OUALITY OF LIFE AND CHARACTERISTICS OF COLOSTOMY PATIENTS

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ABSTRACT

Introduction: Colostomy imposed multiple impacts on the patient's life including physical, psychological, social, and spiritual. This study aims to identify the level of quality of life as well as to examine the differences of quality of life among colostomy patients with regards to certain demographic characteristics. **Methods:** This study used a cross-sectional and descriptive analytical approach. Seventy-one colostomy patients were recruited purposively to participate in the study. The studied variables included quality of life and demographic characteristics. The data was collected by using the WHO Quality of Life – BREF instrument. One-way ANOVA and an independent t-test were employed to analyse the differences in quality of life with regards to certain demographic characteristics. **Results:** The study found that the majority of subjects perceived that their level of quality of life ranged between very low to moderate (77.4%). Satisfaction with support from friends was rated as the highest item of quality of life, whereas satisfaction with sexual relationships was rated as the lowest item of quality of life. There was no significant difference in the patients' quality of life with regards to age group, educational background, occupation, length of being ostomate, sex, and other health problems. **Conclusions:** The study implied that nurses need to realise and pay attention to multiple aspects of stoma patient's quality of life. Nursing care should not merely focus on stoma care but also holistically consider on meeting sexual needs, as well as the psychological, social, and spiritual needs of the patients.

Keywords: colostomy, demographic characteristics, quality of life.

INTRODUCTION

Colorectal cancers remain a serious public health problem in Indonesia. The number of people living with colorectal cancer increases year to year. The data shows that colorectal cancer is listed as the third most prevalent cancer after lung cancer and prostate cancer (Sudoyo, 2012). In Europe and the United States, the number of people living with colorectal cancer was more than in Asia. American Cancer Society (2017) estimates for the number of colorectal cancer cases in the United States for 2017 is 95,520 new cases of colon cancer. Colorectal cancer is the second leading cause of cancer-related deaths in men and the third leading cause in women in the United States. During 2017, it is expected to cause about 50,260 deaths.

One of the common treatments for the colorectal cancer is surgery by removing the section of affected colon, followed by making a hole (stoma) in the abdominal wall to eliminate faeces (Siassi *et al.*, 2008; Carlsson *et al.*, 2010; Edwards *et al.*, 2014). This procedure is known as a colostomy. There are two types of colostomy according to the duration of the treatment that is required: temporary or permanent (Williams and Hopper, 2003; Dabirian *et al.*, 2010). Those who are undergoing colostomy permanently means that they have to live with the colostomy for the rest of their life. Such a

condition would impact to multiple-facets of the patients' life including their physical, psychological, social, and spiritual well-being (Grant *et al.*, 2011; Swan, 2011; Liao and Qin, 2014; Rangki *et al.*, 2014; Faury *et al.*, 2017). In the other words, this may also impact on the life satisfaction, well-being, and quality of life of the patients.

Quality of life has become a major concern among health care professionals since it can be an outcome of health care interventions. Data regarding the quality of life also determine the appropriate interventions for the patients. Several studies have been done to investigate health-related quality of life among colostomy patients. Liao and Qin (2014) found that stoma patients faced difficulties functioning in work and social activities, sexuality and body image, and several problems with leakage and finding privacy to empty the pouch. This included types of personality, specific ego defence mechanisms, spirituality influenced healthrelated quality of life among colorectal cancer patients (Baldwin, C.M., Grant, M., Wendel, C., Rawl, S., Schmidt, Ko and Krouse, 2008; Sales et al., 2014). In addition, the type of ostomy (temporary/permanent), the underlying disease, depression, problem with the location of the ostomy, and changes in clothing style had significant effects on the quality of life of stoma patients (Anaraki et al., 2012). Difficulties with sleep, problems with body

image and depression have also been reported in association with quality of life (Grant et al., 2011). In term of the patients' characteristics, Javarajah and Samarasekera (2017) found that higher quality of life was associated with female sex, colostomies, comfortable income and satisfactory sexual activity, whereas lower quality of life was associated with significant changes in the style of dressing, feeling depressed, having thoughts of self-harm soon after surgery, and taking longer time to learn to take care of the stoma. In the Indonesian population, so far, there is a little known robust study on the quality of life and characteristics of colostomy patients. In fact, understanding the quality of life of patients who have undergone a colostomy is essential for evaluating the full impact of the colostomy on the individual, their family and their community.

