#### REVISTA ONLINE DE PESQUISA

# CUIDADO É FUNDAMENTAL

Universidade Federal do Estado do Rio de Janeiro • Escola de Enfermagem Alfredo Pinto

RESEARCH

DOI: 10.9789/2175-5361.2017.v9i2.495-502

# Sexualidade de pacientes com estomias intestinais de eliminação

Sexuality of patients with bowel elimination ostomy

#### Los pacientes con la sexualidad de ostomía eliminación intestinal

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#### How to quote this article:

Vera SO; Sousa GN; Araújo SNM; et al. Sexuality of patients with bowel elimination ostomy. Rev Fund Care Online. 2017 abr/jun; 9(2):495-502. DOI: http://dx.doi.org/10.9789/2175-5361.2017.v9i2.495-502

### ABSTRACT

**Objective:** To evaluate the impact of ostomy in the sexuality of an stomized individual. **Methods:** A descriptive exploratory study with a quantitative approach, developed in an Integrated Health Center in Teresina/PI. Eighty three patients participated, according to the inclusion criteria. Data were collected using a structured form, stored in Excel 2010 and analyzed through descriptive statistics using chi-squared test. Approval from the Research Ethics Committee CAAE No. 36551714.0.0000.5512 was obtained. **Results:** Three sections were obtained. The first section, referring to the profile of the sample, includes sociodemographic features of patients with intestinal elimination ostomy; the second section features their sexuality; and the third section lists the sociodemographic characteristics and related to the characteristics of sexuality. **Conclusion:** Having an ostomy influences many factors that contribute to the well-being of people. The change of body image changes the psychic functions, influencing sexual activity.

Descriptors: Quality of life, Sexuality, Ostomy.

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DOI: 10.9789/2175-5361.2017.v9i2.495-502 | Vera SO; Sousa CN; Araújo SNM; et al. | Sexuality of patients with...









#### RESUMO

**Objetivo:** Avaliar o impacto da estomia na sexualidade do indivíduo estomizado. **Métodos:** Estudo exploratório-descritivo com abordagem quantitativa, desenvolvido em um Centro Integrado de Saúde de Teresina/PI. Participaram 83 pacientes, de acordo com os critérios de inclusão. Os dados foram coletados através de formulário estruturado, armazenados no Excel 2010 e analisados por meio de estatísticas descritivas utilizando teste qui quadrado. Obteve-se aprovação do Comitê de Ética em Pesquisa CAAE nº 36551714.0.0000.5512. **Resultados:** Foram obtidas três seções. A primeira seção, referente ao perfil da amostra, engloba os aspectos sociodemográficos dos pacientes com estomias intestinais de eliminação; a segunda seção características sociodemográficas com as características relacionadas à sexualidade. **Conclusão:** Ter uma estomia influencia diversos fatores que contribuem para o bem-estar das pessoas. A mudança da imagem corporal altera as funções psíquicas, influenciando a atividade sexual.

Descritores: Qualidade de vida, Sexualidade, Estomia.

#### RESUMEM

Objetivo: Evaluar el impacto de la sexualidad de ostomía de ostomía individual. Métodos: Un estudio exploratorio descriptivo con un enfoque cuantitativo, desarrollado en un Centro de Salud Integrado de Teresina/PI. 83 pacientes participaron, de acuerdo con los criterios de inclusión. Los datos fueron recolectados a través de una forma estructurada, almacenada en Excel 2010 y se analizaron mediante estadística descriptiva utilizando la prueba de chi-cuadrado. Obtenido la aprobación del Comité de Ética de Investigación CAAE Sin 36551714.0.0000.5512. Resultados: Se obtuvieron tres secciones. La primera sección, que se refiere al perfil de la muestra incluye características sociodemográficas de los pacientes con ostomía eliminación intestina; la segunda sección características tales como su sexualidad; y la tercera sección se enumeran las características sociodemográficas y las características relacionadas con la sexualidad. Conclusión: Una ostomía influencias muchos factores que contribuyen al bienestar de las personas. El cambio de la imagen corporal cambia las funciones psíquicas, que influyen en la actividad sexual. Descriptores: Calidad de vida, Sexualidad, Estoma.

