

ORIGINAL ARTICLE

Adaptation Experience of Colorectal Cancer Patients to Stoma in Padang City

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ABSTRACT

Background: Colorectal cancer patients have various effects after colostomy such as skin irritation, problems with odor, and fear of pouch leakage which will affect their daily life. Patients must be able to adapt to new situations due to the stoma so that they can carry out daily activities as usual. **Objective:** This study aims to explore the experience of adaptation of colorectal cancer patients to the stoma. **Methods:** The research was conducted with a qualitative design with a grounded theory approach. Semi-structured interviews were conducted on six participants (one male and five female) who were taken purposively with the criteria that a stoma had been installed for more than 4 months at the General Hospital in Padang. **Result:** The results showed that the core category was the patient adaptation to the stoma based on Roy's adaptation theory with two selective codings, namely the impact of the stoma as a stimulus with axial coding of physical impact, psychosocial impact, and spiritual impact. The second selective coding is a coping mechanism that is carried out by axial coding of strategies to overcome physical impacts, strategies to overcome spiritual impacts, and the existence of social support that helps overcome psychosocial impacts. **Conclusion:** This study shows the process of adaptation of the ostomate to the impact of the stoma with various strategies and the presence of social support.

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1. Introduction

In Indonesia, colorectal cancer is one of the most common types of cancer, with an increasing number of patients every year, and is more often found in men (Sulo et al., 2017). The incidence of colorectal cancer in Indonesia is 12.8 per 100,000 adult population, with a mortality rate of 9.5% of all cancers (Health Research and Development Agency of the Indonesian Ministry of Health, 2018). Most colorectal cancer patients require a colostomy, which is a procedure that connects the colon to a stoma on the skin on the abdomen as a place for the expulsion of fecal material, and then a pouch is attached to the stoma with the help of a special adhesive to collect feces (American Cancer Society, 2017). Dr. M. Djamil Hospital is a type A hospital in West Sumatera and is a referral hospital for central Sumatera. In 2018 the number of colorectal cancer sufferers at Dr. M. Djamil Padang was as many as 51 people, and as many as 22 patients underwent a colostomy from January to June 2019.

Colostomy causes many changes and challenges for patients in living daily life such as stoma care, work problems, and disturbances in doing routines (Zhang, Kam, Wong, & Zheng, 2017). There are several limitations experienced by patients, including limitations on daily activities, limitations in marital and social relationships, negative feelings, financial difficulties along with the increasing needs of life (Alwi & Asrizal, 2018), changes in physical and rest needs,

and challenges to complications that may occur (Susanty & Rangki, 2016). Changes in quality of life and subjective well-being begin when the patient notices gas or odor coming out of the ostomy and when complications begin to appear, such as painful dermatitis. Most patients feel shy so they withdraw from social activities (Salomé, Almeida, & Silveira, 2014). Patients also experience changes in the implementation of worship rituals and there are expectations from patients to further improve the quality of their worship and guidance in worship after having a colostomy (Arafah et al., 2017).

Patients with an ostomy have a perception of self-image, think that their body is different from the usual, and suffer from the views of the social environment (Palomero-rubio, Pedrazmarcos, & Palmar-santos, 2018). Ostomy tends to harm the patient's psychosocial well-being so that the perception of low body image implies that adaptation is not going well and psychological rehabilitation is not optimal (Jayarajah & Samarasekera, 2017). Humans as a system use the coping process to adapt to environmental changes that are influenced by internal and external changes that refer to residual, contextual, and focal stimuli. For research analysis, the results of this stimulus can be seen as 4 interconnected modes of adaptation, namely physiological/physical, self-concept/group identity, role function, and interdependence. Adaptation is described as a process of the thoughts and feelings of a person as an individual or a group using awareness and choices to create conformity (Roy, 2014).

