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RESEARCH

SUBJECTIVITY IN FAMILY CARE FOR THE CHILD WITH A STOMA FROM THE CONSTRUCTION OF HIS AUTONOMY
 A SUBJETIVIDADE NO CUIDADO FAMILIAR À CRIANÇA OSTOMIZADA A PARTIR DA CONSTRUÇÃO DE SUA AUTONOMIA
 LA SUBJETIVIDAD EN EL CUIDADO DE LA FAMILIA PARA EL NIÑO CON UN ESTOMA DESDE LA CONSTRUCCIÓN DE SU AUTONOMÍA

Harlon França de Menezes¹, Fernanda Garcia Bezerra Góes², Simone Maria de Araujo Maia³, Ana Luísa Silva Souza³

ABSTRACT

Objective: To unveil the subjectivity present in family care for the child with a stoma, from the understanding of the construction of his autonomy. **Method:** A descriptive and exploratory study using a script of interviews with qualitative analysis with 07 mothers of children with a stoma. The place was a university pediatric hospital located in Rio de Janeiro, Brazil. The data collection took place from September to November 2011. **Results:** The interpretation of the speech was made through the Thematic Analysis. After categorization of the speeches, emerged the following category, the subjectivity of families in child care with a stoma. **Conclusion:** The experience of families facing a new reality imposed by the treatment makes reflections of sensations, which we consider as subjectivity. The maternal senses in relation to care and child development are based on subjectivity, in which are involved cultural nuances inherent in every being, becoming important the alliance of knowledge between professional and client. **Descriptors:** Pediatric Nursing, Personal Autonomy, Child, Child Health.

RESUMO

Objetivo: Desvelar a subjetividade presente no cuidado familiar à criança ostomizada, a partir da compreensão da construção de sua autonomia. **Método:** Estudo exploratório-descritivo utilizando roteiro de entrevista com análise qualitativa com 07 mães de crianças ostomizadas. O cenário foi um hospital universitário pediátrico localizado no Rio de Janeiro, Brasil. A coleta aconteceu de setembro a novembro de 2011. **Resultados:** A interpretação das falas se deu através da Análise Temática. Após categorização das falas, emergiu a seguinte categoria a subjetividade das famílias no cuidado à criança ostomizada. **Conclusão:** A vivência da família diante de uma nova realidade imposta pelo tratamento desencadeia reflexos de sensações que consideramos como subjetividade. Os sentidos maternos em relação ao cuidado e ao desenvolvimento infantil mostra-se embasado na subjetividade, nos quais são envolvidos nuances culturais inerentes a cada ser, tornando-se importante a aliança de saberes entre profissional e cliente. **Descritores:** Enfermagem pediátrica, Autonomia Pessoal, Criança, Saúde da Criança.

RESUMEN

Objetivo: Comprender la subjetividad presente en el cuidado de la familia para el niño con una estoma, desde la comprensión de la construcción de su autonomía. **Método:** Un estudio exploratorio-descriptivo mediante secuencias de comandos de análisis cualitativo de entrevistas con 07 madres de niños con una estoma. El escenario era un hospital universitario pediátrico ubicado en Río de Janeiro, Brasil. La colecta de datos se llevó a cabo entre septiembre y noviembre de 2011. **Resultados:** La interpretación de la disertación fue realizada a través del análisis temático. Tras la categorización de los discursos, surgió la categoría de la subjetividad de las familias en el cuidado de niños con una estoma. **Conclusión:** La experiencia de las familias que enfrentan una nueva realidad impuesta por el tratamiento desencadena el reflejo de sensaciones, que consideramos como subjetividad. Los sentidos maternos en relación con el cuidado y el desarrollo del niño se manifiesta basado en la subjetividad, en los cuales son envueltos matices culturales inherentes a cada ser, tornándose importante la alianza de conocimiento entre profesional y cliente. **Descriptores:** Enfermería Pediátrica, Autonomía Personal, Niño, Salud del Niño.

