

## Experience of teachers in the daily life of a child with stoma: a Social Phenomenology approach

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\* This article is a part of the Doctoral Thesis entitled "Vivência e experiência no cuidado da criança com estomia na perspectiva dos familiares e dos professores" defended in 2017 in the Graduate Program in Nursing of the *Universidade de Brasília*, Brasília, DF, Brazil.

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Received: 09/04/2016.

Accepted: 05/31/2017.

Published: 08/28/2017.

### Suggest citation:

Melo MC, Kamada I, Dutra LMA, Simões JFFL, Melo EMOP. Experience of teachers in the daily life of a child with stoma: a Social Phenomenology approach. *Rev. Eletr. Enf.* [Internet]. 2017 [cited \_\_\_/\_\_\_/\_\_\_];19:a33. Available from: <http://dx.doi.org/10.5216/ree.v19.43116>.

### ABSTRACT

This study has sought to understand the experience of teachers in the process of inclusion of children with stoma, being Sociological Phenomenology the reference. Interviews were conducted with five teachers between December 2015 and January 2016. Data collection was carried out from the narration of teachers, with later transcription and data analysis. Four thematic categories emerged: feelings experienced by teachers, factors that interfere with care, effective strategies for care, and strategies to improve care. The teachers valued the integration of the child with stoma in the school; they consider that this happens with the modification of the pedagogical formation, and they also pointed out the need for the presence of nurses in schools. The results show the importance of the development of actions and strategies to support teachers and students with stoma in the context of an inclusive school, considering that the school nurse is a determining factor for the health promotion of these children.

**Descriptors:** Health Promotion; Education, Primary and Secondary; Nursing Care; Qualitative Research; Pediatric Nursing.

### INTRODUCTION

Families of children with health problems, particularly children with stoma, go through a long period of treatment and adaptation, whose impact on child growth and development involves not only the biological dimension but also other dimensions, influencing interpersonal relationships, group and intergroup relationships from

school and social interactions, leisure activities, and practice of sports.

Often these children need to be absent from school, and the problems resulting from this lack of participation require a work in harmony between child, family, teachers, and health professionals who accompany the treatment. When leaving school, some negative consequences may arise in the child, such as deficits in their cognitive and motor skills<sup>(1)</sup>.

In this sense, teachers should give lessons that allow children to build their own knowledge in their developmental pace, taking into account the restrictions imposed by the stoma, or other situations that require special health care. In this context, adaptation strategies should be planned for inclusion, together with parents, children, teachers, and health professionals. All children have the right to be in regular education classes, provided that the pedagogical and therapeutic individuality of each is respected, stimulating their potential to the maximum<sup>(2)</sup>. Inclusion should involve the student, the modification of the learning environment, and the suitability of teachers, thus favoring health promotion<sup>(1)</sup>.

"Health promotion" is considered as an essential factor for the quality of life by the World Health Organization (WHO)<sup>(3)</sup>. This widely publicized concept, which started in 1986 with the Ottawa Charter<sup>(4)</sup>, is associated with action strategies of the Government. Following this line, in Brazil, the Health in School Program (PSE, *Programa Saúde na Escola*, in Portuguese)<sup>(5-6)</sup> was instituted in 2007; it presents guidelines for the integral formation of students, from actions that promote health, prevent diseases and health problems, and further health care, inserting the Family Health Strategy nurse into the school environment, a strategy strengthened by the National Primary Care Policy<sup>(7)</sup>.

The interest in carrying out a study involving the teacher and the child with stoma is justified by the lack of studies on the subject, in addition to investing in research related to intervention in stomatherapy. In this sense, in using the sociological phenomenological approach of Alfred Schütz, we seek, in the intersubjective aspect, the episodes narrated by teachers and, thus, we broaden the discussion of the nursing context in the care to students.

This research aimed to understand the experience of teachers in the process of inclusion of students with stoma in basic and special education.

## METHOD

The qualitative research was the methodological foundation of this study and had Social Phenomenology as its theoretical-methodological reference. The core of social phenomenology refers to the sociology of social relations and has the sociologist Alfred Schütz as one of the representatives of Sociological Phenomenology. This phenomenological method is related to the understanding of the actions of persons in their daily lives, conscious of the world in which they are inserted, subjectively presenting anxieties, concerns, and interpersonal relationships. For the understanding of social reality, Sociological Phenomenology values the experience in daily life<sup>(8)</sup>.

At the beginning of the investigation, we contacted the nurse responsible for the Ostomized Group at the hospital of reference in Brasília, who provided the registry of the children with stoma and with it we

contacted each family member, informed about the research objectives, and we learned that the child attended school. After identification of the children who attended school, we contacted the school, by its director, and later the teacher of the child.

We defined as inclusion criterion for the participants of the research: teachers who taught children with stoma in a school unit, of the basic and special education of the Federal District, and who were registered in the ostomized group of said hospital. The exclusion criterion was: teachers of private teaching units. All children from zero to 10 years of age enrolled in an educational unit were considered as school children. The WHO<sup>(3)</sup> defines as a child the period between zero and 10 years of age.

