessment of anxiety and depression. *BR. J. PSYCHIAT.* 1976;128:156-65.
 B.LENGTH: 22 items
 C.ADMINISTRATION: self
 D.COMPONENTS: measurement of anxiety and depression in general psychiatric disorders as well a for measuring severity of primary depression and of anxiety states
 E.VALIDITY: tested in psychiatric patients
 F.RELIABILITY:
 G.RESPONSIVENESS:

XXIII.LIFE CHANGE SCALE

- A.SOURCE: Young KJ, Longman AJ. Quality of life and persons with melanoma: A pilot study. *Cancer Nurs.* 1983;6:219-225.
 B.LENGTH: 18 items
 C.ADMINISTRATION:
 D.COMPONENTS: physical appearance, feelings about self, independence, decision making, sense of achievement, work satisfaction, finances, future outlook, relationships, work performance, endurance, hobbies, social activity, religions, support system
 E.VALIDITY: developed for study, little testing done

F.RELIABILITY: test-retest 0.91
G.RESPONSIVENESS:

XXIV.LIFE SATISFACTION INDEX

A.SOURCE: Wood V, Wylie ML, Sheaffer B. An Analysis of a Short Self-Report Measure of Life Satisfaction: Correlation with Rater Judgements. *J Gerontol.* 1969;24:465-469.

B.LENGTH: 20 items

C.ADMINISTRATION: self

D.COMPONENTS: zest, resolution and fortitude, congruence between desired and achieved goals, positive self concept, mood tone (identification of successful aging)

E.VALIDITY:

- 1.poor correlation with demographic data
- 2.moderate correlations with other QL scales tested in healthy populations

F.RELIABILITY:

- 1.internal consistency; $\alpha = 0.70$ to 0.90

G.RESPONSIVENESS: shown to be responsive in a well population.

XXV.LINEAR ANALOGUE SELF ASSESSMENT

A.SOURCE: Priestman T, Baum M. Evaluation of quality of life in patients receiving treatment for advanced breast cancer. *Lancet* 1976;1:899-900.

B.LENGTH: 5 categories (from Karnofsky scale)

C.ADMINISTRATION:

D.COMPONENTS: patients feelings and subjective responses to treatment

E.VALIDITY: used in CA patients

F.RELIABILITY:

G.RESPONSIVENESS:

XXVI.MCMASTER HEALTH INDEX

A.SOURCE: Chambers LW. The McMaster Health Index Questionnaire in Assessment of Quality of Life in Clinical Trials of Cardiovascular Therapy. edited by Wenger et al. LeJacq Pub Co. 1984.

B.LENGTH: 59 items, 20-40 minutes

C.ADMINISTRATION: self administered

D.COMPONENTS: physical function, mental status, ability to participate in normative social activity

E.VALIDITY: tested

F.RELIABILITY: test-retest physical score 0.80

G.RESPONSIVENESS:

XXVII.MEANING IN LIFE SCALE

A.SOURCE: Warner SC, Williams JI. The Meaning in Life Scale: Determining the Reliability and Validity of a Measure. *J Chron Dis.* 1987;40(6);503-12.

B.LENGTH: 15 items

C.ADMINISTRATION:

D.COMPONENTS: sense of purpose, beliefs and statements of faith
 E.VALIDITY: validated in acute and long term patients
 F.RELIABILITY:
 G.RESPONSIVENESS:
 (there is a french and english version)

XXVIII.MENTAL HEALTH INVENTORY

A.SOURCE: Ware JE, Johnston SA, Davies-Avery A, Brook RH. Conceptualization and measurement of health for adults in the Health Insurance Study:Vol.III, Mental Health. Santa Monica: Rand Corporation. 1979.
 B.LENGTH:38 items (+8 for socially desirable response set)
 C.ADMINISTRATION: self
 D.COMPONENTS: mood, anxiety, depression, general affect, loss of control over feelings, thoughts and behaviour, (15 items from general well being)
 Factors: anxiety, behavioural/emotional control, depression, general positive affect, emotion (these are indicated for each item)
 Higher order factors: psychological distress, psychological well-being
 E.VALIDITY: factor analysis, predictive
 F.RELIABILITY:1yr test-retest 0.64, internal consistency 0.96
 G.RESPONSIVENESS:

XXIX.MCGILL PAIN QUESTIONNAIRE

A.SOURCE:Melzack R. The McGill Pain Questionnaire: major properties and scoring methods. *Pain*. 1975;1;277-299.
 B.LENGTH: 102 words (5-20 minutes)
 C.ADMINISTRATION: interviewer
 D.COMPONENTS:quantitative profile of 3 aspects of pain
 E.VALIDITY:
 F.RELIABILITY: test-retest
 G.RESPONSIVENESS:

