

# Measuring health status: a new tool for clinicians and epidemiologists

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**SUMMARY.** *The development and validation of a short and simple measure of perceived health problems is described. Extensive testing with selected groups, including the elderly, the chronically ill, pregnant women, fracture victims, and a random sample of the community has established the face, content and criterion validity, and the reliability of the instrument. The Nottingham Health Profile is intended as a standardized tool for the survey of health problems in a population, but is equally valid and useful as a means of evaluating the outcome of medical and/or social interventions and as an adjunct to the clinical interview.*

## Introduction

THE increasing cost of the provision of health services, often in the face of meagre evidence about the efficacy of many interventions, together with doubts about the way in which resources are allocated has led to attempts to find efficient and reliable means of assessing health needs and outcomes.

Consequently, in recent years many writers have called for the development of 'sociomedical' or 'subjective' indicators. In general, it has been hoped that such indicators would be capable of measuring the health status of whole populations at a particular time; of providing reliable repeated measures; and of assessing the efficacy of health care practice accurately.<sup>1,2</sup> White suggested that the model for policy planning based on traditional indicators should be replaced by a cybernetic model using information about health status as a basis for problem definition, resource allocation and service organization.<sup>3</sup>

Even 50 years ago MacKenzie suggested that subjective perceptions could be indicators of the onset of disease<sup>4</sup> and such perceptions have been found to be excellent predictors of mortality<sup>5</sup> and to be key factors in adjusting to major illness.<sup>6</sup> Moreover, it is perceived, and not necessarily actual, problems which lead to demand for health care, although several investigators have found perceived health status to be an accurate reflection of so-called objective measures.<sup>7,8</sup> Subjective indices of health also widen theoretical frameworks of aetiology to include perceived occupational stress, domestic strife, sexual conflicts and so on.

There have been several attempts to develop standard measures of self-assessed health, particularly in the USA, and to come to terms with the problems of definition, measurement, weighting, reliability, validity, sensitivity and applicability which are endemic to such endeavours. Examples include the Sickness

Impact Profile;<sup>9</sup> the Cornell Medical Index;<sup>10</sup> the McMaster Health Index Questionnaire;<sup>11</sup> the General Index of Well-being<sup>12</sup> and many others.<sup>13-17</sup>

There are a number of criticisms which can be made of existing measures of self-reported health status, although not all the following comments apply to each instrument. First, they are often long and complicated with ambiguous statements; secondly, scoring and weighting for seriousness often reflect the values of the physician not those of the lay person; thirdly, the focus of the measures may be on too narrow an area, for example disability; and fourthly, where the answers are summed to a single score or index this can be derived in many different ways and involve the addition of scores from areas not logically connected, for example physical mobility and appetite.

A tool for the survey of populations, as Culyer has pointed out,<sup>18</sup> should not be too sophisticated because of the difficulty of interpreting responses and standardizing scores. It must be sensitive enough for the assessment of the health needs of the population and specific enough for the evaluation of health care provision for special groups. It must also be understood by a large majority of potential respondents, be short and simple to answer, cheap to administer and score and, above all, be valid and reliable.

Although 'quality of life' is now widely determined, it is often difficult to know what is being measured since there are no agreed criteria for what constitutes quality of life and such instruments lack validity. It seems more appropriate for those involved in health care to consider a 'health profile' which records the perceived health (or departures from health) of individuals or groups. The relationship between 'objective' and 'subjective' is often regarded as a methodological problem, yet it may be more useful to consider the two aspects as being essential to our knowledge of human beings and their reactions. Most so-called objective criteria involve clinical judgements about normal functioning being essential to a high quality of life but evidence is accumulating which shows that people judge their experiences in relation to their expectations. Certain limitations and disabilities seem normal after an adjustment period.

Comparisons of value in health-related activities must allow the perceptions of the patient an equal, if not greater, place than clinical evaluations. The subjective assessment of the patient may allow more successful interpretations of the impact that disease and treatment have on his or her quality of life, whereas objective indicators may merely be projections of professional mores.

