

Original Articles

Quality of Life of Adult Persons Living with Colostomy: A Review of the Literature

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Abstract

The objective of the study was to describe the quality of life of adult persons living after a colostomy, using the published literature. A review of the literature from December 2010 to May 2016 was done using the Proquest, EBSCOHOST, Science Direct, and Gale search engines. The keywords used were quality of life, colorectal cancer, colostomy, and nursing care. The search yielded 105 articles. However, upon careful reading of the abstracts, only 80 articles were found to focus on the subject of quality of life of persons living with a colostomy. Of these 80 articles, 21 were available as full-text, and only 11 provided significant information regarding the quality of life and experiences of adult persons living after colostomies.

The literature varied from qualitative and quantitative research studies revealing the following significant themes: physical and psychological problems, altered social and family relationships, inability to maintain religious activities, economic challenges, nutritional issues, limited physical activity and sexual functioning, complications with the stoma, self-care and comprehensive health care problems.

The quality of life of adult persons who are living after a colostomy is critically significant. The procedure impacts the health and well-being of these persons. Among groups of patients, those who had colostomies were found to be most vulnerable to societal ostracism, even though they can live long, healthy, and prosperous lives. It is important that nurses today understand and appreciate the difference in the quality of life of persons living after colostomies and then plan the most appropriate care for these persons to improve their health.

Keywords: colorectal cancer; colostomy; quality of life

Background

Colon cancer is still a serious problem in Indonesia. The number of patients with colon cancer rank tenth (2.75%) after other cancers such as uterine, breast, lymphatic areas, skin, nasopharyngeal, ovarian, rectal, soft tissue, and thyroid¹. The incidence of colorectal cancer in the United States shows nearly 150.000 new cases with 52.000 deaths annually². The incidence of colorectal cancers in Indonesia is quite high, and is also increasing among those 40 years old³ and above. In 2006, the number of cases were 1.8 cases per 100.000 residents, becoming the third most prevalent type of carcinomas in Indonesia⁴.

One of the common colorectal cancer treatments 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 products¹. The purpose of a colostomy is to reduce patients' pain and discomfort,⁵ but in many cases, an ostomy can cause increased distress and hurt in patients. This therapeutic approach can be temporary or permanent. Those who need to have a lifetime colostomy are likely to have problems that affect their physical, psychological, social, and spiritual needs. Persons with abdominal stoma will also have concerns in the areas of life satisfaction and happiness.

The stress of the patients can often result from skin irritation (76%), pouch leakage (62%), offensive odor (59%), reduced pleasurable activities (54%), and depression/anxiety (53%)⁵. However, after fitting the colostomy bag, some signs and symptoms manifest such as inflammation and pain around the stoma, sleep disturbance from discomfort due to bag placement, and inability to control gas (flatulence)⁶. Furthermore, patients with abdominal stomas may suffer from sexual difficulties, restrictions in physical activity and diet, and general changes in lifestyles. ⁶Fear of future problems and concern about relationships with families and friends are often the psychological

problems the patients usually face⁶.

Leakages caused by the failure of adhesives or bag welds, the ballooning of bags, difficulties in keeping bags in place, and poor sitting positions are some of the problems that affect the patients' daily lives. ⁷Anxiety and embarrassment can also cause changes in lifestyle, including a diminished ability to find work, a diminished desire to travel, and a decline in their overall self-image. Other patients' feelings about the changes in their bodies can affect their behavior toward family and friends and can influence their sex life. Similarly, some patients also have initial problems with diet and clothing; however, most patients are thought to adapt well with time⁷.

The people who live with colostomies do not experience the same quality of life, so this review will add to the current knowledge about the impact of stoma-related problems on quality of life, which will help detect these stoma-related problems and then formulate possible care methods. The nurses who administer colostomy care can then consult the results of the studies in this review to help them assess the patient's correct area of concern, and so they would be able to adapt their care perspectives and methods. The nurses would also be able to acquire more sensitivity and tact when caring for their colostomy patients, since the nurses-using this review-will be able to distinguish between the differences of their patients' quality of life and their individual difficulties.

Objective of the study

The objective of this literature review was to describe the quality of life of adult persons living after a colostomy, either as a temporary or permanent treatment goal.

Questions for the study

What are the problems/issues related to the

quality of life among adult persons who live with colostomy?

