

# Nurse Media Journal of Nursing, 10(1), 2020, 96-106

Available online at http://ejournal.undip.ac.id/index.php/medianers DOI: 10.14710/nmin.v10i1.28725

# Family's Experience: Nursing Care for Colorectal Cancer Patients with Colostomy

Untung Sujianto<sup>1</sup>, Roland Billy<sup>1</sup>, Ani Margawati<sup>2</sup>

<sup>1</sup>Department of Nursing, Faculty of Medicine, Diponegoro University, Semarang, Indonesia <sup>2</sup>Department of Nutrition, Faculty of Medicine, Diponegoro University, Indonesia Corresponding Author: Untung Sujianto (untung71@yahoo.co.id; untung71@fk.undip.ac.id)

Received: 25 February 2020 Revised: 23 April 2020 Accepted: 24 April 2020

#### **ABSTRACT**

**Background:** Colorectal cancer patients with colostomy have various complaints about changes in their life, including the need for comprehensive and personal care. Ostomy nurses are responsible for managing people with a colostomy, and this particular nursing practice continues to develop globally. Also, previous literature highlights the importance of caregiver's support, particularly family in colostomy patient care.

**Purpose:** This study aimed to explore the family experience of colorectal cancer patients toward colostomy nursing care

**Methods:** The study design used was descriptive phenomenology to explore the experience of ten participants through in-depth interviews The participants were selected using purposive sampling with the inclusion criteria: family members of colorectal cancer patients with colostomy, over 21 years old, and able to communicate verbally. The data were analyzed using Colaizzi's method.

**Results:** The results revealed three themes related to the family's experience: (1) positive and negative behavior in nursing care, (2) living with a colostomy, and (3) expectations for nursing care. The findings showed that the families were happy with the ostomy nursing care though some aspects need to be improved. However, colorectal cancer patients experienced some difficulties in living with a colostomy.

**Conclusion**: The study concluded that the colostomy nursing care still needs to be improved. This study recommends the ostomy nurses to improve their nursing care, especially in terms of skills, responsiveness, and awareness.

**Keywords:** Colostomy; family experience; nursing care; colorectal cancer patients.

**How to Cite:** Sujianto, U., Billy, R., & Margawati, A. (2020). Family's experience: Nursing care for colorectal cancer patients with colostomy. *Nurse Media Journal of Nursing*, 10(1), 96-107. doi:10.14710/nmjn.v10i1.28725

**Permalink/DOI**: https://doi.org/10.14710/nmjn.v10i1.28725

## **BACKGROUND**

Colorectal cancer is one of the predominant cancers in the world. In 2018, this cancer reached 16,000 deaths across Indonesia (WHO, 2018). Several studies stated that the increase in colorectal malignancies significantly contributes to an increase in ostomy procedure, leading to various effects on health-related quality of life (HRQOL) (Barreto

& Valencia, 2013; Dabirian, Yaghmaei, Rassouli & Tafreshi, 2011). Nurses are health care providers who have an important role in caring for patients with colostomy, particularly in identifying their needs, preventing complications, and improving quality of life (Adriana, 2010).

Danielsen, Soerensen, Burcharth, and Rosenberg (2013) stated that ostomy nurses are responsible for managing persons with a stoma, and this specialty nursing practice continues to evolve on a global basis. Ostomy nurses should be able to provide nursing care not only on physiological problems but also other problems related to the ostomy. Vonk-Klaassen, de Vocht, den Ouden, Eddes, and Schuurmans (2016), in their review, identify some problems related to an ostomy. The problems include sexual problems, depressive feelings, gas, constipation, dissatisfaction with appearance, changes in clothing, travel difficulties, feeling tired, and worry about noises. Thus, comprehensive and personalized nursing care is important in order to prevent or manage complications and improve the physiological and psychosocial adjustments to ostomy patients (Klingman, 2009). As a result, it will enhance the patients' quality of life.

