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Submission

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Submitter Untung Sujianto

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Section Articles

Editor Nana Rochana

**Author
comments**

Dear Editor,

I am submitting the manuscript to have your consideration for publication in the Nurse Media Journal of Nursing.

Thank you

REgards,
Untung SUjianto

[NMJN] Editor Decision4

Yahoo/Terkirim

Nana Rochana <na2rochana@gmail.com>

Kepada:Untung Sujianto

Min, 12 Apr 2020 jam 08.25

Untung Sujianto:

The review result from the first reviewer has been issued. Please revise
your article according to the review.

Regards

NMJN editor

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Editors

Nurse Media Journal of Nursing

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Dear Reviewers,

It is with pleasure to introduce you the Nurse Media Journal of Nursing (NMJN), an international journal which is focused on providing publication of results from original research, systematic reviews, and case report, particularly in nursing and health. The journal strives to provide the most current and best research in the field of nursing and health sciences.

The NMJN is published by Department of Nursing, Faculty of Medicine, Diponegoro University and serves as a focal point for nurse-practitioners, academicians, professionals, graduates and undergraduate students, fellows, and associates pursuing research throughout the world.

Given your expertise in the field and, particularly, the link between the topics faced in the following submitted manuscripts and your research activities, I am inviting you to be a reviewer for the following article:

Nurse Caring on the Patients with Colorectal Cancer and Colostomy

I would very much appreciate it if you could promptly find the time to give a quick look at this article and decide whether you can accept the invitation to review it. If you kindly accept the invitation, please return your report within 1 week after you accepted the invitation.

If you need any further inquiry related to this request, please do not hesitate to contact us at media_ners@live.undip.ac.id.

Thank you very much for your kind assistance and cooperation.

Sincerely Yours,

Sri Padma Sari
Editor in Chief,
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ARTICLE REVIEW FORM

TITLE	Nurse Caring on the Patients with Colorectal Cancer and Colostomy
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Please fill in the following information with the result of your review on the article.

Does the article:

1. Meet the aims and scope of Nurse Media Journal of Nursing (NMJN)? Yes_**x**_ No__

Comments:

2. Follow appropriate conventions for a journal article of its type? Yes__ No_**x**_

Comments:

3. Possess a suitable title and an abstract that accurately and concisely summarizes the content?
Yes__ No_**x**_

Comments:

4. Cite, discuss and critically evaluate relevant international literature? Yes_**x**_ No__

Comments:

5. Demonstrate original thought or work? Yes__**x**_ No__

Comments:

6. Does the article have a sound theoretical or policy base? Yes_ No_**x**_

Comments:

7. Are conclusions drawn rigorously? Yes__ No_**x**_

Comments:

8. Are the style and English usage appropriate for the journal? Yes__ No_**x**_

Comments:

The article need to go to the english proofreader

FOR RESEARCH PAPERS

Does the article: -

9. Outline and justify the overall research design? Yes___ No_x__

Comments:

The setting, participant's recruitment and the data collction needs to be outlined

10. Adequately discuss ethical issues? Yes___ No_x__

Comments:

Ethical clearance and principles needs to be elaborated

11. Clearly indicate and discuss data analysis/findings? Yes__x_ No___

Comments:

12. Accurately display statistical data (if any)? Yes__x_ No___

Comments:

The result needs to be rewritten

OVERALL COMMENTS ON THE ARTICLE

This article needs revisions. I recommend the author to revise the article using the template for qualitative research

Nurse Caring on The Patients with Colorectal Cancer and Colostomy

Commented [H1]: The title should be revised to indicate that this is a qualitative study of the family perspective

ABSTRACT

Background: Patients with colostomy get various complaints about changes in their lives, especially on quality of life. People who live with colostomy need comprehensive and personal

care. Ostomy nurses are responsible for managing people with colostomy, and this particular nursing practice continues to develop globally.

Purpose: Aim of this study is to describe the family's experience of nurse caring to colorectal cancer patients with colostomy.

Methods: Ten participants who met the criteria were interviewed about their experience by purposive sampling. Data were generated-collected by semi-structured interview and analyzed using Colaizzi's phenomenological approach.

Results: Three main themes revealed: (1) Family's perspective on nurses' behavior, (2) Quality of life of patients with colostomy, (3) Health service needs of patients with colostomy. The findings of the study revealed the needs for improved services, especially in terms of skills, responsiveness and awareness of nurses.

Conclusion: Furthermore, findings revealed that positive nurse caring had a greater understanding among patients with colorectal cancer and colostomies whose quality of life were changed. Therefore, expectation on nurse caring to the patient with colorectal cancer and colostomy are on the rise.

Key Words: Colostomy, Family, Nurse Caring, Quality of Life

Commented [H2]: Please relate to the family's view of nurses here so it is in line with the aim

Commented [H3]: Design? Place and time setting?

Commented [H4]: How many cycles? How long?

Commented [H5]: What is the type of colaizzi analysing data?

Commented [H6]: This is indeed the family's perspective of nurses caring, could you be more specific on the themes? Are the 2nd and 3rd themes about nurses caring? Please consider revision

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BACKGROUND

Colorectal cancer is one of the health problems in the world. In 2018, this incidence reached 16,000 deaths across Indonesia (WHO, 2018). Several studies (Barreto & Valencia, 2013; Dabirian, Yaghmaei, Rassouli & Tafreshi, 2011) stated that increase in colorectal malignancies significantly contributes to an increase in ostomy procedure therefore the creation has a variable effect on health-related quality of life (HRQOL).

Persons living with an ostomy require comprehensive and personalized care. Nursing care is important in order to prevent or manage complications and improve the physiological and psychosocial adjustment to the ostomy (Klingman, 2009). Danielsen, Soerensen, Burcharth, & 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. Nurses must determine the appropriate health and disease conditions to facilitate the patient to a new condition, be able to evaluate the patient's coping mechanism and its impact, and implement the nursing interventions according to the information they have (Yildirim & Gurkan, 2010).

Caregiving is often a multi-faceted endeavor that can entail both instrumental and affective support (Dumont, Jacobs, Turcotte, Anderson & Harel, 2010). Several studies (Berry, Dalwadi, & Jacobson, 2016; Hawyer, Van, Wilson, & Griffin, 2016; Bevans & Sternberg, 2012) found that over the past decade, the cancer caregiving literature has grown as patients' and partners' needs and quality of life (QoL) have become focus of concern. It is fundamental to understand the habits, perceptions and attitudes, feelings and emotions demonstrated in the most diverse situations that cross the patients, while understanding those who accompany and sustain them in this life-changing experience.

OBJECTIVE

The study aimed to analyze the family's experience of colorectal patients with colostomy about nurse caring in the quality of life that these patients live so that it can be identified the needs of patients who with colostomy while undergoing treatment, thereby improving health services. Nurses are health care provider who have important role in caring for patients with colostomy, particularly in identifying their needs, prevent complications and improving quality of life.

METHODS

Study Methodology Design

This study used qualitative research methods with a descriptive phenomenology approach. This approach, which seeks to describe life experiences tries to find the essence of these phenomena by remaining open to the meanings associated with those who have experienced them (Polit & Beck, 2010). The selection of the subject of this study was carried out using purposive sampling or judgmental sampling techniques, that is taking samples with certain considerations (Soegiono, 2011).

Participants

The sample in this study were 10 patients' families. The criteria of this research subject have fulfilled the inclusion criteria which are: (1) Family members of patients who have colostomy caused by colorectal cancer, (2) family members who are able to communicate verbally, (3) cooperative family members who are willing to be the subject of research and agree on informed consent given, and (4) over 21 years old.

Commented [H8]: What about some studies around this research area (ostomy nurse)? What is the importance if family's views are explored?

Commented [H9]: Before you stated the fundamental here you should outline the research gap.

Commented [H10]: One or two sentences are enough

Commented [H11]: Is this about ostomy nurses? Or nurse caring the colorectal cancer patients? it should be clear

Commented [H12]: This should go to the background

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Commented [H14]: Please explain the process of participant's recruitment? How did you choose the families? How did you get the contacts? Where was the study conducted?

Commented [H15]: Caregiver? Or family in general?

Data analysis

The initial stage of data analyzing was carried out by documenting the results of the interview in the form of interview transcripts. This process is carried out by playing the recording repeatedly. Analysis of the data in this study uses a method created by Colaizzi (2015). The Colaizzi's method has 7 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 need to be considered to ensure the validity of this research. To ensure credibility, researchers build good relationships with participants, namely the families of patients with colostomies, to obtain information. The researcher also clarifies the data obtained with participants (member check). This is done to ensure the validity of the data that researchers have summarized as themes.

RESULTS

This study involved 10 participants who're the families of the patients. The age varied between 21 years and 57 years. Female sex was the most with a total of 6 people while male was 4. After analyzing the transcripts, 3 main themes were revealed (Table 1).

Table 1. Analysis Data Thematic

Participant's Statement	Category	Sub Theme	Theme
Usually, for example, if the medicine (i.v) is running out, they replace the infusion, then check the situation, then ask about possible complaints, like that. [P.7]	Nurses paying their attention to the patients' condition		
Nurses attitude have been really good. They know our names. If they meet my daughter and saw her face. They recognized; "Hi ms.F!" [P.5]			
Yes, I'm not trying to, I'm not covering it up. It's true. So far when my father was treated in here it was very pleasant. The people (nurse staff) were really friendly. What I'm saying that it was good [P4]	Nurses are friendly to patients		
The nurses here... like, it's already stand out well and really good. Because once we asked for help, they responded it really quick. So there's no issue with the nursing here [P2]			
Back then it was good. They teached. They teached the family how to do colsotomy care [P1]	Nurses helping patient and also teaching them		
Yes, like we're being encouraged, for example, they asked how many children does she have...			

Commented [H16]: Data collection? could you tellme about the interview guideline development and interview process?

Commented [H17]: Fix the grammar

Commented [H18]: Only credibility that was ensured?

Commented [H19]: Ethics?

Commented [H20]: Please see the examples of the other qualitative studies that had been published in this journal. You can refer there to write the result:
<https://ejournal.undip.ac.id/index.php/medianers/article/view/21170/15500>
<https://ejournal.undip.ac.id/index.php/medianers/article/view/15136/12377>

Commented [H21]: Where can this information be seen? Could you give a table of participant's characteristics?

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Participant's Statement	Category	Sub Theme	Theme
and are the children still in school or work. If they're in school, the nurse will encourage; "be strong ma'am so you can attend your child graduation" [P2]	Nurses conduct therapeutic communication	Negative behaviour	
I guess it's about health. They encouraged if my family don't want to eat, because there are many patients who don't want to eat from hospital's diet. Then the nurses give encouragement; "please eat, eat a lot so you'll get better soon." That's all [P8]			
The response? Hmm... Perhaps it's about the amount of time. For example, when we have a complaint, or sick or anything, it seems the response were too long [P1]	Slow response of nurse service		
When we asked for the pouch (bag), it almost one day until they gave it. In this ward is three days. Yeah, like 4 days for 1 pouch. Then we move again to Merak ward. On there we also wait for the pouch again [P8]			
When we arrived at half past three she (the patient) was in pain. Although we're there for biopsi, maybe they thought it's just a mild pain but she was really weak at that time [P1]	Nurses did not familiar with patient complaints		
Yes , there is one or two (nurse staff) that sometimes are annoying. Sometimes though. For example, my mother, she doesn't like the smell of a milk. She often vomited because of that. But the nurse insists her to at least try a sip even though she didn't want to and even she's already seems to vomitted [P2]			
Yes there are many nurse, there are good and bad. Once there was someone (nurse staff) who installed (colostomy) it, put in the pouch, but only after a few hours the pouch was released/fallen again [P8]	Nurses who are less reliable		
Well maybe about the pouch, we can change it ourselves. If the nurse doesn't mind, we can ask to them. Hmmm... but there are those who wants to change it, some don't want to [P8]	Nurses do not want to change or do colostomy treatment		

