

Experience of Individual Living with Prolong Ostomy: A Qualitative Study

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Abstract

Objective: This study was conducted to explore individual experiences living with prolong or permanent ostomy to uncover the areas that remained ignore or untreated. Many individuals undergo ostomy surgery every year across the globe. They faced many challenges after surgery however, without knowing their experiences it is impossible to understand how their life is going on with a stoma.

Methodology: A phenomenological research design was implemented for conducting this study by following SRQR checklist of equator network reporting guideline. Approval was obtained from the Ethical Review Board. The research work was accomplished in Hayat Abad Medical Complex (HMC) as per direction of the institutional review board of Khyber Medical University from March 2019 to March 2020. In current study a phenomenological research design was implemented and eight individuals including both male and female were interviewed following the purposive sampling technique. Face to face in depth interviews were conducted, data were recorded, transcribed in the form of verbatim and then translated. The data was further analyzed, codified and categorized; finally different themes were extracted through thematic analysis method.

Results: Five themes were generated including compromised nutritional status; sleep deprivation, financial challenges; restricted social relationship and compromised nutritional status

Conclusion: The outcomes of this study excellently explored and highlighted the experiences of individuals living with prolongs ostomy.

Keywords: Qualitative study, care of stoma, living with an ostomy, nutritional needs of stoma patient, psychosocial impact of stoma and physical influences of an ostomy.

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Introduction

The word "ostomy" comes from the common Greek word "stoma," which refers to a surgically created orifice used to drain stomach contents.^{1,2} The development of an ostomy is done in response to a number of illnesses, including cancer, diverticulitis, dysfunction, irritable bowel diseases, or other related conditions, such as injuries, accidents, and prolonged obstruction.^{2,3} According to research, it is an alteration in the anatomy

rather than a disease.⁴ Surgery's prime objective is to use surgical techniques to establish a connection between the gastrointestinal system's internal region and the outside world⁵. As the surgery is being performed, the bowel is sticking out past the abdominal wall.⁶ Any location in the large or small intestine can produce the fissure.^{7,8} Personal independence and quality of life are impacted by one's physical and mental health^{4, 9}.

Numerous studies revealed that many issues, including

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as family issues, nutritional issues, financial issues, sexual issues, and incontinence, were encountered by many participants when living with an ostomy.^{10, 11} Impaired skin integrity, dirt spills, odour, gas production, disturbed sleep, and embarrassment¹² are further connected issues. According to studies, tension, depression, and anxiety are some of the psychological changes that some people have experienced in the first 16 weeks following stomal surgery (18–25%).¹³

Stoma creation was a common method historically as early as the 18th century.¹⁴ Dr. Pillore was the first surgeon to perform a stoma formation procedure on an adult patient in 1976; however the patient did not survive and passed away from peritonitis a month later.¹⁵ The first stomal surgery was performed on a newborn with an imperforated anus in 1793 while the child was still in the neonatal stage. Norma Gill was the first enterostomal therapist, and the field of enterostomal therapy was established in 1950 to develop specialized, skilled employees. People with stomas are common today.¹⁶

According to one study, 0.75 to 1.0 million Americans are still living with stomas after having them surgically created due to colon cancer.⁹ According to another study, 0.1 million people are got to add to the US community annually as a result of stoma surgery.¹⁷ According to a similar survey, 3000 ostomy surgeries were performed in Iran in 2012. In China, a study conducted in 2005 on the same population indicated that there were more than 10 million ostomats. While 13,000 people in Canada undergo stoma closure surgery annually.⁸ A study done in Pakistan's Allama Iqbal Memorial Teaching Hospital Sialkot from 2012 to 2016 revealed that 107 out of 2243 patients underwent ostomy surgery.⁶

Material and Methods

Following the SRQR reporting guidelines of the Equator Network, a phenomenological study design is used to carry out this research (O'Brien BC, 2014). The investigation was conducted in the tertiary care hospital known as Hayat Abad Medical Complex. After receiving approval from the hospital administration, the Advance Study Review Board (ASRB), and the Ethical Review Board (ERB), data collection began. Prior to conducting the interview, both verbal and written consents were obtained. Participants' privacy, confidentiality, and respect were all upheld. Each participant received an

explanation of the length of the interview. Both male and female participants were included in this study. Based on saturation, eight individuals were interviewed using the purposive sample method.

Each participant had a stoma and had a stoma operation more than three months prior. People who had recently undergone surgery, were mentally stunted, critically ill, had a lower level of understanding, and weren't eager to participate were excluded. The essential elements of the study and the goal of the interview were explained to the respondents. In-depth face-to-face semi-structured interviews were performed using a question-guided format, and audiotape recordings were also made. Data were captured, directly transcribed, and then translated. The information was further examined using codes and categories. Finally, a multitude of themes, such as sleep deprivation, compromised nutritional status, restricted social relationships, psychological impact, and financial issues, were extracted using thematic analysis techniques.

