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Original Article

Neurogenic bowel dysfunction score

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Study design: Cross-sectional questionnaire study.
Objectives: To develop and validate a symptom-based score for neurogenic bowel dysfunction (NBD): NBD score.
Setting: University Hospital of Aarhus, Denmark.
Methods: A questionnaire including questions about background parameters ($n=8$), faecal incontinence ($n=10$), constipation ($n=10$), obstructed defecation ($n=8$), and impact on quality of life (QOL) ($n=3$) was sent to 589 Danish spinal cord injured (SCI) patients. The reproducibility and validity of each item was tested in 20 and 18 patients, respectively. Associations between items and impact on QOL were determined by logistic regression analysis. The NBD score was constructed from items with acceptable reproducibility and validity that were significantly associated with impact on QOL. Based on odds ratios for associations between items and impact on QOL, each item was given a corresponding number of points in the NBD score.
Results: A total of 424 SCI patients responded. The following 10 items met the criteria above: frequency of bowel movements (0–6 points), headache, perspiration or discomfort before or during defecation (0–2 points), tablets and drops against constipation (0–2 points each), time used for each defecation (0–7 points), frequency of digital stimulation or evacuation (0–6 points), frequency of faecal incontinence (0–13 points), medication against faecal incontinence (0–4 points), flatus incontinence (0–2 points) and perianal skin problems (0–3 points). Differences in NBD score among patients reporting no, little, some or major impact on QOL were statistically significant (all $P<0.001$).
Conclusion: Based on valid and reproducible questions, we have constructed a score for NBD that is correlated to impact on QOL.
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Keywords: spinal cord injury; constipation; faecal incontinence; quality of life

Introduction

Spinal cord injuries (SCI) affect colorectal motility,[1–3] transit times[4–7] and emptying at defecation.[8] Accordingly, most SCI patients suffer from constipation and faecal incontinence,[9–14] often resulting in restricted social activities and impaired quality of life (QOL).[6,7] Within the last few years several promising new treatment modalities for neurogenic bowel dysfunction (NBD) have been introduced. These include the enema continence catheter,[15] the Malone antegrade continence enema administered through an appendicostomy,[15,16] serotonin HT_4 agonists[17,18] and sacral nervous stimulation.[19] However, a recent Cochrane review revealed a great need for larger randomized controlled clinical trails to evaluate the effect of the different treatments.[20] Such trails require objective endpoints – for instance validated standardized symptom-based scores. Several scores for clinical assessment of constipation[21,22] or faecal[23–25] incontinence exist. Though widely used in other patient groups, the applicability of these scores has not been validated in SCI patients. Furthermore, most SCI patients do not suffer from either constipation or faecal incontinence but from combinations of the two conditions. Accordingly, the aim of the present study was to develop and validate the NBD score: a questionnaire based symptom score for clinical assessment of colorectal and anal dysfunction in SCI patients.

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Patients and methods

The study was a cross-sectional questionnaire study. We developed a 39 item questionnaire, including eight items describing background parameters (age, gender, time since injury, level and completeness of SCI) and 31 items describing anal incontinence ($n=10$), constipation ($n=10$), obstructed defecation ($n=8$), and impact on QOL ($n=3$). Among the authors were colorectal surgeons, a gastroenterologist, an urologist, a neurosurgeon and an epidemiologist, all with special interest in NBD. Items within the questionnaire were developed from the authors clinical experience and knowledge of existing scores for either faecal incontinence or constipation. The draft questionnaire was studied by a group of members of the Danish Paraplegic Association and adjusted according to their comments.

The questionnaire was sent by mail to all members of the Danish Paraplegic Association ($n=589$). After a month, an identical questionnaire was sent to all nonresponders encouraging them to respond. Details about the respondents symptoms have been published in a previous study.[2]

Statistical analysis was performed using SPSS/PC (SPSS Inc., Chicago, IL, USA). To avoid typing errors, data were entered twice. The study was approved by the Scientific Ethical Committee for the County of Aarhus, Denmark.

Reproducibility and validity of items

Reproducibility In order to test the reproducibility of the questionnaire, an identical questionnaire was sent to 30 randomly chosen respondents 3 months after they had returned the first questionnaire. All were more than 2 years postinjury. In all, 20 responded. κ values[26] were computed measuring the degree of agreement between the answers to the first and the second questionnaire.

