

# Enhancing recovery: raising awareness of everyday struggles of patients with ostomies

## ABSTRACT

**Purpose** Within our facility the number of surgical procedures resulting in ostomy formation is increasing. Inpatient ostomy care helps patients learn how to care for their ostomy and become as independent as possible to maintain a high quality of life (QoL) following surgery. But more needs to be done to assess patients' QoL when they return home. This study was designed to support improvement in the QoL for patients living with ostomies post-discharge. It will assist in promoting patients' full potential and optimal health within the community.

**Method** The Stoma-QoL Tool was used to evaluate patients' perception of living with an ostomy at 1, 2, 4, and 8 weeks post-discharge via a telephone survey. The Stoma-QoL Tool contained 20 closed questions to rate QoL. Ostomy education was provided using multiple written and visual aids.

**Results** There were 28 new ostomy patients who completed the surveys at the stipulated time periods. The highest score achieved in the Stoma-QoL Tool was used as an indicator of QoL at each time period. An example of one patient demonstrated a change in score of 28 to 44 between 1 and 8 weeks. Body image and issues related to the ostomy appliance were the main concerns expressed.

**Conclusion** Quality of life can affect a patient's well-being, not only physically but also emotionally and socially. Using an ostomy QoL survey, patients were able to quantify their QoL, allowing members of the research team to individualise patients' care within the Princeton Healthcare System. (IRB Study: BN2332).

**Keywords** ostomy, ostomy patients, ostomy education, collaboration, quality of life

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## INTRODUCTION

Many ostomy patients who presented postoperatively to the emergency room in our facility to see the wound/ostomy nurse were found to be experiencing difficulties that were often

emotional, not stoma nor appliance related management issues. Several of the new ostomy patients expressed general sadness about their situation; they felt frustrated with a lack of knowledge about the care of their stoma, adjustments to living with an ostomy, and perceived lack of control over their situation, and they were anxious about changes in their body image. In addition, and as a result of the large volume of calls received from ostomy patients weekly expressing similar concerns, the ostomy staff decided to look further into the quality of life (QoL) for ostomy patients.

Quality of life after ostomy surgery is a major factor in a person's rehabilitative processes that impacts on their ability to accept changes to their health and physical status, manage their stoma, connect socially with family and friends, and re-integrate meaningfully with society, inclusive of returning to paid or voluntary work<sup>1,2</sup>.

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Failure to adjust physically and psychosocially after ostomy surgery can have adverse short- or long-term consequences. Therefore, it is important to understand what factors contribute to people's lack of confidence and/or ability to adjust to living with a stoma especially in the immediate postoperative period. There have been a number of tools designed to assess QoL after ostomy surgery, including the City of Hope Quality of Life Scale – Ostomy questionnaire, the Stoma Quality of Life Scale, and the Stoma Quality of Life Index<sup>3,4</sup>.

The Stoma-QoL Tool<sup>1</sup> was developed to measure QoL among people with a stoma (Table 1). The following concerns associated with having a stoma are itemised within the Tool: sleeping; intimate relations; relationships with family and close friends; concerns regarding relationships with people other than family and close friends; wearing an ostomy appliance; access to toilet facilities; body image; and self-worth. The questions asked in the Tool are reflective of those found to be most important in ostomy patients' QoL<sup>1-5</sup>.

Wound/ostomy nurses at our facility provide inpatient education on ostomy care including the supply of an ostomy educational folder. Ostomy educational folders include written information on: all aspects of stoma care; the ostomy appliance and skin care accessories in use; purchasing of ostomy supplies; community resources; and matters related to body image and sexuality. Such education, combined with face to face specific counselling by wound/ostomy nurses, helps patients (and families) to properly care for their ostomy as independently as possible while encouraging patients to maintain a high QoL following ostomy surgery. Patients also receive Your Guide to Recovery after Ostomy Surgery which provides additional guidance<sup>6</sup>. During the course of a hospital stay for a new ostomy patient at our facility, they will be seen on average between 10–14 hours for tuition and counselling on how to manage their stoma.

