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Quality of Life After Ostomy Formation: Perspectives of Patients and Families

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Abstract

Introduction: Ostomy surgery, often required due to severe health conditions such as cancer and inflammatory bowel diseases, significantly affects the lives of patients and also impacts their family members. This surgery, involving creating surgical openings in the gastrointestinal tract, necessitates significant lifestyle adjustments and complex care, often leading to profound psychological and social challenges for both patients and their caregivers.

Aim: To examine the quality of life of patients with a stoma and to investigate how the stoma affects the quality of life of the families of patients with a stoma.

Methods: This cross-sectional study involved 70 participants with different types of stomas including urostomies, colostomies, and ileostomies, surveyed from September 1 to October 28, 2023. A specially designed questionnaire was used to collect data on the self-reported quality of life of stoma patients and their family members.

Results: The majority of the participants were over the age of 65, with 42.9% having colostomies and 35.7% ileostomies. A significant 91.2% self-reported depression post-stoma formation, highlighting the psychological impact of stoma. Adjustments to family life were necessary for 68.6%, indicating the substantial effect on the family's daily routine and emotional status.

Conclusion: Stoma formation adversely affects patients' mental and social well-being, with substantial emotional and financial impacts on families. The study highlights the critical need for comprehensive postoperative support that encompasses both psychological counseling and educational interventions tailored to patients and their families to alleviate the multifaceted burdens of living with a stoma.

Keywords: Ostomy, Quality of Life, Family

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Introduction

Ostomy surgery, which involves creating a surgical opening between a hollow organ and the body surface or between two hollow organs, represents a critical medical intervention often necessitated by severe health conditions such as cancer and inflammatory bowel diseases. Despite the significant advancements in medical treatment, for many individuals, undergoing this life-altering procedure is the only remaining option (1). This intervention profoundly affects not just the physical well-being of patients but also their psychosocial health and, by extension, the lives of their family members.

The placement and type of ostomies, strategically positioned at various points along the gastrointestinal tract, are determined by the underlying medical reasons necessitating the surgery, such as cancer or inflammatory diseases (2). Common types of stomas include colostomies and ileostomies, with each type requiring different management strategies and having distinct implications on the patients' daily lives. Whether managing liquid or solid waste, colostomies may be temporary or permanent, depending on the individual's medical condition and the goals of care (2).

Living with a stoma involves significant lifestyle adjustments and can lead to substantial psychological distress. Patients often face challenges such as changes in stool or urine patterns, loss of peristaltic control, and altered body image. These physical changes frequently contribute to psychological issues, including reduced self-esteem and confidence, depression, stigma, and fear, all of which can drastically diminish a patient's quality of life (1). The necessity for effective management strategies becomes paramount to support both patients and their families through these transitions.

The role of healthcare professionals, particularly nurses and medical technicians, is absolutely crucial in the context of ostomy care. They play a pivotal role in improving the quality of life for ostomy patients by meticulously addressing comprehensive care needs, actively reducing complications, and ultimately enhancing overall patient well-being (3). Their expertise is essential not only in routine care but also in managing early complications associated with stoma formation, such as necrosis, bleeding, and retraction. These complications, which are typically linked to the technical aspects of surgery, can severely impact the patient's recovery process and prolong the duration of hospital stay, emphasizing the need for skilled clinical intervention (4,5).

Moreover, the classification of intestinal stomas significantly influences clinical approaches and decision-making processes. Ileostomies, for example, are often temporarily formed from the ileum section to protect distal anastomoses or manage distal intestinal dysfunction. In more severe cases where the entire colon must be removed, permanent ileostomies become necessary. Such surgeries can lead to significant absorption issues and potential nutritional and metabolic complications, further complicating the patient's post-operative care and adjustment (6,7).

The impact of a stoma, however, extends far beyond the individual patient. Family members often assume new caregiving roles, adapting their daily lives to support their loved one. This dynamic shift can profoundly influence the family's overall quality of life, adding emotional, physical, and financial strains that may not have been anticipated. Consequently, it underscores the necessity for healthcare professionals to provide comprehensive support that encompasses not only medical and technical care aspects but also psychosocial support. Addressing both the physiological and psychosocial challenges faced by stoma patients and their families is essential to enhance outcomes and ensure a higher quality of life. Such comprehensive care includes facilitating support groups, providing educational resources, and ensuring regular follow-up care to monitor both physical and emotional health (8-11).