The guiding phrases focused on the experiences, opinions, social interactions, and feelings of the participants. Data collection took place between November 2015 and January 2016.

Each phenomenological meeting was held in a reserved place, with the presence of the interviewee and the principal researcher. The objective of the investigation was explained, and we started after formal authorization from the signing of the Informed Consent. We requested permission to use a digital recorder. Each interview lasted from 30 to 40 minutes on average.

During interviews, after the fourth one, we verified that there was little variation in the narratives, resulting in saturation of the data, thus we completed the data collection with five interviews.

After completing the field research, each narration was transcribed and then read, seeking familiarization with the text and experiences of the participants. To ensure anonymity the statements were identified by the letter "T" (Teacher), in the chronological order of interviews, and were identified from T1 to T5.

Each narration was carefully read and reread several times, seeking to find meanings, and then synthesized. This process was carried out in order to examine thoroughly what was narrated and, thus, to elucidate the context in its entirety, presenting the experiences of the phenomenon lived by the participants.

National and international ethical procedures in research involving human beings were guaranteed, and the study was approved by the Research Ethics Committee of the Health Sciences Teaching and Research Foundation, under opinion # 1,257,739 of 2015.

## RESULTS

### Characterization of the participants

Regarding the characterization of the five teachers interviewed, we found that most are females, aged between 20 and 40 years, Catholic, and residents of Brasília, in administrative regional areas near their workplace. Regarding employment, all work in the Education Department of Brasília. We also verified that all interviewees had a graduate course. Regarding the training for the care of the student with stoma, all affirmed that they did not receive any training in the area.

The age of the students ranged from five to nine years; in relation to the type of stoma, three children

had one intestinal stoma and two had one gastric stoma – these two with serious neurological impairments.

All participants confirmed that their students were dependent on stoma care and had monitors, who were their supporters in the care and inclusion of these students.

### Qualitative analysis

When conducting a more comprehensive analysis of the narrations, the teachers were unanimous in narrating that in the insertion of the student with stoma or with special health needs, there was a need for a modification in the formation of the pedagogical practice to meet, with quality, the individuality of each student. Another aspect reported was the presence of the health professional, what would facilitate the care given to the student with stoma in the school environment.

The attentive and critical reading of the narratives of the participants gave us an opportunity to understand the phenomenon, thus four thematic categories and their relevant aspects were identified.

#### Feelings experienced by teachers in school environment

In this study we defined as feeling the action or effect of feeling and the willingness to be easily moved or impressed. Two subcategories were identified: positive and negative feelings.

For teachers, positive feelings were expressed by the indicators of sensitivity, challenge, interest, joy, and reward.

*I talk a lot with the parents, and they talk a lot about the dissatisfaction, because they live for their child (...) and they must stay in school while their child studies (T2).*

*(...) who works with this type of child has to like what she does, because what often will remain in the care of this student is that you like your profession (T3).*

Regarding negative feelings, we found the indicators of frustration, incapacity, and insecurity.

*(...) education workers [the teachers] haven't received any instruction or training from the education and/or health department for such care, whether they are simple care or not (...) with stoma, medications, and simple dressings (...) (T2).*

#### Factors that interfere with the care

Based on the assumption that the school was a strategic axis for health promotion, this category involved factors that interfered in this strategy for the inclusion of the student with stoma. We define as factors any element that contributes to the achievement of a result, such as human resources, materials, and the clinical situation of the student. In the narrative analysis, we identified the following subcategories: the resources used and the dimension of the child.

In the subcategory of resources used, we identified three indicators: human resources and available and unavailable material resources.

*We try to do our best; the school has no space to take care of the child, what we have is an improvised space, it is located in the bathroom of special education (...) (T1).*

*One problem that I have experienced is the lack of preparation to take care of these children (T3).*

In the second subcategory, dimension of the child, we sought to identify the factors directly involved with the child, whether they were cognitive, physical, or intellectual limitations, the distance from home in relation to the school, or their family structure.

*(...) the child in this situation also needs attention, and when the child has adaptations, they require a lot of care, as for example, in the application of tasks, I need to think about the stoma (...) (T3).*

### **Effective strategies for the care**

This thematic category sought in the term "strategy" to inform how teachers could overcome the problem of school inclusion. Two relevant subcategories were found: the strategy used in the first contact and daily.

In the subcategory of strategy used in the first contact, the conversation with the mother or family members was identified as valid, determining the clinical, physical, and intellectual situation of the student.

*When we receive a child with some problem, we ask for a medical report, informing what happened, the reason for the colostomy (...) a summary (T4).*

In the subcategory of strategies used daily the following indicators were identified: perseverance, individuality, and having the material for the care.

*(...) we will have days when there will be proposed activities, but which will only be carried out if he is well, depending on how he is (...) he will be unable to do it (T3).*

### **Strategies for improving care**

In this last category, the narratives presented the possibilities of improvement for the care. In the strategies, four subcategories were identified: construction of educational material for guidance in the care of the student with stoma, multiprofessional care, such as the support of the health professional, adaptation to the environment, and care training.