## The Nottingham Health Profile

### *Development of the profile*

In 1975 work started in the Department of Community Health at Nottingham University on the development of a measure for the quality of life. Statements were collected from over 700 people describing the typical effects of ill-health — social, psychological, behavioural and physical — for example, 'I sleep badly', 'I've lost interest in sex', 'I find it hard to walk about'.

An initial pool of 2200 statements enabled key concepts to be identified and after checking for redundancy, colloquialisms and ambiguity, the number of statements was reduced to 138. Combinations of these statements were used in a number of small and large scale studies between 1976 and 1978, using diverse patient populations, and the number of statements was further

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Listed below are some problems people may have in their daily life.

Look down the list and put a tick in the box  under YES for any problem you have at the moment.

Tick the box under NO for any problem you do not have.

*Please answer every question. If you are not sure whether to say yes or no, tick whichever answer you think is more true at the moment.*

	YES	NO
I'm tired all the time	<input type="checkbox"/>	<input type="checkbox"/>
I have pain at night	<input type="checkbox"/>	<input type="checkbox"/>
Things are getting me down	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I have unbearable pain	<input type="checkbox"/>	<input type="checkbox"/>
I take tablets to help me sleep	<input type="checkbox"/>	<input type="checkbox"/>
I've forgotten what it's like to enjoy myself	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I'm feeling on edge	<input type="checkbox"/>	<input type="checkbox"/>
I find it painful to change position	<input type="checkbox"/>	<input type="checkbox"/>
I feel lonely	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I can only walk about indoors	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to bend	<input type="checkbox"/>	<input type="checkbox"/>
Everything is an effort	<input type="checkbox"/>	<input type="checkbox"/>

Figure 1. The first page of the Nottingham Health Profile.

reduced to 82. By relating the scores on the questionnaire to medical information and independent assessments of the well-being of the patients as well as to other standardized measures such as disability scales, statements were found to be reliable and could be used to distinguish between different degrees of disability; they were also sensitive to changes with time. In addition, the statements could be used to distinguish between physical and mental disorders.<sup>19-22</sup>

In 1978 a further grant was obtained from the Social Science Research Council to develop the existing instrument into a population survey tool. This meant refining the criteria by which statements were chosen for inclusion in the questionnaire. In particular it was necessary to have statements which were expressed at a reading level understandable by a great majority of the population, which were short and easy to answer, and the meaning of which was commonly understood. Statements which met these standards were tested on patient and non-patient groups and those statements which proved satisfactory were retained.

*Part 1 of the profile.* Part 1 of the profile comprises 38 statements which met the stringent criteria detailed above and which best reflected problems with health. These problems fall into six areas: sleep, physical mobility, energy, pain, emotional reactions and social isolation. The first page of the questionnaire is shown in Figure 1 and this illustrates how the profile statements from the six areas are randomly distributed. Within each area statements have been weighted for severity using the Thurstone method of paired comparisons, with a sample of 215 members of the general public. Thus the weights reflect the perceived severity of the items from the point of view of the patient.<sup>23</sup> Hunt and McEwen<sup>24</sup> give details of the methodology of this stage.

*Part 2 of the profile.* Part 2 of the profile consists of seven statements relating to those areas of daily life most often affected by health: paid employment, jobs around the house, social life, personal relationships, sex life, hobbies and interests, and holidays.

On both parts of the profile respondents are required to answer yes if the statement applies to them and no if it does not. In part 1 positive answers are given the appropriate weighting and the higher the score on any section the greater the number and severity of perceived problems in that area. The maximum score on any section is 100.

The content and weighting of the statements on the profile are thus designed to determine and quantify, directly, the distress experienced by the respondents in a way which is consistent with everyday life, and lay, rather than professional, values.