Participant's Statement	Category	Sub Theme	Theme
The nurse asked ' who is going to clean it (the colostomy) it?', I answered, 'I don't know, but let me do it', and they give away. Just like that [P6]			
Yes, only the family know that she uses a colostomy. No one else know. Only us. So other people thought that she's alright. If they know it, it might be embarrassing [P1]			
The shame is to the neighbor. She usually can go out from the house with ease, but right now there's a feel of embarrassment, right? If the colostomy is... if it fell then people will recognize the smell, so it will not feel good to other people. That's what she's shamed of [P2]	Feeling of shame and looks dirty		
Even though she only had 2 table spoon, she said that she already full and then vomited up later [P1]	Physical complaints		
Yes, she said that there's still a pain in the waist. Still aches [P5]			
Yes of course there is a change because she is now out of work. Now she's only been sleeping [P1]	Activity complaints	Negative response	
Father was really weak. Because he could not work, could not earned for the family. And the children must be confused by that [P6]			
If mother wants to go to the mosque. She has to bring chair, so we bought her folded chair so she could pray with a chair [P4]	Disturbed worship		
It's complicated to pray, the hard thing is like, there is a lump in here (stomach), if she wants to move, if she prays sometimes there's a voice from the colostomy [P10]			
It's sleep. She can't sleep well. Because it's very hard to lie on the side [P2]			
It is complicated if she wants to sleep, she said it's hard. That's because she shouldn't be able to lie on its side because of the pouch on the stomach [P5]	Disturbed Sleeping		

Quality of life of patients with colostomy

Commented [H23]: This is not a family's view about the nurses but more like about the patient's quality of life, it is inconsistent with the aim

Participant's Statement	Category	Sub Theme	Theme
She doesn't mind using colostomy, till now there is no problem [P1]			
There are no disturbances. Alhamdulillah, my father is still works really well, for example, if he went to work, he is a bus driver. He can still drive to Jakarta and back. There are no obstacles [P7]	No obstacles in working		
He's pretty fine with it. My father wanted to get well [P3]			
From what I saw. It's alright. The same as before using colostomy. She'd be like cheerful, didn't brought too much stress. She's relaxed. Fine as what it is. My point is she didn't gave too much of a thought nor complaining [P1]	No stress	Positive response	
Yea there has been a fair amount of progress, he used to be thin, now he's gaining weight again [P7]			
Before when he wanted to defecate it was difficult, hurt. Now it's good. The stomach doesn't hurt because the stool comes out on its own [P6]	Improvement in physical conditions		
It feels, nausea, no appetite. Now it's not bad. She can eat well now [P8]			
Participant's Statement	Category	Theme	
We are from BPJS (State Insurance Agency), Alhamdulillah if the treatment from the nurses are friendly or respond time is faster [P1]	Nurses can improve nursing services for patients	Health service needs for patients with colostomy	
What I expected is. Patients is the first priority [P2]			
Yes. The problem is that for colostomy users, sometimes there are people with a lot of insecurity of something or what, maybe the nurse can give encouragement so the patients can get through the ordeal [P2]	Nurses can support patients morally		

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DISCUSSION

Family's Perspective on Nurses Behavior

Commented [H25]: Please state your findings first then discuss it with the literature, do not start the discussion with the literature. How are nurses behaviors from the family's perspective? Is it good or bad? Then go to details.

Swanson (2007) suggest 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.

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The results of data analysis obtained from interviews with participants revealed that during hospital treatment, nurses paid attention to the overall condition of the patient. One participant also revealed that nurses asked the patients if there's any complaints. The results of this study also found that in addition to caring for patients, nurses were also friendly to patients. Some participants revealed that the patient was well known by the nurse. Nurses also behave politely and respect the patient. Blacius et al (2016) in his research found that caring has implications for nursing practice so that nurses who have it will show kindness and politeness.

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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 & Rosenberg (2013) and Phatak, Karanjawala, Chang & Kao (2014) identified that the impact of patient education for patients with stoma has potential of good benefits. The results of a systematic review by Faury, Koleček, Foucaud, Bailare & Quintard (2017) also show that educational interventions for patients with colostomy can have a contrast impact on quality of life and a positive impact on patients' psychosocial as well as self-management.

Participants revealed that during their family care in hospital, nurses conducted therapeutic communication with patients. Nurses in this case provide enthusiasm and humor to patients during their treatment in hospital. 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. Some participants also said that nurses' communication with patients and families was very good. The nurse gives a good explanation to the patient, is easy to question and to be asked for consideration. Nurses in interacting with patients and their families need communication skills. Another study by Chan, Wong, Cheung & Lam (2018) revealed that good physical management and involving effective nurse-patient communication in care add psychosocial comfort to patients.

However, although in the first sub-theme found positive behaviors that were classified as caring nurses in patients with colostomy, in this study also some participants revealed that there was a nurse service that they thought was not good. The results of this study reveal that nurse care for patients is slow. In this case the participants said that they were waiting for the old colostomy bag and the i.v fluid that was not replaced. Negative caring behavior in accordance with the results of Ardiana's (2010) study which states that almost half of nurses have not provided caring, especially in communicating with patients.

Commented [H28]: Other studies?

Quality of Life of Patients with Colostomy

Changes in daily life become the main thing in patients with colostomy. Some participants said that their families no longer or limit their activities such as homework, some even stopped working. The findings of this problem are similar to those found by Dabirian et al (2010) where most patients

Commented [H29]: Reconsider this theme

revealed that they had to change or leave work after the onset of their disease and ostomy, and that colostomy also affected their income. Liao & Qin (2014) also found that patients with colostomy experienced disturbances and difficulties at work and also in social situations, body image and stoma function which were similar to other categories of this study.

The existence of new devices in the body certainly has an impact on the daily use of colostomates. In addition to difficult sleep, some participants said that their families experienced interference when they wanted to pray. Some have to use a chair during prayer because of difficulties with a colostomy. This finding is in accordance with research conducted by Cengiz & Bahar (2017) about a phenomenological study they did on 12 participants who were all Muslim received a theme in the form of 'limits on activities in daily life'. From this theme, seven sub-themes were found: dressing, bathing, sleeping, sex, physical activity, prayer, and social life. This finding is further strengthened by Akgul & Karadag's (2016) research where their research 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 discomfort as for example said by some participants that patients still often feel sick, nausea, vomiting, weakness, and still having difficulty on defecating. This is similar to research by Jansen, Koch, Brenner & Arndt (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 & Liang (2013) where they found significant values for physical disorders such as fatigue, pain, constipation and diarrhea.

Besides physical discomfort, psychosocial discomfort was also found when conducting interviews with participants. It includes feelings of discomfort or fear of others knowing the circumstances experienced by patients. This is because the stool is clearly visible in the patient's stomach so that patients are afraid of people seeing them dirty. This finding is also consistent with the results of research by Jansen & Koch (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.

Having a colostomy and receiving treatment in a hospital negatively affects a patient's mood. However, some participants said that patients did not encounter serious problems when using colostomy. Some patients can still do activities when using colostomy like working. Some participants also said that since using a colostomy, the patient felt physical comfort including being painless, gaining weight, being able to eat normally. This is similar to the research of Szpilewska Juzwizyn, Bolanowska, Milan & Chabowski (2018) where a total of 43% 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 do not think too much about the situation they are experiencing. This is in line with research by Tao, Songwanthana & Isaramalai (2016) that although informants' perceptions about 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 colostomy. Popek & 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 disease.

Changes in the quality of life of patients with colostomy vary from negative and positive responses. In this theme, negative sub-themes are more dominant than positive. This finding is similar to the research of Kimura, Kamada, Guilhem, Modesto & de Abreu (2016) which revealed that the obstacles faced by patients with colostomy significantly affect their physical, psychological, social and spiritual well-being. Through the analysis of Kimura et al (2016), it was found that there were more negative subcategories than positive ones.

Health Service Needs of Patients with Colostomy

In the last theme, some participants expect that nurses can improve nursing services for patients and also support patients morally. The role of nurses is as a provider of health services in patients with colostomy because the quality of life of patients with colostomy is not ideal (Liao & Qin 2014). Ferreira & Fort have found expectation in nursing services centered on the desire to be treated humanely, assisting in adaptation as a member of the household, healing and increasing patient strength, and helping to overcome patient weaknesses.

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CONCLUSION

Improved services are needed, especially in terms of skills, responsiveness and awareness of nurses. Skills should be in terms of care or installation of colostomy bags to patients. Responsiveness is where nurses respond faster to patients' needs and awareness that nurses must understand what is felt and the complaints of patients with colostomy in the hospital. Caring which is the art of nursing is intended to provide well-being for others. A person's well-being will have an effect on their quality of life.

Positive nurse caring had a greater understanding among patients with colorectal cancer and colostomies whose quality of life were changed. Therefore, expectation on nurse caring to the patient with colorectal cancer and colostomy are on the rise.

Further research need to get a deeper perspective that might be obtained through patients with a colostomy of variables as diverse as age group and gender. Quantitative research is also needed to measure the level of patient satisfaction with colostomy. With quantitative data collection the respondents and the data obtained can be greater.

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CONFLICT OF INTEREST

The authors report no conflicts of interest in this work.

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Nana Rochana <na2rochana@gmail.com>

Kepada:Untung Sujianto

Rab, 15 Apr 2020 jam 15.26

Untung Sujianto:

The review result from the second reviewers has been uploaded, please

revise as per suggestions. we are looking forward to your revision.

Regards,

Nana Rochana

Department of Nursing, Faculty of Medicine, Diponegoro University

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Editors

Nurse Media Journal of Nursing

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It is with pleasure to introduce you the Nurse Media Journal of Nursing (NMJN), an international journal which is focused on providing publication of results from original research, systematic reviews, and case report, particularly in nursing and health. The journal strives to provide the most current and best research in the field of nursing and health sciences.

The NMJN is published by Department of Nursing, Faculty of Medicine, Diponegoro University and serves as a focal point for nurse-practitioners, academicians, professionals, graduates and undergraduate students, fellows, and associates pursuing research throughout the world.

Given your expertise in the field and, particularly, the link between the topics faced in the following submitted manuscripts and your research activities, I am inviting you to be a reviewer for the following article:

Nurse Caring on the Patients with Colorectal Cancer and Colostomy

I would very much appreciate it if you could promptly find the time to give a quick look at this article and decide whether you can accept the invitation to review it. If you kindly accept the invitation, please return your report within 1 week after you accepted the invitation.

If you need any further inquiry related to this request, please do not hesitate to contact us at media_ners@live.undip.ac.id.

Thank you very much for your kind assistance and cooperation.

Sincerely Yours,

Sri Padma Sari
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Semarang, Central Java, Indonesia 50275
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ARTICLE REVIEW FORM

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Please fill in the following information with the result of your review on the article.

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1. Meet the aims and scope of Nurse Media Journal of Nursing (NMJN)? **Yes**___ **No**___

Comments:

2. Follow appropriate conventions for a journal article of its type? **Yes**___ **No**___

Comments:

3. Possess a suitable title and an abstract that accurately and concisely summarizes the content?
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4. Cite, discuss and critically evaluate relevant international literature? **Yes**___ **No**___

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6. Does the article have a sound theoretical or policy base? **Yes**___ **No**___

Comments:

7. Are conclusions drawn rigorously? **Yes**___ **No**___

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FOR RESEARCH PAPERS

Does the article: -

9. Outline and justify the overall research design? **Yes**___ **No**___

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10. Adequately discuss ethical issues? **Yes**___ **No**___

Comments:

11. Clearly indicate and discuss data analysis/findings? **Yes**___ **No**___

Comments:

12. Accurately display statistical data (if any)? **Yes**___ **No**___

Comments:

State the trustworthiness, result should be in narration, All themes and subthemes can be displayed in diagramm

OVERALL COMMENTS ON THE ARTICLE

Please make a line between abstract and article

State the trustworthiness, result should be in narration, All themes and subthemes can be displayed in diagram

Revised the language

Nurse Caring on The Patients with Colorectal Cancer and Colostomy

ABSTRACT

Background: Patients with colostomy get various complaints about changes in their lives, especially on quality of life. People who live with colostomy need comprehensive and personal care. Ostomy nurses are responsible for managing people with colostomy, and this particular nursing practice continues to develop globally.

Purpose: Aim of this study is to describe the family's experience of nurse caring to colorectal cancer patients with colostomy.

Methods: Ten participants who met the criteria were interviewed about their experience by purposive sampling. Data were generated by semi-structured interview and analyzed using Colaizzi's phenomenological approach.

Results: Three main themes revealed: (1) Family's perspective on nurses' behavior, (2) Quality of life of patients with colostomy, (3) Health service needs of patients with colostomy. The findings of the study revealed the needs for improved services, especially in terms of skills, responsiveness and awareness of nurses. Furthermore, findings revealed that positive nurse caring had a greater understanding among patients with colorectal cancer and colostomies whose quality of life were changed. Therefore, expectation on nurse caring to the patient with colorectal cancer and colostomy are on the rise.

Key Words: Colostomy, Family, Nurse Caring, Quality of Life

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Commented [U36]: Please state the kind of the study, the criteria of participant, the place of study was conducted, number of participant,

BACKGROUND

Colorectal cancer is one of the health problems in the world. In 2018, this incidence reached 16,000 deaths across Indonesia (WHO, 2018). Several studies (Barreto & Valencia, 2013; Dabirian, Yaghmaei, Rassouli & Tafreshi, 2011) stated that increase in colorectal malignancies significantly contributes to an increase in ostomy procedure therefore the creation has a variable effect on health-related quality of life (HRQOL).

