

## The Illness Intrusiveness Rating Scale: A measure of severity in individuals with hyperhidrosis

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**Abstract.** *Objective:* We estimated the reliability and validity of the Illness Intrusiveness Ratings Scale (IIRS) in hyperhidrosis, using an electronic mail form of administration. *Methods:* Recent contributors to an electronic mail discussion group on hyperhidrosis responded to the IIRS, questions about surgical history, items designed to assess severity, and demographic questions, on two occasions four weeks apart. A variety of hypotheses regarding the relationships between these variables were constructed a priori. *Results:* Sixty-eight people replied on two occasions. Internal consistency was high (Cronbach's  $\alpha$  0.88), as was test-retest reliability ( $\kappa$  0.89). The total IIRS score correlated with a global severity question

(0.61;  $p < 0.001$ ). Total IIRS score was lower in participants who had previously had surgery for hyperhidrosis, compared with those who had not (47 vs. 36;  $p = 0.02$ ), and changed dramatically in the direction of diminished severity in four patients who underwent surgery during the course of the study (54 vs. 17;  $p = 0.01$ ). Weak-to-moderate correlations were observed between total score and use of topical preparations, use of medications, number of clothing changes during a day, and limitations in choice of wardrobe. *Conclusions:* The IIRS is both reliable and valid in the assessment of patients with hyperhidrosis. A novel form of administration does not appear to affect its properties.

**Key words:** Hyperhidrosis, Illness intrusiveness, Quality of life, Severity

### Introduction

Hyperhidrosis is a condition characterized by excessive sweating of the palms, axillae or feet with or without facial blushing. The condition is believed to be caused by hypothalamic overactivity, transmitted to the hands, feet and face by the sympathetic nervous system, and its prevalence in young adults is estimated to be 0.6 to 1% [1]. This excessive sweating is elicited by emotional factors, but the view that psychological factors play an important role in the aetiology of the condition is outdated. Symptomatic relief of hyperhidrosis is offered by application of topical agents containing aluminium hydroxide, administration of medications (anticholinergic, antihistaminic, and anticatecholaminergic drugs), and iontophoresis, but their usefulness is limited, especially in patients with severe symptoms. Upper thoracic sympathectomy has been performed for this condition for many years [1]. Traditional open surgical approaches were usually reserved for those patients with most disabling symptoms because of the severity of postoperative pain, prolonged length of stay and complication rate [1, 2]. These problems are not shared by endoscopic sympathectomy which is emerging as the treatment of choice and has allowed the potential benefits of surgery to be extended to

patients with less severe disease. However, the effect of surgery on quality of life has not been studied perhaps, in part, due to the lack of a validated instrument. We were able to identify only one previous publication in which a formal attempt to measure the severity of disease or its impact on quality of life was reported [6]: this study used an ad hoc instrument and did not report its psychometric properties.

To describe the burden of illness due to this condition, and to quantify the effects of therapeutic interventions, an instrument that reflects the severity and disruptiveness of the condition is needed. Because of the highly specific nature of the symptomatology, problems due to the disease are unlikely to be captured by multiattribute utility scores (e.g. Health Utilities Index or EuroQoL) or by generic health-related quality of life scales (e.g. Sickness Impact Profile, Medical Outcomes Survey Short Form 36). These scales capture physical limitations caused by cardio-respiratory and musculoskeletal conditions, experience of pain, and general systemic illness. These attributes are not applicable to patients with hyperhidrosis. We were unable to identify a disease- or symptom-specific instrument which appeared suitable. We chose to investigate the properties of the Illness Intrusiveness Ratings Scale (IIRS) because the concept of intrusiveness seemed to capture the

condition's disruptive effects on many aspects of life described by patients. Previous research has supported the construct validity of the scale in other chronic diseases (rheumatoid arthritis, multiple sclerosis and end stage renal disease) and high levels of internal consistency (Cronbach's  $\alpha$  of 0.80 to 0.88) [7-9] and test-retest reliability ( $\kappa$  of 0.79 to 0.85) [8, 10-13] have been observed. It is a short, self-administered scale of 13 items. The brevity of the scale is an important factor considering the applicability of the instrument to clinical practice. The primary objective of this study is to assess the psychometric properties (reliability and validity) of the Illness Intrusiveness Ratings Scale (IIRS), in subjects with hyperhidrosis. We assessed the properties of the scale using a novel mode of administration (by electronic mail).

