



Original Article

Quality of life of persons with permanent colostomy: a phenomenological study



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ABSTRACT

Objectives: To describe the experiences of persons with permanent colostomy regarding their quality of life.

Methods: The study design used descriptive phenomenology following the approach of Colaizzi. There were 12 participants who qualified using purposive sampling based on the inclusion criteria. The data generated were in-depth interviews. Analysis and interpretation used verbatim descriptions.

Results: The research data revealed seven themes, namely: limitation in daily living activities, limitations in marital relations and social relationship with others, negative feelings about having the colostomy, financial difficulties, increasing demands of living with colostomy, changes in the needs of rest, physical and expectation of complications, and hoping to live a normal life after colostomy.

Conclusion: This study revealed that persons with permanent colostomy 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 persons with permanent colostomy, allowing nurses to provide appropriate nursing care.

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Qualidade de vida de pessoas com colostomia permanente: um estudo fenomenológico

R E S U M O

Palavras-chave:

Qualidade de vida
Câncer colorretal
Colostomia permanente
Abordagem fenomenológica de Collaizzi
Collaizzi
Experiência vivida

Objetivos: Descrever as experiências de pessoas com colostomia permanente quanto à qualidade de vida.

Métodos: O desenho do estudo utilizou a fenomenologia descritiva seguindo a abordagem de Collaizzi. Havia 12 participantes que se qualificaram usando amostragem intencional com base nos critérios de inclusão. Os dados gerados foram entrevistas detalhadas. A análise e a interpretação usaram descrições literais.

Resultados: Os dados da pesquisa revelaram sete temas, a saber: limitação nas atividades da vida diária, limitações nas relações conjugais e relação social com os outros, sentimentos negativos sobre a colostomia, dificuldades financeiras, crescentes demandas de viver com colostomia, mudanças nas necessidades de repouso, físicas e expectativa de complicações, e esperança de viver uma vida normal após a colostomia.

Conclusão: Este estudo revelou que pessoas com colostomia permanente apresentam dificuldades e limitações relativas às atividades da vida diária, incluindo relações conjugais e sociais. É importante destacar que têm preocupações psicológicas, p.ex., sentimentos negativos sobre formas de viver suas vidas, incluindo dificuldades financeiras e adaptação a novas formas de viver. No entanto, há sempre a esperança de viver uma vida normal. Este estudo fornece uma compreensão da qualidade de vida de pessoas com colostomia permanente, possibilitando aos enfermeiros fornecer cuidados de enfermagem apropriados.

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Introduction

Colon cancer continue 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.¹ The WHO has found that colorectal cancer are the third most common cancer in men and second in women in the worldwide.² The incidence of colorectal cancer in the United States shows nearly 145.000 new cases and 50.000 deaths annually.³ While the incidence of colorectal cancers in Indonesia is quite high, and increasing among those aging above 40 years old,⁴ the number of cases 12.8/100.000 residents, claiming the third most prevalent type of carcinomas in Indonesia.⁵

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.¹ 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.⁶

Those who require permanent colostomy are likely to have quality of life issues impacting their physical, psychological, social, and spiritual needs. These issues impact persons' life satisfaction, happiness, and overall quality of life.¹ 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 con-

text of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.⁷

In the study in China found that experienced difficulties functioning in work and social situation, had issues sexuality and body image, difficulties with stoma function, anxiety about privacy when empty the pouch, always anxiety about leakage, always anxiety about social activities, gas, travelling, and skin irritation,⁸ as well as the study by Yang et. al shows that the scores of quality of life are generally better than pre-operative 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.⁹

The study by Kimura et al. revealed that the quality of life stoma patients were 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 persons with stomas.¹⁰

Based on the results of the research above shows that the quality of life of persons with colostomy vary widely. The quality of life of persons with permanent colostomy is very important to explore so as to determine anticipatory programs and improve the rehabilitation results of permanent colostomy. Therefore, this research will study in depth about the various perceptions or experiences of persons with permanent colostomy regarding their quality of life.

The study aimed to describe the experiences of persons with permanent colostomy regarding their quality of life so that health care providers effective ways to improve these. Nurses are important members and have a significant role in caring for persons with permanent colostomy, in particular in identifying the needs of them and their families, limiting complications, and improving quality of life.

Methods

Study methodology

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 persons experience with permanent colostomy regarding their quality of life can be real. Furthermore, the study explores, analyzes and descriptions directly the phenomena of the persons' experience, that tells about the quality of their life after being installed colostomy with as freely as possible from an intuition that cannot directly be measured.¹¹

Participants

Twelve persons with permanent colostomy 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) having end-stoma, (4) physically and mentally healthy, (5) freedom from other diseases, and (6) no history of stoma in their family member.