Methods

A review of published literature between January 2010 and May 2016 was conducted using search strategies in electronic databases such as Proquest, EBSCOHOST, Science Direct, and Gale. These databases provided the best possible retrieval systems considering access to publications in Indonesia. Keywords used included quality of life (QOL), colorectal cancer, colostomy, and nursing care.

Selection criteria

The following inclusion criteria were identified: 1) published articles reporting original data; 2) studies including adult population with permanent and temporary ostomies due to colorectal cancer; and 3) long term

ostomies and measurements of the ostomy-specific quality of life from a multidimensional view. Unpublished studies, abstracts, dissertations, book chapters, and these were excluded from this present review.

Figure 1 shows the flow of the study selection process. First, all titles (n=105) were checked based on the criteria of ostomy-related problems and quality of life using the keywords. The abstracts of 75 articles were retrieved using the inclusion criteria, from which 25 possibly relevant studies were found significant. Of these 25 abstracts, only 11 full-text articles could be accessed. In total, these 11 studies that met the inclusion criteria were reviewed, analyzed, and found to provide substantively significant information/findings.

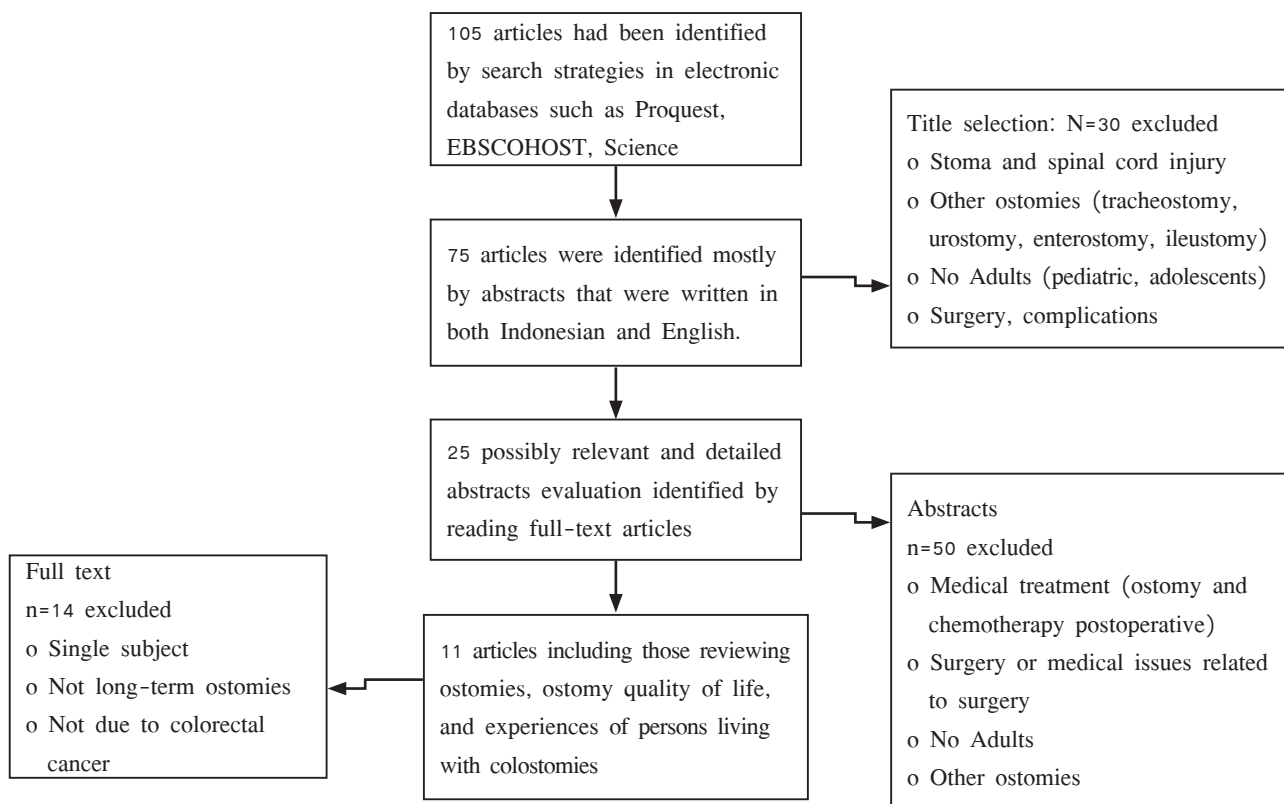


Figure 1. Flow chart of the selection process

Results

The quality of life of adult patients with colostomies is diverse, and many are influenced by equally diverse factors. In the study conducted by Dabirian, Yaghmaei, Rassouli, and Tafreshi,⁵ it was found that the themes related to the quality of life among adult patients with colostomy focused on their physical problems, psychological problems, changes in their social and family relationships, economic challenges, nutritional issues, changes in degrees of physical activity including travel, and maintenance of religious considerations. However, Liao, and Qin⁸ concluded in their study that the quality of life among patients with colostomies was informed by their experienced difficulties in functioning at work and in social situations. They found that patients with stoma had issues with sexuality and body image, as well as difficulty with adjusting to the functions of the stoma, and that the patients were also anxious about privacy when cleaning the pouch, with marked anxiety and concern about leakages, especially when engaging in social activities; the patients expressed grave concerns such as foul-smelling gas leakages during travel, and skin irritations.

However, in the study by Anarika, Vafaie, Behboo, Maghsoodi, Esmailpour, and Safaee,⁶ patients living with stoma confirmed their dissatisfaction with activities regarding sexual expression, noting feelings of depression, particularly after stoma surgery. Other problems with stoma include maintaining a stoma, and the need to change one's clothing style to meet the physical demands of having had a colostomy. The study by Kimura, Kamada, Guihem, and Monteiro⁹ found that their ostomy patients did not find their experience good. The results showed that the tags of 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 accounts of bad

