## **Original Article**

# Experiencing sexuality after intestinal stoma

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ABSTRACT: Objective: Identify the Social Representations (SR) of ostomized people in terms of sexuality after the stoma. Methods: An exploratory, descriptive, qualitative study using the Social Representation Theory with 15 ostomized people (8 females), mean age of 57.9 years, between August and September 2005. Data obtained from transcribed interviews were submitted to content analysis, resulting in the thematic unit "Giving new meaning to sexuality" and subthemes. Results: The study demonstrated that the intestinal stoma interferes in the sexuality experience, showing that the meanings attributed to this experience are based on individual life stories, quality of personal relationships established in practice and perception of sexuality, despite the stoma. Conclusions: The Social Representations, in terms of experiencing sexuality after the stoma, are based on meanings attributed to the body, associated with daily life and present in the social imaginary. It is influenced by other factors, such as physiological changes resulting from the surgery and the fact of having or not a partner. Care taken during sexual practices provide greater security and comfort in moments of intimacy, resembling the closest to what ostomized people experienced before the stoma. The self-irrigation technique associated or not with the use of artificial occluder, has been attested by its users as a positive element that makes a difference in sexual practice after the stoma. The support to ostomized people should be comprehensive, not limited to technical care and disease, which are important, but not sufficient. The interdisciplinary health team should consider all aspects of the person, seeking a real meeting between subjects.

Keywords: colostomy; sexuality; subjectivity.

RESUMO: Objetivo: Identificar as Representações Sociais (RS) da pessoa estomizada intestinal sobre vivência da sexualidade após confecção do estoma. Métodos: Estudo exploratório, descritivo, qualitativo do ponto de vista do referencial da Representação Social. Participaram 15 estomizados, sendo 8 mulheres, com idade média de 57,9 anos, entre agosto e setembro de 2005. Dados obtidos por entrevistas, transcritas, foram submetidos à análise de conteúdo, originando a unidade temática "Ressignificando a sexualidade" e subtemas. Resultados: Demonstrou-se que o estoma intestinal interfere na dinâmica da vivência da sexualidade, desvelando que os significados a ela atribuídos estão ancorados nas histórias individuais de vida, na qualidade das relações pessoais/conjugais estabelecidas na prática e na percepção da sexualidade, apesar do estoma. Conclusões: Representações Sociais sobre vivência da sexualidade após estoma estão ancoradas nos significados atribuídos ao corpo, veiculadas no cotidiano e presentes no imaginário social. É influenciada por outros fatores, como alterações fisiológicas decorrentes do ato cirúrgico e da existência de parceiro. Cuidados adotados nas práticas sexuais propiciam maior segurança e conforto nos momentos de intimidade, tornando-as mais próximas daquilo que vivenciavam antes do estoma. A autoirrigação, associada ou não ao oclusor, constituiu estratégia facilitadora para melhor aceitação do estoma, sendo essencial para vida sexual mais prazerosa. A assistência à pessoa estomizada deve ser integral, não se limitando apenas à doença e ao cuidado técnico, que são importantes, mas não únicos. O trabalho interdisciplinar da equipe de saúde deve vislumbrar a pessoa em sua totalidade, buscando real encontro entre sujeitos.

Palavras-chave: colostomia; sexualidade; subjetividade.

Study carried out at the Department of Nursing and Department of Medicine, Universidade de Taubaté (UNITAU) – Taubaté (SP), Brazil; and at the School of Nursing, Universidade de São Paulo (USP) – São Paulo (SP), Brazil.

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#### INTRODUCTION

Intestinal stoma is an opening of intestine on the anterior abdominal wall. It may have different names, according to the exposed segment<sup>1,2</sup>. Colostomy and ileostomy are some of the common therapeutic procedures to treat physical traumas and several intestinal and anal diseases, such as: colorretal cancer, inflammatory bowel diseases, diverticular disease of the colon, ischemic colitis, familial polyposis, megacolon, anal incontinence and severe anoperineal diseases<sup>3</sup>.

The production of an intestinal stoma leads to uncontrolled elimination of gas and stool, a condition that causes indirect effects on the life in society, and that may lead to psychological and social isolation, interfering in relationships with family, sexual partners, friends and work colleagues, almost always involving negative feelings, such as anxiety, fear and doubts<sup>4-7</sup>.

