QUALITY OF LIFE OF PATIENTS WITH END-STOMA IN MEDAN: A PHENOMENOLOGICAL STUDY

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Abstract
Background: Colorectal cancer continues to be a serious problem in Indonesia. A common colorectal treatment is surgical removal of the diseased colon, followed by the creation of a colostomy through the abdominal wall to bypass the colorectal function of emptying waste products. Those who require permanent colostomy are likely to have quality of life issues impacting their physical, psychological, social, and spiritual needs. There issues impact persons’ life satisfaction, happiness, and overall quality of life.
Objective: The aim of study was to describe the experiences of patients with end-stoma regarding their quality of life.
Methods: The study design used descriptive phenomenology following the approach of Collaizzi. There were 12 participants who qualified using purposive sampling based on the inclusion criteria. The data were gathered in-depth interviews. Analysis and interpretation used verbatim descriptions in Bahasa Indonesia and subsequently translated into English language.
Results: The research emerged seven themes, namely: (i) becoming limited in doing daily activity, (ii) having limitation during sexual and social intercourse, (iii) having various negative feelings after the existence of end-stoma, (iv) having financial difficulties, (v) attempting to survive with end-stoma, (vi) experiencing changes in fulfilling rest and sleep, physic, and complication, and (vii) having expectation which has to be achieved after having end-stoma.
Conclusion: The results show that patients with end-stoma run into spiritual, social, psychological and physical disorder that affect the quality of their life. This study provides an understanding of the quality of life of patients with end-stoma and nurses are able to provide appropriate nursing care.

Keywords: quality of life; colorectal cancer; end-stoma

INTRODUCTION

Colon cancer continues to be a problem in Indonesia. The number of patients with colon cancer rank tenth (2.75%) after other cancers such as uterine, breast, lymph nodes, skin, nasopharyngeal, ovarian, rectal, soft tissue, and thyroid (Ibrahim, Priambodo, Nur’aeni, & Hendrawati, 2017). The WHO has found that colon and rectal cancer are the third most common cancer in men and second women worldwide. The incidence of colorectal cancer in the United States shows nearly 145,000 new cases and 50,000 deaths annually (Smeltzer et al., 2008). Meanwhile in Indonesia the incidence rate of colorectal cancers is quite high, and increasing in number at the above age of 40 (Sjamsuhidajat, 2017).
The number of cases 12.8/100,000 residents, claiming the third most prevalent type of carcinomas in Indonesia (MoH, 2015). A common colorectal treatment is the surgical removal of the diseased colon, followed by the creation of a colostomy through the abdominal wall to bypass the colorectal function of emptying waste products (Ibrahim et al., 2017). Each year approximately 100,000 patients undergo stoma surgeries. More than 70,000 people in the United Kingdom, and approximately 120,000 in the United States experience stomas every year (Ozturko, Unal, Yildrim, & Ozlem, 2015). Those who require permanent colostomy are likely to have quality of life issues impacting their physical, psychological, social, and spiritual needs. There issues impact patients’ life satisfaction, happiness, and overall quality of life (Alwi, Asrizal, & Locsin, 2017).

Quality of life is a series of subjective components reflecting aspects of patients’ physical, emotional, occupational and social experiences. WHO has defined quality of life as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (Whoqol, 1995).

In the study in China, it was found that experiencing functional difficulties at work and social circumstances, having sexual issues and body image, and some functional problem; anxious about privacy when empty the bag, always anxious about leakage, always anxious about social activities, gas, travelling, and skin irritation (Liao & Qin, 2014). Also, another study shows that the scores of quality of life are generally better than preoperative levels until the sixth month postoperative, but social function, body image, chemotherapy side effects and financial difficulties are unusual. Patients without a permanent colostomy have a better score in most categories of quality of life than a permanent colostomy (Yang et al., 2014).