experiences and good experiences held the two highest percentage scores, indicating the inconsistency in the experiences of persons with stomas.

In another study, made by Golicki, Styezen, Szczepkowski,¹⁰ it was found that 59% of patients with colostomy stomas in Poland found their experience to be very good or good. This quality of life assessment showed that related activities such as sexual activity and work were not inhibited too badly, and that their independence of medical treatment, financial sourcing, and satisfaction with their well-being were great indicators of a good quality of life.

In the study by Mahjoubi, Goodarzi, and Mohammad-Sadeghi,⁷ the quality of life among patients with colostomies were considered in terms of appropriate and inappropriate stoma sites, with the patients having appropriate stoma sites citing a better quality of life than those with stomas placed in inappropriate sites (56.2% vs. 49.7%, $p=0.007$). However, in a subsequent study by Mahjoubi, Mirzaei, Azizi, Jafarinie, and Zahedi-Shoolami,¹¹ persons with colostomies had maintained good physical functioning (70.9%), role functioning (68.4%), emotional functioning (56.9%), cognitive functioning (68.7%), and social functioning (64.2%). Men cited their perceptions of a better body image, noted greater sexual enjoyment and sexual functioning. Men also cited a high significant score and role, and better physical and sexual function. More problems with enjoyment in sexual activities were common among older persons with colostomies.

In the study by Kimura, Kamada, and Guilhem,¹² the patients with stomas showed statistically significant scores in the following domains: physical, psychological, social and environment relationships. Quality of life was also statistically significant ($p<0.0001$). The themes revealed that complications with the stoma, self-care, and comprehensive healthcare were predominant concerns. Furthermore, in another study, the perception of other people on ostomized persons due to colorectal cancer impacted their quality of life,¹³ and they showed

statistically significant scores in the following domains: physical, psychological, social and environment relationships. The quality of life in which the statistical significance was established was at $p < 0.0001$. This result shows that the group with stoma due to colorectal cancer was affected by other influential subcategories such as negative-physical strength ($p \leq 0.0001$), negative-sexual activities ($p \leq 0.0001$), and social well-being. Themes that were revealed include physical well-being, psychological well-being, spiritual well-being, and social well-being.