Aim

To examine the quality of life of patients with a stoma and to investigate how the stoma affects the quality of life of the families of patients with a stoma.

Methods

The study was conducted among patients with stomas, including urostomies, colostomies, and ileostomies. The research encompassed 70 participants and was conducted using a cross-sectional method from September 1 to October 28, 2023.

Data were collected using a survey questionnaire specifically designed for the purpose of this study. Participants who agreed to take part in the research were informed about the study's objectives and the anonymity of the survey responses. Participants had the option to withdraw from completing the questionnaire at any point during the study. The research was approved by the Ethics Committee of the Zagreb Health Center, CLASS: 012-30/23-01/004 and REF.NO: 251-510-03-20-23-24.

The questionnaire was divided into three sections to comprehensively address the study objectives. The first section collected sociodemographic information, including participants' age, educational attainment, employment status, place of residence, and marital status. The second section focused on evaluating the quality of life of individuals living with stomas, while the third section explored the impact of stoma formation on the quality of life of their family members.

Statistical analysis of the data was performed using Microsoft Office Excel. The results are presented graphically, and descriptive statistical methods were employed.

Results

In the study, the majority of participants were aged over 65 years, comprising 39 individuals (55.7%). A total of 18 participants (25.7%) were aged between 56 and 65 years, while 13 participants (18.6%) were aged between 46 and 55 years (Figure 1).

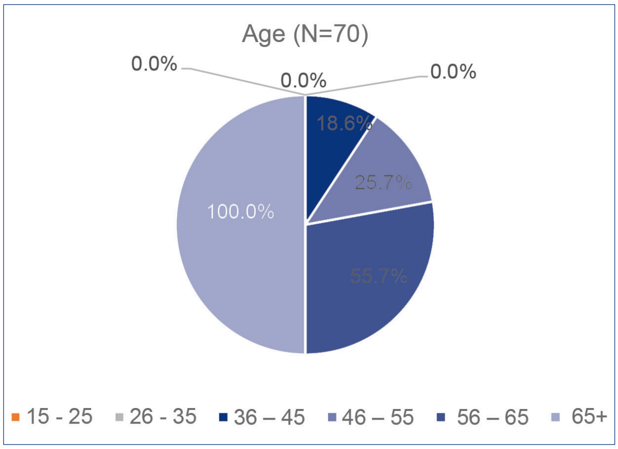

Figure 1. **Age**

The distribution of stoma types among participants showed that 30 individuals (42.9%) had a colostomy, 25 (35.7%) had an ileostomy, and the smallest group, 15 participants (21.4%), had a urostomy as shown in Figure 2.

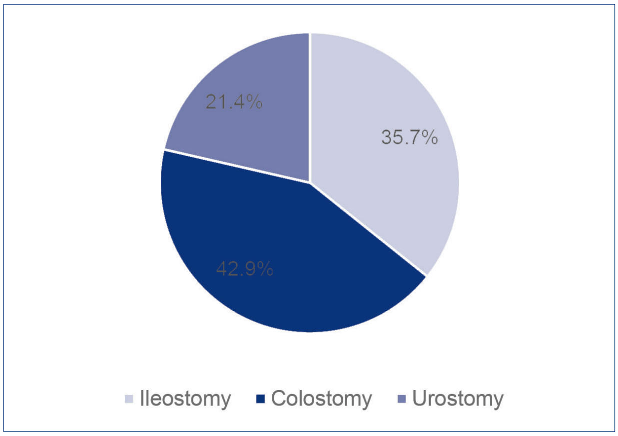

Figure 2. **Distribution of participants depending on the type of stoma**

Participants were asked whether they felt prepared for life with a stoma. Only 2 participants (2.9%) reported feeling prepared for life with a stoma, whereas the vast majority, 67 participants (97.1%), indicated that they were unprepared. One participant did not respond to this question. These findings are presented in Figure 3.