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INTRODUCTION

This study appears as a clipping of the monography of the graduation in nursing titled as "The autonomy of children with a stoma: subsidies for the care in Nursing", completed in December 2011 at the University Center Plínio Leite, Niterói/Rio de Janeiro.

This final project had as main objectives to understand the construction of the autonomy of the child with a stoma within the family ambit and discuss the participation of nurses in searching this autonomy. However, a characteristic was evident from the results obtained regarding to subjective matters that are interwoven into the daily lives of families of Children with Special Health Needs (CSHN), specifically the child with a stoma, who depends on a medical technology for his survival.

The CSHN are those who have or are at increased risk of having a chronic condition either physical, of development, behavioral, or emotional and that require targeted health services bigger than the required by any children, these were called in Brazil in 1998, by Cabral.^{1,2}

The child who has a stoma, whatever it be his anatomical segment, is considered CSHN because this physical condition causes to depend on technology to maintain his survival, as well as his caretaker having to modify or adapt, in relation to other children who do not have a special health care need, his daily care (bathing, feeding, and transportation, among others).

The autonomy is a way of personal freedom based on the right that people have to express taking care of themselves, however, preserving of the interference from other people in situations involving infringement or invasion of privacy and corporal intimacy, in the risk of exposing internal odors, secretions, that is, the necessity to share the more fragile side of the human condition. To be autonomous, the person must be able to think rationally and self-manage, on the other hand, his R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3731-39

capacity for decision-making will be compromised and someone else will decide for him³.

Piaget, children's cognitive development master, explains that during the daily social relations, since small, with their peers, with the school companionship, with the problems that he faces, and also experiencing, the child will build values, principles and his own rules.⁴

The same author also demonstrates that the child is born in anomie, in total absence of rules. The baby does not know what should or should not be done, much less the rules of the society in which he lives. Later, when the child begins to notice him and others, realizes that there are things that can or cannot be done entering in the universe of morals and rules, becoming heteronomous, being subordinated to those people who have the power. On heteronomy, the child knows that there are right and wrong things, but the adults define them, in other words, the rules emanate from the older one.

The small child still does not understand the meaning of the rules, but obeys them because he respects their sources, for example, the parents and/or the significant people to him. In addition to the love that leads to comply with the orders, the child fears the own authority, still fears the loss of affection, of protection, of the confidence of the people who love him. There is also the fear of punishment, censure and loss of care, establishing at that stage an essential external control.⁴

It is considered that the child in the age group of 1 to 3 years (infant) is in the stage of construction of his autonomy, and he needs to dominate skills. He learns to walk and the talk progresses, becoming a separate person, physically and psychologically. In the presence of a disease or disability, it appears the overprotection by parents who want to establish

limits for fear of an injury or excessive effort, even the most basic self-help skills, such as feeding and clothing can be done for the child. And tasks appropriate for the age, as control of the sphincter and bathroom use may be delayed. With simple attitudes, children are afraid to venture and develop little confidence in them, damaging the beginning of this construction of the autonomy.⁵

Children from 3 to 6 years (pre-school) dominate the tasks of the previous period (infant-stage construction of autonomy), they are ready to deal with the challenges of the development of this new stage. The main psychosocial task for the preschool child is the initiative. At this age, are affected a number of tasks that can be seriously compromised by chronic and disabling disease. The commitment can limit the preschool learning about the environment, especially in terms of social development. Instead of being encouraged to play with his colleagues and participate in school activities, he may be confined at home, where socialization is limited to the safe and tolerant family. Consequently, when compared to children of the same age or who attend school, he may not know how to act and can easily be criticized by colleagues and seen as a "baby". The illness or disability can cause a lot less criticism than his inappropriate behavior.⁵

The child of 6 years of age up to about 12 years, that is, the schoolchild, is experiencing a significant impact on the development and relationships. With groups of colleagues, the child establishes the first intimate relationships outside the family. In this age group, the child admires and idolizes his father, can bathe without supervision, performs his own activities at bedtime, brush and comb his hair, likes to read children's magazines and at school he wants to answer all the questions.⁵

The autonomy is real only when the child becomes secure in his act. When he comes away

from the reliance of an adult, he needs to realize and be an enabler when the child begins to see what is happening around him, allowing living his own challenges, discoveries and frustrations. So, he will begin to exercise his own autonomy considering, therefore, that at certain times they will need guidelines without authoritarianism, respecting the time living by him.