The profile has been tested for face, content and criterion validity<sup>25</sup> with diverse groups of people. It has been found to differentiate successfully between elderly people who do not consult general practitioners, those who are physiologically 'fit' and those with chronic illness.<sup>26</sup> A comparison of individuals who consulted their general practitioner more often than average with those who had had no contact with a doctor in the previous six months showed that scores on every section of the profile differentiated between these two groups with a high level of statistical significance. Moreover, days of absence from work through ill-health were also significantly related to profile scores. Age and sex differences were in agreement with other studies concerning their effects on perceived health and consultation rates.<sup>27</sup> Projects have been undertaken to measure the perceived health of men who could be presumed to be in good physical health — firemen and mine-rescue workers. Section scores on the profile showed that, as expected, both groups had low scores.<sup>28,29</sup>

The profile was also used to monitor a group of women throughout pregnancy and scores reflected those physical and emotional changes which are well authenticated in the literature. In addition, an evaluation of the effect of minor surgery was carried out<sup>30</sup> and an assessment of the effects of a fractured limb on patients and their families.<sup>31</sup> Table 1 shows some comparative scores for Part 1 of the profile.

Table 1. Mean scores on Part 1 of the Nottingham Health Profile for selected groups.

	Mine-rescue workers	'Fit' elderly	Pregnant women at		Patients with minor non-acute conditions	Fracture victims	Patients with peripheral vascular disease	Chronically ill elderly	Patients with osteoarthrosis
			18 weeks	37 weeks					
Energy	1.0	4.1	31.4	39.6	24.2	25.8	30.3	38.0	63.2
Pain	1.4	1.1	2.1	11.2	15.9	26.5	22.6	29.2	70.8
Emotional reactions	1.3	3.3	15.7	15.7	14.7	13.7	13.9	15.1	21.3
Sleep	4.2	0.7	11.3	28.3	18.7	28.0	24.7	32.1	48.7
Social isolation	0.4	1.3	6.4	6.2	5.1	8.0	9.2	12.8	12.5
Physical mobility	0.5	1.9	7.3	26.0	7.3	27.6	22.0	29.2	54.8

To test the reliability of the instrument it was necessary to find groups of people who could be expected to give fairly consistent responses gathered on two different occasions, where the time lag between test and re-test was long enough to avoid contamination from one occasion to the other. Accordingly, two groups of patients were chosen, one group with osteoarthritis<sup>32</sup> and a second group with peripheral vascular disease.<sup>33</sup> In both cases little change would be expected in the objective condition of such patients over the projected four weeks between administrations of the questionnaire. A successful postal survey was carried out using the test-re-test method and gave high correlation coefficients between the two sets of scores for both groups, as shown in Tables 2 and 3. These studies indicate that the profile is a valid and reliable indicator of subjective health status in physical, social and emotional areas.

**Table 2.** Reliability coefficients (Spearman's *r*) for each area of Part 1 of the Nottingham Health Profile.

Area concerned	Patients with osteoarthritis (n = 58)	Patients with peripheral vascular disease (n = 93)
Energy	0.77	0.77
Pain	0.79	0.88
Emotional reactions	0.80	0.75
Sleep	0.85	0.85
Social isolation	0.78	0.77
Physical mobility	0.85	0.79

All correlation coefficients are significant ( $P < 0.01$ ).

**Table 3.** Reliability coefficients (Cramer's *o*) for each statement in Part 2 of the Nottingham Health Profile.

Area concerned in each statement	Patients with osteoarthritis (n = 58)	Patients with peripheral vascular disease (n = 93)
Paid employment	0.86	0.55
Jobs around the home	0.85	0.64
Social life	0.59	0.61
Family relationships	0.64	0.89
Sex life	0.84	0.85
Hobbies/interests	0.44	0.86
Holidays	0.71	0.72

All correlation coefficients are significant ( $P < 0.01$ ).

### A population survey

Having established the validity and reliability of the profile it was necessary to gauge its usefulness and acceptability as a survey tool. Previous studies using it as a postal questionnaire had yielded response rates ranging from 72 per cent to 93 per cent, but these were from highly motivated patient groups. Following the Black Report,<sup>34</sup> a study was set up to use the profile to examine social class differentials in perceived health by taking a random sample from the records of a group practice in Nottingham. Questionnaires, together with a covering letter and prepaid reply envelope, were posted to 3200 patients.

