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PSYCHOSOCIAL EXPERIENCES OF COLORECTAL CANCER PATIENTS WITH STOMA

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ABSTRACT

The formation of a stoma impacts various aspects of a patient's life, including physical, psychosocial, and spiritual well-being. If these impacts are not properly managed, it could decline the patient's quality of life. This study aimed to explore the psychosocial experiences of colorectal cancer patients living with a stoma. Method: twenty participants were interviewed using semi-structured questions, and the data was analyzed using a phenomenological approach. the findings revealed three key themes: emotional reactions having a stoma, limited social interactions, and worries about performing religious practices. Based on these results, the study recommend the need for education for colorectal cancer patients with stomas, particularly psychosocial aspects, to improve adaptation and quality of life.

Keywords: colorectal cancer; colostomy; psychosocial experience; stoma

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INTRODUCTION

Colorectal cancer is one of the most prevalent cancers in worldwide. It ranks as the third most common cancer globally and is the second leading cause of cancer-related deaths (WHO, 2023). In Indonesia, colorectal cancer is the fourth most prevalent cancer incidence and mortality rate is the fifth largest (WHO, 2022). These statistics highlight the significant role colorectal cancer plays as a leading cause of mortality in Indonesia.

Surgery is the primary treatment for colorectal cancer, alongside chemotherapy and radiotherapy. The type of surgery performed depends on the location of the cancer. The goal of this surgery is to preserve natural bowel function. However, when the cancer is located in the lower rectum, the procedure typically involves removing the entire lower rectum, along with the anal sphincter (Rogers, 2022). This results in the patient being unable to defecate naturally and necessitates the formation of a stoma.

A stoma is an artificial opening created in the body to allow the passage of food, urine, or feces (Hinkle et al., 2021). Colostomy and ileostomy are two common types of stomas that replace the function of the anus. A colostomy involves diverting the colon through the abdominal wall to create an artificial anus, while an ileostomy involves bringing a part of the ileum (the small intestine) through the abdominal wall. Both colostomies and ileostomies serve the purpose of removing waste (Hinkle et al., 2021) . However, stoma formation can have a range of impacts on a patient's life, affecting them physically, psychosocially, spiritually, and sexually (Simpson et al., 2023). Patients with stomas often experience body image disturbances, higher levels of depression, and sexual dysfunction compared to those who have not undergone stoma surgery (Aktas, 2015).

These negative impacts can significantly reduce the quality of life for colorectal cancer patients with a stoma (Zewude et al., 2021). Despite this, the psychosocial challenges faced by these patients have not received sufficient attention from healthcare providers, particularly nurses. Nurses play a critical role in supporting colorectal cancer patients with stomas by support patients adapt to their new condition and by preventing the negative impacts associated with stoma formation.

Exploring the psychosocial experiences of colorectal cancer patients with stomas is vital. Understanding their emotional responses, perceptions, and challenges in adapting to life with a stoma will allow nurses to gain deeper insights into the psychosocial issues these patients face. This knowledge equips nurses to provide more effective support and interventions, helping patients adjust to their new circumstances and mitigate the negative psychosocial impacts of living with a stoma. Although studies on the psychosocial experiences of colorectal cancer patients with stomas have been conducted in several countries, research in Indonesia remains limited. This gap prompted the current study, which aimed to explore the psychosocial experiences of colorectal cancer patients with stomas in Indonesia.

METHOD

This study employed a phenomenological approach to explore the experiences of colorectal cancer patients who have undergone stoma surgery. Twenty participants were selected from two hospitals in Jakarta. The inclusion criteria were colorectal cancer patients who have a stoma, are married, and have had a stoma for at least three months. Participants were selected using purposive sampling. Semi-structured interviews were conducted with each participant for approximately 45-60 minutes, continuing until data saturation was reached with the twentieth participant. The location and the time of interviews were conducted based on the patient’s agreement. Prior to the interviews, participants were provided with an explanation of the study and informed consent was obtained. Ethical approval for the study was obtained by Dharmais Cancer Hospital: number: L.B.02.01/1/5388/2016. The interview was transcribed verbatim and the data was analysed using thematic analysed.

