



A Different View of Stoma: Living with a Person with Stoma

Stomaya Farklı Bir Pencereden Bakış: Stoması Olan Bireyle Yaşamak

Buket Çelik¹, Fatma Vural¹, Özgül Karayurt², Özlem Bilik¹

¹Dokuz Eylül University Faculty of Nursing, Department of Surgical Diseases Nursing, İzmir, Turkey

²Economy University Faculty of Health Sciences, Department of Nursing, İzmir, Turkey

ABSTRACT

Stomas cause various physical, psychological and social problems among individuals and their family members both when they are created and in the post-hospital period. In the present study, an in-depth interview was conducted with a family member of a person with stoma. A structured questionnaire was utilized in this interview period. The entire 60-minute interview was recorded with a voice recorder. The collected data were analyzed by inductive method, and themes and sub-themes were identified. The daughter of the stoma patient, E.Y., is a 51-year-old married housewife with two children. Her mother underwent ileostomy due to rectal cancer. From the results of the analysis of the interview, four core themes were determined as need for information, quality of life, adjustment issues and difficulties, and suggestions to other individuals with stoma, together with their sub-themes. The core and sub-themes structured within the present study vividly illustrate how her life was affected and the problems she encountered. Therefore, adjustment to living with stoma must be regarded as a process that includes all family members. In order to accelerate the adjustment process to living with person with stoma, it is also important to include family members in this adjustment process. Hence, needs of the family of a person with stoma must be determined in advance, prior to the surgery, and relevant nursing interventions appropriate for the family must be determined and implemented.

Keywords: Stoma, family member, living with stoma, nursing care to a person with stoma, rehabilitation

ÖZ

Stoma hem ilk görüldüğü anda, hem de taburculuktan sonra bireylerin ve aile üyelerinin fiziksel, psikolojik ve sosyal açıdan çeşitli sorunlar yaşamasına neden olmaktadır. Bu olgu sunumunda stomalı bir bireyin aile üyesi ile derinlemesine görüşme yapıldı. Yapılandırılmış soru formu ve ses kayıt cihazı kullanılarak gerçekleştirilen görüşme 60 dk sürdü. Veriler tümevarım yöntemiyle analiz edilerek temalar ve alt temalar oluşturuldu. Rektum kanseri nedeniyle geçici ileostomi açılan stomalı bireyin kızı E.Y. 51 yaşında, evli iki çocuk sahibi ve ev hanımıdır. Görüşmenin analizi sonucunda bilgi gereksinimi, yaşam kalitesi, uyum sorunu ve güçlükler ve diğer stomalı birey ve ailelere öneriler olmak üzere dört tema ve bu temaların alt temaları belirlendi. Bu çalışmada oluşturulan temalar ve alt temalar olgunun yaşamının etkilendiği yönleri ve yaşadığı sorunları çarpıcı olarak göstermektedir. Bu nedenle stomayla yaşama uyum tüm aileyi içine alan bir süreç olarak değerlendirilmelidir. Stomalıların stomayla yaşama uyumlarının hızlandırılması için aile üyelerinin de uyum sürecine dahil edilmesi önemlidir. Bu amaçla stomalı bireyin ailesinin gereksinimleri ameliyat öncesi dönemden itibaren belirlenmeli ve aileye uygun hemşirelik girişimlerinin planlanması ve uygulanması gerekmektedir.

Anahtar Kelimeler: Stoma, aile üyesi, stomayla yaşam, stomalı bireye bakım verme, rehabilitasyon

Introduction

Stoma is one of the surgical procedures commonly used in the management of many conditions, primarily cancer. The main purpose of opening a stoma is to resolve the pathological condition, to extend life expectancy, to improve quality of life and to help patients return to a productive life.¹ However, stomas cause various physical,

psychological and social problems in patients and their families, both when first introduced and after discharge from the hospital.^{2,3,4,5,6}

In addition to these problems, stomas also result in a need for care. This care includes meeting the needs of a chronically ill person such as feeding, dressing and hygiene, as well as providing emotional, physical and financial support.



