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Perception of sexual activities and the care process in ostomized women

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ABSTRACT

Introduction: the making of a stoma may result in adverse effects on the social and psychological dimensions, affecting relationships with family and friends, at work and in sexual activity.
Objective: to analyze the perceptions of ostomized women regarding sexual activity as an important dimension of quality of life and in the care process.
Methods: cross-sectional, descriptive epidemiological study. A sample of 40 patients enrolled in the Ostomized Patient Program of Health Secretariat of the Federal District – Brazil was assessed through a demographic and clinical questionnaire and personal interviews. Data were analyzed using the software programs Microsoft® Office Excel 2010 and SPSS (Statistical Package of the Social Sciences, SPSS Inc, Chicago, USA) for Windows 20.0. Statistical significance was set at 5%.
Results: ostomized women face several adaptation and rehabilitation problems that interfere with social relationships and, consequently, with body image and self-esteem, which reflects on the sexual activity.
Conclusion: the results show the need for health professionals involved with these patients to have a wider view on the making of the stoma, their sequelae and rehabilitation, to ensure the process of care that will improve the quality of life of ostomized women.

As percepções das mulheres estomizadas acerca das atividades sexuais e no processo de cuidar

Palavras-chave:
Ostomia
Comportamento sexual
Qualidade de vida

RESUMO

Introdução: a confecção de um estoma pode resultar em efeito adverso na dimensão social e psicológica, afetando nos relacionamentos familiares, com amigos, no trabalho e na atividade sexual.
Objetivo: analisar as percepções das mulheres estomizadas quanto à atividade sexual como

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dimensão importante na qualidade de vida e no processo de cuidar.
Métodos: estudo de base epidemiológica transversal descritivo. Amostra constituída por 40 pacientes cadastradas no Programa de Estomizados da Secretaria de Saúde do Distrito Federal - Brasil. Utilizou - se questionário sócio-demográfico, clínico, e uma entrevista individual. Os dados foram analisados pelos programas Microsoft® Office Excel versão 2010 e SPSS (Statistical Package of the Social Sciences, SPSS Inc, Chicago, EUA) para Windows versão 20.0. A significância estatística aceita foi de 5%.
Resultados: a mulher com estoma enfrenta vários problemas de adaptação e reabilitação que interferem na relação social e, consequentemente, na imagem corporal e auto estima, refletindo na atividade sexual.
Conclusão: os resultados mostram a necessidade dos profissionais de saúde envolvidos com essa clientela, terem uma visão mais ampliada sobre a confecção do estoma, suas sequelas e a reabilitação, a fim de garantir o processo do cuidar que contribuirá na melhoria da qualidade de vida da mulher estomizada.

Introduction

The making of a stoma may result in adverse effects on the social and psychological dimensions, affecting relationships with family and friends, at work and in the sexual activity, often determined by negative feelings such as anxiety, fear and doubts.[1-6] Thus, ostomized individuals experience critical moments in life, as they tend to feel stigmatized, by considering themselves to be different from other people, or for not having the characteristics and attributes considered normal by society.[1,4,7-9]

In this sense, the presence of a stoma determines the loss of control regarding the elimination of gas and stool, leading to body dissatisfaction and resulting in changes in body image and self-esteem, which influence ostomized women's sexual activity and sexuality, affecting their quality of life.[10-12]

For the ostomized individual, the meaning of the physical body alteration and suffering related to the new lifestyle greatly affects the sexual activity, social interactions and consequently the quality of life, as there is concern regarding gases, odor from eliminated stool, leaks and physical discomfort.[10-15] Furthermore, most ostomized women do not find it easy to resume their sexual life.

Considering the above-mentioned facts, the rehabilitation and adaptation are key elements in the care process of the ostomized individual. Therefore, one of the aims of the care process is the reinsertion of ostomized patients into society, as well as helping them to identify and overcome barriers that may prevent their adaptation.

Thus, the care process should be understood as an interactive process, as well as a growth and development one, which occurs continuously or at any given time, but one that has the power to direct the modification.[16-17] This study aimed to analyze the perceptions of ostomized women regarding sexual activity as an important dimension of quality of life and the care process.

