Original article

Patient-reported outcomes from individuals with intestinal stoma: a phenomenological study

ABSTRACT

Aim To determine patient outcomes reported by wound/ostomy nurses, surgeons, individuals with intestinal stomas and their caregivers.

Methods A qualitative phenomenology design was used. The sample comprised wound/ostomy nurses (n=9), surgeons (n=9), caregivers (n=9) and ostomy patients (n=9), in all 21 women and 15 men in Turkey. The consolidated criteria for reporting qualitative research was used. The study was conducted with the nurses working in nine stomatherapy units in Turkey. Written permission from the relevant ethics committee and verbal permission from the participants were obtained. The interviews were conducted online using a semi-structured interview form between June 2020 and 2021. Descriptive statistics and content analysis methods were used.

Results The recovery indicators were grouped under the headings of: indicators of general health status; indicators of daily living activities; indicators of social life and adaptation relationships; indicators of psychological well-being; stoma management; and empowering the individual.

Conclusion These results are relevant to planning training and consultancy services, starting from the preoperative period of the individual with stoma through to developing institutional care strategies and algorithms and creating relevant guides in the literature.

Keywords ostomy, patient outcomes, patient-centered care, patient-reported outcomes, caregiver.

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INTRODUCTION

In 2001, the Institute of Medicine (IOM) published a report on how patients and clinicians should interact, and how care processes can be designed to optimise responsiveness to patient care needs and to improve the quality of health care. In this report, IOM defined patient-centered care as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions".[1] In 2015, the World Health Organization (WHO) defined person-centred care (PCC) as "an approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that respond to their needs and preferences in humane and holistic ways".

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In the report titled *WHO global strategy on integrated people-centred health services 2016-2026,* WHO emphasised that all people should have access to safe, effective, timely, efficient and acceptable health care that is coordinated throughout the care process, provided in a way that meets their lifelong needs and preferences, and that appropriate care processes used at country level need to be designed and developed considering local values and preferences.[2]

In the development of clinical support systems, ways of realistically assessing and effectively addressing patient needs should be identified.[3] In the literature, approaches used for assessing PCC include patient-reported outcomes[4] (PROs) and patient-reported outcome measures[5] (PROMs). These are "measures of a patient's health status as reported directly by the patient without added interpretation by a healthcare worker or anyone else, such as when a pain scale is used."[4] PROMs are used as screening tools in PCC, identifying unmet needs, adapting treatment to individual needs,[6] clinical monitoring of symptoms, monitoring treatment responses, patient self-management and care planning.[7] Patient outcome is a concept reflecting the patient's subjective point of view. It provides a view from the patient's perspective and focuses on the perception of the patient's current health status at a

single point, including functional abilities and psychological dimension. Although patient outcomes are reported in the relevant literature, it is noteworthy that the indicators reported by health professionals and patients are often different from each other. In nursing, caregiving is the basic role and care is the most unique feature of nursing.[8]

In this context, individuals with a stoma are among those special groups that need to be cared for using a PCC approach in terms of addressing their specific problems and needs.[9-11] In order to provide PCC, it is necessary to know the person's values, perspective, needs, experiences and well-being indicators related to themselves. Although there are some patient outcomes described in the existing literature for individuals with colorectal cancer and stomas, outcome indicators obtained by scientific methods from the opinions of patients, relatives, physicians and nurses are needed and there is a gap in both practice and literature in this area. It is thought that indicators created by a consensus may be meaningful for planning the care of patients, assessing the effects of nursing or medical interventions and making comparisons, thus personalising and improving the quality of care. Therefore, this study was conducted to determine patient outcomes reported by wound/ostomy nurses (WONs), surgeons, adult individuals with intestinal stomas and their caregivers.

METHODS

Study design

This study was conducted using a qualitative phenomenological design. The research questions were:

1. What are the patient outcomes reported by WONs?
2. What are the patient outcomes reported by surgeons?
3. What are the patient outcomes reported by individuals with intestinal stomas?
4. What are the patient outcomes reported by caregivers of individuals with intestinal stomas?

Setting and participant

The data was collected online by the researcher between June 2020–2021. In determining the sample, the information on stoma therapy units (n=35) on the Turkish WOC Nurses Association (YOIHD) web page was utilised. The WONs working in stoma therapy units (SU) in Türkiye, patients, caregivers and surgeons monitored through these units constituted the study population. The nine stoma units were purposively selected from the initial pool of 35 units using a maximum variation sampling approach. Units were chosen to reflect diversity in terms of patient volume, patient characteristics and geographical catchment areas, with priority given to units serving a high number of patients from different regions. Only units that met the inclusion criteria (Table 1) and agreed to participate in the study were included. From these units, WONs (n=9) working in nine stoma units located in four major cities (Izmir, Istanbul, Ankara, and Adana) were recruited. These units provide follow-up care to patients referred from various cities across the country. In addition, patients with stomas followed up in these units (n=9), their primary relatives responsible for their care (n=9), and the surgeons who performed the stoma operations (n=9) were included in the study on a voluntary basis.