Validity To test the validity of each item in the questionnaire, 18 of the 20 respondents from the reproducibility study underwent a structured telephone interview. This was performed as soon as possible upon receiving the second questionnaire. The interviews were based on an interview guide describing all items in the questionnaire. During the interview, the interviewer, without knowing the results from the previous questionnaires, filled in an identical questionnaire. Interviews were taped. κ values were computed to compare answers from the telephone interview with those from the questionnaire.

κ values may range between -1 and 1. If no correlation is found, the κ value is 0 and if all answers are identical the κ value is 1. The degree of agreement has previously been described for κ values as follows: 0–0.20 = poor; 0.21–0.40 = moderate; 0.41–0.60 = fair; 0.61–0.80 = good; 0.81–1.00 = very good.[27] Items for which κ values for reproducibility and validity were fair, good or very good were considered for construction of the NBD score. Items not meeting those demands were not further used in the study.

Construction of the NBD score

Based on self-reported impact on QOL patients, were divided into two groups: Those reporting no or little impairment and those reporting some or major impairment. A logistic regression analysis was performed with the degree of self-reported impairment of QOL as the dependent variable and all the other items forming the symptom complex as the independent variables. Items not significantly associated with impact on QOL were excluded from the multivariate model. Based on this multivariate analysis, odds ratios (OR) and 95% confidence intervals for each item's impact on QOL were computed making corrections for the other independent variables. Based on the OR, each item was given a value in the score: the higher the OR the higher the value in the score. For instance an OR of 2.0 would result in that particular item giving 2 points in the NBD score. Items not significantly associated with self-reported impairment of QOL were not included in the score. Some questions had more than two possible answers. For instance the frequency of faecal incontinence could be (1) no faecal incontinence, (2) a few times each year, (3) a few times each month, (4) once or more each week and (5) daily. However, the impact on QOL caused by the five steps of increasing severity was not necessarily linear. Accordingly, for each question with more than two possible answers, a new logistic regression analysis was performed to determine the weight of each step using the normal answer (for instance: 'no faecal incontinence') as reference value.

Validity of the NBD score

For each of four groups of patients (ie those reporting major, some, minor or no impact on QOL) mean and standard deviation (SD) NBD score was computed. Overall score difference was tested by the Kruskal–Wallis test and each group was compared with the next group of increasing severity by the two-sided *t*-test.

Results

SCI patients

Among 589 patients, 72% responded, 300 men (72%) and 124 women (29%), aged 8–88 years (mean 41 years). Time since injury was from 0 to 59 years (mean 14 years). The level of lesion was cervical in 174 (43%), thoracic in 155 (38%) and lumbar in 79 (19%). The lesion was sensory complete in 254 (60%) and incomplete in 166 (40%). Lesions were caused by trauma (75%), spinal surgery (8%), myelomeningocele (4%), infection (4%), spinal thrombosis or haemorrhage (3%), or other causes (6%).

In the following, proportions are given as percentages of respondents to each item. Owing to missing values,

this number may not always correspond to the total number of respondents.

Reproducibility and validity of items in the questionnaire
The reproducibility and validity of most of the items are shown in Table 1. For most questions describing severity of symptoms and bowel-emptying procedure, reproducibility and validity were good or very good. For questions describing average time used for each defecation and frequency of digital stimulation or evacuation, reproducibility was a little lower ($\kappa = 43$ and 59 (fair)). This was caused by the larger number of possible answers to these questions. However, answers generally only moved one group, that is, from 0–5 to 6–10 min. The reproducibility and validity of questions describing impact on QOL were fair, good or very good.

The telephone interview revealed that the meaning of a few questions was not well defined. The questions 'Do you feel constipated?' and 'Have your problems with constipation (or faecal incontinence) changed over time?', were difficult to answer because only few knew how to define constipation and because respondents did not know whether the severity of symptoms changed or they had just learned to live with the inconvenience. Therefore, results from these questions are not further presented in the study.

