Technology for self-care for ostomized women’s sexual and reproductive health

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ABSTRACT
Objective: to validate the technology of printed booklets on self-care for ostomized women’s sexual and reproductive health.
Method: a methodological study was performed with focus on the construction and validity of a printed booklet. The content of this booklet was validated by 11 specialist judges/nurses, according to a Content Validity Index (CVI) equal to or higher than 0.80. Appearance was validated by nine ostomized women, according to an assessment of the difficulty and convenience of the educational material.
Results: the booklet was validated by specialists, with an overall mean CVI equal to 0.87. Moreover, the target population showed 100% of agreement in terms of the adequacy of organization, writing style, appearance and motivation of this booklet.
Conclusion: the educational technology in question was validated according to content and appearance, thus representing an adequate, reliable and easily understandable resource to acquire knowledge about self-care for ostomized women’s sexual and reproductive health.
Descriptors: Ostomy; Women; Validity Study; Self-care; Sexual and Reproductive Health.

RESUMO
Objetivo: validar uma tecnologia do tipo folleto impresso para o autocuidado da saúde sexual e reprodutiva de mulheres estomizadas. Método: estudo metodológico, com foco na construção e validação do folheto impresso. O conteúdo do folheto foi validado por 11 enfermeiros juízes especialistas, segundo o Índice de Validade de Conteúdo (IVC) maior ou igual a 0,80. A aparência foi validada por 9 mulheres estomizadas segundo avaliação da dificuldade e da conveniência do material educativo.
Resultados: o folheto impresso foi considerado válido segundo os especialistas, com média global de IVC igual a 0,87 e, segundo o público-alvo, com 100% de concordância quanto à adequação da organização, estilo da escrita, aparência e motivação do folheto impresso.
Conclusão: a tecnologia educativa em questão foi validada segundo conteúdo e aparência, constituindo-se, portanto, em um recurso adequado, confiável e de fácil compreensão para a aquisição de conhecimentos sobre o autocuidado na saúde sexual e reprodutiva de mulheres estomizadas.
Descritores: Estomia; Mulheres; Estudo de Validação; Autocuidado; Saúde Sexual e Reprodutiva.

RESUMEN
Objetivo: validar una tecnología de tipo folleto impreso para el autocuidado de la salud sexual y reproductiva de las mujeres ostomizadas. Método: estudio metodológico, centrándose en la construcción y validación del folleto impreso. El contenido del folleto fue validado por 11 enfermeros jueces expertos, de acuerdo con el índice de validez de contenido (IVC) mayor que o igual a 0,80. El aspecto visual fue validado por nueve mujeres estomizadas con respecto a la evaluación de la dificultad y la adecuación del material educativo. Resultados: el folleto impreso fue considerado válido según los expertos, con media global de IVC igual a 0,87, y según el público objetivo, con el acuerdo del 100% sobre la idoneidad de la organización, el estilo de escritura, el aspecto visual y la motivación del manual impreso. Conclusión: la tecnología educativa en cuestión fue validada de
INTRODUCTION

The term “ostomized” has been used to describe individuals who have an ostomy. In its turn, ostomy refers to the surgical exposure of any hollow organ, whether temporary or permanent(1).

According to the International Ostomy Association, in countries with a good level of urban medical care, there is approximately one ostomized individual per each 1,000 inhabitants, a figure that can be significantly higher in less developed countries. The most recent statistical survey conducted by the Brazilian Ostomy Association indicated that, in 2003, there were 34,262 ostomized individuals in this country, of which 53% were women(2).

Epidemiological data point to malignant neoplasms and intestinal inflammatory diseases as the main causes of ostomies. However, there has been a significant increase in the incidence of external causes in great urban centers, changing the profile of ostomized individuals, from a predominantly elderly group to an increasing young adult group of women and men(2).

Individuals undergoing an ostomy surgery face the need to overcome not only the difficulties associated with the disease treatment or underlying disease, but also the changes in life resulting from an altered body image. Alterations in body shape and perception can lead to difficulties to accept this new condition of life, on different levels of intensity and repercussions, including aspects related to care for sexual and reproductive health(4,6).

Regarding the female body, the impact on sexuality can be even more negative, considering the stereotype of perfect body culturally held by society, represented by the integrity and standardization of good fitness(4).

The psychological impact caused by the strong influence of change in body image on the social concepts of beauty, body and sexuality is also included among the possible physiological dysfunctions secondary to the ostomy surgery. For women, the surgical process frequently results in a reduction in or loss of libido, dyspareunia, vaginal dryness and stenosis or even the development of feelings of insecurity due to the device attached to their abdomen, self-disgust and shame regarding the new body(5).