Participants were sampled according to selection criteria (Table 1). Participant inclusion was stopped when data saturation was reached.

Ethical consideration

Ethical approval was obtained from Koç University Social Research Ethics Committee (2020.121.IRB3.059). Before the interview, the participants were informed about the research and their verbal permission was obtained.

Study procedures

Three forms were used to collect the data.

Participant Information Form: This form asked for descriptive characteristics of the study participants and provided information about each group.

Patient Outcomes Determination Form: Consisting of four sections, this form has semi-structured, open-ended questions to determine patient outcomes by utilising the literature. Examples of questions are provided in Appendix 1.

Participant Observation Form: This was created to record the interviewer's observations about the interview.

The primary investigator (PI) contacted the WONs in the identified SUs by telephone and invited them to participate in the study. The WONs randomly identified patients meeting the inclusion criteria. The identified nine patients with stomas and their primary caregivers were first contacted by the WON of the SUs. If the patients and caregivers agreed to participate in the study, the PI contacted them. After identifying the patients and caregivers, the investigator contacted the surgeon of the same patient with a stoma and invited him/her to participate in the study. The investigator conducted individualised in-depth interviews with each participant on the day and time they

Table 1. Sample inclusion criteria

Wound/ostomy nurses	Working in the SU for at least one year Having a nationally recognised Stoma and Wound Care Nursing Certificate For SU where more than one WON works, having the most work experience
Surgeons	Actively performing colorectal cancer surgery in the clinic Having the title of Associate Professor and Professor
Caregivers of patients with stomas	Being over 18 years old Being in the position of caring for a relative of a patient with a stoma
Patients with stomas	Being over 18 years old Living with a temporary or permanent intestinal stoma for at least three months

were available, in separate sessions, online, using the semi-structured interview form. At the beginning of the interview, the investigator filled out a Particpant Information Form. It was emphasised that the voice recordings would not be used for any purpose other than research. The interviews lasted between seven and 47 minutes.

Data analysis

Quantitative data related to the descriptive characteristics form were assessed using descriptive statistical analyses with SPSS 25.0 package program. In qualitative data analysis, content analysis was performed by following an inductive approach. The four stages followed in content analysis are: data coding; finding themes; organisation of codes and themes; and describing and interpreting the findings.[12] A code was determined for each interviewee. For example, the codeword N1 was designated for the first WON, the codeword S1 for the first surgeon, O1 for the first ostomy patient, and C1 for the caregiver of O1. After the themes and sub-themes of each group were formed separately, common themes and sub-themes were determined. Both investigators independently reviewed the transcripts for themes. In addition to the investigators, three meetings were held with two expert faculty members in the field of nursing to discuss the themes and sub-themes. Necessary changes were made in line with the feedback received.

The rigor of the study

The validity and reliability of the data of the study were assessed under the headings of credibility, transferability, dependability and confirmability. Credibility was considered as deciding on the method in line with the objective of the study, randomly selecting the participants, recording with the approval of the participants, and presenting the results to experts to incorporate their opinions. To ensure transferability, the collected data were presented in a comprehensive manner. Reliability was ensured by repeating the study in the same design, data collection and analysis stages, themes created, and reporting of the data in detail. To ensure confirmability, the investigators and experts held meetings at regular intervals and discussed the data analysis process and theme/sub-themes identification.

RESULTS

Participants demographics

Table 2 shows the characteristics of the participants.

Themes

The themes of patient outcomes generated from the data are provided in Figure 1 and the themes, sub-themes and participant expressions are given in Table 3. The themes obtained were indicators of general health status, life activities, social life and adherence to recommendations or regimens, psychological well-being, stoma management and empowering the individual. Additionally, two to eight subthemes related to each theme were identified.

DISCUSSION

Indicators for physical health status

In parallel with the developments in the field of surgery and oncology, a positive increase in survival rates after stoma surgery has been observed with individuals returning to their healthy lives. Along with the positive developments reported, individuals with stomas also experience physical, social, sexual and adherence problems.[13-15] They have also reported needing case managers and up-to-date and understandable information.[11] Patient-clinician communication problems and unmet needs are frequently emphasised in the relevant literature.[10] These problems make it difficult for individuals to adapt to life with a stoma.

