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"My Stoma And Me Run Away From Life With My Concerns": A Qualitative Study

"Stomam İle Birlikte Yaşamın İçinden Kaygılarımla Kaçıyorum": Nitel Bir Çalışma

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ABSTRACT

The aim of the study is to determine the perceptions and lived experiences of persons with a stoma. The study group of this qualitative study consisted of 14 persons with a stoma (ileostomy and colostomy) determined with the purposive sampling method. The data were collected using a semi-structured interview method and evaluated with the phenomenological analysis method. Three main themes emerged in the study; *"unmet information needs"*, *"I am dependent and anxious"*, and *"the transition from one life to another"*. Most of the persons with a stoma reported that preoperative information was not sufficient, and therefore they encountered difficulties in their later lives. Some participants think that the stoma has ended their independence, negatively affects their self-confidence and is a burden. It is necessary to provide adequate preoperative information to individuals who will have a stoma to ensure success in the process. This study provides comprehensive information about how a stoma and the physiological problems it causes affect persons' lives and is believed to contribute to the planning and implementation of holistic care.

Keywords: Life, phenomenology, qualitative research, stoma, stoma care nurse.

ÖZ

Araştırmanın amacı; stoması olan bireylerin stoma ile yaşamaya ilişkin algı ve deneyimlerini belirlemektir. Nitel türde olan olan araştırmanın çalışma grubunu amaçlı örneklem yöntemine göre seçilmiş stoması olan (ileostomi ve kolostomi) 14 hasta oluşturdu. Veriler yarı yapılandırılmış görüşme yöntemi ile toplandı ve fenomenolojik analiz yöntemi ile değerlendirildi. Araştırmanın sonucunda *"karşılanmayan bilgi gereksinimi"*, *"bağımlı ve kaygılıyım"* ve *"bir hayattan bir başkasına geçiş"* olmak üzere üç ana tema oluşturuldu. Stoması olan hastaların çoğunluğunun ameliyat öncesi yeterli bilgi alamadıkları, bu nedenle sonraki yaşamlarında zorluklar yaşadıkları belirlendi. Katılımcıların bazılarının stoma nedeniyle yaşamlarındaki bağımsızlıklarının sona erdiğini düşündükleri, stomanın öz güvenlerini olumsuz etkilediği ve stomayı kendilerine bir yük olarak gördükleri saptandı. Stoma açılacak bireylere ameliyat öncesi bireylere yeterli bilginin verilmesi süreç açısından önem taşımaktadır. Bu çalışmada stomanın kendisi ve neden olduğu fizyolojik sorunların hastaların yaşamlarını nasıl etkilediğine ilişkin kapsamlı bilgi edinildi. Bu bilgi bütüncül bakımın planlanması ve gerçekleştirilmesine katkı sağlayacaktır.

Anahtar kelimeler: Fenomoloji, nitel araştırma, stoma, stoma bakım hemşiresi, yaşam.

Ethical approval was obtained from the Ege University Faculty of Medicine Clinical Research Ethics Committee, where the study was conducted. This study was presented as an oral presentation at the International Congress of Ethics in Nursing Practices held in Izmir on 11-12 September 2017.

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INTRODUCTION

Colorectal carcinoma is the third most common cancer type and the second leading cause of mortality worldwide, and approximately 1.931.590 million new cancer cases were reported in 2020. [1] According to the 2018 data of the Ministry of Health in Turkey, colorectal cancer ranks third among all cancer types with 8.0% in women and 9.9% in men. [2]

Surgery, radiotherapy, or chemotherapy is used in the treatment of colorectal cancers. Surgical treatment includes resection of the tumor with end-to-end anastomosis or colostomy. Colostomies can also be opened to protect the anastomosis line or in cases where the anus is not/cannot be used depending on the type of surgery. [3,4]

It is aimed to increase the quality of life of individuals with a stoma. However, individuals with a stoma may have physical, psychosocial, emotional, and sexual problems, etc. [5,6] Frequently encountered physical problems due to colostomy are gas, constipation, fatigue, loss of appetite, parastomal hernias, stoma dermatitis, and stoma strangulation. [7-9]