The study by Kimura, Kamada, Guilhem and Monteiro revealed that the quality of life stoma patients was very bad (11.11%), bad (48.16%), neither good nor bad (14.81%), good (22.22%) and very good (3.70%) did not present a unidirectional finding. In fact, the results showed that bad experience and good experience held the first two highest percentage scores indicating the inconsistency in the experiences of patients with stomas (Kimura, Kamada, Guilhem, & Monteiro, 2013).

Based on the results of the research above shows that the quality of life of stoma varies widely. The quality of life of patients with end-stoma very important to explore so as to determine anticipatory programs and improve the rehabilitation results of patients with end-stoma. Therefore, this research will study the various perceptions or experiences in depth of patients with end-stoma regarding their quality of life.

METHODS

Study design
The study used qualitative with design descriptive phenomenology. Why this design was chosen is that the experience of participants can be explored to be more revealed that the image of the patients experience with end-stoma regarding their quality of life can be real. Moreover, the study explores, analyzes and describes directly the phenomena of the patients’ experience, that tells about the quality of their life after being installed end-stoma with as freely as possible from an intuition that cannot directly be measured (Speziale, Streubert, & Carpenter, 2011).

Sample
Twelve patients with end-stoma who volunteered to participate in this study were selected by purposive sampling. Inclusion criteria included: 1) willing to be a participant, 2) no communication disorder, 3) physically and mentally healthy, 4) freedom
from other diseases, and 5) no history of stoma in their family member.

**Data collection**

Data collection was conducted by in-depth interviews and the probing technique is used to ask questions to get deep information about their experiences recorded by voice record. Each participant was informed of the purpose of the study and a consent form guaranteeing participants anonymity and confidentiality was signed. The participants were able to withdraw from the study at any time. The time and place of the interview were arranged depending on participants’ preferences but all of the participants were interviewed in their homes. Researchers attempted to arrange a calm environment in which the participants could be interviewed. Each interview lasted about 55-60 minutes. Data collection continued until saturation, where no new information is obtained and redundancy is achieved (Polit & Beck, 2008). After that, the researchers used verbatim descriptions in Bahasa Indonesia and subsequently translated into English language and grouped the data into the form of themes, sub-themes and main categories.

**Instrument**

The researchers using the instrument in this study were the researchers themselves. Using semi structured interviews with the interview guide consists of 5 open-ended questions were developed by the researchers themselves and have been validated by three experts in stoma.

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<tr>
<th>No.</th>
<th>Possible Questions to Guide the Participants</th>
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<tr>
<td>1.</td>
<td>How do you feel after you have stoma?</td>
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<td>2.</td>
<td>How is your relationship with others after you have stoma?</td>
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<td>3.</td>
<td>What is your purpose and life expectancy after you have stoma, how could you achieve it?</td>
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<td>4.</td>
<td>What are your obstacles and challenges that you feel after have stoma?</td>
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<td>5.</td>
<td>As patients with stoma, what kind of nursing cares that you would expect?</td>
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**Ethical consideration**

This study was approved by the Commission of Health Research Ethics of the Faculty of Nursing University of Sumatera Utara (Approval No. 1229/VI/SP/2017).

**Data analysis**

Using software Welf-QDA version 1.0.1, it has been helped researchers to data analysis. Researchers used the Collaizzi method (Polit & Beck, 2008). The process of data analysis includes; 1) reading and rereading all transcripts of interviews that participants have disclosed, 2) extracting of significant statements related quality of life of patients with end-stoma, 3) describing the meaning contained in the significant statements, 4) organizing the meaning formulated into the theme group, 5) developing a complete theme description, 6) identify the structural basis of the phenomenon, and 7) returning to the participant to validate the finding of phenomenon. The principles of trustworthiness were applied to ensure the rigor of the study (Schwandt, Lincoln, & Guba, 2007). A member checking was done with participants as ways of ensuring that the researchers have analyzed the data correctly (Gunawan, 2015).

**RESULTS**

The results of this study found seven themes: 1) becoming limited in doing daily activity, 2) having limitation during sexual and social intercourse, 3) having various negative feelings after the existence of stoma, 4) having financial difficulties, 5) attempting to survive with stoma, 6) experiencing changes in fulfilling rest and sleep, physic, and complication, and 7) having expectation which has to be achieved after having stoma.