The adaptation process is a lifelong process of adjustment to new circumstances where this individual process takes time starting when the patient with an ostomy needs help until he can be independent in self-care (Salomé et al., 2014). Several studies state that patients with chronic diseases need time to adapt and rearrange their lives according to the changes that occur. Patients with colostomy face changes related to fecal elimination function, limited dressing and always use several strategies to adapt to their new body conditions. This new condition sometimes creates embarrassing situations and anxiety which negatively affects the adjustment process (Sun et al., 2013). Knowledge and understanding of patient adaptation are very important in helping to develop nursing knowledge to plan appropriate nursing care so that it can improve the patient's quality of life. Research on the adaptation of colorectal cancer patients to ostomy in Indonesia is still limited. It is hoped that by knowing the patient's adaptation process to the ostomy, nursing care can increase the role and ability of nurses in providing care. Therefore, this study aims to understand and explore the experience of adaptation of colorectal cancer patients to an ostomy.

2. Method

This research is qualitative research with a grounded theory design and uses the Strauss-Corbin approach. Grounded theory research is qualitative research that has been widely used in nursing, this theory is to study the design process that describes the patient's experience of adaptation to their illness (Donsu, 2016). The population in this study were all colorectal cancer patients with an ostomy at the General Hospital in Padang, which is a regional referral hospital. The selection of participants was carried out purposively with the inclusion criteria being willing to be a participant, having an ostomy for at least 4 months, and without complications with a total of six participants. A written consent statement was obtained before the interview was conducted. The study was conducted from January to December 2020. This research has passed the ethical test at the Health Research Ethics Committee of RSUP DR. M. Djamil Padang with the number: 158/KEPK/2020.

Data were collected by semi-structured interviews conducted in the Minang language following interview guidelines with several open-ended questions and then developing questions that explored feelings, perceptions, and thoughts about participants' experiences in adaptation to ostomy for 30 to 55 minutes. All interviews were conducted by the first researcher. Key points and participants' non-verbal responses were recorded as field notes at each interview. Data collection and analysis were carried out simultaneously. Data collection was stopped because

saturation had been reached where no new information was obtained. All interviews were recorded and transcribed verbatim in Minang language which was then adapted into Indonesian.

Data analysis was carried out simultaneously using the constant comparative method which involved concept formation (open coding, axial coding, and selective coding) (Japhet & Usman, 2013) and concept development (comparing with existing literature and concepts) (Afiyanti & Rachmawati, 2014). At the stage of forming the concept, the researcher analyzed the transcript line by line using open code 4.0 software. Validation of research results was carried out by member check where participants re-examined the transcripts that had been made and ensured that the interpreted information was correct. Trust and credibility are carried out by peer debriefing and comparing the data with the existing literature.

3. Results and Discussion

3.1. Result

Six participants were interviewed with an age range of 27-60 years. Participants consisted of one male and five females. All participants are Minang ethnic and Muslim, five people are married and one is a widow. two participants with a permanent ostomy, two temporary ostomies, and two have undergone ostomy closure. This study reports two selective codings, namely the impact of the stoma as a stimulus to the patient and the coping mechanisms that the patient uses to overcome the impact with one core category that unites all data, namely adaptation in stoma patients.

Selective coding: Stoma impacts as a Stimulus Ostomy impacts as a stimulus

1) Physical Impact

The physical effects felt by the participants included irritation of the skin, difficulty in finding a sleeping position, and the feeling of an enlarged stoma during activities.

"The discharge can't be controlled, right, sometimes we just want to pray, sometimes we fart... sometimes it comes out a little" (P1)

".. it's moist, sis.. in that stomach.. so red, sis.. itchy, sis.. at that time I was in the car for a long time, sis.. didn't have time to exchange it right.. that's why it's moist, sis.. the meat is red, sis..." (P2)

"When you sleep, the intestines are okay, but when you stand up, they swell up, what's the swelling? We've been a little bit tougher for a long time if yesterday it was soft, so it hurts, there's a stinging pain in the pouch, right, around the intestines... so it seems that if you change the bag over time, it becomes a bit red (P4)

"Uni, when I sleep, it's hard to tilt, right... well... when I open the bag, it hurts... it hurts so bad" (P3)