Individuals with a stoma feel an intense threat to their physical integrity and self-concept with the change in body image. It is difficult for many to discuss their sexual feelings, especially after body image change. [10] After colorectal surgery, persons may experience anxiety, marital problems, introversion due to the fear that the ostomy will cause leakage and odor, desire to be alone, social isolation and, depression, [6, 11] Such persons should be evaluated ethically, especially in terms of informing and autonomy. [12]

It is important to understand the emotions and challenges faced by patients with stoma. Nursing interventions in the care process of patients with stoma aim to adapt individuals to life with stoma quickly. The first important stage for a patient is to agree for artificial anus. At this time nurse supports patient and his family in a psychological way, giving tips and advice at the same time. It is crucial for patient's cognitive, motivating and information sphere. It helps patient to accept his body after changes, with unusual place of expelling a stool. Therefore, nurses should be able to empathize with patients with stoma.

Identifying the problems faced by persons with a stoma will contribute to setting a roadmap for the solution of these problems. Thus, the treatment and care of these persons can be provided more holistically following ethical principles.

Aim: The aim of this stıdy to obtain comprehensive information about the lived experiences of individuals with a stoma and determine how they perceived life.

Problem Phrase: The problem phrase of the study; “*How do individuals with a stoma perceive their stoma and living with it?”* and *“How does the stoma affect the daily lives of individuals?”*

MATERIAL and METHODS

Study Design

The study was conducted in an interpretative phenomenological design. Interpretive phenomenology focuses on what people imply about their daily life experiences. [13] According to Heidegger, the representative of interpretative phenomenology [14], phenomenological inquiry should focus on the individual relationships of people within their life experiences.

Study Sample

The study group of the study consisted of persons followed in the stoma therapy unit of a university hospital in October-November 2014. The criterion sampling method, one of the purposeful sampling methods, was used in the study. The inclusion criteria were being 18 and over, speaking and understanding Turkish, and having a stoma opened for the first time (ileostomy and colostomy) in the last three years due to malignancy. Those with a psychiatric disorder requiring treatment were excluded from the sample.

In qualitative research, sample saturation is reached when statements and processes start to repeat. [15] Accordingly, data collection in this study was continued until the statements and processes that could be the answer to the study question began to repeat. The study group consisted of 14 persons fulfilling the inclusion criteria. The guidelines for Consolidated Criteria For Reporting Qualitative Research (COREQ) checklist was followed.

Data Collection Tools

The data were collected using the person descriptive information form and a semi-structured interview form.

The person descriptive information form

The form includes nine questions regarding the sociodemographic and clinical information of persons (age, education level, occupation, marital status, elapsed time after surgery, type of surgery, the person's state of being informed about the surgery and marking, and type of stoma).

The semi-structured interview form

It consists of four open-ended questions developed to determine the perceptions of the participants about living with a stoma using the relevant literature. [16-18] The questions in the form are as follows:

- What does your stoma mean to you?
- What do you think about your stoma right now?
- How has a stoma affected your daily life (nutrition, clothing, work-life, travel, and sleep)?
- How has a stoma affected your relationships?

Data Collection

Patients followed by a stomatherapy nurse came to the hospital for routine control. The participants were informed about the purpose of the study and the audio recording by the fifth researcher, who is a stoma therapy nurse in a room suitable for interviews in the stoma-therapy unit. Both verbal and written consent was obtained from the participants, indicating their voluntary aggrement to participate in the study. Each participant was interviewed face-to-face. The open-ended questions previously created by the researchers were asked by the fifth researcher, the stoma therapy nurse, and the answers were recorded with a voice recorder.

The average of the interviews is approximately 32 minutes. The interviews were terminated when the data began to repeat.