Persons living with an ostomy require comprehensive and personalized care. Nursing care is important in order to prevent or manage complications and improve the physiological and psychosocial adjustment to the ostomy (Klingman, 2009). Danielsen, Soerensen, Burcharth, & 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. Nurses must determine the appropriate health and disease conditions to facilitate the patient to a new condition, be able to evaluate the patient's coping mechanism and its impact, and implement the nursing interventions according to the information they have (Yildirim & Gurkan, 2010).

Caregiving is often a multi-faceted endeavor that can entail both instrumental and affective support (Dumont, Jacobs, Turcotte, Anderson & Harel, 2010). Several studies (Berry, Dalwadi, & Jacobson, 2016; Hawyer, Van, Wilson, & Griffin, 2016; Bevans & Sternberg, 2012) found that over the past decade, the cancer caregiving literature has grown as patients' and partners' needs and quality of life (QoL) have become focus of concern. It is fundamental to understand the habits, perceptions and attitudes, feelings and emotions demonstrated in the most diverse situations that cross the patients, while understanding those who accompany and sustain them in this life-changing experience.

OBJECTIVE

The study aimed to analyze the family's experience of colorectal patients with colostomy about nurse caring in the quality of life that these patients live so that it can be identified the needs of patients who with colostomy while undergoing treatment, thereby improving health services. Nurses are health care provider who have important role in caring for patients with colostomy, particularly in identifying their needs, prevent complications and improving quality of life.

METHODS

Study Methodology

This study used qualitative research methods with a descriptive phenomenology approach. This approach, which seeks to describe life experiences tries to find the essence of these phenomena by remaining open to the meanings associated with those who have experienced them (Polit & Beck, 2010). The selection of the subject of this study was carried out using purposive sampling or judgmental sampling techniques, that is taking samples with certain considerations (Soegiono, 2011).

Participants

The sample in this study were 10 patients' families. The criteria of this research subject have fulfilled the inclusion criteria which are: (1) Family members of patients who have colostomy caused by colorectal cancer, (2) family members who are able to communicate verbally, (3) cooperative family members who are willing to be the subject of research and agree on informed consent given, and (4) over 21 years old.

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trustworthiness

Data analysis

The initial stage of data analyzing was carried out by documenting the results of the interview in the form of interview transcripts. This process is carried out by playing the recording repeatedly. Analysis of the data in this study uses a method created by Colaizzi (2015). The Colaizzi's method has 7 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 need to be considered to ensure the validity of this research. To ensure credibility, researchers build good relationships with participants, namely the families of patients with colostomies, to obtain information. The researcher also clarifies the data obtained with participants (member check). This is done to ensure the validity of the data that researchers have summarized as themes.

RESULTS

This study involved 10 participants who're the families of the patients. The age varied between 21 years and 57 years. Female sex was the most with a total of 6 people while male was 4. After analyzing the transcripts, 3 main themes were revealed (Table 1).

Table 1. Analysis Data **Thematic**

Participant's Statement	Category	Sub Theme	Theme
Usually, for example, if the medicine (i.v) is running out, they replace the infusion, then check the situation, then ask about possible complaints, like that. [P.7]	Nurses paying their attention to the patients' condition		
Nurses attitude have been really good. They know our names. If they meet my daughter and saw her face. They recognized; "Hi ms.F!" [P.5]			
Yes, I'm not trying to, I'm not covering it up. It's true. So far when my father was treated in here it was very pleasant. The people (nurse staff) were really friendly. What I'm saying that it was good [P4]	Nurses are friendly to patients		
The nurses here... like, it's already stand out well and really good. Because once we asked for help, they responded it really quick. So there's no issue with the nursing here [P2]			
Back then it was good. They teached. They teached the family how to do colsotomy care [P1]	Nurses helping patient and also teaching them		
Yes, like we're being encouraged, for example, they asked how many children does she have...			

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Please present data in narration

Participant's Statement	Category	Sub Theme	Theme
and are the children still in school or work. If they're in school, the nurse will encourage; "be strong ma'am so you can attend your child graduation" [P2]	Nurses conduct therapeutic communication	Negative behaviour	
I guess it's about health. They encouraged if my family don't want to eat, because there are many patients who don't want to eat from hospital's diet. Then the nurses give encouragement; "please eat, eat a lot so you'll get better soon." That's all [P8]			
The response? Hmm... Perhaps it's about the amount of time. For example, when we have a complaint, or sick or anything, it seems the response were too long [P1]	Slow response of nurse service		
When we asked for the pouch (bag), it almost one day until they gave it. In this ward is three days. Yeah, like 4 days for 1 pouch. Then we move again to Merak ward. On there we also wait for the pouch again [P8]			
When we arrived at half past three she (the patient) was in pain. Although we're there for biopsi, maybe they thought it's just a mild pain but she was really weak at that time [P1]	Nurses did not familiar with patient complaints		
Yes , there is one or two (nurse staff) that sometimes are annoying. Sometimes though. For example, my mother, she doesn't like the smell of a milk. She often vomited because of that. But the nurse insists her to at least try a sip even though she didn't want to and even she's already seems to vomitted [P2]			
Yes there are many nurse, there are good and bad. Once there was someone (nurse staff) who installed (colostomy) it, put in the pouch, but only after a few hours the pouch was released/fallen again [P8]	Nurses who are less reliable		
Well maybe about the pouch, we can change it ourselves. If the nurse doesn't mind, we can ask to them. Hmmm... but there are those who wants to change it, some don't want to [P8]	Nurses do not want to change or do colostomy treatment		

Participant's Statement	Category	Sub Theme	Theme
The nurse asked ‘ who is going to clean it (the colostomy) it?’, I answered, ‘I don’t know, but let me do it’, and they give away. Just like that [P6]			
Yes, only the family know that she uses a colostomy. No one else know. Only us. So other people thought that she’s alright. If they know it, it might be embarrassing [P1]			
The shame is to the neighbor. She usually can go out from the house with ease, but right now there’s a feel of embarrassment, right? If the colostomy is... if it fell then people will recognize the smell, so it will not feel good to other people. That’s what she’s shamed of [P2]	Feeling of shame and looks dirty		
Even though she only had 2 table spoon, she said that she already full and then vomited up later [P1]	Physical complaints		
Yes, she said that there’s still a pain in the waist. Still aches [P5]			
Yes of course there is a change because she is now out of work. Now she’s only been sleeping [P1]	Activity complaints	Negative response	
Father was really weak. Because he could not work, could not earned for the family. And the children must be confused by that [P6]			
If mother wants to go to the mosque. She has to bring chair, so we bought her folded chair so she could pray with a chair [P4]			
It’s complicated to pray, the hard thing is like, there is a lump in here (stomach), if she wants to move, if she prays sometimes there’s a voice from the colostomy [P10]	Disturbed worship		
It’s sleep. She can’t sleep well. Because it’s very hard to lie on the side [P2]			
It is complicated if she wants to sleep, she said it’s hard. That’s because she shouldn’t be able to lie on its side because of the pouch on the stomach [P5]	Disturbed Sleeping		

Quality of life of patients with colostomy

Participant's Statement	Category	Sub Theme	Theme
She doesn't mind using colostomy, till now there is no problem [P1]			
There are no disturbances. Alhamdulillah, my father is still works really well, for example, if he went to work, he is a bus driver. He can still drive to Jakarta and back. There are no obstacles [P7]	No obstacles in working		
He's pretty fine with it. My father wanted to get well [P3]			
From what I saw. It's alright. The same as before using colostomy. She'd be like cheerful, didn't brought too much stress. She's relaxed. Fine as what it is. My point is she didn't gave too much of a thought nor complaining [P1]	No stress	Positive response	
Yea there has been a fair amount of progress, he used to be thin, now he's gaining weight again [P7]			
Before when he wanted to defecate it was difficult, hurt. Now it's good. The stomach doesn't hurt because the stool comes out on its own [P6]	Improvement in physical conditions		
It feels, nausea, no appetite. Now it's not bad. She can eat well now [P8]			
Participant's Statement	Category	Theme	
We are from BPJS (State Insurance Agency), Alhamdulillah if the treatment from the nurses are friendly or respond time is faster [P1]	Nurses can improve nursing services for patients	Health service needs for patients with colostomy	
What I expected is. Patients is the first priority [P2]			
Yes. The problem is that for colostomy users, sometimes there are people with a lot of insecurity of something or what, maybe the nurse can give encouragement so the patients can get through the ordeal [P2]	Nurses can support patients morally		

DISCUSSION

Family's Perspective on Nurses Behavior

Swanson (2007) suggest 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.

The results of data analysis obtained from interviews with participants revealed that during hospital treatment, nurses paid attention to the overall condition of the patient. One participant also revealed that nurses asked the patients if there's any complaints. The results of this study also found that in addition to caring for patients, nurses were also friendly to patients. Some participants revealed that the patient was well known by the nurse. Nurses also behave politely and respect the patient. Blacius et al (2016) in his research found that caring has implications for nursing practice so that nurses who have it will show kindness and politeness.

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 & Rosenberg (2013) and Phatak, Karanjawala, Chang & Kao (2014) identified that the impact of patient education for patients with stoma has potential of good benefits. The results of a systematic review by Faury, Koleček, Foucaud, Bailare & Quintard (2017) also show that educational interventions for patients with colostomy can have a contrast impact on quality of life and a positive impact on patients' psychosocial as well as self-management.

Participants revealed that during their family care in hospital, nurses conducted therapeutic communication with patients. Nurses in this case provide enthusiasm and humor to patients during their treatment in hospital. 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. Some participants also said that nurses' communication with patients and families was very good. The nurse gives a good explanation to the patient, is easy to question and to be asked for consideration. Nurses in interacting with patients and their families need communication skills. Another study by Chan, Wong, Cheung & Lam (2018) revealed that good physical management and involving effective nurse-patient communication in care add psychosocial comfort to patients.

However, although in the first sub-theme found positive behaviors that were classified as caring nurses in patients with colostomy, in this study also some participants revealed that there was a nurse service that they thought was not good. The results of this study reveal that nurse care for patients is slow. In this case the participants said that they were waiting for the old colostomy bag and the i.v fluid that was not replaced. Negative caring behavior in accordance with the results of Ardiana's (2010) study which states that almost half of nurses have not provided caring, especially in communicating with patients.

Quality of Life of Patients with Colostomy

Changes in daily life become the main thing in patients with colostomy. Some participants said that their families no longer or limit their activities such as homework, some even stopped working. The findings of this problem are similar to those found by Dabirian et al (2010) 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. Liao & Qin (2014) also found that patients with colostomy experienced disturbances and difficulties at work and also in social situations, body image and stoma function which were similar to other categories of this study.

The existence of new devices in the body certainly has an impact on the daily use of colostomates. In addition to difficult sleep, some participants said that their families experienced interference when they wanted to pray. Some have to use a chair during prayer because of difficulties with a colostomy. This finding is in accordance with research conducted by Cengiz & Bahar (2017) about a phenomenological study they did on 12 participants who were all Muslim received a theme in the form of 'limits on activities in daily life'. From this theme, seven sub-themes were found: dressing, bathing, sleeping, sex, physical activity, prayer, and social life. This finding is further strengthened by Akgul & Karadag's (2016) research where their research 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 discomfort as for example said by some participants that patients still often feel sick, nausea, vomiting, weakness, and still having difficulty on defecating. This is similar to research by Jansen, Koch, Brenner & Arndt (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 & Liang (2013) where they found significant values for physical disorders such as fatigue, pain, constipation and diarrhea.

Besides physical discomfort, psychosocial discomfort was also found when conducting interviews with participants. It includes feelings of discomfort or fear of others knowing the circumstances experienced by patients. This is because the stool is clearly visible in the patient's stomach so that patients are afraid of people seeing them dirty. This finding is also consistent with the results of research by Jansen & Koch (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.

Having a colostomy and receiving treatment in a hospital negatively affects a patient's mood. However, some participants said that patients did not encounter serious problems when using colostomy. Some patients can still do activities when using colostomy like working. Some participants also said that since using a colostomy, the patient felt physical comfort including being painless, gaining weight, being able to eat normally. This is similar to the research of Szpilewska Juzwizyn, Bolanowska, Milan & Chabowski (2018) where a total of 43% 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 do not think too much about the situation they are experiencing. This is in line with research by Tao, Songwanthana & Isaramalai (2016) that although informants' perceptions about 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 colostomy. Popek & 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 disease.