Results

After analyzing the transcript five main themes were emerged these are, restricted social relationship, sleep deprivation, psychological impact, compromised nutritional status, and financial challenges.

Theme 1: Sleep Deprivation

Sleeplessness is one of the most encountered issues explored by every individual due to different reasons, like laying in same posture for long time, hopelessness and fear of leakage due to side change at night. Two participants verbalized that:

"I'm sleeping upright, but the bag leaks, which is really distressing, every-time I move position to either side."

"Sleep is quite disrupted, it is one of the challenges, A person might imprecate to oneself and lose hope." I had leaks for two nights, and the bed's foam, sheets, and other components became filthy. I was awake throughout the Morning Prayer call and had no sleep.

Sleeplessness is correlated with uncontrolled dirt spillage at night by some individuals which causes coldness and leading to sleeplessness. One individual reported that;

"Every time the bag separates or leaks, I become chilly. I once shifted over in the middle of the night, and the dirt

came out of the bag. After that, I didn't sway from my upright, alert position".

The usage of medicine is also acknowledged; one person revealed that he often takes medication for sleep.

"I was unable to go asleep or stay asleep for 30 minutes, so my doctor gave me an Alp pill."

Theme 2: Compromised Nutritional status

Participants looked at a number of underlying causes of nutritional status impairment, including indigestion, fast bag discharge, and weakened gastrointestinal function. Two people discover that:

Every time I consume something, it immediately expel in the bag.

"After eating, I noticed the same items in the bag and thought, Oh Allah... Its unprocessed and undigested food that is fresh.

Some people also claimed having a loss of appetite and throwing up after eating, while others admitted to taking medicine before meals on the doctor's advice. Two people stated the following:

"Food... I haven't taken in the the past three months despite the physicians' instructions to do so. I started taking the motilium tablet after informing the doctor I couldn't take anything, which prompted me ought to eat for around ten days.

Every time I ate something, I immediately puked."

Additionally, several said that they had to limit their meal intake because of gas development and stink. Two people reported that:

"Every time I eat a potato, cucumber, turnip, or a cabbage, flatulence occurs; even mustard leaves can do this."

"I've had awful experiences with red paper, chicken, onions, cabbages, radish, and chickpeas, etc."

In contrast, people named a few meals that don't cause flatulence or smell. Participants said:

"I've always had good luck with peas, green vegetables, and fruits like guava and grape as well as apples, oranges, and bananas.

Fruits are generally healthy and perceive good taste including custard and soup."

Theme 3: Restricted Social Relationship

Due to stomal gas leaking and poor self-esteem, the participant discusses experiencing little social interaction. They claim that they are unable to participate in any celebration, including weddings, funerals, or bereavement services for close family members and relatives. Some participants expressed that they find it difficult to maintain relationships with friends and family when they are unclean and unsanitary for an extended period of time: Several people stated that:

I have never been to a relative's wedding or given condolences to anybody since the gas leak and loudness from the bag embarrass me too much.

You are not allowed to sit with anybody for a meal, you are not allowed to stroll with anyone, and there is an uncontrolled air leakage.

"I can't clean myself every day, and sometimes I don't clean it for weeks."

The person stated that people do not see them warmly and favourably. They claim that although most individuals are unaware of what exactly is going on with stomas, when they do learn about them, they become quite aware. One person claimed that:

"People dislike me because of what has happened to me, but when I reveal everything, they begin to change their minds."

Respondents also discussed how they are attempting to keep their stomas a secret since the loud noise it generates is incredibly embarrassing and isolates them from friends and family. A 24-year-old person stated the following:

"A few days ago, several visitors arrived. I was attempting to go, but they said you would have meals with us, so as I seated, the colon began making a loud noise. I was too embarrassed by how miserable I was with my life."

Theme 4: Psychological Impact

Nearly all participants address the psychological effects. Some people admitted to being afraid of dying rather than living longer, having little or no resilience, having bad feelings about themselves and other people, and even attempting to physically harm themselves and other people. Two participants reported that

"I was contemplating suicide, but may Allah grant my wife a long life since she refrained from brandishing a knife in the space. Every time I went to sleep at night, I was worrying about what would happen to me and when it would end. I'm considering that I must murder the individual or he must kill me."

Depressed mood, loss of happiness, going unconscious and rapid fall are other psychiatric symptoms that some people have researched. According to two respondents:

"Even more than three months have gone, yet I still don't enjoy a single day of happiness because I'm too melancholy."

"It's disheartening since I keep getting two bags here and there, can't turn to either side, and frequently collapse and get unconscious."