During the process of adaptation to ostomy, the repercussions for the sexual life of some women result from the loss of self-recognition as an attractive sexual being for their partner, denial of basic sexual needs and perception of sexuality as secondary, thus representing a high level of impact on their quality of life(4,6).

In spite of this, the approach to sexuality in multi-disciplinary care of ostomized individuals is very restricted and influenced by taboos(7). Studies point to health guidance being frequently restricted to the material used and ways to prevent skin injuries(8-9).

Seeking actions that minimize the impact caused by ostomy, the World Council of Enterostomy Therapists (WCET) defined the offer and development of new educational resources and materials in specialized health care, among other recommendations, focusing on education for self-care and the adaptation process(10), which implies the recognition of general biopsychosocial needs of ostomized individuals.

Thus, the multiprofessional team, particularly nurses as they stand out in the health education process, must emphasize the search for educational strategies that help to establish an effective communication with ostomized individuals and the restart of routine activities in an inclusive, participatory and empowering way, beyond the physical aspects of care(10). This requires that professionals have a sensible view of questions associated with self-care for sexual and reproductive health.

In this sense, educational technologies have been regarded as tools that facilitate dialogue, the strengthening of the client-professional relationship and the formation of a critical awareness geared towards healthy living. Thus, the effectiveness of nursing care, in the perspective of ostomized women’s sexual and reproductive health, presupposes the use of educational technologies as an innovative path for health information.

The use of printed educational materials such as booklets plays an important role in the educational process, not only to promote the mediation of learning contents, but also to function as a resource for easy access to information. Thus, it is possible for patients and their families to check such booklet whenever necessary, including at home(12). So that the information meets the objective proposed for readers, health education booklets require a certain level of validity and meeting of methodological prerequisites of selection and presentation of content and language that contribute to better assimilation of information(13).

Therefore, enabling an educational material to be validated and made available to ostomized women improves the quality of the teaching-learning process in health care, emphasizing the reliability of instructions.

Based on what has been described, the present study aimed to describe the process of construction and validity of the educational technology of booklets, including instructions on self-care for ostomized women’s sexual and reproductive health.

METHOD

Ethical aspects

The present study was approved by the Research Ethics Committee of the Federal University of Pernambuco, meeting the requirements of Resolution 466/12, which foresees the directives and regulating norms for human research.

Study design and period

A methodological study was performed, involving the construction and validity of an educational technology, from October 2013 to November 2014. This study refers to a research
strategy focused on the development, validity and assessment of research tools and methods\(^{(14)}\).

**Population**

For the selection of participants, the recommendations made by Pasquali\(^{(15)}\) for the ideal number of specialist judges and target population were followed. Consequently, 11 nurses and nine ostomized women participated in the stages of content and appearance validity respectively.

Specialist judges with a high level of knowledge and experience in their area were selected by an adapted Fehring model\(^{(16)}\) when reaching a minimum score of five points, according to the following aspects: titles; scientific production; and length of time working with the theme in question. Professionals who did not reach the minimum score established, i.e. with a low level of knowledge and experience in their area, were excluded.

In the stage of content validity, ostomized women registered with the Ostomy Support Program in the city of Recife, PE, Northeastern Brazil, were selected considering the following inclusion criteria: to have had an intestinal and/or urinary ostomy for at least one year; and to be aged 18 years or older.

Women with other ostomies that were not intestinal and/or urinary, with a length of time since surgery of less than a year and aged less than 18 years were excluded from this study. In terms of the length of time since surgery, we considered the fact that patients report a lower level of acceptance of their new condition of life in the first year after surgery, as they are involved with physiological aspects and equipment handling. This is because changes secondary to the ostomy, involved in the life of ostomized individuals, require time to be accepted and for self-care to be learned\(^{(9,17)}\).

**Study protocol**

The booklet content, selected through a review of the scientific literature and bibliographic survey, was comprised of a brief presentation, followed by sections with instructions on Self-care, Sexual and reproductive health, Safe sex, Sex and Ostomy, Tips for intimate moments, Pregnancy and ostomy, Self-esteem in sexual and reproductive health care, and Support network, in addition to illustrations with captions.

For the booklet to be constructed, a process-based model of design of printed health materials was followed, including recommendations for language, layout and illustration\(^{(12)}\). The design of the illustrations, text formatting and layout were performed by a designer.

The recommendations for health education materials to be written in easily understandable, readable and legible language justify the use of the Flesch Reading Ease Score (FRES), which predicts the level of education and measures the structural difficulty of a written text. In Brazil, the FRES adapted to Portuguese texts classifies texts with a FRES higher than 50 as compatible with a level of education of six to nine years of school, i.e. from a very easy to an easy reading level\(^{(18)}\).