A response rate of 68 per cent was obtained. Results showed that social class differentials in perceived health reflect overall patterns of morbidity as calculated from routinely collected vital statistics. Younger people (aged 20–44 years) of both sexes in social classes 4 and 5 achieved significantly higher scores on emotional reactions, sleep, social isolation and energy than did respondents of the same age in classes 1, 2 and 3. These social class differences were not significant in older age groups. These findings were interpreted as suggesting a greater vulnerability

to social and economic stresses among younger people in lower socioeconomic groups, with some adaptation and resignation occurring after middle age.<sup>35</sup>

This study indicated that the profile would be of value as an epidemiological tool as well as being an aid to clinical evaluation.

### Limitations of the profile

The Nottingham Health Profile has some limitations of which prospective users should be aware. The items on Part 1 represent rather severe problems. This was found to be necessary in order to avoid picking up large numbers of false positives. However, it does mean that some milder forms of distress may not show up on the profile. Members of 'normal' populations, or those with minor ailments may affirm very few statements. This makes it difficult to compare their scores or to evaluate change. In pre- and post-intervention studies improvement in condition for those who score zero on the first occasion cannot be demonstrated on the profile. Scoring on Part 1 involves six outcomes plus a further seven scores if Part 2 is used. Analysis can, therefore, become cumbersome if large numbers of other variables need to be taken into account. The profile investigates negative aspects of health only, since all the items refer to problems. Therefore, it cannot be used to assess positive feelings of well-being, as zero scores do not necessarily indicate a total absence of distress.

### Advantages and uses of the profile

The profile has some important advantages. It is sensitive to change with time and different patterns of scores can be a useful indication of particular problems being experienced by patients. For example, in a study of cancer patients, although pain and physical mobility scores were relatively low as a consequence of symptom-relieving medication, the profile recorded high levels of emotional distress and sleep disturbance which indicated the need for a more psychological type of intervention. On the other hand, scores on pain and physical mobility may be high, while sleep and emotional distress scores are low, suggesting that the patient is able to adapt to his illness without excessive anxiety.

A recent study of heart transplants has shown that the profile could be a useful adjunct in evaluative studies of the cost of medical interventions.<sup>36</sup> The profile is currently being used in studies on stroke, myocardial infarction, cancer and multiple sclerosis as an outcome measure.

From an epidemiological standpoint the profile can be used to record patterns of perceived health in a community. Its most recent use in this respect was in a survey of health in London, where it was found to be a highly reliable and satisfactory indicator of variations in health experiences.<sup>37</sup> A project is currently under way to examine patterns of perceived health among the unemployed.<sup>38</sup>

From a clinical perspective, as the principal problems of our time tend to be those of a chronic and intractable kind, the treatment of which may be associated with a variety of side-effects, some assessment of the quality of life of the patients and their levels of distress and discomfort would seem to be a vitally necessary addition to the usual outcome measures both in clinical trials and in assessing needs for counselling and support.

The use of the profile in epidemiological studies is to provide information, not readily available in routinely collected statistics, concerning the experience of people at the community level. Morbidity surveys are time-consuming and expensive, but the profile can provide a cheap, quick and easy means of assessing those experiences and effects on daily life which are known to be associated with the demand for services.

The profile questionnaire takes only a few minutes to complete and is acceptable and understood by a majority of

respondents. The statements are easy to score and compute and are particularly suited for analysis using the Statistical Package for the Social Sciences and other statistical packages. Graphical presentation of profile scores aids assessment of specific areas of dysfunction.

Since the profile does not ask directly about symptoms, it is more likely to identify people who are in distress or at risk, but who do not see their problems being specifically related to health. The profile can be used to measure general perceived health status or specific conditions of ill-health. Above all, it provides a measure of the perceptions of patients and thus can be regarded as a direct reflection of need and possible demand, and an accurate guide to the efficacy of health care in affecting how people feel. It has proved its usefulness in a wide variety of medical and non-medical settings and with a wide range of clinical conditions. In addition, it may be of value in the exploration of theoretical aspects of the relationship between pathology and phenomenology.

Applied appropriately, the Nottingham Health Profile provides a much needed additional tool for clinical and epidemiological research.

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