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LIVING WITH AN INTESTINAL OSTOMY AND URINARY INCONTINENCE

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ABSTRACT

Objective: to understand how aged people with intestinal ostomies experience this situation together with urinary incontinence.
Method: a qualitative, descriptive and exploratory research study, developed with 77 aged individuals with intestinal ostomies assisted by the Unified Health System, in four municipalities from the Metropolitan Region of Florianópolis. Data collection was conducted using semi-structured interviews from October 2019 to February 2020. The theoretical framework used was Dorothéa Orem's Self-Care Theory and the data were submitted to content analysis, in its thematic modality.
Results: the analysis allowed generating three thematic categories: 1) Feelings generated by the intestinal ostomy and urinary incontinence: acceptance, denial, fear, insecurity, constraints experienced due to the ostomy and to the urinary incontinence symptoms; 2) Lifestyle changes; and 3) Deficit in self-image.
Conclusion: it was evidenced that, for most of the research participants, it is difficult to accept the experience of living with an intestinal ostomy and urinary incontinence, which generally produce negative feelings. However, the participants proved to be resilient and able to adapt to the changes in lifestyle. Many of these behaviors are due to the health professionals' important contribution in providing them the necessary attention, encouraging self-care strategies in both situations.

DESCRIPTORS: Aged. Ostomy. Colostomy. Ileostomy. Surgical ostomies. Urinary incontinence.

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CONVIVENDO COM ESTOMIA INTESTINAL E A INCONTINÊNCIA URINÁRIA

RESUMO

Objetivo: compreender como o idoso com estomia intestinal vivencia essa situação em conjunto com a incontinência urinária.
Método: pesquisa qualitativa, descritiva e exploratória, desenvolvida junto a 77 idosos com estomia intestinal atendidos pelo Sistema Único de Saúde, em quatro municípios da Região Metropolitana de Florianópolis. A coleta de dados foi realizada de outubro/2019 a fevereiro/2020, por meio de entrevista semiestruturada. O referencial teórico utilizado foi a Teoria de Autocuidado de Dorothéa Orem; os dados foram submetidos à análise de conteúdo, na modalidade temática.
Resultados: a análise permitiu a geração de três categorias temáticas: 1) sentimentos gerados pela estomia intestinal e pela incontinência urinária: aceitação, negação, medo, insegurança, constrangimentos vivenciados pela estomia e os sintomas da incontinência urinária; 2) alterações do estilo de vida; 3) déficit na autoimagem.
Conclusão: evidenciou-se que para a maioria dos participantes da pesquisa é difícil aceitar a vivência com estomia intestinal e incontinência urinária, que geralmente lhes provocam sentimentos negativos. No entanto, os participantes mostraram-se resilientes e aptos a se adaptar às mudanças no estilo de vida. Muitos desses comportamentos se devem à importante contribuição dos profissionais da saúde em dar-lhes a necessária atenção, estimulando estratégias de autocuidado em ambas as situações.

DESCRITORES: Idoso. Estomia. Colostomia. Ileostomia. Estomas cirúrgicos. Incontinência urinária.

VIVIR CON UNA ESTOMÍA INTESTINAL E INCONTINENCIA URINARIA

RESUMEN

Objetivo: comprender de qué manera los ancianos con ostomías intestinales viven esta situación junto con la incontinencia urinaria.
Método: investigación cualitativa, descriptiva y exploratoria, desarrollada con 77 ancianos con estomías intestinales atendidos por el Sistema Único de Salud en cuatro municipios de la Región Metropolitana de Florianópolis. La recolección de datos se realizó entre octubre de 2019 y febrero de 2020 por medio de entrevistas semiestructuradas. El marco de referencia teórico empleado fue la Teoría de Autocuidado de Dorothéa Orem; los datos se sometieron a análisis de contenido, en su modalidad temática.
Resultados: el análisis permitió generar tres categorías temáticas: 1) Sentimientos generados por la estomía intestinal y por la incontinencia urinaria: aceptación, negación, miedo, inseguridad, restricciones experimentadas a raíz de la ostomía y de los síntomas de la incontinencia urinaria; 2) Cambios en el estilo de vida; y 3) Déficit en la imagen propia.
Conclusión: se hizo evidente que a la mayoría de los participantes de la investigación les resulta difícil aceptar la vida con una estomía intestinal e incontinencia urinaria, que generalmente les provocan sentimientos negativos. Sin embargo, los participantes se mostraron resilientes y aptos para adaptarse a los cambios en el estilo de vida. Muchos de estos comportamientos se deben al importante aporte de los profesionales de la salud al brindarles la atención necesaria, estimulando estrategias de autocuidado en ambas situaciones.

DESCRIPTORES: Anciano. Estomía. Colostomía. Ileostomía. Ostomías quirúrgicas. Incontinencia urinaria.

INTRODUCTION

Intestinal ostomies consist of surgically opening the abdominal wall to the outside, in whose opening an external bag is attached to collect the effluents[1], either temporarily or permanently. The diseases that may require intestinal ostomies are intestinal and rectal neoplasms, inflammatory bowel diseases and diverticular diseases, among others[2–3]. The number of people with intestinal ostomies is increasing due to the rise of these diseases, in which such a procedure may mean extension of life and/or a possibility of cure.

However, intestinal ostomies usually exert an impact on the person's daily life, independence and autonomy, in addition to interfering with other aspects of daily living. This impact can be enhanced in aged individuals, causing greater self-care demand, mainly in relation to handling the ostomy, caring for the peristomal skin and handling the collection equipment and its adjuvants. It can also cause a decrease in self-esteem due to the body changes, leading to social isolation[4].

The health professional closest to the person with an ostomy and their family is the nurse, who must act as a link between the aged person, the family and the multiprofessional team. In this sense, health professionals must be trained to assist the various care demands of this specific population, so that care and monitoring are effective, comprehensive and, above all, humanized, always aiming at improving quality of life[4].

Aged people with ostomies face a variety of physical and psychological challenges due to the primary disease, to the surgery and to the presence of an intestinal ostomy that can compromise their quality of life. A study carried out with 55 patients with intestinal ostomies, of which 23 (41.8%) were aged 70 years old or over, showed that these individuals presented a significantly lower perception of quality of life than those with urostomies, mainly due to their impact on social relationships with family members and friends, self-esteem and self-image. Therefore, evaluating the quality of life standard and its determinants is an essential step to better understand these patients and improve the health care provided[5].

Aged people may also present other dysfunctions, such as Urinary Incontinence (UI), which expands the negative impact on their quality of life, with the possibility of also causing greater limitations in the basic and instrumental activities of daily living. In addition to the physical limitations, these conditions change their perception of health, independence and self-image, increasing the need for self-care. This entire set of situations experienced by the patient can lead to depression and to low self-esteem[6].

A cross-sectional study carried out with 227 women, of which 120 (52.9%) were of advanced age, evaluated the prevalence of double incontinence (UI and fecal incontinence), associated factors and the impact on quality of life. Among the findings, the prevalence of double incontinence in 32 (14.1%) participants stands out, whose associated factors were as follows: higher number of comorbidities, polypharmacy, presence of rectocele and high Body Mass Index (BMI). There was no association between double incontinence and worse overall health perception, but there was quality of life impairment, mainly in social interaction and behavior[7].

Thus, when an aged individual has an intestinal ostomy associated with the UI symptoms, these health deviations produce changes in self-concept and self-image and generally compromise the course of the basic and instrumental activities of daily living, their social interactions and quality of life. From this perspective, the demands for self-care increase, and this aged person or family caregiver is not always prepared to develop it.

Given the above, the health professionals' role is reinforced as indispensable to recover the patient's health, implementing assistance and educational practices that value self-care. It is up to nurses to provide Nursing care. For such purpose, nurses will adopt the help methods recommended

for: “acting or doing for the other; guiding the other; supporting the other; providing an environment that promotes personal development, in terms of becoming capable of satisfying future or current demands for action; and teaching the other”[8:169], in order to help people take care of themselves, focusing their actions on the self-care requirements.

Thus, the following research question arose: which is the impact of intestinal ostomy associated with urinary incontinence on the aged individuals’ living process? Therefore, this study aimed at understanding how aged people with intestinal ostomies experience this situation together with urinary incontinence.

METHOD

A descriptive and exploratory study with a qualitative approach, carried out in four municipalities from the Metropolitan Region of Florianópolis, in the places responsible for registering people with some type of ostomy, as well as for the management and distribution of materials for the care of ostomies in each city.

The study participants were 77 aged individuals with intestinal ostomies, in an intentional sampling in the records of the services from each municipality. The invitation to participate in the research was made by telephone to all the aged individuals who met the inclusion criteria: age equal to or greater than 60 years old; both genders; use of permanent or temporary intestinal ostomies, with a use period of at least six months; preserved cognition, according to the Mini Mental State Examination (MMSE) score; and living in the Metropolitan Region of Florianópolis. The exclusion criteria were as follows: aged individuals with neurological diseases that could interfere with data collection, or with acute polypathologies, and hospitalized aged individuals.

Data collection took place between October 2019 and February 2020, through semi-structured interviews with the aged individuals, most often accompanied by a family member, caregiver or friend. It should be noted, however, that only the aged participants answered the questions. The interviews were carried out by the research author, mostly at the participants’ homes, on previously scheduled days and times.

An interview script was developed with closed questions to characterize the participants, as well as with semi-structured questions: Tell me about the diagnosis of your primary disease until performance of the intestinal ostomy. What does it mean for you to use an ostomy bag? How was that experience like? Does UI interfere with your daily routine? How is self-care conducted with an intestinal ostomy and UI? Did you receive any guidance from health professionals and do you follow their guidelines? Based on these answers, it was possible to explore the aged individuals’ experience with intestinal ostomies and UI, in addition to knowing the self-care strategies employed.

With a mean duration of 50 minutes, the interviews were audio-recorded and then literally transcribed, maintaining fidelity of the information. During the search for informants, 34 refusals were recorded: 18 for being hospitalized or debilitated, 11 for having had ostomy reversal, four for also presenting urostomies and one for having moved to another city.

The data were analyzed through content analysis, in its thematic modality[9], and interpretation of the textual data was guided by Dorothéa Orem’s Theoretical Framework[10]. In the pre-analysis, a fluctuating and comprehensive reading of all the interviews was carried out. Subsequently, an exhaustive reading took place in order to organize the thematic units. When exploring the material, the contents of the thematic units were grouped and classified to define the pre-categories, considering the comprehension nuclei of the text. In the stage for the treatment and interpretation of the results obtained, it was possible to highlight the diverse information, observing the agreement and soundness of the thematic categories and subcategories. The entire process was carried out manually, without the aid of any software.

The final analysis resulted in the elaboration of two main thematic axes: the experience of aged people with intestinal ostomies and urinary incontinence; and self-care of aged individuals with intestinal ostomies and urinary incontinence. This paper only contemplates the first thematic axis, which consists of the following categories: feelings generated by the intestinal ostomy and urinary incontinence; changes in lifestyle; and deficit in self-image.

The project was approved by the Committee of Ethics in Research with Human Beings. The participants signed the Free and Informed Consent Form and were informed about the research risks and benefits, in addition to all the other ethical aspects that permeate it. The participants were guaranteed anonymity by using the alphanumeric system to identify them: the letter P and the order number of the interviews.

RESULTS

Characterization of the Participants

Of the 77 aged individuals with intestinal ostomies, 42 were female and 35 were male, aged between 60 and 97 years old, with 45 married individuals. In addition to that, 60 aged individuals had a colostomy-type intestinal ostomy and 17, an ileostomy; of these, 45 presented UI symptoms within a period of between one month and 19 years of symptoms.

Below are the results of the categories described.

Feelings generated by the intestinal ostomy and urinary incontinence

In the analysis of this category, some feelings experienced by the aged people with intestinal ostomies and UI were observed. As for discovery of the ostomy, the participants reported different feelings. In some, conformism and acceptance of the intestinal ostomy, as expressed in the following statements:

[…] *It's my life; if I didn't use it, I wouldn't be here anymore; I fight to live* (P51).

[…] *I accepted from the beginning, I wasn't angry; for me it's normal life* (P3).

On the other hand, other aged individuals showed dissatisfaction with the need for the intestinal ostomies, reporting feelings of sadness, insecurity and denial; they considered it an unpleasant situation, as can be seen in these reports:

[…] *It's an inconvenience here; it's boring, I didn't settle for this bag* (P19).

[…] *It's very unpleasant to walk around with this here, it's not the right place, feces are not to go out through here, but through somewhere else* (P34).

The feelings of insecurity mainly originate in the fear of effluent leakage, of other people smelling the odor, generating a negative impact, feelings that can generate embarrassment with the new condition, with repercussions on these participants' quality of life.

[…] *I'm insecure: I'm always afraid, nervous, agitated, God forbid something happens* [loss] *at church* (P23).

[…] *I don't want to smell it, I don't want to go to the salon to get my hair done, I don't want to go to church so that others can smell something on me, I don't want to, I prefer to stay at home. If it's not so cool, because what I've already been through... I saw myself in a mess* (P46).

These are feelings that individuals with intestinal ostomies end up experiencing and due to which they eventually distance from people and from the places they used to frequent, leading them to social and, sometimes, even family withdrawal. Another aspect to be highlighted is the feeling of being afraid of using public or unfamiliar restrooms, due to the lack of adapted facilities, as illustrated in these reports:

[…] *Not having a proper bathroom, this is the difficulty of the ostomized; going out and not finding a place to wash the bag... but it's part of it* (P3).

[…] *And we have no specially adapted bathroom for that. At home I have an adapted bathroom, my family did it* (P15).

It is noticed that these aged individuals express the feeling of being afraid of going some places, due to the lack of adapted restrooms. On the other hand, in some cases, the family members end up adapting their own bathrooms, to facilitate hygiene of the collection bag, easing the home daily routine.

Another issue raised about the intestinal ostomy refers to the hope of reversal. Some participants stated that they still have high expectations of undergoing the ostomy reversal surgery, as revealed in these statements:

[…] *The concern is important, I'm anxious to make this reversal, that time passes by fast to do it* (P24).

[…] *So I have a hope to reverse the bag, today I live day by day* (P31).

In addition to the presence of the intestinal ostomy, some research participants reported the existence of UI symptoms, increasing their embarrassing situations, as can be seen in these reports:

[…] *It bothers me, I always feel wet, I'm afraid to sit here or there, I've never ironed my clothes, but it's unpleasant, double work: the bag and the diaper* (P25).

[…] *I don't like it, because this urine is there wet, even more getting old* (P3).

[…] *It doesn't bother much, because all the ladies I know have the same problem. I've already talked to the doctor, but she never referred me for treatment* (P29).

The statements highlighted three problems: the first refers to how unpleasant urine loss is, reflecting the feelings of restlessness, embarrassment and fear of getting wet. The second concerns unawareness of the aged individuals themselves, who consider UI a normal condition for their age; and the third is lack of knowledge in the health professionals, who fail to refer the patient to conservative treatments.

The feelings generated by the use of intestinal ostomies can influence the way in which each person understands and experiences their daily life, such as those with UI. For the aged individuals who have not yet adapted or that are not satisfied with the ostomy, there is always the hope of reversal, despite the complications in restoring intestinal transit. For this, a detailed analysis of the indication and pre- and post-operative care is necessary to achieve reestablishment of the effluents' path in the body. It is no different for the UI symptoms: there are also limitations that involve this topic, such as the taboo on the subject matter, as the symptom is still concealed by aged people, underestimated by the family members and ignored by the health professionals.

Changes in lifestyle

This category groups the interviewees' statements about the main consequences of the intestinal ostomies and UI in their lives. These conditions can generate physical, psychological and social changes, caused by loss of control over the sphincters and body image.

With regard to professional life, the need for changes and/or interruption of daily activities after the use of an intestinal ostomy was reported. Some people needed to early interrupt their professional activities, generating feelings of loss and frustration. For example:

[…] *I started having medical leaves, forensic procedures, I couldn't even make, I don't know, 10 or 15 steps... it still bothers me today, because then I got my clothes soiled, I gave up* (P2).

[…] *I don't like having it* [the ostomy]*, because I wanted to work, but with the bag in my service it's not possible* (P45).

From the moment that the patients' life changes with the new condition of being a person with an ostomy, new challenges arise. Therefore, another issue raised refers to changes in the development of household chores, as attested in these reports:

[…] *House chores like this, I don't do everything I used to do, I can't bend down too much, I'm afraid of getting hurt* (P65).

[…] *I used to do a lot of work at my sisters' house, weeded the yard, painted the house, worked on the roof, but now it stopped suddenly and I don't do it anymore* (P16).

In addition to these aspects, others were identified, such as changes in the daily activities of aged people with ostomies, which include adaptations when taking baths and sleep changes. The following statements portray this reality:

[…] *I shower like this: I wash my hair first so I don't get the bag wet, I dry my hair, then I take the soap and wash from the waist down, remove the foam, take a cloth and wash from here, and then I don't wet the bag* (P59).

[…] *I clean the bag at dawn; sometimes I need to get up three times to clean, that's boring* (P27).

Another point that was observed in the interviews with the participants was the urinary symptoms interfering with sleep:

[…] *I don't have urine loss, but I get up four or five times during the night to urinate* (P11).

[…] *I go to the bathroom without wanting to urinate, so I don't have any risk for urine loss* (P7).

The UI symptom negatively interfered in these aged individuals' sleep quality: they ended up adapting new routines, such as waking up at night to change a diaper or emptying the effluents from the ostomy collection bag and for the need to urinate. These adverse situations impair their sleep quality.

Another change in the lives of these aged individuals is their impaired sexual performance resulting from physiological and bodily changes, due to loss of libido and to impotence:

[…] *I got no erection; darn! This put me down, I put the penile prosthesis, because the doctor said that during the surgery some nerve was removed nearby* (P69).

[…] *The fear is that someone will go there and rip me apart; people don't know, but I'm sorry, kind of: how am I going to feel with someone looking at my belly* (P40).

This category shows the participants' feelings, as the changes in sexual performance, mainly for males, were especially related to erectile dysfunction, while for females, the concern was in relation to the partner's reactions to the altered body image.

The eating habits are also modified after the intestinal ostomy, due to the relationship between the quality and amount of food ingested, which directly interferes with the volume and consistency of the effluent, the formation of gases and the emergence of bad odors. They also change when there is intestinal constipation, which can generate discomfort, as shown in these statements:

[…] *Eating was reduced; when I'm at home I eat at ease, only when I go out do I take a lot of care, so that I don't fill my bag* (P63).

[…] *I always try to adapt a diet so that my body doesn't get stuck, you know? I eat a lot of fiber, so it doesn't cause discomfort* (P71).

Another aspect to highlight is the change in social life, as some aged individuals with ostomies end up restricting their leisure activities. The reason for deprivation is generally related to insecurity, shame and difficulty in self-cleaning, in addition to being afraid of facing public places, due to the fear of being stigmatized, contributing to social isolation. For example:

[…] *Sometimes I think about going somewhere, but I don't go, because I don't feel confident enough to go out like this, the bags aren't holding up* (P39).

[…] *Look, it's a nuisance; my friends have a house with a pool... bathe in the sea, I didn't do it anymore because of the bag, because then it can get loose* (P37).

Corroborating this social issue, it was found that aged people with ostomies prefer to remain isolated, without participating in some activities for finding the place inappropriate or for fear of public embarrassment. However, they also noticed the distancing of some people, as revealed in the lines below:

[…] *I had partners, who participated in my life... at first they came to support, but soon they disappeared, and you see... this already changes your psychology* (P24).

[…] *This year, no one came to invite me for a walk, because they already know that I have a colostomy bag, and I even think it's people's prejudice* (P31).

Unfortunately, people with intestinal ostomies face prejudice that often comes from those least expected. This is very painful because, in addition to the adaptations and changes, they need to face people's judgment in their social environment.

Another modification is in the way of dressing, to conceal the collection bag or diaper, in the case of those with UI. The feeling is of shame due to the volume of effluents from the bag and diaper. Therefore, people change their outfits and stop wearing the clothes they used to wear, as shown in these statements:

[…] *I really liked walking in jeans, but now I can't* (P36).

[…] *If I got better* [referring to UI] *I could only wear my underwear that I always wore; the diaper is uncomfortable, I need to put on wider shorts* (P20).

This type of strategy harms body aesthetics, affecting self-esteem. In due course, the next category to be described will be about the body image deficit.

Deficit in self-image

In addition to the impact caused by the intestinal ostomy and by the natural aging process, many aged individuals presented low self-esteem and anxiety due to their altered body image. It should be clarified that the intestinal ostomy is an alteration in the normal physiology of effluent elimination, requiring the use of an external collection bag.

[…] *I wasn't in the mood for the bag, I was prejudiced against myself: talking, exposing, I thought it was a strange body, you know?* (P31).

[…] *At the beginning I was very devastated, and I even made a little pillow to put on the* other *side, to stay the same, but now it doesn't even show up* (P4).

Another condition related to the self-image deficit is the aged individuals' concern with the way others see the ostomy. Sometimes, with prejudice for being a "different" person, as revealed in these lines:

[…] *People keep staring... one day, in the health unit, a woman was looking at me; another day, coming from the fishmonger, a couple started to laugh* (P59).

[…] *I've already been somewhat embarrassed; when you walk into a store with people looking and commenting and they think you stole something*, [but it is] *the hernia* (P37).

Thus, it is necessary to go further, to discuss the problem in order to break down the barriers. Unfortunately, society is very attached to stereotypes and standards.

Another condition raised by the participants was lack of control, both regarding the ostomy and urine loss; in other words: there is no more sphincter control, generating the sensation of being a child again:

[…] *It's very difficult, lack of control* [over the ostomy] (P2).

[…] *I wear a bed protector and two diapers because of the pee* (P51).

[…] *There are days that I need to empty, several times... it's* [like] *a little child that needs diaper changes, even at night I have to clean* (P44).

[…] *I wear a mean of ten panties a day, everything gets wet* (P64).

If on the one hand, lack of control is seen as uncomfortable and embarrassing, on the other hand, infantilization due to the health condition may make these aged individuals feel diminished and have their self-esteem severely affected. In contrast, revealing sportsmanship and good mood, some participants ended up giving a "loving" name to the ostomy:

[…] *I get ready, clean the whole 'boy' here, clean everything* (P32).

[…] *I call it the strawberry ostomy* (P11).

People with intestinal ostomies refer to them with mild words, in order to minimize or conceal them from other individuals. It is the way they found to lighten the problem and, driven by the desire to live well, they always try to lead their lives normally or closer to how it was before.

DISCUSSION

In the results presented, there are important aspects worthy to be discussed in relation to the experience underwent by aged people in the care process regarding the intestinal ostomies and UI. To discuss the self-care aspects that involve this moment with the ostomies and UI, the Self-Care Theory was used as framework[10].

A number of studies indicate that the feelings related to the ostomy are variable, revealing situations ranging from acceptance and conformity to rejection. Acceptance of the ostomy occurs when people realize that it is the best option to avoid future complications. On the other hand, there are cases where the ostomy was rejected by the patients, with serious negative feelings about themselves: they feel inferior, ashamed of the situation, upset and sometimes alone, with the sensation that this is happening only to them. It was also noticed that being afraid of emptying the bag, smelling bad, disturbing others, fear of disability, hopelessness, denial, anxiety, less optimism and more shame were also frequent[11–12].

According to the Self-Care Theory, the disease or health problem not only affects the physiological or psychological structures and mechanism, but also comprehensive functioning of the human being, when seriously affected by a pathology or dysfunction, as is the case of aged individuals with intestinal ostomies[10]. One of the requirements for self-care due to a health deviation is to understand the "change in self-concept and self-image, in self-acceptance as being with a special health condition and in need of specific forms of treatment and care"[13:70–71].

In the current research, it was noticed that acceptance of the ostomy is approached in different ways by the informants and that, when it causes a major negative impact on their routine, it affects their quality of life. At the same time, some people perceive surgery as the only possibility to continue living, not worrying so much about the condition of having an intestinal ostomy.

However, the constraints reported by the individuals with an ostomy in their daily life cannot be omitted, either due to the unpredictability of effluent elimination or to the release of gases, noise and odor, even with the use of an activated charcoal disk. These issues also generate embarrassment, causing discomfort and interfering with social life, often leading the person with an ostomy to isolation and reclusion[14].