Consistent with these findings, it is recommended that WONs and surgeons provide holistic, multidisciplinary and patient-centred follow-up starting from the postoperative period and continuing after discharge, through regular physical assessments (such as pain, nutrition, hydration, stoma function), effective patient communication, coordinated care and structured education to support treatment adherence and adaptation to life with a stoma.

Table 2. Characteristics of participants (n=36)

Variable	WONs	Surgeons	Stoma patients	Caregivers
Sex: Female n (%)	9 (100)	0	4 (44.4)	8 (88.9)
Sex: Male n (%)	0	9 (100)	5 (55.6)	1 (11.1)
Age: mean (SD)	40.0 (4.7)	46.9 (10.6)	54.0 (15.5)	43.1 (17.3)
Working as WON: mean (SD)	9.6 (5.7)	—	—	—
Performing colorectal cancer surgery: mean (SD)	—	14.6 (8.7)	—	—
Relationship with ostomy patient: n (%)				
Spouse	—	—	—	3 (33.4)
Mother/father				1 (11.1)
Child				4 (44.4)
Friend				1 (11.1)
Received caregiver training: n (%)	—	—	—	9 (100)

Indicators for life activities

Although stoma surgery prolongs patients' lives, it may cause changes and problems in life activities. In the study, all of the WONs, surgeons and patients and the majority of the caregivers used the expression "doing their routine work" under the sub-theme of work and entertainment of the individual with a stoma in the discharge period. The majority of the participants in the study used the expressions "having no nutritional problems" under the sub-theme of nutrition of the individual with a stoma. All of the WONs and the majority of the surgeons used the expressions "being mobile" for the postoperative period. All of these statements are related to the individual's return to activities of daily living and are interpreted as the reflection of Roper-Logan-Tierney's Activities of Daily Living Care Model.[16] WONs and surgeons are encouraged to consider changes in activities of daily living due to illness, injury or hospitalisation and improvements in these changes as indicators of well-being and patient outcomes, which form the core philosophy of this model.

Individuals with stomas may make some changes in their clothing style, such as preferring wide clothes, so that the stoma bag is not visible after surgery.[14] While the sub-theme of personal hygiene and care was mentioned by only a minority of surgeons and caregivers, the majority of the WONs noted whether the individual "maintains his/her care, especially women wearing makeup, and does not change his/her clothing". These issues have been mentioned in the literature as a patient outcome, related to individuals with stomas maintaining their personal hygiene, not changing their clothing style or being able to choose clothes to adapt to their stoma.

Sexual life can be affected by stomas for both functional and psychological reasons. This is one of the most common problems reported by individuals with stomas.[17] In the study, this problem was expressed only by the WONs and surgeons, as an "individual with a stoma resuming sexual activity, wanting to resume sexual activity". A striking finding here is that individuals with stomas and their caregivers did not mention sexuality among their indicators of well-being. These results may be related to reasons such as the fact that sexuality is not always easily expressed, and may only be shared with professionals with whom a trusting relationship is established, as it is among private, and often taboo subjects. This finding is similar to other results in the literature that have noted the expression of sexuality varies according to culture and it is an area more private, hidden and expressed with less priority than other physiological well-being indicators.[18,19]

