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Original Research Article

Evaluation of the quality of life of adult patients with digestive stomas in Congo-Brazzaville: a multicenter study

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ABSTRACT

Background: Digestive stomas remain a surgical option indicated for various gastrointestinal pathologies. However, living with a stoma can significantly impair a patient's quality of life. The objective of this study is to evaluate the perceptions of adult Congolese patients with digestive stomas regarding their quality of life.

Methods: This multicenter, descriptive, and prospective study was conducted from 01 August 2019 to 01 November 2020. It included patients aged 18 years and older living with digestive stomas. They were consecutively recruited from seven hospitals in Congo-Brazzaville. Quality of life (QoL) was assessed using the Stoma-QoL questionnaire.

Results: In total, 56 patients (39 men and 17 women, male/female ratio of 2.29), aged. A mean age of 42±17 years (range: 18–75 years) participated in the study. All ostomy patients reported a change in body image. They felt self-conscious about their appearance and significantly affected their physical attractiveness. Nearly all patients (96%) experienced negative psychological repercussions (depression, anxiety). Most of them (87%) had stopped their professional or daily activities due to the ostomy. The quality of sexuality was impaired for both patients and their partners. Those close to the patients experienced anxiety and spent more time at home.

Conclusion: The daily lives of ostomy patients are significantly disrupted in every way. It is therefore essential to provide more support to ostomy patients to help them better adapt to daily life. To this end, a multidisciplinary approach involving surgeons, ostomy therapists, and psychologists is crucial to improving their quality of life.

Keywords: Digestive stoma, Colostomy, Ileostomy, Adult, Quality of life, Congo-Brazzaville

INTRODUCTION

Digestive stomas are temporary or permanent palliative surgical procedures that involve bringing a segment of the healthy digestive tract to the skin, either upstream or downstream of an injury, either to provide supplemental nutrition, to decompress and drain an obstructed digestive tract, or to protect a digestive anastomosis by temporarily diverting intestinal flow.[1] Their locations are diverse, namely: the esophagus, the stomach, the jejunum, the ileum and the colon. Stomas can affect the quality of life of patients who have them, as well as their immediate family and caregivers. Indeed, after surgery, the individual's quality of life and daily activities are compromised by the loss of control over bowel movements. and possible leaks from the bag. The concept of quality of life integrates, in a complex way, the interactions between the patient and their environment.

Although often considered a life-saving medical solution, digestive stomas cause physical and psychological harm to patients. They lead to numerous changes, such as altered body image, a disruption in the individual's mental representation of their own body, sometimes perceived as a feeling of being amputated or damaged, thus causing a decrease in self-esteem, feelings of worthlessness, and depressive reactions.[1] Professionally, patients may experience a reduction in their workload or lose their jobs. Sexually, the psychological difficulties and changes in body image caused by the stoma influence the desire for sexual activity.[4]

Although they are performed less and less frequently, digestive stomas remain relevant in visceral surgery.[5] Nearly two million people worldwide live with a stoma, including approximately 80,000 people in France.[6]

In Congo, given the lack of data on the quality of life of ostomy patients, we undertook this study, the overall objective of which is to evaluate the quality of life of adult patients with digestive stomas in relation to their sociodemographic and clinical characteristics. The specific objectives are: to establish the impact of digestive stomas on body image, psychological profile, socio-professional life, and sexuality; and to determine the potential changes in the lived experience and perceptions of adult patients with digestive stomas by their families and friends.

METHODS

Type, framework and period of study

The study, which is multicenter, prospective, descriptive and analytical, it took place from 01 August 2019 to 01 November 2020 in three cities in Congo-Brazzaville. It involved the surgical services (digestive or general) of seven hospital structures: the University Hospital Center and four reference hospitals in Brazzaville (political capital); the reference hospital of the city of Oyo located in the northern part of Congo; one of the four reference hospitals in Pointe-Noire (economic capital).

Study population and sample

Target population consisted of all adult patients with temporary or permanent digestive stomas. The sampling method used in the study was systematic sampling. All patients meeting the inclusion criteria during the study period were included. The selection criteria resulted in the consecutive creation of a sample of 56 patients.