Salome, Almeida, Mendes, Carvalho, and Junior¹⁴ defined in their own study the quality of life of patients with intestinal stoma using the mean of their Flanagan Quality of Life Scale score, which was 26.16, and the means for the domains included in the subjective well-being scale were: positive effects: 2.51; negative affect: 2.23, and life satisfaction: 2.77. This finding showed that patients with stoma have negative feelings often related to self-esteem, leading to decreased self-love that in turn influences their quality of life. Another study shows that the quality of life of persons with intestinal stoma often manifests

in negative feelings related to self-esteem and shows decrease of the quality of life, reflecting low class.¹⁵

The results of the review presented in the preceding section are in Table 1. There the process via which the researchers have arrived at their consequent summary and impressions of the literature of patients' quality of life post-colostomy and also formulated their perceived implications of the literature on the nursing profession and healthcare in general can be seen. Presented in Table 1 are the studies and the themes emerging from the researchers' perusal. From the readings it has been gathered that the pertinent themes regarding the quality of life of patients after colostomy engage the aspects of the physical, psychological, socio-familial, economic, nutritional, travel, and religion. The physical aspect also contains the subsets of physical activity and sexual function. Another theme that emerged is body-image. These themes are elaborated in succeeding sections. The data gathered and presented in the table have been found to be statistically significant and are thus considered to be factually valid and appropriate in the context of this review.

Table 1 Summary of Literature about Post-Colostomy Care Quality of Life (2010-2016)

Title	Study design	Population	Instruments	Results	Country
Quality of life in ostomy patients ⁵	Qualitative research	14 participants with purposive sampling	Interview semi-structured	Themes: physical problem, psychological problem, social and family relationships, economic challenges, nutritional issues, physical activities, travel, and religious considerations	Iran
Quality of life analysis in ostomized colorectal cancer patients ⁹	Cross-sectional and descriptive	54 respondent with purposive sampling	Questionnaire WHOQOL-BREF	Very bad (11.11%), bad (48.16%), neither good nor bad (14.81%), good (22.22%), and very good (3.70%)	Brazil
Factors associated with stoma quality of life among stoma patients ⁸	Correlation	76 respondents with convenience	Survey stoma-QOL, Stoma self-care agency scale, and Herth Hope Index assessed QOL, self-care, and hope	Experienced difficulties functioning in work and social situation, had issues with sexuality and body image, difficulties with stoma function, anxiety about privacy when emptying the pouch, always anxious about leakage, always anxious about social activities, gas, travelling, and skin irritation	China
Quality of life in stoma patients in Poland ¹⁰	Cross-sectional	737 respondents	Interview and WHOQOL-BREF	59% patients defining their quality of life as very good or good, assessment of quality of life less in physical states than psychology. Less assessment related to sexual activities, work ability, independence of medicine treatment, financial source, satisfaction with well-being	Poland
Quality of life outcomes in patients living with stoma ⁶	Cross-sectional study	102 respondents with random sample	City of Hope Quality of Life Ostomy Questionnaire (COH-QOL-Ostomy)	Dissatisfaction with sexual activities and feelings of depression after stoma surgery, problem with stoma site, and consequent change in clothing style	India
Quality of life in stoma patients : Appropriate and inappropriate stoma sites ⁷	Cross-sectional study	348 respondents with 174 patients in appropriate stoma site and 174 patients in inappropriate stoma site, with convenience sampling	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire/ EORTC QLQ-C30	Patients with appropriate stoma site general scored significantly higher than inappropriate stoma site (56.2% vs. 49.7% ; p=0.007)	Iran

Table 1 Summary of Literature about Post-Colostomy Care Quality of Life (2010-2016)

Title	Study design	Population	Instruments	Results	Country
A cross-sectional survey of quality of life in colostomates: a report from Iran ¹¹	Cross-sectional study	96 respondents with purposive sampling	EORTC QLQ-C30 and EORTC QLQC38 Questionnaires	Persons with colostomies had maintained good physical functioning (70.9%), role functioning (68.4%), emotional functioning (56.9%), cognitive functioning (68.7%), and social functioning (64.2%). Males had better body image, sexual enjoyment; sexual function vary between males and female, but males had high significant score and role, also better physical and sexual function. More problem with sexual enjoyment noted in older persons, observed in males and females	Iran
Assessment of subjective well-being and quality of life in patients with intestinal stoma ¹⁴	clinical, primary, descriptive, analytical, and prospective study	59 respondents with convenience non-probability sampling	Subjective Well-being Scale and Flanagan Quality of Life Scale.	The quality of life in patients with intestinal stoma was defined using the mean of their Flanagan Quality of Life Scale score, which was 26.16, and the means for the domains included in the subjective well-being scale were: positive effects: 2.51; negative affect: 2.23, and life satisfaction: 2.77	Brazil
Quality of life and self-esteem of patients with intestinal stoma ¹⁵	clinical, primary, descriptive, analytical, and prospective study	70 respondents with convenience non-probability sampling	Rosenberg Self-Esteem Scale/ UNIFESP-EPM, and Flanagan Quality of Life scale	Stoma patients had negative feelings related to self-esteem, showing decrease in quality of life, change in patients' quality of life and self-esteem, reflect low level of class, namely dissatisfaction with their life	Brazil
Quality of life in ostomized colorectal patients: an approach of integrity from Brazilian Unified Health System ¹²	quantitative and qualitative approach	120 subjects with convenience sample	Interview, and WHOQOL-Bref	Show statistically significantly different mean score for domains such as physical, psychological, social and environmental relationships, and quality of life in general had statistically significant results at p<0.0001 Emerging themes: complication with the stoma, self-care, and comprehensive healthcare	Brazil