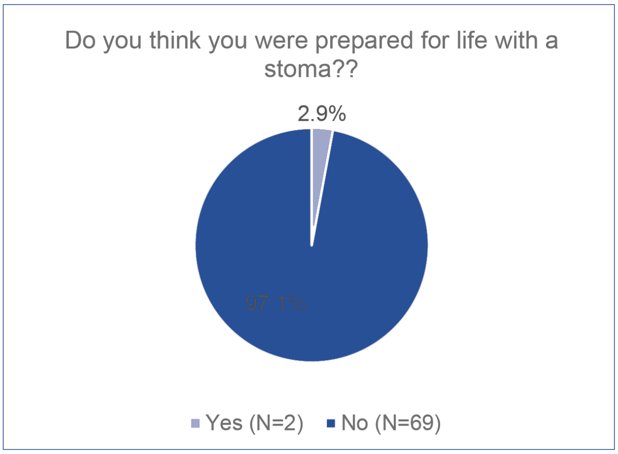

Figure 3. **Distribution of participants according to answers about readiness to live with a stoma**

The study also aimed to examine the prevalence of depression following stoma formation. A significant proportion of participants, 62 individuals (91.2%), reported experiencing depression after stoma formation, while only 6 participants (8.8%) reported no such experience (Figure 4).

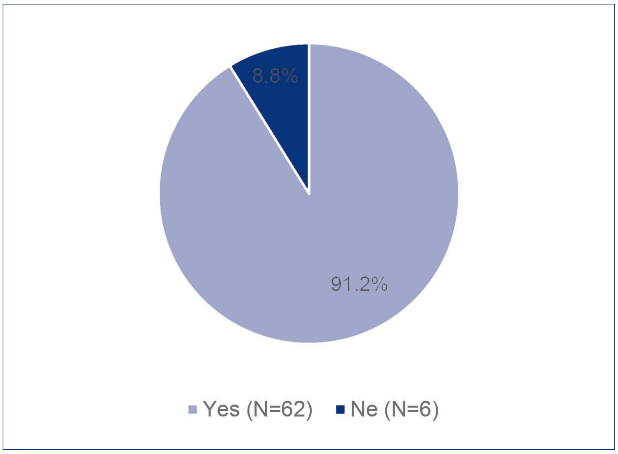

Figure 4. **Distribution of participants according to self-reported incidence of depressive feelings after stoma formation**

Regarding family adaptation to the changes brought about by stoma formation, 48 participants (68.6%) indicated that their family members adapted well, while 10 participants (14.3%) reported that their family members adapted exceptionally well. Conversely, 12 participants (17.1%) stated that their family members adapted poorly, and none reported extremely poor adaptation, as shown in Figure 5.

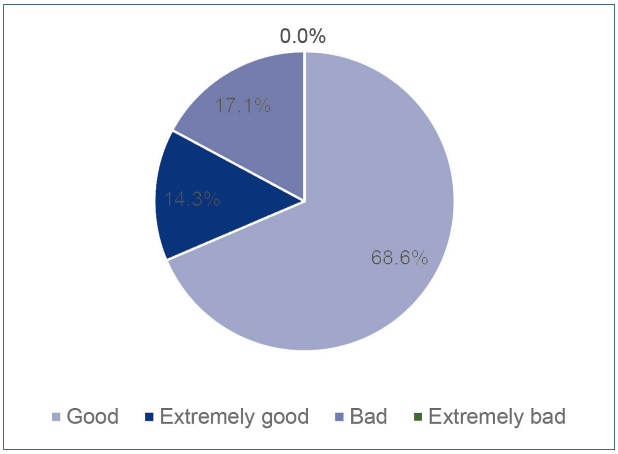

Figure 5. **Adaptation of family members to a stoma**

The results revealed that for 49 participants (70.0%), the stoma did not affect their relationship with the family member who had undergone stoma formation. However, 39 participants (55.7%) reported a mildly negative impact of the stoma on their emotional status. Most participants, 56 individuals (80.0%), stated that the stoma did not influence their social status. Nevertheless, the stoma was reported to have a mildly negative effect on the daily routine of family members by 48 participants (68.6%) (Table 1).

A financial burden associated with caring for a family member with a stoma was reported by 59 participants (84.3%), while 11 participants (15.7%) did not experience financial loss, as shown in Figure 6.

