

# Turkish adolescents' experiences of living with a stoma: a qualitative study

Experiências de adolescentes turcos de viver com ostomia: um estudo qualitativo

Experiencias de adolescentes turcos que viven con ostomía: un estudio cualitativo

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## Abstract

**Objective:** This study's purpose was to investigate the experiences of Turkish adolescents with stoma in greater depth.

**Methods:** This is qualitative, hermeneutic phenomenological study. The study population consisted of 11 adolescents with stoma aged 12-21 years, in Turkey. Adolescents took part in semi-structured interviews consisting of open-ended questions about their experiences about stoma. Data were collected between January-May 2019.

**Results:** Forty-six significant statements were extracted and clustered in seven themes. The themes were, discomfort, concealing the stoma, changed body image, protective social environment, praying experiences, experienced problems about stoma bag and stoma care, altered future plans.

**Conclusions:** The findings of the study identified a number of challenges in the life for adolescent with ostomy. The results can be helpful for the health care providers to support their adolescent patients with ostomy. In addition, these findings can be base data to conduct future studies to improve quality of life of the adolescents with ostomy.

## Resumo

**Objetivo:** O objetivo deste estudo foi investigar em profundidade as experiências de adolescentes turcos vivendo com ostomia.

**Métodos:** Este é um estudo fenomenológico hermenêutico qualitativo. A população do estudo foi composta por 11 adolescentes ostomizados da Turquia, com idades entre 12 e 21 anos. Os adolescentes participaram de entrevistas semiestruturadas com perguntas abertas sobre suas experiências com a ostomia. Os dados foram coletados entre janeiro e maio de 2019.

**Resultados:** Quarenta e seis afirmações significativas foram extraídas e agrupadas em sete temas. Os temas foram: desconforto, ocultação da ostomia, imagem corporal alterada, ambiente social protetor, experiências de oração, problemas vivenciados com a bolsa de colostomia e cuidados com ela, planos futuros alterados.

**Conclusão:** Os resultados do estudo identificaram uma série de desafios na vida dos adolescentes com ostomia. Os resultados podem ser úteis para os profissionais de saúde apoiarem seus pacientes adolescentes com ostomia. Além disso, esses achados podem servir de base para a realização de estudos futuros para melhorar a qualidade de vida dos adolescentes ostomizados.

## Resumen

**Objetivo:** El objetivo de este estudio fue el de investigar en profundidad las experiencias de adolescentes turcos que viven con ostomía.

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**Conflicts to interest:** none to declare.

**Métodos:** Este es un estudio fenomenológico hermenéutico cualitativo. La población objeto del estudio estuvo compuesta por 11 adolescentes ostomizados de Turquía, con edades entre los 12 y los 21 años. Los adolescentes participaron de entrevistas semiestructuradas con preguntas abiertas sobre sus experiencias con la ostomía. Los datos fueron recopilados entre enero y mayo de 2019.

**Resultados:** Cuarenta y seis afirmaciones significativas fueron extraídas y agrupadas en siete temas. Los temas fueron: incomodidad, ocultación de la ostomía, imagen corporal alterada, ambiente social protector, experiencias de oración, problemas vividos con la bolsa de colostomía y sus cuidados, planes futuros alterados.

**Conclusión:** Los resultados del estudio identificaron una serie de desafíos en la vida de los adolescentes con ostomía. Los resultados pueden ser de utilidad para que los profesionales de salud les brinden apoyo a sus pacientes adolescentes con ostomía. Además, esos hallazgos pueden servir de base para la realización de estudios futuros para la mejora de la calidad de vida de los adolescentes ostomizados.

