Development of an "Individually-Defined" Activities Limitation Scale for Urinary Incontinence

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Objectives:

To review the literature, focusing on the Juniper and Guyatt method of eliciting and scoring individualized activity restrictions

To use this method to develop a self-report activity limitations measure specific to urinary incontinence

Methods:

Patients were recruited via local clinic referrals, newspaper advertisements and urology clinic referrals in Seattle and Philadelphia. Patients were over 18 years of age and were currently experiencing symptoms of stress, urge or mixed incontinence. They were excluded if their incontinence was related to treatment for a terminal illness, spinal cord injury or major neurological conditions. Men were also excluded if their incontinence was due to BPH or complications from prostate surgery.

At the baseline appointment, patients completed the Scale for Activity Interference and Limitations (SAIL), the Medical Outcomes Trust Short Form 36-Item Health Status Survey (SF-36), the Incontinence-specific Quality of Life measure (I-QOL), and other demographic questions. All of these measures were self-administered. A follow-up assessment using the SAIL was made by mail about one month after the baseline.

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Scale for Activity Interference and Limitiations :

This measure is modeled after the activity limitation scale used by Juniper and Guyatt[1] in the Asthma Quality of Life Questionnaire. The participant was given a list of activities where incontinence may interfere with his or her activities in usual daily life. They were asked to identify the five most important activities, write them into the blanks in the question format box, and then respond to a 7-point Likert scale (1, *totally limited* to 7, *not at all limited*) expressing the degree of limitation experienced in that activity during the past month (30 days). Scores are generated by summing the responses and transforming to a 0 to 100 scale with a greater SAIL score implying better quality of life.

[1] Juniper EF, Guyatt GH, Epstein RS, Ferrie PJ, Jaeschke R, Hiller TK. Evaluation of impairment of health-related quality of life in asthma: development of a questionnaire for use in clinical trials. Thorax 47:76-83, 1992.

Interference with your activities

This section is about the ways which your urinary problems limit or interfere with your normal activities. This can mean urinary problems cause you to do activities you like to do less often. It can also mean that your urinary problems cause you to enjoy these activities less when you do them.

Please think of the range of activities you have done in the past month (30 days) and pick from the following list five activities where you have felt the most limitation or interference.

These should be activities you try to do regularly and ones that are important to your every-day-life. **Once you select your five activities, please write them on the five blank lines below.**

Examples of Daily Activities

traveling in a car or public transport
doing home maintenance chores
doing housework
gardening
walking
exercise (jogging, running, biking)
traveling
playing sports
going up or down stairs
sleeping
regular social activities
having sexual activity
_____ *(another activity important to you?)*

activities with your family
taking care of children
personal relationships
shopping
hobbies and past-times
going to new places for the first time
entertainment (movies, concerts)
going to church or temple
having friends visit
going out for meals
going on vacation
physical recreation
_____ *(another activity important to you?)*

During the past month, how much have your urinary problems limited you or interfered with these activities? *(place a check mark in the box under the best response for each activity)*

Activity	Totally Limited	Extremely Limited	Very Limited	Moderately Limited	Somewhat Limited	Mildly Limited	Not at all Limited	Not Done
1.								
2.								
3.								
4.								
5.								

Results:

Table 1: Demographic Characteristics of the UI Sample (n=41)

Demographics	
Age (Years)	
- Mean (Std.Dev.)	51.2 (10.6)
- Minimum	18
- Maximum	79
Gender:	
% Male	19.5
% Female	80.5
Ethnicity	
% White (non-Hispanic)	83
% Black/African American	10
% American Indian/Alaskan Native	2
% Asian/Pacific Islander	0
% Hispanic/Latino	5
% Other	0
Marital Status	
% Married or Living As Married	37
% Widowed	10
% Separated	2
% Divorced	37
% Never Married	15
Income	
% Under $25,000	41
% $25,000-$49,999	32
% $50,000 and Over	22
% Missing	5
Education	
% High School	27
% College	34
% Graduate and Professional School	39

Missing Data: SAIL scores were not computed if any participants identified less than the 5 allocated activities. One participant was dropped from the analysis due to missing data, making the final dataset n=40. The person indicated only 3 of the 5 activities hence a SAIL score was not computed. The remaining 40 participants had no missing data.