Material and methods

Study methodology

This is a descriptive cross-sectional epidemiological-based study carried out in the Wound Care and Ostomy Outpatient Clinic of Hospital Regional de Taguatinga (HRT), the Ostomy Outpatient Clinic of Hospital Regional do Gama (HRG) and the Proctology Outpatient Clinic, Hospital de Base do Distrito Federal (HBDF), Brazil, in the period between May 2011 and November 2011. The study was approved by the Ethics Committee on Human Research of the State Department of Health of Distrito Federal (CEP/SES/DF), protocol number 418/09. All patients who met the selection criteria and agreed to participate signed the Free and Informed Consent Form (FICF), after learning the detailed information about the study aims and procedures used. In order to preserve patient anonymity, patients' names were substituted by names that represent flowers.

Patients

The sample consisted of 40 patients enrolled in the Ostomized Patient Program of the Health Department of Distrito Federal, Brazil. The patients were selected according to the following criteria: inclusion - female gender, ostomized, aged twenty years or older, with definitive stoma, and with stable marital status; exclusion - children, adolescents, pregnant or lactating women, bedridden, other physical disabilities, male gender, and patients who refused to participate.

Data collection

For data collection, the socio-demographic and clinical questionnaire was applied and an individual interview was performed. The interviews were transcribed in full after each report. The responses were read in full, several times, and at different moments, to make it possible to understand the speeches, identifying main ideas and key words, observing the repetitions and similarities between the interviews. The following stage was that of transcription of parts of the interviews to begin categorization.

Statistical analysis

A descriptive, statistical analysis of data was performed by mean and standard deviation, using the software Microsoft® Office Excel 2010 and SPSS (Statistical Package for Social Sci-

ences, SPSS Inc, Chicago, USA) for Windows 20.0. Statistical significance was set at 5%.

Results

The sample consisted of 40 patients, mean age 50.75 ± 11.95 years. Regarding the level of education, 32.5% (n = 13) of women had finished Elementary School, 22.5% (n = 9) had not finished High School, 30% (n = 12) had finished High School, 10 % (n = 4) had not finished College/University and 5% (n = 2) had finished College/University. It was observed that the mean family income was 2.98 times the minimum wage and the predominant working activity was that of retired individuals or on sick leave, 70% (n = 28). Regarding religion, in this sample most individuals were Catholics, 65% (n = 26), followed by the Protestant/Evangelical religions, 30% (n = 12) and Spiritist religion 5% (n = 2). There were no atheists (Table 1).

Regarding the causes of the stoma, 65% (n = 26) had colon and rectum cancer, whereas 35% (n = 14) had different causes: Crohn's Disease, Ulcerative Colitis, Diverticulitis, Chagas disease and gunshot accident (Fig. 1). Regarding the use of the irrigation system, 17.5% (n = 7) used the system and 82.5% (n = 33) did not use the irrigation system (Fig. 2). The results of categorization of the interviews are shown in Table 2.

Discussion

The mean age of patients was 50.75 years. These results corroborate other studies that indicated a prevalence of colon and rectal cancer in the age group > 50 years.[1-2,18-19] In addition, over 90% of colon and rectum cancers occur in individuals older than 50 years and 75% involve patients with no other risk factors besides age.[18-19]

Family income and level of schooling were relatively low, with a mean family income of 2.98 times the minimum wage. These data emphasize the importance of government assistance to these patients. The low educational level may be a factor for the non-prevention of colon and rectum cancer, due to lack of information on the factors that can trigger the disease, including dietary habits.[2]

There was a prevalence of 70% (n = 28) of patients that were retired and/or on sick leave, as the ostomized individual is considered a person with special needs in accordance with Decree No. 5296 of December 2nd 2004.[20] According to Fortes *et al.*,[2] the capacity to work is affected in 20% to 90% of ostomized individuals due to advanced age and not to the stoma or the disease itself.

There was a higher prevalence of the Catholics in the sample; however, the study showed that all patients followed a

Table 1 – Sociodemographic characteristics of ostomized women enrolled at the Ostomized Patient Program of the Health Secretariat of Distrito Federal, Brazil (n = 40).