#### INTRODUCTION

Ostomy is a word of Greek origin (*stocum*) that means mouth or open surgical origin, dodging temporarily or permanently the flow of eliminations. In ostomy occurs the externalization of hollow viscera, with the objective of carrying out the functions of the organ that is damaged through an opening for contact with the external environment. There are numerous reasons that lead to the construction of a stoma, and the nomenclature of ostomy changes according to the targeted body segment.<sup>1</sup>

Among the main reasons that lead to ostomy, there are the cancers, tumors, chronic diseases and injuries by firearm or weapon. Thus, an ostomy in the trachea, is called tracheostomy; the stoma in the stomach, gastrostomy; urinary ostomy are classified in pyelotomy, ureterostomy and vesicostomy; and, finally, the intestinal ones are divided into colostomy, ileostomy and jejunostomy according to the affected portion.<sup>1-2</sup>

The construction of a stoma generates major changes in a person's life, mainly due to difficulties related to work, leisure, social and family life, feeding feelings of shame, insecurity and sexuality that can awaken this individual's feelings of frustration and failure, and can bring to social isolation. Such changes are due to the difficulties of adapting the ostomy as regards to deprivation of fecal control and elimination of gases.<sup>3-4</sup>

Society shows itself as a world of appearances, where there are standards of beauty and body cult. Physical changes resulting from a stoma results mainly in a sexual change, due to the inadequacy of social standards. The ostomy patient may encounter difficulties around their sexuality, as the surgery itself contributes to this and may cause, in men, changes in erection and ejaculation, vaginal stenosis and perforation in women, and decreased libido in both sexes. Psychological and emotional problems can also arise during this period, mainly related to physical problems, problems with the device and the fear of not being accepted by their partner.<sup>5-6</sup>

In the earliest days, sexuality was seen as an issue that should not be discussed in public. Sex was seen as a means of reproduction and not of pleasure, so any sexual manifestation beyond the act of procreation was considered demoniacal.<sup>7</sup> Women were most affected, being reserved a less prominent place. The Greeks believed that a woman was an inferior being and their rights and duties always focused on raising children and nursing their homes.<sup>8</sup>

Sexuality is considered as one of the pillars of quality of life, with multidimensional aspects, involving the biopsychosocial aspects of each individual, including their biological potential, emotions and beliefs acquired and modified in their socialization process.<sup>9</sup>

The issue of sexuality in individuals with ostomy is something that instigates due to the many repercussions that stoma takes at the life of the affected. Even with the technological advance that is the field of stomatherapy, sexuality is not addressed often in the practice of nursing and the multidisciplinary team, either for the taboo that the subject itself is, either by forgetting of this intervention or the lack of reporting to the patient about the problem.

It is evident, therefore, the importance and relevance of research on sexuality of ostomy patients. Based on the above, this study was designed to evaluate the impact of ostomy on the sexuality of the stomized individual.

#### **METHODS**

This is an exploratory-descriptive study with a quantitative approach developed in an Integrated Health Center, which runs a scholarship distribution program for ostomy patients, located in Teresina, Piauí's state capital and is a reference to the population of ostomy to a state level.

For the composition of the sample, it was opted for the probabilistic sample of accidental type, which is formed by the elements that appear successively in the order of arrival services, until completion of the sample number. Thus, considering a total of 329 patients enrolled in the aforementioned ostomy program by April 2015 and a tolerable error of 5% of the sample, with 95% confidence level, it amounted to 83 patients.

Data collection took place between September and October 2015, where the criteria for inclusion of patients in the sample were: being 18 or older at the time of data collection; have intestinal ostomy disposal for at least a month. For sample exclusion, it was used impaired communication skills.

It was used, as a data collection instrument, a form developed by the authors of this research, used for broader responses and can be applied to any type of informant, once the researcher completes it. This form contains sociodemographic, clinical and sexual related questions concerning the patient.<sup>10</sup>

In the event of conditions that made it impossible for the participant's trip to the center, for example, age and mobility problems and, after the request and authorization of participants, the interview was scheduled and performed at their households.

The data obtained were stored in an electronic database created in Excel 2010 program (Windows 7) and then analyzed using descriptive statistics. To study the associations between socio-demographic and sexual variables, we used the chi-square test ( $XX^2$ ) considering statistically significant test results that presented p-value lower or equal to 0,005.

The project was submitted to both the Hospital Foundation Ethics Committee of Teresina (FHT) and approved, as well as the Ethics Committee of the Universidade Paulista (UNIP) and approved under protocol CAAE No. 36551714.0.0000.5512. Only after obtaining a favorable opinion is that the data collection was initiated.