## Introduction

Stomas are indicated in several disease processes including malignancy, inflammatory bowel disease, neurologic problems, urologic disease, traumatic injury, and diverticulitis.<sup>(1)</sup> Various studies have focused on the physiological, economic, and psychological burdens of adults living with stoma, such as their physical complications, decreased sexual lives, sleep disturbances, and fatigue, in addition to deteriorations in body image, social lives, and working conditions, as well as social issues associated with all of these.<sup>(2-5)</sup>

Adolescents may have ostomy due to congenital conditions or acquired diseases such as anorectal malformation, Hirschsprung's Disease, intestinal perforation, cancer, inflammatory bowel disease.<sup>(6)</sup> Specific developmental issues emerge during the period from adolescence through young adulthood (i.e., autonomy, relationships). As some youths have difficulty achieving all of them flawlessly, having a chronic illness represents an additional hurdle.<sup>(7)</sup> Dealing with stoma surgery during adolescence compounds challenges already associated with this life phase. However, the literature focusing on adolescents with stoma is currently insufficient because four study was found on this subject and these studies were not published recently and one of those was designed retrospectively.<sup>(8-11)</sup>

A study of adolescents with stoma was conducted by Erwin-Toth (1999), whereby the problems faced by adults, who had undergone stoma surgery between the ages of 6-12 years, were evaluated retrospectively. According to the results, the adults stated that they had experienced difficulties during their adolescent period such as; achieving a normal quality of life while managing their stoma at school; additionally, they stated that they had body image

problems and felt anger, shame, and depression.<sup>(8)</sup> Another study conducted by Nicholas et al. (2008), analyzed the experiences of adolescents living with an ostomy or a J-pouch from the ages of 13 to 19 years. In this study, body intrusion, body image changes, decreased independence, secrecy around the ostomy, adjustments over time, challenges for the family, and strategies for constructively moving forward were identified as themes on the challenges the adolescents faced.<sup>(9)</sup> Likewise, a qualitative study by Savard and Woodgate (2009) among 6 young adults with stoma, aged 19-24years, found that they had experienced negative emotions, such as embarrassment, feeling different, frustration, and worry, as well as a sense of restriction, loss of control, and pain.<sup>(10)</sup> Results of another qualitative research on adolescents with stoma, showed that the pouches had negative physical and social effects on peoples' lives.<sup>(11)</sup>

Stoma experiences may vary according to an individual's social and cultural characteristics.<sup>(12,13)</sup> For example, there are no studies on the experiences of adolescents with stoma specifically in the Turkish culture, where the majority is of the Muslim faith.

In the Islamic religion, five daily prayers are prescribed and for each, the devotee must be in a state of ritual purity entered into through physical ablution. This state must be maintained throughout the duration of each prayer (5-10 min) or the prayer is considered invalidated. Bodily functions including voiding and passing flatus or faeces all necessitate repeat ablution.<sup>(14)</sup> This may be a reason for the significantly lower quality of life reported by Muslim patients following stoma surgery in comparison to non-Muslims.<sup>(15)</sup> Therefore, this study's purpose was to investigate the experiences of Turkish adolescents with stoma in greater depth.

## Methods

In order to explore adolescent's experiences with the stoma, a qualitative, hermeneutic phenomenological study was designed. Hermeneutic phenomenology is a special kind of phenomenological interpretation, designed to unveil otherwise concealed meanings in the phenomena. This approach was chosen because phenomenological-hermeneutic approach is essentially a philosophy of the nature of understanding a particular phenomenon and the scientific interpretation of phenomena appearing in text or written word.<sup>(16,17)</sup>

Rather than age 10–19 years, a definition of 10–24 years corresponds more closely to adolescent growth and popular understandings of this life phase because adolescence encompasses elements of biological growth and major social role transitions, both of which have changed in the past century.<sup>(18)</sup> The study sample included 11 adolescents with stoma who were identified using a purposive, homogeneous sampling method. Inclusion criteria were: i) have had a colostomy, ileostomy, or urostomy for at least two months, ii) aged 10–24 years old, iii) not hospitalized at the time of data collection, iv) being able to speak and understand Turkish, v) the adolescent and his/her family agreed to participate, and vi) having no diagnosed mental disorders that may interfere with the interviews.