Data Analysis

The phenomenological data analysis process suggested by Moustakas was used in the analysis of the data. [19] The approach includes (a) *identifying remarkable expressions,* (b) *grouping common expressions,* (c) *theming sets of meanings,* (d) *creating structural and textural descriptions,* and (e) *combining structural and textural* descriptions. [13]

For the phenomenological data analysis in our study, firstly, each sentence said by the participant was numbered, then repetitive sentences in the participant's expressions were determined, and irrelevant sentences were removed (first stage). After this refinement, the expressions were grouped into sets of meanings (second stage). In the next stage, the grouped meaning clusters were gathered under a theme (third stage).

In the next stage, textural and structural descriptions were separated for each participant (fourth stage). In the final stage, the data set for all participants was organized in the same way for each participant, and common groupings were created (fifth stage). Following the first draft report, including more specific descriptions and long quotations from the participants, the second draft report, in which we also included our comments, covered the presentation of the research findings. [20]

Rigour and Trustworthiness

The principles of credibility, transferability, consistency and confirmability were used to ensure the validity and reliability of the research. The fifth researcher, the stomatherapy nurse, had an in-depth interview with the participants. Thus, long-term interaction was ensured. The adequacy of the answers obtained from the research was clearly presented to the reader in the findings section (depth-oriented data collection). The researchers took a critical look at all the processes from data collection to data writing at every stage of the research and gave each other feedback (expert review). The concepts and themes that emerged from the raw data were conveyed to the reader in a rearranged manner, as faithfully as possible to the nature of the data. All participants were treated similarly/consistently in the collection and analysis of research data. The researchers compared their results with the raw data to see if the confirmation mechanism worked. All data is stored for review when necessary.

Ethical Approval

Ethics committee approval was obtained from the non-interventional clinical research ethics committee of a university to conduct the study. Each participant was informed about the purpose of the study and that the interview would be recorded with a voice recorder, and their informed consent was obtained.

Limitations

The main identified limitation of the study is that the sample consists of persons who have had a stoma in the last three years because the prolongation of the time after the stoma was opened can also change the compliance status of the persons. The stoma acceptance status of persons with a permanent and temporary stoma may be different. Therefore, the fact that the sample included both groups can be considered a limitation. However, the study includes the views of both groups that can be a strength in terms of bias and diversity. The study sample were persons with cancer diagnoses. Having a stoma due to cancer may also have affected individuals' approaches to the stoma. Therefore, the results cannot be generalized to those whose stoma was opened for non-cancerous reasons.

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RESULTS AND DISCUSSION

The mean age of the participants, aged 21-72, was 51.0 (SD±17.03). 64.3% (n=9) of the participants were male, 28.6% (n=4) were high school graduates, 85.7% (n=12) were married, 50% (n=7) were employed, 64.3% (n=9) had a permanent stoma. The characteristics of the participants are shown in Table 1:

Table 1. Characteristics of the Participants

Participants	Age	Sex	Type of stoma according to their purpose
1	34	Female	Temporary
2	21	Female	Permanent
3	54	Female	Temporary
4	72	Male	Permanent
5	35	Male	Temporary
6	60	Female	Permanent
7	68	Male	Temporary
8	72	Male	Permanent
9	65	Male	Temporary
10	39	Male	Permanent
11	47	Female	Permanent
12	28	Male	Permanent
13	63	Male	Permanent
14	57	Male	Permanent

The three main and four sub-themes emerging from the analysis are as follows (Table 2):

Table 2. The Main and Sub-themes

Unmet Information Needs	I Am Dependent And Anxious	The Transition From One Life To Another
		My social life ended because of the fear of getting gassy *I can't dress the way I used to* *The stoma alienated me from sex* *My work life is over*

Unmet Information Needs

Being informed about treatment and care can offer individuals the opportunity to make choices that are more appropriate for them. Failure to inform about the disease or the prognosis of the disease or giving wrong/missing information to the persons with the intention of not upsetting or being more beneficial can, unfortunately, lead to violations of the persons' knowledge, decision-making about their bodies, and the dignity of private life. In addition, hiding information may lead to the persons' inability to comply with the treatment. The majority of persons with a stoma (n=9) reported that they were not given any information or the information given was missing.