### RESULTS

# Socio-demographic profile of patients with intestinal elimination ostomy

For a better presentation and understanding of the results, these were divided into three sections that focus on different aspects of data analysis. The first section, referred to the profile of the sample includes sociodemographic features of patients with intestinal elimination ostomy. The second section features these patients and their sexuality, the third section lists the sociodemographic characteristics and the characteristics related to sexuality.

Among the 83 people with bowel elimination ostomy investigated in this study, more than half, 63.9%, were male. The predominant age group was individuals aged 60 years old or more, represented by 38.6%, followed by the range of 31-59 years old, with 37.3%. The age range of 18-30 corresponded to 24.1%.

The average age was 52.47 years with a standard deviation of 15.158, being the minimum age found 22 years

old and maximum 80 years old. Of the total of people who participated, 22.9% declared themselves as white, 18.1% as black, 55.4% declared themselves brown, 3.6% yellow and none declared itself as indigenous. Regarding marital status, it was observed that 27.7% of respondents were single, 44.6% were married, 8.4% widowed, 8.4% divorced and 10.8% had stable partners.

As for profession, 57.8% said they still work after making the stoma, 10.8% said they did not work, 27.7% were retired and 3.6% reported receiving disability compensation. Most of the participants, 61.4% claimed to have monthly income of up to one minimum wage, while 6% reported not having any kind of compensation, 25.3% reported having income between two and four minimum wages and only 7.2 % said they earned more than four salaries.

With regard to education, it was noted that most of the individuals interviewed falls in the categories of incomplete primary education, 48.2%, with secondary education, 16.9%, while 13.3% were illiterate, 8.4% had completed elementary school, 6% incomplete secondary education and 7.2% complete higher education. In the studied clientele, there was no case of incomplete higher education. The results are shown in Table 1.

**Table 1** - Socio-demographic profile of patients with intestinalelimination ostomy (n = 83). Teresina/PI - 2015

Variables	N	%
Sex		
Male	53	63,9
Female	30	36,1
Age group*		
18 - 30	20	24,1
31 - 59	31	37,3
60 - 82	32	38,6
Color/Race		
White	19	22,9
Black	15	18,1
Brown	46	55,4
Yellow	3	3,6
Marital Status		
Single	23	27,7
Married	37	44,6
Widowed	7	8,4
Divorced	7	8,4
Stable Union	9	10,8
Profession		
Does not work	9	10,8
Retired	23	27,7
Disability Compensation	3	3,6
Works	48	57,8

(To be continued)

#### (Continuation)

Variables	Ν	%
Monthly Income		
Unpaid	5	6
Up to 1 salary	51	61,4
2 to 4 salaries	21	25,3
Over 4 salaries	6	7,2
Educational Level		
Illiterate	11	13,3
Incomplete Primary Education	40	48,2
Complete Primary Education	7	8,4
Incomplete Secondary Education	5	6
Complete Secondary Education	14	16,9
Complete Higher Education	6	7,2

\*Age: Medium (<sup>XX</sup>): 52.47; Standard deviation: 15,158; Min-Max: 22-80. Confidence interval (IC): 95%.

# Characterization of the sexuality of patients with intestinal elimination ostomy

The variables investigated on sexuality were being sexually active, degree of satisfaction with sex life, pain during intercourse, desire for sexual activity, initiative and refuses to sexual practice, functioning responses of sexual organs and the importance of sexuality.

Regarding sexuality, 45.7% of respondents reported having an active sexual life, while 54.3% denied the practice of sexual activity. Among sexually active people, 89.5% said they were happy with their sex lives against 10.9% who found themselves unhappy, only one person, 2.6%, reported feeling pain during intercourse.

Regarding the desire for sexual activity, 47.4% reported that their desire for sexual activity decreases after making the stoma, 52.6% reported not having had any kind of modification, 26.3% reported that their partners desire to have relations less often after making the stoma, and the majority, 73.7% reported that there was no loss of sexual interest for their partner.

After making the stoma, 23.7% reported that they refuse to have sex due to the stoma, while 76.3% maintain relations as usual. Among the sexually active participants, 71.1% reported that their organs function as usual, while 28.9% reported having undergone changes in sexual function, 63.2% claim to take initiatives to have sex and all considered that sexuality plays an important role in their lives, according to Table 2. **Table 2** - Characterization of the sexuality of patients with intestinal elimination ostomy. Teresina/PI, 2015 (n = 83)

Variables	N	%
Sexually active		
Yes	38	45,7
No	45	54,3
Total	83	100
Happy with sexual life		
Yes	34	89,5
No	4	10,9
Total	38	100
Feels pain during sexual relations		
Yes	1	2,6
No	37	97,4
Total	38	100
Decreased desire for sexual activity		
Yes	18	47,4
No	20	52,6
Total	38	100
Partner wants to have sex less often than patient		
Yes	10	26,3
No	28	73,7
Total	38	100
Refuses to have sex with partner		
Yes	9	23,7
No	29	76,3
Total	38	100
Sexual organs responds to desires as usual		
Yes	27	71,1
No	11	28,9
Total	38	100
Takes initiative to have sex		
Yes	24	63,2
No	14	36,8
Total	38	100
Sexuality plays an important role in life		
Yes	38	100
No	0	0
Total	38	100

# Association between sociodemographic characteristics and sexuality of people with bowel elimination ostomy

When verifying the association between sociodemographic and sexuality related variables, Table 3, it was observed that there was a significant association between gender and an active sexual life (p-value = 0.000), noting that male is associated with a more active sexual life than female. By associating an active sexual life and marital status (p = 0.051) results were obtained noting that married individuals have a higher prevalence of sexual activity than other groups.

It was also associated with statistically significant difference among the variable age and desire for sexual activity (p = 0.005), noting that participants aged 18 to 30 are more associated with the preservation of the desire for sexual activity, regardless of ostomy. Different from other age groups, which showed reduced sexual desire after ostomy.

Thus, there is a significant association between marital status and desire for sexual activity (p = 0.005), noting that the married participants are more associated with decreased sexual drive after ostomy, unlike singles who showed a preservation of desire for sexual activity regardless of ostomy.

There was also the significant association between age and functioning of the sexual organs (p-value = 0.012), noting that participants aged 31-59 years old are more associated with the response maintenance of their sexual organs to their stimuli, regardless of ostomy.

Table 3 - Association between an active sexual life and other variables (n = 83). Teresina/PI, 2015

ACTIVE SEXUAL L	IFE				
Variables	Yes N(%)	No N(%)	Total	X2	p-value
Sex					
Male	34 (40,9%)	19 (22,8%)		19,115	0,000
Female	4 (4,8%)	26 (31,3%)			
Total	38 (45,7%)	45 (54,3%)	83 (100%)		
Marital status					
Single	9 (10,8%)	14 (16,8%)		9,420	0,051
Married	22 (26,5%)	15 (18,0%)			
Widowed	-	7 (8,4%)			
Divorced	2 (2,4%)	5 (6,0%)			
Stable Union	5 (6,0%)	4 (4,8%)			
Total	38 (45,7%)	45 (54,3%)	83 (100%)		
SEXUAL DRIVE					
Variables	Yes N(%)	No N(%)	Total	X2	p-value
Age					
18-30	1 (2,6%)	11 (28,9%)		10,743	0,005
31-59	7 (18,4%)	4 (10,5%)			
60-82	10 (26,3%)	5 (13,1%)			
Total	18 (47,3%)	20 (52,7%)	38 (100%)		
Marital status					
Single	1 (2,6%)	8 (21,0%)		15,291	0,005
Married	15 (39,4%)	7 (18,4%)			
Widowed	-	-			
Divorced	2 (5,2%)	-			
Stable Union	-	5 (13,1%)			
Total	18 (47,3%)	20 (52,7%)	38 (100%)		
SEXUAL FUNCTIO	NALITY				
Variables	Yes N(%)	No N(%)	Total	X2	p-value
Age					
18-30	9 (23,6%)	3 (7,8%)		8,909	0,012
31-59	11 (28,9%)	-			
60-82	7 (18,4%)	8 (21,0%)			
Total	27 (71,0%)	11 (29,0%)	38 (100%)		

## DISCUSSION

Regarding the sociodemographic characteristics, the male gender was specifically predominant in relation to women. Several studies showed the male gender predominant.<sup>11-12</sup> In controversy, in a survey, 60% were female and 40% male.<sup>13</sup> In these studies, male dominance is involved in emergency services and emergency scenarios and the underlying cause is associated with trauma and violence.