Table 1 Summary of Literature about Post-Colostomy Care Quality of Life (2010-2016)

Title	Study design	Population	Instruments	Results	Country
Perception of ostomized persons due to colorectal cancer on their quality of life ¹³	quantitative and qualitative approach	120 respondents convenience sample	Interview, and WHOQOL-Bref	Statistics shows significantly different mean score for domains such as physical, psychological, social and environment relationships, and quality of life in general had statistically significant results at $p < 0.0001$. Shows that group with stoma due to colorectal cancer were affected in these subcategories: negative-physical strength ($p \leq 0.0001$), and negative-sexual activities ($p \leq 0.0001$), and finally in the category of social well-being Emerging themes: physical well-being, psychological well-being, spiritual well-being, and social well-being	Brazil

Findings and Discussion

The results of the study revealed varied themes that affected the quality of life of patients after a colostomy. The main influencing factor was the existence of a stoma. The presence of the stoma has led to various effects which have been found to influence the experience of concerned patients. The themes that were found to influence the quality of life of adult patients with stomas after colostomy include *physical and psychological problems, social and family problems, economic challenges, nutritional issues, traveling and religious considerations, sexual functioning, complications with stoma, and self-care. Physical and psychological problems*

The impact of colostomy on the patient's quality of life was explored across many dimensions. The physical problems are related to the effects of the colostomy procedure, including irritations and rashes around the stoma site, sleep disturbance, bad breath, gas emissions, and weight loss.⁵ Also, the emotional and mental concerns described by patients in this study have been reported by Salome, Almeida, Silveira.¹⁵ Mitchell et al.,¹⁶ which report indicates that leakages, odor, and noise from the appliance were the primary sources of the embarrassment identified by patients.

Social and family relationships

Family problems were encountered by most patients, especially a few months after the colostomy. This was caused by the patients' anxieties in family or school gatherings because of their fear of offensive gas emissions.⁵ The ostomy surgery and its associated problems may affect the patients' relationships with their intimate partners.¹⁷ According to Kimura, Kamada, Guilhem, Modesto, and Abrue,¹³ man is a social being, but physical and psychological integrity is indispensable to his enjoyment with other persons.

Economic challenges

Coons, Chongpison, Wendel Grand, and Krouse¹⁸ had demonstrated that the cost of colostomy is an important quality of life consideration. Nichol and

Riemer¹⁷ have further referred to loss of employment as one of the consequences of a stoma. Equal statements from Dabirian, Yaghmaei, Rassouli, and Tafreshi⁵ reported that patients had to change or leave their job after a colostomy, which affected their income, and also to incur additional disease-related costs, e.g. buying bags and gloves.

Nutritional issues

Dabirian, Yaghmaei, Rassouli, and Tafreshi⁵ reported that patients did not receive any education about their diet and nutrition status, but they considered it to be an important issue and were doing the best to control it. Loss of appetite was also more prominent in the stoma group.¹⁹

Physical activity

Dabirian, Yaghmaei, Rassouli, and Tafreshi⁵ reported that patients experienced limitations in physical activity after their ostomies. The patients stated that they have experienced a reduction in their usual activities and a limitation in lifting heavy objects, for it can induce peristomal hernia, which is one kind of complication from a stoma.²⁰

