

OSTOMATE RECOLLECTIONS OF WHAT THEY REALLY NEEDED TO KNOW AFTER SURGERY

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Rationale

Following life-altering surgery, such as ostomy surgery, it is necessary for the professional healthcare provider to present information so patients have sufficient comprehension of the life forces that will impact them as they move forward with their recovery. Shortened hospital stays often make it difficult to provide the patient with generalized and fundamental information at a time when the patient is cognitively unable to process the information. Additionally, the type of information required by the patient may be specific and, thereby, poorly understood by the professional caregiver. Poor comprehension of information by the patient can lead to improper life choices, anxiety over life events and a reduction in overall life involvement.

Purpose

While professional caregivers can be described as diligent in their responsibilities to the post-surgical patient, the question that should be asked is whether the patients feel they have the answers to their most

important questions. Secondary to this is whether receiving satisfactory information regarding their altered state has any measurable effect. This study describes how ostomates responded when they were asked to recall their immediate post-surgical experience regarding what they needed to know. To this end, they were asked a simple question “What was the one thing that you really needed to know?”

Methodology

Data source: Ostomy Comprehensive Health and Life Assessment (N = 1507)

Subset (n = 656) includes:

Eighteen years of age or older

Provided a response to the open-ended question, “Think about the first days after your surgery, what was the one thing you really needed to know?”

Ostomates were also asked if they were satisfied with the information they did receive.

Profile

The sample includes 656 people with ostomies between the ages of 20 and 89 reporting a median of 53 months since surgery. An overview of other characteristics is shown in the accompanying graphs.

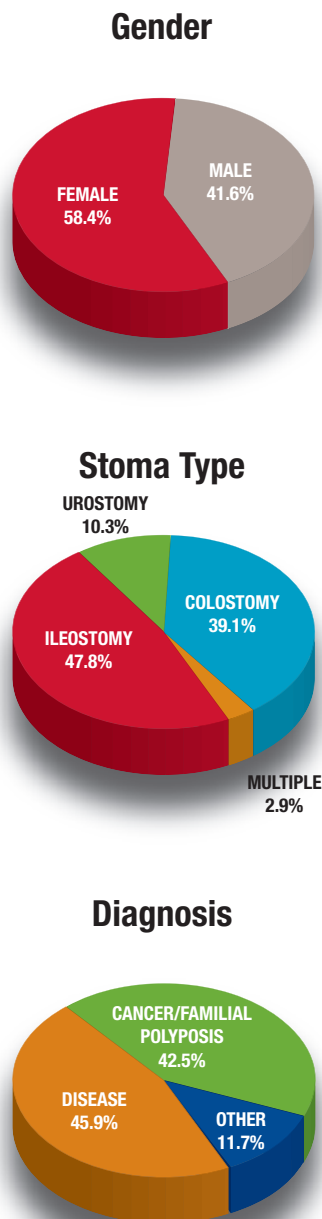


Figure 1

Results

Among those who provided a response to an open-ended question regarding the one thing they really needed to know in the first days after surgery, 43% either did not receive information they needed or were not satisfied with what they did receive.

Did you ever receive the proper information?

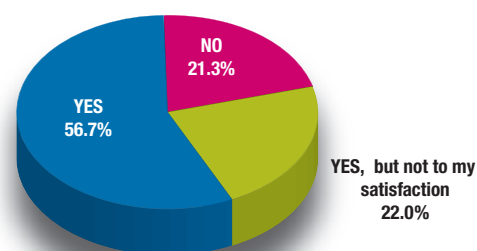


Figure 2

A review of the responses given by those who did not receive the information they needed, or were not satisfied with what they did receive suggests four major themes:

- **Technical:** Questions related to practical aspects of stoma care.
- **Health:** Questions about general or stoma-related health.
- **Adaptive:** Questions about life in general following surgery.
- **Emotional:** Questions about and requests for emotional support.

Overall Contentment and Adaptation to Life with a Stoma

To provide a cursory look at whether satisfactory post-surgical information can be associated with measurable effects on the patient, participants were asked to first choose a response to the following statement "All things considered, I am..."

