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Original Article

A European snap shot of psychosocial characteristics and patients' perspectives of faecal incontinence – do they correlate with current scoring systems?

Authors

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Running header

Psychological characters and patients' perspectives of FI

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Abstract

Purpose: To compare the current clinical scoring systems used to quantify the severity of symptoms of faecal incontinence (FI) to patients' subjective scoring of parameters of psychosocial wellbeing.

Methods: Patients referred to six European centres for investigation or treatment of symptoms of FI between June 2017 and September 2019 completed a questionnaire that captured patient demographics, incontinence symptoms using St. Mark's Incontinence score (SMIS) and ICIQ-B, psychological wellbeing (HADS: Hospital Anxiety and Depression Scale), and social interaction (a three-item loneliness scale).

Results: 318 patients completed questionnaires (62 men, mean age 58.7). 60% of the respondents were aged under 65. Median SMIS was 15 (11-18), ICIQ-B bowel pattern was 8 (6-11) and bowel control was 17 (13-22), similar across all demographic groups; however younger patients were more likely to experience symptoms of depression and anxiety (HADS score >10: 65.2% of patients age < 65 vs 54.9% of those age ≥ 65, $p=0.03$) with lower quality of life (ICIQ-B QoL: median score 19 (14-23)) vs age over 65 (16 (11-21)) [$p<0.005$]. On loneliness score 25.5% reported often feeling isolated from others. One of the most significant concerns by patients was the fear and embarrassment related to unpredictable episodes of incontinence.

Conclusion: The SMIS remains a useful tool for quantifying incontinence symptoms but may underestimate the psychosocial morbidity associated with unpredictable episodes of incontinence. Interventions aimed at decreasing anxiety and to address feelings of disgust may be helpful for a significant number of patients requiring treatment for FI.

Introduction

Faecal incontinence (FI), defined as the involuntary passage of faeces, is a common and life changing condition estimated to affect between 2-15% of the population^{1,2,3}. FI symptoms can impact on nearly all activities and have been shown to result in anxiety, depression, loss of income and social isolation^{2,4}.

Although often considered to be a condition affecting predominantly elderly women, cross-sectional studies in the UK, USA and Australia have shown that the burden of disease is spread more widely across age groups and sexes^{3,5,6}. It would follow that the impact of FI symptoms can vary significantly depending on many aspects of the patient's lifestyle and health expectations. However, there is currently a lack of data on the characteristics, perspectives and coping strategies of people suffering from FI. A better understanding of how physical symptoms correlate with psychosocial wellbeing could therefore be helpful both in guiding treatment strategies and addressing barriers to seeking or receiving treatment.

Traditional scoring systems such as the St Mark's incontinence score (SMIS)⁷ and Wexner score⁸ focus mainly on physical symptoms, are simple to use and offer a useful way of assessing response to treatment. However their design lacked patient input or consensus process and so relying on these alone risks minimising the more subjective impact of symptoms on overall well-being. The ICIQ-B⁹ was developed with both expert and patient input and whilst it seeks to measure both psychological and physiological elements of the experience of incontinence, it is more complex to use and has been criticised for retaining unscored elements.

This exploratory study aimed to compare patients' subjective scoring of parameters of psychosocial wellbeing to the severity of faecal incontinence as measured by the existing scoring systems. The primary endpoint was the correlation between the subjective rating of incontinence symptoms and the St Mark's incontinence score. The secondary endpoints are the relationship between the demographic, psychological and quality of life data and incontinence scores plus an exploration of

extra comments made by the patients completing the questionnaires to identify the issues that matter most to them.

Methods

Participants

Patients referred to six tertiary European centres for investigation or treatment of symptoms of FI between June 2017 and September 2019 were considered for inclusion in this study. As this was intended to be an exploratory snapshot study, no limits were set for participant recruitment. The exclusion criteria were those aged under 18, patients with a stoma at the time of enrolment, patients with incontinence due to faecal impaction and those unable to give consent.

Instruments

Data was gathered from eligible participants using a questionnaire. This was designed to capture demographic data along with subjective ratings of well-being, incontinence symptoms and some profiling questions about self-esteem, sexual experiences and social interactions. The St Mark's incontinence score (SMIS)⁷ and ICIQ-B⁹ were used to score incontinence and the Hospital Anxiety and Depression Scale (HADS)¹⁰, EQ-5D-L¹¹ and 3-point loneliness scores¹² were used to assess psychosocial wellbeing. **The Hospital Anxiety and Depression Scale (HADS) comprises 7 questions each for anxiety and depression and the numerical scores are categorised into 'mild', 'moderate' and 'severe'. The loneliness score was introduced as this aspect of the potential psychological impact of FI is not covered by any other existing scoring system.** The data from all centres were entered into a central database by the investigators.

