

Misinterpretation of the international prostate symptom score questionnaire by Indian patients

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ABSTRACT

Introduction: The international prostate symptom score (IPSS) is commonly used in the evaluation of the severity of symptoms of patients with prostatic enlargement. It is a self-administered questionnaire. It has not been validated in any Indian language and an English version is used which can be difficult to interpret by our patients who do not have English as their primary language. In this study, we evaluate the patient's ability to understand the IPSS by comparing the scores when the IPSS questionnaire was self-administered versus when it was administered using the assistance of a clinician.

Materials and Methods: Patients who presented with lower urinary tract symptoms suggestive of benign prostatic hyperplasia, who had passed at least twelfth grade of school and had a reasonable command over English were included in the study. They were allowed to self-administer the IPSS questionnaire following which a clinician, blinded to these scores, assisted the patient in filling the questionnaire. For each question, the score in both the questionnaires was noted and kappa agreement statistical test was used to assess the agreement between the two scores.

Results: A total of 87 patients were included in the study. It was found that none of the questions had a perfect agreement of scores in the self-administered and the assisted administration.

Conclusion: Our results show that our patients misinterpret the IPSS questionnaire. This problem can lead to significant errors in interpretation of the symptom severity.

Key words: Benign prostatic hyperplasia, lower urinary tract symptoms, prostate questionnaires

INTRODUCTION

Benign prostatic hyperplasia (BPH) is a commonly encountered clinical condition in the elderly population. It presents with various obstructive and irritative lower urinary tract symptoms (LUTS) like frequency, urgency, nocturia, intermittency, weak urinary stream etc.^[1] The international prostate symptom score (IPSS) is a tool which is very commonly used in the evaluation of the severity of symptoms of

the patients. It is a self-administered questionnaire which scores the symptoms the patient has experienced over of the preceding 4 weeks.^[2] This questionnaire has been validated by numerous researchers in well-educated patients.^[3,4] It helps the clinician understand the severity of patient's symptoms and can guide treatment.^[5]

The IPSS questionnaire can be difficult for an average patient to comprehend. Hence the responses can depend upon the level of education and understanding of the patient. This can have a significant bearing on the ultimate score and can lead to improper selection of treatment.^[6,7] It can lead to significant distress both to the patient and to the treating physician due to the lack of optimum response by the treatment based on the IPSS.

The IPSS questionnaire has been translated and validated in various languages but it has not been validated in any of the Indian languages.^[8-10] We commonly employ the English version of the questionnaire. For a population that does not have English as its primary language, this issue may have a serious impact on the understanding of questions and the scoring. In this study, we evaluate the patient's ability to understand the IPSS by comparing

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the scores when the questionnaire was self-administered versus when it was administered using the assistance of a clinician.

MATERIALS AND METHODS

The study was approved by the institutional ethics committee. A total of 87 patients were included over a period of 10 months. Patients who presented with LUTS suggestive of BPH, those who had passed at least twelfth grade school and had a reasonable command over English (assessed by their ability to have a conversation in English with the clinician) were included in the study. A written and informed consent was obtained from all the patients. Those who had previously filled an IPSS questionnaire or those who were < 40 years of age were excluded from the study.

The patients were first given the IPSS questionnaire and were allowed to self-administer it. The score sheet was taken away and then a blinded clinician (2nd year resident in urology), who was not aware of the score on the self administered questionnaire, assisted the patient in filling the responses (English version) by interpreting and explaining the meaning of the questions in English. The second questionnaire was administered on the same day, 4-5 hours after the administration of the first questionnaire.

The IPSS questionnaire comprises of eight questions, seven regarding the symptoms over a period of the preceeding last 1 month and one assessing the quality-of-life. The seven questions assessing the symptoms include incomplete

emptying, frequency, intermittency, urgency, weak stream, straining and nocturia. Each of these symptoms is assigned a score from 0 to 5 for a maximum 35 points. The scores of these seven questions are added to determine the severity of patient urinary symptoms as follows, mild – 0-7, moderate – 8-19 and severe – 20-35. The eighth question assesses the quality of life is assigned a score of 0-6.

For each question, the score in both the questionnaires was noted and kappa agreement statistical test was used to assess the level of agreement between them. By convention, a kappa of 0.0 means that the agreement is no better than a chance event. Kappa scores of 0.01-0.20, 0.21-0.40, 0.41-0.60, 0.61-0.80 and 0.81-0.99 are interpreted as showing poor, fair, moderate, substantial and almost perfect agreement, respectively.^[11]

RESULTS

The mean age of the patients was 61.4 years. The kappa values of the scores for each question have been shown in Table 1. No question had a perfect agreement of scores in the self-administered and the clinician assisted scoring scenarios. Only the scores of questions about weak stream and nocturia showed “moderate” agreement of score while the quality-of-life question revealed a “fair” agreement. The scores for all the other questions had a poor agreement.