Changes in the quality of life of patients with colostomy vary from negative and positive responses. In this theme, negative sub-themes are more dominant than positive. This finding is similar to the research of Kimura, Kamada, Guilhem, Modesto & de Abreu (2016) which revealed that the obstacles faced by patients with colostomy significantly affect their physical, psychological, social and spiritual well-being. Through the analysis of Kimura et al (2016), it was found that there were more negative subcategories than positive ones.

Health Service Needs of Patients with Colostomy

In the last theme, some participants expect that nurses can improve nursing services for patients and also support patients morally. The role of nurses is as a provider of health services in patients with colostomy because the quality of life of patients with colostomy is not ideal (Liao & Qin 2014). Ferreira & Fort have found expectation in nursing services centered on the desire to be treated humanely, assisting in adaptation as a member of the household, healing and increasing patient strength, and helping to overcome patient weaknesses.

CONCLUSION

Improved services are needed, especially in terms of skills, responsiveness and awareness of nurses. Skills should be in terms of care or installation of colostomy bags to patients. Responsiveness is where nurses respond faster to patients' needs and awareness that nurses must understand what is felt and the complaints of patients with colostomy in the hospital. Caring which is the art of nursing is intended to provide well-being for others. A person's well-being will have an effect on their quality of life.

Positive nurse caring had a greater understanding among patients with colorectal cancer and colostomies whose quality of life were changed. Therefore, expectation on nurse caring to the patient with colorectal cancer and colostomy are on the rise.

Further research need to get a deeper perspective that might be obtained through patients with a colostomy of variables as diverse as age group and gender. Quantitative research is also needed to measure the level of patient satisfaction with colostomy. With quantitative data collection the respondents and the data obtained can be greater.

CONFLICT OF INTEREST

The authors report no conflicts of interest in this work.

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Kepada: Nana Rochana

Rab, 22 Apr 2020 jam 21.33

Thank you, the article that was sent, I immediately corrected it.

Untung Sujianto

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

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ABSTRACT

Background: Colorectal cancer patients with colostomy have various complaints about changes in their life including the need of comprehensive and personal care. Ostomy nurses are responsible for managing people with colostomy, and this particular nursing practice continues to develop

globally. Also, previous literature highlights the importance of caregiver's support, particularly family in the colostomy patient care.

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

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

Results: The results revealed three themes related to the family's experience: (1) Patients' experiences of nurses' behaviour, (2) Quality of life of patients with colostomy, (3) Patient's family expectations for nursing services. The findings found that the families were happy with the ostomy nursing care though some aspects need to be improved. However, colorectal cancer patients experienced some difficulties to live with 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.

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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 a various effect on health-related quality of life (HRQOL) (Barreto & Valencia, 2013; Dabirian, Yaghmaei, Rassouli & Tafreshi, 2011). Nurses are health care provider who have important role in caring for patients with colostomy, particularly in identifying their needs, prevent complications and improving quality of life.

Persons living with an ostomy require comprehensive and personalized care. Nursing care is important in order to prevent or manage complications and improve the physiological and psychosocial adjustment to the ostomy (Klingman, 2009). Danielsen, Soerensen, Burcharth, & 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. Nurses must determine the appropriate health and disease conditions to facilitate the patient to a new condition, be able to evaluate the patient's coping mechanism and its impact, and implement the nursing interventions according to the information they have (Yildirim & Gurkan, 2010). Therefore of problems related to ostomy including sexual problems, depressive feelings, gas, constipation, dissatisfaction with appearance, change in clothing, travel difficulties, feeling tired and worry about noises, and require more spesicif nursing care (Vonk-Klaassen, S., Vocht, H., at al (2016). In this sense, the

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individuals who live with an ostomy demand specialized care management to maintain physical and psychological health and quality of life.

Caregiving is often a multi-faceted endeavor that can entail both instrumental and affective support (Dumont, Jacobs, Turcotte, Anderson & Harel, 2010). Several studies (Berry, Dalwadi, & Jacobson, 2016; Hawyer, Van, Wilson, & Griffin, 2016; Bevans & Sternberg, 2012) found that over the past decade, the cancer caregiving literature has grown as patients' and partners' needs and quality of life (QoL) have become focus of concern. Existing research recognizes problems with collaboration between the hospice major barrier in delivering high-quality care for patients (Deborah., H., M Joan et al (2014). It is fundamental to understand the habits, perceptions and attitudes, feelings and emotions demonstrated in the most diverse situations that cross the patients, while understanding those who accompany and sustain them in this life-changing experience.

OBJECTIVE

The study aimed to analyze the family's experience of colorectal patients with colostomy about nurse caring the colorectal cancer patients that it can be identified the needs of patients who with colostomy while undergoing treatment, thereby improving nursing care.

METHODS

Study Methodology Design

This study used qualitative research methods with a descriptive phenomenology approach. This approach, which seeks to describe life experiences tries to find the essence of these phenomena by remaining open to the meanings associated with those who have experienced them (Polit & Beck, 2010). The selection of the subject of this study was carried out using purposive sampling or judgmental sampling techniques, that is taking samples with certain considerations (Soegiono, 2011).

Participants

Ten patient family participated in this study (Table 1). The criteria of this research subject have fulfilled the inclusion criteria which are: (1) Family members of patients who have colostomy caused by colorectal cancer, (2) family members who are able to communicate verbally, (3) cooperative family members who are willing to be the subject of research and agree on informed consent given, and (4) over 21 years old.

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 from family. Permission to audiotape the interview session was also sought from each participant; confidentiality and anonymity were guaranteed.

Data collection was conducted by semi-structured interview and ask question to get deep information about their experiences recorded by voice record. The time and place of the interview were arranged depending to participants' preferences but all of the participants were interviewed in the hospital (Table 1). Researchers attempted to arrange a calm environment in which the participants could be interviewed. Each interview lasted about 30–60 min. Data collection

continued until saturation, where no new information is obtained and redundancy is achieved. After that, the researchers used verbatim descriptions grouped the data into the form of themes, sub-themes and main categories.

Data analysis

The initial stage of data analyzing was carried out by documenting the results of the interview in the form of interview transcripts. This process is carried out by playing the recording repeatedly. Analysis of the data in this study uses a method created by Colaizzi (2015). The Colaizzi’s method has 7 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.

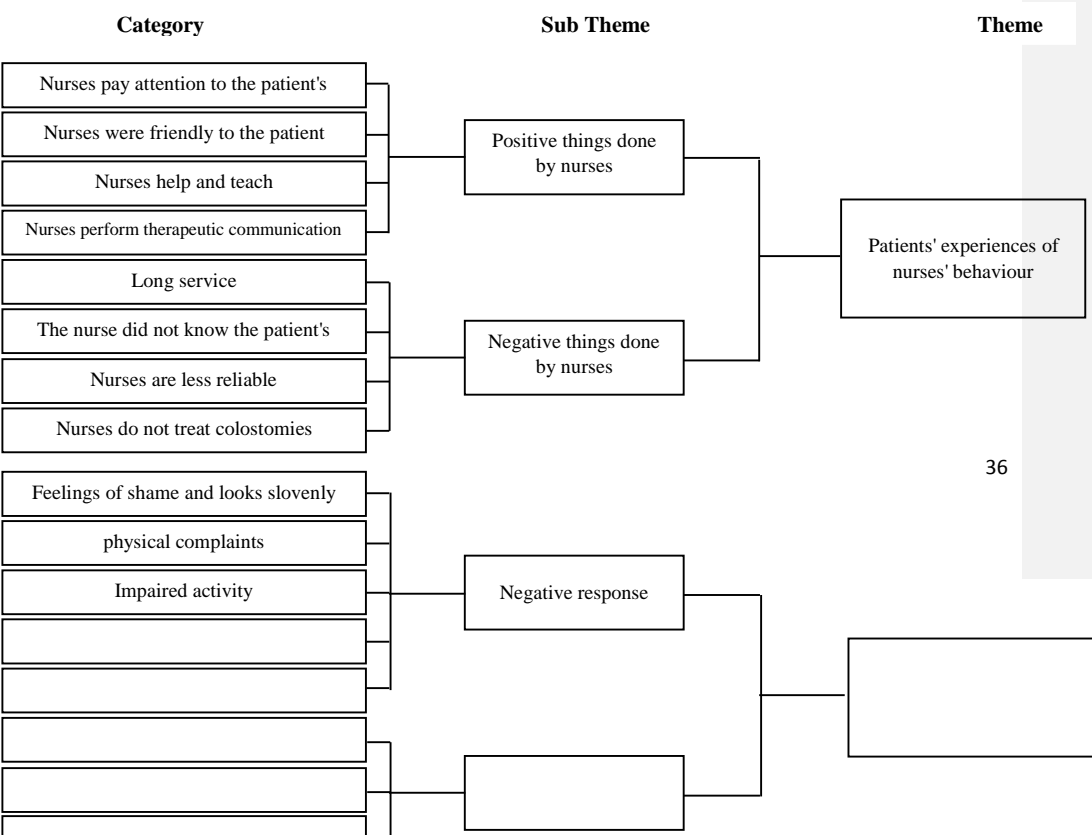
Many factors need to be considered to ensure the validity of this research. To ensure dependability, credibility, confirmability, and transferability researchers build good relationships with participants, namely the families of patients with colostomies, to obtain information. The researcher also clarifies the data obtained with participants (member check). This is done to ensure the validity of the data that researchers have summarized as themes.

Ethics?

The ethical considerations of this study were carried out on the principle of the five rights of human subjects in research (Macnee CL., 2004). These five rights include the right to self-determination, privacy, dignity, anonymity and confidentiality.

RESULTS

The results of this study found three themes : (1) Patients' experiences of nurses' behaviour , (2) Quality of life of patients with colostomy, (3) Patient’s family expectations for nursing services. The findings of the study revealed the needs for improved services, especially in terms of skills, responsiveness and awareness of nurses.



Themes 1 : Patients' experiences of nurses' behaviour

Example

The fulfillment of sexual need of PLWHA

The participants in this study mentioned that ARV treatment could improve their conditions. As a result, the participants felt healthier and were able to meet their sexual needs like a normal person.

“Ehm... My sexual activity remains the same as before. I’m infected with HIV/AIDS. So, it’s normal, and when I do the sexual intercourse, I just do it as normal...” (P1) “...it (sexual fulfillment) is just the same as the other person. Moreover, when I begin to consume the medicines, I’m becoming healthy. I usually do that”. (P8)

In addition, the participants also revealed that the fulfillment of sexual need was not necessarily done by coitus. Instead, they could have jokes, chats and received attention from their mates.

“It is normal; there is always a desire for sexual activity.” (P10) “...maybe, if I’m doing the sexual activity, I forgot my sickness, and it made me feel more relaxed...” (P9) “...instead of making love, I also need attention from my wife, love, and attention...” (P1)

Sub theme positif :

Nurses pay attention to the patient’s condition. The statement is in accordance with the following participant’s expression : “.....I am grateful for being treated in this hospital, nurses always pay attention to the state of the father such as asking the state of the father and ensure that the father feels comfortable” [P.4].

The nurse is friendly to the patient, the statement is in accordance with the following participant’s expression: “...The attitude of nurses in the hospital is all good. They already know my child. If

their meet somewhere else, they recognized my child's face and always ask first" [P.5]. "...Nothing is lacking in their attitude. The nurses here are subtle and polite. The nurse is also good and likes to joke" [P.6]. "...Nurses at the hospital are polite and respect each other to the patient. The language they speak is also rambling and polite. There is nothing to say loudly like yelling or angry" [P.10].

Nurses help and teach, the statement is in accordance with the following participant's expression : "...when first using a colostomy the nurse teaches family and caregiver. They teach how to replace a colostomy" [P.1]. "...The nurse here is alert, every time there is a problem or when we ask for help they act quickly" [P.7]. Nurses good communicate, the statement is in accordance with the following participant's expression : "...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].

Sub theme 2 : negative things that nurses do.