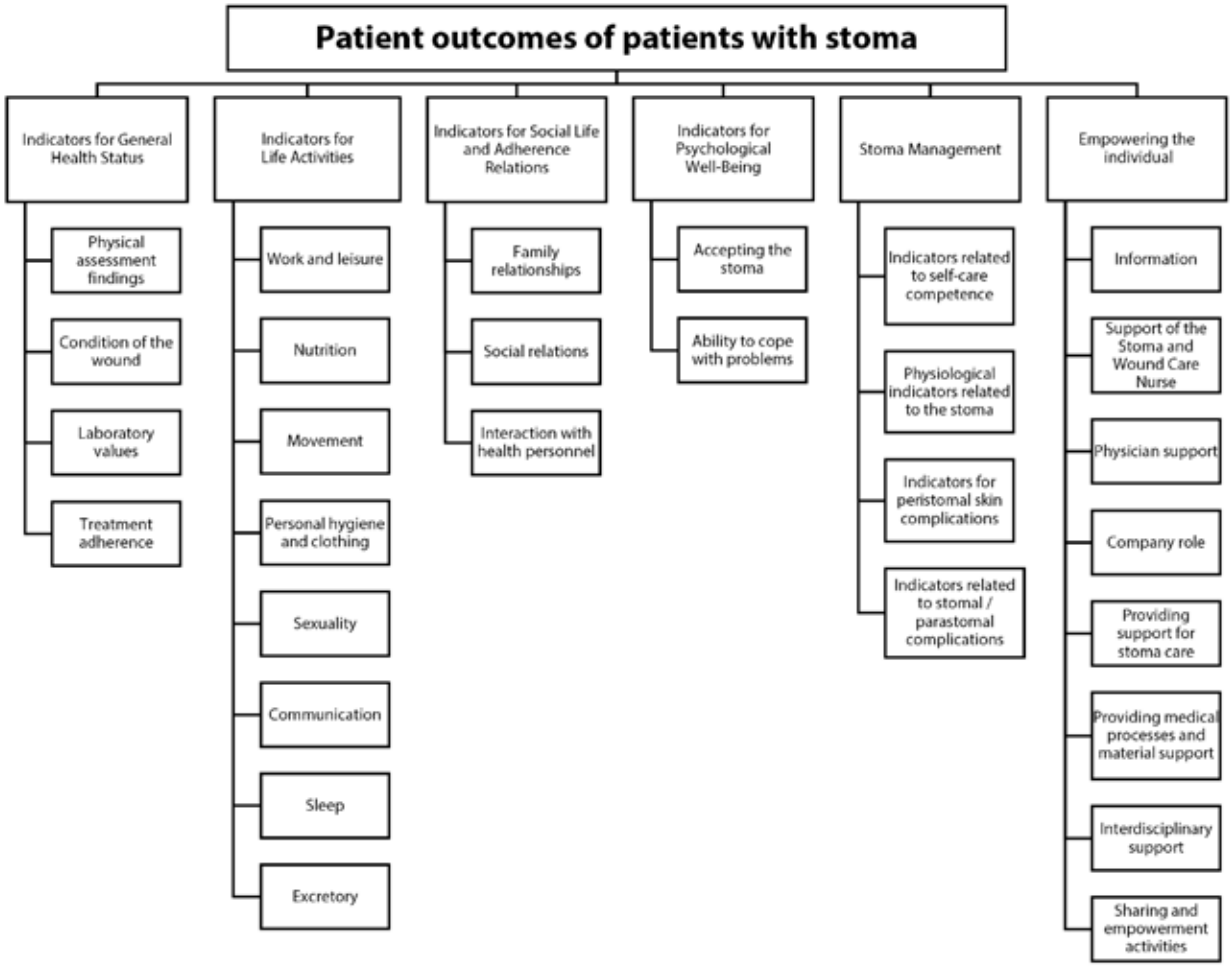

Figure 1. Themes and sub-themes related to patient outcomes reported by individuals with stomas

Table 3. Patient outcomes related to physical health, activities of daily living, stoma management, social life and adherence to recommendations or regimens, psychological well-being and empowering of patients with stoma

Theme	Sub-theme	Quotation
Indicators of physical health status	Physical assessment findings	*"... It turns into a condition that affects almost every system of the patient in general. I can state that not eating causes the digestive system not to work properly, not drinking fluids causes the kidneys not to work properly, and a chain of deterioration follows itself ..."* (N2)*
		"... there should be indicators of the well-being of a completely normal individual ..." (S2)**
		"... it is very important that they do not lose weight and maintain their current weight if they are healthy ..." (C2)***
	Condition of the wound	*"... There is an operation on the abdomen and there is a wound healing process. I think this also shows the patient's recovery process. If the healing process there is normal, it means that the patient seems to be getting better ..."* (N9)
		"... it is necessary to look for any infective appearance around the wound. Whether there is separation of the sutures or not ..." (S9)
	Laboratory values	*"... For example, we saw a patient clinically dehydrated, we thought that fluid intake was insufficient. Firstly, we perform a BUN test and check creatinine values. Kidney functions, blood count and CRP are checked."* (N1)
		"... all blood parameters should be good ..." (S2)
	Treatment adherence	*"We evaluate the patient's compliance with the education acceptance-stoma education, the patient's ability to manage stoma care, to perceive it when it is managed by us, to ask questions other than that ... we evaluate it with the compliance of the stages of the education plan ..."* (N3)
		"... Whether or not the patient himself makes an effort. Whether or not he/she wonders how it is done, he/she looks at it, he/she read the documents given about it, he/she listens to the nurse ..." (S4)
Indicators of life activities	Work and leisure	*"... I have patients who continue their daily life activities and even return to work. But others do not want to work at all, questions come while they are still in hospital. How can I retire on disability, how can I get a report not to work at work ..."* (N1)
		"... resumption of active participation in life through meetings, courses or professional associations or social gatherings, days out with friends, acquaintances and loved ones. Being lively, productive, returning to work, working efficiency, in other words, not retiring to pasture, being detached from life ..." (S5)
		"... If I can do everything. If I can do what I want, when I want, with the people I want, I am good ..." (O2)****
		"... My father goes to the workplace with the bag. He has a medical examination. If he can get there and back, he is good ..." (C8)
	Nutrition	*"... he eats the food himself, first of all. He does not get help ..."* (N4)
		"... whether his/her oral intake is good or not ..." (S4)
		"... I can eat and drink anything ..." (O6)
		"... when she followed her diet she had no problems because my mother used to have problems when she ate dehydrated food ..." (C9)
	Movement	*"... for example, we recommend walks, outdoors, to distract themselves ..."* (N1)
		"... can he/she fulfil his/her exercises, social activities at work, with his/her stoma ..." (S3)
		"... there was nothing to prevent me from running, although not very, very fast ..." (O1)
		"... he/she started walking after the operation, he/she says he/she is better ..." (C9)
	Personal hygiene and clothing	*"... My patient made make-up, dressed very beautifully, although it was very cold weather, she wore a mini skirt, pulled her boots, dressed very elegantly and I could not recognise her, she made very beautiful make-up and I cannot tell you (smiling) I was very happy and my patient made cookies and brought them, which was very nice ..."* (N4)
		"... women doing their makeup, lifting their spirits. Taking care of themselves, prioritising their personal care ..." (S5)
		"when women wear make-up, it regulates their mood. Care, taking care of personal hygiene ..." (S5)
		"... these are micro issues, but I can't wear whatever I want. I had to make my trousers high-waisted ..." (O2)