Inclusion criteria

The study included patients aged at least 18 years regardless of sex; living with a stoma for at least one month; having consented to participate in the study.

Exclusion criteria

It excluded patients with a history of psychiatric disorder likely to limit their ability to answer questions; with at least one history of a disabling pathology (hemiplegia, paraplegia, cancer other than of the digestive system); lost to follow-up.

Data collection

Initially, the patient's sociodemographic and clinical data were collected from patient records in the surgical departments of various hospitals. Subsequently, the survey focused on the quality of life of ostomy patients. For this purpose, the survey tool was a questionnaire centered on the two dimensions of patient quality of life: personal factors and social factors. It comprised 20 questions, divided into two sections: self-image perception (body image), psychological consequences, socio-professional impact, sexuality, and the experience of those close to the patient. The questionnaire, formulated in French, was developed based on the revised and validated version of the stoma quality of life (Stoma-QoL) questionnaire by Prieto et al.[7] It demonstrated strong internal consistency, with Cronbach's alpha values of 0.94 for personal factors and 0.87 for social factors, values that attest to the questionnaire's reliability. The questionnaire underwent pretesting with seven patients not included in our sample. Preliminary contact with the respondents allowed us to explain the purpose and objectives of the study. Subsequently, when the questionnaire was distributed, they were instructed on how to complete it and were informed of the confidential nature of the study.

The affirmative responses of the study participants regarding the presentation of anxiety were subsequently assessed by a neuropsychiatrist based on the diagnostic criteria of the MINI (Mini International Neuropsychiatrics Interview)-DSM IV-TR.

Data analysis

The analyses statistics were compiled using Microsoft Excel ® 2023 and then processed and analyzed using predictive analytics software (PASW) statistic 18.0 software. Categorical variables were analyzed using absolute frequencies and proportions, while quantitative variables were presented as mean ± standard deviation, minimum and maximum values.

The comparison of two means was performed using Student's t-test. Indicators of the quality of life of ostomy patients (body image, psychological effects, social relationships, professional life, sexuality, relationships with their social circle) were assessed based on their responses to the various questionnaire items. Pearson's chi-squared test was used to compare two percentages of responses, while the Sokal-Rohlf test was required for more than two percentages. The study of the effects of ostomies on social interactions between people living as couples versus widowed and single individuals used Fisher's exact test. The statistical significance level for the tests was set at 5%.

Ethical considerations

The study adhered to rigorous standards throughout its implementation. The research project was reviewed and approved by the Research Ethics Committee in Health Sciences of the General Delegation for Scientific and Technological Research of the Republic of Congo.

RESULTS

Sociodemographic aspects

The mean age was 42±17 years (range: 18–75 years); the 18–29 and 30–54 age groups were the most represented. There were more men (69.7%) than women (30.3%), with a sex ratio of 2.2. The distribution of patients by age and sex is illustrated in Figure 1.

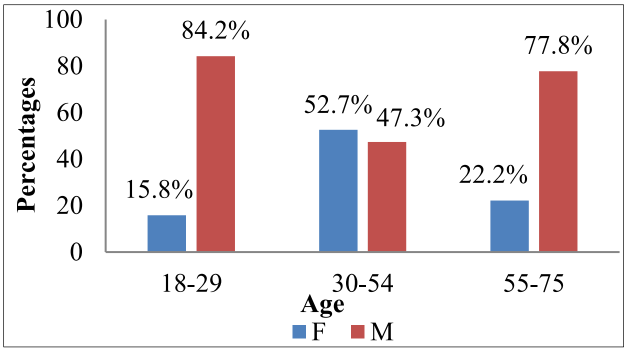

Figure 1: Distribution of patients according to age and sex.

Regarding professional status, 22 patients (39.29%) belonged to the category of unskilled workers, and 13 patients (23.21%) were skilled workers. Retirees and the unemployed comprised 12 patients (21.43%). In our series, 28 patients (51.79%) had a middle socioeconomic level, and 27 (48.21%) a low socioeconomic level. Of all the patients with stomas, 31 (55.36%) lived with a partner, 18 (32.14%) were single, and 7 (12.5%) were widowed.