## Materials and methods

### Participants

Participants were individuals who contributed to an electronic mail (e-mail) discussion group on the subject of hyperhidrosis. Consecutive potential subjects (223) were identified from recent contributions: addresses were selected from different threads of the discussion. All subjects but one either identified themselves as believing that they suffered from hyperhidrosis or indicated symptomatology in keeping with the disease. (One mother replied on behalf of her son, and is counted among nonresponders.)

### Materials

#### *Illness Intrusiveness Ratings Scale*

Using a Likert scale ranging from one (not very much) to seven (very much), patients rated the degree of interference caused by their illness or its treatment with 13 aspects of their lives. These domains are: health, diet, work, active and passive recreation, financial situation, relationship with spouse, sex life, family and other social relations, self-expression/self-improvement, religious expression, and community/civic involvement. Individual item ratings and the sum across ratings were obtained. The total scale has a range of 13 (minimum intrusiveness) to 91 (extreme intrusiveness).

#### *New items*

In order to have measures of severity other than the scale itself, we developed 11 new items which were administered at the same time as the IIRS. The items were derived from a review of the literature, theoretical constructs, personal clinical observations and from review of spontaneous contributions to an e-mail hyperhidrosis discussion group. We asked 48 discussion-group participants for feedback about the items, receiving 10 replies. Having incorporated these

**Table 1.** New items

*How do you describe your condition? (If you had surgery, please answer describing your present condition and not the one before surgery)*

Mild 1 2 3 4 5 6 7 Severe

*If you had surgery how do you rate the results of this treatment?*

No improvement 1 2 3 4 5 6 7 Major improvement

*Do you use cosmetic preparations (topical powders, astringents, etc.)?*

Times in one day 0 1 2 3 4 5 6  $\geq 7$

*Do you use medications in pill form (anticholinergic, sedatives)?*

Times in one day 0 1 2 3 4 5 6  $\geq 7$

*Do you use any other device or treatment (i.e., iontophoresis or electronic devices) for hyperhidrosis?*

Times in one month 0 1 2 3 4 5 6  $\geq 7$

*How many times in a day do you shower/bathe because of excessive sweating?*

Times in one day 1 2 3 4 5 6  $\geq 7$

*How many times in a day do you change your clothes because of excessive sweating?*

Times in one day 1 2 3 4 5 6  $\geq 7$

*Does excessive sweating limit the kinds of clothes you wear (in terms of colours, material or design)?*

Not Very Much 1 2 3 4 5 6 7 Very Much

*How much does alcohol increase sweating or blushing?*

Not Very Much 1 2 3 4 5 6 7 Very Much

*How much does spicy food increase sweating or blushing?*

Not Very Much 1 2 3 4 5 6 7 Very Much

*How much do caffeine-containing drinks (coffee, chocolate, cola, etc.) increase sweating or blushing?*

Not Very Much 1 2 3 4 5 6 7 Very Much

suggestions, we pretested the 11 new items with five mailing-list contributors to assess for readability and lack of ambiguity. The new items are shown in Table 1.

### Method

Potential participants were contacted individually by e-mail and informed of the reason for the study, of the identity of the investigators, the time course of the study and the anticipated amount of effort that participation would involve. The blind-carbon-copy facility in the mail program was used in the generation of the mailing list to ensure that individuals were not able to identify other recipients. Assurance was provided that responses would be treated confidentially and that anonymity would be preserved in the reporting of results. People wishing not to participate were invited to reply to that effect, in order to avoid receiving follow-up reminders and questionnaires. The first mailing contained background questions,

the new items, and the IIRS. Participants were asked to delete their record of responses after replying. Four weeks later, a second questionnaire was distributed. Reminders were sent one week after the first questionnaire and one and two weeks after the second questionnaire. At the end of the study results were shared with everyone who had been contacted.

