Nottingham health profile questionnaire incorporates important aspects of the patient perspective into outcome assessment in rheumatoid arthritis

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Abstract

Objective

There is a consensus on the need for a more thorough assessment of outcome of RA from the perspective of those who experience the disease. Our objective was to assess the health- related quality of life (HR-QOL) of RA patients by the Nottingham Health Profile (NHP), the measurement of subjective experienced distress.

Methods

One hundred and nineteen consecutive out-patients were cross-sectionally assessed. HR-QOL was evaluated by using the first section of the NHP, a generic quality of life instrument, that assess subjective distress on six dimensions: mobility, pain, energy, sleep, emotional reaction and social isolation. Functional capacity was measured by the Health Assessment Questionnaire (HAQ).

Results

The NHP scores for mobility, pain, energy and sleep showed a linear association ($p < 0.001$ for each) with HAQ disability level. In addition to pain, patients with mild disability (HAQ 0-1) may suffer from remarkable fatigue (loss of energy) and problems in sleep. Even at the HAQ level 0, there was some perceived distress in almost all of the NHP dimensions.

Conclusions

Poor HAQ levels were associated with patient perceived distress in dimensions which are getting minor attention in clinics, i.e., energy and sleep. It is to be noted that RA patients who reported no disability or its lowest levels measured by HAQ perceived notable distress in many NHP dimensions. Our results suggest that NHP is a potential candidate for a HR-QOL questionnaire which should considered to be used in routine clinical assessment of RA patients.

Key words

Quality of life, energy, fatigue, Health Assessment Questionnaire, hospital-based series.

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Introduction

Over the past two decades, assessment of patients' health status had undergone a remarkable shift from predominant reliance on biomedical and physical measurements to an emphasis upon health outcomes based on patients' personal assessment of their health status (1). In the context of handicap, too, the assessment of patients' perception of the impact of the disease and the particular problems they experiences, *i.e.* patient-perceived handicap, is relevant at a clinical level (2).

The Health Assessment Questionnaire (HAQ) is the most widely used quantitative measurement of functional disability caused by rheumatoid arthritis (RA) (3). HAQ was developed based upon clinicians' perceptions of the important abilities they believe RA patients need to acquire. There is, however, a wide consensus on the importance of incorporating subjective experiences of RA identified by patients as important but not encompassed within the current "core set" of outcome measures (such as fatigue and disturbed sleep) (4). Particularly fatigue has been recognized such a specific outcome in RA. Fatigue is a frequent, extreme, and multidimensional experience (5). However, the patients report that they struggle to manage their fatigue with little professional support (5).

In the present series, we especially wanted to examine subjective experienced health problems of RA patients. Therefore we selected the Nottingham Health Profile (NHP), the measurement of subjective experienced distress. Namely the development of the NHP was based on interviews with lay persons, in which they were asked to assess how they felt when they were experiencing various states of ill health (6). NHP also differentiates between the important aspects of multidimensionality of health (7). NHP has been shown to be a suitable HR-QOL instrument for patients with chronic disease (8, 9). NHP is also sensitive to discriminate RA patients according to their health states (10).

The aim of this study was to explore the impact of NHP on the assessment of the overall state of RA patients in a hospital-based outpatient series when it is used in combination with the HAQ.

Patients and methods

The study is one part of our HR-QOL survey of RA, and it was performed at the out-patient clinics of the Department of Internal Medicine, Central Hospital of Lapland, in Northern Finland. The out-patient clinics is the only centre which provide rheumatological services for the 129.000 inhabitants of the very sparsely populated province of Lapland. The design of the study was approved by the ethical committee of the Central Hospital of Lapland.

A total of 234 consecutive patients aged ≥ 18 yrs with various rheumatic diseases were cross-sectionally assessed. The first study group was collected during September 1998 (n = 97) and the second one during September 1999 (n = 137). From the total of 234 patients 124 fulfilled the American College of Rheumatology (ACR)(formerly American Rheumatism Association, ARA) 1987 classification criteria for RA (11). The different QOL questionnaires used in the series were available from 119 patients, and these subjects constituted the present study group.

The patients were examined by one of the authors (TU) and the examination included an HR-QOL measurement by using the first section of NHP (6) as the authorized Finnish version of the NHP (7), an assessment of the functional capacity by using the direct Finnish translation of HAQ (12), as well as some clinical and socioeconomic data. The NHP and the HAQ were self-completed by the patients and the clinical and socioeconomic data were gathered by structural interview.

