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Giving a voice to families of people with intestinal stoma: reflections on training, care and management

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ABSTRACT

Objective: To reflect on aspects of training, care and management that contribute to supporting families of people with intestinal stomas. **Method:** A theoretical reflection study based on a substantive theory developed with 12 families of people with ostomies due to intestinal cancer. **Results:** With the development of the substantive theory, it was possible to give a voice to families of people with ostomies due to intestinal cancer based on what they identify as the need for multidisciplinary and interdisciplinary care capable of completing the procedural phases experienced throughout the investigated trajectory. For these care changes to be effective, healthcare professional training must include intestinal ostomy care in their curricula. Also, changes in intersectoral management are updating the Management of Users with Disabilities, investing in infrastructure, mainly in adequate public restrooms. **Conclusion:** This reflection demonstrates the importance of implementing these changes in training, care and management, which help in planning family-centered care, considering that the family provides home care based on interactions, and helps and empowers their family member to implement self-care for ostomy.

DESCRIPTORS: Ostomy. Family. Family Health. Patient Care Team. Nursing. Enterostomal Therapy.

Dando voz às famílias de pessoas com estomia intestinal: reflexões sobre formação, assistência e gestão

RESUMO

Objetivo: Refletir sobre aspectos da formação, da assistência e da gestão que contribuam para o cuidado com as famílias de pessoas com estomia intestinal. **Método:** Estudo de reflexão teórica partindo de uma teoria substantiva desenvolvida com 12 famílias de pessoas com estomia por câncer intestinal. **Resultados:** Com o desenvolvimento da teoria substantiva, foi possível dar voz às famílias de pessoas com estomia por câncer intestinal com base no que elas identificaram como necessidade de assistência multiprofissional e interdisciplinar capaz de perfazer as fases processuais experienciadas ao longo da trajetória investigada. Para que essas mudanças assistenciais sejam efetivadas, a formação de profissionais da saúde deve instituir nos currículos os cuidados com estomias intestinais, também são necessárias alterações na gestão intersetorial visando atualizar

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o Gerenciamento dos Usuários com Deficiências e investir em infraestrutura, principalmente banheiros públicos adequados. **Conclusão:** Esta reflexão demonstra a importância de efetivar essas modificações na formação, na assistência e na gestão, a fim de auxiliar no planejamento de um cuidado centrado na família, tendo em vista que ela presta os cuidados no domicílio, partindo das interações e auxiliando e potencializando seu familiar para efetivar o autocuidado com a estomia.

DESCRITORES: Estomia. Família. Saúde da família. Equipe de assistência ao paciente. Enfermagem. Estomaterapia.

Dando voz a las familias de personas con estomía intestinal: reflexiones sobre formación, asistencia y gestión

RESUMEN

Objetivo: Reflexionar sobre aspectos de la formación, la asistencia y la gestión que contribuyan al cuidado de las familias de personas con estomía intestinal. **Método:** Estudio de reflexión teórica basado en una teoría sustantiva desarrollada con 12 familias de personas con estomías por cáncer intestinal. **Resultados:** Con el desarrollo de la teoría sustantiva se logró dar voz a las familias de personas estomáticas por cáncer intestinal a partir de lo que identifican como la necesidad de una asistencia multidisciplinaria e interdisciplinaria capaz de completar las fases procesuales vividas a lo largo de la trayectoria investigada. Para que estos cambios de atención sean efectivos, la formación de los profesionales de la salud debe incluir el cuidado de las ostomías intestinales en sus planes de estudio. También son necesarios cambios en la gestión intersectorial, como la actualización de la Gestión de Usuarios con Discapacidad e inversiones en infraestructura, principalmente en baños públicos adecuados. **Conclusión:** Esta reflexión demuestra la importancia de implementar estos cambios en la capacitación, la asistencia y la gestión, que ayuden en la planificación del cuidado centrado en la familia, considerando que la familia brinda cuidados en el hogar a partir de interacciones y ayuda y empodera a su familiar para llevar a cabo el autocuidado de la estomía.

DESCRIPTORES: Estomía. Familia. Salud de la familia. Grupo de atención al paciente. Enfermería. Estomaterapia.

INTRODUCTION

The family has been considered the primary caregivers of their members and, in chronic situations, their care actions are accentuated, becoming essential in the home. Thus, it is important to prepare and train the family in advance to develop the skills inherent to care. From the perspective of chronicity, experiencing the creation of a stoma and living with this new life condition causes a symbolic and functional rupture in the family, since the need for care encourages changes in relationships, commitments and tasks[1].

Intestinal ostomies emerge as a treatment for colon and rectal cancer and can be characterized as a chronic health condition by mobilizing daily, continuous and prolonged care[2], considering the multiple contexts that are impacted by stoma emergence and maintenance, whether temporary or permanent, in the lives of people with stomata and their families, such as psychosocial and physical changes[3].