Participants also said that they limit activities such as not lifting heavyweights

"As usual... but not heavy work... like washing... washing clothes right, there are my children who help" (P3)

"I can now go to the market but when I go shopping, I go with my children or my husband... because I can't carry heavy items, right.." (P6)

Two participants said they had no appetite

"When it was installed, my body was thin, sis... Only 36 kgs.. I didn't want to eat.. I even couldn't have a half portion of my food at that time, because I thought about ostomy, right sis..." (P2)

"I used to lose 20 kilograms of weight, now I have gained more weight" (P5)

2) Psychosocial Impact

Some participants said that they felt ashamed of their friends and even family, they felt ashamed and had low self-esteem and did not want to leave the house, as follows:

"... the first time it was installed, there was a feeling of inferiority, right... What we are afraid of its smells.... (P1)

"... it's a shame to meet friends in this condition... I'm afraid that I'll smell... I used to be like that when I had my ostomy. I never left the house... it's a shame if I meet friends," (P5)

".. at the first time is.. I just stayed at home.. about a month sis.. I just stayed in my room sis.." (P2)

Other participants also had a fear of seeing the stoma for the first time so they were unable to clean themselves.

"Yes.. I was surprised to see the ostomy... I used to be afraid if I had to clean it, I always asked my wife to clean it," (P5)

3) Spiritual Impact

Most of the participants initially felt hesitant to do worship because they felt smelly and because of uncontrolled defecation, such as the following statement:

"Ah, sometimes we just want to pray, sometimes we fart out... sometimes it's a little feces that comes out... aaa So I never prayed to the mosque since then... for five years... yes I was disturbed when I worship..." (P1)

"if" To worship, I have a desire to worship, but my clothes smell... I was still hesitant about praying right... I want to ask the doctor if it's okay for me to pray in this condition or not... so I have not prayed yet, if there is so much defecation that the smells will stick to the clothes, then our prayers are invalid, right... that I want to pray, but because the smell sticks to the clothes... it doesn't touch the clothes but the smell sticks to it..." (P3)

"Prayer... when it's new, when it's just installed, I couldn't prayer... then I sit... but when I sit, I couldn't be too stooped, now it's okay... (P4)

"I used to have doubts about this prayer, didn't I.. How do I feel about it... because the discharge doesn't feel right... so I don't feel clean right..." (P5)

"I was hesitant at first, didn't I want to pray like that.. but I still wanted to pray.. when the defecation came out, I repeated the prayer... well, I repeated it quite often, right..." (P6)

One participant said that he felt he had sinned as follows:

"This is sis.. my thoughts at that time sis.. it feels like that.. is there anyone else who also has a disease like this... is it just me... what sins have I committed, sis... to get this disease.." (P2).

Selective coding: Strategy Coping

1) Strategies to Overcome Physical Impact

Participants were able to adapt to several strategies carried out such as strategies for diet and ostomy management. such as the participant's statement as follows:

" Alhamdulillah, I can control the smell... ooo I don't wait until the pouch is full... so I, just think about it... if it's more than half the pouch is full... I'll replace it again... So I, just think about it... so it doesn't smell like that, right?" (P1).

" recently yeah... it's not too much of a problem, that's the pouch, right... if it's full, I'll replace it quickly. I'm wearing diapers... I'm just doing it again... don't bother.. because I'm wearing diapers... I put on diapers, right, so it's not too bad... oops if it gets swollen... it's rocking and hurts... if I wearing a diaper, then pants.. doubled in wearing diapers and pants.. okay.. ooo the smell also doesn't come out right.." (P4)

Some participants made dietary modifications by avoiding certain types of food and adjusting food portions, such as the following statement:

"mmmhh.. I avoid jengkol and petai, huh... haha I don't eat it... I eat every food other than those two.., I eat everything... aaa, only I eat a lot of fruits and vegetables..." (P1)