Data were collected between January–May 2019, by using in-depth interviews. Data were collected through either face-to-face (2 participants) or telephonic (9 participants) interviews, according to the preferences of the participants.<sup>(19)</sup> Face to face interviews were carried out the researchers' office room at university and telephonic interviews were carried out in adolescents' home. Because there is not any formal data record of adolescent with stoma in Turkey, the contact information of the participants, and their families, was obtained from the records of two companies selling stoma materials. The adolescents' parents was called by phone by the researchers. The purpose and content of the study were explained to each persons. First, signed informed consent forms were received then the interviews being arranged with the adolescents

who had agreed to participate in the study by the researchers. Interviews were conducted at suitable times for both the participants and researchers, and were done once with each adolescent. All interviews with the participants were conducted by two researchers. The interviews were recorded using a voice recorder after obtaining written permission from the participants and their parents. The length of interviews varied from 20 to 60 minutes. Before starting each interview, the "Individuals with stoma identification form" was filled out by the participants, with interviews being conducted according to the "Semi-structured interview format."

Simultaneously, attention was paid to the environment of the face-to-face interviews. The physical environment was clean, pleasant smelling, airy, kept at a suitable temperature, comfortable, and calm. In the interview environment, mutual seating arrangements were organized to enable appropriate face-to-face communications, with water and napkins also being provided. During the phone calls, the adolescents were asked to be in an environment where in they could speak alone and comfortably. All the interviews were conducted without adolescent's parents' presence. The data collection was terminated based on the saturation of data (i.e. receiving no new information, receiving repeated information, and when no further meaning unit is available).

### Data collection tools

- **Individuals with stoma identification form:** This form was created by researchers of this study after reviewing the corresponding literature.<sup>(8,9,11,20)</sup> This form has 2 sections and consists of 14 questions overall. The first section, composed of 8 questions, addresses personal information. The second section, consisting of 6 questions, was designed to assess the stoma characteristics of the individuals.
- **Semi-structured interview form:** This form was created by the researchers aiming to discover experiences of the adolescents with stoma.<sup>(8,9,11,20)</sup> The form consists of open-ended questions providing general and in-depth answers in order to identify potential experient-

es. The interview began with a broad and open question, “What kind of experiences do you have with the stoma?” This general query was then followed by prompting questions to encourage participants to provide more in-depth responses.

In order to assess the appropriateness of the general prompting questions, the semi-structured interview form was evaluated by three nurses/academics that specialized in qualitative research, stoma, and adolescent experiences, prior to data collection.

The frequency and percentage distributions for the participants’ descriptive characteristics were calculated using the SPSS package program (SPSS for Windows, version 15.0; Chicago, IL).

A hermeneutic phenomenological analysis was conducted manually on the interview transcripts, with the aim of exploring the main themes related to adolescent’s experiences with the stoma by the first and second author. Three main steps were followed for the analysis;<sup>(15)</sup>

1. All the interviews read individually by two researcher to gain a sense of the whole text. Impressions of the researchers on the text were then documented and discussed.
2. The text was divided into meaning units, which were transformed with the contents intact. Arising from every transformed meaning unit a number of labels were created, to discover common themes.
3. The researchers read the text several times and performed interpretation of the data during this step and described themes within the data. An example of data analysis process in this research is presented in chart 1.

**Chart 1.** Examples of the analysis process

Meaning Unit	Label	Theme
"...I don't see much of my friends after surgery. I only have one friend because she knows I have a stoma so I keep meeting her. I don't meet other friends."	Feeling discomfort with the friends	Discomfort
"...when there is an odor in class, they open the window or use the room spray. I do not want to go to school"	Feeling discomfort at school	
"...I wear more loose and more comfortable things. The bag sometimes swells. So, if I'm wearing small (clothes), now I'm buying a medium size."	Concealing the stoma by wearing loose clothing	Concealing the stoma

Scientific rigor in a qualitative research can be ensured through four criteria of credibility, transferability, dependability, and confirmability.<sup>(21)</sup> In this study, credibility was facilitated by constant engagement with data during all phases and performing collaborative analysis. In order to conduct an external check, emerging themes were reviewed and refined by two nursing academics, who had not participated in the interviews. With credibility being assured, dependability was in turn guaranteed. In order for the transferability of the findings to be judged, we described the findings to two audiences. Finally, an audit trail served as a document to assure confirmability.