Table 1 Reproducibility and validity of questions describing colorectal problems in patients with spinal cord lesions

Item	*Reproducibility (κ coefficient)*	*Validity (κ coefficient)*
Frequency of bowel movements	0.78	0.92
Desire for defaecation (any)	0.80	0.89
Normal desire for defaecation	0.74	1.00
Abdominal discomfort	0.37	0.83
Perspiration, headache, or general discomfort during defecation	0.73	0.82
Oral laxatives	1.00	1.00
Enemas	0.69	0.77
Average time for defecation	0.43	0.79
Use of Clysma	0.82	0.90
Frequency of digital stimulation	0.59	0.77
Need help from others for defecation	0.73	—[a]
How much does disturbed defecation restrict social activities?	0.55	0.63
How much does disturbed defecation restrict quality of life?	0.49	0.83
Frequency of faecal incontinence	—[a]	0.79
Flatus incontinence	0.51	0.53
Medication against faecal incontinence	1.00	1.00
Perianal skin problems	1.00	0.60
How much does faecal incontinence restrict social activities?	0.54	0.62
How much does faecal incontinence restrict quality of life?	—[a]	0.52

[a]κ values could not be computed for these crosstables because the number of rows did not equal the number of columns

Construction of the NBD score
Items significantly associated with self-reported impact on QOL are given in Table 2. The OR-based total (maximum) number of points for each item is given. In items with more than one step each of increasing severity, the average increase in OR for each step up and thus the contribution to the total NBD score is given in Table 3. For nearly all of these items OR for impact on QOL increased with increased severity of the symptom. OR for impact on QOL caused by daily use of digital stimulation/evacuation (corresponding to 4 points) was smaller than for 1–6 times per week (corresponding to 6 points) (Table 3). Accordingly, maximum number of points given to digital stimulation/evacuation of the rectum was 6 (Table 2). However, we also chose to give 6 (instead of 4) points for daily stimulation (Table 3).

Interpretation of the NBD score
Within this group of patients median NBD score was 10 (range 0–31), and 90% of patients had NBD scores between 0 and 18.

For respondents reporting major impact on QOL ($n = 57$), mean NBD score was 15.2 (SD = 5.4), for those reporting some impact on QOL ($n = 73$), mean NBD score was 11.4 (SD = 5.8), for those reporting minor impact ($n = 124$), mean NBD score was 8.1 (SD = 4.7) and for those reporting no impact ($n = 101$), mean NBD score was 4.8 (SD = 4.2). Overall, differences in NBD score between the groups were highly significant ($P < 0.001$, Kruskal–Wallis test). When each group was

Table 2 OR, level of significance and points in the NBD score for items significantly associated with impact on quality of life

Item	*OR*	P-*value*	*Points in NBD-score*
Frequency of bowel movements	6.1	<0.0001	6
Headache, perspiration or dyscomfort before or at defecation	2.4	<0.01	2
Tablets against constipation	1.9	<0.001	2
Drops against constipation	2.3	<0.0001	2
Time used for defecation	6.8	<0.0001	7
Digital stimulation or evacuation	5.0	<0.01	6
Frequency of faecal incontinence	13.1	<0.0001	13
Medication against faecal incontinence	3.6	<0.01	4
Flatus incontinence	1.8	<0.05	2
Perianal skin problems	2.6	<0.01	3
Total points in NBD score			47

compared with the next group of increasing severity, differences were all highly significant ($P<0.001$, two-sided *t*-test).

Accordingly, we decided that the NBD score corresponding to severe NBD should be $\geqslant 14$, moderate NBD should correspond to an NBD score of 10–13, minor NBD corresponds to an NBD score of 7–9 and very minor NBD to 0–6. Based on this, neurogenic dysfunction was severe in 29% of respondents, moderate in 28%, minor in 15%, and very minor in 28%.

Table 3 OR, level of significance and points in the NBD score given to items with more than two possible answers

Item	*OR*	P	*Points in NBD-score*
Frequency of bowel movements			
Daily	1		0
Every second day	1.9	<0.05	1
1–3 times per week	3.2	<0.01	1
<once per week	14.3	<0.001	6
Time used for defecation			
5 min or less	1		0
6–15 min	1.2	NS	0
16–30 min	1.5	NS	0
31–60 min	3.4	<0.01	3
>60 min	8.7	<0.001	7
Digital stimulation or evacuation			
Never	1		0
A few times each year	1.2	NS	0
1–4 times each month	1.3	NS	0
1–6 times each week	2.6	<0.01	6
Daily	1.9	<0.05	6
Frequency of faecal incontinence			
No incontinence	1		0
A few times each year	1.2	NS	0
1–4 times each month	4.4	<0.001	6
1–6 times each week	5.6	<0.01	7
Daily	10.0	<0.05	13

NS-not significant

A cross table of severity of bowel dysfunction interpreted by the NBD score and QOL is shown in Table 4. Overall correlation was moderate ($\kappa=0.25$). However, most answers only moved one group, that is from no impact to minor impact on QOL. Thus, 92% of patients with very minor bowel dysfunction (NBD score 0–6) reported little or no influence on QOL, 87% of patients with minor bowel dysfunction (NBD score 7–9) reported some, little or no influence on QOL, 77% of patients with moderate bowel dysfunction (NBD score 10–13) reported little, some or major influence on QOL and 65% of patients with severe bowel dysfunction (NBD score $\geqslant 14$) reported some or major impact on QOL.