> *"I didn't know anything. They said I had cancer and operated on me. They did not ask my opinion when determining the stoma site. I think that was the biggest mistake. My surgery site is wrong. My stoma is just below my belly button. That's why no matter how firmly I insert the adapter there is always a leak." (7th Participant)*

> *"I think I was not given enough information, unfortunately, I thought that all of my bowels would be left out, and I was extremely scared." (6th Participant)*

> *"I would have been more comfortable if they had taken my opinion on where to put the bag because it is exactly where the belt is attached. If it were anywhere else, my bag wouldn't be affected when I was wearing pants." (8th Participant)*

Some persons expressed that they experienced anxiety because they misunderstood the information given.

> *"Before the surgery, when I was told that I would be put on a bag, such an exaggerated thing came to my mind: a big garbage bag came to my mind. I was thinking how I would carry this bag on my back, how it would work." (9th Participant)*

I Am Dependent And Anxious

The stoma, which is opened to prolong the life of the persons, increase their quality of life, and enable them to continue their previous lives, can be physically and psychosocially challenging for them. Although some participants (n=6) have different stoma-related reasons, they experience similar fear and anxiety and see the stoma as a burden on themselves.

> *"There were times when I couldn't sleep until the morning, worrying if the bag would overflow. As a result, my family was also worried about why I wasn't sleeping." (11th Participant)*

> *"I prefer to sleep on my right side while sleeping. My bag is on my left, and I am afraid that I will have a discharge. It was very difficult to overcome the fear that something would happen to my stoma. I used to wake up every*

> *half hour from sleep." (13th Participant)*

> *"Using a bag is something really difficult. Before the operation, of course, I did not have such a workload. After the surgery, my workload increased." (5th Participant)*

Some persons (n=5) perceived life with a stoma as something that made them dependent on someone else. For this reason, the stoma meant the end of freedom, individuality, and a life that belonged to them.

> *"My life is over. I can't go anywhere without my wife or daughter. I cannot do anything physically." (7th Participant)*

> *"My psychology is terrible, I always depend on my relatives. I want to be free (crying). My illness has overtaken my individuality. My relatives see my bag as a disease. I can't tell anyone what I'm thinking." (2th Participant)*

The change caused by the stoma in their appearance negatively affected the persons' body images and self-esteem.

> *"I honestly don't like myself anymore because of my bag. My self-confidence was shaken. I don't see the bag something my own. I often have the feeling that I am carrying something that does not belong to me." (1th Participant)*

> *"I couldn't adopt my stoma. The shape of my stomach has changed. I don't like my surgery site at all. It makes me suffer." (2th Participant)*

Some participants (n=4) stated that they could get used to the stoma over time and could accept it.

> *"At first, I felt sorry and angry with myself. But now I have become friends with my bag." (3th Participant)*

> *"If we want to live, we must accept the bag." (4th Participant)*

The Transition From One Life To Another

As a result of the evaluation of the persons' experiences with a stoma, the sub-themes of "*My social life ended because of the fear of gas*", "*I can't dress the way I used to", "The stoma alienated me from sex", and "My work life is over."*

My social life ended because of the fear of getting gassy

Individuals with stoma experience less contact with close friends and relatives, a decrease in social activities, and social isolation. Individuals may resort to social isolation so that the stoma is not noticed by other people. Most persons (n=11) stated that they limited their social life due to their anxiety depending on the involuntary gas/stool discharge and embarrassment.

> *"Sometimes I go to visit someone, the bag can fill up when I least expect it. I feel so panicked. Then I have anxiety about how to empty it. I'm worried about leaks. Sometimes when I'm in public I can get gassy and feel embarrassed." (5th Participant)*

> *"It restricted my movements. It restricted my home visits and travels. I've only been to places with friendly people. I was worried about what they would think if I changed bags." (8th Participant)*

Uncontrolled stool and gassing anxiety cause change not only in the social life of the persons but also in their eating patterns. It was determined that most of the persons (n=9) avoided watery foods, did not eat late or avoided gas-producing foods because of this anxiety. In fact, the methods used by persons are those recommended by healthcare professionals. However, the persons described the change in their eating habits as a factor that limited their lives.

