

# Prior Knowledge, Acceptance, Adaptation, and Challenges Following Stoma Formation among Colorectal Cancer Patients in Northern Peninsular of Malaysia: A Qualitative Study

Md Ali SM<sup>a</sup>, Ahmad F<sup>a</sup>, Mohamad Noor MHS<sup>b</sup>

<sup>a</sup>Clinical Research Centre, Hospital Sultanah Bahiyah, Alor Setar, Kedah, Malaysia.

<sup>b</sup>Surgical Department, Hospital Sultanah Bahiyah, Alor Setar, Kedah, Malaysia.

## ABSTRACT

**INTRODUCTION:** Stoma formation affects an individual in various ways, including physical, emotional, social, and cognitive functions. Diverse studies report ways of an individual lives with new stoma formation. However, the comprehensive understanding of the entire process by the patient, which includes knowledge before the surgical procedure, as well as the subsequent acceptance, adaptation, and challenges to living with a stoma is lacking. **MATERIALS AND METHODS:** In-depth interview session were conducted with 12 colorectal cancer patients who have undergone surgical procedures for intestinal stoma formation. The patterns and themes within the data were identified by thematic analysis, involving data familiarisation and coding followed by themes' generation and refinement of the themes. **RESULTS:** Four themes and 9 subthemes were identified, which revealed the sufficiency of stoma-related information and understanding prior to surgery as well as positive acceptance of self and family members reflected through their reactions and support. Nonetheless, the challenges were anticipated which highlights the complications of the stoma itself, obstacles surrounding social life, and financial burdens. **CONCLUSION:** This study provided valuable insights into the experiences of individuals living with a stoma following colorectal cancer surgery. The themes and subthemes highlight the need to address social stigma as well as financial issues to alleviate the burden of stoma-related expenses. Increasing public awareness and improving financial assistance could be a way to enhance the overall quality of life for patients living with stoma.

## Keywords

Stoma, prior knowledge, acceptance, adaptation, challenges

## Corresponding Author

Dr. Siti Maisarah Md Ali  
Clinical Research Centre,  
Hospital Sultanah Bahiyah, KM 6,  
Jalan Langgar, 05460 Alor Setar, Kedah.  
E-mail: sara\_ally85@yahoo.com

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## INTRODUCTION

Living with a stoma among colorectal cancer (CRC) is a frequent condition seen in the communities in many parts of the world. Approximately one in 500 persons are living with a stoma, which contributes to an estimated 21,000 formation of stomas each year in the United Kingdom.<sup>1</sup> In Japan, it was reported that 29.6% of permanent stoma was done for male patients with poor healing of anastomotic leakage.<sup>2</sup> A study conducted in a single centre in Singapore reported about 93 colostomy were done in five years.<sup>3</sup> Intestinal stoma is created through colostomy or ileostomy surgical procedure, mostly done if gastrointestinal malignancy and other causes of intestinal obstruction, trauma, bowel ischemia, and inflammatory diseases, as part of the treatment that requires faeces diversio.<sup>4,7</sup> In stoma formation, the waste matter is collected in a bag that is attached to a small opening on the surface of the abdomen.<sup>7-8</sup> There are different types of stomas based on the location created along the colon, which can be temporary or permanent.<sup>6,9</sup> Temporary stomas are reversible, where reconnecting the remaining parts of the bowel by further surgery to allow the patient to defecate normally, while permanent stomas are irreversible and thus retained lifelong.<sup>7,10,11</sup> The formation of both types of stomas are to improve the situation of the patients by removing symptoms and parts of treatment.<sup>10</sup> Despite the benefits stomas provide, there were complications reported post construction of the stoma locally, causing skin irritation, re-construction issues, and loss of control