Study procedures were reviewed and approved by the Ankara University Ethical Committee on January 7 2019—being given the approval number 911. Confidentiality was assured and participants were free to withdraw from the study at any time. The investigators assigned each adolescent a number in order to hide their identities. The researchers gave each participant and their parents an information sheet, containing details on the study, which was read carefully and explained by the investigators prior to the interviews. The interviewers allowed participants and their parents to read the written information, reflect on it, and to come to their own decisions, before giving their informed consent. Informed consent forms were mailed out to the participants and parents who were not met face-to-face.

## Results

Eleven adolescents were involved in this study—two men and nine women. Distribution of the participants according to their introductory information is given in table 1.

Seven themes emerged from the data analysis. The themes were; discomfort, concealing the stoma, changed body image, restrictive social environment, praying experiences, experienced problems about stoma bag and stoma care, and altered future plans. The distrubition of themes and participant count are presented in chart 2.

**Table 1.** Demographics and stoma characteristics

Demographics and stoma characteristics	Mean±SD; n(%)
Age (year)	16.00±3.28 (R: 12-21)
Time lived with stoma (month)	73,36±65.93 (R: 3-192)
Gender	
Male	2 (18.2)
Female	9 (81.8)
Education status	
Attending School	6 (54.5)
School break	2 (18.2)
Left school	3 (27.3)
Type of Stoma	
Colostomy	2 (18.2)
Ileostomy	9 (81.8)
Stoma care	
Doing it him/herself	3 (27.3)
Mother is doing	4 (36.4)
Doing it with help	4 (36.4)
Medical Diagnosis	
Inflammatory Bowel Disease	3 (27.3)
Cancer	2 (18.2)
Other	6 (54.5)
Stoma Duration	
Temporary	9 (81.8)
Permanent (1 ileostomy+ 1 colostomy)	2 (18.2)

**Chart 2.** Themes and participant count

Themes	Participant
1. Discomfort	7 participant reported
2. Concealing the stoma	5 participants reported
3. Changed body image	5 participants reported
4. Restrictive social environment	4 participants reported
5. Praying experiences	2 participants reported
6. Experienced problems about stoma bag and stoma care	7 participants reported
7. Altered future plans	2 participants reported

### Theme 1: Discomfort

Adolescents reported that they had experienced discomfort in various social settings because of their stoma. They stated that this discomfort caused them to, subsequently, avoid social environments and that they could not be comfortable in social settings. The participants expressed this with the following statements:

*"I don't see much of my friends after surgery. I only have one friend because she knows I have a stoma so I keep meeting her. I don't meet other friends. My friends are always asking me about my surgery, such as, what kind of surgery I had. I don't want to lie to them. That's why I don't want to see the others...If I tell them...I feel like people are going to run away from me...I hesitate... I don't know how they might react. It (the stoma) bothers me. That's why I became introverted to people. I don't*

*want anyone to see it. People's gazes make me feel discomfort"* (Participant 3).

*"...my friends do not want to come close to me at school. They do not want to sit next to me. They're not coming. I think, I guess they don't sit next to me because I smell. Sometimes I feel like the odor come from me, so I don't talk too much. When there is an odor in class, they open the window or use the room spray. I do not want to go to school (Participant 7).*

### Theme 2: Concealing the stoma

Adolescents stated that they did not want their stoma bags to be seen or known about and would try to hide them using various methods. One male participant explained how he hide his stoma bag using their clothing:

*"I wear more loose and more comfortable things. The bag sometimes swells. So, if I'm wearing small (clothes), now I'm buying a medium size. The shoes are the same, but I get loose clothes. So that my bag won't become visible when it's swollen"* (Participant 4).

Another female adolescent stated that she concealed her stoma by not telling her friends and teachers at school that she had it:

*"Sometimes my bag comes out at the school. Sometimes I have trouble with it. I lie to my teachers that my stomach hurts when it happens. Teachers also think I have had a period. None of my friends know my stoma now. I thought it would be unnecessary to share it with my friends. Because I thought they could not help me, so I decided not to say it"* (Participant 7)

### Theme 3: Changed body image

Adolescents who participated in the study expressed experiencing changes in their body images in various quotes. A female adolescent reported the change in her body image as follows:

*"So... after surgery everything changed. For example, I don't wear the clothes I used to wear any-*



