

# Validation of a Dutch version of Stoma-QoL

Lucienne Dol<sup>1</sup>, Paula van Keizerswaard<sup>2</sup>, Sandra Smits<sup>3</sup>

1: Medisch Centrum Alkmaar, The Netherlands; 2: VU Medisch Centrum, Amsterdam, The Netherlands; 3: Amphia Ziekenhuis, Breda, The Netherlands.

## Introduction

- The development and validation of a DET score quality of life instrument for people with a colostomy or ileostomy (Stoma-QoL) has recently been described<sup>1</sup>. The instrument was found to be suitable for use in clinical practice and research.
- After translation of the Stoma-QoL questionnaire into Dutch, a linguistic validation of the translated version was needed.
- The Stoma-QoL questionnaire has never been validated in a urostomy population.

## Aims and objectives

- To examine the reliability and validity of the Dutch version of the Stoma-QoL questionnaire, including how accurately mental and psychological functions are measured among people with a stoma.
- To validate the Stoma-QoL questionnaire for all three ostomy indications: urostomy, colostomy and ileostomy.
- To assess whether time since surgery influences the quality of life.

## Materials and methods

- The Stoma-QoL questionnaire was translated from English to Dutch through a 3-step process according to internationally acknowledged procedures.
- Three investigators at 3 different centres in the Netherlands executed the study among 106 persons with a colo-, ileo- or urostomy.
- The participants answered the questionnaire twice. Following informed consent, the participants completed the first questionnaire. Additional demographic data was also obtained at this visit. Four to five weeks later, the second questionnaire was completed through a phone interview by one of the two other investigators. The investigator performing the interview was randomly selected.
- The items were scored on a 4-point scale: 1 (always); 2 (sometimes); 3 (rarely) and 4 (not at all) and transformed into a scale from 0 (worst quality of life) to 100 (best quality of life).

## Results

### Population

- 106 persons with a stoma participated in the study. Table 1 describes the distribution and demographic characteristics of the Dutch population compared to the population examined in the validation study by Prieto et al<sup>1</sup>.
- 80% had normal peristomal skin and 20% had a peristomal skin disorder. Of the 106 patients that were included, 92 gave an answer to all 20 questions in both questionnaires, and it took approximately 10 minutes to complete the questionnaire.

### Baseline questionnaire

- The total Stoma-QoL score at baseline was  $63.1 \pm 9.5$  (mean  $\pm$  standard deviation, SD). The score for each stoma type was: colostomy,  $64.5 \pm 10.7$ ; ileostomy,  $60.1 \pm 10.7$  and urostomy  $66.0 \pm 9.6$ . The score for those with a urostomy was significantly higher than for those with an ileostomy ( $p=0.02$ , independent t-test). There were no significant differences between the scores of those with a colostomy and those with an ileostomy or urostomy ( $p>0.05$ ).

- The mean score for each item in the questionnaire is displayed in Figure 1. There was a trend towards those with an ileostomy having more troubles sleeping than those with a colostomy or urostomy (non-significant finding,  $p>0.05$ , Mann-Whitney test). In addition, the feeling of sexual unattractiveness seemed more pronounced among those with an ileostomy (non-significant finding,  $p>0.05$ ).

- There was no correlation between time elapsed since stoma surgery and total baseline Stoma-QoL score,  $r=0.04$ .

### Comparison of first and second questionnaire

- The total Stoma-QoL score was consistent over time: There were no significant differences between the mean total Stoma-QoL score from visit 1 to visit 2 (Figure 2) among the participants who completed both questionnaires ( $n=92$ ). The medians were: 62.5 (range: 36.3 – 100) for the baseline questionnaire and 61.7 (30.3 – 100) for the second questionnaire,  $p=0.44$