Chronic illness causes repercussions and expressions experienced by the family unit so that relationships can be altered both within and outside the family, in addition to their roles, tasks and the environment in which they live[4]. Thus, it is through interactions that individuals establish among themselves and with others, through symbolic collective action, that they define how they will act when faced with an illness of their family member. Furthermore, considering their beliefs, knowledge and experiences, the family will give meaning to the meaning and place of the illness in their lives[5].

Evidence in the scientific literature in national[6] and international[7] scenarios has revealed the lack of guidance and preparedness of professionals regarding ostomy care. Furthermore, it is understood that it is complex to view the family group as a system that is affected by interactions with other subsystems, so as not to focus care only on a person with a stoma, aiming at care with the family and not for the family. From this perspective, the group needs to be understood and viewed as an active participant in the care of their family member with a stoma, but for this to happen, they need to receive guidance on how to develop it[8]. Therefore, knowing the specificities of the family, their social and economic context, their relationships with the community and society as well as their difficulties and potential needs to be part of nursing care.

Therefore, it is necessary to reflect on the need for care that involves collaborative and participatory planning between the family and healthcare professionals. Thus, the question "What are the care needs of this family that lives with a relative with an intestinal elimination stoma?" needs to be linked to professional attitude and practice in order to understand the real demands of each family. Therefore, it is believed that it is necessary to advance knowledge in this area so that the process of acceptance and adaptation of families to this new living condition occurs as early as possible as well as to assist in coping and in the way of caring for these families.

OBJECTIVE

To reflect on aspects of training, care and management that contribute to caring for families of people with intestinal ostomies.

METHOD

This is a theoretical reflection arising from the substantive theory "Strengthening oneself to move forward with life: families' experience of living with an adult family member with a stoma due to intestinal cancer", which was developed based on the experience of 12 families, 12 adults with a stoma due to intestinal cancer and 16 family members, living in two cities in the countryside of Rio Grande do Sul, Brazil[9]. Blumer's Symbolic Interactionism was used as a theoretical framework and Grounded Theory as a methodological framework, following Glasser's analysis.

The theory is developed by the concepts "Unveiling an (un)known world", "Facing obstacles", "Seeking alternatives to help in the new condition", "Obtaining support", "Developing ways to take care of oneself" and "Recognizing the need to move on with life", as well as by the central concept "Caring through interactions". The theory presented a comprehensive level of knowledge for the multidisciplinary team that provides care in this particular area[9]. Thus, based on the voice of the participating families, it was decided to assist in the construction of more effective practices aimed at people with ostomies and their families, based on the dimensions explored, in addition to subsidizing continuity of care within the healthcare network.

The research was approved by the *Universidade Federal de Santa Maria* Research Ethics Committee, under Opinion 2.760.036.

RESULTS

Families, when living with a relative with a stoma due to intestinal cancer, care for this person based on interactions that occur throughout their experience. These care actions require formulations and adjustments according to each stage and situation that they experience and are necessary for this care to be effective, since quality of life is not promoted only by caring for the physical body, but rather for all dimensions that constitute the human being.

The experience of families explained in the substantive theory developed allowed the authors of this study to reflect on healthcare professionals' knowledge deficits. This lack of care permeates both the initial guidance in the preoperative period and specific care in the postoperative period, in hospital settings, as well as continuity of care in primary healthcare.

Considering that intestinal ostomies are one of the main therapeutic approaches for intestinal neoplasms, training schools, both those at the technical level for nursing and those at the undergraduate level for healthcare professions, need to be aware of the need to emphasize the care of intestinal ostomies and the families that live with this situation, in addition to instituting them in their theoretical-practical curriculum and developing extension activities as a strategy to enhance adaptation, assist in ostomy acceptance and provide continuity of care within the healthcare network.

This study highlighted the need for continuing education activities aimed at healthcare professionals so that they are able to understand postoperative complications and occurrences and intervene in these cases. Offering theoretical and practical training courses for care at the three levels of healthcare, with the aim of developing skills and competencies in this unique context of family life, is a learning opportunity for the multidisciplinary team.

It is believed that understanding that chronic conditions affect the family and not just the person affected by the chronicity should permeate healthcare networks, constituting a prerequisite for developing care strategies. The care provided to families must have meaning for them so that their concerns and doubts are questioned, their manual skills are encouraged and a learning process is made possible that makes sense to the people involved, consistent with the daily lives and particularities of each of them.

Thus, Chart 1 presents some reflections that would assist in multidisciplinary and interdisciplinary care to families of people with intestinal stomas, according to the concepts that make up the substantive theory, which signify the procedural phases that families go through throughout the trajectory investigated.