Five ordinal choices were provided ranging from Very discontent with myself to Very content with myself. Secondly, participants were asked to choose a response to the question, “Have you adapted to living with a stoma?” The response choices to this question were: Not at all, Yes, Somewhat, and Yes, Quite well.

The data suggest that those who were satisfied with the information they received gave higher self-assessments of both their overall contentment (Wilcoxon rank-sum, $p < .0001$, Figure 3) and adaptation to life with a stoma (Wilcoxon rank-sum, $p < .0001$, Figure 4) than those who did not.

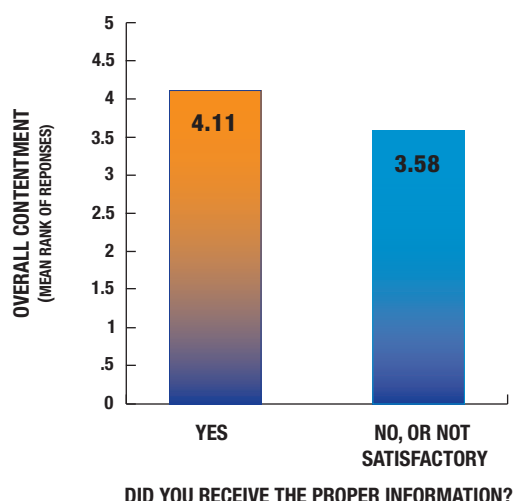


Figure 3

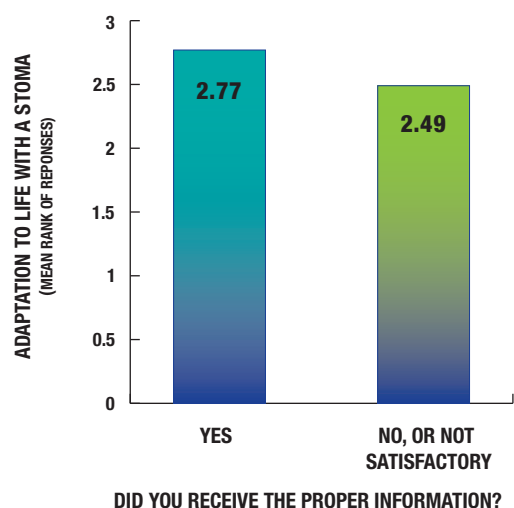


Figure 4

Discussion

The data suggests a positive association between receiving satisfactory post-surgical information and the life attributes of contentment and adaptation. However, this is a cursory investigation and much more needs to be done to establish this relationship.

Shown below are representative samples of the anecdotal responses provided by the respondents. These are presented by the four major themes identified in the data.

Technical

- “How long I should expect a wafer to hold.”
- “More help about showering and finding the right product for me.”
- “How to cope in public when leakage occurs.”
- “How to change my pouch standing up straight.”
- “How to find an ostomy system that worked with my changing stoma.”
- “How to change skin barrier and what to use—paste, rings, etc.”

Health

- “How to regulate my bowels because of all the pain medicines.”
- “I needed to know about hernias.”
- “How long could I live with an ostomy.”
- “How to address skin irritations and rashes.”
- “Wondering if I would live or die.”

Adaptive

- “Will I be able to swim and take hot tubs and play golf?”
- “How much my work, leisure and family time would be affected by having a stoma to deal with.”
- “Impact on sexual relationship.”
- “How would I be able to wear normal clothing again?”
- “What could I eat or not eat to affect the quality and frequency of the stool.”
- “I was worried about dating.”

Emotional

- “How can I live with this?”
- “How normal will my life be and who will be there if I need help?”
- “Why did this have to happen to me?”
- “The depression of losing a part of yourself.”

“That I wasn’t alone.”

“Was overwhelmed by whole thing.”

“I wanted to talk with someone who went through this.”

Conclusions

The quantitative data suggests that patient satisfaction with the information received following surgery may affect subsequent adaptation and life contentment. However, the qualitative information provided by a review of survey responses suggests that the information that patients report not receiving would be routinely disseminated in the course of treatment. In addition, it is notable that 88% of patients overall report having had the assistance of an Enterostomal Therapist after surgery. These results suggest that both the appropriate information and the opportunity for its transmission exist. A study of the process by which information is received and retained by new ostomates may identify interventions that will improve the transfer and application of critical information.

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