The surgery that produces a stoma may represent invasion of physical and psychological intimacy, generating changes in the daily life and lifestyle of ostomized people and their family, with different levels of intensity and types of repercussion<sup>5</sup>.

In the presence of a stoma, the anatomical position of the anus is changed and eliminations are not controlled, influencing these people's body image reorganization. Besides the surgical treatment of the stoma, these people have to carry the fecal collection bag attached to their abdomen. Their body image is gradually renewed with the experiences and experiments with their body, enabling to build new meanings and images concerning this matter<sup>2</sup>.

Along the health-disease process, people's relations and actions are not only cognitive or social; they also have great symbolic, subjective influences, and are directly related to affectivity. In people with stoma, alterations to body image are considered key elements that determine aspects of their trajectory and quality of life, in the different phases of the rehabilitation process<sup>2</sup>. A healthy and attractive look plays an important role in the life in society, constituting everyone's object of desire. The consumer market has intensified and popularized the representation of an "ideal body" through repetition and normalization, something almost intolerable and useless, which favors the self-perception of ostomized people as "different" in terms of physical aspect<sup>2,8-10</sup>.

People with stoma considers they have an imperfect, and for this reason, different body, without the characteristics regarded by the society as normal attributes<sup>11</sup>. Unsatisfied with their body, they may present low self-esteem, as well as feelings of self-exclusion<sup>11,12</sup>, involving feelings of inadequacy, guilt or shame or loss of confidence and self-appreciation, affecting their self-image and self-esteem, elements that are part of the human identity and subjectivity, which are partially based on symbolic representations<sup>2</sup>.

The production of a stoma is a milestone in the life of those undergoing this surgical procedure, determining singular ways to face the situation, according to each one's particularities and world view, in the different aspects of life, also regarding sexuality.

The identification of personal values, the way to perceive the world, life and the disease treatment are especially important when confronted with the possibilities or impossibilities that the stoma may impose to the person.

The ostomized people's approach to sexuality is poorly explored or limited to aspects such as having or not an active sex life. The reasons for having this lifestyle many times result from difficulties faced by both assisted people and professionals, either for personal aspects that involve the practice of one's own sexuality or due to gaps in the professional training, considering that sexuality is still not sufficiently discussed in undergraduate courses in the area of health.

Thus, the purpose of this study was to identify Social Representations of people with intestinal stoma regarding how they experience sexuality before and after the stoma production.

#### **METHODS**

An exploratory, descriptive, qualitative study was performed, using the Social Representation (SR) Theory, which analyzes the phenomena of a specific group and the imaginary processes of the members of this group<sup>13</sup>, through categories that explain, justify and question the actions and feelings of those experiencing such reality<sup>14</sup>.

The study project was approved by the Research Ethics Committee at the Universidade de Taubaté (UNITAU), under protocol # 326/05. Data were collected in individual interviews, performed in Taubaté (SP), from

August to September 2005. The study analyzed 15 ostomized people, who fulfilled the inclusion criteria in terms of time since stoma production (1 year or more) and who, after receiving explanations about the study purpose, signed the Informed Consent Term.

The interviews, privately performed, started with the collection of data about the person's identification and characterization and at what health services he/she was treated. After that, the study questions were made:

What can you say about your sexuality after the stoma?

What about now, how is it now?

All interviews were recorded and fully transcribed; the content was analyzed using a group of techniques for communication analysis, seeking explicit or hidden, manifested or latent signification<sup>15</sup>, and knowledge behind the words, other realities not clearly expressed in the messages. After exhaustively reading the transcribed interviews, key expressions were identified to examine the literality of speeches and select the focus of the analysis of all speeches, which originated the first categorization.

Speech cutting was the next phase, as well as the verification of how often the speeches fitted the categories, and then they were sorted into initial subgroups, for subsequent definitive categorization in the next phase, resulting in the thematic unit: "Giving new meaning to sexuality" and subthemes.

#### RESULTS AND DISCUSSION

## Characterization of studied population

All interviewees were ostomized and were registered in the service to ostomized people in Taubaté, 12 (80%) of them presented definitive left colostomy due to intestinal cancer; 2 (13.4%) had ileostomy due to chronic inflammatory bowel diseases; and 1 (6.6%) had loop transversostomy. Eight (53.3%) were females. Regarding their age group, 8 (53.3%) were between 50 and 69 years old: 4 (26.6%) females and 4 males; 5 (33.3%) were 70 years old or older: 3 (20%); and 2 (13.4%) were between 30 and 49 years old: 1 female and 1 male.

