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## KNOWLEDGE OF THE PROFESSIONAL ABOUT NURSING CARE OF PEOPLE WITH OSTOMIES AND THEIR FAMILIES

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**ABSTRACT:** Assistance-convergent survey that aimed to understand the nursing care of people who underwent ostomy surgery in a university hospital in the south of Brazil. The study was conducted in the surgical units via semi-structured interviews with nursing professionals between April and August 2011. The data were analyzed in four steps: collection, synthesis, theorization and transfer. The following categories were then created: The knowledge of the nursing professional regarding the role of the person with ostomy in self-care; the knowledge of the nursing professional regarding the role of the family; and professional education and performance. It was observed that the ostomy patient requires special attention in health care for their rehabilitation and autonomy.

**DESCRIPTORS:** Perioperative nursing. Ostomy. Nursing care. Self-care. Professional competence.

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## CONHECIMENTO DO PROFISSIONAL ACERCA DO CUIDADO DE ENFERMAGEM À PESSOA COM ESTOMIA INTESTINAL E FAMÍLIA

**RESUMO:** Pesquisa convergente-assistencial que teve como objetivo conhecer o cuidado de enfermagem às pessoas submetidas à cirurgia de estomia intestinal, em um hospital universitário do Sul do país. Foi realizada nas unidades de internação cirúrgicas, nos meses de abril a agosto de 2011, através de entrevista semiestruturada com os profissionais de enfermagem. Os dados foram analisados em quatro processos: apreensão, síntese, teorização e transferência. Originaram as categorias: o conhecimento do profissional de enfermagem frente ao papel da pessoa com estomia intestinal para o autocuidado, o conhecimento do profissional de enfermagem com relação ao papel da família e formação e atuação profissional. Observou-se que a problemática da pessoa com estomia intestinal é complexa e determinante de condições especiais no atendimento à sua saúde para a sua reabilitação e autonomia.

**DESCRIPTORES:** Enfermagem perioperatória. Estomia. Cuidados de enfermagem. Autocuidado. Competência profissional.

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## CONOCIMIENTO DEL PROFESIONAL ACERCA DEL CUIDADO DE ENFERMERÍA A LA PERSONA ENTERECTOMIZADA Y SU FAMILIA

**RESUMEN:** Este estudio tuvo como objetivo conocer el cuidado de enfermería a las personas sometidas a cirugía de enterectomía en un hospital universitario del sur del país. Fue realizada en las unidades de internación quirúrgica de un hospital universitario del sur de Brasil, durante los meses de abril a agosto de 2011, por medio de entrevista semi-estructurada con los profesionales de enfermería. Los datos fueron analizados en cuatro procesos: recolección, síntesis, teorización y transferencia, originando las siguientes categorías: El conocimiento del profesional de enfermería frente al papel de la persona enterectomizada para el autocuidado; El conocimiento del profesional de enfermería frente al papel de la familia; y Formación y actuación profesional. Se observó que la problemática de la persona con enterotomía es compleja y determinante de condiciones especiales, en el atendimento de su salud para su rehabilitación y autonomía.

**DESCRIPTORES:** Enfermería perioperatoria. Enterotomía. Cuidados de enfermería. Auto-cuidado. Competencia profesional.

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## INTRODUCTION

Nursing has evolved from a practical area towards the search for systems and concepts that define and correlate basic principles, which are a particular set of knowledge that make it a unique science and guide the practice of the profession.<sup>1</sup>

Thanks to the technical and scientific body, nursing has the ability to promote comprehensive care, so as to meet the basic needs affected by illness, for which the treatment may be clinical or surgical. It can therefore rehabilitate ostomy patients to their new health condition and reintegrate them into society. In addition, nursing is continually developing self-care education in order to promote better quality of life for patients and their relatives.

In this study, the individual concerned is the ostomy patient, who has undergone surgery and who is a unique member of a family. The ostomy patient is faced with a diversion of fecal elimination resulting from a surgical process, in which an opening called a stoma is created. The stoma can be temporary or permanent;<sup>2</sup> it is generally located in the abdominal wall and results in loss of sphincter control. This new condition requires the continuous use of a specific device called a pouch, which also requires systematic and multidisciplinary attention.

After the ostomy is performed, the person may experience feelings of anger, depression, fear and even grief due to the change in their body image, thus needing psychological support from relatives and friends in order to ease the adaptation and acceptance of this new condition.<sup>3-4</sup> The acceptance of the ostomy directly affects the individual's self-image and self-esteem. The ostomy creates a negative self-image, and consequently makes it difficult to develop self-care, which can result in social isolation.<sup>5-6</sup>

Due to this complex situation, coordination of a well-prepared multidisciplinary team is necessary.<sup>7</sup> In this sense, we can say that the nursing professionals require technical and specialized knowledge to be able to provide proper assistance to ostomy patients and also to guide them in self-care. Given the situation above, we aim to study nursing care of hospitalized people who underwent ostomy surgery in a university hospital in the south of Brazil.

## METHOD

This is a qualitative, exploratory and descriptive research developed in the surgical units of a public university hospital in southern Brazil, between April and August 2011. Nursing professionals from Surgery Clinics I and II were asked to participate in the study via a personal invitation. In addition, the invitation was extended by the researcher during shift changes. There were a total of 23 participants who signed an informed consent form (TCLE, as per its acronym in Portuguese). They were divided as follows: nine nurses, 11 nursing technicians and three nursing assistants. The selection was based on the following criteria: assigned to surgery units, and agreed to participate in this study, excluding those who were on vacation, on sick leave or on maternity leave. The majority of the 23 people surveyed were young adults; two nurses and two nursing technicians were male and the rest were female, which created a prevalence of females. Regarding professional education, eight were specialized nurses and one had their masters; six nursing technicians were undergraduates and two were specialists.

The research was conducted in compliance with resolution 196/96/CNS of the Brazilian National Health Council and was submitted to the Human Research Ethics Committee for approval under number 1150/2010. Anonymity and privacy were ensured by replacing the names with acronyms followed by a number. Therefore, nurses are ENF1, ENF2; nursing technicians and nursing assistants are designated by TE1, TE2, AE1 and AE2, respectively and successively.

Data were obtained by the main author of this study, through semi-structured and individual interviews that were recorded and later transcribed. The interviews were carried out following a script divided into two parts: the first refers to the identification of the professional; the second references the specific knowledge of the nursing team concerning the patient's care, based on nine questions.

The criterion adopted to end data collection was saturation. The data analysis was conducted in four steps: collection, synthesis, theorization and transfer. The collection process begins simultaneously with the analysis of information; data are recorded and organized and, after transcription, reading and reflection are performed. Each piece of

information received a code, and the most significant of them were chosen and categorized.<sup>9</sup> Thus, three categories were created: the knowledge of the professional nursing regarding the role of the ostomy patient in self-care; the knowledge of the professional nurse regarding the role of the family; and education and professional performance. These categories are presented below.

## RESULTS AND DISCUSSION

### The knowledge of the nursing professional regarding the role of the ostomy patient in self-care

This category presents the aspects related to the professional's view of self-care and the individual's reaction following ostomy surgery. Nursing professionals focus their actions directly on health education. Care of ostomy patients and their families includes self-care education, taking into account the chronic health condition of these patients. This care involves a relationship of empathy, with understanding of the individual's needs and limitations, and promoting self-care that leads to their autonomy.<sup>10</sup>

In the initial contact with the patient undergoing ostomy surgery, the nursing professional observes feelings of angst, fear and difficulty in accepting the situation and adapting to this new health condition. Ostomy patients may feel rejected, and as a defensive mechanism of this non-acceptance that they sense from the people around them, they experience feelings of disablement and discrediting.<sup>2</sup> In addition to the feelings of the patients, people who have a social relationship with them, mostly relatives, are also fragile. When they exhibit signs of rejection, patients build a negative self-image which affects self-care learning, which is confirmed by the following statements: *the patient who is more educated and who is better informed finds it easier to accept, but some patients who are less well educated cannot accept it: they say 'I'm not touching this'; I've seen patients saying 'I won't touch this', who utterly refused; it is like they think they have become less human; they are disgusted by that and don't want to hear about it (ENF4); I notice that, in the beginning, most people find it difficult and they put up actual physical barriers; it's a new discovery, of image and all that [...]. I notice that it's a long process, a very long process that requires a lot of maturing from the person, as it's not just a matter of aesthetics. It really changes the person's life; it's sometimes the only way for*

*that person to remain healthy, but still, it's a big change [...] (TE7); there are people who deny, reject, and can't accept it: 'No, I won't do it! No, no, no...I'm not even going to learn nor look at it because I'm not doing it'. And then you have others who say 'I will learn'...it is very individual. There are people who, even if they are upset, they do want to learn 'I have to, I'm going to live with this, even if it's temporary' (AE2).*

