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# Impact of intestinal stoma on physical, nutritional, and psychosexual well-being in patients with stoma.

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#### **KEYWORDS**

# Ileostomy, Colostomy, Skin excoriation, Nutritional status, Sexual health.

#### **ABSTRACT**

**Introduction:** An intestinal stoma is surgically created openings from the intestine to the skin for fecal diversion. Though the goal of an ostomy is to alleviate and lessen a patient's pain and discomfort, ostomies frequently result in patients experiencing more pain and suffering as well as significant stress. This study aimed to elaborate on the various physical, psychosexual, and nutritional issues faced by the ostomates in their everyday life.

**Methodology:** This Study is a qualitative type with a sample size of 40 patients with stoma. A questionnaire was formulated to gather responses from the participants. A purposive sampling technique was used in this study. The frequency of responses and percentage are noted in the datasheet.

**Results:** Most of the patients had experienced various physical issues with a stoma, followed by psychological and sexual issues the least were in dietary habits. In the section on physical problems, 102 responses were recorded, followed by 28 responses for psychosexual problems and 17 responses for nutritional problems.

**Conclusion:** Surgeons are required to do proper counseling with patients before creating the stomas. Nursing care as well as appropriate patient education in the prospective period may reduce the time until proficiency in stoma handling, as well as the time until discharge from the hospital.

**Introduction:** An intestinal stoma is surgically created openings from the intestine to the skin for fecal diversion. Because the ancient Greeks were frequently at war and seem to have had a great deal of experience with abdominal perforations, the word "stoma" comes from their language.

Colostomy or Ileostomy is the surgical creation of a stoma for the evacuation of bodily waste (1). Even though the goal of an ostomy is to alleviate and lessen a patient's pain and discomfort, ostomies frequently result in patients experiencing more pain and suffering as well as significant stress (2). The common problems experienced by the subjects have been reported to be skin irritation (76%), pouch leakage (62%), offensive odor (59%), reduction in pleasurable activities (54%), and depression/anxiety (53%) (3). The creation of an ostomy leads to various physiological problems for patients.

Ostomy patients are apprehensive about leakage and odor from the stoma, and might therefore avoid interactions with people, become introverted, and seek solitude. Over time, this insecurity in social situations and lack of trust could lead to total social isolation (4). In physical terms, ostomates face many problems. Ostomates fear that the ostomy bag might leak or smell, especially when away from home. This includes the fear of not waking up before a leak happens. Often the fear of a leak is worse than the experience of having an accident. Many patients feel the stoma is a sanitary nuisance for themselves and others around them, feeling dirty and unclean. People with fecal stomas no longer have control over flatulence from the stoma, lacking a voluntary sphincter as the anus provides. The existence of an opening in the anterior abdominal wall creates a problem because of the lack of sphincter control and the irritant

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effect of fecal efflux on the surrounding skin. There is also the problem of the collection, storage, sight, sound, and odor of the fecal stream. In addition to these, the projecting part of the bowel mucosa needs protection from the external injury.

Patients with an Ileostomy face many dietary challenges relevant to the location of the stoma. Without the colon, the absorption of electrolytes, water, Vitamin K, and biotin are affected (5). There are different problems which are faced by patients with stoma i.e., gas, odor, obstructive foods, constipation, socio-economic, sexual, psychological problems, and other complications related to stoma. A descriptive survey collected data related to individual dietary recommendations and restrictions for people with stoma. The findings revealed that 88.4% of respondents were not following a special diet, and 11.6% had modified their diet. The odds because of the stoma included fresh fruits, nuts, coconut, and vegetables such as corn, popcorn, cabbage, beans, and onions. The major problems reported were blockage and increased gas (6). Sexuality is deeply affected by body image, feelings, and interpersonal relationships. A person's sexual behaviour is closely associated with their physical appearance. Many people with stomas have concerns that their sexual attractiveness has been diminished (7). Individuals who have stomas sometimes struggle with their sexual attractiveness and have varied coping mechanisms for this issue. Some want to expose themselves and see how their partner responds. If their partner doesn't see the stoma as a problem, they could more easily accept the stoma as a part of themselves. Some hide their stoma bag while undressing; keeping it out of their partner's sight believing that their body is 'destroyed'. Some are afraid of discussing sex with their partner, and worried about their reactions. They fear that ultimately their relationship will fail (8-10).

A person's body image and sexuality are major factors in determining the effect of a stoma on a person's quality of life. This study aimed to investigate the effects of a stoma on the body, health, nutrition, and sexuality of the patients.