Clinical aspects

All patients were physically independent prior to the stoma. In most cases, the patients had not received any preparation or psychological support. The rates of colostomies and ileostomies were respectively 50% (28 cases), 48.2% (27 cases) (Figure 2) and that of jejunostomy was 1.8% (1 case). Of these 56 stomas, 49 were temporary (87.5%; $p<0.01$) and 7 were permanent (12.5%). Ileostomies were all temporary, while colostomies were temporary in 21 cases (75%; $p<0.05$) and permanent in 7 cases (25%). Peritonitis due to intestinal perforation was the most represented indication (n=20; 35.7%), followed by colonic or colorectal tumors (n=19; 33.9%) (Table 1). Of all patients with stomas, only 16 (29%) wore conventional pouches. The others (n=40; 71% - $p<0.05$) remaining, were carrying unconventional pouches such as bags and various linens.

Twenty-seven patients (48.2%) experienced postoperative complications related to their stoma. These complications, which affected ileostomy patients more frequently (n=25; 44.6%), consisted of skin irritation lesions in 24 patients (42.9%) and stoma prolapse in one patient (1.7%). Malnutrition was associated with skin irritation lesions in 13 patients (23.2%). Among the 28 patients with colostomies, only 2 (3.5%) experienced complications: prolapse in one patient and stoma retraction in the other.

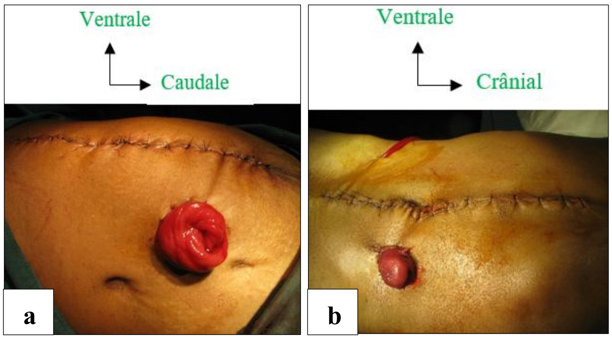

Figure 2: (a) Ileostomy and (b) colostomy.

Source: Digestive Surgery Department, University Hospital, from Brazzaville

Quality of life

Body image

All patients with digestive stomas reported a significant deterioration in body image. The disturbance was significant in 34 patients (60.7%; $p<0.005$) and very significant in 4 patients (7.1%). All reported feeling self-conscious about their appearance and greatly affected by their physical attractiveness. They also felt diminished in terms of their gender (male and female), less sexually attractive, and fearful of those around them because of the stoma. They were dissatisfied with their bodies and felt that the treatment had left them feeling less whole.

Table 1: Distribution of patients according to indications.

Indications	Effective	Percentage (%)
Peritonitis due to intestinal perforation	20	35.7
Colorectal tumor	19	33.9
Intestinal obstruction	14	25
Penetrating abdominal wound	1	1.8
caustic lesion	1	1.8
Rectovaginal fistula	1	1.8
Total	56	100

Psychological impact of a stoma

Although seven patients (12.5%) were aware of the stoma before their treatment, 49 (87.5%; $p<0.01$) had not been informed. Almost all patients (n=54; 96.4% - $p<0.001$) reported psychological distress following the stoma. They stated that they were upset upon receiving the diagnosis or discovering the stoma, experiencing feelings of sadness, anxiety, disappointment, and sometimes anger. Only 2 patients (3.5%) reported having an apparently normal reaction. Depression was reported by 50 patients (89.2%; $p<0.001$). It was mild in 18 patients (32.1%), moderate in 14 patients (25%), moderately severe in 13 patients (23.2%), and severe in 5 patients (8.9%). All patients reported experiencing anxiety. The disorder was mild in 33 patients (58.9%), moderate in 18 patients (32.1%), and severe in 5 patients (8.9%). However, the neuropsychiatrist's assessment of anxiety using the MINI-DSM-IV revealed that only 44 patients (78.5%) presented with this psychiatric disorder.

As for the major problems encountered by all patients, they were essentially represented by: the inability to relax, the difficulty falling asleep, the appetite problems, the difficulty concentrating, the fear of the worst, despair and the fear of dying.

