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RESEARCH ARTICLE

Investigation of the Stoma Individuals Home First Day Experience

Stomalı Bireylerin Evde İlk Gün Deneyimlerinin İncelenmesi

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ABSTRACT

Aim: Stoma surgery is a common treatment method for lower gastrointestinal tract cancers. However, stoma is an intervention that negatively affects the patient's whole life and requires special care. What kind of problems can patients experience on the first day after discharge, when the individual no longer has professional support? This study was conducted to answer this question.
Method: This was a phenomenological study. Eighteen individuals were interviewed using a semi-structured questionnaire to learn their experiences on the first day after hospital discharge. Individuals were informed about the study and written approval was obtained. The participants' statements were recorded via voice recorder. The data were coded and clustered to examine underlying phenomena.
Results: Our results showed that on the first day home after hospital discharge, stoma patients had difficulty changing stoma bags and needed assistance, felt fatigue, had concerns about nutrition, and had trouble sleeping due to fear the bag would burst or leak.
Conclusion: It is clear that stoma patients have many problems at home after discharge, and most of these problems were due to the patients not being adequately prepared for discharge and living at home with a stoma. Based on the results of this study, we recommend providing necessary practical training and counseling services to inpatients prior to discharge, especially in cases of interventions like stoma which cause dramatic lifestyle changes.
Keywords: Stoma care, stoma problems, first day stoma experiences at home

ÖZ

Amaç: Alt gastrointestinal sistem kanserlerinde stoma açılması sık başvurulan bir tedavi yöntemidir. Bununla birlikte stoma tüm yaşamı olumsuz etkileyen ve özellikli bakım gerektiren bir uygulamadır. Bu araştırma stomalı bireylerin evde ilk gün deneyimlerinin incelenmesi amacıyla yapıldı.
Yöntem: Bu çalışma fenomen tipte yapıldı. Etik kurul izni ve kurum çalışma izinleri alındı. Bireyler çalışma hakkında bilgilendirildi ve yazılı onamları alındı. Günlük yaşam aktiviteleri doğrultusunda 18 birey ile görüşülerek taburculuk sonrası evdeki deneyimleri öğrenildi. Görüşmelerden elde edilen ve yazıya dökülen veriler kontrol edilerek kodlanmaya başlandı; araştırmada ne gibi kümelerin olduğunu belirlemek için açık kodlama yapıldı. Daha sonra bu kümelerin kendi içlerinde alt kodlamalara gidildi ve veriler analiz edildi.
Bulgular: Bu araştırma sonucunda bireylerin taburcu olduktan sonra evde ilk gün, "torba değişiminde zorlandıkları ve yardıma gereksinim duydukları, yorgunluk ve halsizlik hissettikleri, beslenme ile ilgili kaygıları olduğu, torbanın patlaması ve sızdırması korkusu nedeniyle uyku problemleri yaşadıkları" belirlendi.
Sonuç: Bu çalışmada stomalı bireylerin taburculuk sonrası evde günlük yaşam aktiviteleri sürdürme ile ilgili birçok sorun yaşadıkları, sorunların büyük bir kısmının taburculuğa ve evdeki yaşama yeterli hazırlanamamadan kaynaklandığı belirlendi. Bu araştırma sonuçlarına dayanarak hastanede yatarak tedavi edilen bireylerde, özellikle stoma gibi yaşam biçimi değişikliklerine neden olan uygulamalarda gerekli uygulamalı eğitimlerin ve danışmanlık hizmetlerinin verilmesi önerilmektedir.
Anahtar Kelimeler: Stoma bakımı, stoma sorunları, stomalı bireylerin evde ilk günkü deneyimleri

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Introduction

Cancer is a global problem that causes increasing morbidity and mortality. It affects human life in physical, emotional, social, and psychological aspects. It is estimated that there will be a total of 19.3 million new cases of cancer in 2025 due to the growing and aging world population. Colorectal cancer has the third highest incidence among cancers worldwide. According to 2016 data published by the Ministry of Health in Turkey concerning the most common types of cancer in males, colorectal cancer followed prostate cancer as the third most common, with 24.4%. In females, it accounts for 15.3% and is third most common after thyroid cancer. Considering the fact that most colorectal cancer patients undergo stoma surgery, cancer combined with stoma opening means being faced with two conditions that adversely affect the patient's life. Colorectal cancer is treated using chemotherapy or radiotherapy. Surgical treatment is also utilized. Life expectancy and quality of life are both increasing in parallel with technological developments.[1,2]