The feelings identified by the professionals are negative ones and make it difficult for ostomy patients to face their new reality, as this means a change in lifestyle and quality of life. Therefore, care of these people becomes a challenge to nursing, as professionals will have to deal with these feelings and try to reverse the situation so as to make the patient capable of self-care.<sup>11-13</sup> Self-care consists of the practice of activities that people undertake to care for themselves in order to keep on living and to continue their personal development and maintain their well-being.<sup>14</sup>

The self-care education process for the patients and their relatives must begin when the need for an ostomy is confirmed and must continue in the immediate, intermediate and late postoperative period. The biological, sociological and cultural conditions of each individual must be taken into account.<sup>12</sup> It is essential that preparation of the ostomy patients and their relatives begins before the surgery takes place, so that the ostomy is not an unknown entity. This can help remedy the situation and make self-care education easier, including handling of the pouch and care of the skin. This practice favors social reintegration, reduces complications and makes problem identification easier.<sup>10</sup> These statements attest to this situation: *[...] some of them are well prepared in the preoperative stage, and they know about the ostomy, so they react better. Those who face emergency surgery are really scared, also their families, so we have to go slowly, gradually [...] (ENF4); some of them get depressed, even sorrowful; it's an affront to them. Even if they are performing self-care, it's not a good thing for them and for others [...]. I see that there is a difference, and to me, it's all related to preparation, to the preoperative teaching, whether they know what's coming. If everything is clear from the beginning, it makes a huge difference in the end (TE8).*

Ostomy patients who were informed about their health situation and were given instructions about self-care preoperatively were better able to accept the stoma and managed to adapt to their new condition.<sup>12</sup> Therefore, nursing professionals must promote self-care in a slow and gradual



manner, respecting the patient's situation and getting the family involved early on in the process. These professionals play an essential role in the rehabilitation process, as they work closely with the patient and the family in a complete, personalized and systematic way in order to promote better quality of life.<sup>13</sup>

*Depending on the patient there is this denial issue, but there are others who can handle self-care correctly. They learn how to change the pouch, they are guided, so they manage to do it. If the patient is an elderly person, they need more help from the relative, who is often the one to give support, the one who will be at home helping the patient (ENF3).*

*Most people need some time to assimilate to the new equipment, the new condition; then, day after day, we manage to help the patient handle it (ENF8).*

*I think it differs from one person to another, from the education level to cognitive understanding. Sometimes we have patients who have huge difficulties in understanding. It's also a question of hygiene habits, which counts a lot because sometimes it's cultural (TE7).*

In daily practice, nursing care of ostomy patients aims to establish an effective care relationship, a reflection on this experience and on how to contribute to improve this care, making rehabilitation easier and developing efficient self-care. In this way, nursing care of ostomy patients must include broad guidelines concerning surgical treatment and its consequences, and specific actions for self-care that must be planned and executed at every stage of the treatment. Thus, nursing care will help to reduce postoperative complications and create the conditions for developing self-care abilities.<sup>15</sup>

Nursing professionals play a key role as mediators in the self-care education process, as they provide clear and objective guidance, respect the education levels, beliefs and values of each person and their families and act as a theoretical-practical and emotional support, answering questions about the subject. They use pictures of the digestive system, with and without a stoma, in order to demystify it; this happens with the full use of dialogue in a horizontal relationship. As such, actions that address these needs create helping methods that are selected and combined according to the patient's limitations, as a consequence of their state of health.<sup>14</sup>

Health education emancipates the human being; it awakens people to exercise their citizenship.

In addition, the professional must understand the patient's rights in order to apply them in practice.<sup>10</sup> Health education promotes autonomy, which consequently reduces the dependence of the one who learns on the one who teaches. The support of the health professional is essential to the individual's emancipation, so they can live without the help of someone else, which is the expected and desired result.<sup>16</sup> It is agreed that the appropriation of knowledge and the development of hands-on skills is essential to the process of resumption of the daily routine, in the search for independence and to avoid home restriction and social isolation.

### **The knowledge of the nursing professional regarding the role of the family**

The emotional support given by the relative to the ostomy patient is evidenced by dialogue, explanations and advice, which relieve them and make them feel more secure, thus reducing fears and angst. In this way, the patient's relative plays a key role in patient care as they participate in this care, looking for information and guidance regarding the current situation.<sup>17</sup>

Nursing care is mostly provided by relatives, who may be the spouse, the children, the parents or even a person who is close to the patient and is ready to help and learn. The following statements confirm that: *the caregiver is the person who is closer to the patient, who is following them, the one who wants the best for the patient. It can be the mother, it can be the wife, it can be the son, it can be the daughter-in-law, it doesn't matter; it's the one who's there and who's ready to learn and provide care [...]. The one who wants to accept and help that person who is ill, I think that's the right caregiver, that's the right relative to learn and help that patient, to teach them and support them in self-care (ENF9); [...] this caregiver is very important because they will maintain integrity, they will make the necessary changes at home, they know how to seek assistance [...]* (ENF3).

