

Original Article



The Effect of Education with a Family-Centered and Client-Centered Approach on the Quality of Life in Patients with Stoma

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Abstract

Introduction: Colorectal cancer is known as the third leading cause of death from cancer in the world and the second cause of death in developing countries. Family care can positively affect the patient's general health system. The present study was conducted to determine and compare the effect of family-centered and client-centered training approaches on the life quality of individuals with digestive ostomy.

Methods: This is a semi-experimental study conducted on 60 individuals. The individuals participating in the present study were chosen from either those with digestive ostomy or their attendants. The participants fulfilled the requirements (criteria) for entering the present study. For conducting the training procedure, both groups received family-centered or client-centered training. Two months later, the quality of life of the individuals with digestive ostomy was measured once more. The data were then analyzed in SPSS version 21 by using chi-square test, paired *t* test, and independent *t* test.

Results: According to the findings of the present study, there is no significant difference between the family-centered and the client-centered groups in terms of demographic features. By investigating the mean changes of both groups, there was a significant difference between quality of life score and spiritual-psychological aspect of scores before and after the intervention in the family-centered group.

Conclusion: The findings of the present study showed that family-centered education can increase the quality of life for people with gastrointestinal ostomy. This study concluded that family-centered education can be considered an effective intervention in people with gastrointestinal ostomy.

Introduction

Colorectal cancer is known as the third prevalent cause of deaths from cancer in the world and the second cause of deaths in developing countries.¹ The therapeutic methods (including surgery, radiotherapy, and chemotherapy) are often associated with digestive ostomy. Stoma is the outcome of surgeries performed to remove the damaged parts of the ileum (ileostomy) or colon (colostomy). Stoma is likely to be temporary (to protect against low anastomosis in rectum cancer) or permanent (for the cancer of upper rectum). Stoma can be also due to other reasons such as the poor control of anal sphincter.² The main reasons behind stoma include a variety of disorders including colorectal cancer, diverticulitis, inflammatory bowel disease, trauma, congenital anomalies, and abdominal neoplasms.³

The World Health Organization (WHO) has defined the quality of life in five aspects including physical health, psychological state, level of independence, social relationships, and their relationship to the environment.⁴ Patients with stoma deal with various physical and

psychological problems including a negative attitude and image of themselves, limitations in conducting individual activities, and changes in the lifestyle affecting their sexual relationships as well.⁵ The complications arising from ostomy including skin problems, leakage, and adaptive problems can affect the quality of life associated with the health of these patients.⁶

Quality of life is a set of mental components reflecting the patients' physical, emotional, vocational aspects as well as their social experiences.⁷ The quality of life is an important aspect in the life of patients with stoma. These patients undergo a surgery that can bring out permanent changes in their quality of life. Most of these patients suffer from colorectal cancer. Thus, they are required to not only adapt themselves with cancer but also deal with a wide range of surgery effects. Since they lose one part of their body and experience a significant change in the anatomy and performance of their body, these patients will experience various problems in terms of different aspects of life quality.⁸

It has been widely observed that the performance of

stoma results in the feeling of disability and being rejected by the family or the society. Improvement of the quality of life is required to be conducted. Thus, the main purpose of caregivers and medical staff is providing proper care for such patients.⁹ Over the recent years, efforts toward promoting the quality of life in patients suffering from cancer (as one of the main results of treatment in oncology) has attracted the medical team's attention toward identifying different aspects of quality of life and searching effective ways to promote and improve these patients' quality of life. The role of the nurses is included as one of the most highlighted ones; nurses, as one of the members of the medical team, have a significant role providing care for cancer patients. Through identifying the caring needs of patients and their families, the nurses can have a significant role in controlling the complications of the disease and promoting their quality of life.¹⁰ The nurses are required to play a basic role in ostomy care. They need to train the patients and their families about strategies of coping with the new life.⁶ The patient needs information about changing the ostomy bag, taking care of the skin around the ostomy, ostomy cleaning, type and consumption of food materials, food limitations, and activity limitations. Thus, nursing care play an important role in returning these individuals to normal life.⁸