Address for Correspondence/Yazışma Adresi: Nurse Buket Çelik
Dokuz Eylül University Faculty of Nursing, Department of Surgical Diseases Nursing, İzmir, Turkey
Phone: +90 232 412 69 75 E-mail: akyol_buket_62@hotmail.com
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Providing this complex support makes the living conditions of the caregiving family member more difficult and increases the burden placed on them. Family members who bear the responsibility of primary caregiver experience considerable physical, emotional and social hardships during this time.^{6,7,8} For this reason, the family members of patients with stomas also need support.

In Turkey and abroad, there are few studies that aid the adaptation of family members of adults with stoma or evaluate the problems they face.^{7,9,10,11} The aim of this case report is to share the experiences of a daughter caring for her mother, who has a stoma. We believe this case will contribute to the planning of approaches to ease adaptation among family members living with stoma patients and will serve as a guide to studies in this area in Turkey.

Case Report

For this case report, an in-depth individual interview with the daughter (E.Y.) of a patient with a stoma was conducted in a quiet room. E.Y. provided written informed consent. An unstructured interview form was used and the interview was recorded using an Olympus WS 760M audio recorder. The interview lasted about 60 minutes; the data obtained were analyzed by inductive approach, and main and subthemes were created.

E.Y., the daughter of a stoma patient, is a 51-year-old married housewife and mother of two children. Her mother

had a temporary ileostomy opened due to rectal cancer, but it was later converted to a permanent ileostomy. E.Y. has been caring for her mother for 3 years. The patient she cares for is 71 years old, female, 96 kilos, and has Parkinson's disease and vision impairment. The site of the stoma was marked preoperatively by a stoma nurse.

Analysis of the interview resulted in the identification of 4 main themes, "need for information", "quality of life", "adaptation problems and difficulties" and "recommendations for other family members of stoma patients", with subthemes under some of these (Figure 1). Within these themes, the actual words used by the subject are presented.

1) Need for Information

Subthemes are "being informed preoperatively" and "being informed about treatment duration."

Being informed preoperatively: E.Y. expresses that she was not adequately informed about stomas and stoma care before her mother's surgery.

"It has a powder, and a substance that creates a foundation for closure, there are sprays. No one told me these about things, I found them all on the internet and bought them...", "If I had been fully informed about this topic before the surgery, I wouldn't have had my mother undergo the surgery..." (her voice was teary when expressing this, and she cried again after finishing the last sentence).