Social relations and the stoma

Fifty-two patients (92.9%, $p<0.001$) reported that their stoma had affected their social relationships: 44 patients (78.5%) stated that they now avoided social circles because of their stoma, 18 patients (32.1%) felt abandoned by their social circle, and according to 9 patients (16.7%), their stoma had permanently ended their social relationships. Single and widowed individuals (n=25) appeared to experience 1.7 times more difficulties with family interaction ($p<0.05$).

Impact of a stoma on professional life

During the study, all patients with stomas reported an impact of the stoma on their professional and/or daily activities. Among them, 49 (87.5%) had completely suspended their activities, and in 7 patients (12.5%), activities were reduced.

Sexuality and ostomy

The couple relationship was assessed in only 31 patients, the other 25 being single or widowed. In the single patients, communication within the couple was not impaired. Regarding sexual desire and activity, 29 (93.5%) reported a decrease in sexual attraction and felt sexually inactive. The stoma made sexual intercourse uncomfortable. Concerning the sexuality of the partner, 30 partners were included in the study. Among them, 28 partners (93.3%) reported that the stoma made their partner less attractive, and 29 partners (96.6%) stated that the stoma had impaired the quality of the couple's sexual relationship.

Surroundings and stoma

The patients' support network consisted of their spouse, brother, or sister. Responses from all study participants revealed that all members of the support network had been negatively affected by the stoma; they were worried, embarrassed, and anxious, and had increased their time spent at home, regularly taking on stoma care themselves.

DISCUSSION

Epidemiological aspects

We noted a male predominance: 39 males (69.7%) versus 17 females (30.3%). Similar results have been reported in most studies.8-10 The male predominance may be explained by the higher prevalence in men of peritonitis, colorectal cancer, or intestinal obstruction, the main indications for digestive stomas.

The average age in our series was 42±17 (ages range: 18-75 years), the 18-29 and 30-54 age groups were the most represented. Our results are comparable to those of other authors.[8,10,11]

Clinical aspects

Eighty-seven percent (87.5%) of ostomy patients had not been informed or prepared for the stoma before their treatment. Furthermore, no patient received psychological support during their stoma care. The main reason for our observations lies in the impossibility of preoperative psychological preparation. However, it should be noted that the psychological dimension is very poorly integrated into patient care in the Congolese setting; consequently, psychological support is very rarely provided in our hospitals.

Therapeutic aspects

We observed 50% colostomies, 48.2% ileostomies, and 1.8% jejunostomies. Our results are comparable to those of Sanogo et al in Mali, but differ from those of Rasoanambinintsoa in Madagascar and Bail et al in France.[10,12,13] This difference can be attributed to the wide variability in the indications for digestive stomas.

Digestive stomas were more often temporary (87.5%) than permanent (12.5%). Ileostomies were only temporary. The results of our study are consistent with those reported in the literature.[12,14,15] These differences can be explained by the fact that the indications for colostomies, which are primarily colon and/or rectal tumors, generally make preserving intestinal continuity impossible due to the removal of the sphincter mechanism or the presence of irreparable downstream lesions. Therefore, the indications for ileostomies very rarely prevent the preservation of digestive continuity.

The indications in our study were primarily peritonitis due to intestinal perforation (35.7%), colonic or colorectal tumors (33.9%), and intestinal obstructions (25%). Our results show some similarities with those of Guiet et al in Mali.[15] However, compared to other studies differences are observed, due to the difference in samples but also to the great variability in the indications for digestive stomas.[12,16]

Regarding the type of stoma bag, while 29% of patients had conventional bags, 70.9% could not afford them. These latter patients resorted to traditional materials such as bags, and various cloths. This trend can be directly linked to the patients' socioeconomic status, which was middle for 51.8% of patients and low for 48.2%. Thus, due to a lack of sufficient and consistent financial resources, the vast majority of patients could not obtain a conventional stoma bag.

Regarding postoperative complications related to the stoma, in our series they were found in 27 patients (48.2%). In this group, nearly 9 out of 10 patients (n=25; 92.6%) had an ileostomy, with 25 cases (44.4%). Our results are comparable to those of some African authors.[13,14] However, they present points of divergence with other authors from Western countries.[17] These differences are attributable to the more advanced means of care for ostomy patients in these countries and to the existence of ostomy therapists who properly care for these patients.

