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The Short Health Scale: A valid and reliable measure of health related quality of life in English speaking inflammatory bowel disease patients



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KEYWORDS

Inflammatory bowel disease; Crohn's disease; Ulcerative colitis; Health related quality of life; Disease activity; Short Health Scale

Abstract

Background: Health related quality of life in inflammatory bowel disease is influenced both by disease activity as well as by the psychosocial characteristics of the individual patient. The Short Health Scale (SHS) is a four-part visual analogue scale questionnaire using open-ended questions that are designed to assess the impact of inflammatory bowel disease on a health related quality of life. The four dimensions include bowel symptoms, activities of daily life, worry and general wellbeing. It has previously been validated in Swedish and Norwegian speaking patients.

Aim: To evaluate the SHS in an English speaking inflammatory bowel disease population. Methods: Four hundred and ninety Crohn's disease and ulcerative colitis patients completed the SHS. Individual SHS items were correlated with Inflammatory Bowel Disease Questionnaire (IBDQ) dimensions and with disease activity to assess validity. Test—retest reliability was assessed in 38 patients who completed the Short Health Scale two weeks apart.

Results: All four items correlated with corresponding IBDQ dimensions with correlation coefficients ranging from -0.66 to -0.74 (all p values <0.001). In addition, total SHS scores correlated with total IBDQ scores in both Crohn's disease (-0.836) and ulcerative colitis (0.797). There was a stepwise increase in Short Health Scale scores with increasing disease activity (all p values <0.001). Reliability was confirmed with test-retest correlations ranging from 0.70 to 0.89 (all p values <0.005).

Conclusions: The Short Health Scale is a valid and reliable measure of health related quality of life in English speaking inflammatory bowel disease patients.

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78 (16%)

267 (55%)

138 (28%)

85 (17%)

1. Introduction

Crohn's disease and ulcerative colitis are chronic relapsing, remitting and disabling disorders that have biological, psychological and socioeconomic implications for patients, their families and society. 1—4 The biological burden of inflammatory bowel disease (IBD) is frequently measured using disease activity scales. However, even a precise measurement of activity may reveal comparatively little about the overall health of patients with chronic disease states. 5 Rather, health related quality of life is a multidimensional construct that involves psychological and social, as well as physical domains. It evolved as an important health concept in the 1980s and instruments have since been developed to assess quality of life in patients with chronic diseases, including IBD. 5 Quality of life scales are frequently incorporated as secondary endpoints in clinical trials and are also used in clinical practice.

Many early quality of life scales for chronic disease involved extensive questions relating to specific symptoms, social functions, limitation of activities and mental health. 6,7 Since then, shorter scales have been developed, 8 culminating in the Short Health Scale (SHS) for IBD patients. 9 This instrument was developed in Sweden and consists of four simple 100 mm visual analogue scales assessing symptom burden, activities of daily life, disease related worry and sense of general well-being. The questions were designed to be open ended, so that patients could take any or all aspects of their life that they felt were important to them into account when completing the questionnaire. 9 It was initially designed as part of a network strategy to describe various aspects of the health concept¹⁰ and was validated in Swedish speaking patients with ulcerative colitis9 and Crohn's disease¹¹ and more recently in Norwegian IBD patients. 12 The aim of our study was to evaluate the SHS in English speaking IBD patients.

2. Materials and methods

The study included 490 ambulatory IBD patients attending a specialised clinic in a Dublin University Hospital. Patients were approached in clinic and asked to participate in the study prior to their medical consultation. Five hundred and eight patients were approached of whom 505 agreed to participate (two patients with presbyopia were unable to participate because they did not have reading glasses at the clinic and a single patient, who was unable to read or write, was also unable to participate). Fifteen patients, whose questionnaires did not have evaluable SHS data, were also excluded, leaving a final study population of 490. The demographic and clinical details of the study population are shown in Table 1. Ethical approval for study was obtained from the St. Vincent's University Hospital Ethics Committee.

2.1. Questionnaires

Quality of life was measured using the SHS (Fig. 1). The questionnaire was designed to be self-administered and patients were asked to place a mark on the 100 mm visual analogue scale that they thought was appropriate to their condition. Scores are presented for each dimension and were also added together to form a total, or overall, score.

Demographic and clinical details of the 490 study Table 1 patients. Variable Disease Ulcerative colitis 216 (44%) Crohn's disease 274 (56%) Gender Male 242 (49%) Female 248 (51%) 38 (16-89) Age (year)(median [range]) Disease duration (year)(median [range]) 7 (0.1-49) Family history No family history 392 (80%) First degree relative affected 98 (20%) Smoking status a Non-smoker 397 (82%) Smoker 90 (18%) Education a 137 (28%) Junior (education to 16 years) 139 (28%) Leaving (education to 19 years) Third level education 213 (44%) Previous surgery No 357 (73%) Yes 133 (27%) Current treatment with immune modulator 356 (73%) Yes 134 (27%) Current treatment with biological agent No 412 (84%)

^a Data on smoking and education were not available for all patients.

Yes

Remission

Clinical disease activity

Mild disease activity

Moderate disease activity

Quality of life was also determined using the 32-item Inflammatory Bowel Disease Questionnaire (IBDQ) that collects data on the four dimensions including bowel symptoms, social function, emotional function and systemic symptoms. The Harvey–Bradshaw index was used to assess Crohn's disease activity and the partial Mayo score to measure ulcerative colitis activity. Crohn's disease remission was defined as a Harvey–Bradshaw score of 0–4, mild disease 5–8, and moderate \geq 9. Ulcerative colitis remission was defined as a Mayo score of 0–2, mild disease 3–5, and moderate \geq 6. The consulting physician assessed disease activity without knowledge of the questionnaire results.

We assessed validity by correlating both individual SHS items and total SHS score with IBDQ dimensions and total score. To establish validity, the four individual SHS dimensions should correlate most closely with similar items in the IBDQ (concurrent validity) than with other dimensions (discriminant validity). We also compared SHS scores in patients who were in remission and those who had mildly and moderately active IBD with the expectation that disease activity would influence a valid quality of life scoring system (known-groups comparison/

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