*more. Now I'm constantly wearing casual clothes. I used to do makeup, dress up differently, but now there's nothing left. Because I think it doesn't suit me" (Participant 3).*

A quote from another, male adolescent went as follows:

*"I don't want to have a girlfriend when my body is like this. I mean, when I get to heal. If it does, it only happens when I get better. Only if the stoma is closed" (Participant 4).*

#### Theme 4: Restrictive social environment

Adolescents stated that they were seen as ill in their social environments, as well as by their family members. One adolescent, who is not allowed to perform stoma care herself, stated the following:

*"I never do my stoma care. I have not even tried yet... Mom says don't start now. She says I need to grow up to do it" (Participant 1).*

This quote is from another adolescent who does not want to participate in volleyball matches because of her teachers' fears:

*"I'm a volleyball player. I'm thinking about going to volleyball games. Our school team will play with other school teams in different cities. I can't go because I'm sick. Some of my teachers are afraid that if anything happens to me because of my stoma. That's why they don't want me to attend" (Participant 10).*

#### Theme 5: Praying experiences

All of the participants were Muslim. Ablution is regularly taken before Islamic worship and gas/feces can disrupt this process. To be able to continue with worship, ablu-tion is then needed to be undergone again, if necessary. The participants talked about their experiences related to worship as follows:

*"For a while, I didn't do anything. I thought that I cannot pray with the stoma. I wasn't praying. Then, I thought God gave it to me, and I prayed.*

*It hasn't been long since I started again. But there was trouble. I wasn't feeling comfortable, I kept changing my clothes to be clean for praying when the bag comes in contact (with the clothes). I felt uncomfortable with the stoma. I was worried if my ablution was broken. But then it's not in my hands, it's not deliberate, it happens spontaneously, I'm used to it now" (Participant 6).*

*"Before the operation, we used to go to the mosque with my mother, we would pray. After the operation... for example, yesterday I did not go to the mosque. My mother went, I did not. It was Kandil (a special night for Islamic religion) yesterday. The bag is constantly leaking; I did not go because ablu-tion would be broken. Also, I am not going because the mosque is very crowded place. I don't like the places with a lot of people. I'm not going" (Participant 3).*

#### Theme 6: Experienced problems about stoma bag and stoma care

Most of the participants stated that they had different problems with the stoma bag and its care. These problems generally included fecal leakage, audible gas output, odor, burning and other peristomal skin problems, lack of education on stoma care, and lack of expert physicians/nurses who understand stoma care in the home.

One of the adolescents expressed problems with the stoma bag as follows:

*"...But when the fistulas opened, I had a difficulty to place the ostomy bag on my skin, then, very often, the leaks began. When there is fecal leakage from my bag, smell can occur. Sometimes there is an audible gas output" (Participant 6).*

An adolescent spoke on the problems related to stoma care education as follows:

*"No one trained me on stoma care. I had surgery in Adana and Hatay. Nobody taught me. Sometimes, I have redness around the edges of stoma. I'm applying a cream or oil myself. Sometimes it goes away" (Participant 10).*

## Theme 7: Altered future plans

Adolescents talked about changes in their plans for their futures due to the stoma. The response of an adolescent related to this theme is as follows:

*"I was studying fashion design. I was thinking of going to Istanbul because there wasn't any school about fashion in Izmir. So, I was planning to go to Istanbul this year, but canceled it because of surgery. I hope to do it after surgery (stoma closure surgery). So I postponed" (Participant 3).*

*"In fact, life has taught me not to plan much. I came to realize that I was happier when I lived without any plan. No matter what you plan to do, every time I say this is in my hands, life always comes across. Life showed me it wouldn't" (Participant 6)*

## Discussion

This study provided a comprehensive understanding of Turkish adolescents' experiences with stoma and, despite the limited literature, the results are quite similar to other research.<sup>(9,10)</sup> This study's findings revealed that adolescents with an ostomy experience "discomfort" in their social lives. In Savard and Woodgate's (2009) study, young adults, aged 19-24 years, who had stoma due to Ulcerative Colitis (UC), expressed similar problems under the theme of "uneasy feelings".<sup>(10)</sup> In Mohr and Hamilton's (2016) study conducted with 12 English-speaking adolescents aged 13-18 years with ostomy, similarly, adolescents often reported not feeling well enough to engage in meeting with friends.<sup>(11)</sup>