Living with colostomy causes negative impacts on the overall quality of life of the patients (Von-Klaassen et al., 2016). This will affect their family or caregiver in providing support. Caregiving is often a multi-faceted endeavor that can entail both instrumental and affective support (Dumont, Jacobs, Turcotte, Anderson & Harel, 2010). Several studies found that over the past decade, the cancer caregiving literature has grown as patients' and partners' needs and quality of life (QoL) have become a focus of concern (Berry, Dalwadi, & Jacobson, 2016; Bevans & Sternberg, 2012; Hawyer, Van, Wilson, & Griffin, 2016). Existing research recognizes problems with collaboration between the hospice major barrier in delivering high-quality care for patients in the nursing home (Hwang, Teno, Clark, Shield, Williams, Casarett, & Spence, 2014). However, little evidence was found related to the experience of a family on colorectal cancer-related ostomy nursing care in the hospital setting. Therefore, it is fundamental to understand the habits, perceptions, and attitudes, feelings, and emotions demonstrated in the most diverse situations across the patients while trying to understand those who accompany and sustain them in a patient's life-changing experience.

### **PURPOSE**

This study aimed to analyze the family's experience of colorectal cancer related to colostomy nursing care in the hospital.

#### **METHODS**

## Research design

This study used a qualitative research method with a descriptive phenomenological approach. This approach, which seeks to describe lived-experience, tries to find the essence of these phenomena by remaining open to the meanings associated with those who have experienced them (Polit & Beck, 2010).

## **Setting and participants**

This study was carried out in a hospital in Semarang, Central Java, Indonesia. The selection of the subject of this study was carried out using purposive or judgmental sampling techniques, which was taking samples with certain considerations (Soegiono, 2011). The participants were the family members of colostomy patients due to colorectal cancer in inpatient units, which met the inclusion criteria. In this study, the inclusion criteria were patients who were able to communicate verbally, cooperative, and over 21 years old. As many as ten patient's families participated in this study according to the point of data saturation.

### **Data collection**

Persons who agreed to participate in the study signed the free and informed consent form after receiving detailed explanations of the proposed objectives and procedures. All participants were recruited in the hospital. Permission to audiotape the interview session was also sought from each participant. Confidentiality and anonymity were also guaranteed. Data collection was conducted by semi-structured interviews and asking the question to get deep information about their experiences recorded by voice recording. The time and place of the interview were arranged in a calm environment within the hospitals, which were according to the participant's preferences. Each interview lasted for about 30-60 minutes. Data collection continued to the point of saturated data, where no new information was obtained, and redundancy was achieved.

## Data analysis

The initial stage of data analysis was carried out by documenting the results of the interview in the form of interview transcripts. This process was carried out by playing the recording repeatedly. Verbatim transcription was then done to all interview recordings, and the data were grouped into the form of themes, sub-themes, and main categories. Analysis of the data in this study used a method created by Colaizzi (Morrow, Rodriguez, & King, 2015). The Colaizzi's method has seven stages in analyzing data: (1) familiarization, (2) identifying significant statements, (3) formulating meanings, (4) clustering themes, (5) developing an exhaustive description, (6) producing the fundamental structure, and (7) seeking verification of the fundamental structure. Many factors were considered to ensure the validity of this research. This research ensured dependability, credibility, confirmability, and transferability through some measures. First, a good relationship with the patients and their families was established. Second, member checking was done to clarify the transcripts, keywords, themes, and subthemes.

#### **Ethical consideration**

This research had obtained ethical approval from dr. Kariadi Hospital Health Research Ethics Committee with the ethical number of 198/EC/KEPK-RSDK/2019. The ethical considerations of this study were carried out based on the principle of the five rights of human subjects in research. These five rights include the right to self-determination, privacy, dignity, anonymity, and confidentiality.

#### RESULTS

## **Participant characteristics**

As seen in Table 1, the result showed that the majority of the participants were female (60%), aged less than 40 years old (60%), had primary school as an educational background (40%), and was the children of the patients (40%).

*Table 1. Characteristics of participants* (n=10)

Characteristics	f	%	
Age			
< 40 years old	6	60	
$\geq$ 40 years old	4	40	
Gender			
Male	4	40	
Female	6	60	
Education			
Primary school	4	40	
Junior high school	1	10	
Senior high school	2	20	
Diploma	1	10	
Bachelor	2	20	
Relationship			
Children	4	40	
Parent	2	20	
Spouse	3	30	
Brother	1	10	

The study resulted in three themes related to the family's experience: (1) positive and negative behavior in nursing care, (2) living with colostomy, (3) expectations for nursing care.