of bowel opening including loud flatulence and leakage.<sup>4,12</sup> The presence of stoma is also shown to have an impact on the patients' self-confidence concerning appearance and self-image.<sup>4</sup> In addition, previous studies demonstrated that the quality of life (QOL) among patients living with stoma also affected in general, regardless of the type of stoma.<sup>5,11,13</sup> As a result, living with a stoma leads to an alteration in their physical activities and psychosocial responses.<sup>14,15</sup> Delays in adapting to living with a stoma and less social support from family members increase stress of these patients, leading to feeling of stigma and restricted.<sup>13,16-18</sup> This showed that living with a stoma influences the general aspect of their overall QOL<sup>19</sup> (ideas repeated). The data on stoma formation based on the perspectives of patients is scarce including in Malaysia. Thus, this study was aimed to explore the perspectives on the acceptance, impact, and QOL of CRC patients who must live with a stoma.

## **MATERIALS AND METHODS**

### **Study Design and Participant**

A phenomenological study design was adopted, using purposive sampling. An individual who was diagnosed with CRC in Hospital Sultanah Bahiyah (HSB), over the age of 18 years who had undergone stoma formation surgery (both elective and emergency surgery) within a month period and can communicate in Malay or English were recruited. In all 12 Patients were recruited. The reporting of this study complies to the information of the standard for reporting qualitative research (SRQR).<sup>20</sup>

### **Data Collection**

The interview was conducted using a semi-structured guided, developed by the authors following a five-step process.<sup>21</sup> The process began with important review by all authors in developing the interview questions to reflect the study objectives based on previous available knowledge.<sup>4,13,14,22,23</sup> To avoid biases and also ensure the appropriateness of the content, two other experts from the related field were also invited to revise, validate, and improve the interview questions. Later, the preliminary semi-structured interview guide was developed and tested for a pilot study with two participants who met the study criteria to refine the interview questions. Finally, a set of

several interview questions was developed, covering the participants' knowledge regarding stomas prior to the procedure, their experiences with close friends or family members afterward, and also the difficulties they (as patients) and their caretakers encountered in adjusting to life with a stoma. The first author is a medical doctor, and the second author is a research officer both have experience in conducting qualitative research and work in a clinical research department and are involved in multiple clinical trials surrounding the CRC area. The second author is a certified translator of Malay to the English language.

The third author is a nurse who is a certified stoma care educator who works in a surgical department. Potential participants were approached during their admission in the wards in Hospital Sultanah Bahiyah and briefed them on the objectives and methods of the study. All queries and concerns were answered accordingly before consent from the patients was obtained. The interview sessions were arranged according to the availability of the patients. Some participants were willing to be interviewed immediately after the consent was obtained, but others for personal reasons wished to proceed with phone-call interviews. Phone-call interviews were arranged within a week of obtaining the consent. The interview sessions were done between 3<sup>rd</sup> July and 1<sup>st</sup> August 2022, conducted in the presence of all the authors. The duration for each interview session varied for approximately 34 to 57 minutes.

### **Data Analysis**

The audiotaped interviews were transcribed verbatim and translated within a week of each interview session. To ensure accuracy, completeness, and consistency, the transcripts were reviewed carefully. We adopted the six-stage comprehensive thematic analysis (TA) approach by Braun and Clarke in conducting the TA, included reading the transcripts multiple times to immerse in the content, identifying the meaningful quotes and describing them into codes, and developing themes from the collated codes and subtheme to create a relationship with the theme.<sup>24</sup> To ensure data consistency, triangulation was conducted between all authors. The final themes that suited the

objectives are presented herein. The interview sessions were stopped when the data had reached saturation points.<sup>25</sup> No repeat interviews of patients were carried out.

## RESULTS

### Characteristics of Participants

Most of the 12 participants were females (~58%, n=7), of Malay ethnicity (~83%, n=10), with educational level up to secondary school (~75%, n=9), and married (~83%, n=10) (Table 1).

### Themes and Subthemes

Four themes and eleven subthemes were identified from the analysis.

#### Theme 1: Prior Knowledge

##### Subtheme 1: Information From the Attending Physician

The participants reported that they were informed by the attending physician about the importance of stoma formation, to relieve the symptoms and there will be some changes to their life routine.