In addition to the need for training and care, health management needs to meet the demands of people living with intestinal ostomies. The online information system for data on people with ostomies needs to be constantly updated and provide complementary data, including the type and time of ostomy creation and the health unit to which a person belongs. In this way, healthcare professionals will be able to carry out epidemiological surveys quickly within the territory in which they work, which contributes significantly to targeted planning of health actions and optimization of care, enabling these people to receive care in a network, i.e., longitudinal care.

DISCUSSION

Analyzing the training process in the health area, it was identified that the reductionist view, not centered on the individual and their interactions, with roots in the biomedical model, is still in force. Reflections of this conception have been present since the initial period of training, which emphasizes only people with a stoma, and only they are visualized, often reducing it to the exchange and emptying of the collection equipment. Thus, care for families of these people still permeates superficiality or is non-existent within the training and care process. The Brazilian Consensus on Care for Adults with Elimination Ostomies[2], through scientific evidence, systematized care in order to minimize complications, assist professionals and enable self-care for people with stoma. This Consensus constitutes a guide for care, configuring itself as a step forward for improvement and continued qualification of many of these professionals who, during training, were little equipped for this care or who have knowledge gaps in this area.

It is worth noting that, in Brazil, within the scope of professional training, enterostomal therapy is a specialization exclusive to nurses, recognized as such since the 1990s, but there is still no effective national coverage of these professionals. A study that aimed to characterize the training profile and performance of enterostomal therapists in Brazil, trained in courses accredited by the Brazilian Association of Enterostomal Therapy, had a sample of 548 nurses. Regarding the distribution of these professionals according to the region of activity, the largest number, 328 (59.9%), were in the southeast, followed by the northeast, with 110 (20.1%), and the south, with 74 (13.5%). It is also worth noting that 157 (27.6%) worked in care and teaching, 138 (24.3%) exclusively in care and 66 (11.6%) in teaching and research[10].

This survey allows us to reflect on the need for more nurses who are specialists in this area and who can work in educational institutions, in order to provide more qualified professional training. Moreover, it is necessary to occupy more care spaces so that people with ostomies and their families have their care demands met. With a greater number of specialized professionals, improvements in the care provided would be foreseen.

Chart 1. Reflections on multidisciplinary and interdisciplinary care according to the substantive theory "Strengthening oneself to move forward with life: families' experience of living with an adult family member with a stoma due to intestinal cancer"

Concepts	Multidisciplinary and interdisciplinary care
Unveiling an (un)known world	- Prevention of bowel cancer through healthy eating and physical activity; - Early screening with fecal occult blood tests and colonoscopy, prioritizing risk groups; - Help in identifying signs and symptoms of bowel cancer; - Disclosure of diagnosis and its therapeutic possibilities through clear, objective and explanatory language; - Emotional strengthening for the family in the face of cancer diagnosis and its treatment (radiotherapy, chemotherapy and surgery); - Preoperative consultation to identify specific family needs; - Use of audiovisual materials and prior handling of collection devices during preoperative nursing consultation; - Availability to answer questions; - Guidance on the consequences of creating a stoma; - Identification of the family's limits of understanding regarding the guidelines, adapting communication; - Marking of the stoma in the elective preoperative period and demarcation protocols in emergency surgeries; - Information on registration with the Health Department; - Referral to the reference health unit; - Information on the rights of people with a stoma in the social sphere.
Facing obstacles	- Instruction during hospitalization on changing and cleaning the pouch and using adjuvants as needed; - Guidance on identifying early complications with the stoma that may occur after discharge; - Guidance on identifying late complications; - Psychological assessment; - Home visits in the postoperative period to verify whether a patient has been registered with the Health Department, assess the stoma and be available to the family to answer questions; - Monitoring the first changes of the collection pouch at home to identify the family's limitations in living with and caring for the family member with a stoma; - Emotional strengthening of a person with a stoma and the family, paying attention to issues of self-image and psychosocial changes; - Moments of active listening; - Encouragement for social inclusion.
Seeking alternatives to help with the new condition	- Continuity of care in healthcare networks, referring patients to a health unit or specialized service; - Identification of sources of social support, encouraging interactional processes; - Identification and recognition of beliefs.
Obtaining support	- Encouragement of expressions of spirituality; - Strengthening of the family's internal and external resources; - Organizing and/or encouraging participation in support groups for people with stomas on more accessible days and times; - Creation of a support group for caregivers.
Developing ways to take care of oneself	- Guidance on possibilities and needs for adaptations for home care; - Knowledge of the home environment and care in adapting to care; - Information on reliable sources for searching for guidance on the internet; - Provision of audiovisual materials with guidance; - Self-care encouragement and promotion; - Emotional strengthening of the family, demonstrating recognition of their role as caregivers; - Attention to family caregivers' mental health; - Carrying out regular health checks, both for a person with a stoma and their family, paying particular attention to the risk of recurrence/appearance of intestinal cancer.
Recognizing the need to move on with life	- Encouragement of the gradual resumption of daily activities; - Encouragement of participation in associations of people with stomas as an alternative for strengthening and social involvement; - If reversal is possible, preoperative physiotherapy is indicated; - If possible, irrigation, guidance and training are necessary; - Continuity of care within the healthcare network.