Most of the participants was in the corresponding age group for the elderly. In this finding it is important to note that the elderly have unique biological characteristics and are more vulnerable to chronic diseases, for example neoplasms, such as colorretarias, which often culminate in ostomy.<sup>14</sup> It is noteworthy that there are no studies in the scientific literature that assess the race of ostomy patients.

Regarding marital status, most were married, though much of the sample reported having no sexual partners. Some characterization studies of ostomy patients point out that most of these are married, have partners, but does not say whether they are sexually active.<sup>15</sup> Analyzing the marital status is important because the marital status of ostomy patients and their sex life is directly linked to the problems arising from the ostomy, caused in part by anatomical mutilation resulting resections involving muscles and nerves responsible for the functioning of the sexual organs or feelings of shame and sexual disinterest.

A relevant fact was found to be the existence of a considerable portion of stomized people having leading causes of inflammatory bowel diseases, injuries from weapon and fire. These people are economically active and the presence of an ostomy can lead to losses in industrial activities, and generate more costs to the social security machine and impact on social issues such as in leisure activities and sexuality.<sup>16</sup>

In this study, it was found that, in relation to work, most ostomy patients stated keeping their work activities. A study carried out <sup>17</sup> showed that among the participants, those with employment preferred to retire and move away definitively from labor activities, and the unemployed were unable to enter the labor market due to the condition of ostomy.

With the publication of Law 5296 of December 2, 2004, in which Article 5 classifies patients with ostomy as physically disabled, they now have an extension of their rights, including the right to retirement. The ostomy alone, that is, by itself, without its bearer presenting a serious and conical disease, does not give right to retirement. Pensions for disability of stomized people usually have to justify the diseases that led to this condition, as in case of Cancer, Crohn's Disease, Colitis Ulcerative, etc. Thus, the difficulty of reinsertion of individuals in the labor market leads to idleness, isolation and changes roles and social status.<sup>18</sup>

With regard to income, it was observed that most of the participants received minimum wage and the minority an income exceeding four salaries. Low income presents a difficult situation and social exclusion. That could influence the ability to purchase materials needed for the therapeutic regimen of use of ostomy and the provision of basic allowances of life such as food, housing, health, education, safety and leisure, essential for the establishment and maintenance of life quality.<sup>18</sup> SUS is an essential tool for an access, almost impossible before for the poor, to health services. The stomized population is guaranteed by the principles of free and universal provision of collection bags, as provided for in Decrees No. 116/93 and 146/93, by the Ministry of Health.<sup>19-20</sup>

Most interviewees had incomplete primary education or were illiterate. It is inferred that education is characterized as an important point, since the ostomy patients receive a variety of information regarding ostomy and their new condition of life. To this end, it is believed that the more education, the higher its capacity for understanding and learning. The patient with ostomy should be well guided, taught and trained with skills necessary for self-care, especially regarding the handling of the stoma, such as cleaning peristomal skin, specifications and availability of specific equipment and aids for the collection of effluent.<sup>21</sup> It is important to note that low educational level is not configured as an impediment to action with this population, given the fact that the interaction between users, services and health and education professionals has been providing overcomes for difficulties imposed by this variable.

Regarding sexuality, most participants denied the practice of sexual activity. Of those with active sexual lives, most stated to be happy with their sex lives and only one person reported feeling pain during intercourse. The Miles surgery (surgical removal of the rectum end, adjacent nodes, anus and anal sphincter) causes often erectile dysfunction, as during surgery occurs vessel section and nerve endings responsible for erectile function in men. In women at the time of removal of the colon and rectum tumor causes the shortening of the vagina, since this is very close to the rectum, occurs dyspareunia and loss of libido, distancing any sexual activity when not guided by a health professional and also for consequences of psycho-emotional order for carrying a stoma, which generates often feelings of shame, isolation and lack of sexual interest.<sup>22</sup>

The influence on sexuality is committed even further with the passage of age that is accompanied by triggering physiological changes such as decreased vaginal lubrication, decreased erection, which will be accentuated by the type of stoma.<sup>23</sup> The support of family and partner is essential for the development of positive attitudes towards the disease and new situation, making the process of postoperative recovery, adaptation and return to activities of daily living, including how the experience sexuality, faster and easier.<sup>13,24</sup>