Travel and Religious considerations

Although there are researches reporting the restrictions on traveling for ostomy patients as a quality of life issue, the study conducted by Dabirian, Yaghmaei, Rassouli, and Tafreshi⁵ stated that patients do travel with a colostomy bag. Another study said that post-ostomy patients' most commonly cited concerns were those regarding privacy when emptying the pouch as well as worries about leakage when traveling.⁸ Another important finding in this study relates to religious issues. Although most participants stated that they did not have a major problem in this aspect, nurses should still pay attention to spiritual needs and the relevant religious rituals of their clients. As with many religions, it is important in Islam for a person to be clean and free of any fecal material, especially when praying; so nurses need to optimize patient hygiene as much as possible.⁵

Sexual functioning

The sexual activity of individuals with ostomies is complicated due to the surgery itself, which can cause dysuria, pain during intercourse, urinary incontinence, and reduction or loss of libido.⁹ In a study by Dabirian, Yaghmaei, Rassouli, and Tafreshi,⁵ married participants encountered some form of sexual difficulty, particularly early on in the course of their disease or after surgery. Also, Symms et al.,²¹ showed in their study that almost half of ostomy patients who were sexually active before surgery became inactive after the procedure. Therefore, referral for counseling and evaluation of sexual health may be appropriate.

Complication with the stoma, and self-care

In the study by Kimura, Kamada, Guihem, and Monteiro⁹ reports were identified from participants concerning complications with the stoma. Living with a bowel ostomy requires its user to adopt several measures of adaptation and adjustment to daily activities—including learning care actions that target their ostomy and the peristomal skin, as well as to the handling of the collector equipment—in order to avoid future complications with the stoma. Furthermore, dermatitis is considered the most common complication of an ostomy, for its occurrence is generally the result of an inappropriate use of the collector device.¹² Bulging or hernia around the stoma was present, and operation due to parastomal hernia has been performed in the stoma group.¹⁹

Ostomy patients who perform self-care reported that self-care is fraught with several difficulties. Considering this aspect, a comprehensive health assistance is vitally important, particularly in relation to ostomy self-care. The issues in the correct orientation or the exchange technique of the collector equipment, as well as on the observation of the ostomy during the exchange, highlight the importance of the health professional in helping prevent complications, and also to make life with the stoma more manageable.²²

Conclusion

In conclusion, eleven studies provided information about quality of life of adult persons living after colostomies and the problems or issues related to quality of life. While the range of publication of studies covered only 6 years, the compiled reports show that the topic of quality of life of persons after colostomies is critical and important to nursing. A systematic or integrative review is vital in designing evidence-based nursing interventions insofar as instituting current, innovative, and creative ways of practicing nursing is the item of concern. Therefore, now that we know the state-of-the-science of living with colostomies, the development of interventions crucial to maintaining quality of life is made highly valuable. The impact of ostomy-related problems on the quality of life of persons living after colostomies demonstrates that having a colostomy is life-changing. The overall quality of life of the patient is affected and nurses must take a critical role in instituting interventions which can positively influence his quality of life. This review adds to the existing knowledge of the impact of ostomy-related problems on the quality of life of ostomates. In all the articles included, ostomy-related problems were described in all domains of quality of life.

Implications for Nursing

The results of this study can support the recommendation for nurses to be more cognizant of the physical, psychological, and physiological issues of patients with colostomy. Assessment requires focused nursing care in which expertise in ostomy care can be made a requirement for nurses caring for persons with colostomies. The results of the study also demonstrate that maintaining the quality of life of persons living with colostomies requires expertise from nurses.

The aim of the review of the literature was to examine the quality of life of adult patients after colostomy. Using the findings of the study, nurses

are able to appreciate the importance of understanding the life of persons who have had a colostomy. Important as well is the nurses' focus on the technical skills involved in nursing patients after colostomy, such as knowledge of stoma-care and others, so that their quality of life will be maintained. It was found that qualitative research about this subject described the experiences of the persons living with colostomies thereby informing nurses about the optimal and appropriate nursing care practices. The quantitative research findings provided more detailed information, such as stoma-care and physical dependence on nurses' skills in caring for patients and their families. All these findings provide a more wholesome perspective on what it is like to live with a colostomy. Issues of care about the quality of life after a colostomy are critical to nursing practice expertise. Colostomy care challenges nurses to be more cognizant of advanced practices. Ostomy care can change over the years, meaning that the problems experienced can vary over time, but the quality of life issues remain.

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