The HAQ is a functional capacity questionnaire comprising eight subdimensions that represent the activities of daily living (ADL): dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities. Each category consists of 1-4 items (13). For each item, the scores are: 0 = no difficulty, 1 = some difficulty, 2 = much difficulty or with assistance, and 3 = unable to perform. The highest score for each of the 8 subdimensions is summed (range = 0-24) and divided by 8 to yield on a continuous scale (0-3) as an overall HAQ score (14).

The NHP contains 38 statements that assess subjective distress in six do-

Table I. Demographic and clinical characteristics in 119 RA patients.

Variable	
Number of females, (%)	93 (78%)
Mean age, yrs(SD)	56 (12)
Median duration of diseases, yrs(IQR)	10 (3, 20)
Number of seropositive, (%)	95 (80%)
Median number of used DMARDs, (IQR)	3 (2, 5)
Total joint replacement, n (%)	30 (25%)
Comorbidity, n (%)	47 (39%)

mains: physical mobility (8 items), pain (8 items), sleep (5 items), energy (3 items), social isolation (5 items) and emotional reactions (9 items). These were selected from the statements generated in large surveys of people randomly selected from the general population. The respondent is required to answer 'yes' or 'no' to each statement depending on whether he or she is currently bothered with problems in the area. The statements are weighted empirically in terms of their perceived severity (6, 7). The scores of each dimension may range from 0 (no problems or absence of limitations) to 100 (all problems listed are present) (6). Because the values concerning health and QOL vary across different countries, this weighting process has to be done in every user's country. The Finnish version of NHP, used in our study, is the evaluated and validated HRQOL measure reflecting the values of the general population in Finland (7, 15).

The details of demographic, clinical and socioeconomic data of the 119 RA patients are shown in Table I. During an average illness history, the RA patients had used several disease-modifying antirheumatic drugs (DMARDs) and 25% had undergone total joint replacement surgery. Thirty-nine percent of RA patients suffered from other chronic conditions. Based on an assessment of comorbidity, the most chronic conditions reported by RA patients were hypertension (n = 12), ischemic or other heart diseases (n = 11), gastrointestinal symptoms (n = 10) and asthma (n = 8). Twelve RA patients had two or more other chronic disease.

The mean (SD) HAQ score of the 119 RA patients was 1.05 (0.75; range 0.00-2.75). We divided our RA patients into four functional capacity groups according to the HAQ score; 0, 0.1-1.00, 1.1-2.00 and > 2. There were 12 (10%) patients with completely normal functional capacity (HAQ score = 0), 51(43%) with some difficulty in ADL- activities (HAQ score 0.1-1.00), 47 (39%) with much difficulty or need for assistance (HAQ score 1.1-2.00) and 9 (8%) > 2 severely disabled. Only three (3.6%) patients were very severely disabled, with HAQ scores of 2.75, and all of them had been suffering from RA for over 13 years, and one of them also had severe polymyositis. The socioeconomic data of the 119 RA patients are shown in Table II. Forty-five per cent were unable to work because of illness, and the main cause of work disability was RA. Fifty-four per cent were workers with low level of formal education (from 8 to 9 years). In most cases, the RA patients estimated their financial situation as a moderate one.

Statistics

The results were expressed as means or medians, with standard deviation (SD) or interquartile range (IQR). Statistical comparison between the groups was made by using the Normal Score test with Monte Carlo *p*-values and bootstrap-type analysis of variance (ANOVA). However, as variables were skewed, bootstrap estimation was used to derive a 95% confidence interval; confidence

Table II. Socioeconomic characteristics in 119 RA patients.

Variable	No. (%)
Marital status:	
married / cohabiting	84 (70%)
single	6 (5%)
widowed	15 (13%)
divorced	14 (12%)
Occupation:	
self-employed	27 (23%)
clerical worker	24 (20%)
worker	41 (34%)
professional / managerial	8 (7%)
other	19 (16%)
Employment situation:	
employed	35 (29%)
unemployed	3 (2%)
work disabled	54 (46%)
retired	27 (23%)
Financial situation (self-estimated):	
very good / good	27 (23%)
moderate	63 (53%)
very poor / poor	28 (23%)
not known	1 (1%)