XXX.MEASURE OF SOCIAL SUPPORT

A.SOURCE: Cobb S. Social support as a moderator of life stress. Psychosom. Med. 1976;38:300-314.
 Davidson et al. Social support and post burn adjustment. Arch Phys Rehabil Med, 1981;62:274-8. (developed for study of post-burn adjustment)
 B.LENGTH: 15 items
 C.ADMINISTRATION:
 D.COMPONENTS: family support, friend support, peer support
 E.VALIDITY:
 F.RELIABILITY: internal consistency 0.86
 G.RESPONSIVENESS:

XXXI.MULTILEVEL ASSESSMENT INSTRUMENT

A.SOURCE: Lawton MP et al. A research service oriented Multilevel Assessment Instrument. *J of Gerontol*. 1982;37(1):91-99.
 B.LENGTH: 50 minutes

C.ADMINISTRATION: interviewer
 D.COMPONENTS: physical health, cognition, ADL, time use, social interaction, personal adjustment, perceived environment
 E.VALIDITY: tested in elderly population
 F.RELIABILITY: internal consistency said to be acceptable, test-retest said to be acceptable (actual values given for neither)
 G.RESPONSIVENESS:

XXXII.NOTTINGHAM HEALTH PROFILE

A.SOURCE: Hunt SM, McEwen J, McKenna SP. Measuring Health Status: a new tool for clinicians and epidemiologists. JR Coll Gen Pract. 1985;35:185-188.

B.LENGTH: 45 items,10 min (2 versions: 1) patients ability to carry on normal life, 2) demand for care in the population)

C.ADMINISTRATION: self admin

D.COMPONENTS: pain, physical mobility, sleep, emotional reactions, energy & social isolation in each of the following areas; employment, household work, relationships, vacations, personal life, sex, & hobbies

Scoring sections: energy level, pain, emotional reactions, sleep, social isolation, physical ability

E.VALIDITY: tested in hip replacement and chronic illness

F.RELIABILITY: test retest 0.75-0.88 internal consistency 0.90-0.94

G.RESPONSIVENESS:

-has been used to measure quality of life in CABG and in Cardiac transplants, non responsive in pacer studies

XXXIII.THE OECD LONG-TERM DISABILITY QUESTIONNAIRE

A.SOURCE:McWhinnie JR. Disability assessment in population surveys: results of the OECD common development effort. Rev Epidemiol Sante Publique. 1981;29:413-419.

B.LENGTH:16 questions

C.ADMINISTRATION:self

D.COMPONENTS:self care, mobility, body movement, senses

E.VALIDITY:

F.RELIABILITY:

G.RESPONSIVENESS:

XXXIV.PERCEIVED QUALITY OF LIFE SCALE

A.SOURCE: Patrick DL et al. Quality of life following intensive care. J Gen Int Med. 1988;3:218-223.

B.LENGTH: 11 items

C.ADMINISTRATION: self

D.COMPONENTS: health, thinking, happiness, family, help, community, leisure, income, respect, work

E.VALIDITY: assessed in patients after discharge from intensive care

F.RELIABILITY:

G.RESPONSIVENESS:

XXXV. PROFILE OF MOOD STATES

A.SOURCE: Pollock V, Cho DW, Reker D, et al. Profile of Mood States: the actors and their psychological correlates. *J Nerv Ment Dis.* 1979;167:612-615.

B.LENGTH: 65 descriptors

C.ADMINISTRATION:

D.COMPONENTS: tension, depression, anger, vigour, fatigue, confusion
(assessment of current emotional state)

E.VALIDITY: most testing done on psychiatric patients.

F.RELIABILITY:

G.RESPONSIVENESS:

XXXVI. PSYCHOLOGICAL GENERAL WELL-BEING INDEX

A.SOURCE: Fazio, 1977

B.LENGTH: 22 items, 12 min

C.ADMINISTRATION: self administered or interviewer

D.COMPONENTS: six dimensions; freedom from bodily distress, life satisfaction, sense of vitality, cheerful vs distressed, relaxed vs anxious, self control

E.VALIDITY:

F.RELIABILITY:

G.RESPONSIVENESS:

XXXVII. QUALITY OF LIFE IMPAIRMENT SCALE

A.SOURCE: Sengupta RP et al. Quality of survival following direct surgery for anterior communicating artery aneurysms

B.LENGTH:

C.ADMINISTRATION:

D.COMPONENTS:

E.VALIDITY:

F.RELIABILITY:

G.RESPONSIVENESS:

XXXVIII. QUALITY OF LIFE INDEX

A.SOURCE: Spitzer WO, Dobson AJ, Hall J, et al. Measuring the quality of life in cancer patients: a concise QL-Index for use by physicians. *J Chron Dis.* 1981;34:385-397.