"Right before the operation, the doctor had a brief chat with me and mentioned that because of the tumour, I wouldn't be able to pass stool as usual. He explained that getting a stoma could help solve this problem." (#01)

"Hmm, the doctor informed me that the tumour near my anus was causing severe constipation. He explained that after the surgery, it wouldn't be possible to reconnect the colon to the anus opening. That's why they recommended creating a stoma to help me defecate." (#03)

##### Subtheme 2: Patient's Understanding of Stoma Formation and Function

Following the explanation provided, the understanding of stoma formation and function among the participants is acceptable.

"The colon was connected to the abdominal wall like an opening for passing stool" (#02)

The participants understand that the stoma creation is part of the treatment strategy:

"Because I got tumour near the anus, I cannot pass faecal normally, so the doctor connecting my colon with a stoma bag, meanwhile, I need to undergo 12 cycles of chemotherapy. And if the healing process is well, the doctor might reconnect back." (#11)

These facts assisted them in appreciating the stoma formation even before the surgery happened:

"After the stoma formation, I feel better and comfortable, I can eat and pass stool well and it easier for me to go anywhere" (#04)

#### Theme 2: Acceptance

##### Subtheme 1: Individual Acceptance

In general, most of the participants felt unhappy the first time saw the stoma. Their most concerning issue was to manage the stoma on being discharged. Eventually, the participants reported that they could accept the stoma completely:

"Initially, I really cannot accept it. To manage the stoma and the bag is a bit complicated. But after, I get used to it." (#05)

"I felt worried in the beginning. I think it is difficult to wear and carry the stoma bag, I felt sad, but now...I'm okay" (#06)

##### Subtheme 2: Family Members' Acceptance

The participants claimed that their family members could accept the fact that they need to live with stoma but there is some concern regarding the development management and of later complications:

"My family was worried about me having to live with a stoma. Ultimately, they are fine and assisted me to manage it" (#07)

“My children supporting me and helped me to manage the stoma, I feel so grateful” (#01)

“Initially I felt that I’m a burden to my family. But they are fine and supporting me” (#09)

### **Theme 3: Adaptation**

#### **Subtheme 1: Self-Managing of Stoma**

At initial phase, the participants reported that they were assisted by other family members in managing the stoma before they are on their own:

“Before this, my daughter helped me. But now I can do it myself, it is easy” (#06)

“At the beginning, it is difficult. But after a while, I get used to it. My children care and help me” (#05)

#### **Subtheme 2: Support of Family Members**

Participants reported that they get full support from their spouses, children, and their colleague. They have no problem doing routine activities like sleeping and eating together.

“All my family members are positive about the situation, and they advise me to accept this. There is no issue with eating and sleeping together with them” (#02)

“I’m grateful because my friends, and family members, they did understand and accepted my condition” (#09)

### **Theme 4: Challenges**

#### **Subtheme 1: Complication from The Stoma**

Despite positive acceptance and adaptation, they claimed that wearing a stoma bag somehow makes them feel some discomfort and awkwardness in doing routine activities.

“I find it difficult to take care of this. It is dirty. I must change the bag every two to three days. My wife helped me. It is a bit challenging to go out and do activities. I did experience leaking and limitation in doing activities” (#08)

The complication is even harder for the participants with a visual disability and food allergies:

“My eyes can’t see clearly where a hole is to stick the bag. So, I need help from my children. Sometimes I got some rashes surrounding the skin. If I ate certain food...I got itchy, but it resolved after applying cream” (#01)

#### **Subtheme 2: Social Life**

Almost all participants reported that their social life is very much affected, particularly when it comes to managing the stoma bag when they are out in public and surrounded by other people. One of the participants detailed:

“I’m unable to control the bowel open anymore. When I go visit some friends at their house, I’m afraid to eat because usually after eating the stools will come out...I felt embarrassed to manage this at someone's house. If I do it at a gas station, the equipment is not complete, and difficult for me. At the beginning, it was hard to adapt. Later, I get used to it and prepared everything in the car boot so that it will be easier for me to manage it everywhere I go” (#09)

A Muslim participant stressed the challenges when it comes to performing prayer:

“I went to the mosque for prayer, when the gas coming out from the stoma, occasionally it makes a loud sound and I feel embarrassed” (#10)

Meanwhile, participants clarified that the stoma formation indirectly affected their sex life.