Long nurse service the statement is in accordance with the following participant's expression : "...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 they had to wait all the time. [P.8]. Nurses do not recognize patient complaints. The statement is in accordance with the following participant's expression : "...When the patient entered for a biopsy, he felt in pain. Maybe the nurse thinks that it doesn't hurt so that it doesn't really matter even if the patient looks very weak" [P.1]. Unreliable nurses. The statement is in accordance with the following participant's expression : "...there are good work and not good work. There are nurses who put up a colostomy bag but only a few hours apart, the colostomy is gone again" [P.8]. Nurses do not want to replace or treat a colostomy. The statement is in accordance with the following participant's expression " "...I want the nurse to treat you well and cleanly. So far it hasn't been like that. The nurse just told us to" [P.9]

Themes 2 : Quality of life of patients with colostomy

Sub theme 1 : negative response. Feelings of shame and looks dirty the statement is in accordance with the following participant's expression : "...only families know that mothers use colostomy. If other people know and see the poop suddenly out of the bag, maybe people can feel strange with the device on the body of the mother and judge that it is dirty" [P.10]. Physical complaint. The statement is in accordance with the following participant's expression : "...what he (patient, sister P1) complained about was his stomach which was always tense. Just eat a little already feels full. Now the patients is also rather weak, maybe because he can't eat because when he eats even just a little he feels vomiting right away, now his body also feels more pain" [P.1] "...according to him (patient, child P5) his waist still had pain" [P.5]. Activity disruption. The statement is in accordance with the following participant's expression : "...before there was a colostomy, all activities could be carried out, since there is a colostomy the activities have been limited, it cannot be complete as before" [P.5]. "...now they are not fit anymore so they cannot work and support their family" [P.6]. Rest interrupted. The statement is in accordance with the following participant's expression

: "...it's different now because I can't sleep anymore. Usually can sleep freely when there is no colostomy. Now be more careful when sleeping because there are wounds (ostomy)" [P.5]

Sub theme 2 : positive response. Work activities are not hampered. The statement is in accordance with the following participant's expression : "...for him (patient, sister P1) there are no obstacles when using a colostomy" [P.1]. "...Alhamdulillah no interference, can still work as a driver smoothly. During driving a bus back and forth in Jakarta there are no obstacles" [P.7]. No stress. The statement is in accordance with the following participant's expression : "...he (patient, child P7) never told about complaints and disorders. During this time what I saw he seemed to enjoy and relax with his current situation" [P.7]. Improvement of physical condition. The statement is in accordance with the following participant's expression : "...previously often nausea when aeting and no appetite, now can eat" [P.8]. "...Now sice using colostomy is healthy, it's not like it used to be. Mother said that she was healthier" [P.10]

Themes 3 : Patient's family expectations for nursing services

Patients become the main priority in the work of nurses in hospital. The statement is in accordance with the following participant's expression : "...our hope is that patients services can be prioritized because this hospital is already a central hospital, so the servants must be better than the regional hospitals" [P.2]. "...I want you (patient, husband P9) to be treated well and clean. So far, the nurses have not only told us (family) only" [P.9]. Patients are encouraged by nurses. The statement is in accordance with the following participant's expression : "...Patients with colostomies have a lot of thoughts so maybe nurses can encourage patients to pass their exams" [P.2]

Participant characteristics

Demographic characteristics	Gender (%)		Amount (%)
	Female	Male	
1. Relationship status with patients			
- Son	3 (30)	1 (10)	4 (40)
- Brother	1 (10)	0 (0)	1 (10)
- Father	1 (10)	0 (0)	1 (10)
- Wife	2 (10)	0 (0)	2 (20)
- Mother	1 (10)	0 (0)	1 (10)
2. Education			
- Primary school	3 (30)	1 (10)	4 (40)
- Junior high school	1 (10)	0 (0)	1 (10)
- Senior high school	1 (10)	1 (10)	2 (20)
- Diploma	1 (10)	0 (0)	1 (10)
- Bachelor	1 (10)	1 (10)	2 (20)
3. Age			
≥ 40	3 (30)	1 (10)	4 (40)
< 40	3 (30)	3 (30)	6 (60)

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Table 1: participant demographic characteristics

DISCUSSION

Patients' experiences of nurses' behaviour

The results of data analysis obtained from interviews with participants revealed that during hospital treatment, nurses paid attention to the overall condition of the patient. One participant also revealed that nurses asked the patients if there's any complaints. The results of this study also found that in addition to caring for patients, nurses were also friendly to patients. Some participants revealed that the patient was well known by the nurse. Nurses also behave politely and respect the patient. Blacius, D., & Setyowati, K. Y. A. (2016) in his research found that caring has implications for nursing practice so that nurses who have it will show kindness and politeness. Swanson (2007) suggest 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.

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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 & Rosenberg (2013) and Phatak, Karanjawala, Chang & Kao (2014) identified that the impact of patient education for patients with stoma has potential of good benefits. The results of a systematic review by Faury, Koleck, Foucaud, Bailare & Quintard (2017) also show that educational interventions for patients with colostomy can have a contrast impact on quality of life and a positive impact on patients' psychosocial as well as self-management.

Participants revealed that during their family care in hospital, nurses conducted therapeutic communication with patients. Nurses in this case provide enthusiasm and humor to patients during their treatment in hospital. 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. Some participants also said that nurses' communication with patients and families was very good. The nurse gives a good explanation to the patient, is easy to question and to be asked for consideration. Nurses in interacting with patients and their families need communication skills. Another study by Chan, Wong, Cheung & Lam (2018) revealed that good physical management and involving effective nurse-patient communication in care add psychosocial comfort to patients.

However, although in the first sub-theme found positive behaviors that were classified as caring nurses in patients with colostomy, in this study also some participants revealed that there was a nurse service that they thought was not good. The results of this study reveal that nurse care for patients is slow. In this case the participants said that they were waiting for the old colostomy bag and the i.v fluid that was not replaced. Negative caring behavior in accordance with the results of Ardiana's (2010) study which states that almost half of nurses have not provided caring, especially in communicating with patients.

Quality of life of patients with colostomy

Changes in daily life become the main thing in patients with colostomy. Some participants said that their families no longer or limit their activities such as homework, some even stopped working. The findings of this problem are similar to those found by Dabirian et al (2010) 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. Liao & Qin (2014) also found that patients with colostomy experienced disturbances and difficulties at work and also in social situations, body image and stoma function which were similar to other categories of this study.

The existence of new devices in the body certainly has an impact on the daily use of colostomates. In addition to difficult sleep, some participants said that their families experienced interference when they wanted to pray. Some have to use a chair during prayer because of difficulties with a colostomy. This finding is in accordance with research conducted by Cengiz & Bahar (2017) about a phenomenological study they did on 12 participants who were all Muslim received a theme in the form of 'limits on activities in daily life'. From this theme, seven sub-themes were found: dressing, bathing, sleeping, sex, physical activity, prayer, and social life. This finding is further strengthened by Akgul & Karadag's (2016) research where their research 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 discomfort as for example said by some participants that patients still often feel sick, nausea, vomiting, weakness, and still having difficulty on defecating. This is similar to research by Jansen, Koch, Brenner & Arndt (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 & Liang (2013) where they found significant values for physical disorders such as fatigue, pain, constipation and diarrhea.

Besides physical discomfort, psychosocial discomfort was also found when conducting interviews with participants. It includes feelings of discomfort or fear of others knowing the circumstances experienced by patients. This is because the stool is clearly visible in the patient's stomach so that patients are afraid of people seeing them dirty. This finding is also consistent with the results of research by Jansen & Koch (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.

Having a colostomy and receiving treatment in a hospital negatively affects a patient's mood. However, some participants said that patients did not encounter serious problems when using colostomy. Some patients can still do activities when using colostomy like working. Some participants also said that since using a colostomy, the patient felt physical comfort including being painless, gaining weight, being able to eat normally. This is similar to the research of Szpilewska Juzwizyn, Bolanowska, Milan & Chabowski (2018) where a total of 43% 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 do not think too much about the situation they are experiencing. This is in line with research by Tao, Songwanthana & Isaramalai (2016) that although informants' perceptions about 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 colostomy. Popek & 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 disease.

Changes in the quality of life of patients with colostomy vary from negative and positive responses. In this theme, negative sub-themes are more dominant than positive. This finding is similar to the research of Kimura, Kamada, Guilhem, Modesto & de Abreu (2016) which revealed that the obstacles faced by patients with colostomy significantly affect their physical, psychological, social and spiritual well-being. Through the analysis of Kimura et al (2016), it was found that there were more negative subcategories than positive ones.

Patient's family expectations for nursing services

The colostomy procedure is included as a severe adaptation for patients who experience it and produce additional problems. From the family's perspective on caring for nurses and the quality of life of colostomy patients, a final theme was found, namely the expectations of participants for nursing services at the hospital for patients with colostomy. Some participants hope that nurses can improve nursing services for patients and also support patients morally. The role of nurses as health care providers in patients with colostomy because the quality of life of patients with colostomy is not ideal (Liao, C., & Qin, Y. (2014). Other studies have found expectations for nursing services centered on the desire to be treated humanely, assisting in adaptation as a member of the household, restoring and increasing patient strength, and help overcome the patient's weakness (Ferreira-umpiérrez A, Fort-fort Z. (2014). Expectation is an important factor in the biopsychosociospiritual aspect. Expectations relate to how people's beliefs affect their behavior. Improved self-concept can be done by nurses through 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.

In the last theme, some participants expect that nurses can improve nursing services for patients and also support patients morally. The role of nurses is as a provider of health services in patients with colostomy because the quality of life of patients with colostomy is not ideal (Liao & Qin 2014). Ferreira & Fort have found expectation in nursing services centered on the desire to be treated humanely, assisting in adaptation as a member of the household, healing and increasing patient strength, and helping to overcome patient weaknesses.

CONCLUSION

The patient's family has the perspective that caring positive nurses have a greater understanding of negative nurse caring. Quality of life shows that the number of categories and participants who express negative responses is more than positive responses and patients with a colostomy needs professional nursing care. Further research need to get a deeper perspective that might be obtained through patients with a colostomy of variables as diverse as age group and gender.

CONFLICT OF INTEREST

The authors report no conflicts of interest in this work.

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

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ABSTRACT

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

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

Methods: The study design used descriptive phenomenology to explore the experience of ten participants through in-depth interview. The participants were selected using purposive sampling with the following 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) Patients' experiences of nurses' behaviour, (2) Quality of life of patients with colostomy, (3) Patient's family expectations for nursing services. The findings found that the families were happy with the ostomy nursing care though some aspects need to be improved. However, colorectal cancer patients experienced some difficulties to live with 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.

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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 a various effect on health-related quality of life (HRQOL) (Barreto & Valencia, 2013; Dabirian, Yaghmaei, Rassouli & Tafreshi, 2011). Nurses are health care provider who have important role in caring for patients with colostomy, particularly in identifying their needs, prevent complications and improving quality of life.

Persons living with an ostomy require comprehensive and personalized care. Nursing care is important in order to prevent or manage complications and improve the physiological and psychosocial adjustment to the ostomy (Klingman, 2009). Danielsen, Soerensen, Burcharth, & 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. Nurses must determine the appropriate health and disease conditions to facilitate the patient to a new condition, be able to evaluate the patient's coping mechanism and its impact, and implement the nursing interventions according to the information they have (Yildirim & Gurkan, 2010). Therefore of problems related to ostomy including sexual problems, depressive feelings, gas, constipation, dissatisfaction with appearance, change in clothing, travel difficulties, feeling tired and worry about noises, and require more spesicif nursing care (Vonk-Klaassen, S., Vocht, H., at al (2016). In this sense, the individuals who live with an ostomy demand specialized care management to maintain physical and psychological healthand quality of life.

Caregiving is often a multi-faceted endeavor that can entail both instrumental and affective support (Dumont, Jacobs, Turcotte, Anderson & Harel, 2010). Several studies (Berry, Dalwadi, & Jacobson, 2016; Hawyer, Van, Wilson, & Griffin, 2016; Bevans & Sternberg, 2012) found that over the past decade, the cancer caregiving literature has grown as patients' and partners' needs and quality of life (QoL) have become focus of concern. Existing research recognizes problems with collaboration between the hospice major barrier in delivering high-quality care for patients (Deborah., H., M Joan at al (2014). It is fundamental to understand the habits, perceptions and attitudes, feelings and emotions demonstrated in the most diverse situations that cross the patients, while understanding those who accompany and sustain them in this life-changing experience.

OBJECTIVE

The study aimed to analyze the family's experience of colorectal patients with colostomy about nurse caring the colorectal cancer patients that it can be identified the needs of patients who with colostomy while undergoing treatment, thereby improving nursing care.

METHODS

Study Methodology Design

This study used qualitative research methods with a descriptive phenomenology approach. This approach, which seeks to describe life experiences tries to find the essence of these phenomena by remaining open to the meanings associated with those who have experienced them (Polit & Beck, 2010). The selection of the subject of this study was carried out using purposive sampling or judgmental sampling techniques, that is taking samples with certain considerations (Soegiono, 2011).

