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## Original Article

# The influence of time on the quality of life of patients with intestinal stoma<sup>☆</sup>



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## ABSTRACT

**Introduction:** the changes caused by ostomy are not restricted to gastrointestinal physiology, but also affect self-esteem and body image, causing changes in family, professional, social and emotional life.

**Objective:** to evaluate the quality of life in ostomized patients.

**Method:** a cross-sectional epidemiological study was carried out in individuals enrolled in the Valeparaibana Ostomy Association. We analyzed thirty individuals divided into two equal groups according to the time of the stoma: group I included individuals with up to two years and, group II, those who had been ostomized for more than two years. A form was applied to evaluate the quality of life (WHOQOL-BREF).

**Results:** the acceptance of physical appearance was observed in 100% of the participants. The performance of daily activities was not limited by the use of the ostomy bag for either group and the mean occurrence of eventual negative feelings in all subjects was 40 to 60%. Regardless of the time of ostomy, those individuals who did not feel supported by family and/or spouse had a lower quality of life, with no observed association with sexual life satisfaction.

**Conclusion:** patients with an ostomy for more than two years have a better quality of life.

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## A influência do tempo na qualidade de vida do paciente portador de estomia intestinal

## RESUMO

**Introdução:** as alterações causadas pela estomia não estão restritas a fisiologia gastrointestinal, afetam também a auto-estima e a imagem corporal, causando mudanças na vida familiar, profissional, social e afetiva.

### Palavras-chave:

Estomia

Ostomizados

<sup>☆</sup> Study conducted at Universidade de Taubaté, São Paulo, Brasil.

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Qualidade de vida  
Colostomia  
Íleostomia

**Objetivo:** avaliar a qualidade de vida em indivíduos ostomizados.

**Método:** realizado um estudo epidemiológico transversal em indivíduos cadastrados na Associação Valeparaibana de Ostomizados. Foram analisados trinta indivíduos divididos em dois grupos iguais de acordo com o tempo da estomia, onde no grupo I encontramos aqueles com até dois anos e no grupo II aqueles que eram ostomizados há mais de dois anos. Foi aplicado o formulário para avaliação da qualidade de vida (WHOQOL-bref).

**Resultados:** a aceitação da aparência física foi observada em 100% dos participantes. A execução das atividades diárias não foi limitada pelo uso da bolsa de estomia para nenhum dos grupos e a média da ocorrência de sentimentos negativos eventuais, em todos os indivíduos, foi de 40 a 60%. Independente do tempo de estomia, aqueles indivíduos que não se sentiam apoiados por familiares e/ou cônjuge apresentavam uma baixa qualidade de vida, não sendo observada relação entre a satisfação na vida sexual.

**Conclusão:** os pacientes ostomizados com mais de dois anos de estomia tem uma melhor qualidade de vida.

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## Introduction

The World Health Organization (WHO) was responsible for the creation of the Study Group on Quality of Life (WHOQOL Group), aiming to promote quality of life assessment from a cross-cultural perspective. The WHOQOL method was developed simultaneously in several countries with cultural and economic differences.<sup>1</sup>

The need for shorter versions that required less time to be completed led the same group to develop the short form of the WHOQOL-100, i.e. the WHOQOL-BREF, which maintained the adequacy of the psychometric properties of the original tool. The WHOQOL-BREF consists of 26 items with the following domains: physical health, psychological health, social relationships, and environment. The answers to all questions of the WHOQOL-BREF are obtained through a Likert scale of five points, in which scores can range from 1 to 5, plus two questions about overall quality of life calculated together to generate a single score, with higher scores representing better quality of life.<sup>1,2</sup>

## Material and methods

This is an epidemiological study of subjects enrolled in the Valeparaibana Ostomy Association (AVO). The research was approved by the Ethics in Research Committee of Universidade de Taubaté (Protocol CEP/UNITAU n. 490/11).

For the assessment of quality of life, patients were analyzed according to time of stoma and were divided into two groups: Group I – patients with stoma for less than two years and Group II – patients with more than two years. The evaluation was performed through interviews applying the WHOQOL-BREF, in 30 subjects, with 15 individuals allocated to group I and 15 to group II. The topics covered were: determining the underlying disease that required the ostomy, quality of sex life, ability to perform daily activities, self-rated quality of life and health, acceptance of physical appearance and frequency of negative feelings such as moodiness, hopelessness, anxiety and depression.

The analysis of the quality of sexual life and satisfaction with health status was performed by means of the answers, which could be: very satisfied, satisfied, non-satisfied, dissatisfied, neither dissatisfied nor very dissatisfied.

The self-assessment of quality of life was assessed by a score ranging from 1 to 5, in which score 1 is considered the worst and 5 the best quality of life.