“My genital...I think it is functional but not as good as before. I mean...sometimes it’s not functioning at the right time but luckily my wife understands this situation. Sometimes this issue can cause marriage problems” (#09)

“I tried having sex with my wife. But it cannot last long, and I became tired instantly. My wife is not complaining as this is beyond my control” (#08)

#### Subtheme 4: Financial Burden

Most of the participants were unable to continue working after the surgery. They reported that living with the stoma increases their cost of living.

“For me, it is a bit of burden, I cannot work anymore. Need to buy the stoma bag and the price is quite expensive...depends on the quality” (#08)

“I need financial assistance to reduce my financial issues. In this situation, I regularly need to buy spray, cotton, and stoma bags. I did apply for financial assistance from the welfare department, but it was rejected since I got a business registered” (#09)

“For me, financially burden, I don't have enough money to buy all the stuff. It can cost up to RM10 per day or for 2 days depending on how frequently I changed the stoma bag. Estimated about RM300 needed to be spent per month, to buy the cotton, the sterile water, sometimes it will take up to RM400 per month.” (#03)

Financial aid is an important element of support that is needed by the participants. At this stage of disease, they lose their employment due to physical incapability and treatment engagement. The participants claimed they got financial aid but not enough to cover the entire cost.

“I got financial aid but not enough, I still need to add from other sources to accommodate the cost...and I need to reapply for the financial aid every 6 months” (#03)

“I feel quite a burden... I got financial assistance from “*zakat*” every month... this helped me a lot of cause to buy the stoma bag is too expensive” (#07)

#### DISCUSSION

The study explored the individual perceptions of living with stoma among CRC patients. The information that is valuable to be brought into attention, especially to the health care provider and related agencies in achieving better outcomes to improve the quality of life among the patients and their caretakers. Majority of study patients had sufficient basic knowledge of stoma formation and its

function, which they had acquired pre and post-operatively from the healthcare providers. This helped them psychologically in better accepting of the stoma. This is consistent with a previous study where understanding the stoma formation and its function is crucial in managing the stoma, and being mentally prepared in the aspect of stoma appliances, appropriate exercise, proper diet, and its complications.<sup>26</sup>

Furthermore, a comprehensive evaluation was conducted to determine whether education of patients with stoma formation improves their quality of life and is cost effective. This study demonstrated that structured patient education tailored to patients' psychosocial needs appears to have a positive effect on both quality of life and cost, and the procedure could be carried out before, during or following the admission.<sup>27</sup> Poor acceptance and adaptation among the stoma patients were anticipated. The participants felt insecure and concerned about managing the stoma at home immediately after getting discharged. However, they were fortunate to have great family support and empathy.

Realization and support from family members are critical in reducing the burden of the individual in coping with the situation.<sup>22</sup> Acceptance of bodily change following stoma formation is important to be achieved soon after operation to expedite the familiarity with the practical management skills of the stoma including its possible later complication.<sup>28</sup> The complications from stoma formation starting from the first year up to year five of the formation, are categorized into early and late complication, including skin excoriation and leakage from the appliance.<sup>29-31</sup> Early developed complications such as stomal ischemia, retraction, parastomal abscess, and mucocutaneous separation, and late complications included parastomal prolapse, hernia, retraction, and varices.<sup>29,31</sup> Participants clarified that they experienced similar to those commonly reported complications throughout the period. however, it is tolerable. Participants were assisted by their family members to manage the stoma in the early days but later, they were able handle it themselves. The stoma has been reported affected the individual relationships with their caretakers, in the aspects of emotional, health, and economic.<sup>24,32,33</sup>

However, this study found that the relationship between participants and their spouses, and the people surrounding them are significantly not affected in that the relationships were not changed.