## METHODS

### Institutional Review Board: study approval

According to Section 5.05 in the Rules and Regulations of The Medical Staff of Princeton HealthCare System, staff are guided by "federal, state and institutional regulations, including all aspects of informed consent and patient protection"<sup>7</sup> for the conduct of any research.

A facility-based Institutional Review Board (IRB) is a committee that applies all relevant regulations and the principles of research ethics by reviewing the methods proposed for research to ensure that they are ethical. The IRB board at our facility is comprised of a designated panel incorporating medical, nursing, quality assurance and legal representation for example, which approve or reject research studies and continue to monitor approved studies when it involves humans.

Research applications must be submitted prior to any study starting, and a formal meeting with the IRB is held to determine whether or not a research study should proceed. The IRB also

Table 1. The Stoma-QoL Tool

**Stoma-QoL**  
A quality of life questionnaire for people with an ostomy

Please check the response that best describes how you are feeling *at the moment*.

	Always	Sometimes	Rarely	Not at all
1. I become anxious when the pouch is full	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I worry that the pouch will loosen	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I feel the need to know where the nearest toilet is	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I worry that the pouch may smell	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I worry about noises from the stoma	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I need to rest during the day	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. My stoma pouch limits the choice of clothes that I can wear	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I feel tired during the day	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. My stoma makes me feel sexually unattractive	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I sleep badly during the night	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I worry that the pouch rustles	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I feel embarrassed about my body because of my stoma	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. It would be difficult for me to stay away from home overnight	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. It is difficult to hide the fact that I wear a pouch	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15. I worry that my condition is a burden to people close to me	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16. I avoid close physical contact with my friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17. My stoma makes it difficult for me to be with other people	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18. I am afraid of meeting new people	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19. I feel lonely even when I am with other people	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20. I worry that my family feels awkward around me	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please answer all questions. Thank you for filling out the questionnaire.

protects the rights and welfare of humans participating as subjects in a research study. Potential risks to study participants are to be disclosed within an application to the IRB. Study researchers declared there were no risks – physical, confidential or legal – involved in this study<sup>8</sup>. It was noted that potential discomfort might be experienced by some study participants when asked to respond to questions that addressed intimate relations or relationships. Obtaining approval from the IRB panel took several months to complete. Study researchers were awarded IRB study approval #BN2332 and were given 1 year for data collection.

Interviewing patients was performed by an ostomy nurse (while inpatient), use of visual materials (ostomy folders/brochures, ostomy apron), and analysis of documents (Stoma-QoL Tool) was performed across the continuum of care, beginning in acute care. Patients in our community teaching hospital were identified through inpatient consult lists.

### Research method and data collection

This study used a quantitative methodological approach. Quantitative research can be applied by patients assigning numbers to their answers using a validated survey tool. The Stoma-QoL<sup>5</sup> Tool was chosen to measure QoL in this study as it was simple to execute. It was also deemed to assist in identifying QoL issues that facilitated better planning processes to improve QoL for patients living with ostomies. The instrument has 20 items, each of which were to be rated by study participants on a 4-point Likert scale<sup>9</sup> using numbers ranging from 1 to 4 (Always, Sometimes, Rarely, and Not at all). The questions are closed end. The highest and lowest possible

Table 2. Study demographics

Characteristic	N=28
Gender n(%)	
Female	21 (75)
Male	7 (25)
Age, mean (range)	59 (29-89)
Type of ostomy	
Colostomy	17 (60)
Ileostomy	11 (40)

raw scores to be achieved are 80 (best QoL) and 20 (worst QoL) respectively<sup>3</sup>.

The Stoma-QoL Tool was administered over five time periods – before surgery, and then 1, 2, 4 and 8 weeks after surgery – by wound/ostomy nurses during scheduled interviews with consenting participants.

