

Patients' quality of life and role of the ambulatory in after-surgery stoma care

A single Center experience



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Paolo Magistri*, Maria Rosa Scordamaglia*, Diego Giulitti, Vassilios Papaspyropoulos, Edoardo Eleuteri, Marcello Coppola

University of Rome "Sapienza", "St. Andrea" Hospital, Department o Azienda Ospedaliera Sant'Andrea, Department of General Surgery, Rome, Italy

**These two authors equally contributed to the final edition of the manuscript*

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AIM: *The aim is to assess on which aspects of everyday-life the post surgery stoma-care ambulatory should physically and psychologically assist the patients.*

MATERIAL OF STUDY: *Seventy patients (33 male, 37 female, mean age 68 years) accepted to fill-in the Stoma-QoL questionnaire from January to December 2011. The questionnaire consists of 20 questions addressing different possible discomforts of everyday life.*

RESULTS: *Our results demonstrate that patients with temporary ileostomy have a mean score of quality of life index of 63. Patients with ileostomy demonstrated a higher quality of life score compared to patients with colostomy.*

DISCUSSION: *Our results confirmed that patients with ileostomy have a better perception of quality of life compared to patients with colostomy. Moreover, our data clearly show that patients are more concerned on stoma management compared to the hypothetical prejudice of society.*

CONCLUSIONS: *The stoma care ambulatory have a crucial role, offering to the patient and his/her family an adequate psychological support, and teaching the management of the stoma and the pouch.*

KEY WORDS: Colostomy, Colorectal surgery, Ileostomy, Quality of Life, Stoma care

Introduction

In recent years, the problem of abdominal stoma (enterostomy and urostomy) has become increasingly important. In particular, the main interest is how to improve stoma patients' quality of life ¹. As the disease always represent an alteration of physical and mental state of the patient, the management of a life with the

stoma determines a new social and psychological condition that may dramatically modify the quality of life; the change of identity and body image, together with learning techniques and strategies to manage patient's new life are the most difficult problems to overcome ². The change of body image is often associated with weakness, fragility, impaired social relationships, depression and fear of being marginalized³. This condition affects the patient as a bio-psychosocial unit characterized by biological, emotional, cognitive and relational appearance⁴. The alteration of perception of themselves, a sense of disgust and dirty due to the continuous excretions, and the fear of having to manage embarrassing and uncontrollable situations, can lead to a loss of self-esteem and also sexual activity in patients who were previously active ⁵ Moreover, the patient may express mood disorder

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Correspondence to: Prof. Marcello Coppola, Sapienza, Università di Roma Azienda Ospedaliera "Sant'Andrea", Via di Grottarossa 1035, 00189 Roma, Italy (e-mail: marcello.coppola@uniroma1.it)

ders, for example depression, anxiety, and fear of recurrence or further treatment. Therefore, physical and mental rehabilitation are important for the patients to reach a complete acceptance of themselves, to be autonomous, and for a gradual and complete reintegration into society ⁶. In the past these patients were considered “problematic patients” but now they have real opportunities for reintegration into society, mainly thanks to rehabilitation and appropriate management of the stoma through specialized post-surgery ambulatories.

Here we present the results of our experience in post-surgery intestinal stoma care at Ospedale Sant’Andrea in Rome. The ambulatory for stoma patient started its activity in 2009, medical and nurse staff involved in stoma-care daily assist in-patient during the week, with pre- and post- surgical counseling, and receive discharged patients two days per week. Up to now, 210 patients are assisted in our ambulatory, and the number of admitted patients is increasing monthly, with a rate of 70% increase of patient number each year. Therefore, we decided to submit the patients a quality of life questionnaire, the Stoma-QoL, in order to assess properly which problems are of concern for them ⁷. The aim was to assess on which aspects of everyday life the ambulatory should physically and psychologically assist the patient.