The complete NBD Score is shown in Appendix A.

Discussion

Most SCI patients suffer from colorectal symptoms.[9–14] Within the last 2 decades a number of studies have been published on bowel symptoms,[9–14] pathophysiology[2–8] and new treatment modalities for NBD.[15–19] However, as described in a recent Cochrane review, large controlled clinical trials are needed to improve treatment of bowel dysfunction in SCI patients.[20] In such studies, radiographically determined colonic transit times[4–7] or colorectal emptying at defecation[8,28,29] could be used as objective measures of colorectal transport. However, correlations between objective measures and patient's symptoms need further evaluation. Furthermore, the severity of other aspects of NBD such as anal incontinence, the need for laxatives, etc. are not covered by objective measures. Accordingly, we find that a validated symptom-based score for NBD needs to be developed.

The present study is an attempt to construct a symptom-based score for NBD: the NBD score. In contrast to previous scores for bowel[21–25] dysfunction it has been developed among SCI patients and covers both constipation and faecal incontinence. It was developed according to well-established and generally accepted principles,[30] and only items with acceptable reproducibility and validity were included. We found that the

Table 4 NBD score *versus* impact on QOL caused by bowel dysfunction

	Very minor dysfunction (NBD 0–6)	*Minor dysfunction (NBD 7–9)*	*Moderate dysfunction (NBD 10–13)*	*Severe dysfunction (NBD≥14)*	*Total*
Major impact on QOL	0% ($n=0$)	13% ($n=7$)	10% ($n=10$)	38% ($n=40$)	57
Some impact on QOL	8% ($n=8$)	13% ($n=7$)	30% ($n=30$)	27% ($n=28$)	73
Little impact on QOL	34% ($n=34$)	46% ($n=24$)	36% ($n=36$)	29% ($n=30$)	124
No impact on QOL	58% ($n=58$)	27% ($n=14$)	23% ($n=23$)	6% ($n=6$)	101
Total	100 (28%)	52 (15%)	99 (28%)	104 (29%)	355

Percentages given within the table are calculated from the respondents within each of the four groups of the NBD score. To be included in the analysis of the total NBD score *versus* self-reported impact on QOL a respondent had to have filled in all items within the questionnaire. Accordingly, the number of respondents within the table ($n=355$) is smaller than the total number of respondents within the study ($n=424$)

number of respondents ($n = 424$) was large enough to allow the use of logistic regression analysis. As shown in Table 2 associations between the 10 items included in the NBD score and self-reported impact on quality of life were very strong and most associations were statistically highly significant. However, a score will always be limited by the questions it is based on. We described bowel dysfunction measured with 28 items. In all, 10 of these had both acceptable validity and reproducibility and were significantly associated with self-reported impact on QOL. However, other questions not included in our 28 item questionnaire could be important. In a logistic regression analysis, the choice of the dependent variable is very important. The dependent variable in our analysis was self-reported impact of NBD on quality of life. We simply asked patients: to what degree do bowel problems affect your quality of life? The four possible answers were no, little, some or major impact on QOL. Using logistic regression analysis, the dependent parameter has to be dichotomized with only two possible answers. Accordingly, we divided respondents into those reporting little or no impact and those reporting some or major impact. Of course, this does not allow more thorough assessment of which aspects of QOL were affected. Such assessment was beyond the aim of the present study. However, the patients reporting impact on QOL and those reporting restriction of social activities were almost identical,[2] indicating a strong correlation between self-reported impact on QOL and restriction of social activities due to bowel dysfunction.

The questionnaire was intended for use among adult SCI patients and questions within it were self-explanatory. As shown in the results section, the youngest respondent was 8 years old. However, the number of respondents aged <15 years was four from a total number of respondents of 424. Accordingly, we find that the potential bias caused by child respondents being instructed by their parents is insignificant.