B.LENGTH: 5 items, 2 minutes

C.ADMINISTRATION: two versions; self administered or professionally administered

D.COMPONENTS: activities of daily living, health support, outlook

E.VALIDITY:

1.content validity; judged by a panel

2.construct validity; better correlations with other scales in cancer patients than in well subjects (both discriminant and convergent)

F.RELIABILITY:

1.internal consistency; $\alpha = 0.77$ to 0.85

2.interrater reliability 0.81 to 0.84

G.RESPONSIVENESS: discriminates between healthy subjects and other categories of patients

XXXIX.QUALITY OF LIFE INDEX

A.SOURCE:Ferrans CE, Powers MJ. Quality of Life Index:development and psychometric properties. Adv in Nsg Science. 1985;8(1):15-24.

B.LENGTH:32 items

C.ADMINISTRATION:self

D.COMPONENTS:health care, physical health and functioning, marriage, family, friends, stress, standard of living, occupation, education, leisure, future retirement, peace of mind, personal faith, life goals, personal appearance, self acceptance, general happiness, general satisfaction

E.VALIDITY:content, criterion related

F.RELIABILITY:test-retest $0.81-0.87$, internal consistency $0.90-0.93$

G.RESPONSIVENESS:

*uses an adjustment for importance

XL.QUALITY OF LIFE INDEX

A.SOURCE:Padilla GW et al. Quality of life index for patient with cancer. Res Nurs Hlth. 1983;6:117-126.

B.LENGTH: 23 items

C.ADMINISTRATION: self

D.COMPONENTS: physical strength, sleep, fatigue, anxiety, body weight, sexual activity, present state of health, ease of adjustment to colostomy, hobbies, recreation, social activity, eating, performance of tasks, pain, happiness, usefulness, QL, contact with friends or family, rejection, privacy

E.VALIDITY: content derived from patients, validity tested in cancer patients

F.RELIABILITY: test retest assessed, internal consistency 0.84

G.RESPONSIVENESS:

XLI.QUALITY OF LIFE SCALE (QOLS)

A.SOURCE:Flanigan JC. A research approach to improving our quality of life. Am Psychol. 1978;33:138-47.

B.LENGTH: 15 items

C.ADMINISTRATION: self

D.COMPONENTS:material comforts, health, relationships, children, learning, understanding self, job, leisure time

E.VALIDITY:factor analysis

F.RELIABILITY: Chronbach's $\alpha = 0.87$, test-retest reliability $0.53-0.90$

G.RESPONSIVENESS: developed in a healthy population

XLII.QUALITY OF LIFE SCALE

A.SOURCE: Young N, Longman AL. Quality of life and persons with melanoma: A pilot study. Cancer Nurse 6:219-25 1983

B.LENGTH:

C.ADMINISTRATION:
 D.COMPONENTS:
 E.VALIDITY:
 F.RELIABILITY:
 G.RESPONSIVENESS:

XLIII.QUALITY OF SURVIVAL SCALE

A.SOURCE: Spunberg JJ et al. Quality of long-term survival following irradiation for intracranial tumour in children under the age of two. Int J Radiat Oncol Biol Phys, 1981;7:727-736.

B.LENGTH:
 C.ADMINISTRATION:
 D.COMPONENTS:
 E.VALIDITY:
 F.RELIABILITY:
 G.RESPONSIVENESS:

XLIV.RAND HEALTH INSURANCE STUDY (HEALTH PERCEPTIONS QUESTIONNAIRE)

A.SOURCE: Brook RH et al. Overview of adult health status measures fielded in Rand's Health Insurance study. Med Care. 1979;17(suppl 7):1-131.

B.LENGTH: 29 items,7 min
 C.ADMINISTRATION: interviewer
 D.COMPONENTS: six dimensions; past, present and future perceptions of health, health related worry and concern, resistance vs susceptibility to illness, tendency to view illness as a part of life
 E.VALIDITY: some testing done
 F.RELIABILITY: internal consistency 0.50-0.90, test retest values not reported
 G.RESPONSIVENESS:

XLV.RAPID DISABILITY RATING SCALE

A.SOURCE: Lim MW. A Rapid Disability Rating Scale. J Am Geriatric Soc. 1967;15:211-14.