Theme	Sub-theme	Quotation
Indicators for life activities	Sexuality	*"... If there is no condition that causes dysfunction in the surgical sense, it is necessary to encourage people to express their feelings with their partner, that there is no problem in being together sexually as soon as they feel ready, and if there is any problem in sexual intercourse, they should be encouraged to share this with their partner by talking more ..."* (N6) *"... sexual function is very important ..."* (S6)
	Communication	*"... if he/she comes to the outpatient clinic and is open to communication with you, he/she does not hesitate to contact you ..."* (N9) *"... communication. Whether they co-operate with us or not ..."* (S1) *"... when they spend time with us, when we talk to each other, I think they are fine ..."* (C5)
	Sleep	*"... do they sleep well at night? Sleep quality is really important ..."* (N3) *"... when I can sleep at night ..."* (O3) *"... I mean, if they sleep too much during the day, I say it is not good ..."* (C8)
	Excretion	*"... Did you have problems during micturition?"* (S1) *"... it was only a problem in the bathroom. My mum is going with someone because she is partially paralysed. At the moment, more precisely, in fact, she himself can go ..."* (C4)
Indicators of stoma management	Self-care competence	*"... if the individual can participate in their stoma care ..."* (N5) *"...then adherence to care. Beginning to do stoma care on his/her own ..."* (S3) *"...I support care, but I can do more ..."* (O9) *"...of course, it would be good for him/her if he/she did, otherwise there was no ... problem for us. It would be better if he/she did it ..."* (C8)
	Physiological indicators related to the stoma	*"... stoma output is not what we want. Either constipation or too high flow rate output may indicate that it is not getting better ..."* (N3) *"... physiologically, of course, in the first place, whether the stoma works or not ... a discolouration, whether the stoma is properly opened, ileostomy, especially if it is not opened by a capping method ..."* (S6) *"... when there is a nutritional irregularity, there is difficulty in faecal output, I pay a lot of attention to what I eat now ..."* (O9) *"... proper functioning of the stoma, not too liquid, not too solid, these are very important ..."* (C2)
	Indicators for peristomal skin complications	*"... so have any peristomal skin complications developed?"* (N5) *"... we can question whether there is erosion around it, whether a granulation tissue has formed there, whether it hurts you every now and then ..."* (S7) *"... after the wound healed, I started eating a little bit, walking ..."* (O7) *"... we used to cut that battery big and stick it on his/her belly, the size of a hole. Because there was a wound around it, when my mother's faeces came out, she said that it was burning like pouring acid and the woman was falling apart ..."* (C7)
	Indicators related to stomal/ parastomal complications	*"... is there any evidence of haemorrhage, is there any necrosis ..."* (N1) *"... no mechanical problems with the stoma ..."* (S3) *"... I went there when the bag exploded. The woman's house was filthy. I was so sad and cried ..."* (O6) *"... I know I change it three times a day. The dirt on her clothes, the pain she was in, she was in pain all the time if you see her, it makes you feel worse ..."* (C4)
Indicators for social life and adherence to recommendations or regimens	Family relationships	*"... there are no problems in family relations. The spouse or the person next to him/her has learnt to do it very well and says that he/she does not have any problems physically ..."* (N7) *"... being able to maintain the necessary family relationships comfortably in the family, with his/her children, with his/her spouse ..."* (S2) *"... He/she gave me a lot of money. He/she said you gave too much. He/she said, "Is it worth more than you? I'll sell my house, I'll sell my car, as long as you don't have pain. They looked me in the eye. I got up with their love, nurse lady ..."* (O7) *"... I would like my husband to fulfil all his needs by himself. Living free, not being dependent on me ..."* (C6)