After surgical treatment of colorectal cancer, most patients undergo stoma surgery. Stomas can be permanent or temporary.[3] Stomas are known to cause negative physical and psychological effects on human life and to adversely affect the quality of life.[4] Furthermore, it may take a long time to adapted to and accept a stoma; however, it is believed that the beginning of this process is important. The care process is complex and involves several important steps. The individual is first evaluated according to a model, and the results are used to identify that individual's problems. A plan is then made to manage these problems, and nursing interventions are implemented within that plan. Finally, the patient is followed and evaluated to determine whether the interventions made eliminated their problems. These phases come together to form the scientific nursing process. The Life Model used in many areas of nursing promotes approaching the individual and family from a holistic perspective when identifying problems and developing solutions. The "Activities of Daily Living (ADL) Model", developed in 1980 by Roper, Logan, and Tierney, constitutes the scientific process of nursing practices, both for patients and healthy individuals.[5]

Stoma surgery is a common medical practice in Turkey. It is known that for stoma patients and their families, the process of adapting to this major life change begins at home when they are discharged from the hospital, but how do these patients spend their first days (especially the first 24 hours) at home following stoma surgery, how do they change the pouches, and what kinds of physical and psychosocial problems do they experience? This study aimed to find answers to these questions and shed light on discharge training in order to eliminate these potential problems prior to discharge from the hospital.

Materials and Methods

This was a qualitative phenomenological study. The study started in November 2016 in the General Surgery B Stoma Therapy Unit of İstanbul University İstanbul Faculty of Medicine and continued until the targeted patient number was reached. Since this study the aim of this study was to use the ADL model to address all aspects of the problems encountered at home by stoma patients, we preferred the qualitative phenomenological research design because of the importance given to the participant's statements. The phenomenological approach seeks to describe experiences and understand the essence of these experiential phenomena. The research sample was identified using criterion sampling. In the criterion sampling method, cases which meet predetermined criteria are selected.[6] Furthermore, it has been stated that failure to obtain new data can be used as a criterion for discontinuing the interviews.[7] In the present study, the interviews were discontinued when the responses to the study questions became repetitive and stopped providing new data.

Inclusion criteria were:

1. Volunteering for participation in the research.
2. Knowing and speaking Turkish.
3. Having no psychiatric diseases.
4. Being over 18 years of age.
5. Having no speech or hearing disabilities.
6. Having spent the first day at home after discharge from the hospital following stoma surgery.

The stoma patients who met the inclusion criteria were informed prior to the interview about the purpose and time of the research, about the confidential nature of research data, and that they were at liberty to stop the interview and/or withdraw from the study at any time. Written consent was obtained from the participants.

The interviews were conducted in the stoma therapy unit of the İstanbul University İstanbul Medical School Hospital and lasted about 30 minutes. They were guided by a semi-structured questionnaire including 8 questions which was prepared by the researchers and then submitted to specialists for review, and then revised according to their feedback. The study was approved by the İstanbul University Clinical Research Ethics Committee (approval number: 1208). Written permission was also obtained from the Dean of İstanbul University İstanbul Faculty of Medicine Hospital and the İstanbul Faculty of Medicine Department of General Surgery. The interviews were recorded using a voice recorder and a computer was used to transcribe them and analyze sociodemographic data.

The data were evaluated using the content analysis method, which is one of the analytical methods used in qualitative research. The basic purpose of content analysis is to identify the concepts and relations that may explain the collected data.[6] The data collected through the interviews and transcribed were checked and coded. Open coding was used to determine the types of clusters obtained in the research. Responses to each question were clustered separately. These sets were subcoded within themselves and the data were analyzed.

Results

Stomas are known to adversely impact quality of life. The semi-structured questionnaire used in the interviews included the individual and medical characteristics of the study participants and 8 questions about their experiences during their first day at home after stoma surgery. The participants' statements (data) collected are presented below.

Of the 18 individuals that participated in the study, 15 were males, 9 were between the ages of 49-65 years, 9 were primary school graduates, 16 were married, 14 lived with nuclear family, and 6 were employed in the civil service.