Variables	n (40)	%
Age range		
20 to 29 years	01	2.5%
30 to 39 years	04	10%
40 to 49 years	10	25%
50 to 59 years	19	47.5%
60 to 69 years	06	15%
Level of schooling		
Finished Elementary School	13	32.5%
Did not finish High School	09	22.5%
Finished High School	12	30%
Did not finish College/University	04	10%
Finished College/University	02	5%
Working activity		
Active	12	30%
Retired (or on sick leave)	28	70%
Income (Minimum wages – MW)		
< 1 MW	00	0.0%
1 - 2 MW	12	30%
3 - 4 MW	25	62.5%
> 4 MW	03	7.5%
Religion		
Catholic	26	65%
Protestant/evangelical	12	30%
Spiritist	02	5%
Atheist	00	0.0%

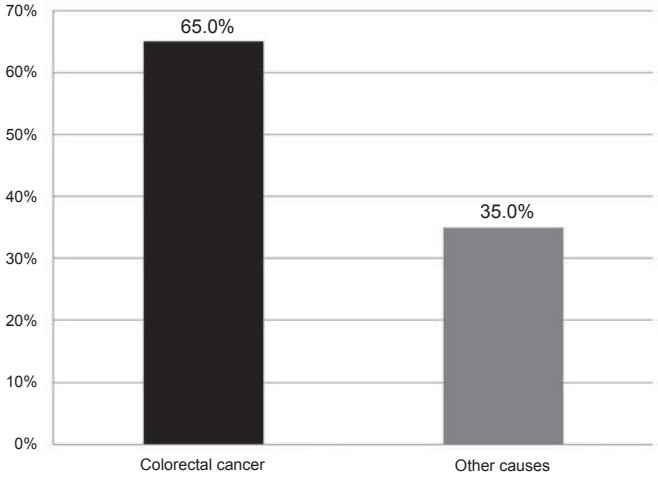

Fig. 1 – Reasons for needing a stoma in women (n = 40) enrolled in the Ostomized Patient Program of the Health Secretariat of Distrito Federal, Brazil.

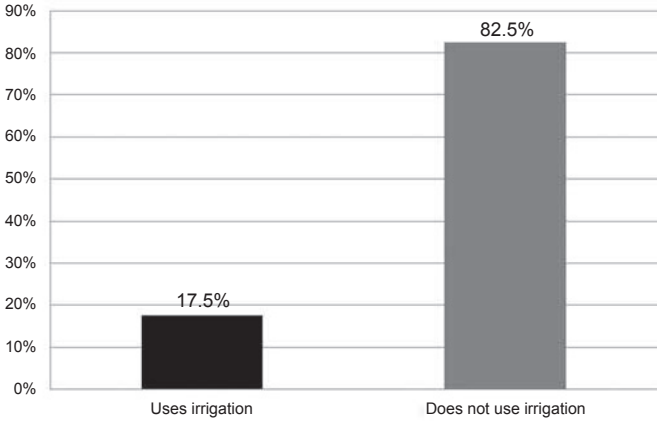

Fig. 2 – Demonstration of the irrigation system use in ostomized women (n = 40) enrolled in the Ostomized Patient Program of the Health Secretariat of Distrito Federal, Brazil.

Table 2 – Categorization of the interviews of ostomized women enrolled at the Ostomized Patient Program of the Health Secretaria of Distrito Federal, Brazil (n = 40).