Data collection

The data collection procedure begins from the passing of ethical clearance from the Faculty of Nursing, Universitas Sumatera Utara. After the research passed the ethical clearance and the permit was obtained, the letter was submitted to the research and development of the hospital. The researcher explains the research procedure and the installation head allows and gives direction. The head of the installation coordinates with the head of the surgical polyclinic about this study, which helps the researcher to get the participants.

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 on a voluntary basis. They were assured that their refusal to participate would not affect the care they would receive from the hospital. Permission to audiotape the interview session was also sought from each participant; confidentiality and anonymity were guaranteed.

Data collection was conducted by in-depth interviews and the probing technique is used to 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 their homes (Table 1). Researchers attempted to arrange a calm environment in which the participants could be interviewed. Each interview lasted about 55–60 min. Data

Table 1 – Interview guide.

No.	Possible questions to guide the participants
1	How do you feel after you have colostomy?
2	How is your relationship with others after you have colostomy?
3	What is your purpose and life expectancy after you have colostomy, how could you achieve it?
4	What are your obstacles and challenges that you feel after have colostomy?
5	As a person with permanent colostomy, what kind of nursing care that you would expect?

collection continued until saturation, where no new information is obtained and redundancy is achieved.¹² After that, the researchers used verbatim descriptions grouped the data into the form of themes, sub-themes and main categories.

Ethical consideration

The Research Ethics Committee from the Commission of Health Research Ethics Faculty of Nursing Universitas Sumatera Utara No. 1229/VI/SP/2017.

Data analysis

Using software Welf-QDA version 1.0.1,¹³ it has been helped researchers to data analysis. Researchers used the Collaizzi method.¹² 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 permanent colostomy, (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 and a member checking was done with participants as ways of ensuring that the researchers have analyzed the data correctly.¹⁴

Results

The results of this study found seven themes: (1) limitation in daily living activities, (2) limitations in marital relations and social relationship with others, (3) negative feelings about having the colostomy, (4) financial difficulties, (5) increasing demands of living with colostomy, (6) changes in the needs of rest, physical and expectation of complications, and (7) hoping to live a normal life after colostomy.

Theme 1: limitation in daily living activities

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, 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, where 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: limitations in marital relations and social relationship with others

Limitations have been experienced by participants in sensual intercourse such as; worried about getting divorced and no longer having sexual intercourse. The statement in accordance with the expression: "I was afraid . . . I have never contacted her anyway." (Participant 4).

When interacting with others, the obstacles the persons 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 can not be predicted. Just like normal defecating, so it could possibly smell due to the defecating" (Participant 12).

Theme 3: negative feelings about having the colostomy

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: financial difficulties

Participants had had many difficulties, especially in working, many participants quit their jobs due to colostomy, 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: increasing demands of living

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 since it is so expensive" (Participant 12).

Efforts by participants to overcome the irritation are varied such as using Betadin, using powder and wasp oil, Cusson baby powder, intravenous fluids, and hot water. The above mentioned disclosed some participants as follows: "well, sometimes Betadin, 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: changes in the needs of rest, physical and complications

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 happen to persons who can not 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, that 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: hoping to live a normal life after colostomy

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 can not 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 cause of permanent colostomy is by colorectal cancer. This will lead to limit daily living activities. Every human being does everything what he wants to live freely, but not with permanent colostomy. This situation can make permanent colostomy who feel limited to do everything. Persons with permanent colostomy deal with problem in performing religious worship activities. Some of participants have experienced limitations in performing worship, especially for congregational prayers at Masjid. This limitations are due to many things, such as the feeling of being unacceptable or not and the smell coming out from the dirt in the colostomy hole.

According to Herek et al. found that, after colostomy, patients refrained from religious activities and experienced problems such as insufficient information and inability to obtain sufficient information.¹⁵ While Kuzu et al. shows that the presence of colostomy is significantly an aspect that affects the quality of life related to health and is associated by decreased activity of prayer.¹⁶ This finding is also in accordance by Rangki, Ibrahim, and Nuraeni which states of the

eight participants all experiencing limitations in religious rituals or spiritual distress.¹⁷

Important findings in this study relate 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 persons. 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 colostomy. Where participants said they could not longer work due to the colostomy. The persons experience difficulty in work and social situations with colostomy function.⁸ It also shows the biggest problem after the colostomy is the reduced capacity to work.¹⁸ Persons with inactive stages worked 11.11% while those who did not work at all 27.77%.⁹

Marital relationship experienced limitations in which participants were afraid and had never any marital relationship after the colostomy. Individual sexual contact with a colostomy is problematic due to the surgery itself, which can cause dysuria, pain during intercourse, urinary incontinence, and reduction or loss of libido. Therefore, 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 colostomy, and among men, sexual disadvantages, as men suffer greater pressure on sexual performance.⁹

Colostomy creates problems that may affect the relationship of persons with their intimate partners.¹⁹ According to Brown and Randle, persons with colostomy tend to be concerned about sexual problems, and sexual problems occur in persons, especially in the early period after surgery and colostomy formation,²⁰ and lead to further decline of quality of life.²¹ It turned out that almost half of the persons who were sexually active before the colostomy surgery became inactive after the procedure.²¹ Therefore, referrals for sexual health counseling and evaluation may be more appropriate with colostomy.