Additionally, this study found that changes in lifestyle following surgery might result in psychological side effects. One person spoke out loud that:

"I was considering shooting myself with a gun because I thought that my life was different before and is different today."

5: Financial challenges

The main problems in Pakistan are unemployment, a lack of health insurance, and a low socioeconomic status; as a result, every person encountered financial difficulties. Many people revealed their struggles with paying for stomas. Other issues were sudden money losses and the need to often change bags due to detachments or bag catastrophes. Certain participants said that:

"Money.... For bag management, I borrowed from others. I'm too poor to pay; one bag costs RS 750 or RS 900 and occasionally multiple bags are screwed up, especially at night."

"To cover the cost of my bags, I was raising cows and buffalo."

Some individuals also mentioned being unemployed and needing financial support from others. People expressed gratitude to individuals who assist them in managing

their stomas. Some people said that they were the sole providers of income for their families, but following stoma surgery they were unable to put in long hours, make a good living, or care for their families. Certain participants said that:

"Before, I was a distributor for WHA Medicine (business name), but now that I'm sick, I'm out of a job."

"Yes. Allah (SWT) blessed all those who assisted me, because after my operation, I lost everything and had no income."

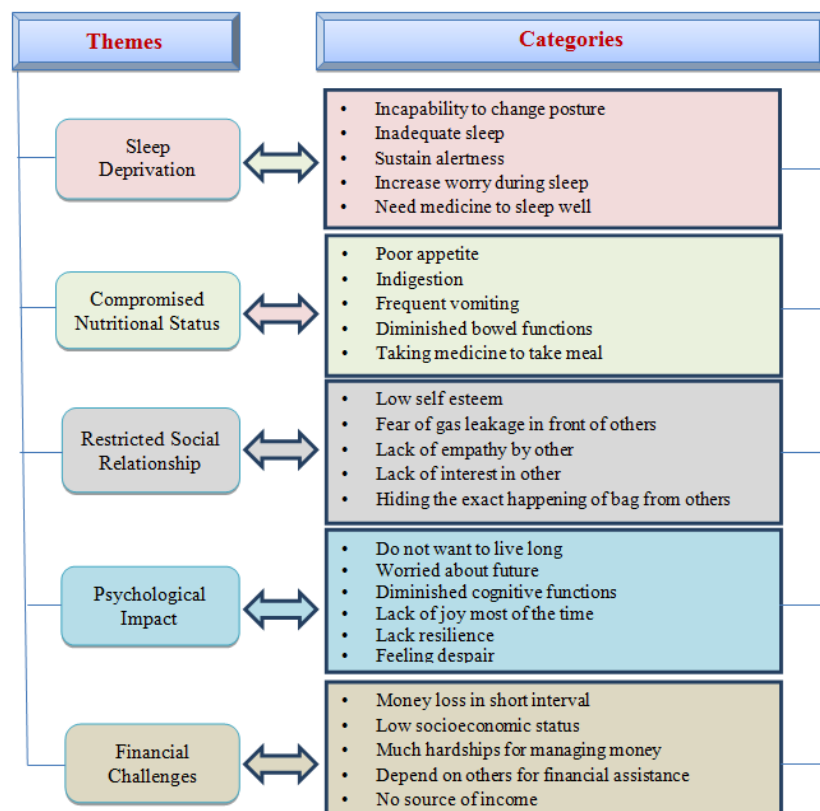


Figure 1. Five main themes and categories, identified in patient living with prolong ostomy.

Discussion

Sleep Deprivation

The participants said that the main causes of their inability to sleep at night were pain and stomal leaks.²⁰ Similar studies show that individuals with permanent or temporary ostomies have significantly disrupted sleep as a result of unchecked gas formation.¹⁸ According to another study²¹, stoma bag overfilling and restricted posture are the causes of sleep disruption. Some participants in this study claimed they did not want to alter their posture and remained awake for extended

periods of time in the same position. According to a study from Turkey, people are too concerned because they don't want to get their sheets and clothes soiled, so they keep waking up in the middle of the night, which disrupts their sleep.²² One responder to this survey stated that he frequently wakes up at night to check for bag overfilling, dirt spills, and GI content, making it difficult for him to go asleep peacefully.