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Participants

Ten patient family participated in this study (Table 1). The criteria of this research subject have fulfilled the inclusion criteria which are: (1) Family members of patients who have colostomy caused by colorectal cancer, (2) family members who are able to communicate verbally, (3) cooperative family members who are willing to be the subject of research and agree on informed consent given, and (4) over 21 years old.

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 from family. Permission to audiotape the interview session was also sought from each participant; confidentiality and anonymity were guaranteed.

Data collection was conducted by semi-structured interview and ask question to get deep information about their experiences recorded by voice record. The time and place of the interview were arranged depending to participants' preferences but all of the participants were interviewed in the hospital (Table 1). Researchers attempted to arrange a calm environment in which the participants could be interviewed. Each interview lasted about 30–60 min. Data collection continued until saturation, where no new information is obtained and redundancy is achieved. After that, the researchers used verbatim descriptions grouped the data into the form of themes, sub-themes and main categories.

Data analysis

The initial stage of data analyzing was carried out by documenting the results of the interview in the form of interview transcripts. This process is carried out by playing the recording repeatedly. Analysis of the data in this study uses a method created by Colaizzi (2015). The Colaizzi's method has 7 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.

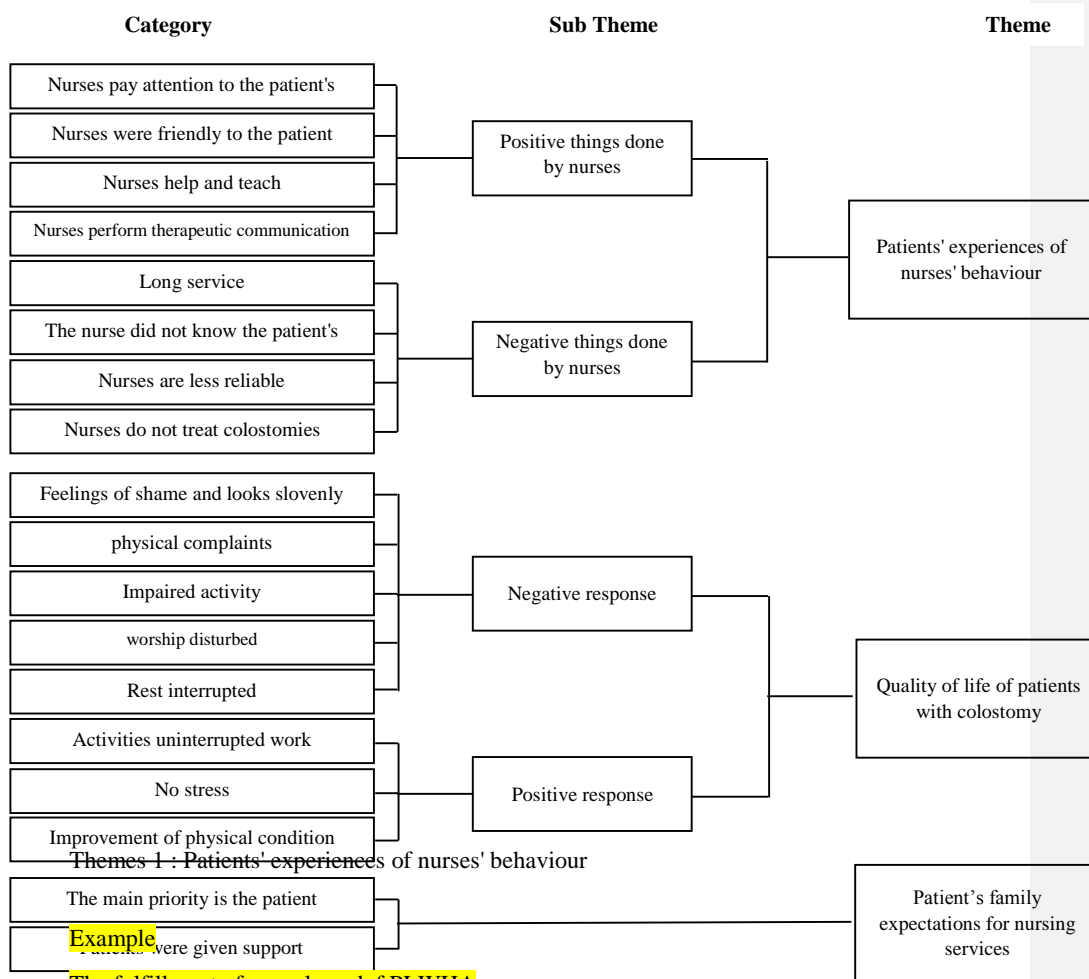
Many factors need to be considered to ensure the validity of this research. To ensure dependability, credibility, confirmability, and transferability researchers build good relationships with participants, namely the families of patients with colostomies, to obtain information. The researcher also clarifies the data obtained with participants (member check). This is done to ensure the validity of the data that researchers have summarized as themes.

Ethics?

The ethical considerations of this study were carried out on the principle of the five rights of human subjects in research (Macnee CL., 2004). These five rights include the right to self-determination, privacy, dignity, anonymity and confidentiality.

RESULTS

The results of this study found three themes : (1) Patients' experiences of nurses' behaviour , (2) Quality of life of patients with colostomy, (3) Patient's family expectations for nursing services. The findings of the study revealed the needs for improved services, especially in terms of skills, responsiveness and awareness of nurses.



The fulfillment of sexual need of PLWHA

The participants in this study mentioned that ARV treatment could improve their conditions. As a result, the participants felt healthier and were able to meet their sexual needs like a normal person.

“Ehm... My sexual activity remains the same as before. I’m infected with HIV/AIDS. So, it’s normal, and when I do the sexual intercourse, I just do it as normal...” (P1) “...it (sexual fulfillment) is just the same as the other person. Moreover, when I begin to consume the medicines, I’m becoming healthy. I usually do that”. (P8)

In addition, the participants also revealed that the fulfillment of sexual need was not necessarily done by coitus. Instead, they could have jokes, chats and received attention from their mates.

“It is normal; there is always a desire for sexual activity.” (P10) “...maybe, if I’m doing the sexual activity, I forgot my sickness, and it made me feel more relaxed...” (P9) “...instead of making love, I also need attention from my wife, love, and attention...” (P1)

Sub theme positif :

Nurses pay attention to the patient’s condition. The statement is in accordance with the following participant’s expression : “.....I am grateful for being treated in this hospital, nurses always pay attention to the state of the father such as asking the state of the father and ensure that the father feels comfortable” [P.4].

The nurse is friendly to the patient, the statement is in accordance with the following participant’s expression: “...The attitude of nurses in the hospital is all good. They already know my child. If they meet somewhere else, they recognized my child’s face and always ask first” [P.5]. “...Nothing is lacking in their attitude. The nurses here are subtle and polite. The nurse is also good and likes to joke” [P.6]. “...Nurses at the hospital are polite and respect each other to the patient. The language they speak is also rambling and polite. There is nothing to say loudly like yelling or angry” [P.10].

Nurses help and teach, the statement is in accordance with the following participant’s expression : “...when first using a colostomy the nurse teaches family and caregiver. They teach how to replace a colostomy” [P.1]. “...The nurse here is alert, every time there is a problem or when we ask for help they act quickly” [P.7]. Nurses good communicate, the statement is in accordance with the following participant’s expression : “...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].

Sub theme 2 : negative things that nurses do.

Long nurse service the statement is in accordance with the following participant’s expression : “...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 they had to wait all the time. [P.8]. Nurses do not recognize patient complaints. The statement is in accordance with the following participant’s expression : “...When the patient entered for a biopsy, he felt in pain. Maybe the nurse thinks that it doesn’t hurt so that it doesn’t really matter even if the patient looks very weak” [P.1]. Unreliable nurses. The statement is in accordance with the following participant’s expression : “...there are good work and not good work. There are nurses who put up a colostomy bag but only a few hours apart, the colostomy is gone again” [P.8]. Nurses do not want to replace or treat

a colostomy. The statement is in accordance with the following participant's expression " "...I want the nurse to treat you well and cleanly. So far it hasn't been like that. The nurse just told us to" [P.9]

Themes 2 : Quality of life of patients with colostomy

Sub theme 1 : negative response. Feelings of shame and looks dirty the statement is in accordance with the following participant's expression : "...only families know that mothers use colostomy. If other people know and see the poop suddenly out of the bag, maybe people can feel strange with the device on the body of the mother and judge that it is dirty" [P.10]. Physical complaint. The statement is in accordance with the following participant's expression : "...what he (patient, sister P1) complain about was his stomach which was always tense. Just eat a little already feels full. Now the patients is also rather weak, maybe because he can't eat because when he eats even just a little he feels vomiting right away, now his body also feels more pain" [P.1] "...according to him (patient, child P5) his waist still had pain" [P.5]. Activity disruption. The statement is in accordance with the following participant's expression : "...before there was a colostomy, all activities could be carried out, since there is a colostomy the activities have been limited, it cannot be complete as before" [P.5]. "...now they are not fit anymore so they cannot work and support their family" [P.6]. Rest interrupted. The statement is in accordance with the following participant's expression : "...it's different now because I can't sleep anymore. Usually can sleep freely when there is no colostomy. Now be more careful when sleeping because there are wounds (ostomy)" [P.5]

Sub theme 2 : positive response. Work activities are not hampered. The statement is in accordance with the following participant's expression : "...for him (patient, sister P1) there are no obstacles when using a colostomy" [P.1]. "...Alhamdulillah no interference, can still work as a driver smoothly. During driving a bus back and forth in Jakarta there are no obstacles" [P.7]. No stress. The statement is in accordance with the following participant's expression : "...he (patient, child P7) never told about complaints and disorders. During this time what I saw he seemed to enjoy and relax with his current situation" [P.7]. Improvement of physical condition. The statement is in accordance with the following participant's expression : "...previously often nausea when aeting and no appetite, now can eat" [P.8]. "...Now sice using colostomy is healthy, it's not like it used to be. Mother said that she was healthier" [P.10]

Themes 3 : Patient's family expectations for nursing services

Patients become the main priority in the work of nurses in hospital. The statement is in accordance with the following participant's expression : "...our hope is that patients services can be prioritized because this hospital is already a central hospital, so the servants must be better than the regional hospitals" [P.2]. "...I want you (patient, husband P9) to be treated well and clean. So far, the nurses have not only told us (family) only" [P.9]. Patients are encouraged by nurses. The statement is in accordance with the following participant's expression : "...Patients with colostomies have a lot of thoughts so maybe nurses can encourage patients to pass their exams" [P.2]

Participant characteristics

Demographic characteristics	Gender (%)	Amount (%)
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	Female	Male	
4. Relationship status with patients			
- Son	3 (30)	1 (10)	4 (40)
- Brother	1 (10)	0 (0)	1 (10)
- Father	1 (10)	0 (0)	1 (10)
- Wife	2 (10)	0 (0)	2 (20)
- Mother	1 (10)	0 (0)	1 (10)
5. Education			
- Primary school	3 (30)	1 (10)	4 (40)
- Junior high school	1 (10)	0 (0)	1 (10)
- Senior high school	1 (10)	1 (10)	2 (20)
- Diploma	1 (10)	0 (0)	1 (10)
- Bachelor	1 (10)	1 (10)	2 (20)
6. Age			
≥ 40	3 (30)	1 (10)	4 (40)
< 40	3 (30)	3 (30)	6 (60)

Table 1: participant demographic characteristics

DISCUSSION

Patients' experiences of nurses' behaviour

The results of data analysis obtained from interviews with participants revealed that during hospital treatment, nurses paid attention to the overall condition of the patient. One participant also revealed that nurses asked the patients if there's any complaints. The results of this study also found that in addition to caring for patients, nurses were also friendly to patients. Some participants revealed that the patient was well known by the nurse. Nurses also behave politely and respect the patient. Blacius, D., & Setyowati, K. Y. A. (2016) in his research found that caring has implications for nursing practice so that nurses who have it will show kindness and politeness. Swanson (2007) suggest 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.

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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 & Rosenberg (2013) and Phatak, Karanjawala, Chang & Kao (2014) identified that the impact of patient education for patients with stoma has potential of good benefits. The results of a systematic review by Faury, Koleck, Foucaud, Bailare & Quintard (2017) also show that educational interventions for patients with colostomy can have a contrast impact on quality of life and a positive impact on patients' psychosocial as well as self-management.

Participants revealed that during their family care in hospital, nurses conducted therapeutic communication with patients. Nurses in this case provide enthusiasm and humor to patients during their treatment in hospital. 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. Some participants also said that nurses' communication with patients and families was very good. The nurse gives a good explanation to the patient, is easy to question and to be asked for consideration. Nurses in interacting with patients and their families need communication skills. Another study by Chan, Wong, Cheung & Lam (2018) revealed that good physical management and involving effective nurse-patient communication in care add psychosocial comfort to patients.