From total females, five (62.5%) were married, two (25%) were widows and one (12.5%) was divorced. From total males, five (71.4%) were married,

one (14.3%) was a widower and one (14.3%) was single. Among the married men, 4 had been married for over 20 years; 3 between 5 and 9 years; 2 between 10 and 15 years, 1 between 16 and 20 years.

Regarding the participants' education level, two (13.3%) were illiterate, seven (46.8%) had incomplete primary education, one (6.6%) had complete primary education, four (26.7%) had complete high school and one (6.6%) had incomplete higher education.

Regarding their occupation, six (40%) were retired, three (20%) were housewives, three (20%) were store-keepers, one (6.6%) was unemployed, one (6.6%) was a commercial employee and one (6.6%) was a babysitter.

Regarding the stoma time, 4 people (26.7%) had the stoma from 2 to 5 years, 2 (13.3%) from 6 to 10 years, 4 (26.7%) from 11 to 15 years, 2 (13.3%) from 16 to 20 years and 3 (20%) for 21 years or more.

#### Thematic unit I

## Giving new meaning to sexuality

Having a definitive stoma means living with this body alteration until the end of life. Adaptations in several aspects of life are required, also in terms of experiencing sexuality, which usually involves intimacy and body exposure. These adaptations, in this thematic unit, include changes in how to experience sexuality after the stoma, new concerns related to the sexual act, strategies to adapt moments of intimacy, the technique of irrigation and use of intestinal occluder as factors that facilitate the sexual act, the concern about not damaging the stoma, the sexual disorders or dysfunctions resulting from the surgery, the possibility of fully experiencing sexuality despite the stoma and the distance kept form sex as an option.

The excerpts from speeches presented below show the changes in sexuality after the stoma:

[...] we get apprehensive [...] (A1). It used to be effervescent [...] everything was fun [...]. Now, I almost have no relation. Before, we had nothing [...], I used to be more active [...] (A4). [...] after this surgery, it was all over (A10).

Falling sick causes discontinuity of daily routine and contributes to reanalysis and restructuring of values, priorities and projects in life, many times leading to deep reflections on what is really important to each person<sup>16</sup>. This is a process that directly or indirectly affects other people, especially close family members, in particular, partner and children, who also go through processes of resignification and adaptations in their routines, once they share their life stores.

The diagnosis of cancer, whose treatment requires a large surgical intervention and, many times, the production of a definitive intestinal stoma, triggers a process of addressing the situation, characterized by required adaptations and elaboration of strategies for the new situation and not expected or planned instances. Such strategies are handled in many ways, considering that the experiences are particular of each person, and that everyone finds unique answers and alternatives to the situations experienced, as observed in the excerpts of speeches. The speeches showed apprehensiveness in the practice of sexuality after the stoma, characterized by fear and discouragement, which resulted, to some, in repression and, to others, discovery of alternatives that enabled, some time later, the return to practices in sexuality.

Ostomized people and their partners experience moments of insecurity and uncertainty in relation to sexuality, which may lead to changes in their practices. It was not possible to state that the reported changes occurred only as a result of the stoma, as other factors, such as fear, pain, widow(er)hood, among others, were concomitant and influenced the sexuality experience, but the stoma appeared, in the context of speech excerpts, as an element that influenced such alterations.

Getting old, the development of maturity, the several forms of experiencing relations with the family and spouse, among other factors, are parts of life process and can influence how sexuality is perceived, how it is manifested and how it is experienced. In addition, other physical, sociocultural and psycho-spiritual changes that may occur in the people's daily life should taken into account.

[...] I was younger, seeking to be horny, to have best horny feeling [...] (A12).

The excerpt above refers to the age factor, and not exactly the stoma, showing that it was not the only condition for the changes in behavior and sexuality experience.

The process of getting old is a determinant to be considered in sexual practices, as the possibilities and expectations change with the age. However, neither age nor most diseases automatically imply the end of sex life<sup>17</sup>.