Restricted Social Relationship

According to studies, uncontrolled material leakage and odour from the stoma site might cause people to withdraw and avoid social situations.²³ Numerous people have reported having impaired social relationships for a variety of reasons, including low self-esteem, fear of gas leakage, lack of interest in others, shame, and the desire to keep the stoma a secret. Following stoma surgery, participants also go through a lot of changes that limit their ability to engage with others, such as giving up institutional education, interactive games, personal hygiene, clothing, and hard work. Similar findings, such as poor hygiene, attire, bathing, and activities of daily living (ADLs), have also been documented by other studies.²⁴

Compromised Nutritional Status

After stoma surgery, several people noticed changes in their nutritional habits. According to one study, each form of stoma creation surgery results in different food intake, digestion, and disposal patterns, which contribute to malnutrition.²⁵ In order to maintain an appropriate nutritional status, the sufferer must be instructed to increase their intake of vitamins, minerals, and enough calories in the early days following stoma surgery, followed by a typical diet after 24 to 28 weeks. Some of the respondents to this survey stated that there are a wide range of reasons why individuals reject certain foods, including financial strain, constipation, inadequate appetite, excessive gas production, and other problems.

Another Swedish study indicates that the majority of those who refuse eating do so because of gas production.²⁶ According to research, constipation and gas generation may be avoided by eating small, frequently spaced meals, avoiding eating huge amounts of food at once, and drinking liquids during the meal. There were few self-assessment reports from research participants, but studies have shown that self-ongoing evaluation is necessary to track changes in health status

by assessing daily weight, intake, and output, as well as body mass index (BMI).^{25, 27}

Psychological Impact

According to studies, 18–26% of ostomats exhibit psychiatric symptoms in the first 16 weeks following surgery.²⁸ While a related study found, that 63% of ostomats experience depression following stoma implantation¹⁸. Participants in this research talk about their hate of people, their negative thoughts about others and themselves, and their attempts to damage themselves and others. Similar research has shown that people might hurt themselves due to despair, unfavorable emotions, and insecurity.^{29,30} Another study found that the inability to manage the stoma after surgery or the presence of faces in close proximity might make people feel more uncomfortable.²¹ One young female respondent told that sometime she thinks to shot herself with a pistol when seeing changes in her body after surgery. A similar study was done in Turkey, which suggested that female are emotionally more sensitive and fearful than male and incapable to bear change in body resulting from stoma surgery^{31,32} Impotency is another related factor making the victim anxious and depressed following stomal surgery.²² While conducting this study only one male respondent explored that in the last six month he did not intercourse and the rest of the participants avoid saying something about post stomal sexual life.

Financial Challenges

Some concerns are raised about how they lost their jobs due to stomal surgery and now they are unable to generate money to survive. A related research in Iran found that surgery caused 37 percent of stoma patients to lose their jobs.³³ According to a research from China, 42.5 percent of the patients may return to work following stoma formation surgery.³⁴ The most prominent issues in Pakistan were the lack of a government-sponsored financial or health insurance policy, particularly for those with ostomies. However, other nations where health insurance is not entirely supplied for also experience financial difficulties.²² According to a study, financial hardship is brought on by frequent hospital visits or prolonged post-stomal hospitalization.²² Additionally, the person claims that their poverty prevents them from meeting their nutritional needs as well as stoma and transportation costs. Financial hardship is said to make malnutrition worse in those from poor socioeconomic

backgrounds.²⁷ Additionally, stoma adjustment is substantially better in those with high socioeconomic status compared to those with poor socioeconomic status.³⁴

Conclusion

In conclusion, without investigating his or her experiences, no one can more fully comprehend the pains of those who live with an ostomy. In this study, the perspectives of both male and female patients who have long-term ostomies are thoroughly explored. The findings of the study suggest that in order to make victim life as easy as possible, each individual's hidden aspects of life must be examined and appraised. Restricted Social Relationships, Sleeplessness, Impaired Nutritional Status, Psychological Impact, and Financial Challenges were the life factors that were highlighted in this study.

Additionally, nurses should look at other methods or tactics for minimizing social phobias, addressing nutritional needs, and conducting additional study to find solutions for the aforementioned issues. Government should also create an ostomy Association, financing, and health insurance scheme to meet individual requirements.

Relevance to nursing Practice

- Prior to ostomy surgery, consideration of the stoma must be kept in mind.
- A customized plan of care must be created.
- The diet plan must be modified to meet the demands of each patient.
- The nurses must emphasize the benefits of an ostomy to help each patient adjust to the new way of life.
- For stoma therapy nurses must be hired based on their qualifications and areas of interest.

Relevance to individuals' and families education

- Individual must be encourage about self-ongoing assessment and self-care
- Individuals must be encouraged for reducing social phobia and to maintain social bridge
- Families must be counsel and encourage to learn stoma handling skills
- Old individual should be used as a reference source for the newly diagnose individual to reduce their psychological symptoms
- World Ostomy Day must be celebrated (2 October in 2021) to catch people attention toward this aspect of life.

Relevance to research

- The study finding may provide base that can facilitate nurses for conducting qualitative study.

- Further research can be done to explore other neglected areas to make the life of an individual more comfortable.

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