To assess construct validity, we tested the following hypotheses:

- Patients who have undergone surgery have a lower total score compared with those who have not.
- Patients who have surgery between the first and second questionnaire have a reduction in their scores at the second testing.
- For patients who have had surgery, the total score is negatively correlated with the rating of the perceived effectiveness of surgery.
- Total score is moderately correlated with other items intended to assess aspects of severity (global severity rating, use of medications, numbers of showers or baths per day, numbers of clothing changes, modifications of wardrobe, and modification of diet).
- Scores are lower in patients who are in stable relationships and in employment.

Data on age, sex, employment status, marital status (spouse or boyfriend/girlfriend), and previous surgery were also collected.

#### Statistical analysis

Data were analyzed using BMDP 7.0 and Statistica 5.1. Item-total correlations and Cronbach's  $\alpha$  were calculated to test the internal consistency. Analysis of Variance components were used to calculate test-retest reliability. Sample size calculation and confidence interval estimation for test-retest reliability were based on formulae derived for Pearson correlation coefficients, applied to Fisher's  $z'$ -transformed intraclass correlation coefficients [14]. For continuous variables, data were expressed as mean  $\pm$  standard deviation and Student's  $t$  test used to compare means (paired for within-subject comparisons and unpaired for between-subject comparisons). All statistical tests were two tailed.

Based on an expected reliability of 0.85–0.90 and desired confidence intervals of  $\pm 0.10$  for test-retest reliability, a sample size of 30 to 50 respondents was required. The number of participants who received the original mailing was based on an estimated 20–40% response rate.

#### Results

Seventy-five questionnaires were not delivered (because of incorrect/outdated addresses or technical problems with the server), 57 did not respond, and 11

**Table 2.** Response rates

	N (%)
Potential subjects	223
Unreachable	75 (34)
Unwilling to participate	11 (5)
Non responders	57 (26)
Participants	
Responded on one occasion	80 (36)
Responded twice	68 (30)

declined participation. The first questionnaire was returned by 80 participants, 68 of whom also completed the second questionnaire (Table 2). Respondents included the 11 participants who had pretested the new items.

Descriptive statistics regarding the sample are presented in Table 3. The respondents were in their third to fifth decades ( $32 \pm 9$  y), mostly Caucasian, with high levels of education and employment. Sixty-nine percent had a spouse, boyfriend or girlfriend. The majority of patients (77) indicated that they believed they suffered from hyperhidrosis: the remaining three omitted the item, along with other demographic items. Since it appeared from their responses that they were symptomatic, results from these patients are included in the analyses. A medical diagnosis of hyperhidrosis had been made in only 53%.

The responses to the 11 new items are illustrated in Figure 1. The distribution of responses to the

**Table 3.** Demographics of participants

	Mean $\pm$ SD (%)
Hyperhidrosis diagnosed by patient	96
Hyperhidrosis diagnosed by physician	63
Age (yr)	$32 \pm 9$
Male	65
Ethnic group	
Caucasian	84
Oriental	10
Black	5
Companion (spouse, boyfriend or girlfriend)	70
Paid employment	83
Smokers	11
Education	
Primary	0
Secondary	26
Postgraduate	21
University	53
Family history of hyperhidrosis	43
Surgery	21
Traditional	4
Endoscopic	17

SD: Standard deviation. Small differences in percentages from expected totals are due to rounding error.

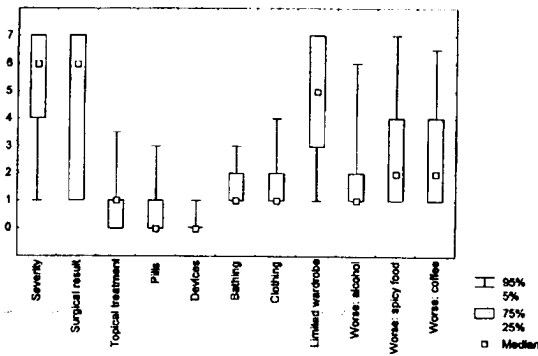


Figure 1. Distribution of responses to new items.

individual items of the IIRS is illustrated in Figure 2. Mean total IIRS score was  $45 \pm 18$ .

There were no differences in either the total IIRS score or the global rating of severity between self-diagnosed patients and those with a medically confirmed diagnosis ( $p = 0.14$  and  $p = 0.84$ , respectively).