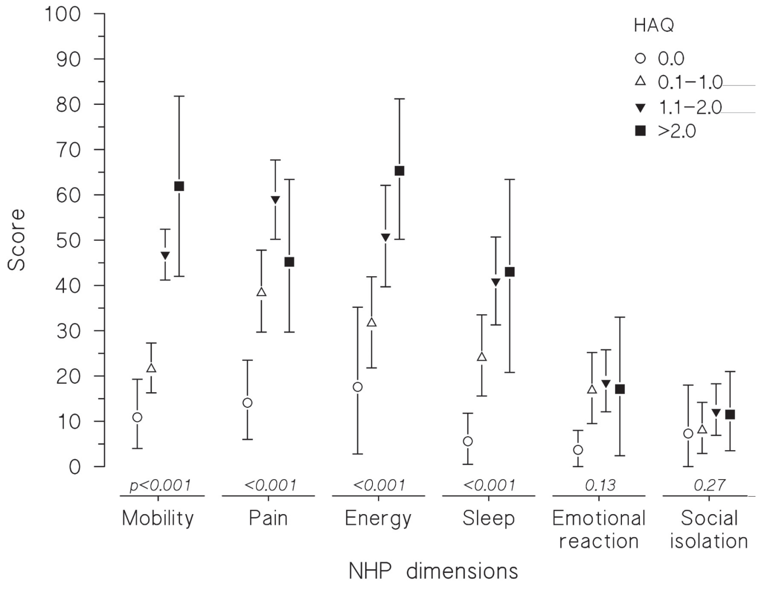

Fig. 1. NHP dimensions according to RA patients' HAQ functional capacity levels (0, 0.1-1,0, 1.1-2.0 and > 2). The bars show mean with 95% confidence interval. *P* value shows significance of the trend.

Table III. Correlation between HAQ subdimensions and NHP dimensions.

HAQ subdimensions	NHP dimensions					
	Mobility	Pain	Energy	Sleep	Emotional reaction	Social isolation
Dressing and grooming	0.58^{***}	0.45^{***}	0.31^{*}	0.23	0.19	0.15
Arising	0.57^{***}	0.44^{***}	0.32^{*}	0.31^{*}	0.24	0.31
Eating	0.58^{***}	0.35^{*}	0.44^{***}	0.22	0.22	0.16
Walking	0.56^{***}	0.33^{*}	0.35^{*}	0.29	0.10	0.18
Hygiene	0.63^{***}	0.41^{**}	0.37^{**}	0.34^{*}	0.18	0.14
Reach	0.55^{***}	0.25	0.41^{**}	0.28	0.21	0.14
Grip	0.44^{***}	0.37^{**}	0.36^{**}	0.33^{*}	0.25	0.18
Activities	0.54^{***}	0.35^{*}	0.34^{*}	0.34^{*}	0.24	0.19

Sidak adjusted significance $^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$.

interval for the means were obtained by bias corrected bootstrapping (5000 replications). The normality of variables was evaluated by the Shapiro-Wilk statistics. Correlation coefficients were calculated by the Spearman method, using Sidak-adjusted probabilities.

Results

NHP assessed health-related quality of life and HAQ functional capacity levels

When the RA patients were divided into four subgroups based on their HAQ functional capacity levels (0, 0.1-1.0, 1.1-2.0 and > 2) the mean NHP scores for mobility, pain, energy and sleep showed a linear association ($p <$ 0.001 for each) with HAQ disability level (Fig. 1). The RA patients at the poorer HAQ levels (1.1-2.0 and > 2) had especially poor quality of life on the NHP dimensions of energy, pain and mobility, with mean scores varying within 45-65. At the HAQ level 0, the NHP instrument also detected some perceived distress in all of the NHP sections. However, the mean scores for emotional reaction and social isolation were low at all HAQ capacity levels.

Association between subdimensions of HAQ and dimensions of NHP

The relationship between the HAQ subdimensions and the NHP dimensions are shown in Table III. NHP mobility had a close correlation with all HAQ subdimensions, the correlation coefficient being lowest for grip (r = 0.44) and highest for hygiene (r = 0.63). Of the other NHP components pain and energy also correlated highly significantly with some HAQ subdimensions: NHP pain with dressing and grooming (r = 0.45) and with arising (r = 0.44), and NHP energy with eating (r = 0.44). No correlations were found between any HAQ subdimensions and the NHP dimensions of emotional reaction and social isolation, and only a weak one emerged for sleep, the correlation coefficient varying from 0.31 to 0.34 for the different HAQ subdimensions.

Discussion

So far, there are data to show that the NHP has given valuable information about HR-QOL in the assessment of RA patients. Apart from the problems of mobility and pain, the NHP has drawn attention to RA patients' poor levels of energy and sleep (10, 16), and poor NHP scores have also been clearly related to disease activity (10). In our study there was a highly significant trend towards poorer HR-QOL in terms of mobility, pain, energy and sleep when shifting towards poorer HAQ levels. At HAQ score levels of over 1, health problems increased remarkably compared to lower HAQ levels, and severe perceived health problems, *i.e.*, NHP mean scores over 45 (6), were seen in the dimensions of mobility, pain and energy. Also in earlier studies, HAQ disability has been correlated with significant impairment in the different HR-QOL domains except that of social functioning measured by the Short Form 36 health survey questionnaire (SF-36) (17).