Another negative feeling reported by the participants in this research was the difficulty using restrooms outside their homes and the lack of adapted environments, preventing them from going out of their house. As in other studies, this difficulty using conventional restrooms, and even those adapted for wheelchair users, is corroborated here, highlighting the need for structural adjustments, as a suggestion to better accommodate people with ostomies, in order to provide a more comfortable and safe life when going out of the house, facilitating social interaction[15–16]. Through the reports by the informants in this research, it is noticed that the family of the person with an intestinal ostomy adapts the home bathroom, so as to improve care with hygiene of the collection bag and provide better conditions for self-care.

It was observed that, when the ostomy is temporary, the hope of reversal generates a lot of anxiety in the ostomized person. Informants from another study evidenced that they did not care undergoing surgery again, nor about the waiting time until the reversal surgery, as they knew that their situation would reverse sooner or later. It was also observed that this factor contributes to better coping with the situation[17].

In the current study, complaints in relation to the UI symptoms were observed, regarding how unpleasant it is from the perspective of the participants who present such symptoms. Similarly, in another study, it was shown that living with UI causes discomfort in the aged individuals' daily lives, the feeling of being powerless for not being able to hold urine, in addition to the embarrassment of getting wet[18].

Another aspect pointed out by the aged individuals with intestinal ostomies who presented UI symptomatology was lack of knowledge regarding the symptoms, considered normal during the aging process. A number of studies have presented reports where incontinent aged individuals do not seek any health professional at onset of the UI symptoms because, even for the professionals themselves, urine loss is related to old age, not knowing the reasons that led the aged individual to develop those symptoms[18–19].

According to a qualitative study carried out in Iran only with women, another reason for not seeking conservative treatments for the UI symptoms were as follows: not noticing the symptoms; shame; negative support from others; and non-optimal health care system[20].

Health professionals must pay special attention to the following assistance needs in these aged individuals: knowing the self-care strategies of aged individuals with intestinal ostomies and UI should be the first step to identify the help required by the patient. Thus, it will be possible to devise an action plan to empower these aged individuals and their family caregivers to assume their self-care for the sake of their health[10].

In this research, lack of referrals by the health professionals for conservative UI treatments was also verified. In theory, it is highlighted that Nursing or other health professionals are required to perform the self-care functions whenever an individual presents limitations or lacks knowledge about their self-care requirements[8].

Given the above, health professionals must pay attention to this aspect and seek to effectively identify the UI cases. Thus, by recognizing the problem, they can act on it. Actions that encourage the promotion of continence and the prevention of UI by the professionals in the clinical practice are required[21]. Therefore, health professionals must provide help, using strategies to develop, support and encourage self-care[9], in order to minimize the urinary symptoms.

Aged people with intestinal ostomies are faced with several issues related to extreme changes in their daily lives, which alter their lifestyle, as we were able to notice in this study, often becoming a challenge to adapt to the new reality. Such being the case, if people are able to, they may and should learn to perform the measures required by self-care, either externally or internally guided[10], to meet all the needs inherent to the adaptations imposed.

Regarding work activity after the ostomy, a study carried out with 10 individuals with permanent colostomies reveals that the participants preferred to apply for the government benefits or disability retirement early in time, generating a decline in the performance of their professional activity[22].

Due to UI and to use of the collection bag, mainly ileostomy, it was noticed that some participants needed to get up during the night to clean the collection bag and/or to urinate, impairing sleep quality. Sleep alteration may negatively interfere with organs and systems, such as sleep-related breathing disorders and cardiovascular diseases. The consequences are numerous, compromising quality of life and contributing to the emergence of other diseases[23].

Another factor that must be considered in the lifestyle changes is impaired sexual performance. The findings of a phenomenological research study conducted with people with permanent colostomies revealed a negative impact on sexual relationships, leading to divorce and total interruption of sexual activity, due to limitations in the marital relationships. Among women, it is possible that there are changes due to difficulty accepting and understanding the new body with the intestinal elimination ostomy[14].

Regarding the eating habits, the changes promoted by the person with an intestinal ostomy are remarkable, seeking to control the odor of feces and gases, as well as to improve consistency of the effluents, and even reduce their volume. It is to be noted that, initially, this habit may seem positive, but it may have negative repercussions on health, causing malnutrition and dehydration. For this reason, nutritional monitoring by qualified professionals is necessary, capable of intervening in a positive way, proposing a balanced and individualized diet so that these patients with intestinal ostomies consume the essential nutrients for their body[24].