Patients' training is reared as an important issue in various studies. Moreover, the positive role of families as a main participatory source has been neglected in promoting medical goals.¹⁰ Family-centered training is a process in which the family members are trained to promote their skills and capabilities for helping a family member suffering from a disease.¹¹ Family-centered training is one of the main issues of nursing the aim of which is preserving the unity and integrity of the patient's family and providing specific care for each patient. In the family-centered approach, the family is actively present and participate in investigating and identifying the needs and trainings. It is believed that if a family member suffers from a disease, all other members are inevitably involved with the disease.¹² Family care is a main source support in the process of chronic diseases. Family care can positively affect the patient's general health system.³ Also, Srisuket et al., showed that educational programs with a family-centered approach can have a positive effect on improving the knowledge of family members and self-care of patients with chronic heart failure.¹³ Another study, showed the presence of family members as a supportive factor in increasing self-care behaviors.¹⁴ Considering the impact of family-based and medical-based education on the quality of life of people with gastrointestinal ostomy in Iran, the researcher decided to study the effect of family-centered and patient-centered education on the quality of life of people with gastrointestinal ostomy.

Materials and Methods

The present study is a semi-experimental and conducted

to determine and compare the effect of family-centered and client-centered training approaches on the life quality of individuals with digestive ostomy (colostomy and ileostomy). The research environment of the present study of the present study is the colorectal clinics of Rasoul Akram hospital and Firozgar hospital in Tehran. The inclusion criteria of the present study included: being an active member of the family (he/she is required to live either in the same place as the patient or somewhere near him/her); having the ability to read and write (to study the written materials); the client and the active member's willingness and consent to participate in the project; having a permanent or temporary digestive ostomy; one year has passed since the surgery; being at least 18 years and at most 60 years; psychological, verbal, visual, and auditory health based on the patient's medical file and doctor's order (not suffering from diseases such as rheumatoid arthritis and physical diseases of the upper limbs). The exclusion criteria include: the patient's death; failure to attend a training session; the occurrence of any severe disability or complication during the study. During the present study, an individual with digestive ostomy and a family member of the experimental group gave from participating in the study. Thus, the present study was conducted on 60 individuals (30 individuals in the family-centered group and 30 individuals in the client-centered group).

In the present study, the main tool used for collecting the required data was the City of Hope Quality of Life Ostomy Questionnaire (COH-QOL). This questionnaire has been developed by the researchers of National Center of Cancer in the City of Hope, California. This questionnaire has 90 questions in three parts. The first part includes questions about the demographic information of the samples. The second part is involved with the effect of ostomy on the patient's lifestyle. The second part contains 34 questions with one-word answers regarding job, medical insurance status, sexual performance, mental-psychological concerns, clothing, diet, daily care of ostomy, and food groups. The answers to the questions in this part were not scored. Thus, in the present study, these questions were merely used to describe the samples. The third and the main part of the questionnaire measures the effect of ostomy on the quality of life. This part contains 43 questions in different aspects of physical health (questions 1-11), psychological health (questions 12-24), social health (questions 25-36), and spiritual health (question 37-43) of quality of life. The questions of this part are scored on Likert's rating scale from 0 to 10; the scores are subsequently applied in measuring the quality of life mean score. In some questions, higher scores indicate a better quality of life. However, for some other questions, lower scores indicate a better quality of life. For measuring the quality of life score, the mean score of quality of life in every aspect as well as the mean score of the general quality of life were obtained by implementing inverse changes

for questions with negative orientation. For the general quality of life and its different aspects, the minimum score (lowest) and the highest scores were determined to be 0 and 10 respectively. Then given the mean score obtained by the samples, their quality of life was judged. To determine the reliability of this questionnaire, 10 patients with stoma who had inclusion criteria were given and their Cronbach's alpha was calculated to be 0.71. Which indicates that it is statistically significant and has the necessary reliability. The validity of the tool was determined based on content validity. In this case, the researcher, after translating the questionnaire and using the opinions of the research colleagues and the statistical consultant, provided it to 10 members of the faculty of Nursing and Midwifery of Tehran University of Medical Sciences. Content validity of the instrument were confirmed after using their suggested comments and corrections. The content validity was confirmed by two methods of test-retest and internal correlation. Questionnaires were completed by 10 eligible clients. At the end, Cronbach's alpha value of 0.95 and correlation coefficient for physical, psychological, social and spiritual dimensions of quality Life expectancy was 0.82, 0.88, 0.83, 0.78, respectively.¹⁵