RESULT

The participants in this study included more females (12 participants) than males (5 participants). The average age of the participants was 46.55 years, with ages ranging from 24 to 75 years. Participants' occupations varied: 11 were housewives, 3 were government employees, 5 worked in the private sector, and 1 had a different type of job. The average duration of having a stoma was 1.6 years, with the shortest duration being 3.5 months and the longest being several years. In terms of stoma type, the majority (11 participants) had a permanent stoma, while 9 participants had a temporary stoma. All participants identified as Muslim. From the participants' experiences, three main themes emerged: Feeling when first having a stoma, limited social interactions, and worries about performing religious practices.

Feeling when first having a stoma/Emotional reactions when having a stoma

Feeling when first having a stoma was the first themes in this study. This theme describes what participants felt, including feelings of sadness, fear, stress and shock when initially having a stoma. As stated in the following statement:
The first is sad. “*Moreover, there is no one in my environment who has a disease like mine*" (P3).
“Yes... when I remember the illness I'm also sad, I want to cry. But yes, it has to be like this, it's taken almost a year" (P5).

"*What I feel is sad. That's sad. Yes, I said something like that, oh my God, why did I become like this? Is this me, yes, it's called a human...". "Yeah, it was stressful, I was crying..."* (P6).

The feelings of sadness felt by most of the participants were experienced by both participants who had temporary stomas and participants who had permanent stomas. This can be seen from the results of interviews where of the 11 participants who had temporary stomas, 10 participants expressed this feeling. Meanwhile, eight out of nine participants with permanent stomas expressed feelings of sadness when they had a stoma.

Limited social interaction

The theme of limited social interaction is the participant's interaction or relationship with other people or the environment which is deliberately limited by the participant due to the presence of a stoma. Restrictions on social interactions were carried out by participants as a result of anxiety felt, namely, odors arising, bag leaks or worry about being discovered by other people. This is as expressed by participants as follows:
"That's what I said earlier, I'm afraid I'll defecate suddenly, it'll smell bad, if we're just playing or something, oh I'll feel like we're going home. I'm insecure, because I might be too insecure." (P1)

"Before I got sick, I liked going out with my friends. But now I don't go anywhere. I just in and out of my house, in and out... go in and out and go inside. And most of the time I only watched TV" (P2).

"That's what I can't do, I never want to go anywhere. For example, if I go to your friend's house, I won't stay overnight until now. Because it's uncomfortable, so we're going to have to bother cleaning this and cleaning that, yes, it's okay if you're a family, it's just our feelings" (P7).

Worries about perform worship

The theme of worries about carrying out worship is the participant's worry about carrying out worship due to the presence of a stoma. Participants felt dirty, worried about having flatus come out during prayer and having to always change the stoma bag and also limiting their worship activities or not doing the worship they were supposed to do. This was expressed from the participants as follows:
"*So when I was praying in congregation, this sounded. That's gas coming out. So people were shocked, but I just kept quiet. So there's no shame anymore. "If people are sick, they laugh at it, actually there's no need to laugh at it" (P17).*

"Sometimes it's our turn to just want to pray, sometimes the term, just "srooot" is like that, how do we feel like that. So I really want to do that all at once, but sometimes I just get out of the bathroom and go straight back out. Sometimes I just feel annoyed there" (P19).

DISCUSSION

Patients diagnosed with colorectal cancer who require a stoma, facing the situation is often emotionally challenging. This is reflected in the first theme, "Feelings when first having a stoma." Participants in the study reported a range of negative emotions upon learning they would need a stoma, including sadness, anxiety, stress, and shock. These findings are consistent with research by Zewude et al. (2021), which found that most patients with a stoma experience mild to moderate levels of anxiety and depression. Further studies by Aktas (2015) and Gautam and Poudel (2016) also suggest that psychological disorders, particularly anxiety and depression, are common among stoma patients.