Living with a family member with a stoma implies the need for care inherent to this chronic condition at home. Therefore, it is emphasized that the family needs to be identified, understood and assisted by professionals as a care unit and care provider. However, for the family to provide care at home, it is essential that the multidisciplinary team sees them as a comprehensive part of their care[8].

Understanding that stoma creation will involve continuous care and that families provide care based on interactions reinforces the understanding of another study[11], in which care for a person with conicity begins with the interactional processes of the person being cared for and the caregiver and extends to other members of society and the environment. Thus, it is up to the family to decide how to provide care, and therefore, care must be shared by professionals and family members, seeking to horizontalize communication and knowledge in order to enhance family care actions[12].

After hospital discharge, challenges are discovered and the adversities experienced by people living with a stoma are accentuated, such as lack of knowledge about their real living situation, difficulty in registering in the material dispensing system and insufficient or even non-existent care in reference health units[13]. However, we recognize that, in order to provide more effective results and for this stage to occur in a more balanced manner, it is imperative that professionals implement actions from an interdisciplinary perspective, aiming at better rehabilitation and adaptation of these families.

From a care management perspective, Rio Grande do Sul has an information system called *Gerenciamento do Usuário com Deficiências* (GUD, Management of Users with Disabilities), which includes people with ostomies, urinary and fecal incontinence, orthoses and prostheses, oxygen therapy, and hearing, visual and mental disabilities. With regard to ostomies, the GUD compiles personal information about each user (name, sex, date of birth, address and telephone number), the cause of the ostomy, using the International Classification of Diseases (ICD10), collection equipment and protective and safety adjuvants, and the date of the last dispensing of the material[14].

Families need continuous care for ostomy as well as collection devices and adjuvants. This continuity of care must occur at various points in the healthcare network and with the use of other strategies that facilitate this daily routine, such as tele-nursing. A clinical trial carried out in Rio Grande do Norte identified the benefits of tele-nursing for the adaptation of people with ostomies, since, via telephone, they had their questions answered and did not need to bear the costs of traveling to in-person consultations[15].

On the other hand, families' demands also include structural issues that encompass the process of resuming their social, work and leisure activities, in addition to their right to accessibility. Families point to the need for adapted bathrooms in hospitals, shopping centers, bus stations, airports, universities, schools and other public places.

More than a decade ago, the city of Juiz de Fora, in the state of Minas Gerais, was a pioneer in drafting a law that provides for constructing public bathrooms adapted for people with ostomies. Following its example, municipalities in several states have created their own laws. Based on this, the Brazilian Association of Ostomized People is offering a draft law that can be used by municipal legislatures[16]. Actions like this should serve as an example for municipal and state managers, as the construction of adapted bathrooms positively helps social inclusion.

It is believed that improvements can and should be made in the care provided to families. To this end, healthcare services need to effectively understand the population to which their activities are intended, planning care, promotion and prevention actions in a cooperative manner and in accordance with the community's demands [17].

The right to universal and equitable health and access to services are principles guaranteed by the current public health system; however, there are numerous difficulties experienced by individuals, especially families living with adults with stomas due to intestinal cancer.

CONCLUSION

Changes in the training process, in care and in health management, resulting from families' experience, can contribute to planning family-centered care. By understanding that a stoma becomes part of the families' way of life and that they provide care at home based on interactions and assist and empower their family member to carry out self-care with the stoma, it is pertinent to listen to the voice of these social actors who experience, in their daily lives, the difficulties that arise with the discovery of cancer and the creation of a stoma.

We know the importance of specialized care in this scenario, so we emphasized that the multidisciplinary team needs to recognize the specificity of stoma therapist nurses' knowledge, referring people with stomas to this professional when the care provided goes beyond generality and demands specialized knowledge.

Caring for families of people with intestinal stomas is broad and complex due to the characteristics, contexts and particularities of each family. However, training, care and management are pillars that can help these families, in their relational context, to regain their balance through new arrangements and reorganizations, and to face this situation in which, gradually, the world that was unknown becomes known through situations in which families, every day, with each new fact, seek support to overcome problems.

Finally, it is believed that the reflections presented here can also support the care of families living with other types of ostomies, whether for urinary elimination, hydration and nutrition or respiratory purposes.

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