However, although in the first sub-theme found positive behaviors that were classified as caring nurses in patients with colostomy, in this study also some participants revealed that there was a nurse service that they thought was not good. The results of this study reveal that nurse care for patients is slow. In this case the participants said that they were waiting for the old colostomy bag and the i.v fluid that was not replaced. Negative caring behavior in accordance with the results of Ardiana's (2010) study which states that almost half of nurses have not provided caring, especially in communicating with patients.

Quality of life of patients with colostomy

Changes in daily life become the main thing in patients with colostomy. Some participants said that their families no longer or limit their activities such as homework, some even stopped working. The findings of this problem are similar to those found by Dabirian et al (2010) 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. Liao & Qin (2014) also found that patients with colostomy experienced disturbances and difficulties at work and also in social situations, body image and stoma function which were similar to other categories of this study.

The existence of new devices in the body certainly has an impact on the daily use of colostomates. In addition to difficult sleep, some participants said that their families experienced interference when they wanted to pray. Some have to use a chair during prayer because of difficulties with a colostomy. This finding is in accordance with research conducted by Cengiz & Bahar (2017) about a phenomenological study they did on 12 participants who were all Muslim received a theme in the form of 'limits on activities in daily life'. From this theme, seven sub-themes were found: dressing, bathing, sleeping, sex, physical activity, prayer, and social life. This finding is further strengthened by Akgul & Karadag's (2016) research where their research 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 discomfort as for example said by some participants that patients still often feel sick, nausea, vomiting, weakness, and still having difficulty on defecating. This is similar to research by Jansen, Koch, Brenner & Arndt (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 & Liang (2013) where they found significant values for physical disorders such as fatigue, pain, constipation and diarrhea.

Besides physical discomfort, psychosocial discomfort was also found when conducting interviews with participants. It includes feelings of discomfort or fear of others knowing the circumstances experienced by patients. This is because the stool is clearly visible in the patient's stomach so that patients are afraid of people seeing them dirty. This finding is also consistent with the results of research by Jansen & Koch (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.

Having a colostomy and receiving treatment in a hospital negatively affects a patient's mood. However, some participants said that patients did not encounter serious problems when using colostomy. Some patients can still do activities when using colostomy like working. Some participants also said that since using a colostomy, the patient felt physical comfort including being painless, gaining weight, being able to eat normally. This is similar to the research of Szpilewska Juzwizyn, Bolanowska, Milan & Chabowski (2018) where a total of 43% 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 do not think too much about the situation they are experiencing. This is in line with research by Tao, Songwanthana & Isaramalai (2016) that although informants' perceptions about 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 colostomy. Popek & 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 disease.

Changes in the quality of life of patients with colostomy vary from negative and positive responses. In this theme, negative sub-themes are more dominant than positive. This finding is similar to the research of Kimura, Kamada, Guilhem, Modesto & de Abreu (2016) which revealed that the obstacles faced by patients with colostomy significantly affect their physical, psychological, social and spiritual well-being. Through the analysis of Kimura et al (2016), it was found that there were more negative subcategories than positive ones.

Patient's family expectations for nursing services

The colostomy procedure is included as a severe adaptation for patients who experience it and produce additional problems. From the family's perspective on caring for nurses and the quality of life of colostomy patients, a final theme was found, namely the expectations of participants for nursing services at the hospital for patients with colostomy. Some participants hope that nurses can improve nursing services for patients and also support patients morally. The role of nurses as health care providers in patients with colostomy because the quality of life of patients with colostomy is not ideal (Liao, C., & Qin, Y. (2014). Other studies have found expectations for

nursing services centered on the desire to be treated humanely, assisting in adaptation as a member of the household, restoring and increasing patient strength, and help overcome the patient's weakness (Ferreira-umpiérrez A, Fort-fort Z. (2014). Expectation is an important factor in the biopsychosociospiritual aspect. Expectations relate to how people's beliefs affect their behavior. Improved self-concept can be done by nurses through 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.

In the last theme, some participants expect that nurses can improve nursing services for patients and also support patients morally. The role of nurses is as a provider of health services in patients with colostomy because the quality of life of patients with colostomy is not ideal (Liao & Qin 2014). Ferreira & Fort have found expectation in nursing services centered on the desire to be treated humanely, assisting in adaptation as a member of the household, healing and increasing patient strength, and helping to overcome patient weaknesses.

CONCLUSION

The patient's family has the perspective that caring positive nurses have a greater understanding of negative nurse caring. Quality of life shows that the number of categories and participants who express negative responses is more than positive responses and patients with a colostomy needs professional nursing care. Further research need to get a deeper perspective that might be obtained through patients with a colostomy of variables as diverse as age group and gender.

CONFLICT OF INTEREST

The authors report no conflicts of interest in this work.

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

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ABSTRACT

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

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

Methods: The study design used descriptive phenomenology to explore the experience of ten participants through in-depth interview. The participants were selected using purposive sampling with the following 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) Patients' experiences of nurses' behaviour, (2) Quality of life of patients with colostomy, (3) Patient's family expectations for nursing services. The findings found that the families were happy with the ostomy

nursing care though some aspects need to be improved. However, colorectal cancer patients experienced some difficulties to live with 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.

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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 a various effect on health-related quality of life (HRQOL) (Barreto & Valencia, 2013; Dabirian, Yaghmaei, Rassouli & Tafreshi, 2011). Nurses are health care provider who have important role in caring for patients with colostomy, particularly in identifying their needs, prevent complications and improving quality of life.

Persons living with an ostomy require comprehensive and personalized care. Nursing care is important in order to prevent or manage complications and improve the physiological and psychosocial adjustment to the ostomy (Klingman, 2009). Danielsén, Soerensen, Burcharth, & 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. Nurses must determine the appropriate health and disease conditions to facilitate the patient to a new condition, be able to evaluate the patient's coping mechanism and its impact, and implement the nursing interventions according to the information they have (Yildirim & Gurkan, 2010). Therefore of problems related to ostomy including sexual problems, depressive feelings, gas, constipation, dissatisfaction with appearance, change in clothing, travel difficulties, feeling tired and worry about noises, and require more spesific nursing care (Vonk-Klaassen, S., Vocht, H., at al (2016). In this sense, the individuals who live with an ostomy demand specialized care management to maintain physical and psychological healthand quality of life.

Caregiving is often a multi-faceted endeavor that can entail both instrumental and affective support (Dumont, Jacobs, Turcotte, Anderson & Harel, 2010). Several studies (Berry, Dalwadi, & Jacobson, 2016; Hawyer, Van, Wilson, & Griffin, 2016; Bevans & Sternberg, 2012) found that over the past decade, the cancer caregiving literature has grown as patients' and partners' needs and quality of life (QoL) have become focus of concern. Existing research recognizes problems with collaboration between the hospice major barrier in delivering high-quality care for patients (Deborah., H., M Joan at al (2014). It is fundamental to understand the habits, perceptions and attitudes, feelings and emotions demonstrated in the most diverse situations that cross the patients, while understanding those who accompany and sustain them in this life-changing experience.

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OBJECTIVE

The study aimed to analyze the family's experience of colorectal patients with colostomy about nurse caring the colorectal cancer patients that it can be identified the needs of patients who with colostomy while undergoing treatment, thereby improving nursing care.

METHODS

Study Methodology Design

This study used qualitative research methods with a descriptive phenomenology approach. This approach, which seeks to describe life experiences tries to find the essence of these phenomena by remaining open to the meanings associated with those who have experienced them (Polit & Beck, 2010). The selection of the subject of this study was carried out using purposive sampling or judgmental sampling techniques, that is taking samples with certain considerations (Soegiono, 2011).

Participants

Ten patient family participated in this study (Table 1). The criteria of this research subject have fulfilled the inclusion criteria which are: (1) Family members of patients who have colostomy caused by colorectal cancer, (2) family members who are able to communicate verbally, (3) cooperative family members who are willing to be the subject of research and agree on informed consent given, and (4) over 21 years old.

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 from family. Permission to audiotape the interview session was also sought from each participant; confidentiality and anonymity were guaranteed.

Data collection was conducted by semi-structured interview and ask question to get deep information about their experiences recorded by voice record. The time and place of the interview were arranged depending to participants' preferences but all of the participants were interviewed in the hospital (Table 1). Researchers attempted to arrange a calm environment in which the participants could be interviewed. Each interview lasted about 30–60 min. Data collection continued until saturation, where no new information is obtained and redundancy is achieved. After that, the researchers used verbatim descriptions grouped the data into the form of themes, sub-themes and main categories.

Data analysis

The initial stage of data analyzing was carried out by documenting the results of the interview in the form of interview transcripts. This process is carried out by playing the recording repeatedly. Analysis of the data in this study uses a method created by Colaizzi (2015). The Colaizzi's method has 7 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.

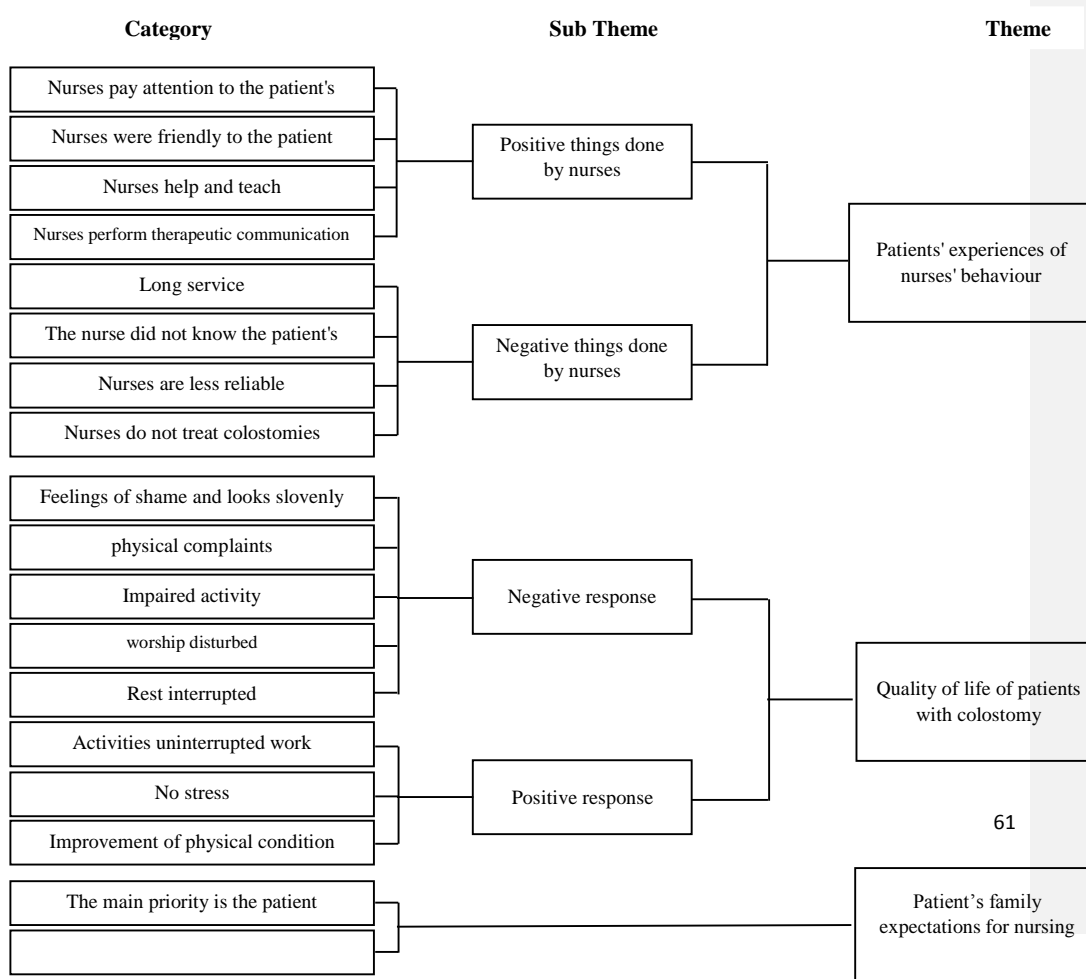
Many factors need to be considered to ensure the validity of this research. To ensure dependability, credibility, confirmability, and transferability researchers build good relationships with participants, namely the families of patients with colostomies, to obtain information. The researcher also clarifies the data obtained with participants (member check). This is done to ensure the validity of the data that researchers have summarized as themes.

Ethics?

The ethical considerations of this study were carried out on the principle of the five rights of human subjects in research (Macnee CL., 2004). These five rights include the right to self-determination, privacy, dignity, anonymity and confidentiality.