"if for the itchy one, Sis, sometimes it's watery, so the doctor says I should manage it.., Sis... because if we eat a lot of watery food, right... just water comes out, sis... if you eat a lot of hard... then the feces will hardly come out, sis... so I'll just adjust the diet, sis... I manage it by eating half of portion, I just made half of it... let it be often but not much... that's what he said, sis, so the bowel movements are controlled, sis..." (P2)

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"oooo... now I set the food myself... I noticed... now I eat a little but often like that is how I manage it. I Just take watery food less so that the discharge is controlled, right..." (P5)

One person said how to deal with discomfort from a stoma as follows:

"More often to the right... if you go to this side (left) it makes him squeeze... so I tilt to the right more often... if you sleep on your back, it's uncomfortable..." (P3)

2) Strategies to Cope With Spiritual Impact

Spiritually the participants began to accept their current condition by thinking that all diseases came from Allah and to remove sins, as expressed by the following participants:

"Grateful that we are still given our lives, right, Sis... I believe that God will not always give me hard time.... what makes me ashamed... if that is the way that Allah has given to me... I believe that Allah will not last forever gave me a disease like this... that's my answer, sis... I'll be strong when I think that everything will be returned to Allah..." (P2)

"Yeah.. I am doing it right now... it's all from Allah, if we're sick, we just treat it... we don't know that maybe Allah take our sins away, maybe we don't know what behind this..." (P4)

"Now it's okay..., right.. right, if we are sick, we treat it, right... but when you die there, you can't avoid it, but we try... so what's the term? I've given up to Allah right.. " (P6)

Some participants have started to perform worship services such as praying, although some only pray at home and repeat ablution because they fart or defecate, as stated by the following participants:

"That... if we want to pray the witr prayer, do the tarawih prayers, how many times do I repeat the ablution... how many times have my husband wait... for five years, I just pray at home..." (P1)

"For worship, Sis... I asked Ustadz Sis... when I was at M.Djamil, I also asked physician... I asked him... What if our prayers were when we were sick like this, sir... So the ustadz answered that's sis... if it's not unclean... it's a disease that was given by Allah so we return everything to Allah... whether or not our worship is accepted, the important thing is that we are not negligent... we don't forget... still that time" (P2)

"So I asked the ustadz nearby... how I do pray... The ustadz said it's okay to pray, it's a disease... So Alhamdulillah, since then I've been praying.. it happens often again and again... It's Allah who decides right.. whether our prayers are accepted or not, it is Allah who determines what is important is that we carry out .." (P5)

3) Social Support That Helps Cope With Psychosocial Impact

Participants can go through anxiety and fear that cannot be separated from the support given by their partners, families, people around participants, support from fellow survivors, and support from health workers. As stated by the following participants:

"Finally I went to Jakarta where the party was.. aa there was no problem with my family.. even they slept with me... I asked.. did I smell .. my husband is like that, right, if anything... if you want to get married to another woman, please come on.. that's what I said to him.. don't be like that... I don't want to be married anymore.. that's my husband's answer .. Alhamdulillah, my husband always accompanies me while I am sick..." (P1)

"because of I Thinking about my children... the children gave me the strength, right... I have six children, the oldest is in 3rd-grade junior high school, the youngest is 5 years old... so I think about how I can recover quickly... I feel sorry for the children, they are still young, right..." (P3)

Some participants said that they received support from friends such as the following:

"That friend is my inspiration, Sis.... sometimes there are many friends who give support, sis.. they say.. what do I think, we also don't know what the future will be like... maybe we will be worse than this tomorrow... I'm still hanging out with my friends" (P2)

"I'm a person who can't be idle like that, so I went out.. no one looked disgusted at me right.. I can now go to the market .." (P6)

Participants can accept their situation because they feel not alone, and there are other ostomates to share stories

"That's right... then there are also those who have the same illness as I am... so we have shared our stories too, right... I saw that others were strong too, right, we were excited too, right..." (P4)

"When I wanted to go back for treatment, I saw that it wasn't only me who had this disease, I saw many people who had the same disease as me, yes, the term was not myself.. So now I'm used to it..." (P5)