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 persons with colostomy is the fear of gas and odor.²² Because the colostomy has no sphincter, flatus is removed unexpectedly as well as the stool removed from the stomach can make the persons feel dirty and abnormal.²³

Problems that arise during the colostomy are an economic problem where the job opportunities are at worst and the price of colostomy bag is high. It is not easy for someone with a colostomy due to the high cost of living, what is more the cost of colostomy 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. Rangki, Ibrahim, and Nuraeni said persons with permanent colostomy

had difficulties living with the colostomy, which is an economic hardship, the cost of shopping colostomy bags and other living expenses.¹⁷

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 persons with permanent colostomy. Coons et al. shows that the cost of colostomy is an important quality in life considerations.²⁴ Nichols and Riemer have further referred the loss of work as one of the consequences of colostomy.¹⁹

Persons with permanent colostomy survive by adapting to their current state, in which persons with permanent colostomy 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,²⁵ as well as persons with permanent colostomy who adapt to their condition.

According to Mota and Gomes, colostomy is a significant transition moment in the life of people trying to adjust to new conditions because they desire to continue to live. Person with permanent colostomy allow their survival and, therefore, to be viewed positively, as part of solving health problems and a second chance to live.²⁶

Changes in the fulfillment of sleep needs were experienced by participants. The lack of sleep restriction was experienced by participants that is not comfortable to sleep tilting to the right or to the left for fear of colostomy bags will be crushed so that will break. Participants also experienced frequent change of bags at night so that the quality of sleeping was poor. This is in accordance with the study revealing that they cannot sleep well. They had to get up several times each night to drain the colostomy 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.²⁷

Participants experienced a physical change where the time of defecation and gas (flatus) was not noticed by the participants because the colostomy did not have a sphincter, so that flatus and defecate were not noticed.²³ 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 stomahesive, skin barrier should be used.²³ In addition to the irritation around the colostomy, the participants also experienced stenosis where there was narrowness or shrinkage in the colostomy that interfere with the drainage of the colostomy. The cause of poor wound healing process, infection that occurs around the colostomy, and the formation of scar tissue.²⁸

Most participants had a hope to recover after the colostomy although it will not be the same anymore, yet they can still do daily activities. In line with previous research of Erdiana, Effendy, and Pangastuti stated that the expectations expressed by the respondents was to be healed and healthy as before.²² In addition the participants expecting to recover again also hop-

Table 2 – Participant of persons with permanent colostomy, according to social demographic characteristics.

Variables	Persons with permanent colostomy	
	n	%
<i>Age group</i>		
26–35	1	8.3
36–45	4	33.4
46–55	3	25.0
56–65	3	25.0
>65	1	8.3
Total	12	100
<i>Gender</i>		
Female	10	83.3
Male	2	16.7
Total	12	100
<i>Marital status</i>		
Married	11	91.7
Widower	1	8.3
Total	12	100
<i>Religion</i>		
Moslem	7	58.3
Protestant	5	41.7
Total	12	100
<i>Education</i>		
Senior high school	3	25.0
Junior high school	7	58.3
Elementary school	2	16.7
Total	12	100
<i>Employment</i>		
Employee	2	16.7
Farmer	5	41.7
Unemployed	5	41.7
Total	12	100
<i>Long has colostomy</i>		
<5 months	7	58.3
6–10 months	2	16.7
11–15 months	2	16.7
>16 months	1	8.3
Total	12	100

ing to get a health education related colostomy. It is important to help persons to adapt successfully to their new phase of life by providing pre- and post-operative appropriate education. Because the level of problem suffered by colostomy sufferers is largely related to experience and skills in self-care, persons 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.²⁹

Participants also expect a colostomy association to share experiences and discussions related colostomy. According to Mato et al. in addition to individual discussions, it is a fact that combining a support group in stomatherapy services provides persons with colostomy 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 themselves and live with quality (Table 2).³⁰

Conclusions

Based on the results of this study can be concluded that the patient experience with permanent colostomy regarding quality of life to get the theme that are: limitation in daily living activities, limitations in marital relations and social relationship with others, negative feelings about having the colostomy, financial difficulties, increasing demands of living with colostomy, changes in the needs of rest, physical and expectation of complications, and hoping to live a normal life after colostomy. The themes that appear in this study can be used as a reference for nurses in assessing the physical, psychological, social, and spiritual needs of persons with colostomy specially for permanent colostomy. It can be used by nurses in both hospitals and communities.

Conflicts of interest

The authors declare no conflicts of interest.

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