Ethics

Ethical approval for the trial was obtained in UK from Health Research Authority (IRAS ID: 205935, REC ref: 16/LO/1881) and from all other centres according to local protocol. All patients approached for inclusion were given verbal information about the study, a written information leaflet and given time

to consider their involvement before signed consent was obtained by the trial investigators. Participants could withdraw at any time.

Data analysis

At the end of the study period the anonymised data were collated and the numerical scores calculated. Data are presented as median and range if non-parametric and mean and standard deviation if parametric. Parametric data was compared using Spearman's rank. Unpaired data were compared with the Mann-Whitney test and categorical data were analysed using Fisher's exact test. Correlation was calculated using Pearson's. Statistical analysis was performed using software R version 4.0.0 (<http://www.R-project.org>) with appropriate packages.

Although not all data fields were complete on all questionnaires, for the purpose of this exploratory study, questionnaires with missing data were still included in the analysis.

Results

Participant characteristics

318 patients completed questionnaires over the study period with demographics displayed in Table 1. 62 (19.4%) were men with a mean age of 58.7 and 256 (80.5%) women with a mean age of 61.0. Patient characteristics were similar between all participating centres. Women outnumbered men in all centres and the majority of respondents were aged under 65 (60.4%).

Incontinence symptoms

The SMIS could be calculated for 290 patients (91.2%). On this numerical scale where 0 signifies no incontinence and 24 complete incontinence the overall median score was 15 with an interquartile range of 11-18. The scores for men and women were medians of 15 (11-18) and 14 (7-17) respectively

[p=0.03]. The scores were similar for those aged under 65 years (15 (11-17)) and over 65 years (14 (11-18)) [p=0.29](Table 2).

The ICIQ-B score for bowel pattern could be calculated for 304 patients (95.6%) and gave a median of 8 (6-11) from a maximum of 21 (most unpredictable). The ICIQ-B score for bowel control was available for 284 (89.3%) patients with a median of 17 (13-22) from a maximum of 28 (no control). Again the figures were not significantly different for men and women or those aged under or over 65 [p=0.24 for bowel pattern, p=0.20 for bowel control](Table 2).

282 (97.2%) reported episodes of incontinence of flatus, 270 (93.1%) for liquid stool and 214 (73.8%) for solid stool. 186 of 312 patients (59.6%) reported that they sometimes to always had bowel accidents without the feeling of the need to defaecate and 259 of 311 (83.3%) said that these accidents were sometimes to always unpredictable.

Anxiety and Depression Score

The HADS score was calculable for 242 women and 60 men (302 total). Of these 61.6% (149) women and 60% (36) men had a total score greater than 10, indicating clinically significant symptoms. However 65.2% of patients aged under 65 scored above 10 on the scale compared to 54.9% of those aged over 65 [p=0.03]. Seven items on the HADS scale relate to depressive symptoms (HADS-D) and seven to anxiety symptoms (HADS-A). Average scores for anxiety were lower than those for depression symptoms and again the symptom profile was similar for men and women but being aged under 65 gave a significantly greater risk of depression and anxiety (Table 3).

Quality of life

The ICIQ-B Quality of life score could be calculated for 308 people (61 men, 247 women) and gave an average score of 18 (13-22) from a maximum of 26 (lowest quality of life). Patients aged under 65 reported a lower quality of life (median score 19 (14-23)) than those over 65 (16 (11-21))[p<0.005]. The

ICIQ-B data demonstrated that 88.2% of people felt embarrassed by their bowels some to all of the time and that 88.1% of people felt that having an accident was often on their mind.

The EQ-5D-DL scores demonstrated that 4.7% of respondents had moderate to severe problems washing and dressing and 18.2% had moderate to severe problems walking. 23.8% reported moderate to severe problems doing any of their usual activities and 47.0% experienced moderate to extreme pain or discomfort. A total of 36.1% described themselves as moderately to extremely anxious or depressed. On a visual analogue scale rating health that day on a scale of 0-100 (with 100 being best possible health) the average score was 63.9 with a range from 5-100. Again, although there was no significant difference between the experiences of men and women those aged under 65 scored lower (62.1) than those aged over 65 (66.0).

The three point loneliness score was completed by 306 patients and gave an average score of 5, from a maximum of 9 indicating most lonely and minimum 3. 25.5% reported often feeling isolated from others but only 5.5% felt that they were often left out.