According to a member of the Indonesian Enterostomal Therapist Nurse Association Bandung Chapter (personal communication with Nunung Nurhayati, Ners, ETN), there are more than 100 patients currently undergoing colostomy permanently in Bandung City, and their quality of life has not been evaluated. Therefore, the study aims to describe the level of quality of life of colostomy patients, as well as to test the difference in the quality of life of colostomy patients with regards to certain demographic characteristics.

MATERIALS AND METHODS

The study used a cross-sectional and descriptive analytical approach. Seventy-one respondents were recruited purposively. The inclusion criteria of the recruited respondents were being an adult, able to write and read in Indonesian, having no serious health problems such as severe heart disease, severe pulmonary problems, and severe neurologic impairment which would have made them unable to respond to the questionnaire properly, and who are voluntarily willing to participate in the study. The studied variables included quality of life and demographic characteristics. The data was collected using the self-administered WHO-BREF Quality of Life instrument which has already been translated into Indonesian language using a back translation technique by a panel expert (World Health Organization, 1996). Quality of life includes dimensions and

Table 1. Demographic characteristics of the respondents (n = 71)

respondents $(n = 71)$						
	Characteristics	n	%			
1.	Age (year)					
	< 20	6	8.5			
	21 - 30	6	8.5			
	31 - 40	11	15.5			
	41 - 50	17	23.9			
	51 - 60	17	23.9			
	>60	14	19.7			
	M = 46.59 SD = 15.31	R = 17 - 7	8			
2.	Sex					
	Male	49	69.0			
	Female	22	31.0			
3.	Religion					
	Islam	61	85.9			
	Christian	10	14.1			
4.	Education					
	Primary School	18	25.4			
	Junior High School	16	22.5			
	Senior High School	20	28.2			
	University/College	17	23.9			
5.	Occupation					
	Unemployed	15	21.1			
	Farmer	7	9.9			
	Civil servant	6	8.5			
	Employee	7	9.9			
	Self-employed	11	15.5			
	Retirement	12	16.9			
	Housewives	11	15.5			
	Labour	2	2.8			
6.	Monthly income					
	(Indonesian Rupiah)					
	No income	27	38.0			
	< 500,000	9	12.7			
	500,000 - 1,000,000	13	18.3			
	1,000,001 -	18	25.4			
	2,000,000					
	> 2,000,000	4	5.6			
7.	Ethnicity					
	Sundanese	43	60.6			
	Javanese	16	22.5			
	Malay	7	9.9			
	Bataknese	4	5.6			
	Chinese	1	1.4			

items of quality of life that were analysed descriptively. One-way ANOVA and an independent t-test were used to test the difference quality of life-based on certain characteristics. Approval and permission to conduct this study were taken from RSUP Dr. Hasan Sadikin Bandung.

RESULTS Characteristics of the Respondents

The demographic and health characteristics of the respondents are presented in Table 1 and Table 2.