The final version of the booklet measures 15cm x 21cm and it includes 23 pages, excluding the cover, back cover, author’s message and letter to readers. Each page has from one to three illustrations each, totaling 20 illustrations.

As the first version of the booklet was finished, the process of content and appearance validity began.

Content validity included the assessment of the universe of information that provides the structure and the basis to formulate questions that adequately represent the content\(^{(15-16,18-19)}\). After the Informed Consent Form was signed, researchers sent the questionnaire about characterization, online educational material and content validity instrument, which consisted in an adaptation of the Nursing Diagnostic Content Validity model\(^{(20)}\).

For this purpose, a semi-structured questionnaire with 17 statements was prepared according to the Likert scale format with five response options: “I completely agree”, “I agree”, “I neither agree nor disagree”, “I disagree”, and “I completely disagree”. Each statement corresponded to an assessment item, distributed into three assessment domains (Objective, Structure and organization, and Relevance). Moreover, there were spaces aimed at general comments and suggestions. The speech of participating specialist judges was identified by the initials “SJ”, followed by the number of the completed instrument.

When the content validity was finished, the necessary adjustments were made and the booklet was printed for appearance validity.

Apparent validity, also known as semantic or face validity, consists in the assessment of readability, comprehension and appearance by the target population, which is the aim of this technology\(^{(15)}\).

Participants assessed the booklet in terms of organization, writing style, appearance and motivation. A self-administered form was used to characterize participants and to assess the difficulty and convenience of the educational material, adapted from the Suitability Assessment of Materials (SAM)\(^{(21)}\). Finally, researchers questioned whether there were any errors or whether an important topic to be approached was missing, apart from general comments and suggestions. The speech from ostomized participants was coded with the letter “O”, followed by the number of the completed form.

**Analysis of results and statistics**

For the analysis of data on content validity, the Content Validity Index (CVI) was used, considering the Item-Level Content Validity Index (I-CVI) and the Scale-Level Content Validity Index/Average Calculation Method (S-CVI/Ave). A Content Validity Index (CVI) equal to 80% (0.80) was used as the cut-off point\(^{(22)}\). Items that had a mean lower than the CVI established by this study were changed.

The data on appearance validity were tabulated in the Microsoft Office Excel software and the absolute frequency and agreement were analyzed according to the CVI.

**RESULTS**

This booklet was comprised of sections on instructions, in which the concepts of self-care, sexual health, reproductive health and self-esteem were emphasized, in addition to sexual and reproductive rights. There are tips on health care for intimate moments and information about pregnancy, family planning and support network for the adaptation process.
Additionally, there is a section entitled “True or false?”, aimed at reviewing the instructions provided and clarifying possible questions. The cover was designed with several illustrations included in the booklet, so that its content and main message to the reader were represented (Figure 1).

Of all 11 participating specialist judges, seven were enterostomal therapy nurses, with a mean length of time of experience in the health care/research area of ostomies of 16.7 years (standard deviation – sd = 10.6). Experience in sexual and reproductive health care/research was reported by seven judges. A total of six judges had previous experience in the development/validity of educational technologies. The adequacy and validity of themes were confirmed in the content validity process. All the three booklet domains assessed (Objective, Structure and organization, and Revelance) were considered to be valid, as they obtained a mean of agreement per domain equal to or higher than 80%.

Table 1 shows the distribution of absolute frequency of scores obtained from the assessment of specialist judges, according to the domains assessed and analysis of agreement of adequacy of content validity items.

The mean for all booklet items, which represent the overall content validity of this booklet (S-CVI/AVE global) was 0.87, i.e. higher than the expected CVI.

The analysis of comments/suggestions of specialists in the content validity showed the adequacy of the behavioral representation of items and emphasized the required changes.

The following items showed disagreement in clarity and objectivity of language, font size and type, and colors and layout respectively: 2.1 (I-CVI 0.72), 2.4 (I-CVI 0.63) and 2.5 (I-CVI 0.72). Although item 3.3, which refers to the coherence between the information presented and ostomized women’s needs for sexual and reproductive care, showed an IVC lower than the cut-off point defined, it did not receive any suggestions or comments from judges.

As suggested by these judges, the terms/expressions “undesired pregnancy”, “ostomization”, “covering” and “intestinal loops” were replaced by simpler semantic equivalents “unwanted pregnancy”, “ostomy surgery”, “disguise”, and “intestines” respectively.