Thirteen of the participants had colostomy, 13 had temporary stomas, and 10 individuals had their stoma location marked before the operation. The mean hospitalization time was 18 days. Ten of the participants had also received combined chemotherapy/radiotherapy.

Below are the participants' responses to the 8 items in the semi-structured questionnaire used for collecting data in this phenomenological study.

Question 1. What were your experiences on your first day at home after being discharged from the hospital?

Patient 1: (Male, 56, married, temporary stoma) "On the first day, I changed my pouch with my wife. She was afraid when she saw my wound. We were afraid our supplies would run out the first day."

Patient 5: (Male, 55, married, temporary stoma) "I was very tired when I was discharged from the hospital, my wife took care of the bag. She immediately emptied the pouch when filled up."

Patient 8: (Male, 74, married, temporary stoma) "I felt tired."

Patient 15 (Male, 24, single, temporary stoma) "A few hours after I went home I was changing the pouch and when I looked at it, I felt bad, I worried."

Patient 17: (Female, 31, married, temporary stoma) "I went home in the morning, about 12 o'clock I felt pain, severe pain…. By about 1 o'clock I was breathless from the pain. I thought it was because of what I had eaten. They told me I was free to eat anything. Nobody said that food would upset my stomach."

Patient 18: (Male, 73, married, temporary stoma) "The first day after the surgery I had difficulty standing up, there was some leakage when we changed the pouch and the adaptor. The first day we changed the stoma several times. I kept walking, I had pain from the surgery."

The statements show that both male and female stoma patients needed assistance and were dependent on others for stoma care because they felt tired and had postoperative pain.

Question 2. On your first day at home, what did you think when you looked at your stoma?

Patient 2: (Female, 46, married, temporary stoma) "I was worried and I wondered how I would live with it. How will they care for me after the operation. I felt embarrassed when I passed gas through the stoma."

Patient 6: (Male, 59, married, permanent stoma) "It was certainly a bit difficult but I said I will live with it if I have to."

Patient 11: (Male, 80, married, temporary stoma) "I thought that it will be like this from now on probably, I guess I will never get rid of it. I had no hope."

Patient 12: (Male, 69, married, permanent stoma) "The first thing I thought when I looked at it was how I would carry this pouch. The waste goes into a bag and if it leaks, it will ruin my clothes. I wondered how I would go out… I couldn't bear it sometimes. It was very difficult."

Patient 15: (Male, 24, single, temporary stoma) "Looking at the pouch makes you feel bad, you feel incomplete, physically and psychologically."

Patient 16: (Male, 30, single, temporary stoma) "I was worried about how I would empty the stoma bag and how I would change it. I read on the internet that people with stoma can empty the pouch themselves. When I was laying here (in the hospital) my mother used to empty it, but I could not ask her every time at home."

Patient 17: (Female, 31, married, temporary stoma) "Can I live like this, I wonder? My intestine was outside and I was defecating in a bag. I was a psychological wreck. I was totally hopeless."

The statements showed that male participants worried more about adequate stoma care, felt incompetent, could not get used to the stoma on the first day, and come to terms with it (experienced shock) and had adaptation problems with the stoma. The statements of individuals over 65 revealed that they disliked their appearance, feared social isolation, were afraid to go out in society, felt dirty with regard to clothes and hygiene, and felt hopeless.

Question 3. On your first day home, who did you tell you had stoma, did your family know about it or did your first day visitors know about it?

Patient 2: (Female, 46, married, temporary stoma) "My children knew it, everyone knew it. My visitors knew, too, they were all relatives anyway."

Patient 7: (Male, 51, married, permanent stoma) "My family knew it, my children and my friends knew, too."

Patient 8: (Male, 74, married, temporary stoma) "Yes, everyone in the family knew it. My brothers, my sons and daughters, everyone."

Patient 10: (Male, 60, married, temporary stoma) "My whole family knew about it. My friends knew, too."

The responses reveal that the participants did not hide their stomas from their families, and that friends and relatives were also aware of the situation.

Question 4. On your first day home, did you feel helpless because of the stoma or when you thought about the stoma (If so, what made you feel helpless?)?

Patient 1: (Male, 56, married, temporary stoma) "Actually I was afraid. I said I will learn to live with stoma if I have one. But I was a bit afraid."