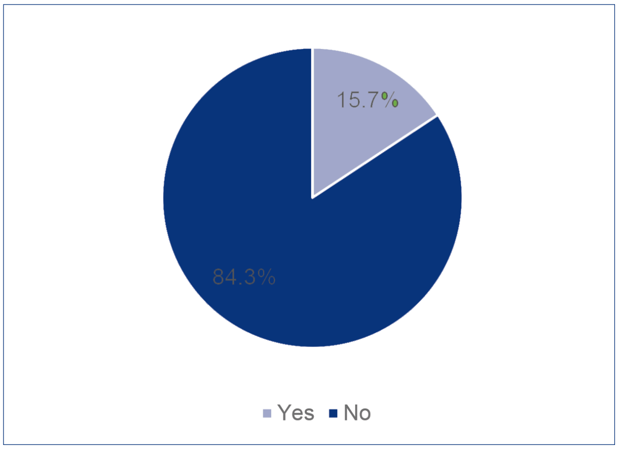

Figure 6. **Distribution of participants according to financial loss due to caring for a family member with a stoma**

Table 1. **The impact of a stoma on family members**

	How has your family member's stoma affected your relationship?		How has your family member's stoma affected your emotional status?		How has your family member's stoma affected your social status?		How has your family member's stoma affected your daily routine?	
Extremely positive	1	1,4%	1	1,4%	0	0%	0	0%
Moderately positive	1	1,4%	1	1,4%	1	1,4%	1	1,4%
Slightly positive	2	2,9%	0	0%	1	1,4%	0	0%
No impact	49	70%	14	20%	56	80%	10	14,3%
Slightly negative	16	22,9%	39	55,7%	12	17,1%	48	68,6%
Moderately negative	1	1,4%	16	22,9%	0	0%	10	14,3%
Extremely negative	0	0%	1	1,4%	0	0%	1	1,4%
Total	70	100%	70	10%	70	100%	70	100%

A total of 64 participants (91.4%) reported that no home adaptations were required to accommodate their family member with a stoma. In contrast, 6 participants (8.6%) indicated that modifications to their home environment were necessary (Figure 7).

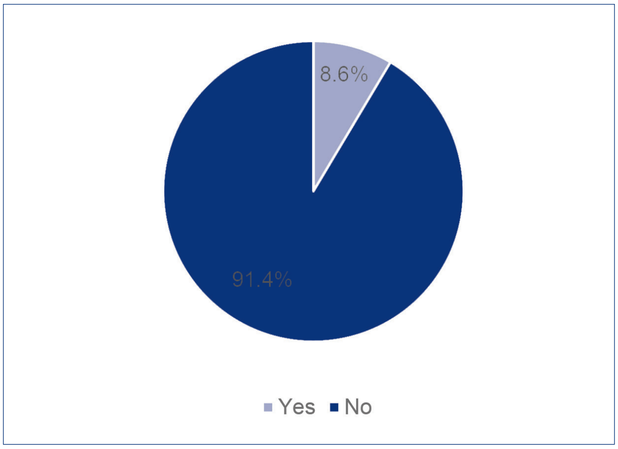

Figure 7. **Distribution of participants according to home adaptation due to the needs of a family member with a stoma**

Discussion

The formation of a stoma influences various aspects of life for both patients and their families. Ensuring a good quality of life is essential for achieving an appropriate approach in treating patients. Family members play a crucial role in treatment and the continuation of care at home. Therefore, this research was conducted with the aim to assess the quality of life of patients with a stoma and their families. The study by Anaraki et al. conducted in Iran showed that factors such as the type of stoma, the underlying disease leading to the formation of the stoma, depression post-stoma, dissatisfaction with sexual activities, problems with the site of stoma formation, and changes in dressing style impacted the quality of life (12). Understanding the experiences of subjects with stomas and their family members enables the improvement of care, thereby enhancing the quality of life.

In this study, the impact of the stoma on the quality of life of patients was explored through several factors. Most participants (55.7%) were aged over 65 years, with colostomies (42.9%) and ileostomies (35.7%) being the most common types. Urostomies and ileostomies are associated with a more frequent occurrence of complications that impair quality of life.