"I'm used to it... because I see there are also people like me... not only myself... so it's okay... it's normal" (P6)

Participants also get support from health workers so they can adapt to the stoma

"Aa, I came for the second control, I tell the doctor's assistant who helped during the operation, Sis... I'll tell you, Sis... Then the doctor said what I was thinking... I understand.. these people never knew about my illness. .. if you are here, the doctor often says... what is currently going on.. what medicine was given... our treatment... Allah will determine that later.. we as doctors are medical personnel .. we can help as much as possible for you, you don't have to think about it.." (P2)

"Ooo, I asked questions.. I asked the doctor when he checked... what kind of food I shouldn't eat, then if there's anything, I ask the doctor.. Alhamdulillah, if you ask, the doctor will explain" (P4)

3.2. Discussion

Therapeutic procedures not only treat the disease but also affect the patient's quality of life. The colostomy procedure aims to reduce gastrointestinal symptoms and prevent disease progression, but inevitable physical changes will result in impaired bodily functions and affect several aspects of participants' lives (Virk & Kaur, 2017). This study shows that there are physical changes that occur such as uncontrolled flatus and feces, skin irritations such as redness, moistness, and tenderness in addition to activity restrictions such as not lifting heavy weights for fear that it will adversely affect the ostomy. To avoid irritation, participants in this study replaced the bag before the bag was full.

Another study also revealed that patients could not hold flatus and feces because the ostomy did not have a sphincter like an anus (Alwi & Asrizal, 2018). In line with other studies that physical activity has decreased in colorectal cancer patients, and the decline will be even greater in patients undergoing colostomy (Beeken et al., 2019). Decreased physical activity in the ostomate due to pain or discomfort in the area around the stoma, feeling worried about the need to clean the pouch (Campos et al., 2017). Patients report that they cannot lift objects weighing more than 5 kg (Dabirian, Yaghmaei, Rassouli, & Tafreshi, 2010).

Participants in this study also reported that they experienced a decrease in appetite at the beginning of the ostomy. bowel surgery contributes to the release of hormones that result in decreased appetite and resulting in weight loss (Changyai, Kongvattananon, & Somprasert, 2020).

Participants in this study said that they felt ashamed, feeling inferior because they felt smelly so they avoided traveling similar to what was revealed in other studies that patients with a stoma had low self-esteem and self-image, thus limiting social interaction (Salomé, De Lima, Muniz, Faria, & Ferreira, 2017). Restrictions on social interactions due to patient's fear of other people's reactions to them and nervousness due to fear of leaks and smells (Sarabi, Navipour, & Mohammadi, 2017). Psychosocial adjustment scores in patients with a stoma due to cancer are lower than ostomy due to other diseases, which is due to the stigma that cancer is an incurable disease (Gautam, Koirala, Poudel, & Paudel, 2016). With the support from family, friends, health workers, and other ostomates, participants' negative view of themselves began to change, participants began to carry out social activities. family is very important in the implementation of therapeutic planning, rehabilitative, and social reintegration (Salomé et al., 2017). Family is the primary source of social support, partner plays an important role as a support figure (Capilla-Díaz et al., 2019). Ostomate views the family as a safe place, and if it wasn't for the family, they would not know how to go through the disease process and colostomy (Campos et al., 2017). Patients

who receive support from family describe it as something that enhances their adaptation to the stoma (Cengiz & Bahar, 2017).

Emotional support from nurses by listening and responding to stories and questions was felt to be very helpful for participants. Sharing stories of stressful events in a supportive context is a key component of successful patient coping (Zhang et al., 2017). Preoperative education significantly reduces the incidence of stoma complications. Communication between the ostomy nurse and the surgeon must be used effectively to ensure that the ostomate does not experience difficulties later on (Richbourg, Thorpe, & Rapp, 2007). The preoperative period is the optimal time to build primary skills and appropriate knowledge for the patient. The internist said that "discharged starts at admission". However, in ostomy education, discharge starts in the preoperative clinic (Wasserman & McGee, 2017).