Patient 3: (Female, 78, married, temporary stoma) "I never felt helpless, I was able to change it myself here."

Patient 5: (Male, 55, married, temporary stoma) "No, I never felt helpless but I could not wear trousers and had to do with tracksuits, that was a bit difficult; also, I had lost a lot of much weight and my clothes didn't fit after the operation."

Patient 9: (Male, 56, married, temporary stoma) "No, I never felt helpless. We had training about it and we were able to change it, I did not feel helpless."

Patient 15: (Male, 24, single, temporary stoma) "Not helpless, but I did feel incomplete; I was not sure about the future, the pouch may become permanent. I was very worried about that."

Patient 17: (Female, 31, married, temporary stoma) "I was worried about my children and what I would do, nobody would care for them, my children were too young."

The statements demonstrated that most of the female stoma patients felt helpless. However, most of the individuals aged 65 and over did not feel helpless on their first day. The responses revealed that most of the individuals aged 49-65 did not feel helpless; on the contrary, they felt strong. Most of the participants 18-49 years of age felt worried rather than helpless, mostly because they were afraid the stoma would become permanent.

Question 5. On your first day home, did you find it difficult to do the activities that you did before the stoma? If so, please explain (sleeping, eating, difficulty in moving, bowing for prayer, etc.).

Patient 1: (Male, 56, married, temporary stoma) "On the first day I could only sleep on my right side. I was scared to eat anything in case something bad happened. I was told to eat meat but I could not."

Patient 4: (Male, 51, married, temporary stoma) "The first night I could not sleep, I was afraid the pouch may burst, the first day I rested and did not move much."

Patient 5: (Male, 55, married, temporary stoma) "The first day I had so much pain that I could not move, I had pain where my stitches were. The first day I could not sleep in my bed, I could not eat as before, I felt full quickly. You cannot lean and bend over much, the stoma pouch adaptor was poking me and making me uncomfortable."

Patient 7: (Male, 51, married, permanent stoma) "I could not bend over and stand up much because of the pain."

Patient 12: (Male, 69, married, permanent stoma) "Of course I had difficulty. I could not move. I could not eat as before. Even getting dressed was difficult."

Patient 15: (Male, 24, single, temporary stoma) "They told me to be careful about what I ate. I could not eat like I used to. I had difficulty moving. I had difficulty bending over and getting back up. I could not sleep like I did before, I was afraid to sleep on the stoma side."

The participants indicated having difficulty with movement due to the stoma pouch and the surgery itself. Furthermore, the participants expressed having sleeping and eating problems related to the stoma.

Question 6. With whom did you care for the stoma on your first day home and what kind of support did this person provide?

Patient 3: (Female, 78, married, temporary stoma) "I did it with my younger daughter. I told her how to do it and she did everything. She prepared the equipment. I explained how and we changed it."

Patient 4: (Male, 51, married, temporary stoma) "I did it with my daughter, my wife did not want to get close to the stoma the first day and my daughters helped me. We had training before we were discharged; we had some difficulties but we managed to do it together."

Patient 9: (Male, 56, married, temporary stoma) "My wife and I handled it. We did everything together, the preparation and the changing."

Patient 14: (Male, 56, married, permanent stoma) "My wife supported me. I tried to help her, she received training from the nurse. She supported me in everything. I could not have done anything if she hadn't been there."

Patient 18: (Male, 73, married, temporary stoma) "My wife and I did it together. She helped me when changing the bag, on the first day we changed a lot, as I said. My wife always supported me."

The statements revealed that male and female stoma patients usually performed stoma care with their family members. The participants over 65 years old performed stoma maintenance with the help of a family member (spouse or daughter) and were dependent on others.

Question 7. Did you have problems with stoma care on your first day home?

Patient 1: (Male, 56, married, temporary stoma) "Yes I did. The opening of my stoma was not completely circular. My wife was unable to cut the adaptor to fit."

Patient 2: (Female, 46, married, temporary stoma) "On the first day my husband did the work, the nurses taught him how to, I did not touch it. He had difficulties."

Patient 7: (Male, 51, married, permanent stoma) "My wife knows, we were used to doing it here, so it was not difficult."

Patient 10: (Male, 60, married, temporary stoma) "No, we didn't have any difficulties. My wife learned everything here and we left the hospital."

