

Patients living 25 years or longer with a urostomy; What can we learn from them?

Cobussen-Boekhorst H¹, Janssen V¹, Smits-van de Camp A¹, Aarts M², Verberk M², Martens F¹, Feitz W¹, Heesakkers J¹



1. Department of Urology, Radboudumc Nijmegen, The Netherlands,
2. Hoge School Arnhem en Nijmegen, Nijmegen, The Netherlands



Introduction

Limited information is available in literature about living ≥ 25 years with a urostomy. At that time stoma care nursing was not standard. Over the years this became more common and nowadays patients see stoma nurses in the pre-and postoperative phase and in follow-up, depending on patient's needs. This study was performed because we were interested in the Quality of Life (QoL) of patients living ≥ 25 years with a urostomy.

Objective

The aim of this study was to find out which experiences, both beneficial and limiting aspects, they cope with and how these aspects influence their QoL. And to find out how we could further develop the current care program for these patients.

Methods and Materials

- Patients with a urinary diversion ≥ 25 yrs were collected; of this list patients using stoma appliances, due to Bricker ileal conduit (n=19) or a ureterocutaneostomy (n=2) were selected.
- A mixed-method study (quantitative and qualitative) was set up.
- Patients were invited by a letter; informed consent was obtained.
- The study received ethical approval, reg. nr2018-4971.

Quantitative data:

- Validated questionnaire^{1 2}, added with questions concerning gender, age and time living with the urostomy.
- QoL-score was determined by the cumulative score of the questionnaire. Higher scores indicate higher QoL.^{1 2 3}
- Data was evaluated using computer SPSS software.

Qualitative data

- Heterogeneous group of patients, generated through constant comparison.
- All interviews were semi structured by themes and sub-themes.
- They were recorded, anonymously transcribed, segmented and coded and analysed by two researchers.
- Logbook and research memos were kept.

Theme	Sub Theme
Urostomy	QoL regarding: - Self-image / Independence / Social contacts Tips & tricks
Outpatient clinic and ward	QoL regarding: - Guidance in the past & nowadays/ Caregiver Tips & tricks
Insurance and reimbursement	1. Extra costs 2. Delivery of materials

Results qualitative data

- Nine gave permission for an interview, after five patients full saturation was achieved.
- Generally they experience few to no limitations in daily activities, as the urostomy became part of them.
- They are always wary of the nearest toilet. This however has become an automatism. Some stated that it is difficult to change their appliances, in public restrooms, when having leakages. Therefore they sometimes worry about release of the pouch.
- Some feel hampered by their choice of clothing .
- Complications of the urostomy and/or the underlying disease/ condition compose the limiting aspects. These problems manifest in additional hospital admissions, poor sleep or other inconveniences. Because of these problems, they experience limitations in energy level.
- In the first years maintaining social contacts and sexuality were experienced limitations. Especially concerning their sexuality, patients feel unattractive due to their urostomy. One patient stated that the adolescent phase was difficult. Sexuality should be discussed more often in follow-up. However they stated that these limitations diminish over the years.
- Involve partners or caregivers in the process. Also the help of fellow sufferers was advised.
- In the early years, information was moderate or non-existing for those undergoing a urostomy procedure. The guidance they receive nowadays is generally experienced as very good. Not all patients have structural stoma nursing care, but are aware of who to contact