> *"When I go out in public, when I go shopping, I pay more attention to what I eat and drink. For example, I stay away from foods that may cause it, so that I do not have gas and experience embarrassment." (14th Participant)*

> *"Getting gassy makes me very nervous. One day before going out, I start not consuming onions, garlic, milk, and carbonated drinks." (1th Participant)*

> *"...I go hungry when I go to a place." (5th Participant)*

The involuntary/uncontrolled gassing anxiety experienced by one of the persons regarding the stoma could prevent him from performing prayers.

> *"Sometimes I want to go to Friday prayers, but I hesitate. I don't know, you are in a mosque, you are in a place of worship, those who know can understand my situation, but those who do not may react, so I am very hesitant." (8th Participant)*

I can't dress the way I used to

The fact that persons have stomas may lead them to hide this situation and may cause a change in dressing style. Most of the participants (n=10) wanted to hide it, so they chose loose clothing or covered it.

> *"I often wear shirts. But I also wear a vest over it so that it won't be visible when my bag is full." (12th Participant)*

> *"In terms of clothing, for example, when I went to the sea, I used to be able to wear a swimsuit. I have a bag now, I prefer long clothes." (2th Participant)*

> *"I can't wear a belt, I wear it above my belly button, I pull my pants up, but this time my trouser legs are getting shorter. I become like a cattle herder, I have to walk around like this among the people." (7th Participant)*

> *"I want to cover it up with a shawl or something in very crowded environments, for example, when I go to a wedding." (11th Participant)*

The stoma alienated me from sex

The concept of body image, which is the physical dimension of the self, includes the perception and experiences of the individual regarding his/her appearance, health, physical skills, and sexuality. Changes in physical appearance and physiological problems can negatively affect the individual's body image perception, making the individual feel unattractive and thus negatively affecting sexual life. Most of the persons (n=8) were worried that the stoma would disturb their sexual partners. This anxiety caused them to distance themselves from their partners or to find a new partner.

> *"The stoma, unfortunately, became a barrier between me and my spouse. I still haven't been able to get over this. It feels like if his/her hand touches my stoma during our sexual intercourse, s/he will startle, withdraw himself/herself, and won't accept me. My relationship with my spouse cannot be naturalized because of this. It's a problem I created, but my spouse never brings it up, s/he says s/he doesn't care about it." (1th Participant)*

> *"I get very tense, especially when I sit and talk to the opposite sex. I wonder, what would s/he think, if s/he noticed." (10th Participant)*

> *"I was married before the surgery... My spouse wasn't near me much during the surgery*

> *process. I felt that my spouse was getting away from me during this process, and we broke up afterward." (2th Participant)*

My work life is over

Postoperative persons did not only experience physiological problems. Some persons (n=4) had problems in their professional life and had to leave their jobs.

> *"I had problems with my job. As I am a medical representative, I could not visit physicians in the hospital." (10th Participant)*

> *"I haven't been able to do anything for 17 months. I'm a long-distance driver, but I haven't even traveled 30 km after the surgery. I cannot do anything physically." (14th Participant)*

Having stoma affects individuals not only physiologically but also psychologically and socially. Although much has been written about the psychosocial problems of individuals with stoma, there is paucity in the literature about qualitative studies that provide detailed information on how a stoma affects an individual's life.