Patient 12: (Male, 69, married, permanent stoma) "We had difficulties. My wife was anxious. She was worried because she was not sure if she could do it or if she would make mistakes. So we had difficulties. If she had learned it a bit better she would have been more comfortable."

Patient 16: (Male, 30, single, temporary stoma) "Since we stayed in the hospital for a long time, it was easy changing at home on the first day. We could not have done it if we were not experienced from the hospital, we were quite familiar with the procedure…"

Patient 17: (Female, 31, married, temporary stoma) "I had difficulties, I did not receive training, only some directions from the medical supply store, I tried to handle the rest. There were no nurses in the hospital where I had the stoma surgery and I could not receive training from anyone…"

These statements demonstrate that the participants and the family members supporting them had difficulties with stoma care. Most of the participants did not have difficulties because they and their family members had received training before being discharged from the hospital. This showed that receiving prolonged professional support helped the individuals perform stoma care on the first day at home more effectively.

Question 8. What does the stoma mean to you (punishment, fate, salvation, etc.)?

Patient 2: (Female, 46, married, temporary stoma) "This is something from God. It is fate. So I have to suffer it…"

Patient 4: (Male, 51, married, temporary stoma) "This is our fate, it was meant to be this way and now we are going through it. I am thankful, it could be even worse…"

Patient 6: (Male, 59, married, permanent stoma) "This is our fate, something from God, we have to go through it, I thank God every day…"

Patient 10: (Male, 60, married, temporary stoma) "This is fate and we have to endure it. We have no choice but to go through it…"

Patient 13: (Male, 64, married, permanent stoma) "This stoma is good for my health, this is God's will, this is my fate…"

Patient 17: (Female, 31, married, temporary stoma) "Nobody supported me. This was sent by God, this is my fate…"

The individuals' statements revealed that they consider having a stoma as their fate, as something caused by God, and most of them had a fatalist perspective. The statements also showed that the individuals considered stoma as a liberation and/or a burden.

Discussion

In this section, our findings regarding stoma patients' first day at home based on the semi-structured questionnaire are discussed in light of the literature.

When asked about their experiences on the first day at home after hospital discharge, both male and female stoma patients expressed needing care support; that is, they were dependent on others for stoma maintenance, felt tired, and had pain. As required by the health care policies of Turkey, patients may be discharged only after physiological stabilization is achieved.[8] However, in the event of surgical procedures which change the patient's way of life, it takes a longer time to adjust to this new lifestyle and adapted to physiological processes such as stoma.[9] This concept is supported by the individuals' statements as described above. Therefore, these patients should be given training and guidance to enable them to care for themselves independently, should be accompanied by a nurse on their first day at home from the hospital, and the discharge process should take into account not only their physiological condition but their level of self-sufficiency and independence as well. Fatigue and weakness is common in the early postoperative period due to reasons such as loss of blood and fluids, changes in feeding, and the magnitude of the operation. Noter and Chalmers[10] reported in a 2012 study that individuals have difficulty returning to their previous energy levels after going through surgery. The participants in this study made similar statements, with their main issues being tiredness and fatigue. Therefore, these patients would benefit from a progressive physical activity plan and the guidance of an attendant while initially following this plan. In addition, nutrition is one of the basic human needs. Nutrition is particularly important for patients who have undergone surgery involving the gastrointestinal system, and these patients should be more closely monitored with regard to nutrition. In a study conducted in 2011, Akbulut[11] determined that patients were at risk in terms of nutrition. Shaffy et al.[12] also found in a 2012 study that the patients in their study experienced problems with feeding and nutrition. The statements obtained in the presence study are consistent with the literature and indicate that patients should be given nutritional training prior to discharge. In addition, stoma patients should be monitored regularly for nutrition and weight.

When the study participants were asked what they felt when they looked at the stoma on the first day, their responses revealed that males mostly worried about how to sufficiently care for themselves, felt incompetent, found it difficult to accept the stoma on the first day (experienced shock), and had problems adapting to the stoma. Patients over 65 expressed disliking their appearance, fearing social isolation, hesitation to go out in society, feeling dirty with regard to clothes and hygiene, and feeling hopeless.