The most common type of complications in our series was cutaneous complications (42.9%). Fotso et al in Côte d'Ivoire reported similar results, stating that these cutaneous complications in patients with ileostomies are attributable to intestinal fluid.[16] Furthermore, according to Pittman et al the most common complication was skin suppuration, occurring in 40% of cases.[14] These differences may be due to the wide variability in indications and complications associated with stomas.

Quality of life

Regarding the degradation of body image, in our series All patients with digestive stomas experienced a decline in self-image or body image. This decline was significant in more than half of the patients (60.7%) and more severe in 7.15%. Indeed, patients felt self-conscious about their appearance and were greatly affected in their physical attractiveness. They emphasized feeling diminished in their gender (male or female), less sexually attractive, and fearful of those around them because of the stoma. They were dissatisfied with their bodies and felt that the treatment had left them feeling less whole. Faury et al in their series in France, also reported a significant alteration in body satisfaction in 31 patients with temporary stomas.[18] We and these authors attribute this to the perceived bodily change when transitioning from an anatomically hidden orifice to a visible one on the abdomen, whether temporary or permanent. Indeed, in our society, individuals feel that excretion is a highly intimate function that they can best manage at home in a familiar environment. This perception can be linked to the notion of the harmful nature of "dirt," both for oneself and for others. Patients often express fear, even terror, of experiencing leaks, of becoming soiled, and of smelling bad. These various factors could be the source of significant shock or trauma and could lead patients to fear being an object of disgust and no longer being accepted by those close to them.

Furthermore, in our study, all patients experienced psychological distress following the stoma procedure. The vast majority of patients (96.4%) were deeply affected upon receiving the diagnosis or discovering the stoma, experiencing feelings of sadness, anxiety, disappointment, and sometimes anger. Only 3.5% had no significant reaction. This result may be attributed to the lack of, or insufficient, prior psychological preparation of patients for the stoma procedure. In some cases, stomas are performed as emergencies and even intraoperatively while the patient is already asleep, rarely giving the surgeon the opportunity to prepare the patient for the procedure.

The patients suffered from depression and anxiety according to the assessment scales used.

This finding was also reported by Anaraki et al in Iran, who found that 70% of patients presented with symptoms of depression.[19] However, Faury et al in France, Knowles et al in Italy reported much lower rates.[18,19] In the first study, the rate of anxiety disorders was of 19.3%, and of depressive symptoms of 4.3%. The authors of the second study note that 10% of participants experienced anxiety, and 16% depression. This difference could be explained by the management of ostomy patients, which, in developed countries, has seen significant progress in recent decades with the implementation of a therapeutic pathway: ostomy therapy. Through this approach, patients benefit from preoperative preparation as well as psychological support and care. This would limit the incidence of symptoms related to psychological distress.

Regarding social relationships, in our study 92.8% of patients felt that their stoma had affected their social interactions. In fact, 78.5% now avoided their social circle because of the stoma, 32.1% felt neglected by their social circle, and 16.7% believed that the stoma could permanently end their social relationships. These findings are linked to the fear experienced by people with stomas of being told their body has changed, or of those around them reacting with withdrawal, fear, or disgust.[20,21] This could lead to a "marginalization reaction," partly related to the attitudes of the people with stomas. When people with stomas feel rejected or isolated, they withdraw from their social circles.[22] Regarding the additional difficulties experienced by single or widowed people with stomas, as observed in our study, this is linked to the challenge of adapting to a new situation.[23,24]

Furthermore, all patients reported that the stoma had an impact on their professional and/or daily activities. More than half of them (87.5%) had completely suspended their activities, while only 12.5% had seen their activities reduced. Feddern et al in Denmark, in a series of patients with permanent digestive stomas, reported that 50% of patients had modified their lifestyle and that the stoma limited their daily activities.[25] The loss of control over fecal or gas retention could explain the abandonment of some activities.[26] In other cases, the stoma was simply not practical or comfortable with certain activities.[27]