Having acquired the required permit from the Iran Faculty of Nursing and Midwifery and acquiring permission from the Ethics Committee of Iran University of Medical Sciences (IR.IUMS.REC.1396.9511686006), the researcher referred to the aforementioned hospitals and selected the subjects based on the inclusion criteria as well as their informed consent. The subjects were then divided into two groups: control and experimental (family centered). The samples were divided into 8-to-10-individual groups. For preventing information pollution, the information of the client-centered group was obtained from the colorectal clinic of Rasoul Akram hospital, and the information relating to the family-centered group was taken from the patients who had referred to the colorectal clinic of Firoozgar hospital. The questionnaires were completed by the participants of both groups. Then, the training course was provided as pamphlets containing useful information on digestive ostomy, late complications of ostomy, nutrition, sport, traveling, and methods of taking care of the skin around the stoma. The training course was conducted in three 30-to-45-minute sessions in three weeks for both groups. However, in the family-centered group, an active member of the family participated in the training sessions as well. The training sessions were administered through lecture, group discussions, and questions and answers by using slides and educational pamphlets. The participants of the sample group were provided with an educational pamphlet containing information about digestive ostomy, late complications of ostomy, nutrition, sport, traveling, and methods of taking care of the skin around the stoma. In the first session, after introducing himself and becoming familiar with the participants, the researcher introduced

the training course as well as its purpose and significance. Moreover, he provided them with useful information about digestive ostomy and its late complications. In the second session, the materials of the previous session were reviewed. Then, the right procedure of changing ostomy bag was practically conducted and practiced. In the third session, materials of the previous session were reviewed. Then, the participants were trained how to take care of the skin around the stoma. In the training sessions, it was attempted to present the materials simply without using medical terms. After the educational intervention, the participants of the group were asked to apply the principles they had learned at home.

Two months after the educational intervention, the participants of both groups were once more asked to attend the clinic to complete the questionnaires. In the interval between the completion of intervention and the post-test stage, the researchers communicated with the participants by making three 5-to-10-minute phone calls to make sure about the durability of the training course. In addition to answering the participant's questions, the researcher evaluated the process of training and care provided. The quality of life was measured in both groups (family-centered and client-centered) both before the training course and two months after the training course by applying COH-QOL. At the end, the quality of life was analyzed by using chi-square test, paired *t* test, and independent *t* test in both groups.

Results

After a two-month follow-up of 33 patients in the family-centered and patient-centered groups, 3 patients in the control group and two in the control group were not willing to continue the study. The mean age of the individuals with digestive ostomy was 48 years with the standard deviation of 12.49. However, in the client-centered group, the mean age was 49 years with the standard deviation of 10.85. The body mass index (BMI) of 60% of the samples investigated was in the normal range of 18.5-24.99. More than 50% of the samples suffered from digestive ostomy owing to colorectal cancer. As many as 53.3% of the caregivers were the participants' spouses. According to chi-squared test, the distribution of quality of life data was homogenous; there was no significant difference between the two groups in terms of their demographic characteristics (Table 1).

Chi-square test showed that there was no statistically significant difference between sex distribution ($P=0.34$), economic situation ($P=0.94$) and both groups were homogeneous in terms of sexual and economic distribution. Fisher exact test results showed that in both groups the samples were homogeneous in terms of type and reason. There was no statistically significant difference between the two groups. The results of one-way ANOVA showed that there was no significant difference between the two groups in the mean BMI of both groups ($P=0.44$). None of the samples had BMI greater than

Table 1. Comparison of the demographic characteristics of the participants at baseline