Acceptance of the partner further enables establishing the new identity as stomized without losing the prospect of possible adaptations to maintain their interpersonal activities, leaving aside the pessimistic view about their new condition as if they were not worthy of life. Often the individual is surprised by an attitude of acceptance by their partner.<sup>25</sup> In contrast, the non-acceptance may result in conflicts both from the patient and the partner for covering various aspects such as changes in body image, self-esteem because of the harm and the conflicting feelings of desire, revulsion, disgust and compassion.<sup>26</sup>

A significant portion of participants reported refusing to have sex due to the stoma. The constant fear of rejection makes people adopt defensive attitudes and behaviors in advance, since they recognize their limitations, and thus isolate from people in general, before the worst, ie, performs negative forecast of the future. However, this is not always concretized.<sup>27</sup>

The results showed changes in sexual life of stomized people resulting from dysfunction and, therefore, the need to control their desires, avoiding affection, touch, in order not to get frustrated. This factor is the most complicating for intimate life of the couple, because for women, love, affection and touch contribute to obtaining pleasure, but to men the pleasure is linked to the sexual act. Thus, as a result of not satisfying their sexual needs, compromised their partner's, causing dissatisfaction in both. The absence of love and affection makes the stomized and their partner feel isolated, anxious or depressed, inadequate or emotionally distant.<sup>28</sup> Moreover, the pessimistic view of oneself results in the absence of an initiative regarding sexuality, mainly because it involves body exposure, leading to a feeling of continuous mutilation.

In this research all sexually active participants said that the maintenance of sexuality plays an important role in their lives. Corroborating with the results of a study <sup>17</sup> which reveals the importance attributed to it by stomized people, as well as their representations were essential elements in determining the mediations established in this regard to the resumption of their life trajectories'.

It was found that the male gender is associated with a more active sex life than females. International study makes clear that sexual activity is affected in both sexes: women because they are more sensitive to body image and may show reduction or loss of libido, and men by increased pressure for sexual performance and may have reduced or no ability to erection and ejaculation. It is proposed, then, counseling people with stoma about sexual health.<sup>29</sup> In another study<sup>30</sup> more than 80% of survey participants found to be sexually active before surgery for making the stoma, only 33.3% returned to sexual activity after surgery.

By associating active sex life and marital status, we obtained results noting that married individuals have a higher prevalence of sexual activity than the other groups. Brazilian researchers have shown that patients who are single, widowed, and separated have greater difficulty finding a sexual partner, for fear of showing its modified body image in this sense encounter obstacles to engage in relationships after surgery, and even add that the spouses would be the only people to accept physical contact.<sup>22</sup>

Participants aged 18 to 30 are more associated with the preservation of the desire of sexual activity, regardless of the stoma. Sexual dysfunction in ostomy patients was associated with the time of injury, surgery and age of the patient.<sup>24</sup> In this study, 82% of males were sexually active preoperatively. These patients maintained 100% of sexual desire after surgery. Retrograde ejaculation was found in 22% of patients, a high rate compared to literature data, which oscillate around 8.5%. The small sample size did not allow to evaluate the age, surgical procedure or time of injury.

### CONCLUSION

This study revealed that the fact of having a stoma, influences many factors that contribute to people's well-being. The change of body image changes the psychic functions, influencing sexual activity. Facing the new situation of having an ostomy, requires physical and psychological changes, so that the routines are taken over by them and their companions.

In assisting the ostomy patient, the sexual aspect is still little explored due to its complexity and lack of knowledge of how to intervene on the part of health professionals and also, by shame or fear of patients to ask questions about it. In most of the literature studied, there was inexistent systematic nursing interventions on sexuality; thus, it is suggested the creation of pre orientation protocols and postoperative directed to patients undergoing ostomy surgery.

It is also highlighted the importance of family, partners and friends in the rehabilitation stage, maintenance, coping and adaptation of current or permanent condition of life of stomized people. Some patients due to age, need constant help for presenting visual or motor impairments of the upper limbs that limit their self-care.

This research could help health professionals identify major changes that occur in the life of an ostomy carrier, and from these rethink the assistance to these patients, as well as implement care actions aimed at minimizing the negative factors present, thus improving their quality of life and therefore their sex life. Thus, it is expected to encourage health professionals to produce more studies on the subject, in order to qualify care to these patients and their families, based on the idea that the more knowledge one has about the subject, more efficient and effective is the assistance provided.

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Received on: 29/02/2016 Reviews required: No Approved on: 15/06/2016 Published on: 10/04/2017

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