Internal consistency of the IIRS was high with Cronbach's  $\alpha$  0.88 and average inter-item correlation of 0.33 (0.14–0.65). Item-total score correlations ranged from 0.43 to 0.68, with lowest values obtained for religious expression (0.43) and diet (0.49). However, Cronbach's  $\alpha$  for the scale with each item in turn deleted ranged from 0.87 to 0.88, suggesting overall homogeneity. Test-retest reliability was estimated as an intraclass correlation coefficient at 0.89. Patients who had undergone surgery between the first and second response were excluded from the analysis in the calculation of test-retest reliability.

Among people who responded on at least one occasion, 17 participants had undergone surgery and 63 had not. Four participants had surgery between the first and second questionnaire. The total IIRS score was significantly lower in patients who had undergone surgery in the past, compared with those who had not (47 vs. 36;  $p = 0.02$ ; Figure 3). In the four patients who had surgery during the course of the

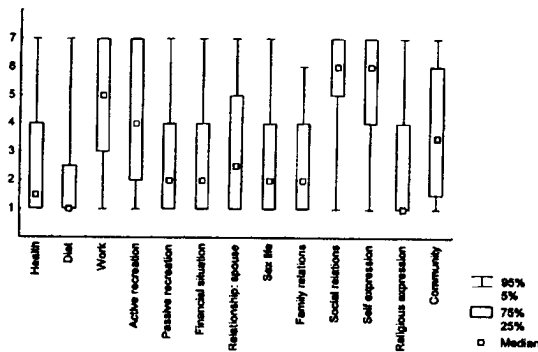


Figure 2. Distribution of responses to individual items of the Illness Intrusiveness Ratings Scale.

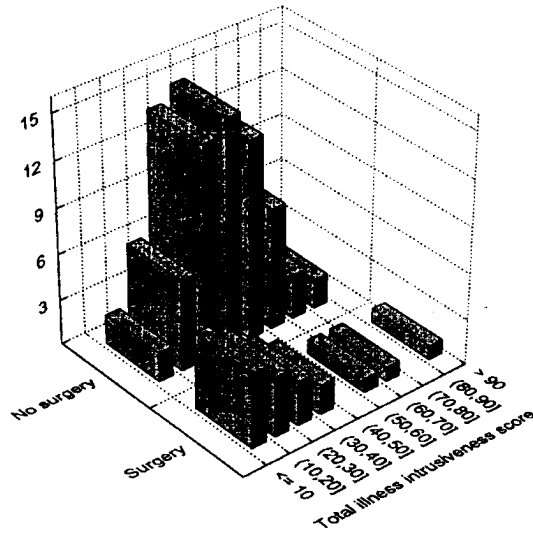


Figure 3. Relationship between total Illness Intrusiveness Ratings Scale score and previous surgery for hyperhidrosis.

study, a large improvement was observed between their preoperative and postoperative scores (54 vs. 17;  $p = 0.01$ ). Patients who had undergone surgery were asked to rate the effectiveness of surgery on a scale from 1 (no improvement) to 7 (major improvement). This item displayed a strong negative correlation with the total IIRS score ( $r = -0.79$ ;  $p < 0.01$ ).

The total IIRS score also correlated with other indices of severity. A strong positive correlation with the global severity question was observed (0.61;  $p < 0.001$ ). Correlations for topical treatments (0.23;  $p = 0.04$ ), medications (0.28;  $p = 0.01$ ), number of clothing changes (0.31;  $p = 0.005$ ) and wardrobe limitations (0.41;  $p = 0.001$ ) were statistically significant, while no significant correlation was observed for use of iontophoresis devices (only five people reported using such devices) or for the number of times a day participants bathed.

There was no statistically significant relationship between the total IIRS score and the socio-economic variables relating to marital status or employment.

Weak statistical correlations were observed between the diet item of the IIRS and the new questions relating to exacerbation of symptoms by alcohol ( $r = 0.21$ ;  $p = 0.06$ ), spicy food ( $r = 0.25$ ;  $p = 0.04$ ), and caffeine-containing drinks ( $r = 0.24$ ;  $p = 0.03$ ).