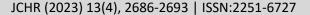
**Methodology**: This Study is a qualitative type that includes all patients with ileostomy and colostomy done in the general surgery department of Patna Medical College and Hospital, Patna during two years from 1.10.2016 to 30.09.2018. Exclusion Criteria were patients undergoing urinary stoma construction,

undergoing stoma constructions as an indication for gynecological disorders, with communicative problems, with HIV infection, or with unsound minds.

The study sample size consisted of 40 patients with colostomy/ileostomy attending the surgical follow-up OPD with a minimum period of six weeks after surgery. A purposive sampling technique was used in this study. The tool used for data collection consisted of two parts. The first part consisted of a sociodemographic data sheet of the patients which had items such as name, age, sex, ERS, type of surgery, educational status, occupation, total family income, total family members, per capita income, etc. The second part consisted of a semistructured interview schedule which was developed by reviewing literature and was given to experts for validity from the field of nursing and the Department of General Surgery to judge its clarity, relatedness, meaning, and contents. Semi semi-structured interview schedule consisted of open-ended questions related to physical, nutritional, and sexual domains.

Ethical permission was obtained from the institutional ethics committee. To assess the feasibility of the study, the study was conducted on five subjects in the surgical Ward, Patna Medical College and Hospital, Patna. The various themes analyzed in the study were Physical problems, Nutritional problems, Sexual problems, psychological problems, and Effects on social, religious, economic, and family relationships. These findings were incorporated into the main study. The written consent was taken from the subjects. The subjects were told that all the conversations would be kept confidential. The interview was recorded in the demonstration room adjacent to the surgical Ward by maintaining privacy during the interview procedure. The time spent for each interview varies from half an hour to one hour, according to the willingness of the patient to talk. Some preferred to talk elaborately, while others wanted to stop it sooner. The data was transcribed into verbatim forms and was analyzed. The data was typed after that reading and proof-reading of participant's descriptions were done. Then significant statements were extracted followed by formulating the meaning of each significant statement. Then categorizing of formulated meanings into clusters of themes was done. Then the extracted meaning and statements were validated by experts in the field of psychiatry and psychology. After careful analysis of the transcript of the in-depth interview, many subthemes

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have emerged. These subthemes were coded under the grouped analytical coding sheet by final description and categorizing the essence of the phenomenon.

A questionnaire was prepared based on subthemes.

- 1. Do you ever experience any change in the sleep pattern related to fear of leakage, pain, or discomfort?
- a. Never
- b. Rarely
- c. Sometimes
- d. Always
- 2. Is there any impact on overall health?
- a. Yes
- b. No
- 3. Is there any effect on the clothes worn?
- a. Yes
- b. No
- 4. Have you noticed any change in skin integrity related to irritation by the stoma content?
- a. Yes
- b. No
- 5. Do you experience abdominal pain due to stoma?
- a. None
- b. Mild
- c. Moderate
- d. Severe

- 6. Is there any change in sexual desires sexual behavior and sexual health due to the stoma bag?
- a. Yes
- b. No
- 7. Does the spouse accept stoma appliances?
- a. Yes
- b. No
- 8. Do you have feelings of embarrassment, anxiety, or refraining from sexual acts due to stoma?
- a. Never
- Rarely
- c. Sometimes
- d. Always
- 9. Do you avoid certain foods due to stoma?
- a. Yes
- b. No
- 10. Is there any modification required with certain food items?
- a. Yes
- b. No

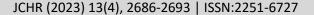
#### **RESULTS**

Among the 40 stoma patients who participated in the survey, 27 (67.5%) were male and 13 (32.5%) were female. The mean age  $\pm$  SD of all participants was 33.6 $\pm$ 13 years. Table 1 shows the demographic and clinical characteristics and table 2 shows the various issues faced by stoma patients.

Table 1 (Socio-demographics & Clinical Characteristics):

Variables	Frequency (n)	Percentage (%)	
Age (Mean)	33.6 years	+/- 13 (SD)	
Males	27	67.5 %	
Type of stoma			
Ileostomy	36	90	
Colostomy	04	10	
Post op Duration			
< 3 months	30	75	
3-6 months	10	25	
Occupation			
Working	23	57.5	
Not working	17	42.5	
Type of Surgery			
Emergency	36	90	
Elective	04	10	
Indications of Stoma			
Abdominal trauma	05	12.5	
Colorectal Carcinoma	01	2.5	

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Enteric Perforation	25	62.5
Abdominal TB	07	17.5
Gangrenous bowel	02	05

In the section on physical problems, 102 responses were recorded, followed by 28 responses for psychosexual problems and 17 responses for nutritional problems (Table 2).