Variable	Group		P value
	Client center No (%)	Family center No. (%)	
Gender			0.34
Male	16(53.3)	12(40)	
Female	14(46.7)	18(60)	
Marriage			0.57
Single	6(20)	2(6.7)	
Married	23(76.7)	27(90)	
Other case	1(3.3)	1(3.3)	
Income			0.09
Sufficient	0(0)	0(0)	
Quite enough	16(53.3)	12(40)	
Not enough	14(46.7)	18(60)	
BMI			0.44
Thin	6(20)	7(23.3)	
Normal	22(73.3)	18(60)	
Overweight	2(6.7)	4(13.3)	
Obese	0(0)	0(0)	
Reason of ostomy			0.30
Colon cancer and rectum	21(70)	23(76.7)	
Other cancers	2(6.7)	1(3.3)	
Inflammatory diseases	3(10)	3(10)	
Other cases	4(13.3)	3(10)	
Ostomy kind			0.24
Permanent	2(6.7)	4(13.3)	
Temporary	0(0)	0(0)	
Permanent	25(83.3)	24(80)	
Temporary	39(10)	2(6.7)	

30 (obese). Before conducting the intervention, the quality of life score was 3.11 in the client-centered group and 3.18 in the family-centered group. There was no significant difference between the two groups in terms of the pre-intervention quality of life score ($P=0.73$). After conducting the intervention, the quality of life score was 3.76 in the client-centered group and 4.15 in the family-centered group. The independent t-test indicated that two groups were significantly different mainly regarding their quality of life scores in terms of their physical health ($P=0.01$). By investigating the mean changes of the groups, it was concluded that two groups were also different regarding their quality of life score in terms of spiritual and psychological aspects ($P=0.04$) (Table 2).

Discussion

The present research aimed at determining and comparing the impact of client- and family-centered training methods

on the quality of life of people with digestive ostomy. According to the mean changes, a significant difference was observed between the groups (client- and family-centered) concerning their life quality scores. In line with these results, a study was performed on patients with heart failure in rural areas of Thailand using a family-based training program. The researchers showed an increase in patients’ self-caring awareness and family member knowledge in the intervention group after holding the training sessions (for 50 patients with active caregiving members) compared with the control group with just the routine training and cares.¹⁶ A further research titled “A trial of family partnership and education interventions in heart failure” revealed that after the training, self-caring behaviors, such as intaking less sodium in the diet, meaningfully increased in the group of patient-family training for four and eight months compared to the control.¹⁴ Also, another study showed significant impacts of family-centered training and interventions on self-caring in patients suffering from chronic heart failure concerning diet and the medicinal instructions.¹⁷ In additional research titled “Effect of family-centered education on the quality of life patients after coronary artery bypass graft surgery,” the researchers showed a significant increase in the quality of life aspects in the post-test phase compared to the control group. Further, family-centered training in patients who experienced coronary

Table 2. Comparison of COH-QOL scores between control and intervention groups

Variable	COH-QOL	Group		P value
		Family center Mean (SD)	Client center Mean (SD)	
Before intervention				
Physical health	3.16(1.50)	2.81(1.06)	0.30	
Mental health	3.42(0.59)	3.48(0.89)	0.75	
Social health	2.11(0.83)	2.11(0.77)	0.97	
Spiritual health	4.58(0.86)	4.61(0.55)	0.85	
Quality of life	3.18(0.76)	3.11(0.71)	0.73	
Two month after intervention				
Physical health	4.52(0.86)	3.85(1.09)	0.01*	
Mental health	4.32(0.68)	4.02(0.82)	0.13	
Social health	3.12(1.30)	2.77(0.68)	0.98	
Spiritual health	5.00(0.81)	4.81(0.65)	0.32	
Quality of life	4.15(0.67)	3.76(0.68)	0.07	
Mean difference				
Physical health	1.36(0.90)	1.03(0.87)	0.15	
Mental health	0.89(0.56)	0.54(0.53)	0.01*	
Social health	1.00(1.05)	0.62(0.33)	1.00	
Spiritual health	0.41(0.36)	0.19(0.45)	0.04*	
Quality of life	0.96(0.45)	0.64(0.42)	0.04*	

*Statistically significant.