The importance of pain and mobility as outcomes of RA patients is well recognized in clinical care. Other negative impacts of RA on patients' life such as fatigue and poor psychosocial functioning are documented in many HR-QOL studies but not regularly assessed in routine care (18). The OMERACT group has stressed the importance of incorporating the patient perspective, particularly fatigue, into outcome assessment in RA (4). It should be mentioned that the newest validated functional ability questionnaire, *i.e.* the Multidimensional HAQ (MD-HAQ) (19-21), has a patient-oriented perspective including a pain scale and ADL items as well as a fatigue scale and items about sleep and emotional state.

Relief from pain has come out as the most preferred area for improved health reported by RA patients (22). From the patients' perspective, fatigue has also been consistently mentioned as an important outcome affecting other outcomes, such as work, health satisfaction and social activities (3, 23-25). Fatigue is a prominent problem both in the early (26) and established disease (25). There is limited research available concerning the fatigue and reduced energy of an RA patient and the related quality of life (25, 27). In addition, a consensus on even one suitable instrument for fatigue measurement is lacking (4).

Despite the difficulties of measuring fatigue in RA, fatigue is a relevant and also treatable target in RA patients' lives. In the recent study of Moreland *et al.*, RA patients achieved clinically meaningful improvement of fatigue during etanercept therapy, assessed by the HAQ vitality domain, both in recent-onset and in established disease (28). One of our main observations was that distress on the dimension of energy was a major problem at different HAQ levels, even at the level of "no difficulty". Recently, a study of the QOL profiles in early RA assessed by different quality of life questionnaires showed that fatigue measured by NHP subscales differentiated the subjects with poorest outcome best (26). The QOL of an RA group suffering "much fatigue" declined the most compared to a "little fatigue" group, especially on the physical domain, but also on the psychosocial one (26).

It is known that the overall HAQ score has some problems of masked effect (29), and therefore we examined the importance of the different subdimensions of HAQ to the HR-QOL of RA patiens. In this analysis, NHP mobility showed the strongest correlation with all the subdimensions of the HAQ, perhaps due to the overlap which is usual between generic and disease-specific measurements (30). Both the items of NHP mobility and the subdimensions of HAQ assess movements of the upper and lower extremities and locomotional activities. The study of Häkkinen *et al*. showed that pain and joint mobility have a major impact on the individual subdimensions of the HAQ compared to the radiographic score or swollen and tender joint counts (31). In our study, NHP pain but also NHP energy correlated with all the subdimensions of HAQ. The multidimensional assessment of fatigue, evaluated by the Multidimensional Fatigue Inventory (MFI-20), has shown that RA patients experience especially general and physical fatigue, then fatigue associated with reduced activity, and less mental fatigue (32). The dimension of NHP energy perhaps reflects physical fatigue primarily, as the section on NHP energy consists of items such as ”I am tired all the time”, ”Everything is an effort” and ” I soon run out of energy”.

The RA patients in the present study represent quite a typical Finnish clinical series with a longstanding disease in the 90s. NHP emotional reaction and social isolation showed no differences between the HAQ disability subgroups. These dimensions may be more interwoven with cultural aspects of life whereas mobility, pain, energy and sleep are more disease-related problems. NHP studies in different countries concerning RA but also other chronic conditions and healthy populations have shown that especially the NHP dimension for social isolation suffers of poor sensitivity to change, probably due to a large floor effect (= the best possible score) or difficulties in conceptualizing social domains (9, 17). The NHP is clearly only touching on the extreme end of perceived health problems (6), meaning that patients with minor distress in HR-QOL may not be detected at all. This must be noted if the NHP is used in clinical care.

In conclusion, NHP as a HR-QOL measurement of patient perceived distress gives a complementary view to the HAQ, especially as it detects energy/fatigue and sleep problems not assessed by the HAQ. Poor HAQ levels were associated with poor HR-QOL levels, especially in terms of energy and sleep, for which data are assessed in specialised studies but not routinely in clinics, and which generally remain undocumented in standard clinical care. It is to be noticed that RA patients who report no disability or its lowest levels measured by HAQ may perceive HR-QOL problems in all six NHP dimensions. NHP should be a potential candidate for clinical use for more thorough assessments of the perspective of those who experience the disease. We wish to suggest further studies concerning comparisons of fatigue, sleep, and emotional items of the MD-HAQ and those of the NHP.

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