B.LENGTH: 18 items
 C.ADMINISTRATION: nurse or person familiar with patient
 D.COMPONENTS: ADL, sensory abilities, mental capacity, dietary change, continence, medications, confinement to bed
 E.VALIDITY: tested in hospitalized patients
 F.RELIABILITY: interrater 0.91, test-retest 0.83
 G.RESPONSIVENESS: would not be responsive in relatively well patients

XLVI.REINTEGRATION TO NORMAL LIVING

A.SOURCE: Wood-Dauphinee S, Williams JI. Reintegration to normal living as a proxy to quality of life. J Chron Dis. 1987;40(6):491-9.
 B.LENGTH: 11 items
 C.ADMINISTRATION: self

D.COMPONENTS:mobility, self care ability, daily activities, recreation, social, family roles, personal relationships, presentation of self, general coping skills (daily functioning, perception of self)

E.VALIDITY:tested in MI and Ca patients, content validity

F.RELIABILITY: Chronbach's alpha 0.90

G.RESPONSIVENESS:

XLVII.SICKNESS IMPACT PROFILE

A.SOURCE: Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. Med Care. 1981;19;787-805.

B.LENGTH: 136 items,30 minutes

C.ADMINISTRATION: self admin

D.COMPONENTS: describes relative disability in 12 categories of daily function; social interaction, sleep and rest, ambulation, eating, work, home management, mobility, body care, movement, emotional behaviour, communication, recreation and pastime, alertness

E.VALIDITY: well tested

F.RELIABILITY: well tested

G.RESPONSIVENESS: not responsive to change

-being used in double blind, randomized control trials in treatment of angina

XLVIII.SINGLE ITEM INDICATORS OF WELL-BEING (Delighted-Terrible Scale, Faces Scale, Ladder Scale, Circles Scale)

A.SOURCE:

B.LENGTH: 1 item

C.ADMINISTRATION: self administered

D.COMPONENTS:

E.VALIDITY:

1.multimethod-multitrait; 0.70 to 0.82, Ladder Scale frequently used but rarely validated

F.RELIABILITY:

1.test-retest reliability; about 0.70 for each scale

G.RESPONSIVENESS:

XLIX.SOCIAL ADJUSTMENT SCALE

A.SOURCE:Weissman MM, Bothwell S. Assessment of social adjustment by patient self report. Arch Gen Psychiat. 1976;33;1111-1115.

B.LENGTH:42 questions

C.ADMINISTRATION:interview and self report versions

D.COMPONENTS:work, social leisure activities,relations ships with extended family, marital roles as spouse, parent and member of family life

E.VALIDITY:

F.RELIABILITY:internal consistency .91-.95, test-retest .68-.85

G.RESPONSIVENESS:

L.SOCIAL DEPENDENCY SCALE

A.SOURCE: Benoliel JQ et al. Developing a social dependency scale. Res Nurse Hlth 1980;3:3-10.

B.LENGTH: 12 -6 point scales

C.ADMINISTRATION:

D.COMPONENTS: everyday self-care competence, mobility competence, social competence

E.VALIDITY: tested in Ca patients

F.RELIABILITY:

G.RESPONSIVENESS: developed for use in CA patients

LI.SOCIAL FUNCTIONING SCHEDULE

A.SOURCE: Remington MM, Tyrer P. The Social Functioning Schedule -a brief semistructured interview. Soc Psychiatry. 1979;14;151-157.

B.LENGTH: 121 question in 12 sections

C.ADMINISTRATION: self

D.COMPONENTS: employment, household chores, contribution to household, self care, marital relationship, care of children, patient-child relationship, patient-parent and household relationships, social contacts, hobbies and spare time activities (uses social role performance approach)

E.VALIDITY: discriminant in psychiatric patients

F.RELIABILITY: interrater 0.45-0.81

G.RESPONSIVENESS:

LII.SYMPTOM DISTRESS SCALE

A.SOURCES: McCorkle K, Young K. Development of a symptom distress scale. Cancer Nurs 1978;3:73-78.

B.LENGTH: 10 items, 5-10 minutes

C.ADMINISTRATION: self

D.COMPONENTS: ten symptoms

E.VALIDITY: studied in cancer patients

F.RELIABILITY: internal consistency 0.82

G.RESPONSIVENESS: not assessed, not likely

LIII.VISUAL ANALOGUE SCALE

A.SOURCES: HUSKISSON EC. Measurement of pain. LANCET 1974;2:1127-31.

B.LENGTH: one analogue scale

C.ADMINISTRATION: self

D.COMPONENTS: pain

E.VALIDITY: tested in rheumatics

F.RELIABILITY: vertical and horizontal scales $r = 0.99$

G.RESPONSIVENESS: