

## Ostomates' perception of the quality of specialized care services and factors associated with adaptation

### Percepção de usuários com estomia sobre a qualidade do serviço especializado e fatores associados à adaptação

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#### ABSTRACT

**Objective:** to identify ostomates' perception of the quality of specialized care services and the factors associated with their adaptation. **Methods:** a cross-sectional study conducted through a telephone survey with 47 questions (35 on service quality assessment and 12 on user characteristics). A total of 234 calls were made to 87 ostomates. **Results:** the sample included 38 ostomates: 36.8% had a permanent ostomy, and 57.8% were awaiting intestinal reconstruction. While 81.6% managed their own pouching system, 21.1% reported receiving an insufficient quantity, and 10.5% were dissatisfied with its quality. Regarding complications, 78.0% had experienced them, and 82.0% could recognize them. Consultations were held with nurses (100%) and physicians (31.6%). Most ostomates (78.9%) frequented public or shared environments. Feeling adapted to life with an ostomy (65.8%) was associated with receiving a sufficient quantity of supplies ( $p=0.011$ ), and dissatisfaction with the physician's care was associated with poorer adaptation ( $p=0.039$ ). **Conclusion:** ostomates have access to specialized care services, supplies, and consultations with nurses. However, a minority had consultations with physicians — whose performance was associated with adaptation — and many were still awaiting intestinal reconstruction. **Contributions to practice:** the findings reveal gaps that impact care quality and highlight the need for targeted improvements in service delivery. **Descriptors:** Quality of Health Care; Ostomy; Secondary Care; Consumer Behavior; Enterostomal Therapy.

#### RESUMO

**Objetivos:** identificar a percepção de usuários com estomia sobre a qualidade do serviço especializado e fatores associados à sua adaptação. **Métodos:** estudo transversal, realizado por meio de inquérito telefônico com 47 questões (35 sobre avaliação da qualidade do serviço e 12 sobre o usuário). Realizadas 234 ligações para 87 usuários com estomia. **Resultados:** amostra de 38 usuários, dos quais 36,8% tinham estomia definitiva, 57,8% aguardavam reconstrução intestinal, 81,6% cuidavam do equipamento coletor, mas 21,1% recebiam quantidade insuficiente e 10,5% estavam insatisfeitos com a qualidade. Em relação às complicações, 78,0% as apresentaram, 82,0% tinham capacidade em reconhecê-las. As consultas foram com médico (31,6%) e enfermeiro (100%). Ambientes coletivos eram frequentados por 78,9%. Sentir-se adaptado à condição de vida (65,8%) estava associado à quantidade suficiente de equipamento ( $p=0,011$ ) e a insatisfação com a atuação do médico estava associada a uma pior adaptação ( $p=0,039$ ). **Conclusão:** o usuário tem acesso ao serviços, materiais e consultas com enfermeiro, mas a minoria passou por consulta médica, o que afeta a adaptação e há espera para reconstrução intestinal. **Contribuições para a prática:** os resultados permitem identificar fragilidades que impactam na qualidade da assistência permitindo intervenções assertivas no serviço.

**Descritores:** Qualidade da Assistência à Saúde; Estomia; Atenção Secundária à Saúde; Comportamento do Consumidor; Estomaterapia.

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## Introduction

Healthcare quality is a multidimensional issue and depends both on service performance and individual perception<sup>(1)</sup>. Understanding healthcare quality presents several challenges. Its definition is essential, as it can facilitate the understanding and improvement of the care provided by healthcare services.

Some health organizations define high-quality clinical care as care that is equitable, timely, safe, efficient, effective, and patient-centered<sup>(2)</sup>. One aspect of care quality that has been used as an indicator is users' perception of what is important in their care<sup>(1)</sup>.

User satisfaction is a key factor in the success of healthcare providers. The main factors influencing satisfaction include users' demographic characteristics, expectations, and care experiences. In addition, communication between healthcare professionals and users plays a key role in shaping how satisfied users feel about the service<sup>(3)</sup>.

Regarding the quality of care provided to people with an elimination ostomy, it has been observed that it is directly influenced by the organization of specialized services and by the performance of trained healthcare teams. Structured care delivery and multidisciplinary care are essential strategies to ensure these users' well-being and rehabilitation<sup>(4)</sup>.

The assessment of the quality of specialized services that care for people with an ostomy remains limited. However, measuring service quality and satisfaction with healthcare is essential for appropriate resource management and allows care to be aligned with users' preferences. This enables users to help shape a personalized healthcare service that meets their needs and expectations<sup>(5)</sup>.

Findings on specialized services for people with an ostomy — considering both process and structural attributes — have shown that these services prioritize the provision of pouching systems and adjunct supplies. Although material resources are available, they are underutilized. Gaps have been identified in care delivery, particularly due to a shortage of professionals to meet the minimum team requirements,

and many existing staff members are not adequately trained to address users' needs<sup>(6)</sup>.

Healthcare systems are continuously evolving and improving quality; therefore, it is essential to establish ways to evaluate outcomes, including service user satisfaction<sup>(7)</sup>. People with an ostomy are the primary stakeholders in ensuring that the existing care network is capable of meeting their needs and achieving the ultimate goal of rehabilitation.

Therefore, considering the existing knowledge gaps regarding specialized care for people with an ostomy — especially from the perspective of those receiving care — this study seeks to answer the following question: What is the quality of care provided by specialized services aimed at rehabilitating people with an elimination ostomy, from the users' perspective?

The objective of this study was to identify ostomates' perception of the quality of specialized care services and the factors associated with their adaptation.

## Methods

### Study design and setting

This is a cross-sectional study. Data organization was guided by the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement, using its extension for cross-sectional studies. The study was conducted in a specialized ostomy care service located in a health micro-region in the Central-West region of Minas Gerais, Brazil, comprising four municipalities. This service, established in 2012, is classified as a secondary-level facility and is part of a Center for Medical and Dental Specialties in the host municipality of the health micro-region.

### Population and sample

As of January 2025, 87 people with an ostomy were actively registered in the specialized care service. Recruitment occurred between December

2024 and January 2025, during which initial phone contact was made to assess eligibility. Those who met the inclusion criteria were informed that data collection would take place later. The date and time of the interview were scheduled according to the participant's availability.

Phone calls were made using a mobile phone, based on the contact list of individuals with an elimination ostomy registered in the specialized care service. A maximum of six attempts were made to reach each person, including three during the week (daytime and evening) and three on the weekend. A total of 234 calls were made during the recruitment period: 186 on weekdays and 48 on weekends. The purpose of the calls was to reach ostomates and invite them to participate in the study.

### **Inclusion and exclusion criteria**

The sample consisted of participants who met the eligibility criteria: being 18 years of age or older, having access to an active landline or mobile phone, and having an elimination ostomy. Participants were excluded if contact was unsuccessful after six attempts on different days and times; if the phone number was incorrect, forwarded to voicemail, or out of coverage area; if the number did not correspond to the participant; or if the participant failed to answer the call at the previously scheduled time.

After applying the inclusion criteria, 80 people were considered eligible. A total of 42 were excluded for the following reasons: incorrect number/voicemail/out of coverage area (n=25); number did not correspond to participant (n=3); missed scheduled call (n=3); declined to participate (n=10); and death (n=1). The final sample consisted of 38 people with an ostomy.

### **Study variables**

The study variables included demographic characteristics (sex, age, years of education); clinical

aspects related to the ostomy (type, duration, complications); and its management (hygiene, pouch emptying, pouch change). These variables are commonly used in descriptive studies on the profile of people with an ostomy.

Variables related to care assessment included: management of complications, adaptation to life with an ostomy, attending public or shared environments, receiving care from healthcare professionals in the service (nurse, physician, social worker), time required to schedule the first consultation and follow-up visits, availability for unscheduled consultations, perception of user embracement, receipt of written instructions, satisfaction with professional care, and adequacy of the quantity and quality of supplies received.

Another group of variables referred to specific cases: for users with a permanent colostomy, whether self-irrigation was indicated and performed; and for those with a temporary ostomy, the reason for awaiting bowel reconstruction. These last two groups of variables were based on the literature<sup>(6-7)</sup> and on the researchers' experience; however, they were not submitted for expert validation.

### **Data collection**

One of the researchers carried out the data collection from January 8 to February 21, 2025, through a telephone survey using a structured questionnaire. This instrument had been previously developed by the research team, who are the authors of this study. It contained 47 questions, 35 of which addressed the evaluation of care quality, while the remaining 12 covered sociodemographic data, clinical conditions, and participants' self-care practices.

Before its use, the questionnaire was completed by a research assistant to assess question clarity and make any necessary adjustments. This step was important, as the questions had been created to address the study variables.

The questions were administered using a tablet, and participants' responses were entered directly

into the device. These data were automatically transferred to and organized in an Excel database. The average interview lasted 28 minutes.

## Data analysis

Data were analyzed using IBM SPSS Statistics, version 20. Continuous variables were initially assessed for normality through graphical inspection and measures of skewness and dispersion. When the data were not normally distributed, results were described using the median and interquartile range (Q1–Q3); when they followed a normal distribution, the mean, minimum, and maximum values were reported.

To compare continuous variables between the two groups (adapted and non-adapted to living with an ostomy), the Mann–Whitney U test was used. Categorical variables were presented as absolute and relative frequencies, and comparisons between groups were conducted using the chi-square test. When the expected frequency in any cell was below 5, Fisher's exact test was applied. A significance level of 5% ( $p < 0.05$ ) was adopted for all analyses.

Sex-disaggregated data were used solely for descriptive and reporting purposes, without statistical inference between groups.

## Ethical aspects

Authorization to conduct the study was obtained from the Municipal Health Secretary of the city where the specialized care service is located, along with access to the contact information of individuals with an elimination ostomy registered in the service. Verbal informed consent was obtained from participants immediately before the interview. Participant anonymity was preserved, and all study procedures followed the ethical principles established in Brazilian National Health Council Resolutions No. 466/2012 and No. 510/2016. The study was approved by the Research Ethics Committee of the Federal University of Minas Gerais, under number 7,307,214/2024, and

Certificate of Presentation for Ethical Consideration No. 83818924.0.0000.5149.

## Results

Among the 38 participants, 21 (55.3%) were female and 17 (44.7%) were male. Age ranged from 31 to 96 years, with a mean of 61 years; 11 participants (29%) were aged 50–59 years, and 11 (29%) were aged 60–69 years. Years of schooling ranged from 0 to 18, with a mean of 7.9 and a median of 8 years; 3 participants (8%) had more than 11 years of education. The Brazilian Unified Health System was the sole source of healthcare for 32 participants (84%), while 6 (16%) also had access to private health insurance. Participants had either temporary or permanent colostomies, ileostomies, or urostomies, for varying lengths of time (Table 1).

**Table 1** – Sociodemographic, clinical, and self-care characteristics of people with an ostomy, by sex (n=38). Belo Horizonte, MG, Brazil, 2025

Variável	Male	Female	Total
	n (%)	n (%)	n (%)
Years of schooling*	8 (4-15.6)	8 (3-11)	8 (3-11)
Age†	64.8 (42-96)	57.3 (31-88)	60.71 (31-96)
Time living with an ostomy (years)*	1 (0-5)	1 (0-2)	1 (0-5)
Type of ostomy			
Ileostomy	4 (23.5)	4 (19.0)	8 (21.1)
Colostomy	6 (35.3)	14 (66.7)	20 (52.6)
Urostomy	1 (5.9)	2 (9.5)	3 (7.9)
Does not know	6 (35.3)	1 (4.8)	7 (18.4)
Temporality			
Temporary	10 (58.8)	9 (42.9)	19 (50.0)
Permanent	4 (23.5)	10 (47.6)	14 (36.8)
Does not know	3 (17.6)	2 (9.5)	5 (13.2)
Previous complication	12 (70.6)	15 (71.4)	27 (71.1)
Emptying/removal of the pouching system			
Self	14 (82.4)	17 (81.0)	31 (81.6)
Others	3 (17.6)	4 (19.0)	7 (18.4)
Peristomal skin hygiene			
Self	12 (76.5)	17 (81.0)	30 (78.9)
Others	4 (23.5)	4 (19.0)	8 (21.1)
Application of the pouching system	13 (76.5)	16 (76.2)	29 (76.3)
Does not apply the pouching system	4 (23.5)	5 (23.8)	9 (23.6)