artery bypass graft surgery could improve their quality of life.¹⁸ A study on the effect of family-based empowerment intervention on high-risk behavior improvement in patients suffering from Brucellosis showed the increased mean of concepts (self-efficiency, attitude, self-esteem, behavior) in the intervention group compared with the control.¹⁰ An investigation of attitude, knowledge, and skill of patients with multiple sclerosis, emphasizing the influence of the family-centered empowerment model, revealed that, in terms of knowledge, the groups were nearly similar prior to the intervention; a significant difference, however, was detected between the groups after the intervention.¹⁹ Two educational approaches (family- and patient-centered) were investigated using a multimedia software on dysrhythmia in patients after acute myocardial infarction.²⁰ Based on the results of this research, a significant difference was observed between the two groups. Also, family-centered training was shown to be more efficient (in decreasing the dysrhythmia) than that of the patient-centered.¹⁰ Additionally, a study about the family-centered training impact on the patients' laboratory indices after acute myocardial infarction showed the medical results, such as blood glucose and blood lipids (TG, LDL, LDH, cholesterol) to be different significantly in the family-centered group compared to the patient-group; however, the above-mentioned indices were not different significantly between the two groups before the intervention. This is in line with the results of the present research. Similar to the present work, all the mentioned studies have shown a significant positive impact of family-centered training on the quality of life of patients. According to the present research, the enhanced life quality in the experimental group was due to the family-centered education sessions, the family's enhanced knowledge and empowerment in providing quality care for patients with a digestive ostomy, the accessibility of appropriate strategies, family's awareness of the complications, and persistent follow-up communication with participants after discharging from the hospital.²⁰

Further, a study on the association of adherence to diet with social support level showed appropriate social support for patients as one of the significant factors in adhering to diet after discharging from the hospital. In patients without appropriate family support, diet adherence significantly decreased after discharging from the hospital.²¹ In another research, the families of patients with stroke were provided with supportive intervention. According to its results, the life quality of patients and their families significantly improved in the experimental group, and also the pressure decreased in the provision of required care for the patient. The present work showed that simple and comprehensible training (in terms of cares after discharging) in some sessions for the family of individuals with a digestive ostomy and the follow-up of the educational programs could improve the life significantly and care quality in these individuals.²²

The present research results were inconsistent with those of another work performed by the title "The effect of self-care program training on the quality of life of gastric cancer patients from gastrectomy surgery." This work showed that, in the experimental and control groups, the general life quality (on the basis of the cancer patients' life quality questionnaire) was not significantly different before and after the intervention. However, there was a significant difference concerning the emotional performance in the experimental group in various factors of life quality and physical issues. Before and after the intervention, the mean difference in the general life quality was insignificant between the two groups, according to the questionnaires.

The groups were significantly different concerning emotional and mental/psychological performance. The inconsistency in results was probably due to various educational interventions and statistical populations of the two studies. The statistical population of the mentioned study above was patients with gastric cancer after gastrectomy surgery, while that of the present work was patients with a digestive ostomy. Other factors considered consisted of age, individual, and cultural differences, as well as the patients' understanding of various components of life quality; they could be another reason for inconsistency in obtained results in the studies.²³

Conclusion

The findings of the present study indicated that family-centered training is likely to bring about a significant increase in the quality of life of individuals with digestive ostomy. Family-centered education can have a positive impact on the quality of life of people with gastrointestinal stoma. This approach, along with teaching to the patient, can have a significant role in the quality of life. In clinical services, family-centered education can reduce the economic burden on the health system because increasing the quality of life for people with gastrointestinal ostomy with the family-centered educational approach can reduce costs, readmission, and mortality rates. One of the implications of this research is to raise the level of community health, provide more effective health services, improve clinical performance and strengthen the health care system.

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Ethical Issues

This study is extracted from a research project approved by Vice President of Research of Iran University of Medical Science with code: IR.IUMS.REC.1396.9511686006 and is registered in Iranian

Research Highlights

What is the current knowledge?

Various texts are available on patient-centered education on quality of life of people with gastrointestinal ostomy.

What is new here?

Education with a family-centered approach can have a positive effect on the quality of life of people with gastrointestinal ostomy.

Registry of Clinical Trials with code IRCT20180628040265N1.

Conflict of Interest

The authors declare no conflict of interest in this study.

Authors' Contributions

Conceptualization and formulation: FNZ; Writing of the review of literature: ShK; Data collection: ShK; Data analysis and processing: ShK; Manuscript writing, review, editing, and revising of final paper: FNZ.

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