Even though each item in a score is valid, the total score does not necessarily have to be so. We found that differences in NBD score between SCI patients reporting no, little, some and major impact on QOL were all statistically highly significant. This strongly supports the validity of the total score. As shown in Table 4, there was a considerable overlap in NBD scores between the four groups of patients. This underlines that the NBD score is constructed for comparison of groups of SCI patients rather than for clinical decision making in individual patients. To a patient unable to use his wheelchair due to severe perianal skin problems, that single problem may have much more severe impact on QOL than indicated by the three points given in the NBD score. However, some lessons from the construction of the score may be useful in clinical practice. For instance it appears that QOL is rather unaffected by digital stimulation less than once every week, episodes of faecal incontinence less than once every month and the need for up to 30 min for each defecation. This is in accordance with our clinical experience from SCI patients referred to our centre for NBD. Thus, we believe that patients with more severe problems than that should be referred to centres with special interest in evaluation and treatment of bowel symptoms in SCI patients.

A large number of respondents ($n = 89$) used enemas. In contrast to digital stimulation and time used for defecation, enema use was not significantly associated with impact on QOL. A possible explanation could be that use of enema reduces time needed for defecation and make the timing of defecation more predictable. It was surprising to us that daily digital stimulation or evacuation was less strongly associated to impact on QOL than digital stimulation or evacuation every second day. This is probably due to confounding by aspects of bowel function not included in our questionnaire. Perhaps daily bowel evacuation is associated with more regular and satisfactory bowel emptying than evacuation every second day. Accordingly, it is open to discussion whether daily use of digital stimulation should be given four points in the score or six points as given to digital stimulation every second day. However, as we found the difference to be caused by confounding, we chose to give six points to digital stimulation or emptying every day.

The present score was based on answers from 424 members of the Danish Paraplegic Association. The number of SCI patients in Denmark is approximately 3000.[31] The respondents are very similar to the whole population of SCI patients in terms of gender, cause of injury, age at injury, whereas the proportion of patients with cervical lesions is smaller in our material (43 *versus* 51%) and the proportion with complete lesions higher (60 *versus* 48%).[31]

Items within most previous scores for constipation or faecal incontinence have been linear and equidistant. For instance, the two most widely used scores for faecal incontinence give 1 point for episodes of incontinence to solid stools a few times every year, 2 points for episodes a few times every month, 3 points for weekly episodes and 4 points for daily episodes.[23,24] However, items within a score are not necessarily linear.[30] Accordingly, we chose to base the contribution within each item on a new logistic regression analysis. Doing so, we found the contribution within each item to be nonlinear. Some scores for gastrointestinal diseases have combined symptoms and objective findings.[32] We chose not to do so because we wanted a score that was easy to use in clinical practice without needing to perform anorectal physiology tests.

We found that the NBD score as shown Appendix A was valid for SCI patients. It is our hope that the score can be used to make future studies of bowel symptoms in SCI patients comparable and to assess changes in bowel function when treatment modalities are evaluated. However, before its use in other patients with NBD such as children with spina bifida, patients with Parkinson disease, stroke or cerebral palsy it should be validated in these groups.

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Appendix A. The NBD score

See Table A1.

Table A1

The number of points for each possible answer is given in parenthesis

	Points
(1) Frequency of defecation Daily ☐$_{(0)}$ 2–6 times every week ☐$_{(1)}$ Less than once a week ☐$_{(6)}$	____
(2) Time used for each defecation 0–30 min ☐$_{(0)}$ 31–60 min ☐$_{(3)}$ More than one hour ☐$_{(7)}$	____
(3) Uneasiness, headache or perspiration during defecation No ☐$_{(0)}$ Yes ☐$_{(2)}$	____

(4) Regular use of tablets against constipation
No $\square_{(0)}$ Yes $\square_{(2)}$ ____

(5) Regular use of drops against constipation
No $\square_{(0)}$ Yes $\square_{(2)}$ ____

(6) Digital stimulation or evacuation of the anorectum
Less than once every week $\square_{(0)}$ Once or more every week $\square_{(6)}$ ____

(7) Frequency of faecal incontinence
Less than once every month $\square_{(0)}$ 1–4 times every month $\square_{(6)}$
1–6 times every week $\square_{(7)}$ Daily $\square_{(13)}$ ____

(8) Medication against faecal incontinence
No $\square^{(0)}$ Yes $\square_{(4)}$ ____

(9) Flatus incontinence
No $\square_{(0)}$ Yes $\square_{(2)}$ ____

(10) Perianal skin problems
No $\square_{(0)}$ Yes $\square_{(3)}$ ____

Total NBD score (range 0–47) ____

NBD score	Bowel dysfunction
0–6	Very minor
7–9	Minor
10–13	Moderate
14 or more	Severe