One participant said that when the ostomy was newly installed, she wondered what sin she had committed so that Allah gave her the disease and regretted her condition, this is because when the ostomy was installed the participant was still a young adult. Older people have higher spiritual well-being because they have stronger beliefs and higher life expectancy (Seraji, Shojaezade, & Rakhani, 2016). The participants in this study were Muslim and there were difficulties in worship, especially prayer due to unholy feelings so that at first the participants were hesitant to pray. However, participants overcome this by asking the ustadz and currently participants say they continue to carry out worship with the belief that the most important thing is to keep doing it and Allah will decide. Other studies also reveal that there are limitations in carrying out worship in patients with an ostomy because they feel unclean (Alwi & Asrizal, 2018). For a Muslim, being clean and free from dirt is an important thing when undergoing worship (Dabirian et al., 2010). Nurses need to pay more attention to the spiritual aspects and worship needs of patients so that they can reduce the occurrence of problems related to spirituality (Rangki, Ibrahim, & Nur'aini, 2014).

Callista Roy in his theory views humans as an open system that responds to both internal and external stimuli through the coping mechanisms of cognates and regulators which are manifested by the patient's disease. Adaptation is considered an effective response to a stimulus (Naga & Al-Khasib, 2014). Stimulus inputs in the adaptive system are seen as various kinds of stressors that force a change to occur. Roy divides the stimulus into three categories, namely focal, contextual and residual (Perrett, 2007). Focal stimuli are defined as internal and external stimuli that directly deal with the adaptive system, contextual stimuli are all other than the focal stimulus that affects the situation and residual stimulus is a stimulus that has an uncertain effect on the stimulus (Fawcett, 2017). The focal stimulus in this study is the impact felt by the participants which make the participants have to make adjustments to various strategies. The contextual stimulus in this study is colorectal cancer and the residual stimulus is a risk factor for colorectal cancer.

In this study, the physical adaptation expressed by the participants included the way the participants carried out various strategies, both in making adjustments to nutrition, resting activities, and protection which is Roy's adaptation model concept was included in the physiological adaptation mode. Physiological mode relates to a person's response or physical response to a stimulus (Erol Ursavas, Karayurt, & Iseri, 2014), participants had a positive physiological adaptation mode as evidenced by the behavior of participants in overcoming the impact that occurred on them such as making dietary adjustments to overcome the frequency and consistency of feces, modifying sleeping positions to meet the patient's rest and sleep needs, replacing the ostomy pouch when its half full to prevent skin irritation due to fecal exposure, and make adjustments by tying the ostomy or ostomy pouch so that you can carry out activities.

In this study, participants currently have a positive self-concept adaptation mode as evidenced by a positive body image where a participant who was initially afraid and shocked to see the ostomy so that he did not want to clean himself, is now able to do so. With the support from family and friends, participants said that they were no longer insecure so they could carry

out social activities and activities as usual. This proves that the participants can fulfill the indicators of positive self-concept and role adaptation.

4. Conclusion

The results of this study obtained two selective codings with six axial codings, namely the impact of the stoma as a stimulus (physical, psychosocial, and spiritual impacts) and coping strategies (strategies to overcome physical impacts, strategies to overcome spiritual impacts, and social support that helps overcome psychosocial impacts) with core categories namely adaptation. This study revealed that colorectal cancer patients with stoma faced several challenges related to the impact of the stoma, but over time patients were able to adapt by adopting various strategies and with the presence of social support. Assessment of patients includes health assessments and also patient and family perceptions about the disease and stoma as well as education to stoma patients given by nurses since preoperatively greatly assisting patients in living their new lives so that patients can adapt to the stoma. This study is an initial study on the adaptation process of colorectal cancer patients with a stoma. This research can be continued with a larger number of participants and with diverse demographics and this research can also be continued by examining patient expectations for the role of nurses.

Ethics Clearance

This research has passed the ethical test at the Health Research Ethics Committee of RSUP DR. M. Djamil Padang with number: 158/KEPK/2020

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