Materials and methods

PATIENTS

Seventy patients (33 male, 37 female, mean age 68 years) accepted to fill-in the questionnaire from January to December 2011. 20% (14) were colostomy patients and 80% (56) were ileostomy patients (75% of them were temporary ileostomy, for a total of 42 patients).

QUESTIONNAIRE

The Stoma- QoL questionnaire is a suitable instrument for both clinical practice and research, which consists of 20 questions addressing different possible discomforts of everyday life. The questionnaire was submitted to each patient who decided to contribute to the study, not later than two weeks after surgery; it was completed anonymously, and the data were then collected and analyzed according to the instruction ⁷. The answers for each item of the questionnaire provide a final score (always 1pt, often 2pt, sometimes 3pt, never 4pt) ranging from 20 to 80: the higher the score, the better the quality of life (Table I).

Table I - Patients’ quality of life perception

Item	Always (%)	Often (%)	Sometimes (%)	Never (%)
1. I become anxious when the pouch is full	66	24	4	6
2. I worry that the pouch will loosen	28	52	4	16
3. I feel the need to know where the nearest toilet is	25	25	36	14
4. I worry that the pouch may smell	33	45	17	5
5. I worry about noises from the stoma	42	33	9	16
6. I need to rest during the day	61	23	9	7
7. My stoma pouch limits the choice of clothes that I can wear	58	15	12	15
8. I feel tired during the day	45	35	18	2
9. My stoma makes me feel sexually unattractive	65	20	2	13
10. I sleep badly during the night	25	43	7	25
11. I worry that the pouch rustles	15	26	27	32
12. I worry that my family feel awkward around me	44	24	9	23
13. I feel embarrassed about my body because of my stoma	35	17	13	35
14. It would be difficult for me to stay away from home overnight	9	26	17	4
15. It is difficult to hide the fact that I wear a pouch	26	34	5	35
16. I worry that my condition is a burden to people close to me	21	11	28	40
17. I avoid close physical contact with my friends	11	14	10	65
18. My stoma makes it difficult for me to be with other people	2	13	14	71
19. I am afraid of meeting new people	2	13	17	68
20. I feel lonely even when I am with other people	4	21	6	69

Results

OVERALL CONSIDERATIONS ON QUALITY OF LIFE

Our results demonstrate that patients with temporary ileostomy have a mean score of quality of life index of 63. Taken together, ileostomy patients have a mean score of 54. Conversely, patients with colostomy have a mean score of 41.

ITEMS OF CONCERN FOR THE PATIENTS

Our results (Table I) show that 66% of the patients always become anxious when the pouch is full, 65% always think that the stoma makes them feel sexually unattractive, 61% always need to rest during the day, 58% always feel like the stoma pouch limits the choice of clothes to wear. Conversely, 48% never think that it would be difficult for them to stay away from home overnight, 65% never avoid close physical contact with friends, 71% never feel like the stoma makes it difficult to be with other people, 68% is never afraid of meeting new people, 69% never feel lonely even when with other people.

Discussion

In this study we analyzed the needs and the problems affecting the everyday life of stoma patients. The abolition of sphincter control and the inability to perform voluntary defecations cause a series of discomforts that may deeply modify patients' social life. For an appropriate management of those patients, it is useful to consider the main differences between ileostomy and colostomy patients and the underlying disease⁸. Patients with ileostomy often have a temporary stoma, and it makes the patient's mental attitude mainly influenced by the idea of being able to heal quickly and obtain again a normal anatomical-functional condition. This frequently led the patient to an optimistic attitude towards the future. Conversely, patients with colostomy are often negative about their life and uncertain about the future. Our results confirmed that patients with ileostomy have a better perception of quality of life compared to patients with colostomy. Moreover, Neuman and colleagues demonstrated that a temporary ileostomy represents significant difficulties, even if it is not perceived as important to overall quality of life compared to the cancer experience⁹. However, we empirically observed an increase of self-esteem and acceptance few months after surgery. Therefore, it would be interesting to study with this same questionnaire the progression of these patients in different moments of their rehabilitation, in order to observe their progression and to assess how to improve the activity of the ambulatory. The stoma care ambula-