**Theme 1. Becoming limited in doing daily activity**

Participants have experienced limitations in daily living activities both in spiritual and
physical activities. Spiritual activity that performs worship is a limitation, experienced by participants. Participants said obstacles in performing worship prayer in term of performing wudhu (taking ablution), the prayer is no longer acceptable or not due to wudhu problem. This corresponds to the participant's statement:

"...When praying, I’d also heard the same thing about it. They said it was acceptable...but they weren’t also sure about it. It was so unintentional.... I did not mean it..." (Participant 6)

Physical limitation has been experienced by participants, which participants said long journey was being a problem and was unfree where to go, and the physical condition of the participants, where the energy is reduced, cause them to be powerless. This statement corresponds to the participant's expression:

"...Energy is also less automatic, lifting something we become very careful, because the energy comes from the stomach..." (Participant 11)

**Theme 2. Having limitation during sexual and social intercourse**

Obstacles have been experienced by participants in sexual intercourse such as worried about getting divorced and no longer having sexual intercourse. The statement in accordance with the expression:

"...I have never contacted her anyway. I was afraid..." (Participant 4)

When interacting with others, the obstacles the patients have are nerves, privacy, difficulties, and being introvert. The participants said it really affected their feeling in public. This statement is in accordance with the phrase:

"...It is arguably difficult. Actually, to get along with the public is very difficult, because defecation cannot be predicted. Just like normal defecating, so it could possibly smell due to the defecating..." (Participant 12)

**Theme 3. Having various negative feelings after the existence of stoma**

Most of the participants had negative feelings about themselves. The negative feelings felt by participants are feeling afraid, feeling alone, feeling suffer, upset easily, feeling inferior, and shameful. Some participants said they are afraid of leaking, smelling and disturbing the others. This statement is in accordance with the phrase:

"...In our sense, fear of leaking...somehow that person knows what we know..." (Participant 5)

**Theme 4. Having financial difficulties**

Participants had had many difficulties, especially in working; many participants quit their jobs due to end-stoma, while the cost of living increases because of need to buy stoma bags that are quite expensive. Most of participants have been experiencing job issues and financial difficulties. Some participants said they could not work. This statement is in accordance with the phrase:

"...It's been more than a year that I don't have any job..." (Participant 3)

Participants stated the high price of stoma bags and the amount of expenses incurred to buy stoma bags. The statement is as expressed by the participant:

"...It’s such a waste of money for me to spend money on such things..." (Participant 4)

**Theme 5. Attempting to survive with stoma**

Participants have made many attempts; such efforts include attempts in making stoma bag, avoiding leakage, efforts to overcome irritation and efforts in treating stomas. This statement corresponds to the participant's expression:

"...I made my own colostomy bag size it is so expensive..." (Participant 12)

Efforts by participants to overcome the irritation are varied such as using Povidone iodine, using powder and wasp oil, Cusson baby powder, intravenous fluids, and hot water. The above mentioned disclosed some participants as follows:

"...Well, sometimes Povidone iodine, sometimes use powder..." (Participant 7)

"...Yes, it is wet, that's why I cleaned with the intravenous fluids...after cleaning and drying it, I directly stick on the stoma bag..." (Participant 2)

**Theme 6. Experiencing changes in fulfilling rest and sleep, physic, and complication**
Participants have undergone many changes, such as in the need for resting, where participants do not feel free, and often awake in the event of leaking stoma bag. Physical changes are also happened to patients who cannot feel the wind (flatus) and defecation. Participants also experienced complications around the stoma caused by outbreaks and also due to increased body weight. Some participants said that they slept so uncomfortably, due to disturbance, which their sleeping hours reduced. This is expressed by the participant as follows:

“...It’s not comfortable to sleep here. I have to move to the right and left. That’s why I prefer sleeping with fluffy pillows…” (Participant 4)

Theme 7. Having expectation that has to be achieved after having stoma.
Participants will get to be able to work again, will get health education of stoma and will be unity for stoma patients. This statement is accordance with the expression by some participants:

“...If the future is still working, the term aids the term to the paddy field, if the heavy lifting cannot anymore, used to I can lift 90 kg…” (Participant 3)

A participant said that hoping for the union of people who have a stoma so that they can share the experience of fellow stoma. This was expressed by the participants as follows:

“...Which seem like I hope there is unity like so we can tell about our experience, my hope there is no problem so…” (Participant 1)

DISCUSSION
One of the causes of end-stoma is colorectal cancer. This will lead to limit daily living activities. Every human being does everything what he wants to live freely, but not patients with end-stoma. This situation can make who suffers from end-stoma feel limited to do everything. Patients with end-stoma deal with problem in performing religious worship activities. Some of participants have experienced limitations in performing worship, especially for congregational prayers at Masque. This limitation is due to many things, such as the feeling of being unacceptable or not and the smell coming out from dirt in the stoma hole.

According to literature, after stoma surgery, patients refrained from religious activities and experienced problems such as insufficient information and inability to obtain sufficient information (Herek, Akbas, Taylan, & Alabaz, 2003). While Kuzu et al. shows that the presence of stomas is significantly an aspect that affects the quality of life related to health and is associated by decreased activity of prayer (Kuzu et al., 2002). This finding is also in accordance with previous research which states of the eight participants, all experienced limitations in religious rituals or spiritual distress (Rangki, Ibrahim, & Nuraeni, 2014).

Important findings in this study were related to spiritual issues. Although not all participants stated that they had no major problems with spiritual problems, it is important for the nurse to pay attention to the spiritual and religious rituals of the patients. In Muslim, to be clean and free of anything like dirt, especially during prayer is compulsory. In that case, nurses need to optimize the hygiene as well as possible.

Limitations of physical activity in work were also experienced by participants after the end-stoma, where participants said they could no longer work due to the end-stoma. Patients with end-stoma experience difficulty in work and social situations with stoma function (Liao & Qin, 2014). It also shows that the biggest problem after the stoma is the reduced capacity to work (Golicki, Styczen, & Szczepkowski, 2013). Patients with inactive stages who worked 11.11% while those who did not work at all 27.77% (Kimura et al., 2013).

Marital relationship experienced limitations in which participants were afraid and had never any marital relationship after end-stoma. Individual sexual contact with a stoma is problematic due to the surgery itself, which can cause dysuria, pain during intercourse,
urinary incontinence, and reduction or loss of libido. Thus, quality of life significantly affects both sexes, among women, because women are more sensitive to changes in their body image, with negative feelings about having part of the body expelled and experiencing the stigma of being individuals with stoma, and among men, sexual disadvantages, as men suffer greater pressure on sexual performance (Kimura et al., 2013).

Stoma creates problems that may affect the relationship of patients with their intimate partners (Nichols & Riemer, 2008). According to literature, patients with stomas tend to be concerned about sexual problems, and sexual problems occur in patients, especially in the early period after surgery and stoma formation, and lead to further decline of quality of life (Symms et al., 2008). It turned out that almost half of the patients who were sexually active before the stoma surgery became inactive after the procedure. Therefore, referrals for sexual health counseling and evaluation may be more appropriate to patients with end-stomas.

In this study, it is proved that a variety of negative feelings were experienced by participants who were afraid of leaking, feeling alone, suffering, irritability, and embarrassment. One of the most common fears has expressed by patients with stoma is the fear of gas and odor. Because the stoma has no sphincter, flatus is removed unexpectedly as well as the stool removed from the stomach can make the patient feel dirty and abnormal (Williams & Hopper, 2003).

Problems that arise during the stoma are an economic problem where the job opportunities are at worst and the price of stoma bag is high. It is not easy for someone with a stoma due to the high cost of living, what is more the cost of stoma bag. This remains a burden for all participants for both retirees and private employees, especially those who no longer have jobs. Each participant underwent changes in economic or financial conditions, especially for participants who did not have proper jobs. Thus, it affects household finances including in terms of efforts to meet family needs. Literature said stoma patients had difficulties living with the stoma, which is an economic hardship, the cost of shopping stoma bags and other living expenses (Rangki et al., 2014).