The possibility of low agreement among judges for the items referring to font size and type, colors and layout was considered to be associated with the fact that the material was assessed online, thus subject to visualization in adjustment proportions lower than 100% and distortions of color shades, not accurately representing the actual display of the printed material on a ½ A4 sheet with a landscape orientation. In this sense, it should be emphasized that the recommendations for the theoretical material used in the booklet design were maintained during the stage of appearance validity by the target population.

Source: Authors

Figure 1 - Booklet sections
The validity of the number of illustrations and number of pages indicate the reach of the visual lightness of the material and the understanding that a greater amount of information does not necessarily mean better use of information, as pointed out by items 2.7 and 2.9 respectively, which achieved an I-CVI of 0.90, positive assessment and layout adequacy.

A total of three specialist judges emphasized the relevance of the booklet in the scientific environment and for the target population:

A contribution to the construction of knowledge about care for ostomized people. (SJ7)

An initiative that can help many women to overcome their fears and to assert themselves. (SJ8)

A colorful and pleasant material with language which is easy to be assimilated. (SJ10)

In the appearance validity performed in one single group, the minimum age of participants was 28 years and the maximum age was 51 years, with a mean age of 38 years. Regarding level of education, it ranged from five to 16 years, with a mean level of 9.6 years (sd = 3.8). Of all women who had an intestinal ostomy, five had a colostomy and four had an ileostomy, six of which were permanent and three, temporary. The mean length of time with an ostomy was three years (sd = 6). The reasons for undergoing an ostomy were intestinal inflammatory disease, Chron’s disease and colon-rectal or gynecological cancer. A total of five women maintained an active post-ostomy sexual life.

In the assessment of difficulty and convenience of the booklet, 100% of the ostomized women answered “yes” for all aspects of appearance validity: Organization – the way that instructions are presented, including coherence, structure and strategy of presentation of information; writing style – linguistic characteristics, comprehension and writing style of the educational material presented; appearance – distribution of information, layout adequacy, font and illustrations; motivation – capacity of the material to cause a certain impact, motivation and/or interest, in addition to the level of significance of the educational material presented.

The following comments reveal the results of this stage of validity:

The cover illustrations show what the booklet is about […] The information makes it clear how we should do it. (O4)
DISCUSSION

Aspects such as sexuality, gender and reproductive health, especially among ostomized women, have been scarcely investigated in the scientific world, thus revealing a deficiency in the area of women’s comprehensive health. In Portugal, a survey on the needs for information about sexuality included 135 ostomized participants and identified that 50% of them had not received any information before or after the surgery, 51% of which women

The majority of ostomized patients have some type of difficulty regarding sexuality, whether related to physiological dysfunctions resulting from surgical procedures – such as the reduction in or loss of libido, dyspareunia, vaginal dryness or stenosis (1–4,8) – or related to the psychological impact resulting from the change in body image, manifested by feelings of insecurity and shame about one’s body (5–7).

However, the analysis of national and international scientific productions on health education practices for ostomized individuals performed by nurses revealed the use of a multimedia program and booklet mainly directed towards the rights of such individuals, health care for ostomy, the importance of family for care, and self-care attitude after surgery (8–10). Other studies also show that instructions on health aimed at ostomized individuals are restricted to the management of collection bags and skin (8–9).

Providing information about sexual and reproductive health – through the educational technology proposed in the present study, in accordance with the Ministry of Health’s proposals of design and distribution of technical manuals and educational booklets on sexuality and reproduction – emphasizes a posture of citizenship and comprehensiveness of care for women and empowering regarding rights such as the exercise of autonomy and self-care (11–13). Additionally, it contributes to the development of new knowledge, attitudes, behavior and abilities in their new condition of life, which can help them in their process of adaptation and performance of basic needs associated with sexuality, self-image and self-concept (8,9).

Among the health education technologies, printed educational materials such as booklets, being tools that facilitate the teaching-learning process, are widely used in the process of acquisition, use and deepening of knowledge, mastery, abilities and decision-making. Their use is justified as a complement to verbal instructions, working as information guidelines in case of subsequent questions and helping users to cope with and find solutions to health problems on their own (11–12).

In view of what has been described, it is believed that experiencing sexuality with knowledge about the sexual and reproductive rights of ostomized women will enable them to experience an informed, pleasant and safe sexual life based on self-esteem, allowing quality of life and personal relationships to be improved, in addition to the expression of their own identity as individuals, to the detriment of the presence of ostomy (20).

In the present study, questions about sexuality were included through information about the benefits of the use of vaginal lubricants to reduce discomfort during sexual intercourse and illustrated suggestions for adequate moments of intimacy for ostomized women, among which is the use of adapted and comfortable clothing and lingerie that highlights sensuality and improve their self-esteem; the search for pleasure through caressing, new positions for sex or mutual masturbation; the use of music to mask the noise from the gases; the emptying or exchange of the collection bag before sexual intercourse; the use of collecting devices adjusted to the type of ostomy; and the possibility of intestinal irrigation as an alternative resource to the use of the collection bag (17).

Once questions about sex are clarified, self-care for sexual and reproductive health of ostomized women must consider the possibility of their desire to become pregnant. Pregnancy is possible for some ostomized women, depending on the type of disease that led to this ostomy and the organs affected by the treatment or surgical procedure (20). Thus, the need for medical evaluation of the conditions and risks of conception was shown, as were some of the possible complications resulting from the growth of the belly during pregnancy, emphasizing the importance of specialized prenatal care in this period.

During the adaptation process, ostomized individuals seek a support network of friends, family members, professionals and others who are also ostomized, as they can contribute to facing the challenges posed by the presence of an ostomy (2,26). The roles of family members, health professionals and other ostomized individuals were emphasized in the learning process of care, resulting in safety, rehabilitation and living harmoniously with this new condition.

Considering the content presented, with an agreement of 90.2% and mean S-CVI/Ave of 0.90 among specialist judges, items related to the objective domain were accepted, i.e. the capacity of instructions presented in the booklet to bring about change in behavior and attitudes through reading.

Although printed educational technologies such as the booklets have been widely used in health communication, aiming to facilitate the teaching-learning process, its applicability is subject to limitations associated with one’s ability to read and level of education (12–13).

To understand that the vocabulary used in printed materials must be coherent with the message one aims to transmit to the target population and, moreover, that its reading must be easy, inviting and comprehensible (12), the words “stoma”, “ostomy” and “ostomized” were selected as a way to identify this population through familiar terms frequently used by them.

With a Flesch Reading Ease Score (FRES) equal to 60, the booklet was classified as easy reading. This converges with the result of 100% of agreement regarding the readability of the booklet by the target population, with a level of education between one and eight years of school.

As they are effective, health messages, whether written or not, must be succinct, relevant, well developed and comprehensible. To achieve this, the importance of the illustrations, layout
and design of the printed material stands out, aiming to attract readers, stimulate reading and reinforce the idea transmitted\(^{13}\). The use of illustrations is essential in health communication as these contribute to the readability and comprehension of the text\(^{13}\). When placed close to the written text, the attention, assimilation and capacity to recall the message significantly increase when compared to this text alone\(^{20}\), a greater benefit for individuals with a low level of education and reading skills.

Simple illustrations or those in the shape of drawings, such as the ones found in this study, can simplify complex situations and emphasize important points of an ideal\(^{12-13}\). With a percentage of agreement equal to 84.1% and a mean of agreement (S-CVI/Ave) of 0.84, the booklet was considered to be valid regarding the “structure and organization” domain.

When reflecting on the fact that sexuality, gender and reproductive health aspects, especially those of ostomized women, have scarcely been investigated in the scientific world, a great deficiency in the area of women’s comprehensive health was found\(^{7}\).

Thus, the guidance provided by the inter-disciplinary team and nurses, whether they are stoma therapists or not, and established through interactive and efficient communication with patients and family, is essential. The relevance of the booklet, in view of the gap found in the scientific environment, obtained a percentage of 90.6% and mean S-CVI/Ave of 0.90, meeting the needs for information about sexual and reproductive health care of ostomized individuals and recommending the construction of nursing knowledge.

**CONCLUSION**

The global CVI reached by the assessment of specialist judges (global S-CVI/AVE of 0.87) and the total agreement of the target population enable, respectively, the content validity and appearance validity of the health education booklet entitled “Booklet of instructions on self-care – ostomized women’s sexual and reproductive health”.

The use of validated educational technologies attributes higher quality to the teaching-learning process and the communication in health care emphasizes the reliability of the instructions presented and the level of coherence of information to meet the proposed objective, an important benefit for the target population and educators.

It is believed that the access to instructions on self-care scientifically validated by the present study will contribute to the acquisition of knowledge that can help ostomized women in the process of adaptation to their new condition of life with ostomy, whether it is temporary or permanent, in the giving of a new meaning to their self-image and self-concept, in the overcoming of fears and taboos resulting from a change in body image and in experimenting their sexuality in a more pleasurable way.

Finally, the performance of clinical validity in future studies – for the assessment of the efficiency of this technology as an instrument that can promote changes in attitudes and practices of ostomized women’s sexual and reproductive health – can emphasize the reach of the objectives of the health education process.

**REFERENCES**