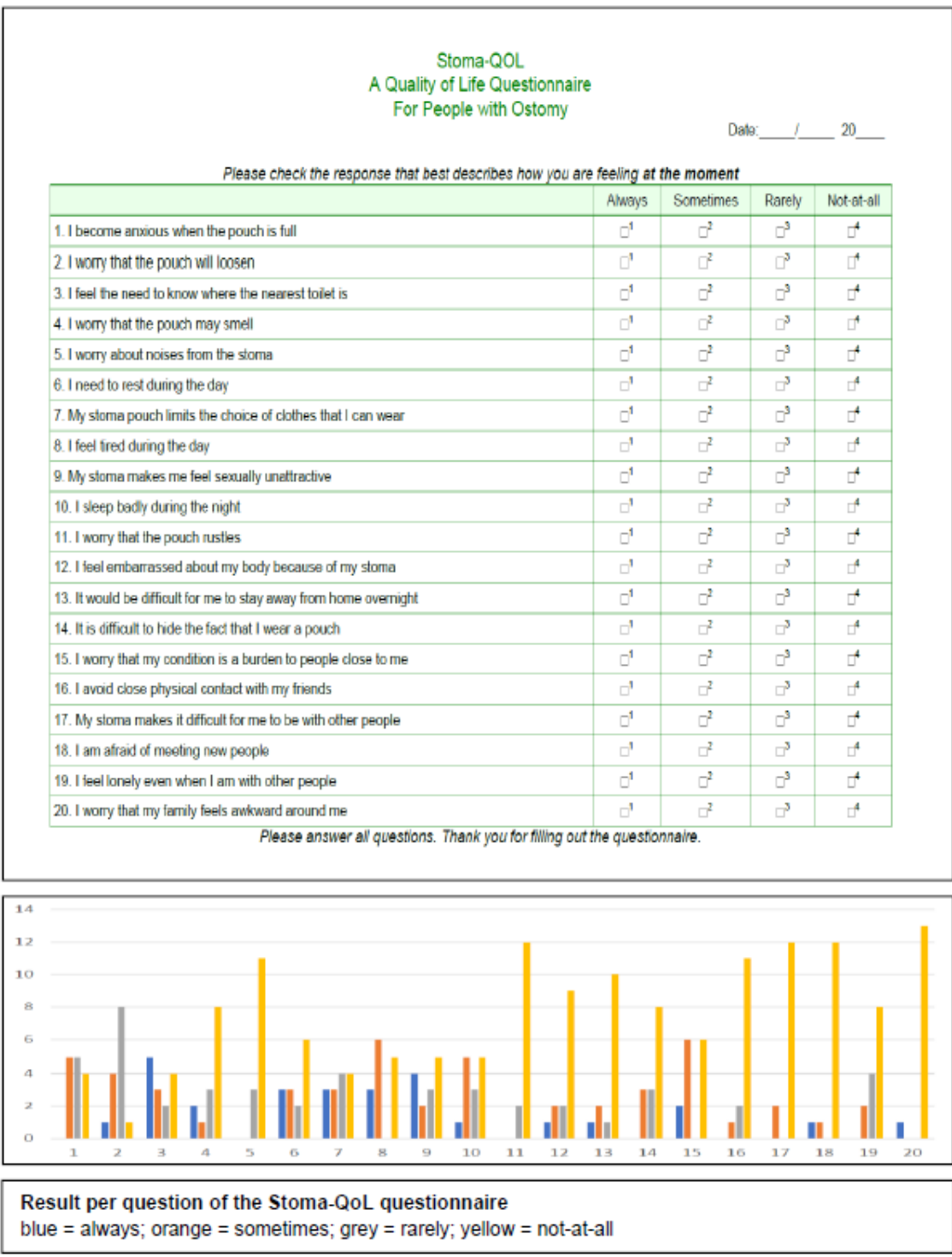
Results quantitative data

Total group n=14		%	n	Mean/range	SD
Gender	Female	50	7		
	Male	50	7		
Age	25-44 yrs	14	2	62 (42-83) yrs	13,35
	45-64 yrs	36	5		
	65-84 yrs	50	7		
Time with urostomy	24-44 yrs	64	9	40 (25-56) yrs	11,23
	45-60 yrs	36	5		
Disease origin	Bladder exstrophy	43	6		
	Urinary incontinence	29	4		
	Spina Bifida	14	2		
	Other	14	2		
Interview group n=5		%	n	Mean/range	SD
Gender	Female	60	3		
	Male	40	2		
Age	25-44 yrs		0	60 (46-75) yrs	11,02
	45-64 yrs	60	3		
	65-84 yrs	40	2		
Time with urostomy	24-44 yrs	40	2	41 (29-56) yrs	10,22
	45-60 yrs	60	3		
Disease origin	Bladder exstrophy	40	2		
	Urinary incontinence	40	2		
	Spina Bifida	10	1		

Table 1 Patient characteristics.

Stoma QoL (n=14)	Score	%	n
Overall	63 (49-74)	100	14
Good	66 (56-74)	79	11
Moderate	52 (49-54)	21	3
Poor			0

Table 2: Stoma QoL Questionnaire score (between 20-80): 70-100 %= good; 30-69%= moderate; 0-29%= poor³
Questionnaire response 71% (n=15). One was invalid due to two missing answers



Discussion

- The results of both studies strengthened each other and are consistent with the (limited) results described in current literature.
- Due to the fact that a urostomy is not listed separately as a medical diagnosis, patients could have been missed.
- The study group was small, which limits the probative force.
- Prospective follow-up studies regarding QoL over the years might give more insight.
- The lowest score of the questionnaire is 20 and the highest 80. However, no further explanation is given about the spread. Therefore the classification described by Gomez, et al (2014)³ was used (70-100% good, 30-69% moderate, 0-29% poor QoL). The score of an incomplete questionnaire can not be calculated.

Conclusions

QoL of patients living ≥ 25 years with a urostomy is generally experienced as good. QoL is not so much influenced by the urostomy itself, but by the underlying disease and/or complications of the urostomy.

During the first years information and guidance is important for the experienced QoL. Honest information has to be given. The guidance patients receive nowadays is generally experienced as very good in our group. Important to discuss sexuality and involve partners/ caregivers and also the help of fellow sufferers.

Prospective multi-centered follow-up studies regarding QoL might give more insight in the experienced QoL over the years.

References

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