LIVING WELL WITH A STOMA: EXPERIENCE REPORT ON THE PREPARATION OF A BOOKLET

VIVA BEM COM UMA ESTOMIA: RELATO DE EXPERIÊNCIA SOBRE A ELABORAÇÃO DE UMA CARTILHA

VIVA BIEN CON UNA ESTOMIA: RELATO DE EXPERIENCIA SOBRE LA ELABORACIÓN DE UNA CARTILLA

ABSTRACT

Objective: to describe the experience of preparing a booklet for stomized children, their parents and health professionals. Method: descriptive study, of experience report type, about the preparation of a booklet for stomized children to be used as an educational strategy. The elaboration was based on the theoretical reference contemplating the suggested steps. Results: the production of the booklet was designed to provide information to stomized children, their parents and health professionals. In order to achieve this, subjects on etiology/pathology, skills for care/self-care, prevention of complications, health promotion and the rights of the stomized child were addressed. Conclusion: the booklet favors the development of skills for the care and promotion of autonomy of the parents and the stomized child for home care, as well as for the social and school life. In addition, it can benefit health and basic education professionals, enabling them to improve their professional performance towards these children and their families.

RESUMO


RESUMEN

Objetivo: describir la experiencia de preparar un manual para niños estomizados, sus padres y profesionales de la salud. Método: estudio descriptivo, tipo relato de experiencia, sobre la elaboración de la cartilla para niños estomizados para utilización como una estrategia educativa. La elaboración fue fundamentada en el referencial teórico contemplando las etapas sugeridas. Resultados: la producción de la cartilla fue elaborada para fornecer informaciones a los niños con estomia, sus padres y profesionales de la salud. Para eso, fueron abordados temas sobre etiología/patología, habilidades para los cuidados/autocuidado, prevención de complicaciones, promoción de la salud y derechos del niño estomizado. Conclusión: la cartilla favorece el desarrollo de habilidades para los cuidados y promoción de la autonomía de los padres y del niño con estomia, para los cuidados domiciliares, así como para el convivio social y escolar. Además de eso, podrá beneficiar profesionales de la salud y de la educación básica, capacitándolos para mejorar su actuación profesional ante esos niños y familiares.
Stoma in children leads to changes in their lives and in the lives of their families, such as complications, hospital discharge, homecare, readmissions, treatments and social interaction, as well as the impact of the disease, which require changes in family dynamics. Thus, caring for the child requires from the family the adoption of new measures and decisions which will contribute to the resumption of daily activities.

For this purpose, planning an comprehensive nursing care during the surgical treatment, teaching techniques and care with the stoma, as well as adaptations for the maintenance of the child's activities, identifying resources available in the community and helping reducing family stress are extremely important. A close relationship between the nurse and the family caregiver allows the understanding of the new condition of the child with the provision of professional support to monitor the growth and development of the child, resulting in improvement of quality of life. In nursing care, professionals must consider the previous knowledge of families, their experience with the disease, the existence of popular practices and the physical and emotional overload resulting from the disease.

During the development of this dissertation, in the ethnographic field work, in-depth interviews, participant observation and field diary revealed that both the children and the parents were unaware of the etiology, of the need to make a stoma, of collection devices and of the rights of stomatazed patients. In addition, during the perioperative phase, parents did not have access to information and training on stoma care. In the home context, although all the children lived in the coverage area of the Family Health Strategy (FHS), there was no follow-up by this team.

Upon returning home with the stomized child, the parents experienced numerous difficulties and, in an attempt to provide better care to their children, they sought information via the Internet, on the management of the stoma and peristomal skin. The parents reported that in the comings and goings to the health services, they had received some guidelines that were incipient and had scientific language, which made it difficult to understand them. Other doubts they expressed were related to feeding, leisure and schooling of these children.

These facts emphasize that nurses and other health professionals should be able to choose, select and prepare a clear and objective message to ensure the accessibility of information and the real understanding of this health problem, treatment and its consequences for the child and to the family. A material that favors understanding increases knowledge, skills, as well as promotes health and the autonomy of this clientele.

We have elaborated this booklet to favor the understanding and to solve or reduce doubts and anxiety of parents and stomized children, as well as of health and basic education professionals. In this study, we describe the experience of elaborating this booklet.

**OBJECTIVE**

- To describe the experience of developing a booklet for stomatized children, their parents and health professionals.

**METHOD**

This is a descriptive study, an experience report of researching nurses on the experience of elaborating a booklet as an educational strategy to solve doubts and to help improving the understanding of stomatized children as well as their parents and health and basic education professionals.

The said booklet was developed during the masters course of the first author mentioned in the academic identification with grant from Coordination for the Improvement of Higher Education Personnel (CAPES in Portuguese), entitled "Meaning of Being a Parent of a Stomatized Child: an Ethnographic Approach", whose participants were parents of children enrolled in care services for stomatized people in the southern region of Minas Gerais.

The elaboration process of this booklet comprised four stages:

- 1st Stage - Situational Diagnosis - listing of the doubts and needs of seven parents of stomized children on etiology/pathology, stoma and peristomal skin care, health promotion, rehabilitation and rights of stomatazed patients. This information was collected during the development of the dissertation of the first author, of fieldwork consisting of reports of in-depth interviews, field diary and participant observation;

- 2nd Stage - Literature review - integrative review carried out on the theme concomitantly to data collection and discussion of the final report of the dissertation;

- 3rd Stage - Preparation of the booklet - elaboration of content, appropriate language,
enjoy the written material provided that the barriers of their understanding are reduced, with coherent vocabulary and capable of stimulating the reader's interest in the educational material. For this purpose, it should be elaborated with simple, direct and easy-to-read language, with illustrative resources for greater efficiency and greater reach.

For the elaboration of simple and fast-to-understand message, researchers emphasized the clear separation between words, lines and paragraphs; use of short and known words; redundancy (repetition of important words) in order to facilitate understanding; structured text with articulated phrases; attention to the amount of information contained in the material.

In the booklet, the characters present the content in short and informative speeches about the care of the stomies. In addition, the redundancy of the terms stoma and collection device/bag was maintained to expand the reader's vocabulary.

Easy-to-understand writing expands knowledge, improves patient coping, helps developing skills and autonomy and makes patients understand about their actions, which directly influence their health status.

Illustrations

Illustrations are resources to explain or emphasize important points and ideas of the text, because, in addition to attracting the reader, they improve the representations of the desired actions, allowing the target audience to identify themselves with these actions.

In this booklet, illustrations represent the care with the stoma and teach the step-by-step of the exchange of the collection device, elaborated through good quality and high definition graphic design.

Layout and design

Another prominent aspect in the production of the printed material is the layout and design, which make the material attractive and easy to read.

The layout and design of this booklet were in A4 sheet in "landscape" configuration whose page size corresponded to its half. The text was written as a comic strip with lines and illustrations, in black Arial font, size 14 for text and 16 for titles, with 1.5 spacing between the lines. In order to make it attractive, the cover was illustrated with stomatized children and with a concise and colorful title (Figure 1) to allow the reader to capture the main purpose of the printed material.
Contents of the booklet

Regarding the elaboration of the content, the booklet was divided into thematic categories of answers to the questions of the stomized children and their parents. These categories addressed the definition and types of stomies; location and characteristics of the effluents; indications about their manufacture; types of collection devices; stoma and peristomal skin care, besides the prevention of complications; cleaning and exchange of collection equipment; and rehabilitation (feeding, physical activity, leisure, schooling and rights of stomatized children).

Definition

The thematic category “definition” aims to clarify what a stoma is, the length of stay for children and its characteristics. Thus, stoma is a surgical opening of an organ, such as intestine and bladder, in contact with the external environment, for the exit of feces or urine. In children, most of the stomies are temporary, performed soon after the neonatal period for treatment of congenital malformations, imperforate anus and acquired diseases.

My story

The thematic category “My story” illustrates the dialogue between two stomatized children, Pedro and Felipe, who tell us about the specificities of colostomy, ileostomy and urostomy, as well as effluent characteristics (Figure 2).

The nomenclature adopted to define the type of stoma is related to the exteriorized body portion, which has different types and purposes. Thus, for the intestinal stomes, when there is exteriorization of the ileum, we have the ileostomies, which are characterized by the outflow of liquid or semi-solid effluent; when there is exteriorization of the colon, we have the colostomy, which has more consistent fecal elimination; whereas for the urinary system, the ureters are implanted in a portion of the ileum and the ileum is externalized, forming the urostomies, which drain urine.
3. My story
Hello my friend! My name is Peter and I have a colostomy because, in my case, the stoma was made in the large intestine. The feces leave through my colostomy, are consistent and fall directly into the bag (collection device), in which they are stored until being discarded.

When surgery is performed on the small intestine, also known as thin intestine, it is called the ileostomy. The feces that leave the ileostomy are liquid or semi-pasty and therefore the bag needs to be emptied several times a day.

Hello, friend! My name is Felipe and I have a urostomy. In my case, rather than feces, urine comes out, which is also stored in a bag.