## Positive and negative behaviour in nursing care

The participant expressed positive and negative behavior in ostomy nursing care, especially nurses. However, the positive impression outweighed the negatives. The participants stated that the nurses were friendly and had good communication.

- "...The attitude of nurses in the hospital is all good. They already know my child. If we met somewhere else, they recognized my child's face and always greeted first" (P.5).
- "...Nothing is lacking in their attitude. The nurses here are subtle and polite. They are also good and likes to joke" (P.6).
- "...Nurses in the hospital are polite and respect the patient. The way they speak is also nice and polite. There is nothing to say loudly like yelling or getting angry" (P.10).

They also said that the ostomy nurses not only paid attention and supports to the patients but also helped and taught the patients and families.

- "...I am grateful for my father being treated in this hospital; nurses always pay attention to the condition of my father, such as asking how my father is doing and ensuring that he feels comfortable" (P.4).
- "...nurses give encouragement to patients. When the patient does not want to eat hospital food, nurses encourage patients to be eager to eat a lot to recover quickly ... nurses give encouragement to patients. When the patient does not want to eat hospital food, nurses encourage patients to be eager to eat a lot to recover quickly." (P.8).
- "...when using a colostomy for the first time, the nurse teaches the family and caregiver. They teach how to replace a colostomy" (P.1).
- "...The nurse here is aware, every time there is a problem or when we ask for help, they respond quickly" (P.7).

On the other hand, negative impressions were also expressed by the family, such as long waits of nursing care, unresponsiveness, lack of skills, and being unreliable.

- "...here to wait for a new colostomy bag can be one, three, even up to four days. When moving to another room, the nurse also said that the bag had run out, so we had to wait all the time ... there is good work and bad work. There are nurses who put up a colostomy bag, but only a few hours apart, the colostomy is already worn off." (P.8).
- "...When my brother came for a biopsy, he felt in pain. Maybe the nurse thought that it didn't hurt so that it didn't really matter even if the patient looked very weak" (P.1).
- "...I want the nurse to treat the patient well and clean. So far, it hasn't been like that. The nurse just told us to clean it up" (P.9).

## Living with colostomy

The participants mentioned that colorectal cancer patients faced some challenges living with a colostomy. The patients experienced some difficulties in living with colostomy though many of them were able to cope with it. Some difficulties reported were feeling of shame and dirty, physical complaints, activity disruption, and altered sleep.

- "...only families know that the mother uses colostomy. If other people know and see the poop suddenly out of the bag, maybe people can feel strange with it and judge that it is dirty." (P.10).
- "...what he (patient) complained about his stomach, which was always tense. Just eat a little bit, he had already felt full. Now he is also rather weak, maybe because he can't eat because when he eats even just a little, he feels like vomiting right away. Now, his body also feels more pain." (P.1).
- "...according to him (patient), his waist is still in pain. Before there was a colostomy, all activities could be carried out, since there is a colostomy the activities have been limited, the activities cannot be done like before ... it's different now because he can't enjoy sleep anymore. Usually, he could sleep freely when there was no colostomy. Now he is more careful when sleeping because there are wounds (ostomy)." (P.5).
- "...now, he is not fit anymore, so he cannot work and support the family." (P.6).

Although the patients experienced some problems, some participants also stated that the patients had been able to adjust to the colostomy. As a result, the patients could return to their jobs, enjoy their life, and improve their health.

- "...for him, there are no problems when using a colostomy (to work)" (P.1)
- "...Alhamdulillah no interference, he can still work as a driver smoothly. During driving a bus back and forth to Jakarta, there is no big deal ... he never told me about complaints and problems. During this time, what I saw he seemed to enjoy and relax with his current situation." (P.7).
- "...previously (the patient) is often nausea when eating, and no appetite, now (the patient) can eat." (P.8).
- "...now since using colostomy, she looks healthy, she's not like she used to be. Mother said that she was healthier." (P.10)

## **Expectations for nursing care**

The family expected better nursing service, especially by the ostomy nurses. They demanded the nurses to motivate and prioritize the patients.