## Discussion

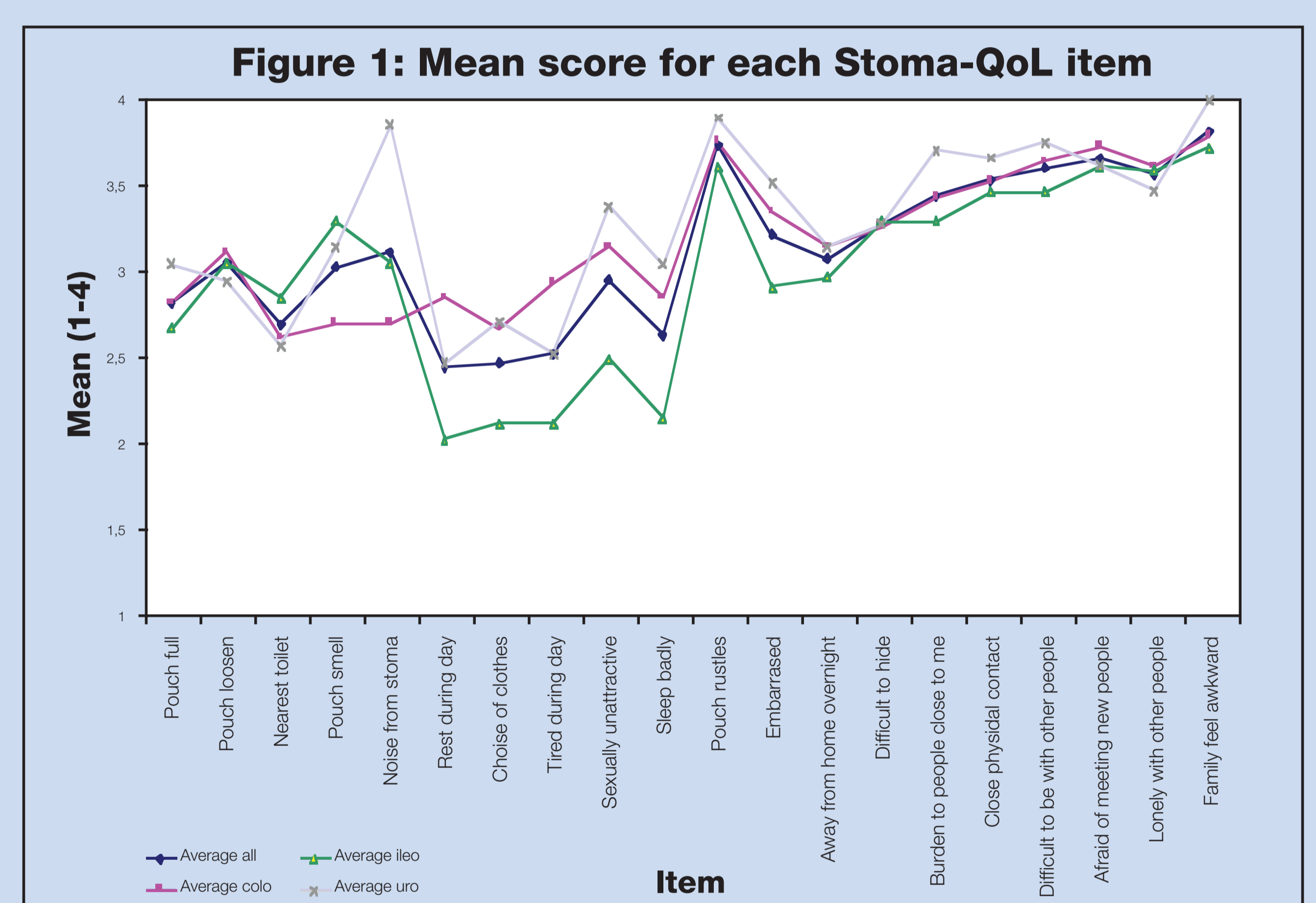
- The trend that people with ileostomies have more troubles sleeping during the night than people with a urostomy or colostomy may be one explanation to their lower quality of life. This also supports avoiding creation of ileostomies, if possible, by low anterior resection.
- In this population, the presence of peristomal skin disorders did not have impact on the quality of life score. However, in future studies, the correlation between the severity of a peristomal skin disorder and total Stoma-QoL score should be examined.

## Conclusions

- The Dutch version of the Stoma-QoL questionnaire is a valid and reliable tool to measure quality of life among people with a stoma.
- The Stoma-QoL score can be used to follow patients over time.
- The individual items in the questionnaire can be used to identify specific problems in the stoma care outpatient clinic population to improve care and enhance Quality of life.
- The Stoma-QoL questionnaire is an easy tool to use and takes approximately 10 minutes to complete.

## References

- Prieto L, Thorsen H, Juul K. Development and validation of a quality of life questionnaire for patients with colostomy or ileostomy. *Health Qual Life Outcomes*. 2005 Oct 12;3:62.



Mean scores for each Stoma-QoL item at first visit separated into each stoma type and reported on a 4-point scale: 1 (always); 2 (sometimes); 3 (rarely) and 4 (not at all).



Boxes represent the interval between the 1st and the 3rd quartiles. Horizontal lines inside the boxes represent the median. Vertical lines represent the minimum and the maximum. 0 is the worst and 100 is the best quality of life.

**Table 1: Demographic data of the Dutch population compared to the demographics presented in the original validation study<sup>1</sup>**

|   | Denmark         | Germany        | Spain           | France          | Total           | Netherlands     |
|---|-----------------|----------------|-----------------|-----------------|-----------------|-----------------|
| N   | 49              | 43             | 58              | 32              | 182             | 106             |
| Age, mean (SD)                                  | 58.2 (12.5)     | 61.9 (11.9)    | 40.7 (11.6)     | 58.5 (14.5)     | 53.4 (15.3)     | 61.3 (14.4)     |
| Sex (Male/Female), N (%)                        | 14/32 (30%/70%) | 33/8 (80%/20%) | 28/30 (48%/52%) | 18/14 (56%/44%) | 93/84 (53%/47%) | 55/51 (52%/48%) |
| Type of stoma                                   |                 |                |                 |                 |                 |                 |
| Colostomy, N (%)                                | 23 (50.0%)      | 34 (100.0%)    | 0 (0.0%)        | 32 (100.0%)     | 89 (52.4%)      | 42 (40%)        |
| Ileostomy, N (%)                                | 23 (50.0%)      | 0 (0.0%)       | 58 (100.0%)     | 0 (0.0%)        | 81 (47.6%)      | 43 (41%)        |
| Urostomy, N (%)                                 | 0 (0.0%)        | 0 (0.0%)       | 0 (0.0%)        | 0 (0.0%)        | 0 (0.0%)        | 20 (19%)        |
| Duration from stoma creation (years), mean (SD) | 15.4 (11.0)     | 4.8 (3.4)      | 4.6 (4.8)       | 2.7 (5.4)       | 7.1 (8.4)       | 2.5 (3.5)       |
| Stomal-QoL score                                |                 |                |                 |                 |                 |                 |
| Mean (SD)                                       | 62.6 (N/A)      |                |                 | 53.8 (N/A)      | 58.1 (N/A)      | 63.2 (9.9)      |