Theme	Sub-theme	Quotation
Indicators of social life and adherence to recommendations or regimens	Social relations	*"... we direct him/her to the cafeteria to socialise, can he/she do this, what does he/she want, can he/she walk around the corridor ..."* (N3) *"... normalising his/her relations with the people around him ..."* (S2)
	Interaction with health personnel	*"... first of all, his/her speech ... if the patient shuts himself/herself down if he/she does not speak if he/she does not listen to me in any way, it is a very big problem. The education I give to the patient, the perspective of the person in front of me, that is, the way he/she looks at me, the way he/she listens to me, they are very important. Apart from that, some patients turn their backs, some pray ..."* (N4) *"... I look at the relationship with the stoma therapy nurse. If it is good, if he/she turns round and looks at me when I ask him/her something, it is okay. No problem ..."* (S1)
Indicators of psychological well-being	Accepting the stoma	*"... First of all, from his/her speech, his/her acceptance of the bag, whether or not he/her wants to see the bag, whether or not he/she wants to attend the education on the bag ..."* (N4) *"... When I see that the patient has no physical problem under optimum conditions, the second thing I will look at is whether the patient has accepted the stoma or not ..."* (S4) *"... psychologically, having something new in the body, your faeces coming to another place, that adaptation made me have more psychological difficulties ..."* (O8) *"... my mum started to get up and cheer up ..."* (C7)
	Ability to cope with problems	*"... it is very much caused by not eating and not drinking fluids so that the stoma does not work. Or the stoma's working too hard. There is a high output stoma, but the patient is not aware that it is a high output stoma, that is, the patient does not perceive the abnormality here and cannot replace himself/herself ..."* (N2) *"... whether he/she has experienced a complication of the stoma, whether he/she has experienced it, whether there was an unplanned hospitalisation related to it ..."* (S8)
Empowering the individual	Information	*"... First I find out who he/she lives with. Who he/she lives with? If he/she lives with his/her spouse, the spouse should also be informed about the problems the person will face. It is also necessary to give information about their social support and how they can support them ..."* (N6) *"... it is also necessary to start prehabilitation and if the patient is planned to have a stoma, living with a bag that mimics the stoma, doing daily work, even going to work if necessary, a day or two before surgery, being able to do these things at home will prepare them for a postoperative period ..."* (S4) *"... education is very important here for patients both in the preoperative period and in the postoperative period."* (O8) *"... patients, for example, should definitely inform their relatives about this ..."* (C7)
	Support of the stoma and wound care nurse	*"... we can only provide training ..."* (N1) *"... maybe a routine stoma outpatient clinic ..."* (S1) *"... when you ask about people's current discomforts and troubles, those people may be relieved when you, as a wound care specialist or nurse ask, and tell you what they cannot tell anyone ..."* (O1) *"... the support of our nurse is undeniable. It was very important for us to be accessible in every problem ..."* (C4)
	Physician support	*"... they should have very easy access to their physician ..."* (N5) *"... it is necessary to be clear, to talk about everything, to talk about all the possibilities and to tell the patients clearly what a stoma is ..."* (S7) *"... the good physician and his/her support ..."* (O5) *"... people need to choose their physician well ..."* (C8)
	Company role	*"... a patient was given the wrong equipment, the wrong training. You know, this was given by the company. It is a very sad situation ..."* (N4) *"... maybe it should be given professionally in health centers where these surgeries are performed. This work should be entrusted to such professional care nurses rather than such company representatives. I think that is the most important thing ..."* (S3) *"... I think your dialog, your communication with the people where you get the material is very important ..."* (O1) *"... companies need to have positive support. Because when you need it, you call immediately ..."* (C1)