\*Median, P25–P75; †Mean, minimum – maximum

The ability to recognize ostomy-related complications was reported by 31 participants (82%), and 27 (71%) took action upon identifying the issue. Among these, 20 (74%) were able to manage the problem at home, 4 (15%) adopted a wait-and-see approach, 2 (7%) sought care at the specialized service, and 1 (4%) asked a family member for help.

Regarding ostomy complications, 11 participants (28.9%) had never experienced any, while 27 (71.1%) had experienced at least one complication. Of these, 2 (7%) occurred during the immediate postoperative period while still hospitalized, 4 (15%) within 30 days after discharge, and 21 (78%) more than 30 days after discharge. The frequency of complications was described as rare by 15 participants (56%), frequent by 7 (26%), and constant by 5 (19%).

With regard to professional care received, all 38 participants (100%) had been seen by a nurse, 21 (55.3%) by a social worker, and 12 (31.6%) by a physician. The initial consultation was conducted by a

nurse for 32 participants (84%), by a social worker for 5 (13%), and 1 participant (3%) could not recall which professional conducted the appointment.

The waiting time for the first consultation ranged from less than 15 days to 90 days, with 28 participants (73.7%) being seen within 15 days (Table 2). Follow-up appointments at the Specialized Care Service for People with an Ostomy occurred at intervals ranging from less than one week to more than one month, with 5 participants (13.2%) waiting over a month for their return visit. Most participants had attended four or more consultations in the past six months (29; 76.3%) and three or more consultations per year (32; 84%).

Among the 19 participants with a temporary ostomy, 11 (58%) were awaiting intestinal reconstruction surgery. The reported reasons for the delay included: awaiting a colonoscopy (3; 27.2%), scheduling of the procedure (4; 36.4%), medical evaluation (2; 18.2%), and other unspecified reasons (2; 18.2%).

**Table 2** – Access of people with an ostomy to specialized services and equipment, by sex (n=38). Belo Horizonte, MG, Brazil, 2025

Variable	Male n (%)	Female n (%)	Total n (%)
Sufficient number of pouching systems			
No	2 (11.8)	6 (28.6)	8 (21.1)
Yes	15 (88.2)	15 (71.4)	30 (78.9)
Satisfaction with the quality of the equipment			
No	1 (5.9)	3 (14.3)	4 (10.5)
Yes	16 (94.1)	18 (85.7)	34 (89.5)
Number of nurse consultations per year (times)			
≥ 3	14 (82.4)	18 (85.7)	32 (84.2)
2	2 (11.8)	2 (9.5)	4 (10.5)
1	1 (5.9)	1 (4.8)	2 (5.3)
Waiting time between hospital discharge and first consultation (days)			
Up to 15	12 (70.6)	16 (76.2)	28 (73.7)
16 to 30	4 (23.5)	4 (19.0)	8 (21.1)
31 to 90	1 (23.5)	1 (19.0)	2 (5.3)
Waiting time between first consultation and first follow-up visit			
Less than one week	2 (11.8)	2 (9.5)	4 (10.5)
One week to 15 days	6 (35.3)	9 (42.9)	15 (39.5)
15 days to one month	7 (41.2)	7 (33.3)	14 (36.8)
> one month	2 (11.8)	3 (14.3)	5 (13.2)
Number of appointments in the first six months			
Up to 3 times	1 (5.9)	5 (23.8)	6 (15.8)
≥ 4 times	14 (82.4)	15 (71.4)	29 (76.3)
Does not know	2 (11.8)	1 (4.8)	3 (7.9)
Attends collective environments			
No	4 (23.5)	4 (19.0)	8 (21.1)
Yes	13 (76.5)	17 (81.0)	30 (78.9)

Self-irrigation was indicated for five participants with a permanent left-sided colostomy, of whom two reported performing the procedure. A sense of adaptation to life with an ostomy was expressed by 25 participants (65.8%), and 30 (78.9%) reported attending public or shared environments (Table 3).