The findings in this study are also consistent with these other studies, which have shown that economic problems can affect the quality of life of stoma patients. Coons et al. show that the cost of colostomy is an important quality in life considerations (Coons, Chongpison, Wendel, Grant, & Krouse, 2007). Nichols and Riemer (2008) have further referred the loss of work as one of the consequences of stoma.

Patients with end-stoma survive by adapting to their current state, in which patients with end-stomas in this study had various attempts to live as well as trying to make bags, avoiding odors, avoiding leaks, overcoming irritation and treating stomas. According to Roy, humans continually gain experience from their environment, so in the end a response is formed and an adaptation takes place where Roy defines adaptation as a process and outcome where individual minds and feelings use consciousness and choice to make people and environmental integration (Alligood, 2014), as well as patients with end-stoma who adapt to their condition.

According to Mota and Gomes, stoma surgery is a significant transition moment in the life of people trying to adjust to new conditions because they desire to continue to live. Stomas allow their survival and, therefore, to be viewed positively, as part of solving health problems and a second chance to live (Mota et al., 2015).

Changes in the fulfillment of sleep needs were experienced by participants. The lack of sleep restriction was experienced by participants that it is not comfortable to sleep tilting to the right or to the left for fear of stoma bags that will be crushed and will break. The participants also experienced frequent change
of bags at night so that the quality of sleeping was poor. This is in accordance with the research revealing that they cannot sleep well. They had to get up several times each night to drain the stoma bag because they were worried the bag would be too full and start leaking. Some felt constrained during sleep, as they feared a change of sleep position (Lim, Chan, & He, 2015).

Participants experienced a physical change where the time of defecation and gas (flatus) was not noticed by the participants because the stoma did not have a sphincter, so that flatus and defecate were not noticed (Williams & Hopper, 2003). Prolonged contact with the effluent may cause a reaction similar to that of a chemical burn. Adhesive picking, especially when frequently done, can lead to red skin irritation. Occasionally, allergic dermatitis may occur to adhesives. To prevent irritation, such as stomahesive, skin barrier should be used (Williams & Hopper, 2003). In addition to the irritation around the stoma, the participants also experienced stenosis where there was narrowness or shrinkage in the stoma that interfere with the drainage of the stoma. The cause of poor wound healing process was infection that occurs around the stoma, and the formation of scar tissue (WOCN, 2014).

Most participants had a hope to recover after the end-stoma although it will not be the same anymore, yet they can still do daily activities. In line with previous research stated that the expectations expressed by the respondents was to be healed and healthy as before (Erdiana, Effendy, & Pangastuti, 2007). In addition, the participants expecting to recover again also hope to have a health education related to stoma. It is important to help patients to adapt successfully to their new phase of life by providing pre- and post-operative appropriate education. Because the level of problem suffered by stoma sufferers is largely related to experience and skills in self-care, patients have the best chance to return to their regular lives if they receive further education during the transition from hospital to their home. Nurses have an important role in training and guiding patients (Richbourg, Thorpe, & Rapp, 2007).

Participants also expect a stoma association to share experiences and discussions related to stoma. According to Mota, et al. (2015) in addition to individual discussions, it is a fact that combining a support group in stoma therapy services provides people with stoma interaction with experience sharing, which facilitates self-care and shows that they are not alone in this journey. It is possible to take care of their selves and live with quality.

CONCLUSION

This study revealed that patients with end-stoma experience difficulties and limitations pertaining to daily living activities, including marital and social relations. Importantly, they experience psychological concerns, e.g. having negative feelings about ways of living their lives, including financial difficulties and adjusting to new ways of living. However, there is always the hope to live a normal life. This study provides an understanding of the quality of life of patients with end-stoma, allowing nurses to provide appropriate nursing care.

Declaration of Conflicting Interest
None declared.

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Author Contribution
All authors contributed equally in this study.

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