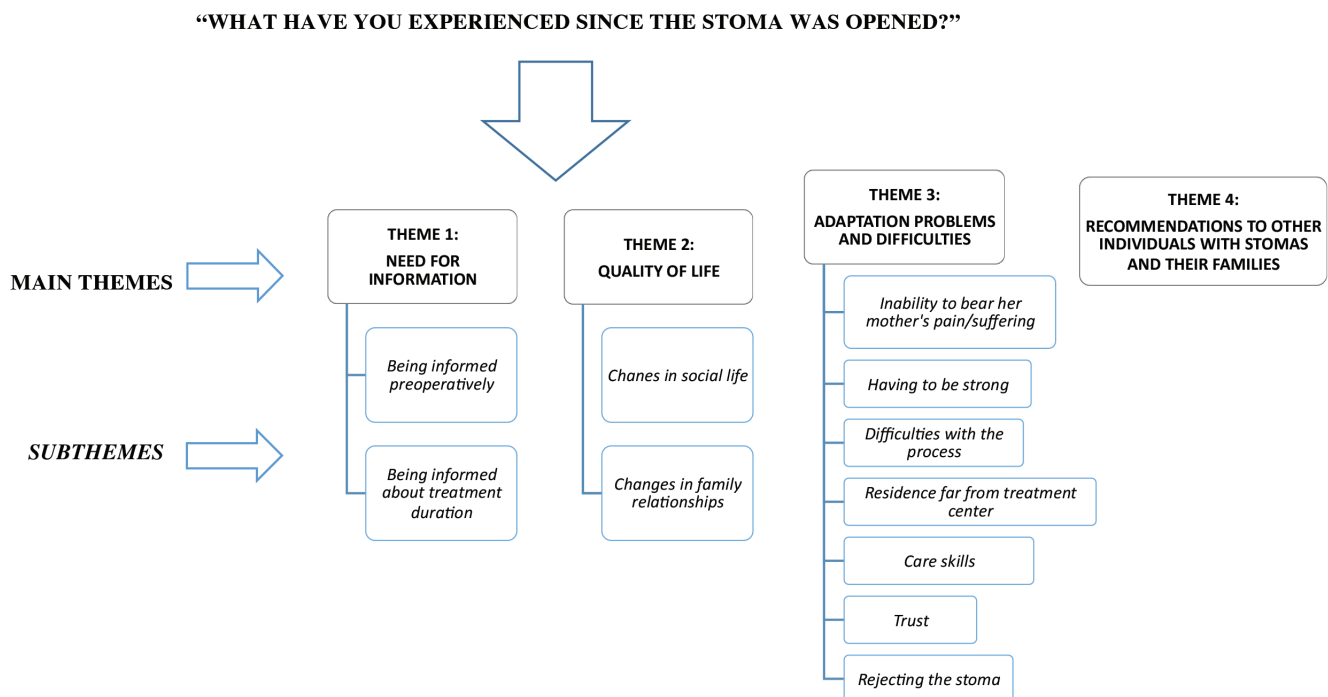


Figure 1. Themes related to experiences caring for someone with a stoma

Being informed about treatment duration: E.Y. stated that she had not been adequately informed about the duration of treatment: “It doesn’t come out like normal waste, it’s generally liquidy... At first we thought she had diarrhea all the time...”, “I tried to educate myself about this by reading books and researching it...”

2) Quality of Life

Two subthemes describing how E.Y.’s quality of life has been affected were identified.

Changes in social life: E.Y. described changes in her social life after her mother’s stoma was opened as follows: “Up until 3 years ago, I had a very social life. I used to meet with my friends and relatives very often, everything was great. After my mother got her colostomy bag, I had to be with her constantly because she couldn’t change the bag herself. My mother’s bag ruined my life...” “I had guests over, and I was sitting across from my mother. I kept watching the bag, because at any moment it could appear above her trousers...”

Changes in family relationships: During the interview, E.Y. said the following to express how her own family became a lesser priority after her mother’s stoma was opened: “My life revolves around my mother’s stoma right now. My husband and children come second...”, “My husband is also tired of it. I’ve forgotten that we are husband and wife. We were a very devoted couple...”, “My mother’s colostomy bag especially harmed my children psychologically...”, “Once the apparatus I stuck on exploded. My son saw my mother in that state and had a crisis for three days...”

3) Adaptation Problems and Difficulties

There are many subthemes within the theme of adjusting to living with a stoma patient.

Inability to bear her mother’s pain/suffering: E.Y. described not being able to bear her mother’s suffering with the following statements: “Caring for my mother is not my only worry. I don’t want her to feel miserable when she dies...”, “For example, when I take off the apparatus, it smells and she feels bad. If I wear a mask, she feels bad. You know? I don’t wear it, so my mother won’t feel bad. Then I hold my breath...”

Having to be strong: E.Y. made the following statements about having to be strong in situations she had to deal with while caring for her mother: “Although I’ve experienced a lot of difficulties over the last 3 years, my husband and mother have never seen me cry. Until morning, for days, I told myself, “You are her daughter, she has no one else.”, “I may need to take loads of pills for depression right now, but I will not be defeated by this disease. I will never be a prisoner to pills...”, “For 3 years I have been treating myself to avoid being miserable...”