Living with an ostomy
"When I go out, I am afraid the colostomy bag will leak and people will see it. Then, I am careful to take along an extra dress and colostomy bags, because sometimes I may have to use them." Acacia
"It was so good before I had to use this bag, because I could do anything, I could ride bikes with my kids and husband and now I cannot anymore." Begonia
"I'm afraid my colleagues will find out that I use a colostomy bag. This situation has been very difficult to deal with; I am still getting accustomed to using this bag." Poppy
"I feel like I am different from other people, I do not feel like other people in society, all this is very annoying and I stopped going to some places ..." Lavender
"My diet is restricted; I cannot eat what I feel like eating because I am ashamed of gas." Violet
The impact of the first sexual activity
"I was very afraid of hurting myself and, at the same time, I had the impression of being dirty." Jasmine
"I was dry, I could not relax and I felt pain, but my husband was very careful." Orchid
"It was horrible, I felt as if I were dirty ... although my husband was very gentle." Daisy
"It is very difficult for me to remember the words and the look in my ex-husband's eyes - he said I was not the same woman and that he did not feel attracted to me anymore." Sunflower
The association between the stoma and sexual activity
"I don't know, I cannot relax anymore, you know? The nurse referred me to the gynecologist so I can get a prescription for a vaginal cream I can use." Iris
"I cannot dance for my husband anymore; I always danced for him before sexual activity. He keeps insisting on it, but I do not feel well with this bag..." Hydrangea
"I feel some pain and so I do not feel the pleasure I used to feel." Orchid
Partner's acceptance
"My husband accepts me, the problem is with me. Sometimes I feel I am incapable of satisfying my husband." Lavender
"In fact, I'm still married, but my husband has changed, he avoids me, do you understand? I think he is still with me because of the children, but in fact he does not accept that his wife wears a colostomy bag." Tulip
"Thank God I have a partner who accepts me and loves me, and that makes me feel better and safe ... The acceptance was not my husband's but mine, do you understand?" Magnolia
"My husband became more affectionate; he accepted it, more than I do. When I got the flu, it was him who changed the bag." Lilly
"My husband was always very good, he always said that nothing had changed; it was me who felt that things had changed..." Rosemary
Clothing adaptation
"I had problems with clothes as I have to wear baggy and dark clothing; the worst is that most of the times clothes show the volume of the bag and there is no way to hide that I have a colostomy bag." Lavender
"In the beginning it was hard; I lost almost all my clothes. Now I wear clothes that are easy to put on and I try to wear dark clothes, so it does not show that I have a colostomy bag." Lavender
"I changed my clothing style completely; I don't feel attractive anymore..." Tulip
The use of irrigation
"With the irrigation, I can once again wear my blouses, I feel more beautiful and attractive to my husband. The good thing is that there is no need to be concerned about people around me and moreover, I have no skin lesions anymore." Rose
"The use of irrigation was very good for me, as I had to change my bag several times and it hindered me while working at my shop. The use of irrigation decreased the need for washing, skin lesions and gas discomfort." Anise

religion or had beliefs. Studies have indicated that faith in God is an essential factor to move on with life and face the new condition.[2,6] The disease may represent an opportunity for spiritual growth, as it makes the patient reflect on the fragility of the human condition and raises questions about the purpose of things. From this perspective, studies have suggested that the spiritual welfare is associated not only with the physical and psychological states but also with the cultural formation.[21-22]

The categorization of the interviews was divided into: Living with an ostomy; The impact of the first sexual activity; The association between the stoma and sexual activity; Partner's acceptance; Clothing Adaptation and Use of the irrigation system (Table 2).

The ***Living with an ostomy*** category shows the points of view of the women regarding the condition of living with an ostomy.

Ostomized women face several losses, including the loss of control in the elimination of stool and gases, a mandatory condition for life in society, which can cause psychological and social isolation and, moreover, lead to a change in body image and self-image based on negative feelings that affect interpersonal relationships. One also perceives that in the social field, the ostomized woman is concerned about keeping the presence of the ostomy a secret.

Most ostomized patients do not resume or resume only partially work and leisure activities, such as traveling or playing sports, due to insecurity regarding the use of the colostomy bag. Moreover, ostomized patients harbor feelings of powerlessness, resulting in their social isolation due to the concern of being judged by others.[10,12-14] On the other hand, changes in eating habits aim to avoid excessive flatulence, as well as complications such as diarrhea, which discourages the consumption of all foods that can cause gas.[12,15,23-24]

As for the ***The impact of the first sexual activity*** category, it showed that the changes in body image and surgery complications are related to feelings of fear, insecurity and concerns about hygiene, resulting in difficulties at the first sexual activity of ostomized women.