Over the 12-month study period new ostomy patients were approached to participate in the study whilst inpatients. Patients at the 8-week period of the study who had been discharged and who remained as study participants were surveyed in the home setting via a contact telephone call. Participants were asked to verbally rate their responses to the Stoma-QoL Tool using the Likert scale.

Patients considered for inclusion within the study were identified through inpatient consult lists.

### Study interventions

Structured telephone interviews were conducted by wound/ostomy nurses of new ostomy patients in accordance with the above time periods prior to and after surgery using the Stoma-QoL Tool. The study used visual materials such as ostomy folders/brochures and an ostomy apron<sup>10</sup> to educate new patients on the gastro-intestinal tract, type of surgical procedure to be formed, type of stoma to be created and how to care for their stomas. Data was analysed using simple descriptive statistics.

## RESULTS

During the 12-month study period there were 102 new ostomy patients. Collectively, over 300 ostomy consults were undertaken during their periods of hospitalisation. Of the 102 new patients, 82 had permanent ostomies, 17 people had colostomies, and 11 had ileostomies. The mean age of patients was 65, and 75% were female and 25% were male (Table 2).

Only 28 patients completed the entire study. An example of one patient's results that examined the differences in QoL scores between 1 week post-discharge and 8 weeks post-discharge are provided in Tables 3 and 4. At 1 week post-discharge the total QoL score was 28 out of 100, with higher scores for the 'Always' category (n=12), with 'Sometimes' receiving 8 checked responses. Nil checks were placed in the

'Rarely' or 'Not at all' categories. The most prevalent themes to responses provided in the 'Always' category were related to body image and stoma equipment respectively. In comparison, at the 8-week interval, the total QoL score was 44 out of 100. The patient's responses from highest to lowest within each category were 'Sometimes' (n=12), 'Rarely' (n=6) and 'Always' (n=2). No responses were checked for the 'Not at all' category. Similarly, body image was identified as the most cause of concern.

## DISCUSSION

Utilising the Stoma-QoL Tool was an objective and consistent method that the wound/ostomy nurses could use for assessing QoL in new ostomy patients at prescribed intervals within our facility for the duration of the study.

The initial patient interview by the wound/ostomy nurse using the Stoma-QoL tool was a revelation for both patients and staff. Patients openly discussed their anxieties relating to their forthcoming ostomy surgery, which was an unexpected outcome. The patient results described in Tables 3 and 4 showed that the higher the score achieved, the better QoL is perceived by the patient post-educational interventions.

The tool helped identify areas of difficulty that patients were experiencing in adapting to life with a stoma post-surgery. The most predominant of these difficulties were body image and factors related to ostomy equipment. These findings are consistent with other studies where body image and appliance management were factors inhibiting QoL<sup>11,12</sup>.

Overall, and anecdotally, it was noted after a 2-week period of education, patients generally became more comfortable with their change of life post-surgery. Furthermore, the results of the survey assisted in developing an individualised plan to improve QoL for each patient.

In addition, participants reported the benefits of taking part in this study as they were identifying issues about their stoma, stoma care, body image or others' perception of themselves as causes of anxiety or concern. In doing so, this helped to enhance their personal care plan to improve their QoL post-stoma surgery<sup>13,14</sup>.

Collaboration is key to all successful interventions with patients. Wound/ostomy staff at our facility work closely with surgeons, nursing staff and case managers to promote the highest level of patient care and outcomes, thereby increasing the QoL. Case management plays a key role in successfully facilitating a smooth transition for the often emotionally fragile ostomy patient from hospital to home. This involves ensuring the patient has home care follow-up as well as supplies for home use.