Correlation between incontinence scores and quality of life measures

There was no correlation between the SMIS and overall HADS ($p=0.78$) or between the SMIS and loneliness scores ($p=0.30$). However there was a correlation between the severity of incontinence symptoms as measured by SMIS and the ICIQ-B quality of life score ($p<0.005$). There was also a correlation between the SMIS and anxiety as measured by HADS-A ($p=0.037$) but not depression as measured by HADS-D ($p=0.25$).

Patient perspectives

A section of free text entry on the questionnaire invited patients to describe symptoms and issues they wanted to elaborate upon. The data were examined to identify common themes. The two most

often repeated concerns expressed by patients were their fear of leakage, soiling and smell and the embarrassment associated with this (“I worry about...smelling bad and how others see me”). Many people felt frustrated over the lack of control of their symptoms and the restriction this put on their daily lives (“It does not allow me to live a normal life, I am always thinking of having a service near me and if that is not possible the feeling of helplessness creates such an anguish” and “Not being able to walk freely on the street and live a normal life”). 10% of respondents felt unwilling or unable to leave the house and 5% felt that their symptoms impacted them at work (“I worry...in my work I can’t go to the toilet every time I want”). Approximately 10% of patients expressed fear at the fact that their symptoms may worsen and leave them dependant in old age (“I worry if some day I can’t take care of myself and someone have to deal with my problem”) and many women felt inhibited from pursuing or continuing a sexual relationship due to their symptoms (“I cannot have a partner because I am afraid he will not understand”, “I’m not really a woman, I don’t have a sexual life anymore”). No men made specific comments about their sexual relationships.

Few patients extrapolated on their coping strategies. Some mentioned dietary manipulation including fasting and avoiding vegetables. Some others mentioned planning their days around available toilets, wearing dark clothes in case of accidents and avoiding certain exercise and social situations.

Discussion

This snapshot study demonstrates that FI is associated with a myriad of psychological and social burdens. The patients participating had all been referred to secondary care for treatment, which implies that their symptoms were too severe to manage in the community and this is reflected in the high average SMIS. Some previous studies have shown that any degree of FI is associated with decreased quality of life^{13,14,15}. However this study supports the observation that the more clinically severe the symptoms, the greater the negative effect on quality of life^{2,3,16}. Despite this correlation

the relationship between physiological FI symptoms and the experience of loneliness, anxiety and depression in this study was incomplete, indicating that symptom severity is not the only influencing factor.

It has been shown by many studies that the association between severity of FI and reduced quality of life is independent of type of incontinence or age¹⁷. However it has been shown in a recent study that women experience a greater decrease in quality of life compared to men with the same clinical severity score¹⁸. It is known that the physiology of FI is different between men and women and this may explain why despite the similar SMIS for both sexes the bowel control score showed a significant difference. The resultant impact on psychological wellbeing did not differ between the sexes, further evidence that overall bowel control is not the most important influencing factor.

Whilst the great majority of patients in this study were female, over half of the participants were aged under 65. This may reflect a greater willingness of younger people to participate in a study and fill in a long questionnaire¹⁹ but it does demonstrate that symptoms of FI are more widespread across the whole population than is often presumed and that many of the people suffering with symptoms of FI would expect to be economically and socially active. It has been demonstrated that younger people with FI have a higher incidence of mental health disorders² but studies have failed to determine whether this is a risk factor for the development of FI or a consequence of living with the symptoms²⁰. It has also been demonstrated that younger people with post-surgical FI are more likely to report a greater negative impact on their quality of life²¹ but the authors of this study could not determine whether it was because of the greater limitations this put on their lifestyle or whether it was due to lower health expectations in an older population²².

Overall levels of mental ill health were high across all participants in this study, with over a third describing themselves as moderately to extremely anxious or depressed. Although the design of this study did not include a healthy control cohort, several previous studies have shown higher levels of depression in people who report symptoms of FI^{23,7}. The current study demonstrated a correlation

between FI severity by SMIS and anxiety by HADS-A but it did not demonstrate this link with symptoms of depression. There is some experimental evidence that there is a link between the altered levels of neurotransmitters in patients with depression and altered bowel function²⁴ and so it is possible that some of this discrepancy could be explained by depressive symptoms preceding FI symptoms rather than being caused by it. The impact of physical health on mental health has been shown to be complex and multifactorial²⁵ and it may also be hypothesised that if even more minor physical symptoms prevent the affected patient from doing necessary or enjoyable activities such as working, caring for children or exercising this may disproportionately predispose them to depression.