The performance of activities of daily living was divided into limited and not limited. Regarding the frequency of negative feelings, the participants had the following response options: never, sometimes, often, very often, and always. The final assessment of quality of life was performed by adding the points in the WHOQOL-BREF questionnaire, concluding that individuals with the highest scores had better quality of life.

## Results

The ages of the subjects ranged from 23 to 81 years, whereas for females the mean age was 48 years and for males, 54 years. There was a predominance of females, representing 70% of the sample (21/30). Regarding the type of ostomy, the group was also divided into ileostomy and colostomy. The causes for ostomy were colorectal cancer (15/50%), Inflammatory Bowel Disease (9/30%), including Crohn's disease (6/20%) and Ulcerative Colitis (3/10%), followed by Familial Adenomatous Polyposis (3/10%) and traumatic bowel perforation (3/10%).

The sum of the scores of the WHOQOL-BREF questionnaire totals 110 points. It was observed that 50% of the subjects in both groups had a score >90, whereas group I had the lowest scores in 20% of the patients (3/15), scoring less than 80 points, while subjects in group II did not have scores <80. The support of the spouse, family and friends influenced the increase in the final score, as individuals who did not feel supported had a lower final score. Regarding sexual life, 60% (18/30) reported satisfaction in both groups, whereas in group I, 20% (3/15) were dissatisfied and 20% (3/15) very dissatisfied. In group II 40% (6/15) were dissatisfied. This review did not observe a direct association between sexual life satisfaction and quality of life.

At the QoL self-assessment, in group I, 40% (6/15) of subjects scored 5 points and 60% (9/15) less than 5 points. In group II, 60% (9/15) scored 5 points, 20% (3/15) scored 4 points and 20% (3/15) 3 points, demonstrating an improvement in quality of life according to time. Acceptance of the current physical appearance was observed in 100% of the participants.

In groups I and II, 60% (18/30) were fully satisfied with their health status, whereas group I had 20% (3/15) of dissatisfied individuals. The remaining patients in both groups were neither satisfied nor dissatisfied. The performance of activities of daily living was not restricted by the collector bag in any of the subjects.

Regarding the frequency of negative feelings in group I, 40% (6/15) denied and 60% (9/15) reported the occurrence of such feelings in some situations, a fact that occurred inversely in group II.

## Discussion

The main situations which require the performance of an ostomy are: trauma, colorectal cancer, inflammatory bowel disease, acute diverticulitis, familial adenomatous polyposis, megacolon, anal incontinence and severe infections of the anoperineal region<sup>3</sup>; it may also be employed in intestinal transit diversion due to pressure sores.<sup>4</sup>

The changes caused by the ostomy are not restricted to gastrointestinal physiology, but also affect self-esteem and body image, causing changes in the professional, family, social and emotional life.<sup>5,6</sup> After the ostomy is performed, the patient goes through the emotional stages of denial, anger, bargaining, depression and acceptance. This occurs because human beings construct, throughout life, their body image, which is related to habits and the environment in which they live, meeting their needs.<sup>3</sup> Disorders of sexual function have two origins: physical or emotional. The surgery performed may cause some physiological disorders: in males, such as the reduction or loss of libido, decrease or absence of erection capacity, abnormal ejaculation, and in females, the reduction or loss of libido, dyspareunia, among others.<sup>5</sup>

The emotional aspect is due to changes in body image, especially due to feelings of being ashamed in the presence of the partner, feelings of being dirty and disgusting, generating the fear of being rejected.<sup>6</sup> Therefore the sexual function disorders can be either subjective, related to the concept of self-image order, or organic, resulting from neurological injury during the surgical procedure.<sup>7</sup> Denial and feelings of depression may be more frequent in the initial phase, due to the shock of having been ostomized, or reaction to the severity of the clinical condition. In this sense, the individual often refuses to talk about it and is prone to isolation. After the initial period of adjustment for ostomized individuals, most of them lead normal lives. The present study observed that although there were no large discrepancies between the responses,

individuals with longer time of ostomy showed a greater degree of life satisfaction. The adaptation of the ostomized individual to a life new condition is a long and continuing process, being related to the underlying disease, degree of disability, individual values and personality.<sup>8</sup>

Sexuality is an aspect that is rarely addressed by health professionals, with the difficulty addressing the subject found in both health professionals and ostomized patients.<sup>7</sup> This is a matter of extreme importance, as it was the topic that got the lowest scores and the highest degree of dissatisfaction. The changes that occur in this area are so deep that for ostomized individuals the sexual activity becomes secondary and may be replaced by feelings of love, affection, companionship, religious activities and others.

It was demonstrated that family support and personalized professional care are crucial for the individual to adapt to the new condition and consequently, to have a better quality of life. Sexual activity and social support are crucial to achieve the best scores, disclosing the importance of social support that starts with the family, and of sexuality, for a better performance in the area of interpersonal relationships.<sup>9</sup>

## Conflicts of interest

The authors declare no conflicts of interest.

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