Majority of participants, 91.2%, were found to self-report depressed feelings after the formation of the stoma, which is associated with a markedly reduced quality of life. This highlights the need for additional support as poor mental health increases the need for stoma care. It is crucial to assess the psychological status of the patient. Sceats et al.'s study also showed an increased rate of depression among patients who had a stoma formed (13). Other research has shown that the psychosocial needs arising from the formation of a stoma are significant in predicting the psychosocial reactions of patients after the stoma is formed (14). The formation of a stoma and associated problems can affect patients' relationships with partners/spouses. Patients report problems with sexuality in the early postoperative period, leading to further deterioration in quality of life. In the study by Symms et al., it was found that nearly half of the patients who were sexually active before the formation of the stoma became inactive after the surgical procedure (15). This may be due to insufficient education about intimacy for patients with stomas. A study conducted in China to assess the quality of life related to the stoma showed that patients had difficulties at work due to the stoma (16). In the study by Dabirian et al., financial problems were shown to significantly impact the quality of life of patients living with a stoma. Nichols and Riemer further highlighted job loss as a common consequence of stoma formation, with Davis et al. reporting that 81.8% of respondents changed occupations after the formation of a stoma, and 66.6% did so solely due to the stoma (17,18). These findings are consistent with the results of our study, where 84.3% of participants reported experiencing financial loss associated with caring for a family member with a stoma (Figure 6).

Additionally, while most participants (91.4%) indicated that no home adaptations were required, a smaller subset (8.6%) reported having to make modifications to their living environment to accommodate the needs of the stoma patient (Figure 7). These results underscore the financial and logistical burden often imposed on families, which may exacerbate stress and further diminish overall quality of life. Within the domain of psychological well-being, it is important to focus on coping styles with the stoma and support groups. In the study by Davis et al., it was also shown that most respondents do not belong to any support group, which was confirmed in this research (18). Support groups increase knowledge about stoma care and strengthen social skills, and also increase independence and reduce the rate of social isolation. Salter conducted a qualitative study related to the quality of life, comparing people with a stoma and people who once had a stoma (19). Patients often felt that they could not wear "normal clothes" because they had to disguise the stoma when it filled. Thus, the nurse must encourage patients to actively participate in support groups.

Friends and family members are an indispensable part of support for individuals living with a stoma. Research by Salter demonstrated that partners of stoma patients often play a crucial role in helping them adapt to their changed body image (19). Similarly, while the study by Krouse et al. did not find direct evidence that having a supportive partner improves overall quality of life, it underscored the significance of social support as a critical factor for patient well-being (20). In our study, the results reflect a nuanced picture of family adaptation. A significant majority of participants (70%) reported that the stoma had no impact on their relationship with the affected family member, indicating a stable interpersonal dynamic despite the challenges posed by the stoma. However, the emotional impact was more pronounced, with 55.7% of participants reporting a slightly negative effect and 22.9% reporting a moderately negative effect on their emotional status. This suggests that while relationships may remain stable, the emotional strain of caregiving and adaptation is substantial. Moreover, the stoma was reported to have no impact on the social status of 80% of participants, highlighting that the social dimension of family life is less affected. However, the daily routine was more disrupted, with 68.6% of participants reporting a slightly negative effect and 14.3% reporting a moderately negative effect. These findings suggest that while families are resilient in maintaining social connections and relationships, the practical challenges of managing daily caregiving responsibilities create a notable burden.

Health professionals can help people with a stoma cope with the problem, using various methods. Wu et al. suggested that a comprehensive assessment of each patient will allow the health worker to identify the patient's needs, particularly how the stoma will affect social life and how to deal with different situations (21). The postoperative period can trigger symptoms of stress, anxiety, and depression in patients with a stoma because it is a transitional period that requires adaptation to a new physical state. After discharge from the hospital, home care nurses are the source of appropriate information and education about stoma care tailored to the needs of each patient. Appropriate information about stoma care improves quality of life, especially during the first months after the formation of the stoma.