Difficulties regarding the process: E.Y. described the difficulties of the process as follows: “If I had known it would be like this after she got the stoma (hits the table with her hands) I wouldn’t have accepted this...”, “It’s such a difficult process...” (sighs), “That first 2.5 months is very difficult. I saw it just wasn’t working and I moved in with my mother. She didn’t want anyone to see her...”, “I can’t even explain... for the love of God, is there anything harder than this?”

Residence far from the treatment center: E.Y. stated that her home is far from the city center where the surgery was performed and expressed the difficulties she experienced in the car:

“We were in Salihli. I can’t come to the hospital all the time, it’s so difficult... We spend 2.5 hours driving there and 2.5 hours driving back.”, “I get my mother into the car. Of course the bag is the biggest problem when my mother sits... Her stomach folds over, and the hole is right at the spot where it folds. When it folds, the edges of the hole also fold, and the apparatus comes unstuck from her skin. The waste leaks out from there. We’re on the road, and again she has diarrhea... Why? Because the radiotherapy wreaks havoc on her. It gives her diarrhea...”

Care skills: E.Y. expressed the following statements regarding the difficulties she experienced due to her inadequate manual dexterity when caring for the stoma: “It’s impossible to put the two parts together...”, “There are snaps under the colostomy bag, and I just couldn’t get that adhesive to hold...”

Trust: E.Y. said the following about her feelings of trust toward the medical staff: “When we were discharged, we completely believed whatever they said...”, “They told us they would change it to an internal pouch in 6 months to a year... OK, let’s be patient, we said, and we trusted the doctor and went home...”

Rejecting the stoma: E.Y. said the following about the feelings of denial she felt about living with her mother’s stoma: “My only wish from God is for the bag to be made internal...”, “They shouldn’t do this to anyone (crying)... Living like this is not nice...”, “Let’s say my mother will live another 10 years like this. If only we hadn’t had to do this, and my mother could have lived 5 years the way I knew her (begins to cry). It hurts so much... If my mother hadn’t had this surgery, she would still be my normal mother now...”

4) Recommendations to Other Individuals with Stomas and Their Families

As a result of the hardships and problems she experienced, E.Y. made the following statements expressing recommendations for other stoma patients and their families:

“If someone came and asked me, I have such and such a situation, like your mother’s... I would say one thing: research it well, really delve into it...”, “... I would advise them to be careful about nutrition in patients who need to have a stoma. Especially stomas with liquid waste... Eat less, eat healthily...”, “The family and the doctors can give psychological support and make them accept that this is a normal part of their life now...”, “If living with a bag will extend someone’s life from 1 month to 2 or 5 years, of course they should have the surgery. It’s also easier to accept in that case. The patient can accept this, so can their loved ones...”, “But make the opening in such a way that they can take care of it on their own, without being dependent on anyone... As long as someone can handle it on their own, no one would realize it with perfume, with the proper equipment, and if they wear a loose top...”

Discussion

This case report presents the results of an in-depth interview with the daughter of an individual with a stoma. It has been previously reported in the literature that stomas have a psychological, physical and social impact and decrease quality of life not only for the patient, but also the family members living with the patient.^{2,3,4,7} In a study investigating burdens on caregivers to colorectal cancer patients, Kaynar⁷ also found that people caring for stoma patients had a greater burden. In this case report, E.Y. states that because of her mother’s stoma, her life and family took secondary importance and her life quality was adversely affected, which illustrates that stomas also result in negative consequences for patients’ family members.

Patients with colorectal cancer may be faced with stoma before they have passed the initial stage of cancer diagnosis. For this reason, E.Y. was also surprised when she was first faced with stoma and blamed herself for her ignorance and not being informed about stomas beforehand. This result may explain why relatives experience difficulty accepting the stoma when they first see it postoperatively. We believe the difficulty experienced by E.Y. during the first stages of the treatment and adaptation process negatively affected the ongoing process.