The family represents a relevant source of support to the ostomy patient because of their emotional ties, which alleviates the situation and brings comfort and security.<sup>18</sup> However, the family must be able to provide care, both during hospitalization and after discharge, at home;<sup>17</sup> they will have to rebuild body image along with the patient and live with the patient's loss of control of the sphincter, flatulence, a decrease in libido and a tendency towards social isolation. Moreover, they will have to handle the pouch and clean and maintain

the integrity of the skin, preventing complications. The family will also have to deal with the patient's psychological experiences, such as depression, the feeling of being a burden, non-acceptance, distrust and dependence.<sup>20</sup>

That said, it is never easy to have the family involved in care, as the statements above show that the patient can reject, fear and feel disgust in the beginning, although there is a later acceptance. There are relatives who are untouched by the patient's situation,<sup>18</sup> which is attested to by the interviewee: *yes, I think that, in the beginning, most people avoid it. They avoid looking at it, or even looking the patient in the eye. They avoid being there during the handling of the pouch, but slowly we try to get them used to it, you know. Some of them accept it, others really don't; they don't want to touch it, or they say they will help but then call another relative, or don't want to learn because they are not the ones who will take care of the person. We see that they are not very comfortable in the beginning. It's not an easy thing for them (ENF3); usually the caregiver is a parent, a spouse or a husband. But they are, in most cases I think, quite reluctant to learn; they don't accept easily in the beginning, as it's a delicate situation. I see it as reluctance by the person [...] (TE1); it is often the wife or the son or daughter, and in the beginning, they avoid even looking or touching when we are giving care; they usually leave the room, but over time they try to learn to do it as well (TE2).*

Feelings of rejection of the patient's condition experienced by some relatives, although they are not discussed in the nursing literature, appear in this study and show another aspect of nursing care of the ostomy patient, which is dealing with relatives' emotions. Hospitalization brings on troubled times in family relationships as attention is focused on the ostomy patient; nevertheless, the relatives also need support and guidance from the nursing team in order to make the adaptation process easier and to help them give homecare properly and confidently.<sup>17</sup>

The family plays a key role in the preoperative period, as well as afterwards, providing care and emotional support. On the other hand, it is a time when the family is weakened and needs support in order to be able to give the necessary care. From that point of view, it is the job of nursing professionals to prepare the ostomy patient and their relatives to face the situation.<sup>18</sup>

The emergence of negative feelings on the part of the relatives reflects on the patient, who

in turn rejects their own condition, which makes acceptance and adaptation harder. In this way, it tends to affect the quality of the nursing care as it implies guidance, and a barrier is created between the professional and the family, who withdraw within themselves and avoid dialogue and instructions, which is harmful to the care education process.

There are other situations that the relatives must deal with that were not mentioned by the professionals, such as the practical and everyday activities. It is clear that the hospital care experience puts both the patient and the family out of context, in terms of aspects of daily life, which are directly related to quality of life and autonomy, but were not mentioned by the professionals.

On the other hand, the professionals consider the presence of family necessary in order to learn how to handle the pouch because very often home care is provided by relatives. This is clear according to the following statement: *[...] the caregiver, the relative is essential for care; so I always try to have the relative with us and I start explaining how to empty the pouch; I pick up an empty one and show how to open and how to close it, because the relative is the one who will be supporting the patient at home (ENF7).*

In view of the complex network that is set up to assist the ostomy patient, mention should be made of the role of the nurse and the nursing team as educators, as it is up to the nurse to develop educational actions that encourage the ostomy patient and the family to overcome psychosocial and psychobiological difficulties.<sup>12-21</sup>

## Professional education and performance

The professional training process in nursing enables the nurse to provide broad assistance, including wide knowledge in dealing with different health and illness situations, including prevention and health education. Care and education represent two elements that are part of the context of health professionals and nursing, which consist of dialogue and actions that integrate the family in providing effectual care.<sup>22</sup> Through the nurses' statements it was found that knowledge regarding ostomy patients was passed on comprehensively: *I found it very superficial; there was only theory in my course. It was rather theoretical; I didn't have much practice until after graduation (ENF3); I am not specialized. I learned a lot during internship, but nothing practical. It was presented to us, but I didn't practice it. I've had to learn now, here*