- "...our hope is that patient services can be prioritized because this hospital is a central hospital, so the service must be better than the regional hospitals ... patients with colostomy have a lot of thoughts, so maybe nurses can encourage and motivate patients to pass their life-changing experience." (P.2).
- "...I want my husband to be treated well and clean (by the nurses), not only told us to do so (colostomy procedures)." (P.9).

### **DISCUSSION**

## Positive and negative behaviour in nursing care

The participant expressed positive and negative behavior in ostomy nursing care, especially the nurses, though their positive impressions were more dominant. In addition, to be attentive and supportive to the patients, the nurses helped and taught the patients and families. These caring behaviors seem important to patients and families. This is supported by Blacius and Setyowati (2016), who point out that caring has implications for nursing practice, so that nurses who have caring behavior will show kindness and politeness. Swanson (2007) also suggests that professional health workers have an important role in nursing services in hospitals. Providing caring can improve and influence the quality of service and improve the well-being of everyone.

Health professionals play an important role in meeting individual information needs regarding colostomy care. Because of the trust in healthcare professionals, the informants in this study had learned about the colostomy and its treatment largely from their surgeons and nurses. Two systematic reviews by Danielsen, Burcharth and Rosenberg (2013), and Phatak, Karanjawala, Chang and Kao (2014) identified that the impact of patient education for patients with a stoma has potential benefits. The results of a systematic review by Faury, Koleck, Foucaud, Bailare and Quintard (2017) also show that educational interventions for patients with a colostomy can have a contrasting impact on the quality of life and a positive impact on patients' psychosocial as well as self-management.

The participants also stated that the nurses were friendly and had good communication. Nurses, in this case, provide enthusiasm to the patients during their treatment in the hospital. They give a good explanation to the patient, are easy to question, and to be asked for consideration. Macdonald (2016) found that nurses are skilled in obtaining clinical information to empower patients and establish therapeutic relationships. Taylor and Morgan (2011) identified that providing quality support before, during, and after colostomy care is needed to improve the quality of life of patients. Nurses in interacting with patients and their families need communication skills. Another study by Chan, Wong, Cheung and Lam (2018) revealed that good physical management and involving effective nurse-patient communication in care add psychosocial comfort to patients.

However, the family identified that long waits of nursing care, as well as nurses being unresponsive, lacking skills, and unreliable as the negative aspects. In this case, the participants said that they were waiting too long for the new colostomy bag and the intravenous fluid that was not immediately replaced. This is in accordance with the results of Adriana's (2010) study, which states that almost half of nurses have not provided caring, especially in communicating with patients. Ostomy nurses need to improve their nursing care, especially in terms of skills, responsiveness, and awareness.

## Living with colostomy

The participants mentioned that colorectal cancer patients faced some challenges living with a colostomy, such as activity disruption, and altered sleep. Changes in daily life become the main thing in patients with a colostomy. Some participants said that their families had limited activities such as housework; some even stopped working. The findings of this problem are similar to those found by Dabirian et al. (2011), where most patients revealed that they had to change or leave work after the onset of their disease and ostomy, and that colostomy also affected their income. However, Dabirian's finding was quite different from the other results of this study, which found that some patients could finally return to their jobs. Liao and Qin (2014) also found that patients with colostomy experienced disturbances and difficulties at work and also in social situations, body image, and stoma functions. These difficulties were similar to other categories of this study, that feeling shame and dirty was reported by the participants. It included feelings of discomfort or fear of others, and knowing the circumstances experienced by patients. This was because the stool was clearly visible in the patient's stomach so that patients were afraid of people seeing them dirty. This finding is also consistent with the results of research by Jansen, Koch, Brenner, and Arndt (2010), where they found that the discharge from the colostomy bag that came out was considered dirty for others. This makes a negative self-image for users of the colostomy so that embarrassment arises.

The existence of new devices in the body certainly has an impact on the daily use of colostomies. Some participants said that the patients experienced difficulties when they wanted to pray and sleep. Some had to use a chair during prayer because of difficulties with a colostomy. This finding is in accordance with research conducted by Cengiz and Bahar (2017) in their phenomenological study on 12 participants who were all Muslim. They obtained a theme in the form of "limits on activities in daily life." From this theme, seven sub-themes were found, such as dressing, bathing, sleeping, sex, physical activity, prayer, and social life. This finding is further strengthened by Akgül and Karadag's

(2016) research, where they found that the procedure for making colostomy gives challenges for various religious practices in Islam, including those related to ablution, prayer, fasting, and pilgrimage.