The health professional, when considering and analyzing the feasible possibilities of attention and care in the process of providing support to an old ostomized person, should investigate and appreciate complaints or statements regarding sexuality, as they are important for the adaptation and resolution of physical, emotional and conflicting problems, aiming at the maintenance of their quality of life.

Instructions and information related to sexuality concerning the attention to people with intestinal stoma should be provided during the entire process of support, based on healthy ways to live, thus, helping achieve the maximum potential of health, in all life phases<sup>6</sup>.

The excerpt below shows new concerns considered by the interviewees, especially related to the sexual act after the stoma, such as the presence of a bag, effluent, noise, odor and changes in the body image.

I had nothing to worry about, and now, it is [...] now, we got used to it, but in the beginning [...] I was traumatized about it [...] there's this bag, it's more complicated (A1).

*Years ago, I had nothing to worry about* (A13).

Adapting, adjusting and reinventing situations, creating moments and elaborating new approaches were attitudes required for the practice of sexuality after the stoma, which certainly generated new meanings and representations, especially about experiencing moments of intimacy.

After the colostomy, I've done many things, I even had 'extramarital relations'. I got another husband, who taught me things I didn't know hehehe (A2).

Today, the symbolization of an ideal body involves signs of youth, beauty, vigor and health; thus, a fertile and healthy body. Body significations and representations based on populations of the modern world make people seek these socially established models, which end up influencing their way of perceiving and appreciating their own figures and how others perceive and appreciate them<sup>2</sup>.

These meanings of a young, slim and sensual body are part of the SRs about sexuality valid in the contemporaneous society.

The ostomized people have their body image changed not only by the stoma, but also by the devices used to collect the effluent. Despite the technological progress for the creation of several types and models of collecting bags, the ostomized person fears the possibility of having accidental losses of gas or feces, especially in situations of friction, during the sexual act.

When we have a new bag is one thing, two days later [sic] it's another thing, it doesn't have the same [...] smell [...] and everything [...] no matter if you clean it, it's not the same thing, we get apprehensive. It's not evident, but we get apprehensive, you see? I'm afraid it gets dirty, there's no freedom, the smell is not the same thing [...] (A1).

The occurrence of any of these events in moments of intimacy makes the ostomized person and his/her partner embarrassed, especially during an intimate relation immediately after the stoma. The possible loss of gas and feces caused by the absence of occluder in the stoma, remains even after many years with the stoma, causing impacts along the person's life, as observed in the speech excerpt below:

Ah, I'll never make sex if I'm not clean and neat (A15).

This excerpt is from the speech of a person that had been ostomized for 18 years, who reported full adaptation to the situation and more intense sexuality experience after the surgery, as her stoma resulted from complications of an inflammatory bowel disease that limited her life in several aspects, including sexual relations. However, it shows her concern about privacy regarding the stoma and the ritual before moments of intimacy with her partner, in this case, in pre- and post-stoma phases.

[...] but there's one thing [...] I never leave the lights on, I've never wanted him to see the stoma very well [...] (A15).

Care taken to make the stoma less visible act as a defense mechanism, through which the person avoids

direct exposure. This way, she feels more comfortable to manage the situation of intimacy and face body alteration, not allowing to be observed, protecting herself and avoiding unpleasant and embarrassing situations, neither for her nor for her partner.

Shame and the need to hide are emphasized in this speech excerpt. According to Lucia<sup>18</sup>, shame is "[...] an explosion of the impossibility to react" (p. 346) that paralyzes and uses concealmente as an attempt to preserve the secret part (in this case, the body image altered by the presence of the stoma, to continue being accepted).

The body image is that perceived from outside the body and, thus, it is characterized by the image that another person (a peer) transmits to the person<sup>19</sup>. Such image is full of affective values that make sense to the person. Hiding the stoma contributes to keep the sexual body veiled, under the imaginary idea of that was captured from outside.

On the other hand, the multiple character of the body can be understood based on the singularity and articulations of thought that determine how the body is established in the world, or based on the how the world imposes itself and the body only defends itself, reacting to the "threats". For this purpose, a group of subjective elements have to be activated, which are always correlated with the personal history of each ostomized person and the cultural context in which the person lives<sup>20</sup>.

The exposure of the "altered" body is also a situation that can generate discomfort, regardless of the time with the stoma e the partner, as seen in the case we have just mentioned. The different aspect still seems to disturb, which confirms the idea of Turano<sup>21</sup> that "the same causes do not always lead to the same effects" (p. 21), as essential human themes, such as sexuality, are immersed in the universe of feelings, which does not enable to theorize the reality as it is, then allowing to change certainty for probability, which characterizes each one's individual reality.

The elaboration of strategies to face the new situations, difficulties and new limits are present in the daily life of ostomized people. Regarding the questions of sexuality, part of the group of ostomized people created strategies to adapt their moment of intimacy, inserting additional care, especially concerning the use of collecting devices.

The bag is what most disturbed [...] (A1 and A12). [...] if we do it in the missionary position, the bag plastic material disturbs a lot [...] (A12).

There are innumerous collecting devices and accessories available in the market, and, no matter how good the product plastic is, the friction between the bodies produces noises, disturbs and may even cause some type of allergic reaction in the person and/or partner, especially in the presence of sweat, a secretion almost always present in moments of intimacy and during the sexual act.

The speech excerpts above explain the inconveniences of this situation and show that the health professionals and companies that produce stoma devices should dedicate more attention to these aspects, seeking for instance, alternative materials to product the bags.

Investigations addressing the people's adaptation to products, their difficulties in using these devices, and the reasons for accepting or rejecting them, are essential for the process to find solutions, propose changes and elaborate specific instructions, to minimize discomfort and suggest optional devices, enabling to expand the possibilities and promoting better and less concerning experience of sexuality.

The speech excerpt below shows that, at times, simple instructions can help overcome difficulties/limitations involved in the sexual act.

[...] the adaptations are positions at the sexual relation moment, just place the bag to the side, and then it doesn't disturb (A12).

The health professional may, in turn, provide practical instructions while providing support to ostomized people, addressing the subject when noticing that the person requires it, and then, contribute to the fastest possible adaptation process.

It is important to emphasize that, regarding sexuality, most professionals that provide support to ostomized people rarely address these aspects spontaneously, except when questioned by such people or their partners. The participation in update courses and especially in stoma therapy trainings showed that professionals from the area and other professionals do not spontaneously address aspects of sexuality, but only when questioned by ostomized people or their partners.

In general, health professionals have small or no preparation to deal with complaints regarding sexuality, and few of them have some kind of training in sexology or sex education. According to Maldonado and Canella<sup>22</sup>, these professionals usually ignore the problem and provide "false" support with very superficial and unspecific information, such as: "that happens to most people undergoing this type of surgery, it will soon return to normal", "you'll get used to the bag, it's a question of time", and many of them soon end up sending the person to other professionals, without eliminating their doubts and/or providing satisfactory answers to their questions.

The development of an "ethical view" that considers the need for recognition of the person in the relation<sup>23</sup>, as well as his/her subjectivity, may help enable to feel the other one's situation and elaborate new possibilities in shared worlds<sup>24</sup>. Then, it will favor the creation of viable strategies to each person, according to each one's particularities, and strengthen the health professional-patient relation.

Addressing sexuality while providing support to ostomized people through active listening may promote information sharing, which is required to improve the quality of life, thus, constituting the dimension of this much desired comprehensive support that associates theory with practice.

The excerpts below show some of the alternations found by the ostomized people to facilitate their sexual practices.

When the bag is loose, of course, it disturbs a little, it gets stuck, it's too bad, it disturbs, so [...] I have SOMETHING LIKE A BELT that I put on much before, it doesn't let the bag disturb. It doesn't let the bag loose, it doesn't disturb at all (A9).

[...] at the moment of sex, I LET THE BAG CLEAN AND WRAP IT WITH MICROPORE, then, it doesn't disturb at all (A14).

The strategies reported are simple and may be considered examples of adaptation during the sexual act, provided in nursing consultation to ostomized person or shared in group meetings or meeting of ostomized people associations. These experiences are relevant, as they can help other people face similar difficulties. Sharing these experiences with the manufacturers of stoma devices may help develop new accessories to be used by the ostomized people in their sexual practices, that reduce or eliminate their current difficulties.

The techniques of irrigation and intestinal occluder are practices that seem to be relevant and beneficial to the sexuality experience and improvement of the quality of life of ostomized people.

The intestinal irrigation is a mechanical method to control the fecal elimination. It consists in the application of an enema each 24, 48 or 72 hours, in the stoma itself. It is indicated to people with definitive left colostomy and without complications, such prolapses, hernias and important retractions<sup>25-27</sup>.

The intestinal occluder or obturator for colostomy is a plug-like flexible and disposable device that controls the fecal elimination, reducing noises and odors. It may be combined or not with the irrigation technique, but it is for users with left terminal colostomy, and the stoma diameter should be between 20 and 45 mm, with max. 25 mm protrusion<sup>26-28</sup>.

The use of intestinal irrigation or occluder is indicated by the physician. The requirements for both are specific and precise. The results are effective, ensuring the ostomized people that correctly use them a satisfactory intestinal control, not requiring, many times, the collecting bag for reasonably long periods. People who adopt the intestinal irrigation associated with the occluder may have effluent control for an average period that varies from 16 to 24 hours, securing the practice of daily activities, without being concerned about losses and stool leaking, also during the sexual act.

The possibility of evacuation control was a positive factor, bringing the perspective of having practices resembling those before the disease, and contributing a milder and less limiting connotation of the stoma. This way, despite the stoma, the irrigation combined with the occluder helped establish new and positive SRs about being ostomized.

Among all 15 participants of this study, 12 (80%) had left terminal colostomy and, among these, 33.33% (4) used the intestinal irrigation. Only 16.4% (2) used this method combined with the occluder.

The indication of these techniques and products is very important to ostomized people with definitive left colostomy; however, physicians do not recommend them very often. On the other hand, stoma therapy nurses frequently recommend them, but, as these procedures require doctor's prescription, they do not always get to effect them in practice.

The following speech excerpts clearly show the benefits of using self-irrigation, especially when associated with the occluder.

After the irrigation my life changed considerably and, with the occluder, it improved much more; if I don't mention, nobody knows I am ostomized (A13). At first, I didn't accept it, now I perform the irrigation and use the occluder, then, no problems, everything is normal! Really normal! I perform the irrigation each 24 hours and use the plug, it's 100% good. With the bag, I had to clean it three times a day. Now, I do it and remain [sic] for 24 hours. It's 100% good. No problem at all (A5).

The first speech excerpt showed that the self-irrigation benefits were important for the person not to feel different from non-ostomized people. The association with the occluder was an additional incentive, as, when definitively suppressing the collecting bag, a full experience was enabled, not only of sexuality, but also of other aspects in life related to social, work and family interactions.

The second speech excerpt shows that the change in how to perceive the ostomized condition occurred between the period before and after the adoption of self-irrigation. It changed from non receptivity to acceptance of a situation, which helped overcome anxieties and control the stoma and its effluents and to new meanings involving the stoma. The person was happy for not having to face embarrassing situations, such as stool leaking, odors, and for not having to use collecting devices that were visible through tight clothes, making the person feel secure and self-confident to experience sexuality.

In terms of sexuality, these procedures seemed to be essential for sexual practices, allowing a more pleasant intimate contact, probably not so timidly, especially due to the security they provided, as well as reduced flatulence and increased comfort for not having to use the collecting bag. Such aspects reduced the sensation of being different.

Body care is essential to keep its integrity. For the intestinal stoma, such integrity is violated, since an intestinal loop is outside the abdominal wall, exposing the intestinal mucosa and, given its fragility, bleeding and inflammation may occur after intense friction, such as the oral mucosa. This a factor that

friction, such as the oral mucosa. This a factor that may have helped prevent intimate contacts, reducing the frequency, mainly of more intense contacts, as the person was concerned about not damaging the stoma.

[...] I get worried about not damaging the colostomy (A13).

Any type of lesion and bleeding generates insecurity and fear, which may be aggravated by the fact that the digestive tract anatomy is unknown.

The presence of blood in the device, due to excessive friction during the sexual act, may produce embarrassment and apprehensiveness to both the ostomized person and his/her partner.

The intestinal mucosa, just as the oral mucosa, is highly vascularized and friable, causing small bleedings when any type of injury occurs, although no pain is felt. Such small bleedings are common and are not important problems, but blood involves some concern to most people, being related to situations of urgency/emergency, requiring prompt actions or care. Thus, knowing these characteristics of the stoma may help minimize excessive concern about small lesions and bleedings of the stoma.

Another factor that limits the sexuality experience of ostomized people is related to possible sexual disorders or dysfunctions resulting from the surgery.

After the ostomy, I didn't have sex for one year [...] because this surgery might have affected any nerve under it (A9).

The surgery, although it was in the intestine, involved the front part, because it was already affected, and, in the sexual act, it hurt a little (A8).

The surgery of abdominoperineal amputation is the curative treatment of distal rectal cancer, but, due to its radicality, it produces a stoma and may cause several disorders or dysfunctions, including those related to sex<sup>29-32</sup>.

Injuries in nerves of the autonomic nervous system that run from the pelvis to the sex organs may occur, leading to implications also in the sexual activity,

including loss of ejaculation, partial erectile dysfunction or even complete impotence<sup>30</sup>. This situation is illustrated in the speech excerpt below:

Now I have erection, but no ejaculation. Only this is different now, the rest is the same (A5).

Erectile dysfunction and dyspauremia are frequently reported complaints of ostomized people, as indicated in the excerpt above.

The correct information about possible alterations and complications that may occur after the surgery should be provided, and the doubts should be properly clarified, to make the person aware of all possible consequences of this surgery. This way, the person will be prepared to face the challenges that appear and effectively collaborate to his/her treatment.

[...] 9 months after the surgery, it returned to what was before the surgery, it returned to normal, thank God, so far, everything has been normal [...] (A9).

Analyses and questioning help the person think of what is required to face the unexpected, in case of sexual disorders and dysfunctions that may occur. On the other hand, when questioning and informing the person, the health professional, with clinical attitude, shows interest in the person's situation, helping him/her demystify beliefs that many times do not correspond to the reality and seek strategies to address these problems, according to the reality of each person and situation<sup>22</sup>.

After the colostomy, I've done many things, I even had 'extramarital relations'. I got another husband. I've lived more, you know!!! I've learned many things [...] (A9).

A new reality is possible when the person is open to changes. The speech excerpt above shows that, indicating that the stoma was not an obstacle in her life, who was open to learn and experience new things.

Then, the same experience does not produce the same effects, and there is no linearity in causes and consequences, as something bad for some people may not be bad to everyone. There are many ways to understand and interpret experiences, which occurs as a result of the specific reality of each person, based on the interaction with others, the significations of the experiences and perception of phenomena<sup>21</sup>.

The stoma, in the case above, does not seem to be a limiting factor to this person, as her speech shows that, after the stoma, her sexl life was renewed. She says that she learned new things and broke barriers and concepts pre-established by the society. The stoma was not a factor that limited her; otherwise, it was part of the changes and the process of building a new phase of her life.

The speech excerpt above pulls down barriers that are often present in the society, such as the idea that a stoma prevents someone from performing some physical, social, labor and sexual activities, among others. Pre-established concepts may permeate, influence and even determine ways of living and experiencing situations, as in the case of a stoma, usually negative and even paralyzing, preventing the person from experiencing moments of pleasure and freedom.

The speech above shows exactly the opposite, full experience of sexuality, despite the stoma; therefore, an example of how it is possible to accept and live someone's current condition, considering it a possibility of renewal. People often stick to models of "romantic love" and forget that "each one's love is invented each new relationship", each new situation, as experienced by A9.

New situations can encourage people to mobilize efforts and seek possibilities and ways that maybe have not been sufficiently or properly been explored. Then, these people will find out that it is possible to fully experience their sexuality in pleasant relationships, despite the stoma in the abdomen, and that a new situation may even cause these discoveries to effectively occur and positively transform some relationships.

It is important to emphasize that these actions are produced based on needs or a system of reasons that are intrinsically associated with the person's emotional status. They correspond to emotional processes that follow the person's actions in various contexts of his/her life, in this case, the subjective sense of sexuality for the person, and translate the expression of a new synthesis, which can be understood only within the constant changes of private meanings and emotions<sup>20</sup>.

The speech excerpts below clearly show this situation:

I think it's better than before (A13). [...] I'm more excited and very active now in all senses (A15).

On the other hand, some of the interviewees indicate that extramarital sex experiences are not possible, as illustrated in the speech excerpt below:

I have nothing to complain about it, but if I had a relation with someone other than my partner, then I believe I would have problems [...] (A12).