The other finding of this study was concealing the stoma. In our study, "concealing" had two meanings. The first is "physically concealing using clothes," whereas the other was "not telling other people about the stoma." Nicholas and colleagues (2008) explained this, using the theme of "secrecy" in their young adult sample.<sup>(9)</sup> However, in their study, this theme was just explained as "considerations in deciding whether to tell others about the ostomy." The reason for this difference might be

due to body image. Body image is more important in adolescents than for young adults.<sup>(22)</sup>

In the study by Nicholas et al. (2008), and Erwin-Toth (1999) the theme of "changed body image" emerged, similar to our study.<sup>(8,9)</sup> However, it is dealt with in different dimensions. Nicholas et al. (2008) discussed body image changes in terms of personal space challenges and related worry in young adults.<sup>(9)</sup> In our study, adolescents expressed changes in their body images in terms of problems around clothing options and sexual attraction. Adolescence, in general, creates various risks for the development of one's body image. Additionally, studies have shown that both having cancer treatment<sup>(23)</sup> and having a stoma leads experience various problems associated with body image of adolescents.<sup>(24-26)</sup> Therefore, changes to body image were found to be an important problem for adolescents with stoma.

In our study, the theme "restrictive social environment" was found to be a problem faced by adolescents. In particular, the protective behaviors of their families and friends made participants feel restricted. In Nicholas and colleague's (2008) study, this problem was expressed by young adults under the theme of "decreased independence and control".<sup>(9)</sup>

Adolescents also stated that praying with their stoma was a problem for them. A person with stoma has no continence. In the Islamic religion, gas/urine/fecal output is a condition disrupting prayer, requiring constant cleaning. According to the statement made by the Presidency of Religious Affairs of Turkey (2017), people with stoma are "excused," and there are no problems for them in terms of prayer.<sup>(27)</sup> However, adolescents still think that they cannot pray because of their stoma. This is an important spiritual problem faced by them.

Adolescents also stated that they experienced problems about stoma bag and stoma care. Most of the participants stated that they had different problems with the stoma bag and its care such as fecal leakage, audible gas output, lack of education on stoma care. In the systematic review conducted by Vonk-Klaassen et al. gas, and worrying about noises described as ostomy related problems.<sup>(28)</sup> In Turkey,

unfortunately, there is not stoma care nurse in every hospital so the individuals may have difficulty on receiving stoma care education. Therefore, in this study adolescents were having stoma care problems. "Altered future plans" represent the primary problems experienced by adolescents in our sample. Therefore, they need more physical, psychological, and social support.

Implications for practice: Research results show that adolescents with stoma experience many problems. Therefore, this study will help to better understanding of adolescent with stoma for the nurses and to conduct future nursing experimental studies to increase adolescents' socialization. In addition, this research provides detailed information to nurses about the problems that may experience by adolescents with stoma. Thus, it is thought to be a good resource for nurses regarding the issues that need to be considered in the follow-up of adolescents with stoma during the hospital stay and after discharge.

We used qualitative methods for data collection and enrolled a small, purposive sample. In addition, the study was conducted in a specific socio-cultural context. Therefore, the results of this study cannot be generalized to all people with ostomies.

## Conclusion

This study's findings show that adolescents experience many problems, mainly in terms of social interactions, while living with stoma. Increasing societal awareness and informing people about stoma will prevent adolescents with this medical condition from experiencing as many social problems. It is especially important to inform teachers about stoma. In addition, it is important to employ stoma and wound care nurses within healthcare institutions in order to protect adolescents with this condition from having problems in getting counseling and guidance on stoma care. In addition, our study findings showed that adolescents with stoma who are the member of Islamic religion also have praying problems. Both stoma care nurses and Islamic authorities should inform these people about praying rituals with stoma.

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## Collaborations

Harputlu D and Esenay FI contributed to the project design, data analysis and interpretation, article writing, relevant critical review of the intellectual content and approval of the final version to be published.

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