Regarding the sexuality of ostomy patients, our results show that among the 53 patients, the other 3 were widowed and had experienced no real desire for sexual activity since the death of their spouse. Of the 53 patients, 98.11% reported a decrease in sexual attraction and felt sexually inactive. The stoma appears to make sexual intercourse uncomfortable. Our results are comparable to those of Anaraki et al in Iran, who reported a rate close to 70% of sexually dissatisfied patients.[19]

Xiaomei et al in China, In their study of the sexual experiences of 75 Chinese patients living with a stoma, they found that these patients suffered from sexual dysfunction and that numerous factors influenced their quality of sexual life.28 This finding is consistent with that of Fang et al in China, but at a lower rate, 63.1%.[29] These results may be explained by the decrease in self-confidence among ostomy patients, following their altered body image.[30,31] The ostomy patient also expresses fear of leakage, fear of soiling and smelling bad, and fear of being seen as an object of disgust. He thus withdraws into himself and loses his desire for sexual activity.

Regarding the sexuality of partners, of the 30 partners interviewed in our study, 93.3% stated that the stoma made their partner less attractive, and it impaired the quality of the couple's sex life in 96.7% of patients. This result is comparable to that of Çakmak et al in Turkey, who, in a series of 56 partners (of both genders) who were sexually active before their partner's surgery, reported a rate of 53.5% of partners who became sexually inactive.[32] One explanatory factor is that the partner of the person with a stoma may experience reactions of fear or disgust related to the fear of odors or the stoma in general. They may experience anxiety and stress from this new lifestyle with the stoma and, in some cases, may exhibit symptoms related to psychological distress. This impact then diminishes the desire for sexual activity.

Finally, regarding the perception and experience of those around them, all family members emphasized being negatively affected by their close relative wearing a stoma bag; they are worried, embarrassed, and anxious. They have increased the time they spend at home, regularly taking on the responsibility of providing support and care for the stomas. Çakmak et al in Turkey, they also noted that 46.4% of caregivers had increased the time they spent at home, thus altering their activity schedules.[32] In African countries, particularly in the Congo, the lack of nurses specializing in stoma care is undoubtedly the most obvious explanation for the change in work schedules or lifestyle in general for the immediate circle of ostomy patients. These specialists, known as stoma therapists, who are present in developed countries, work to promote, in particular, the autonomy of ostomy patients and their families in managing their stoma. In the absence of these specialists, the families of ostomy patients quickly become involved in the care and support process, thus increasing the time spent at home.

In short, ostomy patients are not the only ones who suffer from isolation. Their loved ones who support them daily are also ostracized or at least suffer the consequences. Furthermore, while ostomy patients struggle to adjust to the stoma and social relationships, their partners may also suffer from anxiety and depression.[33]

Limitations and strengths

The interpretation of our results must take into account certain limitations. The first limitation stems from the small sample size, which reduces the statistical power of the observations and makes it difficult to extrapolate the results to the general population. The second limitation is related to the scarcity of African data on the quality of life of patients with digestive stomas. The third limitation relates to the absence of other relevant data. Finally, the fourth limitation lies in the lack of a consensus-based and specific score for assessing the quality of life of patients with digestive stomas.

Despite these limitations, our multicenter study, the first of its kind in our field, relied on a rigorous methodology, using a validated data collection instrument, robust evaluation tools and statistical analyses, ensuring the reliability of the data.

CONCLUSION

Digestive stomas represent a medical and social problem due to the numerous difficulties they cause in daily life. As in other countries, both in Africa and the West, the quality of life of patients with digestive stomas is significantly impaired. The creation of a stoma leads to a significant alteration in self-image or body image. Once the operation is performed, the emotions expressed by those with stomas remain predominantly negative. Most people with stomas stop their professional and daily activities, considering the stoma incompatible with carrying out their various tasks. The sexuality of people with stomas is generally disrupted due to the decrease in self-esteem caused by the bodily changes resulting from the stoma. Family members are not spared the consequences of the stoma; their work or activity schedules may undergo significant changes in order to care for the person with the stoma. It is therefore necessary to pay more attention to people with ostomies to help them better adapt to daily life. To this end, a multidisciplinary approach involving surgeons, ostomy therapists, and psychologists is essential to improve their quality of life.

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