It was observed that sharing the diagnosis of having an ostomy with their partners is a key step that aids in the rehabilitation process of ostomized women. In this regard, the respondents who had the support of their partners had positive attitudes toward the new condition, overcoming their uncertainties and fears.[3,10-11,24-25]

Regarding the ***The association between the stoma and sexual activity*** category, it showed that ostomized women have difficulties with sexual activity due to the surgery itself, which can also cause dysuria, pain during intercourse, urinary incontinence and reduction or loss of libido. Moreover, it interferes with emotional aspects such as concern for the partner's acceptance and satisfaction, and generates a diminished sense of hygiene.[3,10-11,14,24]

The ***Partner's acceptance*** category showed the importance of care by specialized professionals, assisting in the adaptation and rehabilitation processes and offering support to the ostomized person and the partner to adjust to the new lifestyle and find new coping tactics for a functional and enjoyable sex life.[4,10-11,14,24] The ostomized patients reported that it was very complicated to resume sexual activity; most reported the concern with the partner's acceptance and how to satisfy him.

In the ***Clothing adaptation*** category it can be perceived that, due to the use of the collector device, ostomized individuals changed the way they dress, wearing loose clothing, aiming to hide the presence of the collector device. However, this option adds to the decrease in the esthetic view of the body, resulting in low self-esteem.[10,15] It is observed that the use of black or dark clothing may result in a confession of mourning caused by the ostomy, as the grieving process is one way to cope with losses experienced by the suffering caused by the mutilation.[10-11] Due to the presence of the ostomy, women adapt to a new style of clothing, aiming at hiding the ostomized status.

Finally, the ***The use of the irrigation system*** category demonstrates a technique without side effects that allows intestinal control and also benefits social and family interactions, thus promoting quality of life improvement for ostomized individuals.[26-27] Thus, frequent irrigation helps to reduce colonic bacterial flora and also results in a reduction in gas formation.[28] From this perspective, it is necessary to promote the irrigation technique, as well as knowledge and education through the initiative of healthcare professionals. The words of the respondents reported that irrigation allowed them to control the gas and stool elimination and reduce the incidence of changes of colostomy bags and peristomal skin lesions; additionally, it provided positive representations related to body image, self-esteem, social reintegration, thus resulting in improved quality of life, demonstrating the importance of the irrigation system use.

Considering the facts mentioned above-, most ostomized individuals have difficulties with sexual activity and sexuality due to the surgery itself and changes in body image.[1] Therefore, it was observed that ostomized women fear a possible rejection due to their new physical condition, which induces rejection of others and of themselves.

It was demonstrated that most ostomized women do not easily resume sexual activity. Therefore, the care of health professionals and the support and acceptance of the partner become essential in this adaptation and rehabilitation process, as the stoma brings visible and significant physical changes in the body, which may turn it into a body deprived of its integrity, dynamism and autonomy and causing conflicts and internal imbalances, often transforming relationships with the outside world, including with regards to the experience of sexuality, as it modifies body image.[2]

Thus, sexuality goes beyond the physiological need and has a direct association with the symbolization of desire and attraction. Sex produces strong emotions and transcends physical definitions that permeates every moment of life; it has complex and multifaceted meanings that concentrate a large burden of subjectivity.[1]

The care of the ostomized individual in relation to sexuality and sexual activity comprises aspects that are seldom addressed by health professionals and there is much difficulty in approaching and discussing the matter, both on the part of health professionals and the ostomized individual, thus contributing to the fact that these representations and meanings remain little known or explored in the care process.

Conclusion

This study allowed the analysis of ostomized women's perceptions regarding sexual activity as an important dimension in quality of life and the care process. Thus, the research showed that ostomized women face several problems of adaptation and rehabilitation that interfere with social relationships and, consequently, body image and self-esteem, which have an impact on sexual activity, thus compromising quality of life. In this sense, the drainage device is considered a barrier to sexual activity.

Moreover, health services should provide the care process to the ostomized patient to ensure means to care planning, including psychological support and health education, and the development of skills for self-care, which can play a decisive role in the adaptation of sexual, physiological and psychological activities and social status of the ostomized women and their families, thus contributing to improvement in quality of life.

Conflicts of interest

The authors declare no conflicts of interest.

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