Shock is a feeling experienced by individuals who are faced with an unexpected and difficult situation.[5] Stoma surgery is an unexpected situation and alters both the patients' physiological path and their body image. After this procedure, some patients are unable to come to terms with their new state, and may become depressed and suicidal.[13] The patients' responses in our study reveal that they also experience shock in accordance with the aforementioned data. Furthermore, personal hygiene and dressing are concepts that vary depending on an individuals' culture and the social norms with which they live. Being clean and presenting a respectable outer appearance are essential both for individuals to feel self-confident, and for fulfilling their social responsibility. Stoma surgery results in lower self-respect and disturbed body perception, causing the person to feel dirty and to be more selective when dressing, which means they cannot wear what they want or they prefer oversized clothing. In that sense, it is hard for the individual to come to terms with stoma. The individuals in our study also referred to these issues. In a study conducted in 2012, Shaffy et al.[12] found that individuals had difficulties getting dressed. This study is congruent with the literature. Stoma patients should be informed about this subject, encouraged to wear clothes in which they feel more comfortable, and appropriate nursing interventions should be implemented to help them overcome these problems. Individuals should be followed after discharge until they fully adapt to the stoma and professional support should be provided during this process, especially on the first day after discharge when initial adaptation is most difficult.

When the patients were asked who they told about their stoma on the first day home, their responses revealed that they did not hide the stoma from their families, and that their relatives and friends also knew about it. Humans are social beings, which makes it imperative for us to interact with our environment and the society to which we belong. When faced with new situations, humans cope by receiving support from the group or the society it belongs to, and thus communication becomes an inescapable activity.[5] Studies have shown that stoma patients experience several problems including body perception disorder, reduced self-respect, feeling incompetent, social isolation due to fear that the stoma may leak and smell, inability to communicate with society and family, choosing to be alone, and becoming depressed.[13] It is known that such problems may also lead to the disruption of biopsychosocial integrity.[14] In a phenomenological study in 2013, Dorum[15] found that there were some people who chose to inform everyone about their stoma. Patients in a 2014 study by Alp[16] gave similar statements, stating that they did not hide the stoma and chose to inform family and close friends. The stoma patients in the present study also said that they informed their family and their close friends about their stoma, maintained communication, and asked for care support. This sustained communication can also result from the importance of the concept of family in Turkish culture and lifestyle; feelings of affection and mercy are dominant in this culture, and individuals have a humanistic approach. We believe that this open communication is important for individuals and their families, and that it is crucial for patients to maintain this open communication.

When asked whether they felt helpless on their first day home and why, most of the females indicated that they had felt helpless. However, most of the individuals aged 65 and over did not feel helpless on their first day. The responses revealed that most of the individuals aged 49-65 did not feel helpless; on the contrary, they felt strong. Most of the participants 18-49 years of age felt worried rather than helpless, mostly because they were afraid the stoma would become permanent. The statements reveal that most of the females felt helpless. The females who felt helpless did so because of their dependency and their inability to fulfill their maternal role in the family. The females who do not feel helpless were self-sufficient in performing stoma care. Also according to the statements, most of the individuals 65 years of age and older did not feel helpless on the first day. The individuals who felt helpless expressed fear of being dependent and worry about how to perform stoma care. The responses revealed that most of the individuals aged 49-65 did not feel helpless; on the contrary, they felt strong. Most of the participants 18-49 years of age felt worried rather than helpless, mostly because they were afraid the stoma would become permanent. As previously mentioned, the first question of this study concerned the patients' feelings of dependence. Dorum[15] has also determined in a phenomenological study that the patients feel helpless and dependent. In a study conducted in 2014, Alp[16] found that patients made statements such as “I fear when my family members have to go somewhere.” and “I always want someone to stay with me.” In another study by Newcombe[17] in 2016, it was reported that patients felt weak, helpless, and dependent postoperatively. In our study, we encountered more statements expressing dependence rather than helplessness. We attribute this lack of helplessness to the fact that patients motivated themselves with family support and internal motivation. Eliminating patients’ feelings of dependence which have been reported in the literature is only possible by means of nursing interventions and programs that will maximize the patients’ independence.