Table 2 (Problems faced by patients):

Problems	Frequency of	Percentage (%)
Physical Problems	responses (n)	
Altered sleep pattern, related to fear of leakage, Pain & discomfort	33	32.3
Lack of adjustment in daily living	30	29.4
3. Impact on overall health	16	15.7
1		
4. Altered skin integrity related to the leak	12	11.8
5. Effects on the clothes worn	11	10.8
Psychosexual problems	28	
1. Impact on sexual desires, sexual behaviour, and sexual	16	57.1
health due to a stoma bag		
2. The feeling of embarrassment, anxiety, refraining from	07	25
sexual acts, and adjustment toward sex life		
3. Acceptance by the spouse with the stoma	03	10.7
4. Rejection by the spouse due to stoma	02	7.2
Nutritional Problems	17	
1. Discomfort and avoidance of certain food items	10	58.8
2. Modification with certain food items	07	41.2

Discussion: The ostomy patients face an array of challenges due to the uniqueness and consequences of their ostomy bag. The purpose of ostomy is to treat and reduce a patient's pain and discomfort, but in many cases, ostomy leads to intensified distress and suffering for patients and causes severe stress as a result of skin irritation, pouch leakage, offensive odor, reduction in pleasurable activities, and depression/anxiety. In such circumstances, it is worthwhile to know the life experiences and the problems faced by the patients with the stoma, the effect of the stoma on their quality of life, and the strategies used by the ostomates to manage the bag.

The present study was conducted among patients with colostomy/ileostomy. The study aimed to explore the life experiences of the patients with colostomy/ileostomy, to interpret the phenomenon as experienced by them, and to gain insight into the physical, nutritional, and sexual

problems experienced by the patients and the coping mechanisms adopted by patients to combat the stress. An attempt was made to explore their fears in the context of physical, nutritional, and sexual problems for a prolonged time. The researcher wanted to explore their thoughts, problems, and feelings and intrude into their psyche, though it was a tough task. Phenomenology was selected as a medium to enter into their world. Colaizzi's approach simplified analysis by providing a methodical way to break down data into phases that are easily understood, as opposed to merely summarizing the lived experiences.

#### **Physical Problems:**

**Davis et al** conducted a cross-sectional survey in southern India over 55 ostomates and reported that leakage, odor, and noise from the appliance were the primary sources of embarrassment identified by patients. Most of the patients had a lack of adjustment in the

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activities of daily living, altered sleep patterns related to fear of leakage, pain, or discomfort, and altered skin integrity. Most of the participants reported the limitations in physical activity after their ostomy. They experienced a reduction in their routine activities and an inability to do physical work. They often experience tiredness after doing some work. Most participants complained of irritation and rashes around the ostomy site, with sleep disturbance, decreased or nil participation in everyday activities, bathing problems, restricted clothing, and tiredness. The above findings were consistent with one of the studies in which participants complained of irritation and rash around the ostomy site, with sleep disturbance, bad breath, and gas emission in the presence of others (11). Heather Yeo, Farshad Abir, et al studied on Management of parastomal ulcers. The majority of parastomal ulcer patients who do not also have peristomal pyoderma gangrenosum (PPG) inflammatory bowel disease (IBD) frequently recover rapidly to conservative treatment and local wound care. Patients with PPG, IBD, or other systemic causes of their ulceration need both systemic and local and are more likely to need long-term treatment and possibly surgical revision of the stoma (12). Pia Nasvall et al studied the Quality of life in patients with a permanent stoma after rectal cancer surgery A bulging or a hernia around the stoma was present in 31.5 %. Operation due to parasternal hernia had been performed in 11.7 % of the stoma group (13). In one of the studies, the ostomates complained of irritation and rash around the stoma site, with sleep disturbance, bad breath, and gas emission in the presence of others. Moreover, they reported that they could not lift objects weighing more than 5 kgs (14). The findings of the current study seem close to these studies (11-15).