When asked what their greatest worries about their bowels were the most often expressed concerns were regarding the fear and embarrassment linked with leakages and accidents. Nearly all the respondents recorded that having an accident was sometimes to always on their mind. This uncertainty and constant threat of embarrassment seems more important than the absolute number of episodes experienced. Previous studies have shown that anxiety and catastrophizing behaviours are more closely linked to low quality of life in FI than episode frequency or symptoms severity²⁶. Another group demonstrated that high levels of sensitivity to disgust were a major indicator of how significantly an individual's quality of life would be affected by symptoms of incontinence²⁷. **The persistent unpredictability of symptoms can make it hard to develop effective coping strategies. Therefore in order to support patients with this chronic condition, it is essential that clinician input includes facilitating access to information and helping to develop appropriate self-management techniques²⁸.**

Having to restrict one's day to day activity and be constantly aware of the location of toilets and washing facilities seems to be particularly oppressive for this population. The majority of coping strategies seem to be restrictive (not leaving the house, not going to anywhere unfamiliar, not eating) and few people mentioned managing to modify their symptoms rather than their activities. Studies have shown that a sense of not having control over personal activities and outcomes is strongly linked

with mental ill health²⁹ and so this imposed restriction may add to the negative psychological impact of FI.

Current assessments of the severity of faecal incontinence symptoms using scoring systems have not been standardised. The ICIQ-B was developed with both expert and patient input but is too lengthy to be used in daily practice and has retained unscored elements which can be hard to interpret. Whilst traditional scoring systems such as SMIS and the Wexner scores are simpler to use they focus on physiological parameters and may underestimate psychological morbidity and risk giving an incomplete picture of the burden of disease and response to treatment. More studies using qualitative methodology are required to reflect the issues and symptoms that matter most to patients and to aid development of a more satisfactory assessment process for patients suffering from FI.

In conclusion the results from this European snapshot study indicate that, whilst still a useful and easily applied clinical tool, the experience of FI is more nuanced than the SMIS may indicate. Nearly all participants reported some psychosocial morbidity and this burden appears greatest for those aged under 65. The greatest concerns expressed relate to the unpredictability of symptoms and possible embarrassment rather than the absolute number of episodes of incontinence or whether these involve gas, mucous or stool. It is therefore important when assessing the effectiveness of clinical interventions for FI that this is explored as what may appear to be a satisfactory reduction in episodes of FI as measured by score such as the SMIS may not rid the patient of the burden of unpredictability and so risk only partial resolution of the problem. Interventions aimed at decreasing anxiety, catastrophizing and seeking to address feelings of disgust may be helpful for a significant number of patients requiring treatment for FI.

Table 1: Demographics

Centre	Male		Total	Female		Total
	<65	>65		<65	>65	
Barcelona	14 (55.8)	8 (74.0)	22	43 (48.9)	15 (72.3)	58
Dublin	4 (44.2)	0	4	20 (44.0)	7 (71.1)	27
Erlangen	3 (50.0)	2 (67.0)	5	5 (54.0)	4 (66.8)	9
London	8 (45.9)	4 (71.3)	12	38 (48.0)	28 (72.4)	66
Nantes	4 (45.8)	2 (76.5)	6	27 (52.4)	28 (72.4)	55
Tromsø	7 (48.7)	6 (74.3)	13	19 (47.6)	22 (73.6)	41
Total	40 (12.6%)	22 (6.9%)	62 (19.5%)	152 (47.8%)	104 (32.7%)	256 (80.5%)

Values in parentheses are mean ages

Table 2: Physiological experience of incontinence

Score	Male		Total	Female		Total
	<65	>65		<65	>65	
SMIS (n=290)	14 (3-23)	15 (3-20)	14 (3-23)	15 (5-24)	14 (1-24)	15 (1-24)
IQIB bowel pattern (n=304)	7 (2-18)	7.5 (3-16)	7 (2-18)	9 (2-20)	8 (1-20)	8 (1-20)
ICIQ-B bowel control (n=284)	14 (1-28)	16 (4-23)	14 (1-28)	17.5 (2-28)	20 (3-28)	19 (2-28)

Scores are median (range)

Table 3: Psychological scores

Score	Male		Total n=62	Female		Total
	<65	>65		<65	>65	
HADS (n=303)	14 (1-35)	11 (3-24)	12 (1-35)	15 (3-38)	12 (0-33)	13 (0-38)
• HADS- A (n=310)	8 (0-18)	6.5 (1-14)	7.5 (0-18)	9 (1-20)	7 (0-16)	8 (0-20)
• HADS- D (n=311)	6 (0-17)	5 (0-11)	5 (0-17)	6 (0-18)	4 (0-17)	5 (0-18)
ICIQ-B QoL score (n=309)	16 (3-25)	14 (4-25)	15 (3-25)	20 (0-26)	16.5 (0-26)	19 (0-26)

Scores are median (range)

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