The distribution of responses to individual items and the total IIRS score did not differ between those patients who had been diagnosed by physicians and those who had not. The correlations described above between new items and the IIRS were also similar in both groups, though there was a tendency for correlations to be stronger and more statistically significant in patients who had been formally diagnosed; e.g. the correlation between the global severity

and total IIRS score was 0.65 ( $p < 0.001$ ) in those with the diagnosis, and 0.48 ( $p = 0.01$ ) in those without.

### Discussion

In order to document satisfactory psychometric properties in our study, both the use of the scale in the novel electronic presentation and the use of the IIRS as a measure of intrusiveness in hyperhidrosis, were required to be reliable and valid. Had the observed reliability and validity been poor, it would have been unclear whether it was the new means of administration or the use of the scale in hyperhidrosis that was problematic. However, given the satisfactory results above, we feel that both issues have been validated.

In people who have identified themselves, or have been diagnosed, as suffering from hyperhidrosis, we have been able to replicate the high levels of internal consistency and test-retest reliability previously documented for paper administration of this scale to patients with other chronic illnesses. Reliability coefficients should be interpreted in the light of the heterogeneity in responses in our subjects: lower values should be anticipated if the scale is to be used in a more homogeneous population.

Our findings also support the construct validity of the IIRS in hyperhidrosis. The a priori hypotheses were, for the most part, borne out by the results. The lack of observed relationship between total IIRS score and marital status or employment likely results from the numerous other determinants of these variables, and possibly from selection bias. The differences between patients who had undergone surgery and those who had not, and the dramatic change in scores in the few patients who underwent surgery during the course of the study, suggest that surgery appears to convey a substantial benefit. Moreover, in patients who had undergone surgery, higher ratings of effectiveness were associated with lower total IIRS score. However, some patients remain symptomatic after surgery (mean score in postsurgical patients was 36). Since study participants were drawn from active contributors to a hyperhidrosis discussion group, they are likely to represent more severe cases and people with less than optimum response to treatment.

Contamination of the sample with people not suffering from hyperhidrosis is a threat to the validity of our work. However, because of the typical nature of symptoms reported in our ad hoc questions and the high level of information available to our self-diagnosed participants, it is unlikely that we have included many responses from people without hyperhidrosis. The relationships that we chose to define the validity of the instrument were present in subgroup analyses of both self-diagnosed and physician-diagnosed patients.

It is not our intention to present our study population as representative of all patients with hyperhidrosis. Firstly, patients with more severe disease are more likely to participate in the discussion group from whom our participants were drawn, and perhaps more likely to respond to our questionnaire. Secondly, knowledge of and access to the Internet is more likely in those with higher educational attainments, and indeed more than half of our participants had attended university. Finally, as in any study, respondents represent a select group which may differ from nonrespondents in a number of potentially important ways. The educational factor certainly limits the generalizability of our conclusions about the usefulness of the electronic form of administration. Whether education and the other factors discussed above affect the generalizability of our results with respect to the use of the IIRS in hyperhidrosis is less certain. There is no clear a priori reason to hypothesize that the scale would be more reliable or valid in patients with more severe disease or with higher levels of education.

In these patients with hyperhidrosis the total IIRS score was high ( $45 \pm 17$ ) and comparable with observations in severe chronic disease states such as end-stage renal disease ( $39 \pm 17$ ), rheumatoid arthritis ( $38 \pm 17$ ), multiple sclerosis ( $43 \pm 15$ ) [8, 13]. The life domains that were most affected included social relationships, self-expression/self-improvement, work, and active recreation, whereas religious expression, diet, passive recreation, relationship with one's spouse and sex life tended to be least affected. Because of the biased sample, it was not the intention of the study to attempt to describe the severity of this condition. As anticipated, the response rate (36%) was too low for these figures to be considered useful indices of severity even among self-diagnosed discussion group contributors.

The availability of endoscopic thoracic sympathectomy has increased the interest in surgical management of this condition. Studies of the immediate results and long-term effectiveness of this procedure would benefit from the use of a measure of severity, and the IIRS appears to be a useful instrument for this purpose.

### Conclusions

The IIRS captures the impact of hyperhidrosis on people's quality of life. Within the definition of the study design, the scale appears to be reliable both in terms of internal consistency and test-retest reliability and it has good validity as supported by other correlates of severity of hyperhidrosis and the results of surgical treatment. A novel method of presentation did not appear to affect the psychometric properties of the scale.

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