There were also changes in the leisure activities. A study conducted with women with ostomies noticed that they maintained activities that did not require effort, but restricted bus travels and sports activities in clubs, resulting from insecurity due to the fear of embarrassing or disturbing others. They showed to be shaken by the presence of the ostomy and with difficulties in social reinsertion[25].

Changes in the outfits and accessories were also observed in this research, showing the use of large-sized objects, such as bags, for example, in order to conceal the ostomy, as well as choosing loose, dark clothes that define the body less, which are ways to cover up the presence of the ostomy collection bag[26]. Another study showed that readjusting lifestyle and outfits to the physical changes resulted in a financial burden for the participants to change their outfits to accommodate the ostomy and bag[27].

The same happens in relation to urine loss: due to possible leaks, the strategy is to choose darker and looser clothes.

In addition to that, a deficit in body image was noticed. Data from a research study conducted with 44 individuals with intestinal ostomies, 26 of which were aged, presented altered self-esteem and self-image and negative feelings in relation to the body[28].

There is also concern about how others see the intestinal ostomy. Another study highlighted constant curious, indiscreet and speculative looks from third parties, including family members, increasing the embarrassment of the person with an ostomy[26].

Likewise, lack of control over the ostomy and UI generate discomfort in these ostomized aged individuals. The use of external collecting equipment is the vivid image of the mutilation suffered, directly related to the loss of the body's ability to control physiological elimination, meaning a weakening of the control perception[12,29].

Therefore, to minimize this discomfort, some aged individuals ended up giving affectionate names to the ostomy. In a study conducted with nine couples, one of which had a colostomy, the participants reported that naming the ostomy allowed them to talk about it secretly in public without fear of embarrassment. The use of ostomy-related humor allowed the couple to ease the tension around what was a problem and ensure that conversations about the subject matter were not heavy or embarrassing[30].

It is worth reiterating the importance of Dorothéa Orem's theoretical framework used in this research, in which the individuals in need of self-care must be aware of their real health situation. To this end, education in health is one of the motivators for the self-care demands and for how they can be achieved to optimize assistance, that is, to promote self-care. For this reason, it is reinforced that an appropriate level of knowledge about the disease on the part of the individuals and family members is indispensable for positive results linked to self-care[10].

CONCLUSION

In the current study, it was evidenced how the adaptation and acceptance or denial process was for an intestinal elimination ostomy in the aged individuals. This way of living and adapting is a unique process, generating many feelings such as fear, insecurity and constraints, whether these are influenced by the culture, expectations or complications experienced.

Another important and essential aspect was to understand the changes generated in the body and in lifestyle, in order to provide care that meets all the individual needs. Thus, it is possible to choose treatment and guidance strategies for self-care that are more appropriate for each person, in such a way that they favor better adaptation to the situation and greater empowerment in their self-care.

Another fact that deserves to be highlighted is the incorrect belief that UI is part of the aging process. Therefore, it is recommended that health professionals routinely investigate this type of event. Only in this way will it be possible to make the appropriate referrals, treatments and follow-ups, ensuring good assistance and better quality of life for the aged individuals. It is worth remembering that the participants stated that urinary loss was easier to control than the intestinal ostomies, although they revealed that they were burdened by the dual self-care task.

It is believed that this research may stimulate new studies to contribute to improving the assistance provided to aged people with intestinal ostomies and UI, including the development of rehabilitation programs and the promotion of quality of life, considering the lack of studies on these situations, mainly in the aged population.

As a limitation of this study, we mention not having listened to the health professionals to understand how they monitor and guide aged people with ostomies and UI. With such information, it might be possible to better understand how care is provided to this population segment with such health problems.

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NOTES

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Conception of the study: Tomasi AVR, Santos SMA, Honório GJS.
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Data analysis and interpretation: Tomasi AVR, Santos SMA, Honório GJS.
Discussion of the results: Tomasi AVR, Santos SMA, Honório GJS.
Writing and/or critical review of the content: Tomasi AVR, Santos SMA, Honório GJS, Girondi JBR.
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APPROVAL OF ETHICS COMMITTEE IN RESEARCH

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CONFLICT OF INTEREST

There is no conflict of interest.

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