Table 2: Internal Consistency and Test-Retest Reproducibility

	Number of Items in Scale	Cronbach's Alpha	Test-Retest Reliability[1]
SAIL Summary Score	5	0.88	0.75

Table 3: Convergent Validity of the SAIL

	SF36 Physical Component Summary	SF36 Mental Component Summary	I-QOL Summary Score
	Correlation (Significance)	Correlation (Significance)	Correlation (Significance)
SAIL Summary Score	0.50** (0.001)	0.52** (0.001)	0.72** (0.000)

Table 4: Discriminant Validity of the SAIL *(n=40, 1 observation missing)*

Scale and Ranges	n	SAIL Mean (Std.Dev)	SAIL F-value
Severity of the Incontinence			
1. Mild	19	57.38 (19.98)	5.77**
2. Moderate	17	42.35 (19.10)	
3. Severe	4	25.80 (11.00)	
I-QOL Summary Scores (tertiles)			
1. Score (5.68 - 48.86)	14	27.62 (11.80)	19.72**
2. Score (48.87 - 63.64)	15	56.00 (13.17)	
3. Score (63.65 - 84.09)	11	62.43 (20.66)	
I-QOL - Avoidance&Limiting Behavior (tertiles)			
1. Score (12.50 - 37.50)	15	31.77 (16.90)	11.39**
2. Score (37.51 - 56.25)	12	52.78 (15.62)	
3. Score (56.26 - 90.63)	13	61.80 (18.69)	
I-QOL - Social Embarassment (tertiles)			
1. Score (0.00 - 25.00)	15	34.00 (14.76)	9.09**
2. Score (25.10 - 55.00)	14	50.00 (20.63)	
3. Score (55.10 - 80.00)	11	63.94 (17.88)	
I-QOL - Psychosocial Impacts (tertiles)			
1. Score (0.00 - 63.89)	15	32.00 (14.52)	12.37*
2. Score (63.90 - 80.56)	14	51.67 (17.68)	
3. Score (80.57 - 94.44)	11	64.55 (18.75)	
SF36 – Physical Component (tertiles)			
1. Score (27.50 - 50.58)	14	35.47 (19.15)	4.10*
2. Score (50.59 - 63.00)	13	53.33 (17.53)	
3. Score (63.10 - 87.42)	12	55.56 (22.93)	
SF36 – Mental Component (tertiles)			
1. Score (33.30 - 50.45)	13	37.95 (21.92)	7.23**
2. Score (50.46 - 60.30)	12	42.50 (12.32)	
3. Score (60.31 - 71.30)	13	63.85 (19.38)	

Conclusion:

The cross sectional psychometric properties of the SAIL were tested by administering it in a battery with QOL and functional status measures at baseline (n=41). The SAIL proved to be internally consistent (a=0.88) and reproducible (group comparisons only) (r=0.75). Reproducibility was measured with a 4-week retest. SAIL scores were significantly worse as severity classification (mild, moderate, and severe) increased (F=5.8, p<0.01) and scores significantly increased as I-QOL and SF-36 (physical and mental) scores increased (F=19.7, p<0.01; 4.1, p<0.05; 7.2, p<0.01, respectively). Convergent validity analyses confirmed our predictions that the SAIL scores were more closely related to incontinence-specific QOL as measured by the I-QOL (r=0.72) than to generic health status as measured by the SF-36 (physical health r=0.50; mental health r=0.52).

The SAIL proved to be valid and reproducible as a self-administered measure for assessing incontinence-specific activity limitations. This instrument may be useful for assessing the association of activity restriction with disease severity and incontinence-specific quality of life.