When asked whether they had difficulty doing the activities they had done prior to the stoma, such as sleeping, eating, being active, and bowing for prayer, the patients stated that they had difficulties with the movements due to the stoma pouch and the surgery itself. Moreover, the patients had problems sleeping and eating due to the stoma. Individuals undergoing abdominal surgery may have restricted physical activity because of procedures directly affecting the abdominal muscles. The participants in our study indicated having difficulty with movement due to the stoma pouch and the surgery. In a study in the USA conducted by Nichols[18] in 2015, it was found that stoma patients are more prone to exercise and activity restrictions, while in a qualitative study by Sun et al.[19] in 2014, patients reported being unable to perform strenuous movements and having stoma leakage when asked about their stoma-related problems. In a 2016 study by Burch[20], it was also found that patients avoided physical movement for fear of damaging the stoma pouch. Our questionnaire also evoked similar responses from the participants in our study. As stated above, movement is very important for performing daily activities and maximizing patients’ independence. Therefore, training programs should be designed to encourage stoma patients to be physically active from their first day home. Patients should be visited on their first day at home and encouraged to do specific exercises at scheduled times with the support of their families.

Sleep is another basic necessity for life. It is a fundamental need for normal individuals in order to maintain their physiological cycles. Adults should sleep for about 6-8 hours per 24-hour period in order to sustain their other activities.[5] People who do not get adequate sleep may develop various illnesses due to restlessness, stress, and sleeping disorders.

Stoma surgery causes a major change in physiological flow and results in the collection of biological waste in a pouch. It has been reported that stoma patients experience sleep disorders related to the pouch, and it is very important for these individuals to get sufficient sleep after surgery.[21] In a study conducted by Richbourg et al.[22] in 2007, it was found that 35 percent of stoma patients experienced sleeping problems and could not sleep after discharge from the hospital. On the other hand, a study by Shaffy et al.[12] revealed that 32 percent of the stoma patients had sleeping problems because, according to their statements, they feared possible leakage during their sleep. The individuals in this study made statements parallel to those reported in the literature. Precautions should be taken to avoid pouch leakage during sleep; stoma patients can be advised on the use of creams, adhesive pastes, and stabilizing belts that can help prevent leakage. Both the patients and their relatives should be trained in their use.

The concept of pain is as old as humanity itself and we have been tryin8g to define it for centuries. The most comprehensive and effective description to date was put forth by the International Association for the Study of Pain. According to this group, pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”.[23] It is known that no effective analgesia has been created yet. This is because postoperative pain is considered to be a natural consequence which has to be endured.[24] A lack of coordinated teamwork between surgeons and nurses is thought to be another factor that prevents effective analgesia. However, Chen et al.[25] reported in 2015 that pain has the same impacts in abdominal surgery and increases mortality. In a study conducted in 2016, Burch[20] reported that pain is one of the obstacles that prevent improvement in quality of life in stoma patients and that pain has adverse effects on the recovery process. In a 2015 study by Feddern et al.[26] it was reported that 30% of the research participants felt pain at the stoma site. In 2017, Näsval et al.[27] also reported that stoma patients felt pain and that this pain adversely affected quality of life. Consistent with the literature, the patients’ statements in the present study revealed that they felt pain on their first day at home and this pain negatively impacted patients in several ways, including reducing quality of sleep on the first day.

Pain has adverse effects on patients’ physiological and psychological condition. Effective, multidisciplinary pain management approaches based on both pharmacological and non-pharmacological methods should be provided for stoma patients so that they do not feel pain on their first day at home. Patients’ relatives should also be informed about this issue in order to provide a holistic approach to pain management.

When asked with whom they performed stoma care on their first day home and how they were supported, both male and female stoma patients generally said they received help from family members. Their responses revealed that those over 65 years old performed stoma care with the help of a family member (spouse or daughter) and that the individuals were dependent on this support. As mentioned previously in questions 1 and 4 of our study, patients were dependent on their family members and received support from them for stoma care on the first day at home. Dorum[15] also reported that patients received support from family members and that this support facilitated adaptation. Similarly, Alp[16] determined in a 2014 study that stoma patients received help from family members for stoma care. In a qualitative study conducted by Karaveli et al.[1] in 2014, patients reported received help from their family members when doing stoma care and that their families were the greatest source of support in this area. Thus, the patients' statements in our study were in accord with other studies in the literature.