RESULTS

The results of this study found three themes : (1) Patients' experiences of nurses' behaviour , (2) Quality of life of patients with colostomy, (3) Patient's family expectations for nursing services. The findings of the study revealed the needs for improved services, especially in terms of skills, responsiveness and awareness of nurses.



Themes 1 : Patients' experiences of nurses' behaviour

Example

The fulfillment of sexual need of PLWHA

The participants in this study mentioned that ARV treatment could improve their conditions. As a result, the participants felt healthier and were able to meet their sexual needs like a normal person.

“Ehm... My sexual activity remains the same as before. I’m infected with HIV/AIDS. So, it’s normal, and when I do the sexual intercourse, I just do it as normal...” (P1) “...it (sexual fulfillment) is just the same as the other person. Moreover, when I begin to consume the medicines, I’m becoming healthy. I usually do that”. (P8)

In addition, the participants also revealed that the fulfillment of sexual need was not necessarily done by coitus. Instead, they could have jokes, chats and received attention from their mates.

“It is normal; there is always a desire for sexual activity.” (P10) “...maybe, if I’m doing the sexual activity, I forgot my sickness, and it made me feel more relaxed...” (P9) “...instead of making love, I also need attention from my wife, love, and attention...” (P1)

Sub theme positif :

Nurses pay attention to the patient’s condition. The statement is in accordance with the following participant’s expression : “.....I am grateful for being treated in this hospital, nurses always pay attention to the state of the father such as asking the state of the father and ensure that the father feels comfortable” [P.4].

The nurse is friendly to the patient, the statement is in accordance with the following participant’s expression: “...The attitude of nurses in the hospital is all good. They already know my child. If they meet somewhere else, they recognized my child’s face and always ask first” [P.5]. “...Nothing is lacking in their attitude. The nurses here are subtle and polite. The nurse is also good and likes to joke” [P.6]. “...Nurses at the hospital are polite and respect each other to the patient. The language they speak is also rambling and polite. There is nothing to say loudly like yelling or angry” [P.10].

Nurses help and teach, the statement is in accordance with the following participant’s expression : “...when first using a colostomy the nurse teaches family and caregiver. They teach how to replace a colostomy” [P.1]. “...The nurse here is alert, every time there is a problem or when we ask for help they act quickly” [P.7]. Nurses good communicate, the statement is in accordance with the following participant’s expression : “...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].

Sub theme 2 : negative things that nurses do.

Long nurse service the statement is in accordance with the following participant's expression : "...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 they had to wait all the time. [P.8]. Nurses do not recognize patient complaints. The statement is in accordance with the following participant's expression : "...When the patient entered for a biopsy, he felt in pain. Maybe the nurse thinks that it doesn't hurt so that it doesn't really matter even if the patient looks very weak" [P.1]. Unreliable nurses. The statement is in accordance with the following participant's expression : "...there are good work and not good work. There are nurses who put up a colostomy bag but only a few hours apart, the colostomy is gone again" [P.8]. Nurses do not want to replace or treat a colostomy. The statement is in accordance with the following participant's expression " "...I want the nurse to treat you well and cleanly. So far it hasn't been like that. The nurse just told us to" [P.9]

Themes 2 : Quality of life of patients with colostomy

Sub theme 1 : negative response. Feelings of shame and looks dirty the statement is in accordance with the following participant's expression : "...only families know that mothers use colostomy. If other people know and see the poop suddenly out of the bag, maybe people can feel strange with the device on the body of the mother and judge that it is dirty" [P.10]. Physical complaint. The statement is in accordance with the following participant's expression : "...what he (patient, sister P1) complained about was his stomach which was always tense. Just eat a little already feels full. Now the patients is also rather weak, maybe because he can't eat because when he eats even just a little he feels vomiting right away, now his body also feels more pain" [P.1] "...according to him (patient, child P5) his waist still had pain" [P.5]. Activity disruption. The statement is in accordance with the following participant's expression : "...before there was a colostomy, all activities could be carried out, since there is a colostomy the activities have been limited, it cannot be complete as before" [P.5]. "...now they are not fit anymore so they cannot work and support their family" [P.6]. Rest interrupted. The statement is in accordance with the following participant's expression : "...it's different now because I can't sleep anymore. Usually can sleep freely when there is no colostomy. Now be more careful when sleeping because there are wounds (ostomy)" [P.5]

Sub theme 2 : positive response. Work activities are not hampered. The statement is in accordance with the following participant's expression : "...for him (patient, sister P1) there are no obstacles when using a colostomy" [P.1]. "...Alhamdulillah no interference, can still work as a driver smoothly. During driving a bus back and forth in Jakarta there are no obstacles" [P.7]. No stress. The statement is in accordance with the following participant's expression : "...he (patient, child P7) never told about complaints and disorders. During this time what I saw he seemed to enjoy and relax with his current situation" [P.7]. Improvement of physical condition. The statement is in accordance with the following participant's expression : "...previously often nausea when eating and no appetite, now can eat" [P.8]. "...Now since using colostomy is healthy, it's not like it used to be. Mother said that she was healthier" [P.10]

Themes 3 : Patient's family expectations for nursing services

Patients become the main priority in the work of nurses in hospital. The statement is in accordance with the following participant's expression : "...our hope is that patients services can be prioritized because this hospital is already a central hospital, so the servants must be better than the regional hospitals" [P.2]. "...I want you (patient, husband P9) to be treated well and clean. So far, the nurses have not only told us (family) only" [P.9]. Patients are encouraged by nurses. The statement is in accordance with the following participant's expression : "...Patients with colostomies have a lot of thoughts so maybe nurses can encourage patients to pass their exams" [P.2]

Participant characteristics

Demographic characteristics	Gender (%)		Amount (%)
	Female	Male	
7. Relationship status with patients			
- Son	3 (30)	1 (10)	4 (40)
- Brother	1 (10)	0 (0)	1 (10)
- Father	1 (10)	0 (0)	1 (10)
- Wife	2 (10)	0 (0)	2 (20)
- Mother	1 (10)	0 (0)	1 (10)
8. Education			
- Primary school	3 (30)	1 (10)	4 (40)
- Junior high school	1 (10)	0 (0)	1 (10)
- Senior high school	1 (10)	1 (10)	2 (20)
- Diploma	1 (10)	0 (0)	1 (10)
- Bachelor	1 (10)	1 (10)	2 (20)
9. Age			
≥ 40	3 (30)	1 (10)	4 (40)
< 40	3 (30)	3 (30)	6 (60)

Table 1: participant demographic characteristics

DISCUSSION

Patients' experiences of nurses' behaviour

The results of data analysis obtained from interviews with participants revealed that during hospital treatment, nurses paid attention to the overall condition of the patient. One participant also revealed that nurses asked the patients if there's any complaints. The results of this study also found that in addition to caring for patients, nurses were also friendly to patients. Some participants revealed that the patient was well known by the nurse. Nurses also behave politely and respect the patient. Blacius, D., & Setyowati, K. Y. A. (2016) in his research found that caring has implications for nursing practice so that nurses who have it will show kindness and politeness. Swanson (2007) suggest 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.

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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 & Rosenberg (2013) and Phatak, Karanjawala, Chang & Kao (2014) identified that the impact of patient education for patients with stoma has potential of good benefits. The results of a systematic review by Faury, Koleck, Foucaud, Bailare & Quintard (2017) also show that educational interventions for patients with colostomy can have a contrast impact on quality of life and a positive impact on patients' psychosocial as well as self-management.

Participants revealed that during their family care in hospital, nurses conducted therapeutic communication with patients. Nurses in this case provide enthusiasm and humor to patients during their treatment in hospital. 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. Some participants also said that nurses' communication with patients and families was very good. The nurse gives a good explanation to the patient, is easy to question and to be asked for consideration. Nurses in interacting with patients and their families need communication skills. Another study by Chan, Wong, Cheung & Lam (2018) revealed that good physical management and involving effective nurse-patient communication in care add psychosocial comfort to patients.

However, although in the first sub-theme found positive behaviors that were classified as caring nurses in patients with colostomy, in this study also some participants revealed that there was a nurse service that they thought was not good. The results of this study reveal that nurse care for patients is slow. In this case the participants said that they were waiting for the old colostomy bag and the i.v fluid that was not replaced. Negative caring behavior in accordance with the results of Ardiana's (2010) study which states that almost half of nurses have not provided caring, especially in communicating with patients.

Quality of life of patients with colostomy

Changes in daily life become the main thing in patients with colostomy. Some participants said that their families no longer or limit their activities such as homework, some even stopped working. The findings of this problem are similar to those found by Dabirian et al (2010) 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. Liao & Qin (2014) also found that patients with colostomy experienced disturbances and difficulties at work and also in social situations, body image and stoma function which were similar to other categories of this study.

The existence of new devices in the body certainly has an impact on the daily use of colostomates. In addition to difficult sleep, some participants said that their families experienced interference when they wanted to pray. Some have to use a chair during prayer because of difficulties with a colostomy. This finding is in accordance with research conducted by Cengiz & Bahar (2017) about

a phenomenological study they did on 12 participants who were all Muslim received a theme in the form of 'limits on activities in daily life'. From this theme, seven sub-themes were found: dressing, bathing, sleeping, sex, physical activity, prayer, and social life. This finding is further strengthened by Akgul & Karadag's (2016) research where their research 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 discomfort as for example said by some participants that patients still often feel sick, nausea, vomiting, weakness, and still having difficulty on defecating. This is similar to research by Jansen, Koch, Brenner & Arndt (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 & Liang (2013) where they found significant values for physical disorders such as fatigue, pain, constipation and diarrhea.

Besides physical discomfort, psychosocial discomfort was also found when conducting interviews with participants. It includes feelings of discomfort or fear of others knowing the circumstances experienced by patients. This is because the stool is clearly visible in the patient's stomach so that patients are afraid of people seeing them dirty. This finding is also consistent with the results of research by Jansen & Koch (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.

Having a colostomy and receiving treatment in a hospital negatively affects a patient's mood. However, some participants said that patients did not encounter serious problems when using colostomy. Some patients can still do activities when using colostomy like working. Some participants also said that since using a colostomy, the patient felt physical comfort including being painless, gaining weight, being able to eat normally. This is similar to the research of Szpilewska Juzwizyn, Bolanowska, Milan & Chabowski (2018) where a total of 43% 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 do not think too much about the situation they are experiencing. This is in line with research by Tao, Songwanthana & Isaramalai (2016) that although informants' perceptions about 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 colostomy. Popek & 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 disease.

Changes in the quality of life of patients with colostomy vary from negative and positive responses. In this theme, negative sub-themes are more dominant than positive. This finding is similar to the research of Kimura, Kamada, Guilhem, Modesto & de Abreu (2016) which revealed that the obstacles faced by patients with colostomy significantly affect their physical, psychological, social

and spiritual well-being. Through the analysis of Kimura et al (2016), it was found that there were more negative subcategories than positive ones.

Patient's family expectations for nursing services

The colostomy procedure is included as a severe adaptation for patients who experience it and produce additional problems. From the family's perspective on caring for nurses and the quality of life of colostomy patients, a final theme was found, namely the expectations of participants for nursing services at the hospital for patients with colostomy. Some participants hope that nurses can improve nursing services for patients and also support patients morally. The role of nurses as health care providers in patients with colostomy because the quality of life of patients with colostomy is not ideal (Liao, C., & Qin, Y. (2014). Other studies have found expectations for nursing services centered on the desire to be treated humanely, assisting in adaptation as a member of the household, restoring and increasing patient strength, and help overcome the patient's weakness (Ferreira-umpiérrez A, Fort-fort Z. (2014). Expectation is an important factor in the biopsychosociospiritual aspect. Expectations relate to how people's beliefs affect their behavior. Improved self-concept can be done by nurses through 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.

In the last theme, some participants expect that nurses can improve nursing services for patients and also support patients morally. The role of nurses is as a provider of health services in patients with colostomy because the quality of life of patients with colostomy is not ideal (Liao & Qin 2014). Ferreira & Fort have found expectation in nursing services centered on the desire to be treated humanely, assisting in adaptation as a member of the household, healing and increasing patient strength, and helping to overcome patient weaknesses.

CONCLUSION

The patient's family has the perspective that caring positive nurses have a greater understanding of negative nurse caring. Quality of life shows that the number of categories and participants who express negative responses is more than positive responses and patients with a colostomy needs professional nursing care. Further research need to get a deeper perspective that might be obtained through patients with a colostomy of variables as diverse as age group and gender.

CONFLICT OF INTEREST

The authors report no conflicts of interest in this work.

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