In the study by Elshatarat et al., only about 37% of respondents underwent education on stoma care, and many expressed dissatisfaction with the quality of the provided education, perceiving it as insufficient to improve their knowledge and skills for managing stoma-related challenge (22). These findings align with the results of this study, where an overwhelming majority of participants (97.1%) reported feeling unprepared for life with a stoma (Figure 3). This lack of preparedness underscores the critical need for comprehensive preoperative and postoperative education, as well as psychosocial support. The low level of readiness reported by participants may reflect gaps in educational interventions, which should ideally address both the practical aspects of stoma care and the psychological adjustments required. As nurses play a central role in delivering stoma care education, emphasizing this aspect of care could significantly enhance patients' ability to manage their condition and improve their quality of life. Structured and personalized educational programs, tailored to the specific needs of patients and their families, could mitigate the challenges associated with this lack of preparedness and align better with patient expectations.

Additional Recommendations for Healthcare Policy

Development of National Guidelines for the Care of Ostomy Patients:

- The guidelines should include standardized procedures for preoperative education, postoperative care, and continuous psychosocial support for patients and their families.
- Emphasis on collaboration between different sectors (hospitals, primary healthcare, and social services).

Financial Support for Patients and Families:

- Introduce subsidies for purchasing ostomy supplies and making necessary home adaptations.
- Cover the costs of psychological counseling and support groups within the health insurance framework.

Preoperative and Postoperative Education:

- Education should be provided by certified ostomy therapists or nurses specialized in this type of care.

Improving Access to Specialized Care:

- Ensure the availability of ostomy therapists in all regional hospitals.
- Increase the number of mobile home care teams trained to work with ostomy patients.

Conclusion

This study shows that the formation of a stoma impacts the self-assessed quality of life for both patients and their families, affecting physical, mental, emotional, and social dimensions. The study identified critical areas where stoma patients and their families face challenges, particularly noting a high incidence of depression and a decline in sexual activity among patients post-surgery.

Family members often bear a considerable burden as caregivers, which can alter family dynamics and contribute to stress within the household. It is evident that comprehensive care extending beyond mere physical treatment is essential. This care should incorporate robust psychosocial support and effective communication about sexuality and body image, areas identified as particularly vulnerable following stoma surgery.

Future research should focus on developing targeted interventions that address these specific challenges. Studies could explore the effectiveness of integrated care models that include psychological counselling and support groups to enhance coping strategies for patients and families.

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KVALITETA ŽIVOTA NAKON FORMIRANJA STOME: PERSPEKTIVE PACIJENATA I OBITELJI

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Sažetak

Uvod: Operacija stome, koja je često nužna zbog ozbiljnih zdravstvenih stanja kao što su rak i upalne bolesti crijeva, značajno utječe na živote pacijenata i također utječe na članove njihovih obitelji. Ovaj zahvat, koji uključuje stvaranje kirurških otvora na gastrointestinalnom traktu, zahtijeva značajne prilagodbe životnog stila i složenu skrb, često dovodeći do dubokih psiholoških i socijalnih izazova i za pacijente i za njihove obitelji.

Cilj: Ispitati kvalitetu života pacijenata sa stomom i istražiti kako stoma utječe na kvalitetu života obitelji pacijenata sa stomom.

Metode: Ova presječna studija uključivala je 70 sudionika s različitim vrstama stoma, uključujući urostome, kolostome i ileostome, anketiranih od 1. rujna do 28. listopada 2023. Koristio se posebno dizajnirani upitnik za prikupljanje podataka o samoprocijenjenoj kvaliteti života pacijenata sa stomom i članova njihovih obitelji.

Rezultati: Većina sudionika bila je starija od 65 godina, s 42,9% kolostoma i 35,7% ileostoma. Značajnih 91,2% samoprocijenilo je pojavnost simptoma depresije nakon formiranja stome, što ističe psihološki utjecaj stome. Prilagodbe obiteljskom životu bile su potrebne za 68,6%, što ukazuje na značajan utjecaj na svakodnevnu rutinu i emocionalno stanje obitelji.

Zaključak: Formiranje stome negativno utječe na mentalno i socijalno blagostanje pacijenata, s velikim emocionalnim i financijskim utjecajima na obitelji. Studija ističe potrebu za sveobuhvatnom poslijeoperacijskom podrškom koja uključuje i psihološko savjetovanje i obrazovne intervencije prilagođene pacijentima i njihovim obiteljima kako bi se ublažili višestruki tereti života sa stomom.

Ključne riječi: Stoma, Kvaliteta života, Obitelj