Table 2. Health characteristics of the respondents (n = 71)

	Characteristic	n	%
1.	Other health problems		
	None	58	81.7
	Hypertension	8	11.3
	Infection	1	1.4
	Genitourinary	2	2.8
	Diabetes Mellitus	2	2.8
2.	Social activity		
	No	50	70.4
	Yes	21	29.6
3.	Length of time of being		
	ostomate		
	< 12 month	60	84.5
	13 - 24 month	8	11.3
	25 - 36 month	2	2.8
	37 - 48 month	1	1.4
	M = 7.62 SD = 7.9 R = 1	-48	
4.	Cost of stoma care/		
	month (Thousand		
	Rupiah)		
	M = 995 SD = 784.5 R =	20 - 4000	
5.	Perception toward self-		
	health status		
	Good	16	22.5
	Moderate	39	54.9
	Poor	16	22.5
6.	Family relationship		
	Good	69	97.2
	Moderate	2	2.8

Table 3. Perceived quality of life and current health status (n = 71)

	Frequency	Percentage
	(f)	(%)
Perceived quality		
of life:		
Very poor	5	7.0
Poor	15	21.1
Moderate	35	49.3
Good	16	22.5
Very good Perceived current	0	0.0
health status:		
Very unsatisfied	1	1.4
Unsatisfied	18	25.4
Moderate	40	56.3
satisfied Satisfied	12	16.9
Very satisfied		

The majority of the respondents (77.4%) perceived their level of quality of life as ranging from very poor to moderate, and most of them (83.1%) reported being very unsatisfied to moderate satisfaction in relation to their current health status, as presented in Table 3. As shown in Table 4, the core of

each dimension of quality of life, standard deviation, and range. It seems that environmental dimension is the highest mean score chosen by the respondents, and followed by physical health, psychological, and social.

According to Table 5, the ranking of the five top items of quality of life that were selected by the respondents as highly satisfactory items in their quality of life. Satisfaction with support from friends was selected as the highest item in relation to their quality of life. Oppositely, Table 6 presents the ranking of the five lowest items of quality of life that were selected by the respondents as the lower satisfactory items of their quality of life. It seems that satisfaction with their sexual relationship was selected by most of the respondents as the lowest satisfactory item of their quality of life.

Results from the statistical test using ANOVA and the independent t-test found that there were no significant differences in the total quality of life score with regards to age group, education, occupation, the length of time of being ostomate, sex, and other health problems, as presented in Table 7.

DISCUSSION

The results of the study show that the majority of the respondents perceived that their level quality of life ranged from very poor to moderate. None of them perceived that their level of quality of life was very good. It is argued that the presence of the stoma on the part their body may interfere with their daily activities as well as their body image which influences their interactions with others. Thus, the presentation of a stoma would influence their perception of themselves which determines their life satisfaction. This is relevant to the previous study conducted by Liao and Qin (2014) that found that patients with stoma experienced difficulties functioning in work and social situations. The patients also encountered issues with sexuality and body image, and difficulties with stoma function. In our study, the environmental dimension was the highest mean score chosen by the respondents, followed by physical health, psychological, and social. Our findings are consistent with previous studies that found that the stoma patients had more difficulty participating in social activities (Dabirian et al., 2010; Anaraki et al., 2012). Swan (2011)

Table 4. Mean, standard deviation, and range for each dimension of quality of life

	Range	Mean	SD
Physical health	15 - 27	19.24	2.73
Psychological health	12 - 25	17.68	2.37
Social relationship	5 - 14	8.32	2.13
Environmental	14 - 31	23.45	3.39
Total score	52 - 91	68.69	8.77

Table 5. Mean and standard deviation of the five top items quality of life

Quality of Life Items	Range	Mean	SD
Satisfied with support from friends	1 - 5	3.39	0.75
Satisfied with the living place	1 - 5	3.38	0.66
Satisfied with health assistances	1 - 5	3.25	0.95
Meaning of life	1 - 5	3.15	0.75
Enjoying life	1 - 5	3.13	0.67

Note: the range of each item is from 1 to 5, the higher of mean score for each item indicated the higher level of quality of life.