**Table 3** – Association between adaptation to life with an ostomy and sociodemographic and clinical variables (n=38). Belo Horizonte, MG, Brazil, 2025

Variable	Total	No	Yes	p-value*
	n (%)	n (%)	n (%)	
Age <sup>†</sup>	60,71 (31-96)	61.23 (42-96)	60.44 (31-88)	0.325 <sup>‡</sup>
Years of schooling <sup>§</sup>	8 (3-11)	9 (3-11)	8 (4-11)	0.828 <sup>‡</sup>
Time living with na ostomy <sup>§</sup>	1 (0-5)	1 (0-2)	1 (0-6.5)	0.325 <sup>‡</sup>
Sex				
Female	21 (100.0)	8 (38.1)	13 (61.9)	0.575 <sup>  </sup>
Male	17 (100.0)	5 (29.4)	12 (70.6)	
Ostomy temporality				
Temporary	19 (50.0)	7 (53.8)	12 (48.0)	
Permanent	14 (36.8)	3 (23.1)	11 (44.0)	0.279 <sup>  </sup>
Does not know	5 (13.2)	3 (23.1)	2 (8.0)	
Type of ostomy				
Ileostomy	8 (21.1)	3 (23.1)	5 (20.1)	0.666 <sup>  </sup>
Colostomy	20 (52.6)	8 (61.5)	12 (48.0)	
Urostomy	3 (7.9)	1 (7.7)	2 (8.0)	
Does not know	7 (18.4)	1 (7.7)	6 (24.0)	
Previous complication				
No	11 (28.9)	2 (15.4)	9 (36.0)	0.171 <sup>¶</sup>
Yes	27 (71.1)	11 (84.6)	16 (64.0)	
Application of the pouching syste				
No	9 (23.7)	5 (38.5)	4 (16.0)	0.127 <sup>¶</sup>
Yes	29 (76.3)	8 (61.5)	21 (84.0)	
Attends collective environments				
No	8 (21.1)	3 (23.1)	5 (20.0)	0.568 <sup>¶</sup>
Yes	30 (78.9)	10 (76.9)	20 (80.0)	

\*Significance level adopted: p<0.05; <sup>†</sup>Mean, minimum – maximum;

<sup>‡</sup>Mann-Whitney test; <sup>§</sup>Median, P25-P75; <sup>||</sup>Pearson's chi-square test; <sup>¶</sup>Fisher's exact test

No statistically significant association was found between adaptation to the ostomy and socio-demographic variables. However, a statistically significant association was observed between receiving a sufficient number of ostomy supplies and feeling adapted to life with an ostomy. In contrast, dissatisfaction with the physician's care was associated with poorer adaptation to the new condition (Table 4).

**Table 4** – Association between adaptation to life with an ostomy and follow-up variables in the service (n=38). Belo Horizonte, MG, Brazil, 2025