*It would be very interesting if we had something to help with the care of the child with stoma, for example, a booklet that helps professionals, parents/ guardians (...) (T2).*

*Let me vent, in theory a CEE [Special Education Center] must have a health professional responsible for the direct care of these children (...), a nurse besides the existing professionals: pedagogue and physical educator (T3).*

## **DISCUSSION**

The proposal of the study was to deepen the knowledge about this subject from the narratives of subjects; we sought to establish the legal principles that guide signatory Governments to adopt measures for

inclusive education<sup>(9-10)</sup>.

In Brazil, the principles of inclusion are supported by the Law of Guidelines and Bases of the National Education. In 2008, the National Policy on Special Education in the Perspective of Inclusive Education was created, which addressed the exclusion and devaluation attributed to students, based on the conception of Human Rights and its diversity<sup>(11)</sup>.

In this study, the teachers reported that the insertion of students with stoma causes a change in the formation of the pedagogical practice to meet the diversity. Accordingly, there is support in the law, since the individual with stoma has a disability, according to Decree 5,296, of December 2, 2004, which "considers stoma a physical disability, ensuring the rights to persons with stoma" (12). In the support of the training, in 2004, the *Carta de Brasília* was sent to the Ministry of Education, which requested the inclusion of the subject of stoma in the training of teachers<sup>(13)</sup>. In 2011, Decree 7,611 ensured the service of persons with stoma as a public of special education<sup>(14)</sup>.

The adversity makes the teacher develop, in addition to the quality of educator, that of facilitator, in order to promote an environment conducive to education. The work in adversity suggests a challenge, according to which the teacher must overcome his or her own limitations in order to find new knowledge and causes<sup>(15)</sup>. It is in this sense that social phenomenology presents the teacher with the comprehension of the challenges of inclusive education.

A study developed with inclusive school teachers presents inclusion as a suggestion to ease distressing feelings and proposes that "in addition to continuing education it is fundamental that the teacher has a support network in the school to assist him or her in the development of his or her work"<sup>(15)</sup>. In addition to the problems inherent in inclusive education, teachers are faced with the stoma, a situation that intensifies the feelings presented. In this way, the problem is to identify who is responsible for this service<sup>(15-17)</sup>.

The presence of the nurse in the school would help the quality of care, being a qualified professional in the integral care for the individual.

The action of the school nurse in Brazil dates from the 1930s, following the American model, with the objective of meeting the professional demand in the education sector in improving the health conditions of students<sup>(18)</sup>. One of the reasons for this demand was the absence of the medical professional in the distant regions of the country, which aimed to train the health educator. This was initially directed to *normalistas* – an old course that formed teachers for teaching, today known as basic education –, and later it was extended to those who had diplomas of higher education, and among them nurses<sup>(19)</sup>.

In Brazil, nurses are not required in schools, but there is a role for nurses in the Family Health Program in the school environment, promoting prevention and promotion actions for students and education professionals. As an example, we refer to a study developed in the city of Rio de Janeiro, which described the profile and practices of the Family Health Team nurses focused on the health of students. This School Health Program (PSE) showed that the presence of this professional is related to their involvement with the services provided and their identification with these models<sup>(20)</sup>, as well as a greater governmental incentive to this

practice.

The results found in this study are also identical to a study developed in Tomar, Portugal, where pedagogical partnership within the classroom was verified as a strategy of change for the development of better conditions for the management of learning diversity<sup>(21)</sup>, that is, the active role among teachers is a key element for the effectiveness of the inclusion process, and their pedagogical action configures their acquired experiences in educational contexts.

The teachers also report the relevance of having a multiprofessional team collaborating with quality teaching. These references are similar to those of a study carried out with teachers in the city of São Paulo, Brazil, who taught children with disabilities, reinforcing this relevance. In this sense, they point out that in addition to different professionals in the field of education, it is also necessary the professional in the area of health in the network of support for the inclusion of children with disabilities<sup>(17)</sup>.

The presence of the nurse in the school involves the planning of the direct care for the student and the support to educators, facilitating the inclusion of the student with disabilities, since it contributes to their integral care from the beginning of the clinical situation, going through the implantation of the stoma, and acting in interventions and rehabilitation.

## CONCLUSION

This research explored the understanding of teachers in the process of inclusion of students with stoma in basic education. This understanding had as its starting point the experience lived, accessed using phenomenological interviews.

The evidence from this research reinforces the obstacles for the inclusion of the student with stoma, narrated by teachers, and presented the need to revise the curriculum of the courses of permanent formation and specialization and to expand the strategies used by the teachers, as well as promote the health of these students. In addition, it showed the need for the presence of nurses in school teaching units, not only in the care of the student with disabilities, but also in curative and preventive health care, such as in school accidents, in the control of contagious diseases, in educational actions in health, among others.

We identified as a limitation of this study the participation of a specific group in the school unit, which hinders the generalization of the results. However, the scientific evidence should be valued and used, and it may contribute to the quality of the care for students with stomas.

This study shows relevance because of the need of investments in research studies related to intervention in the care of students with stoma, in order to instrumentalize the care and expand the body of theoretical knowledge based on scientific evidence.

## Research supported by

This study received financial support from the *Colégio Doutoral Tordesillas Enfermagem* (CDTE).

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