Although the use of colostomy is a therapeutic treatment for digestive problems, patients still feel physical complaints, as for example, feeling sick, nausea, vomiting, weakness, and having difficulty defecating. This is similar to research by Jansen et al. (2010), where they explain that people with colostomies have many problems in physical function and roles. Fatigue, dyspnea, and loss of appetite are some of the worst categories. This is also significant with the findings of Zhang, Hu, Xu, Zheng and Liang (2013), where they found significant values for physical disorders such as fatigue, pain, constipation, and diarrhea.

Even though patients experienced some difficulties in living with a colostomy, many of them were able to cope with it. As a result, the patients could enjoy their life and improve their health after using colostomy. Some participants said that patients did not encounter serious problems when using colostomy. They even felt physical comfort, including being painless, gaining weight, being able to eat normally. This is similar to the research of Szpilewska Juzwiszyn, Bolanowska, Milan and Chabowski (2018), in which a total of 43% of respondents stated that their health has no bad changes and some have even improved since using a colostomy.

In addition to physical improvement, some participants said that patients did not mind the situation they were experiencing. Despite physical impairments, these patients did not think too much about the situation they were experiencing. This is in line with research by Tao, Songwanthana and Isaramalai (2016) that informants' perceptions of colostomy are often associated with abnormalities, discomfort, difficulty in care, social isolation, and limited job choices. Survival is the most important thing, allowing these informants to accept the possibility of colostomy formation by following the surgeon's advice and embracing their destiny. A positive mood is also useful for individuals to deal with the negative effects associated with a colostomy. Popek and Grant (2010) found that patients who were optimistic and positive to receive their colostomy had a high quality of life. An optimistic attitude can help people to successfully adapt to the disease.

Changes in the quality of life of patients with colostomy varied from negative and positive responses. In this theme, negative sub-themes were more dominant than positive. This finding is similar to the research of Kimura, Kamada, Guilhem, Modesto and de Abreu (2016), which revealed that the obstacles faced by patients with colostomy significantly affect their physical, psychological, social and spiritual well-being. From the analysis of Kimura et al. (2016), it was found that there were more negative subcategories than positive ones. This is also supported by Von Klaassen et al. (2016), who reported that living with colostomy causes negative impacts on the overall quality of life of the patients

## **Expectations for nursing care**

The family expected better nursing service, especially by the ostomy nurses. They demanded the nurses to motivate and prioritize the patients. Some participants hoped that

nurses could improve nursing services for patients and also support patients morally. The role of nurses as health care providers in patients with colostomy needs to be improved due to the low quality of life of colostomy patients (Liao & Qin, 2014). Other studies have found that the expectations for nursing services were focused on the desire to be treated humanely, assisting in the adaptation as a member of the household, restoring and increasing patient strength, and help overcome the patient's weakness (Ferreira-umpiérrez & Fort-fort, 2014). The expectation is an important factor in the bio-psychosocial-spiritual aspect. Expectations relate to how people's beliefs affect their behavior. Improved self-concept can be done by nurses by helping patients to shape their thinking to be more positive, realistic, such as encouraging patients to do something for themselves. Increasing the caring behavior of nurses is an ability to be dedicated to others, showing concern, watching with caution, feeling empathy for others, and feelings of love or love.

### **CONCLUSION**

The findings showed that positive behaviors in nursing care outweighed the negative things. The family was pleased with the ostomy nursing care though some aspects need to be improved. Moreover, colorectal cancer patients experienced some difficulties in living with colostomy, resulting in negative impacts on their quality of life. Therefore, this study concluded that colostomy nursing care still needs to be improved. As a result, it is recommended for ostomy nurses to improve their nursing care, especially in terms of skills, responsiveness, and awareness, and for further research to get a deeper perspective of colostomy patients with a diverse age group and gender.

### ACKNOWLEDGEMENT

The authors would like to thank participants for their voluntary participation in this study.

## **CONFLICT OF INTEREST**

The authors declare no conflicts of interest in this work.

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