*in the workplace (ENF5); I don't remember, I don't think so, I can't remember (TE10).*

In that sense, besides being a topic not widely covered during training, we can see that preparation for care of ostomy patients and their families mostly occurs in practice. It is notable that the family wasn't mentioned by any of the interviewees when discussing their education. Therefore, learning actually took place when the professional was confronted with a person who was going to undergo surgery and was going to need a special device to be able to meet their physiological needs. We can highlight two statements: the first person states that they had a colostomy patient during their training and the other states that the responsibility for learning nursing care took place in practice: [...] *there was a patient with a colostomy pouch, with a stoma, yes. During internship, yes (TE1); [...] I don't think so; I don't remember having taken care of any ostomy patient [...] my first contact was here (TE7).*

It is understood that the educational process is furthered by the pedagogical relationship via reflexive and practical teaching, taking into consideration each individual in their uniqueness in the way that changes are made and they become critical, creative and committed to society.<sup>23</sup> On the other hand, this area requires a specialized knowledge and specific skills in order to develop safe and efficient nursing care, which explains the following two situations: the first regards the introduction of the subject during training that will help the professional face any situations; the second regards the need for periodic updating, provided by institutions where ostomy patients are treated.

As the nurse works directly with the nursing team, this professional is aware of the team reality and tries to identify what is necessary to implement timely or continuous actions that favor the acquisition of knowledge to achieve personal and professional development.<sup>24</sup> As regards the building of capabilities related to the care of ostomy patients and their families, most of them answered that they had never taken part, or that it had been a long time since the last training session. The statements confirmed this: *I think I participated in the training given in the lecture hall. I think it was only once, only that one time [...] I guess it was only one session [...] I think it was in 2008, wasn't it? 2008, yes (ENF1); yes [...] that's how I got in. There were a couple of classes; they were actually given by you, weren't they? I think so (TE2).*

It is worth pointing out that the institution where the study was carried out has a commission in charge of continuing education that regularly consults with different nursing divisions regarding the subjects of training. We can conclude that these professionals have not submitted requests for training regarding this subject very often, which can be the result of a great amount of work and the automation that makes everyday care easier, with no need to think much about the subject. It is necessary to problematize, discussing the theory so that the professional is aware of their strengths and weaknesses regarding the commitment to practice changes and nursing care, especially the topic discussed in this study.<sup>24</sup>

To assist the ostomy patients and their families, nursing technologies are essential for the handling of the pouch, and require practical and theoretical understanding, which is a systematic and specialized knowledge. They are important to the relationship with the ostomy patients and their families, and it is also important to master them in everyday care, as they require scientific and empirical knowledge, as well as reflexive and ethical actions.<sup>25</sup>

The performance of the nursing professional goes beyond teaching patients and families how to handle and empty the pouch. We observed a need for greater discussion about the subject in the place where the study was carried out. The appropriate measure would be the implementation of systematic care of the ostomy patient, along with increased capability and updating of the nursing staff. Together, these actions positively affect the rehabilitation of the ostomy patients and their families, offering them better lives and social reintegration.<sup>26</sup>

## CONCLUSIONS

The results of this study show that nursing professionals realize that ostomy patients and their families first experience feelings of rejection and fear that are later softened. These negative feelings make it difficult to learn self-care and to adapt to the new reality of life. We observed that the ones who are guided during the preoperative period adapt better to the situation, as well as those who are well educated.

With respect to the education of the nursing professional, it was noted that it occurs in a broad manner during the course of nursing education but is often restricted to theory. A general educa-



tion gives a broad overview of the care of ostomy patients and their families; however, as it is a complex situation, the building of capability and updating is essential, in addition to interacting with the ostomy patients and their families, which gives the professional a better understanding of what it is like to live with an ostomy.

It should be restated that systematization of nursing care provided to ostomy patients and their families is essential to their rehabilitation, autonomy and exercise of citizenship in a dignified and human manner. Thus, we can highlight that the families must be involved in nursing care, and must be guided, supported and taught how to manage the equipment to provide care at home.

Finally, the authors of this study consider that the aim of the study was achieved. However, the study has its limitations: small sample size, performance in only one hospital and no continuity in following up the knowledge of the nursing professionals. It is suggested that new studies include the following topics: systematization of nursing care provided to ostomy patients and their families, and building of capabilities and updating of the knowledge of nursing professionals.

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