When asked whether they had problems with stoma care on their first day home, their responses indicated that the family members who assisted in stoma care experienced difficulties while most of the patients themselves did not. Patients are continuously supported and helped during their stay at the hospital. They may feel insecure after being discharged from the hospital. They may be faced with problems such as reintegration into society and reshaping their altered lifestyle. Furthermore, they may be living in less than ideal conditions at home and have difficulties acquiring supplies needed for stoma care.[28] Therefore, it is imperative that the person have come to terms with the stoma and be completely trained in stoma care when they are discharged. Özaydın et al.[29] emphasized in their 2013 study that proper patient training may help reduce stoma complications. In 2005, Ito et al.[30] also established that receiving professional support facilitated patients' adaptation to stoma. In a study by Dorum[15] in 2013, it was reported that the individuals had professional support and that this support was important in stoma care. The patients in their study stated that this training helped them feel more comfortable at home. The statements from patients in the present study were in parallel with the literature. Patients and their families must complete their training and be fully knowledgeable about stoma care and maintenance before returning home. Furthermore, as mentioned above, patient discharge must be based on the degree of patient independence, and patient discharge protocols must be designed accordingly so that patients will feel better on their first day at home and the subsequent processes may be better managed.

When asked what the stoma meant to them in terms of concepts like punishment, fate, and liberation, the individuals stated that they considered stoma their fate, that it was God's will, and most of them had a fatalistic perspective. However, some individuals also assigned such meanings as liberation and burden to their stoma. Individuals may develop many mechanisms to accept and cope with their illnesses. A stoma results in many social, economical, and physiological changes in people's lives, and undergoing stoma surgery and living with a stoma is difficult for many patients to accept.[15] However, patients may improve their health through positive thinking rather than denying the illness based on their beliefs.[31] In a study performed in 2013, Dorum[15] observed that the patients considered stoma as their fate, accepted it, resigned themselves to the situation, considered it their destiny, and adapted to life with stoma without feeling resentment or denial. On the other hand, Dabirian et al.[32] believed that the reason why the patients in their 2011 study took a fatalistic approach to their stomas and made no changes in their lives may be attributed to being Muslim and believing in God. Similar statements were also made by the participants in our study. Muslims have a strong belief in God, and resisting one's fate is incongruous with Muslim beliefs. The Turkish population is known to be predominantly Muslim. The patients in our study also considered stoma their fate. However, contrary to the fatalistic statements similar to the other studies, the patients between 18 and 49 years old in our study expressed a different point of view. This suggests that how a person perceives and comes to terms with stoma strongly depends on their age. In other words, this fatalistic perspective changes as age increases, which may be the result of cultural differences between generations in Turkish society. In that sense, the nurses should take factors such as age, gender, culture, and belief systems of patients into consideration when planning their care. In conclusion, we determined that on their first day home, stoma patients found it difficult to change the pouch and needed help, were worried about the appearance of stoma region, felt fatigue and weakness, and were concerned about nutrition. On the other hand, they were cared for by their families and by the people who provided care support and felt free talking about the matter, but they were afraid of being unable to find stoma maintenance supplies and being dependent on others, and they had problems sleeping because of the fear that the pouch may burst or leak. It was also noted that on the first day, patients had pain, were not knowledgeable about nutrition and what they should or should not eat, had difficulty with physical movement due to the stoma pouch and the surgery, and considered stoma as their fate. Based on the findings obtained from this study, we make the following recommendations:

Because patients and their relatives had difficulties with stoma care on their first day at home, they should be trained extensively in this matter prior to discharge, and the patient should be provided nursing support on the first day home. Secondly, discharge decisions should be based on how independent the person is with regard to self-care, and discharged individuals should be regularly subjected to nutritional checks to ensure their diet at home is as regular and balanced as it was in the hospital. Moreover, more effective analgesia should be provided against any expected pain, since patients have pains on their first day at home. Finally, similar studies should be conducted with stoma patients who have been treated in different health care centers.

Ethics

Ethics Committee Approval: The study was approved by the İstanbul University Clinical Research Ethics Committee (approval number: 1208).

Informed Consent: Informed consent form has been obtained from all the participating individuals.

Peer-review: Externally and internally peer-reviewed.

Authorship Contributions

Concept: B.K., F.E.A., Design: B.K., F.E.A., Data Collection or Processing: B.K., F.E.A., Analysis or Interpretation: F.E.A., B.K., Literature Search: B.K., F.E.A., Writing: B.K., F.E.A.

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