Variable	Total	No	Yes	p-value*
	n (%)	n (%)	n (%)	
Medical appointment at the service				
No	26 (68.4)	11 (84.6)	15 (17.1)	0.117 <sup>†</sup>
Yes	12 (31.6)	2 (15.4)	10 (40.0)	
Satisfaction with physician's performance				
No	27 (71.1)	12 (92.3)	15 (60.0)	0.039 <sup>†</sup>
Yes	11 (28.9)	1 (7.7)	10 (40.0)	
Appointment with social worker				
No	17 (44.7)	6 (46.2)	11 (44.0)	0.584 <sup>†</sup>
Yes	21 (55.3)	7 (53.8)	14 (56.0)	
Time between hospital discharge and first appointment (days)				
Up to 15	28 (73.7)	11 (84.6)	17 (68.0)	
16 to 30	8 (21.1)	2 (15.4)	6 (24.0)	0.436 <sup>‡</sup>
31 to 90	2 (5.3)	0 (0.0)	2 (8.0)	
Appointments within six months				
≥ 4	29 (76.3)	10 (76.9)	19 (76.0)	
2 to 3	6 (15.8)	1 (7.7)	5 (20.0)	0.329 <sup>‡</sup>
Does not know	3 (7.9)	2 (15.4)	1 (4.0)	
Nurse appointments/year				
≥ 3	32 (84.2)	11 (84.6)	21 (84.0)	
2	4 (10.5)	1 (7.7)	3 (12.0)	0.830 <sup>‡</sup>
1	2 (5.3)	1 (7.7)	1 (4.0)	
Sufficient number of pouching systems				
No	8 (21.1)	6 (46.2)	2 (8.0)	0.011 <sup>†</sup>
Yes	30 (78.9)	7 (53.8)	23 (92.0)	
Quality of pouching systems				
No	4 (10.5)	2 (15.4)	2 (8.0)	0.424 <sup>†</sup>
Yes	34 (89.5)	11 (84.6)	23 (92.0)	

\*Significance level adopted: p<0.05; <sup>†</sup>Fisher's exact test; <sup>‡</sup>Pearson's chi-square test

## Discussion

The assessment of healthcare services has increasingly been used as a management support tool within the Brazilian Unified Health System. It aims to help identify problems, guide planning, and measure the impact of policies, programs, services, and actions on the population's health status<sup>(8)</sup>.

Self-care practices can be interpreted as indicators of both functional ability and the quality of care received<sup>(9)</sup>. Including indicators related to self-care as a complementary measure in the assessment of specialized services for people with ostomies represents an advancement in the care evaluation model, as it acknowledges the central role of ostomates in defining care quality.

Overcoming social barriers is essential for self-care to go beyond its technical aspects and effectively contribute to rehabilitation and quality of life<sup>(10)</sup>. Social reintegration not only enhances quality of life but also serves as a meaningful indicator of therapeutic success<sup>(11)</sup>.

An evaluation involving 2,504 users revealed that many ostomates felt unprepared to manage self-care and face daily challenges. The main difficulties reported included proper use of pouching systems, leakage management, diet, and hygiene. Most accounts indicated that the care received was almost exclusively technical and physical, with little or no attention given to mental health or to the emotional aspects related to this new life condition. Initial reactions to the ostomy — such as fear, shame, and loss of identity — were not adequately addressed by healthcare services<sup>(12)</sup>.

The worldview of individuals with an ostomy influences their rehabilitation process<sup>(13)</sup>. *Worldview* refers to the set of beliefs, values, experiences, cultural background, life history, and personal meanings that individuals construct over time, shaping how they interpret themselves, others, and the world around them. It is a subjective lens through which people perceive, evaluate, and respond to life events, including illness, loss, and bodily changes. Healthcare professionals often overlook certain ostomy-related issues during patient care, partly due to a lack of training or awareness of existing support systems. However, understanding the factors that shape worldview and influence care is becoming increasingly important<sup>(14)</sup>.

Individuals whose worldview is grounded in the acceptance of bodily impermanence and who view health as dynamic tend to cope better with physical

changes. In contrast, those who adopt a worldview based on rigidity or perfectionism are more likely to face challenges in accepting the new body with an ostomy. This worldview also influences how individuals perceive the gaze of others — whether anticipating judgment, exclusion, or acceptance — which can affect self-esteem, sexuality, social interaction, and reintegration into work or public life<sup>(15)</sup>.

Spiritual or religious beliefs can provide emotional support or cause distress when the ostomy is perceived as a form of punishment. In a study conducted in Saudi Arabia, people with ostomies reported quality-of-life impacts, particularly related to the practice of Hajj and Ramadan fasting, underscoring the need to adapt religious practices to the new health condition<sup>(16)</sup>. Another study identified a significant association with the physical, psychological, social, and spiritual domains, affecting the quality of life and care practices of individuals with ostomies and their families<sup>(17)</sup>.