All participants in this study expressed negative emotions when they first encountered their stoma, regardless of whether it was permanent or temporary. Many described their initial reaction as one of shock, as the appearance of the stoma did not match their expectations. Over time, some participants reported coming to terms with their condition, but the initial impact remained significant. The presence of a stoma made many feel that their bodies were different from others, as they had to expel waste through an artificial opening in the abdomen. This feeling of bodily difference often led to disturbances in body image, a challenge frequently experienced by stoma patients, as highlighted by Jayarah and Samarasekera (2017). Body image disturbances can significantly affect a patient's psychological well-being and require intervention to address these concerns. However, studies indicate that interventions to address these psychological issues are still limited (Perrin., 2019; Koplin et al., 2016). The lack of focus on psychological care for stoma patients is often due to these issues being overlooked or not prioritized in clinical practice (Ayaz-Alkaya, 2019). Therefore, it is crucial to develop and implement interventions to help patients cope with the psychological challenges associated with having a stoma.

The presence of a stoma also poses significant challenges in the social aspects of patients' lives, as reflected in the second theme of this study: "Limited social interaction." Many participants reported feeling embarrassed about having a stoma, primarily due to concerns about odor, leakage, and the possibility of flatus. These concerns are consistent with findings from Capilla-Diaz et al. (2019) and Zewude et al (2021), who noted that patients with a stoma often worry about these issues. As a result, participants in this study chose to limit their social interactions. They were anxious about how others would react, which led them to restrict their activities, avoid leaving the house, and shy away from meeting others. This finding aligns with research by Capilla-Diaz (2019), who found that stoma patients often experience social withdrawal due to similar concerns.

In addition to the fear of social judgment, participants also limited their ability to engage in social activities because of the physical challenges associated with having a stoma. For instance, the need to regularly change the stoma bag and carry necessary supplies made going out feel burdensome. As a result, some participants chose to avoid social outings altogether. This is in line with Perrin (2019), who found that stoma patients often face difficulties with psychosocial adaptation and exhibit lower levels of psychosocial functioning. Similarly, Gautam and Poudel (2016), observed that patients with stomas experience moderate psychosocial challenges compared to those without a stoma. These findings highlight the need for interventions aimed at improving patients' psychosocial adaptation and social functioning. By addressing these challenges, healthcare providers can help stoma patients enhance their ability to engage in social interactions and improve their overall quality of life.

The presence of a stoma also affects the spiritual aspects of a patient's life, particularly in relation to religious practices. Participants in this study expressed concerns about performing worship due to feelings of impurity associated with the stoma and the constant passage of feces. This is reflected in the third theme of the study: "Worries about carrying out worship." Many participants worried that, during worship—especially in a place of worship—there might be an unexpected release of feces, which could make others aware of their stoma. These conditions indicate stoma patients often worry about their ability to perform religious duties properly, fearing that the stoma might interfere with their worship. As a result, some participants preferred to pray at home rather than attend communal worship, reflecting a sense of discomfort and reluctance.

This finding is consistent with the work of Cavdar et al., which showed that stoma patients experienced a decline in participation in religious activities after their surgery compared to before. Another major concern expressed by participants was the constant worry about cleanliness. Due to the continuous passage of feces, many felt they were unfit to worship and, as a result, avoided performing religious rituals. All participants in this study were Muslim, and in Islam, maintaining ritual purity and performing ablution (wudu) before prayer are essential components of worship. The participants' worries about their physical cleanliness—especially when feces might continue to leak—created anxiety about their ability to perform worship properly. Given these concerns, it is essential to provide stoma patients with education about how to maintain cleanliness and perform religious rituals despite having a stoma. Teaching practical solutions for performing ablution and offering guidance on how to manage the stoma during worship can help alleviate these worries and enable patients to continue practicing their faith with confidence and comfort.

CONCLUSION

This research identified three main themes: feelings about having a stoma, limited social interactions, and worries about perform worship. The findings indicate that patients with a stoma experience a range of psychosocial challenges, which, if left unaddressed, can negatively impact their quality of life. Therefore, interventions, particularly education focused on the psychosocial aspects of living with a stoma, are crucial for colorectal cancer patients. Providing such education is expected to enhance patients' ability to adapt to their condition, ultimately improving their overall quality of life.

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