Theme	Sub-theme	Quotation
Empowering the individual	Providing support for stoma care	*"... I think the counselling service is very valuable. They are very confident about it. In other words, just knowing that they have someone to consult is very good for them. Of course, we have to teach them how to perform care without any problems ..."* (N7) *"... caps, bags, such cute babies with ladybugs on them, because it is not only the elderly with a stoma, it also happens in young people. For example, tattooed people, etc. Then there are those who produce specially designed clothes for it, there are sites that share different alternative methods of preventing odour ..."* (S6) *"... the nurse who took care of us gradually acclimatised us, I emptied the bag, changed it. It was not that easy ..."* (O2) *"... I think support is essential, especially for a serious period of time until you have fully learned and gotten used to it ..."* (C7)
	Providing medical processes and material support	*"... the patient can have serious economic problems. There may be product support needs. Maybe some measures can be taken to ensure that they can access the right product ..."* (N3) *"... if one with stoma should prefer filtered bags ..."* (O8) *"... early supply of materials, quality of materials, no problems when buying materials, how the use of the material will be used in the most correct way for your freshness, comfort and health ..."* (C1)
	Interdisciplinary support	*"... I am definitely in favour of patients being followed up by a psychologist or psychiatrist ... there should be someone in the teams who has the ability of expert psychoanalysis and who has this authorisation, so that we can monitor these patients in all aspects ..."* (N2) *"... there is a great need for an out-of-hospital support system. Home care services and the ability of stoma therapists to follow up with these patients not only in the hospital but also at home will greatly increase their comfort of life ..."* (S2) *"... the workplace supported me; they gave me a car to use when I had a problem ..."* (O5) *"... psychological support should be provided...we caught this disease unexpectedly, we melted down ..."* (C8)
	Sharing and empowerment activities	*"... bringing people with a stoma together once a month to talk about their experiences with each other or their concerns with each other. We can do these kinds of things ..."* (N5) *"... surely only the wearer knows where the shoe pinches, So I usually match my patients with each other. What I mean is that you can learn best from those who have lived it. No matter how much I tell it, there may be parts that I forget and don't think of ..."* (S6) *"... if there was someone like me, I would support, I would help ..."* (O8) *"... we always looked up to people who lived a normal life. We always looked up to them. We were making her talk on the phone. We used to show patients on the Internet. Look, Mum, the woman is praying, cooking, etc. You need to be like that too, don't let yourself go ..."* (C7)

* The code N was assigned to the Wound Ostomy Nurses. The WON participants were sequentially numbered N1–N9
** The code S was assigned to the surgeons . The surgeon participants were sequentially numbered S1–S9
*** The code C was assigned to the caregivers . The caregiver participants were sequentially numbered C1–C9
**** The code O was assigned to the patients. The patient participants were sequentially numbered O1–O9

Based on these findings, it is recommended that WONs and surgeons adopt a holistic care approach grounded in the Activities of Daily Living Model to guide postoperative care planning, discharge preparation and patient education, with particular attention to mobility, nutrition, self-care and return to routine daily activities.

Indicators for social life and adherence to recommendations or regimens

Social support provided by family members, spouses and close friends has been consistently identified in the literature as a key factor influencing individuals' ability to maintain daily life activities, adhere to care recommendations and adapt to social life following stoma surgery.[13,20,21] In line with these findings, participants in the present study also emphasised the importance of close social relationships in facilitating social participation, emotional adjustment and continuity of care, as reflected in the social life and adherence-related outcomes presented in Table 3. These findings suggest that social support functions not only as an emotional resource but also as a practical and motivational factor that may enhance adherence to stoma care and promote adaptation to daily and social life. From a clinical perspective, this underscores the importance of adopting a family-inclusive approach to care. Accordingly, WONs and surgeons should consider actively involving family members, spouses and close friends in the care and education process during hospitalisation and follow-up, as such involvement may strengthen social support networks, support adherence to care practices and facilitate individuals' longer-term adaptation to life after stoma surgery.

Indicators for psychological well-being

Acceptance is a condition that directly affects the psychological state and behaviour of an individual with a stoma. In this adaptation process, the presence of the stoma changes the life of individuals in many ways, so individuals need to adapt to this new situation.[22] The statements of the participants, such as talking comfortably, making eye contact with the WON, not being shocked when they first saw the stoma, not being disgusted by the stoma and not feeling dirty, touching the stoma, not hiding the stoma from people, having a positive facial expression, not focusing on the stoma, not feeling dependent on someone, having self-esteem, not crying were offered as "indicators of psychological well-being" of individual with a stoma. The ability to cope with problems was suggested by the WONs and surgeons as a patient outcome in assessing the well-being of the individual with a stoma. These indicators, obtained from the study, are also consistent with the literature.[13,20,22,23] Based on these findings, it is recommended that WONs and surgeons systematically assess psychological acceptance and coping abilities as part of routine follow-up, and provide ongoing emotional support and counselling interventions, or refer individuals to appropriate psychosocial services when needed, to promote self-esteem, independence and psychological well-being in individuals with stomas.