Individuals with an elimination ostomy are the primary stakeholders in the quality of care they receive and in the materials provided (pouching systems and adjunctive products). Thus, the findings confirm that rehabilitation extends beyond self-care practices. It requires a multidisciplinary approach, with professionals who possess both the knowledge and sensitivity to care for people with ostomies<sup>(16)</sup>.

Nurses with expertise in ostomy care — such as certified wound, ostomy, and continence nurses — are a critical factor in delivering high-quality care. Nurses working in surgical units may offer non-specialized care that does not fully address the needs of people with ostomies, often due to limited knowledge, insufficient skills, or a lack of up-to-date local clinical guidelines. Access to such guidelines is essential for providing evidence-based care and avoiding arbitrary or inadequate practices<sup>(18)</sup>.

The presence of nurses in caring for people with ostomies, especially during initial contact with specialized services, is particularly important. This finding is supported by the literature, which highlights

the central role of nurses in the rehabilitation process and underscores their strategic position as care coordinators within the multidisciplinary team<sup>(19)</sup>. However, some professionals may lack the necessary skills to effectively assume this leadership role.

Standardized ostomy care provides benefits, but its implementation is often hindered by variations in resource availability. Although there is evidence to guide care, standardization is limited — particularly in primary care. At this level of care, service delivery may be inconsistent, depending on the nurse's training and experience. People with ostomies tend to have greater needs in the early months following surgery, which may be exacerbated by complications<sup>(19)</sup>.

Nurses can offer practical and psychological support and encourage adaptation. Caring for people with ostomies requires advanced skills and a trusting relationship. These competencies highlight the importance of having a certified wound, ostomy, and continence nurse involved in care delivery<sup>(20)</sup>. This professional can help ease the rehabilitation journey for people with ostomies.

Many people with ostomies experience sleep disturbances and difficulties in their relationships with family and friends due to physiological and psychological distress. In addition, some do not receive proper guidance during hospitalization regarding self-care, diet, or sexual activity. As a result, they may struggle to cope with these challenges after hospital discharge, including financial difficulties in acquiring pouching systems and adjunctive supplies<sup>(21)</sup>. The enterostomal therapy nurse — particularly the one responsible for the specialized service — can help mitigate these challenges and implement measures to prevent complications.

Peristomal dermatitis is a common complication experienced by people with ostomies<sup>(22)</sup>. It is multifactorial, and its causes generally go beyond the physical effects of appliance changes and routine management of the pouching system. Therefore, the nurse's assessment must be thorough and holistic, incorporating a complete clinical history and a review

of contributing factors, along with an evaluation of the change schedule and the technique used<sup>(23)</sup>.

Several manufacturers have recently developed pouching systems with flanges that contain additives designed to protect and treat the skin. Enterostomal therapy nurses should remain attentive to emerging evidence regarding the effects of these additives on peristomal skin health<sup>(24)</sup>. People with ostomies need to use appropriate products tailored to their individual needs, including the pouching system that offers the best fit and most effective seal with the skin<sup>(23)</sup>.

The appropriate pouching system should prevent leakage and maintain peristomal skin integrity, without causing discomfort or distress. Support from healthcare professionals also enhances the individual's ability to become more skilled in changing appliances and maintaining healthy skin. These two factors can make the pouching system less likely to leak. Another relevant point is the quantity of appliances and supplies available to the individual<sup>(23)</sup>.

Satisfaction with the quantity and quality of supplies indicates that the service meets the minimum criteria for safety and comfort. The number of pouching systems received influenced adaptation to the ostomy. In Brazilian Unified Health System, these supplies are provided free of charge, with a recommendation of 10 drainable or 30 closed-end pouches per month. At the studied facility, nurses adjusted the quantity according to individual needs. When properly indicated and periodically reassessed, these supplies promote confidence, satisfaction, and help prevent complications<sup>(25)</sup>. Hygiene and handling practices may also be enhanced by access to technology, such as mobile applications, when users are outside of healthcare institutions<sup>(26)</sup>.

Access to specialized professionals, such as surgeons, nurses, and essential diagnostic tests, is a frequent challenge in the follow-up of people with ostomies, particularly in the post-discharge period. The literature reports that access to specialized nurses varies by region and is especially limited after hospital discharge<sup>(12)</sup>.

