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## The care of the ostomized child in the household: a case study

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### ABSTRACT

**Aims:** To identify when nurses start guiding the caregiver/family of the ostomized child towards hospital discharge; to discuss the participation of the family in the care of the child with stoma, from admission to discharge, from the nurse's perspective.

**Method:** This is a descriptive study, in which we use a qualitative approach, performed with 31 nurses of a Neonatal Intensive Care Unit of a hospital in Rio de Janeiro. Data were collected through interviews with the aid of a semi-structured script and analyzed using the content thematic analysis technique.

**Previous results:** Nurses propose hospital discharge as soon as they are aware of the construction of the stoma, something that the family has difficulty handling.

**Discussion:** The orientation is an instrument that minimizes the difficulties presented by the caregiver.

**Conclusion:** The systematic involvement of not only the nurse, but also of the multidisciplinary team, is essential in terms of hospital discharge guidance for the caregiver of the ostomized child.

**Keywords:** Special Needs; Child; Discharge; Ostomy; Nursing.

## PROBLEM SITUATION AND ITS SIGNIFICANCE

Currently, assistance to newborns and children has undergone advancement by means of the advanced technology used in Intensive Care Units (ICU). The growth of these units comes with the latest technology and professionals are continually faced with more modern, accurate and invasive machines. Because of these advancements, many children can overcome hospital barriers and continue receiving this assistance in their homes, where they may need to receive special care. These children are referred to as Children with Special Needs (CWSN). Since 1998 in Brazil, there has also been the additional designation of Children with Special Health Care Needs (CRIANES). These children may be suffering from disorders resulting from prematurity or other health problems such as chronic degenerative diseases, or those presenting limitations in their lifestyle and normal functions for their age, requiring severe changes in their daily care. This might involve continuous and interdisciplinary monitoring by healthcare service providers, in addition to special care provided by their family members <sup>(1)</sup>. It is not difficult to verify the existence of stomata in these children. The word stoma derives from the Greek and means mouth, which involves a surgical opening that allows contact between an internal organ and the external environment <sup>(2)</sup>. It is noteworthy that 90% of ostomized children reach adulthood. Thus, caregivers/family members need to be able to perform such specific care in an environment outside the hospital. A possible strategy is the creation of a partnership between them and health professionals in order to minimize care damage to CWSN, while still in the hospital environment, from the moment of the construction of these stomata until hospital discharge<sup>(3)</sup>. This research

proposes to cooperate in the training of new nursing professionals, through the preparation of an orientation guide so that such nurses can lead caregivers and/or family members of children with stomas (especially: tracheostomies, gastrostomies, jejunostomies and colostomies) through to hospital discharge, to ensure that the vision of caring will be focused not only on the child, but also on the caregiver, from the point of decision with regard to the construction of the stoma. We aim to encourage further research in order to increase the interest in this area of study, since very little literature on the subject can be found. The dissemination of knowledge in this area may reflect in improved care, and consequently, on the improvement of the quality of life of this population through an early and appropriate preparation of the caregiver/family member of the CWSN, along with the reduction in the length of time in hospital.

## METHOD

The strategy used was a case study associated with a descriptive study, in which we used a qualitative approach. The study was conducted in the NICU of a university hospital located in the northern area of Rio de Janeiro. This sector is composed of 21 beds (13 intensive care beds and eight intermediate nursery beds) and a medication preparation room. The intensive care beds are designated as follows: ICU 1 (incorporating eight beds for newborns bigger than 2 kg) and ICU 2 (five beds for newborns weighing less than 2 kg). The number of beds may be increased according to the vacancy needs and the possibility of adding new patients to the unit. The study was conducted with 31 nurses on duty, working in the various sectors of this neonatal ICU, including day service (DS) and night service (NS).

Data collection was terminated upon the occurrence of repeated information on the theme. Interviews were conducted with the aid of an interview script, from January to March 2012, after approval by the Research Ethics Committee of Pedro Ernesto University Hospital, under the registration number 3139/2011, according to Resolution 196/96 of the National Health Council. The instrument used was composed of 13 questions, which aimed at collecting socio-demographic data and specific information about the performance and perception of the professionals on "stoma". The data were subjected to the content thematic analysis technique, according to Bardin. This technique required the skimming of the text and exhaustive reading of the entire content, after which we verified the occurrence of repetitions of words/expressions in the statements of the interviewees. Thereafter, the registration units were coded and seven categories emerged.

## PREVIOUS RESULTS

The research is in progress and, as in previous studies, we noticed that nurses have specific moments when they start dealing with family members/caregivers concerning the guidelines for hospital discharge. Nurses tend to start the process of health education as soon as they have knowledge about the need to construct

the stoma, in order to minimize the difficulties presented by the caregiver, who is fearful when faced with the knowledge and the need to take care of the ostomatized child.

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