#### **Psychosexual Problems:**

**Kyung Sook Hong** et al studied many psychological problems in patients with stomas that have been addressed in several studies. The mean differences in body image, self-esteem, and depression scores between patients with permanent and temporary stomas were not statistically significant. However, patients with a permanent stoma tended to have a worse body image and lower self-esteem on some specific items within the questionnaires (16). **Fatma Vural et al** studied the impact of an ostomy on the sexual lives of persons with stomas. People with stoma experience changes in their

physical appearance, along with a decline in sexual Respondents described avoiding sexual intercourse and abstaining from sleeping with their parties (17). Zhang Xi et al conducted a multicenter cross-sectional study to evaluate the influence of stigma and disability acceptance on psychosocial adaptation in patients with a stoma and found that the stigma and disability acceptance of patients with a stoma are serious problems that are closely related to their psychosocial adaptation. Medical staff should take some interventions based on different paths to reduce stoma patients' stigma and guide them to improve disability acceptance, thus improving the level of psychosocial adaptation of stoma patients (18). Wiktoria et al reviewed the quality of sexual life in patients with stomas and reported that a very important issue for enabling a return to sexual activity is the appropriate patient education prior to and following surgery. Sex education should also include the partner to whom the stoma patient often finds support (19) In the present study, married participants encountered some sexual problems, particularly early on in the course of their disease or after surgery, which resolved gradually when they learned how they could tackle this problem. Some of them had a normal sexual life but most of the participants reported that there was a tremendous change in their sexual life. The feeling of anxiety and embarrassment with the stoma bag refrained many of the subjects from the sexual act. While some had adapted by shifting positions, the majority refrained from engaging in sexual activity with the bag. They had a decreased desire to indulge in the act because of feelings of weakness while few experienced rejections by the spouse. These findings were consistent in three of the studies in which participants' sexual relationships were affected after the ostomy and reported a decreased desire to indulge in sexual acts which ultimately resulted in inactive sexual life (20-22) The findings of the current study were mostly closer to these studies (16–19)

# **Nutritional Problems**:

Nawaz A. et al conducted a prospective study to assess the nutritional status, self-esteem, and quality of life in stomatized patients and reported that anyone with a stoma had low self-esteem and that the stoma impacts the patient's diet significantly (23). Izabella et al reviewed the nutritional issues faced by patients with intestinal stoma and reported that progress in stoma care has improved the prognosis and quality of life for many

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patients worldwide. However, they also revealed the essential role of providing professional care by the interdisciplinary team: a doctor, an ostomy nurse, a psychologist, and a nutrition specialist (24). Regarding Nutritional Impact, the participants had gas, odor, constipation, or diarrhea with certain food items like cauliflower, cabbage, yogurt, etc, and hence they avoided those food items. In the present study, nutritional problems were not less important. The majority of the participants reported that although they did not receive any education about their diet and nutritional status, they considered it to be an important issue and were doing their best to control it. The participants in the current study had reported discomfort with certain food items which led to modification of their routine diet. They complained of blockage of stoma with 'some of the foodstuffs like beans and nuts. They complained of gas emissions from certain food groups like cabbage and cauliflower. They avoided the spicy and oily food. They ate the food items according to their interest and found that some of the food items were discomforting. So they used to avoid these food items and focused on the high protein content food groups. Some of the participants used to skip dinner and others had their dinner early to avoid emptying of the bag at night.

The findings of the study revealed that the ostomy pouch led to serious maladjustment in the everyday life of the patient. The findings of the study would be useful for healthcare providers when creating a supportive environment to improve the quality of life in ostomy patients. Support groups in which therapists and patients could interact would provide an opportunity for participants to express their concerns about the quality of life issues and ultimately it would lead the ostomates to a better life. The findings of the current study regarding nutritional issues seem closer to these studies (23,24)

Conclusion: The construction of a stoma for bowel perforation and obstruction is considered to be a safe and life-saving procedure in an emergency but it has its morbidity and mortality and a variety of problems like stoma-related complications, psychiatric disorders, altering dietary patterns, and sexual dissatisfaction. Surgeons are required to do proper counseling with patients before creating the stomas. It has been proposed that patients could act and adapt themselves to the stoma better if their forthcoming problems were discussed with them properly before surgery. Appropriate patient

education in the prospective period may reduce the time until proficiency in stoma handling, as well as the time until discharge from the hospital. Furthermore, there is some evidence showing, that patient education may help to increase patients' knowledge about their health, their condition, and their self-care possibilities. Careful surgical techniques, proper counseling of patients before and after surgery, education about stoma care to the patients, and trained nursing staff could help stoma patients adjust to new situations and improve their quality of life.

# The result of this study calls for the following recommendations

- \* Stoma patients should receive adequate education and counseling regarding ostomy self-care, lifestyle changes, and self-efficacy.
- \* Assessment of patients, self-care performance, knowledge, and quality of life during the first few weeks after the operation considered as evidence of his educational needs and concerns.
- \* Training programs for nurses to be well prepared to provide instructions and training for stoma patients but these kinds of programs are not a routine part of the majority of medical institutions in our country.

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