The disparities experienced by people with ostomies may reflect unequal access to surgical care, underscoring the need for intersectoral protocols to ensure access to ostomy reversal when indicated, thereby preventing the chronicity of a temporary condition. The reversal of temporary ostomies not only restores physiological function but also significantly contributes to individuals' psychological and social well-being<sup>(27)</sup>.

Rehabilitation strategies should begin during hospitalization. The adoption of a structured program — including clinical assessment, health education, ostomy care, specific support, discharge review, medication reconciliation, and the use of checklists, referrals, and post-discharge follow-up — has proven effective in preparing patients for discharge. Participants in such programs demonstrated greater self-efficacy in ostomy management, improved quality of life, and reduced complications and unplanned readmissions<sup>(28)</sup>.

Many users reported not receiving straightforward, sufficient, or understandable information at the time of surgery or during follow-up care. Many felt unprepared to manage self-care and face daily challenges, such as proper use of the pouching system, leakage management, diet, and hygiene. The data suggest that postoperative guidance should be reinforced with ongoing support over time. Lack of follow-up shortly after discharge may impair individuals' confidence and comfort in managing their ostomy, especially during the early postoperative months, and negatively affect their ability to perform self-care<sup>(12)</sup>.

Male participants and those over the age of 70 demonstrated lower ability to identify complications and make decisions, highlighting the need for transitional care after hospital discharge, especially during the first month. Interventions should focus on promoting self-efficacy, self-management, and social and environmental support. Moreover, the quality of life of people with an ostomy can be enhanced through pre-operative education, strengthened care, family relationships, self-acceptance, and social participation<sup>(29)</sup>.

User satisfaction is an indicator of care qualit-

ty and requires investment in resources and professional training to meet specific demands<sup>(20)</sup>. Service quality dimensions that emphasize a person-centered environment and an efficient service delivery system should be integrated and strengthened by managers. This approach tends to increase user satisfaction<sup>(30)</sup>. Investments are urgently needed in cost-benefit analyses and comparative evaluations of the effectiveness of service quality dimensions on clients' behavioral intent<sup>(28)</sup>.

This study is justified by the importance of understanding the quality of care from the user's perspective — the primary beneficiary of the service. Its findings will provide input for discussions among the professionals involved and support decision-making by managers to address system weaknesses.

## Study limitations

The study experienced substantial sample loss (38 out of 87 eligible participants), influenced by the use of telephone-based data collection and the data collection period (December to January). While telephone interviews may encourage more candid responses, they may also introduce bias due to the respondent's reduced sense of commitment. The small sample size may have resulted in selection bias and limited the potential for more robust analyses. The data collection instrument was not formally validated, highlighting the need for validation in future studies. The fact that the study was conducted in a single specialized service limits the generalizability of the findings. Moreover, the absence of healthcare professionals' perspectives restricts the understanding of care quality, reinforcing the need for future mixed-methods studies that incorporate both users' and professionals' perspectives.

## Contributions to practice

This study contributes to nursing practice in multiple dimensions. In the dimension of care, by identifying ostomates' perception of care quality, it

offers support for nurses to adjust their care practices, aligning them more closely with users' needs, expectations, and experiences, thereby strengthening selfcare. The findings related to access to the service, professionals, and supplies contribute to healthcare management by supporting actions that ensure comprehensive access to care. They also serve as input for nursing education by identifying areas that need to be strengthened in training and professional development, especially in ostomy care, health education, and quality of care evaluation.

## Conclusion

From the perspective of ostomates, access to the service, supplies, and nursing consultations was considered adequate. The factors associated with adaptation were the availability of a sufficient number of supplies and dissatisfaction with the physician's performance.

## Authors' contributions

Study conception and design or data analysis and interpretation; drafting of the manuscript or critical revision for important intellectual content; final approval of the version to be published: Borges EL, Otoni CC, Lisboa CR, Spira JAO. Agreement to be accountable for all aspects of the manuscript in ensuring that any issues related to the accuracy or integrity of any part of the work are properly investigated and resolved: Borges EL, Spira JAO.

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