Previous studies have documented that stoma patients and their families are not adequately informed preoperatively, and that this can lead to feelings of regret and guilt in the patients and their families postoperatively.^{5,6} In her interview, E.Y. also expressed regretting the decision to have the surgery. Based on these sentiments, it is believed that although the stoma area is marked, the individual and their family are not sufficiently informed about the stoma or are not able to internalize the education they receive due to anxiety and stress. Therefore, stoma education may be more

effective if different methods are employed, such as giving patients and their families opportunities to ask questions and making the process interactive. This approach may help to reduce negative feelings in family members like those experienced by E.Y.

The burden of care on family members of individuals with stoma may be higher when the patient is unable to independently care for the stoma, either for reasons related to the stoma region or due to other diseases, and therefore requires constant assistance.¹⁰ This burden can negatively affect the social life and family relationships of the caregiver. Various physical, psychological and social difficulties have been reported in caregivers who are not able to make sufficient time for their family and social life.^{5,6,10} In the literature, the ability to independently care for one’s stoma is described as a skill.¹² However, the opening of a stoma negatively affects an individual as much psychologically and socially as it does physically; therefore, patients fail to develop the skills required for stoma care, are unable to manage independently and require support to care for their stoma. In addition, there is also a need for family support while the patient is adjusting to having a stoma. In this case, because the stoma patient was 71 years old and had Parkinson’s disease and visual impairment, she had difficulty performing stoma care and we believe this further increased the burden of care on E.Y. In addition, E.Y.’s account shows that her social life and family relations were severely impacted when she prioritized caring for her mother over attending to her own needs. Therefore, in order to reduce the burden of care, family members must also be included with the patient in training and education conducted at discharge.

Another key factor in stoma care is the proper placement of the adaptor and bag. For this reason, manual dexterity is important in stoma care. Manual dexterity improves while living with a stoma.¹² However, stoma patients may experience various physical difficulties until the manual dexterity of the stoma caregiver, be it the patient or a family member, develops sufficiently. In our case, the caregiver also expressed that her manual dexterity was not adequate to care for the stoma at first, but improved over time. To ease this adaptation process, both patients and their caregiving family members should undergo practical training before discharge.

Moreover, based on the statements of E.Y., we believe that living far from the treatment center and having difficulty reaching it had negative impacts on both the physical and psychological aspects of her life. Therefore, as in this case, it may be beneficial to provide counseling on the phone to stoma patients and their families who live far from treatment centers and for whom face-to-face communication may not

be possible, in order to answer their questions, allow them to share their problems, and provide guidance.

The difficulties faced by E.Y. while caring for her mother and her recommendations for minimizing these problems are important for other stoma patients and their families. The views emphasized by E.Y. during the interview include key points for facilitating adaptation in family members of stoma patients. Her account also underlines the critical role medical staff have in training and informing stoma patients and their families.

In conclusion, the themes and subthemes developed in this study present a striking picture of how the subject's life has been affected and what problems she has experienced. This case demonstrates that adjusting to life with a stoma should be considered a process that involves the entire family. To accelerate adjustment to living with a stoma, it is essential that family members also be included in the adaptation process. Therefore, it is recommended to determine the needs of stoma patients' families starting in the preoperative period and to address these needs through the planning and implementation of appropriate nursing interventions.

Ethics

Informed Consent: Consent form was filled out by participant.

Peer-review: External and internal peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: Buket Çelik, Fatma Vural, **Concept:** Buket Çelik, Fatma Vural, **Design:** Buket Çelik, Fatma Vural, **Data Collection or Processing:** Buket Çelik, **Analysis or Interpretation:** Buket Çelik, Fatma Vural, Özgül Karayurt, Özlem Bilik, **Literature Search:** Buket Çelik, Fatma Vural, Özgül Karayurt, Özlem Bilik, **Writing:** Buket Çelik, Fatma Vural.

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