Nevertheless, participants reported that their sexual relationship is affected indirectly by the stoma, as the root of the issue could be probably due to the complications of the cancer itself, which caused them to be easily tired on exertion and malfunction of the genital organ. Stoma formation can affect sexual ability in various ways, attributable to feelings of being unattractive, sexual performance anxiety, and issues related to stoma appliances like leakage and odour.<sup>35</sup> Moreover, participants reported that they needed a few months to resume back to the normal routine especially taking part in the heavy duties, due to fear of harming the stoma.<sup>36</sup> Social lives of the participants are affected in general, they felt embarrassed, stigmatized, and had low self-esteem while in public, especially for the Muslim community during performing prayer in congregation.

However, to overcome these issues, the National (Malaysian) Fatwa has announced the decision of the 79<sup>th</sup> National Fatwa Declaration concerning the Law on the Implementation of the prayer for patients with stoma bag which the patient with stoma bag is categorized as those who have an emergency problem and are not considered to be bearer of dirt. Therefore, he/she does not need to clean the stoma bag every time want to take *wudhu* and perform prayers. Notwithstanding, they should take *wudhu* every time before performs the prayer.<sup>37</sup> Moreover, previous studies have reported that stoma affected their physical, mental, and social well-being.<sup>32,38</sup> The participants clarified they were encountering financial constrain since living with the disease and stoma, as they are unable to continue working. Furthermore, it was reported that the individuals who were younger with income instability showed distress on their employment and financial status while individual who is retired and with continuous income reported to be more tolerant in accepting the stoma.<sup>39</sup> Most of the participants needed financial assistance in managing the stoma. Partly of them got financial aid from an authorized government agency, although it is not enough to cover everything, the financial support can ease

parts of their financial burden. Thus, it is crucial for stoma educator (stoma nurse/physician) to provide correct education and management of stoma to improve the QOL of the patients, especially prior knowledge, so the patients are adequately prepared both physically and mentally before undergoing the procedure.

## CONCLUSION

In this study, individuals with stoma formation were mentally prepared to start their journey with stoma alongside getting support from family members. So, they can cope with complication and social issues. However, sexual dysfunction is an issue mainly among male patients. An individual who is unable to earn for living faces a financial burden and is supported by other family members. This information could be a guide to relevant authorities in revising their priority of financial aid, or the public health sector in refining their health awareness campaign which ultimately could improve the QOL of patients.

## RECOMMENDATION

A prospective study should be conducted in the future to address and understand the effect of stoma over a longer time. The combination of qualitative and quantitative research should be done to obtain richer information on this issue.

## LIMITATION

This study did not include the perspective of the stoma educator, this information should be explored to determine any deficiencies in stoma education and could enhance patients' knowledge in the future.

**Table 1:** Summary of socio-demographic characteristics of the participants

Patient code	Age (years)	Gender	Ethnicity	Level of education	Occupation	Marital status
#01	71	Female	Malay	Secondary	Housewife	Married
#02	28	Female	Malay	Tertiary	Unemployed	Single
#03	53	Male	Malay	Tertiary	Unemployed	Married
#04	64	Female	Malay	Secondary	Housewife	Married
#05	69	Female	Malay	Secondary	Housewife	Married
#06	53	Female	Malay	Secondary	Housewife	Married
#07	22	Female	Malay	Secondary	Unemployed	Single
#08	56	Male	Chinese	Secondary	Retired	Married
#09	53	Male	Malay	Tertiary	Fisherman	Married
#10	56	Male	Malay	Secondary	Bank officer	Married
#11	63	Male	Chinese	Secondary	Retired	Married
#12	53	Female	Malay	Secondary	Housewife	Married

## INSTITUTIONAL REVIEW BOARD (ETHIC COMMITTEE)

This study was approved by the Medical and Ethics Committee, Ministry of Health Malaysia (NMRR ID-22-00251-0XV).

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