The total scores for each patient were calculated for both the clinical scenarios and they were classified into mild, moderate and severe categories as per the criteria mentioned

Table 1: The overall mean scores, kappa value and its interpretation for each question of the IPSS questionnaire

Question	Overall mean IPSS score		Kappa value	Interpretation of kappa value
	Self-administered	Clinician assisted		
Incomplete emptying				
How often have you had the sensation of not emptying your bladder?	2.87	2.75	0.077	Poor
Frequency				
How often have you had to urinate less than every 2 h?	2.5	1.75	0.034	Poor
Intermittency				
How often have you found you stopped and started again several times when you urinated?	2.75	2.5	0.095	Poor
Urgency				
How often have you found it difficult to postpone urination?	2.5	1.5	0.037	Poor
Weak stream				
How often have you had a weak urinary stream?	3.6	3.5	0.489	Moderate
Straining				
How often have you had to strain to start urination?	3.0	2.2	0.186	Poor
Nocturia				
How many times did you typically get up at night to urinate?	2.8	2.5	0.529	Moderate
Quality of life due to urinary symptoms	3.5	3.8	0.259	Fair

IPSS = International prostate symptom score

Table 2: The categorization of patient's symptoms as per the IPSS questionnaire when it was self-administered compared to when it was administered by an assessor

Symptom category (score)	No. of patients (IPSS)	
	Self-administered	Clinician assisted
Mild (0-7)	11	28
Moderate (8-19)	31	25
Severe (20-35)	45	34

IPSS = International prostate symptom score

before. The results have been shown in Table 2. It was found that total scores in the self-administered and the clinician assisted scoring agreed “poorly” with each other as the kappa value was 0.19.

DISCUSSION

IPSS questionnaire is recommended by the American Urological Association during the work up of a patient with LUTS. Apart from helping the clinician in assessing the severity of the symptoms of a patient, it also acts as a guide in selecting the appropriate mode of treatment which can vary from watchful waiting to surgery.^[5]

Studies in the Western population have pointed out that there can be significant misinterpretation of the IPSS by the patients.^[6,7,12] Some of these studies have shown that it depends upon the level of education, with patients having a low level of education showing marked misinterpretation. The issue of non-availability of the questionnaire in a local language and its impact on the ability of a patient to self-administer a questionnaire in English has been highlighted by Ogwuche *et al.*^[13] We also believe that a validated IPSS questionnaire in an Indian language may be helpful in decreasing the error in interpretation, but additional studies will be needed to prove this.

It has also been reported that the error in interpretation of the IPSS questionnaire can lead to miscategorization of the patients' symptoms and selection of a treatment that may not be effective for him. For example, a patient who on self-administered IPSS questionnaire has a score of 6 (mild symptoms) may be offered only watchful waiting while he actually may be having moderate or severe symptoms which becomes evident when the questionnaire is explained to him by a medical assistant. Johnson *et al.* have pointed out that 25% of patients who self-reported a mild score on IPSS actually had a moderate or severe score.^[14] In our study too, there was a misinterpretation of the IPSS questionnaire by the patients. The scores for each question showed a poor agreement for five out of seven questions. The quality-of-life question too could only show a fair agreement. There was also significant miscategorization of patients' symptoms (mild/moderate/severe) when the scores on self-administered questionnaire were compared

to the clinician assisted questionnaire. Thus it is important to realize that although IPSS questionnaire is an important tool in the work up of patients with LUTS, it should not be the *sole guide* for the treatment offered. Our study shows that there are some questions that are more prone for misinterpretation by the patients hence assistance by a clinician may be desirable.

Our study does have some potential causes of bias. We administered the questionnaire on the same day which might have an effect on the results as the patients might have been able to recall their responses in the first questionnaire. The second issue is that we did not stratify our results according to the level of education of the patients included in the study. It is possible that people with a higher education may have a lesser chance of misinterpretation of the questions.

CONCLUSION

Our results show that our patients, who do not have English as their primary language, misinterpret the IPSS questionnaire. There are significant differences in the symptom scores when the IPSS is self-administered as compared to the assisted scoring. This problem can lead to errors in interpretation of the symptom severity of patients by the health care providers; may affect the choice of treatment and ultimately, the clinical outcome.

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