The contact with an abnormality in the body, in this case, the intestinal stoma, may generate embarrassment between the people and affect the different areas of social life and sexuality. These difficulties can be more intense in the initial phase of relationships. The speech below illustrates one of these difficulties, which are not common to non-ostomized people.

People are not used to what they will see in the sexual act [...] the stoma (A12).

Speaking of the presence of something different in the body may be embarrassing not only in new relationships, but also in stable relations, in which the partners, despite being together for a long time, are reserved, especially regarding their bodies.

The psychological problems of these people may often be more intense than the physical difficulties, affecting the relations with their partners. Adjustments in the relation may be performed using strategies involving the partner, using the dialog, to clarify doubts and eliminate uncertainties. The efficiency of the strategies depends on flexibility, stability and mutuality of both individuals in the relation.

*Today I sit and talk about it [...] more openly* (A13).

Sharing expectations, being supportive and especially the empathy and love are essential and indispensable factors to enable sexuality manifested in various forms. Sexual partnership is considered the key that shapes the details in the relationship

and may contribute positively to a successful relation, or negatively to a failed relation. Experiencing sexuality involves individual well-being and well-being of the couple<sup>33-35</sup>.

[...] some times he reaches out, but no way in [...] the [...] we hardly talk about it (A10). I avoid doing only what he wants, if I don't feel well [...] only wants to benefit from me [...] (A10).

These excerpts illustrate relations with difficulties, which seems to have no pleasure, dialog, respect between the partners. They feel they are only the other one's object of pleasure, without any exchange, even before the stoma. These characteristics remained or were intensified after the stoma. This way, the stoma became a justification to effectively establish the distance from sexual practices.

The speech excerpts below illustrate these situations.

[...] today, there's only affection without sex life [...] and we live well this way (A3).

I've had no sex life after the divorce and I'm fine this way" (A11).

[...] I'm fine this way, I have no relation (A8).

Establishing contact, communication and connection through the body is essential, not only for social relations, but also for the practice of sexuality<sup>36</sup>, which assumes an important meaning in the historical and cultural context of people. Then, when the body connection is, for any reason, weakened or ceased, recovering it is very complex, as it is determined by multiple factors based on the social elaboration of roles impregnated by feelings and emotions of each partner and molded by themselves in the couple's daily life.

The sex life is directly related to emotion, which, according to Rey<sup>20</sup>, represents an "essential moment in the definition of a person's subjective sense of processes and relations" (p. 247), once that even one's own reflections are sources of emotional production.

The way the ostomized people adapt to the new situation, their own altered body image, affects their capability to establish personal relations, experience, express their sexuality and go through the rehabilitation process<sup>16</sup>.

The option of being distant from or giving up sexual practices may become a system of reference to these people, when incorporated into their life. It appears as images that condense a group of significations that enable to interpret the facts and even give a sense to the unexpected. It is changed into categories to classify the circumstances, phenomena and individuals, resulting in opinions about themselves, that is, they are representations of the individuals characterized by subjectivity, thus permeating the construction of knowledge<sup>37</sup>.

#### FINAL CONSIDERATIONS

The SRs, in terms of experiencing sexuality after the stoma, are based on meanings attributed to the body, associated with daily life and present in the social imaginary. It is influenced by other factors, such as physiological changes resulting from the surgery, the fact of having or not a partner and relationship quality.

Care taken during sexual practices provide greater security and comfort in moments of intimacy, resembling the closest to what ostomized people experienced before the stoma.

The self-irrigation technique associated or not with the use of artificial occluder, has been attested by its users as a positive element that makes a difference in sexual practice after the stoma.

The elaboration of support projects shared with the person receiving the support is an essential health service, which should involve the ethical and esthetical aspects, once its practice is directed to subjects, and not only to the technical axis that builds support objects. This way, health professionals that work with ostomized people, to achieve this objective, have to seek knowledge that enables to establish suitable support projects to each individual in particular.

The support to ostomized people should be comprehensive, not limited to technical care and disease, which are important, but not sufficient. The interdisciplinary health team should consider all aspects of the person, seeking a real meeting between subjects (health professional-assisted person).

Sexuality of both ostomized and general people is determined by multiple interconnected factors

that will influence their experience and often define their way. The capability to understand the reality, pull down obstacles, beliefs, symbols, perceptions and values, the quality of the couple's relation and the access to qualified health information, products and services are essential to determine it.

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