♦ Why do I have a stoma?
Intestinal stomies are made when some part of the intestine presents dysfunction, obstruction or injury. The most frequent causes in infants are when the baby has necrotizing enterocolitis, imperforate anus and Hirschsprung’s disease (HD), also known as congenital aganglionic megacolon; in older children, inflammatory bowel diseases, congenital malformations and ureterostomies are the most common causes when there are injuries in the bladder or in the distal portion of the ureter.¹¹

Urinary stomies are called urinary derivations and are performed in children with neurogenic bladder, spina bifida, congenital obstructions, among others, which impair the renal pelvis, ureters, bladder and urethra, in order to preserve renal function.¹²

In this sense, in our booklet, Pedro tells us that he became ill and the main symptoms. Complementing this information, Felipe describes the main pathologies that lead to the making of a stoma.

♦ What are collection devices?
This category presents specifications of the collection device: one or two pieces; for colostomy/ileostomy or urostomy; size (pediatric and neonatal) (Figure 3).
How to take care of my stoma?

In the thematic category “How to take care of my stoma?”, authors address the handling of the stoma and of the collection device, indication for the disposal of the effluent and the frequency of exchange of such devices.

The proper handling of the device is essential for the prevention of complications and the teaching of self-care is one of the challenges that require continuous intervention to minimize possible discomforts, such as device detachment, favoring the daily life of the child and of their parents.²

For 34.6% of the people, device change was one of the greatest difficulties experienced, of which 5.7% had sleeping disorders, 3.8% were afraid of device detachment, 3.8% had problems in social life and 1.9% had adaptation difficulties.

How to change the collection device?

In order to avoid such disorders, this category explained, step by step, the exchange of the collection device by ordering the steps of stoma hygienization, measurement, trimming of the equipment and proper placement/gluing of its base in the abdomen.

Tips and how to resume activities?

The stomatized child and their family need to reorganize and adapt their daily activities. For this purpose, the presence of health professionals, especially the nurse, becomes essential to guide them and to assist them in the process of adaptation of the child to the new life condition.¹³ An adapted child presents an improvement in their body image, self-esteem, school performance, as well as in social and school life.¹³

For patients’ rehabilitation, some recommendations were made at health promotion, such as care, food, leisure and physical activity, prevention of complications, return to social life and school activities.

Rights of stomatized people

Collecting devices are not is financially accessible to all social classes and therefore there are federal public policies that guarantee the provision of specialized care to people with stomes, as well as the supply of collection devices, protection and safety assisting devices.²

The Secretariat of Health Care published in the Union Official Journal No. 220 the Ordinance No. 400, on November 16, 2009, on the National Health Policy for the Disabled Person.¹⁴ This Ordinance ruled that the
stomatized person has the right to: be informed in the preoperative period about the stoma and the future quality of life prospects; appropriate demarcation for the preparation of the stoma at the appropriate site; have a well built stoma; receive skilled nursing care in the postoperative period; emotional support; orientation for self-care, prevention of complications in the stomies and access to collection devices, protection and safety assisting devices; besides social benefits, according to the Brazilian legislation.

In this category, authors addressed the rights of stomatized patients, as well as Law No. 12.738/12 on acquisition of collection device in the supplementary healthcare plan agencies. The validation of the material by specialized health professionals with clinical and research experience with the target audience will provide information, suggestions and opinions that will facilitate decision making. To this end, we finished the fourth stage of the elaboration of the booklet, in which health professionals participated, such as stomatherapist nurses, participants in the extension/research group of two public universities.

Thus, we learned from the preparation of this material that the educational process carried out by the nurses must be developed in the perioperative period and extended to households, considering the practices, potentialities and knowledge of the stomatized child and of their caregivers, as well as their sociocultural reality for more effective health actions. This booklet can be a facilitating strategy for deepening the knowledge of the child, parents and for training professionals who take care of the child, either in the health area or in basic education. The booklet enables to reinforce information and solve doubts that may arise in the daily routine, in addition to remembering the seized content.

CONCLUSION

The booklet favors the development of abilities for the care of the stomatized child by contemplating information with quality, illustrations and simple language, solving doubts, promoting parents and the child’s autonomy for the care at home, besides social and school living.

On the other hand, this booklet can benefit health and basic education professionals, enabling them to improve their professional performance towards this clientele.

FINANANCING

This booklet was developed during the dissertation of the first author mentioned, entitled “Meaning of being a father of a stomatized child: an ethnographic approach”, with grant from CAPES.

REFERENCES


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