tory have a crucial role, offering the patient and his/her family an adequate psychological support, and teaching the management of the stoma and the pouch. In fact rehabilitation is crucial for a complete acceptance and / or adaptation to achieve maximum independence and a gradual and hopefully complete reintegration into society. Moreover, Altuntas and colleagues already demonstrated that group educations is beneficial for stoma patients in the context of stoma therapy units¹⁰. Our results clearly show that patients are more concerned on stoma management compared to the hypothetical prejudice of society. Nowadays, five decades after the pioneering work of Bryan Brooke e Rupert Turnbull¹¹ despite the innovations in surgical technique and materials, stoma complications are still difficult to manage. Peristomal dermatitis is the most frequent complication observed in our stoma care ambulatory, accounting for 90% of the morbidities. However, this is not the only complication found in these years: the retraction of the stoma accounts for the 2%, the prolapse for the 0.5%, the stomite more than 5%. We also observed stoma hypertrophy, fistula, hemorrhage, suppuration and ischemia. These data demonstrate the necessity to develop another instrument to detect not only the psychological effects of living with a stoma, but also the relevance and the role of stoma complications in affecting every day life.

Riassunto

In questo articolo abbiamo riportato i dati relativi alla nostra esperienza nel trattamento post-chirurgico e nell'assistenza ambulatoriale dei pazienti portatori di stomie digestive. Lo scopo di questo studio è di stabilire quali aspetti della vita quotidiana sono maggiormente influenzati da tale condizione e, di conseguenza, in che modo e misura il personale dell'ambulatorio può intervenire per migliorare la qualità di vita dei pazienti. Con questi obiettivi in mente, è stato richiesto ai pazienti di compilare un questionario, lo "Stoma-Qol", composto da venti domande che affrontano molteplici aspetti della vita quotidiana, dall'intimità ai rapporti sociali e familiari. Ciascuna domanda offre quattro possibilità di risposta, ognuna associata ad un punteggio: *sempre* 1 punto, *qualche volta* 2 punti, *raramente* 3 punti, *per niente* 4 punti. Il punteggio finale, che varia da 20 a 80, costituisce l'indice della qualità di vita; più nello specifico, maggiore è il punteggio, più è alta la soddisfazione del paziente. 70 pazienti hanno accettato di partecipare allo studio, ed i dati sono stati raccolti tra Gennaio e Dicembre 2011. I nostri risultati dimostrano come i pazienti con un'ileostomia temporanea abbiano una migliore percezione della qualità di vita, con un indice medio di 63. Tale risultato si contrappone ai risultati dei pazienti con ileostomia (considerati complessivamente) o con colostomia, con indici rispettivamente di 54 e 41.

Inoltre, il 65% dei pazienti riferisce di pensare sempre che la stomia lo renda sessualmente non attraente ed il 58% si sente sempre limitato dalla stomia nella scelta dei vestiti da indossare. Viceversa, per il 71% dei pazienti la stomia non rende per niente difficile stare con altre persone, così come il 68% non si sente per niente spaventato dal conoscere nuove persone. In questo studio confermiamo pertanto i risultati della letteratura precedente, relativamente alla migliore percezione della qualità di vita dei pazienti con ileostomia. Dimostriamo inoltre che i pazienti confidano molto nella famiglia e nelle relazioni amicali e che le maggiori preoccupazioni quotidiane riguardano il rapporto con sé stessi e l'accettazione della nuova immagine corporea. Pertanto, il compito principale dell'attività ambulatoriale deve essere quello di aiutare il paziente e la sua famiglia, fornendo non solo un adeguato supporto psicologico, ma anche insegnando le corrette tecniche di gestione della stomia e prevenendone le complicanze.

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