Table 6. Mean score and standard deviation of the five low items quality of life

Quality of Life Items	Range	Mean	SD
Financial sufficiency	1 - 5	2.63	0.76
Ability to do activity daily living	1 - 5	2.62	0.82
Ability to work	1 - 5	2.45	0.81
Ability to walk or going around	1 - 5	2.34	0.91
Satisfaction with sexual relationship	1 - 5	2.01	1.08

Note: the range of each item is from 1 to 5, the lower of mean score for each item indicated the lower level of quality of life.

and McMullen et al. (2008) pointed out that the colostomy application might have a negative impact on the patients' quality of life with regards to both social and family relationships, travelling, physical activity, sexual function and finances. The meaning of quality of life was constructed from a transactional process between an individual with an environment that is influenced by personal background, health, social situation, culture, and age. Anaraki et al., (2012) argued that the underlying disease of the stoma, the ostomy (temporary/permanent), location of ostomy, depression, and changes in life style had a significant effect on overall quality of life.

The majority of the respondents rated their general health at a level of very unsatisfied to moderately satisfied. Results from the identification of other health problems (Table 2) indicated that a few of the respondents reported other health problems such as hypertension, infection, genitourinary, and diabetes mellitus. In addition, 16 of 71 respondents reported that their perception of self-health status was poor, and more than half of them perceived it as being moderate and

good. It explained that other health problems being faced by the respondents influenced their perception towards their general health. The general health condition of colostomy patients was usually good as long as there were no associated complications which might impact on their general health.

Satisfaction with support from friends was selected by the respondents as the most satisfactory item of quality of life (M = 3.39,SD = 0.75), followed by satisfaction with their living place, health assistance, the meaning of life, and enjoying life. This result reflects the culture of collectivity that is commonly embedded in Eastern Society, including the Sundanese culture which constitutes the majority of the respondents. The Sundanese philosophy of saling asah, saling asih, dan saling asuh (reciprocity in caring and empowerment) has underlying moral values to provide care, assistance, help, and support among family members, relatives, neighbours, and the community at a larger scope (Garna, 1984). It was a common phenomenon in Sundanese society that when a community members is sick, he/she would receive a lot of attention from their relatives, neighbours, and

n

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Variable

Housewives

Table 7. The differences of total mean score of quality of life-based on age group, education, occupation, length of time of being ostomate, sex, and other health problems

Mean

SD

7.992

95% CI/SE*

60.09 - 70.82

p-value

Age (year)					0.49
< 20	6	69.67	6.976	62.35 - 76.99	
21 - 30	6	64.50	8.666	55.41 - 73.59	
31 - 40	11	68.64	10.053	61.88 - 75.39	
41 - 50	17	70.59	7.001	66.99-74.19	
51 - 60	17	70.41	10.168	65.18 - 75.64	
> 60	14	65.71	8.651	60.72 - 70.71	
Education					0.96
Primary school	18	68.61	9.172	64.05 - 73.17	
Junior High School	16	69.69	10.084	64.31 - 75.06	
Senior High School	20	68.15	7.372	64.70 - 71.60	
University/College	17	68.47	9.274	63.70 - 73.24	
Occupation					0.96
Unemployed	15	66.80	8.521	62.08 - 71.52	
Farmer	7	75.00	4.243	71.08 - 78.92	
Civil servant	6	73.50	11.675	61.25 - 85.75	
Employee	7	67.29	8.381	59.53 - 75.04	
Self-employee	11	70.09	8.893	64.12 - 76.07	
Retirement	12	65.83	6.780	61.53 - 70.14	

Labor	2	78.50	17.678	-80.33 –237.33	
Length of time of being ostomate					0.96
< 12 month	60	69.13	-	-	
13 - 24 month	8	66.75	1.155	66.82 - 71.44	
25 - 36 month	2	63.00	3.075	59.48 - 74.02	
37 – 48 month	1	69.00	4.000	12.18 - 113.82	
Sex					0.19
Male	49	69.61	9.14	1.30	
Female	22	66.64	7.68	1.64	
Other health problems					0.93
Yes	13	68.85	5.90	1.22	
No	58	68.66	9.34	1.64	