Collaborative processes also extend to our hospital's Center for Pelvic Wellness (CPW). Pelvic rehabilitation focuses on the treatment of pelvic and abdominal wall disorders in men, women and children. It is recognised that many ostomy patients experience some form of pelvic or abdominal

Table 3. Example of one patient: at 1 week post-discharge

Please check the response that best describes how you are feeling **at the moment**.

	Always	Sometimes	Rarely	Not at all
1. I become anxious when the pouch is full	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I worry that the pouch will loosen	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I feel the need to know where the nearest toilet is	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I worry that the pouch may smell	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I worry about noises from the stoma	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I need to rest during the day	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. My stoma pouch limits the choice of clothes that I can wear	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I feel tired during the day	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. My stoma makes me feel sexually unattractive	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I sleep badly during the night	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I worry that the pouch rustles	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I feel embarrassed about my body because of my stoma	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. It would be difficult for me to stay away from home overnight	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. It is difficult to hide the fact that I wear a pouch	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15. I worry that my condition is a burden to people close to me	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16. I avoid close physical contact with my friends	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17. My stoma makes it difficult for me to be with other people	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18. I am afraid of meeting new people	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19. I feel lonely even when I am with other people	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20. I worry that my family feels awkward around me	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

wall dysfunction. Therefore, pelvic rehabilitation is seen as beneficial<sup>15,16</sup>. On referral to the CPW the physical therapist performs a thorough musculoskeletal assessment and provides the patient with an individualised rehabilitation program to meet their needs<sup>15,16</sup> that may include further education, fluid and dietary management, pelvic floor physical therapy, pelvic support devices or other conservative treatments. The CPW also coordinates treatment across multiple providers.

An adjunct study finding indicated patients who regularly attended pelvic rehabilitation sessions reported improvements in QoL. Patients also stated that having someone else to speak to made it easier to deal with their ostomy<sup>15,17</sup> which in turn was felt to improve the QoL score.

It is critical that health professionals subscribe to collaborative inter-professional practice to ensure the best possible patient outcomes for those discharged with major life-changing illness. This will ensure that patients are better able to cope with those phases of psychological adaptation that may include shock, denial, acknowledgement and adaptation to their situation<sup>18</sup>.

### STUDY LIMITATIONS

As participant numbers in this study were very small and only one patient's example of changes in the QoL score was highlighted post-study interventions, the findings of this study would need to be supported by further large-scale research before being generalised to all patients post-ostomy surgery.

### CONCLUSION

This study was designed to support improvement in the QoL for postoperative patients living with ostomies. Using a validated instrument over time, the researchers obtained clinical indicators of where patients are struggling the most in adjusting to the presence of a stoma. The main areas of concern were body image and issues related to the ostomy appliance. The study has assisted in promoting patients' full potential and optimal health within the community through further education. Our analysis showed us that QoL for postoperative ostomy patients is very important.

Table 4. Example of the same patient: at 8 weeks post-discharge

Please check the response that best describes how you are feeling **at the moment**.

	Always	Sometimes	Rarely	Not at all
1. I become anxious when the pouch is full	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I worry that the pouch will loosen	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I feel the need to know where the nearest toilet is	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I worry that the pouch may smell	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I worry about noises from the stoma	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I need to rest during the day	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input checked="" type="checkbox"/> 3	<input type="checkbox"/> 4
7. My stoma pouch limits the choice of clothes that I can wear	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I feel tired during the day	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. My stoma makes me feel sexually unattractive	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I sleep badly during the night	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I worry that the pouch rustles	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I feel embarrassed about my body because of my stoma	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. It would be difficult for me to stay away from home overnight	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. It is difficult to hide the fact that I wear a pouch	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15. I worry that my condition is a burden to people close to me	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16. I avoid close physical contact with my friends	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17. My stoma makes it difficult for me to be with other people	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18. I am afraid of meeting new people	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19. I feel lonely even when I am with other people	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20. I worry that my family feels awkward around me	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input checked="" type="checkbox"/> 3	<input type="checkbox"/> 4

### CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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