Stoma management

Patient outcomes related to stoma management were described by participants in relation to self-care competence, physiological indicators of stoma function, peristomal skin-related indicators and indicators associated with stomal and parastomal complications. Participants highlighted the importance of these outcomes in supporting effective stoma care and overall well-being. Notably, surgeons placed particular emphasis on the importance of surgical technique, whereas other participants more frequently described outcomes in terms of functional and observable indicators, such as normal physical assessment findings, effective stoma function and an appropriate stoma output. These indicators are also in line with the literature[24] and reflect the multidimensional nature of stoma management, encompassing both surgical and self-care-related aspects. From a clinical perspective, these findings underline the importance of a coordinated and collaborative approach to care. WONs and surgeons should therefore regularly assess self-care ability, stoma function, peristomal skin condition and stoma-related complications, particularly during the early postoperative and post-discharge periods, in order to support effective stoma management and promote overall patient well-being.

Empowering the individual

WONs play a key role in the care and treatment practices and adaptation to new life for individuals who have stomas.[25] The continuous evidence-based care provided by WONs is reported to improve health outcomes in individuals with stomas. In this group of patients requiring continuous care, it is important to recognise patient needs and to support patients.[26] Drawing attention to the fact that the information was provided especially by WONs, the participants mentioned the importance of the support of WONs as a sub-theme to the theme of empowering the individual. WONs reported: "patient follow-up, marking the stoma area, teaching stoma care, making themselves accessible, providing continuous education and developing educational materials, counselling individuals, good communication and understanding the feelings of an individual with a stoma in the process of caring for a person with a stoma". The surgeons, in responses similar to answers to given by WONs, mentioned: "individuals with a stoma and their relatives should be directed to centres where there is a dedicated stoma care team". Individuals with stomas and their caregivers also emphasised the importance of this issue by mentioning the importance of "the presence and support of WONs". Another issue associated with WON support in the study, and noted by participants to be important, was the provision of support for stoma care.

When the participants' statements were analysed, it was seen that each group drew attention to different dimensions. The WONs made statements about person-centred care, such as "knowing their social support, determining the problems of the individual, providing rehabilitation at the level they need"; the surgeons made statements about the materials used, such as "recommending stoma accessories, using stoma caps and using appropriate products"; the patients made statements about comfort, such as "considering the comfort of the person in material selection"; and the caregivers made statements about "providing care support".

Multidisciplinary teams including WONs, physicians and psychologists are very important in stoma care.[22] More than half of the participants in the study made statements about the importance of interdisciplinary support. Medical supports, such as "following the patients as a team, providing psychiatry support when necessary, having home care services", and social support, such as "raising awareness of the people who are with the individual", have an important place for individuals with stomas to have smooth lives. For individuals with stomas experiencing problems in different areas of life, positive social support such as family and friends make them feel more comfortable and less depressed and contribute to the reduction of stoma-related problems and complications.[10,14,15,20]

Accordingly, these findings underscore the importance of continuous, evidence-based and person-centred care led by WONs within multidisciplinary teams, in which coordinated educational, psychosocial and material support tailored to individual needs can facilitate empowerment, support adaptation to life with a stoma, and contribute to improved patient-reported outcomes.

CONCLUSION

This study identified six interrelated patient-reported outcome themes - physical health status, life activities, social life and adherence to recommendations or regimens psychological well-being, stoma management and empowering the individual - through the perspectives of individuals with

intestinal stomas, their caregivers, wound/ostomy nurses and surgeons. Together, these themes provide a comprehensive understanding of recovery and adaptation following intestinal stoma surgery.

The identified themes may inform the planning of education and counselling services from the preoperative period onwards, support the development of institutional care strategies and clinical algorithms, and facilitate the evaluation of interventions for individuals with stomas. Overall, the findings highlight the value of person-centred and multidisciplinary approaches in stoma care and may guide future research and clinical practice.

LIMITATIONS

As a qualitative study, the findings should be interpreted within the context in which the data were generated. The study was conducted using purposive sampling, which allowed for an in-depth exploration of experiences from multiple stakeholder perspectives; however, this approach inherently limits the transferability of the findings. Although there were 35 stomatherapy units in Türkiye at the time of the study, participants were recruited from nine units, which may not fully capture the diversity of organisational structures and care practices across all centres.

In addition, the study focused exclusively on individuals with an intestinal stoma; therefore, experiences related to other stoma types, such as urostomies, were not included. Finally, while the qualitative design enabled rich and detailed insights into patient-reported outcomes, the findings are context-specific and are not intended for statistical generalisation but rather to inform understanding and guide clinical practice within similar care settings.

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CONFLICT OF INTEREST

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