65.45

community s which emphasises on providing support, comfort, and prayers for the sick. It is supported by the data that almost all of the respondents (97.2%) acknowledged support from their family. Like other studies demonstrate that patients with a permanent satisfactory family stoma had support (Ciorogar, G., Zaharie, F., Ciorogar, A., Birta, D., Degan et al., 2016). Satisfaction with their living place indicated that most of the respondents felt comfort with their home condition. It can be a base level of data to help develop home-based care for colostomy patients. In terms of health assistance received, most of the respondents felt satisfied with the health service given by the health care provider. Although the respondents have to undergo a stoma on their abdomen, they are still able to enjoy their life and experience the meaning of life.

Satisfaction with their sexual relationship was chosen as the lowest item in relation to quality of life by most respondents. The findings of the study are consistent with previous studies that reported that stoma patients experienced a loss in their sexual activity after stoma surgery (Gemmill *et al.*, 2010; Anaraki *et al.*, 2012). This condition has

^{*95%} CI for variable age group, education, occupation, and length of time of being ostomate; and SE for variable sex and other health problems.

resulted in low self-confidence of the respondents in performing sexual activities. The majority of the respondents' ages ranged from 21 to 60 years old, and they were married. In the range of age, they were considered to be sexually active, particularly the males. The presentation of the stoma hole on the abdomen often resulted in a negative self-perception towards their body image, and they had become less sexually attractive to the spouses. As a consequence, their sexual desire might decrease.

Several socio-demographic and disease parameters have been identified to correlate with the health parameter of the quality of life of patients with colorectal cancer and a stoma (Dunn et al., 2003; Sales et al., 2014). The results of the study revealed that there were no significant differences between the quality of life score with regards groups, education background, occupation, the length of being ostomate, sex, and other health problems experienced. This is possibly due to the respondents' variations regarding their characteristics not being very much different, which led them to selecting the same items in relation to quality of life. There was difficultly to drawing up a heterogeneous subject in this study.

The findings of the study were also consistent with the previous study that found that there was no significant correlation between sex or age group and the quality of life in a patient with colorectal cancer (Dunn *et al.*, 2003). However, a few studies reported that there was a significant difference in the patients' quality of life with regards to sex which was that women with stoma scored consistently lower than men with a stoma for the overall quality of life domains (Krouse *et al.*, 2007, 2009; Grant *et al.*, 2011) (Grant *et al.*, 2011).

This study found that the majority of patients were young or of middle adult age (< 60 years), their monthly income was less than IDR 2,000,000 (\$ 140), and their length of being ostomate was under 12 months. Previous studies documented that younger patients with rectal cancer felt more stigmatised than older patients. In addition, low-income earners were more likely to have a lower quality of life compared to patients with higher incomes (Dunn *et al.*, 2003). The study conducted by showed Jansen *et al.* (2010) that colorectal cancer survivors who have been living with

the disease for more than five years indicated that their overall domains of quality of life were better than those who had ived with it for under five years. The other study demonstrated that ostomy patients with more than two years experience had shown a better quality of life (Fucini *et al.*, 2008; Sales *et al.*, 2014). It is understandable that the more time the survivors live for, the more chance there is to learn and adjust to the new conditions of living with cancer and stoma treatment.

CONCLUSIONS

Colorectal cancer and colostomy treatment have caused several health problems to arise which have impacted on the quality of life of the survivors. The majority of the subjects in the study reported that their level of quality of life was from very low to moderate. The variation of personal characteristics and experience in dealing with the disease could affect their perception regarding quality of life. This study highlighted the common phenomenon of the impact of colostomy on the quality of life and several characteristic factors that may influence the quality of life. It implies that nurses need to take into consideration evaluating the quality of life of colostomy patients following colostomy surgery as an integrated part of comprehensive nursing care.

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