It is reported that with adequate and planned information before the surgery, the stress experienced by the persons can be minimized, postoperative complications can be reduced, and persons can better cope with the treatment process. [21] It is essential to inform the persons about the surgeries that may cause a change in lifestyle and appearance after the surgery. This intervention, which prepares the person for the operation cognitively and mentally before the operation, is also pivotal in terms of fulfilling the obligation of enlightenment. [22] Our study revealed that most of the participants did not receive sufficient information before the operation, and those who were given information experienced anxiety due to misperception. Çevik et al. (2020) found that 62.0% of the persons were informed about ostomy opening. [23]

Some of the participants perceived the stoma as the end of their life, being dependent on someone else, and could not accept it. The change in appearance caused by the stoma negatively affected the persons' body image and thus their self-esteem, and they considered the stoma a burden on themselves. However, it was noted that some participants were able to get used to the stoma over time and accept it. In the study by Ceylan & Vural (2017), some participants were ashamed of their stomas but they accepted their stomas despite this negative perception they experienced after the surgery. [18]

Studies have concluded that stoma negatively affects the body image of persons, but as time passes, some of them can adopt it. [24-26] A stoma can cause individuals to experience fear and anxiety. [27] They often worry about uncontrolled gas/odor and leakage. Some of the participants in our study experienced intense anxiety due to different reasons. Consistent with this result, relevant studies show that individuals with stoma experience pain and anxiety about leakage from the stoma. [7, 28-30] In the study by Kara and Eti Aslan (2017), persons with a stoma had difficulty in sleeping because of the fear that the bag would burst or leak. [31]

Persons in this group avoid social relations because of the concern that the people around will notice the bag or hear involuntary gas. In our study, most of the persons avoided social relations and did not want to be in social environments due to the embarrassment they felt depending on the stoma and involuntary gas/stool discharge. Aktaş and Gocmen Baykara (2015) found that more than half of the persons in the study avoided social activities and stayed away from their friends. [25] They may experience the anxiety of being noticed by others and gassing. [7, 32] In our study, most of the persons used methods such as not eating watery food, eating late, or avoiding gas-producing foods to get rid of this anxiety.

In our study, the involuntary/uncontrolled gas outflow anxiety experienced by one of the persons prevents her/him from performing prayers. Due to the involuntary discharge of gas and stool, individuals may experience anxiety while performing their prayers and may not want to worship. In the study of Cengiz and Bahar (2017), one of the participants stated that s/he could not pray when her/his bag was full, and s/he was upset about it. [33] The Presidency of Religious Affairs of Turkey states that gas or stool coming out of the stoma bag during worship does not prevent worship. [34, 35]

Individuals dissatisfied with their appearance due to stoma may also change their clothing style to hide it, which means a new situation to adapt. Our study demonstrated that most participants wanted to hide and close the stoma by choosing loose fittings and covering the stoma. Studies show that individuals with a stoma change their clothing styles to hide their stomas. [36-38] We think that the change in the dressing styles of individuals may be related to hiding their negative body image experiences from the social environment.

Not only are the body image of individuals with a stoma but also their sexual lives negatively affected. [39] The majority of persons were concerned that the stoma would disturb their sexual partners, which caused them to distance themselves from their existing partners and not be able to find a new one. In a systematic review, Ayaz-Alkaya (2019) stated that women with a stoma have sexual reluctance problems. [24]

A stoma not only creates physical difficulties in individuals but also negatively affects the work-life of individuals. Individuals may have to leave or change jobs due to both hiding the negative body image caused by the stoma and their anxiety about the places where they can clean the stoma. [40] In our study, some of the persons had problems in their professional life and had to leave their jobs. Alwi and Asrizal (2018) stated in their study that many participants left their jobs due to colostomy. [16]

CONCLUSIONS AND SUGGESTIONS

It may be challenging for persons whose lifestyles or conditions have changed after some medical interventions to assess their condition accurately. Therefore, it is important to provide medical and psychological support for them and continue providing accurate information. Considering that persons can accept this situation or get used to it, healthcare professionals should not ignore psychosocial support for persons and should holistically approach persons.

Supporting the areas of expertise such as stoma care nursing, which helps to establish the bridge between the old habits of persons with a stoma and the new process, and completing the holistic approach by involving them in the process are significant steps to be taken.

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