In this sense, the contribution of the adult needs, whenever possible, to wait for the child to perform his activity rather than anticipate it, allowing him to live, without completing his ideas. In addition, this waiting behavior is enriching for the child, because the child learns that he can do it, becoming confident and secure. It is important to know to listen to him, allowing him to organize his thoughts and perform his tasks on his own time, having adults as base of support rather than as total executors.

Parents should find the meaning that the disease has for the family and determine what are the perception and behaviors related to the situation of the disease, having as goal the maintenance of independent and enjoyable life of the child. The disease situation of the child to the family is not easy, because over time, unexpected and threatening situations can happen. Therefore, when facing stress behaviors of child disease situation, will be strengthening the family through the years.⁷

Facing caring for a child with special needs, such as with stomas, the same authors cite that the family develops strategies to live with the disease. With this, health professionals need to know these strategies, and in this context, nurses, by staying more time with the child and his family, must recognize the crisis situations, the overload that is provoked and the quality of life of this group of people and from all this, offer support and discuss alternatives of care in the daily of the family.

The action of taking care of the family creates a sense of security not being alone in the responsibility to care for the child that generates a demand. We can highlight that, when parents believe in the potential of children, whether they are people with special needs, or not, they invest on it and seek internal and external resources to assist them in the process of growth and development, giving them great chances to acquire skills to live with freedom and happiness.⁸

Therefore, confidence is one of the essential elements of care, so parents need to believe that the child with a stoma is a child with countless potentialities and limitations as any other person.⁸

Taking care of the family, the nurse should be able to know the particularities of each one and their needs, while respecting the rules, values and principles, acting with honesty and always making decisions in conjunction with other professionals and the family, with that when looking after/educating, the family consubstantiate the care practices for the child.⁷⁻⁹

After a searching in the Brazilian scientific literature, it was found a poor number of studies on the autonomy of the child with a stoma. In this way, it is justified the realization of this research.

Therefore, this study aims to unveil the subjectivity in family care to the child with a stoma, from the understanding of the construction of his autonomy.

The implementation of this research ruled in its contribution to the field of teaching, research and assistance. In teaching, providing subsidies for the consolidation of an academic approach of care centered on child with a stoma and the family, in its social context, through the children's growth and development.

In this research, we show new trends to treat the subject, stimulating other studies that could lead to the recognition of child development of these children, using theoretical solid R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3731-39

references that meet this perspective and covering a greater number of subjects.

And in the assistance, we contribute to the sort of alternative and effective assistance programs to the child, in order to improve the quality of care for these individuals. The nurse, recognizing the limits and possibilities of the family and this child, can offer qualified and consistent care to lead to the promotion of the quality of life of this cycle.

METHODOLOGY

This study was characterized as exploratory and descriptive type, with qualitative methodological approach. It is detached that the qualitative methodological approach, concerns itself with the social sciences, covering a universe of meanings, motives, beliefs, values and attitudes which cannot be reduced to a simple operation of variables.¹⁰

The descriptive research occurs without the intervention of the researcher, but seeks the interpretation of the facts and the exploratory research, is the one that emphasizes the integral knowledge along the problem with focus on improvement of ideas.¹¹

It is a field research having as a data collection a public pediatric university hospital, located in the municipality of Rio de Janeiro. Thus, the subjects were 07 (seven) families, only mothers of children with stomas. For this, the target population was defined from the following eligibility criteria: 1) relatives of children served in the ambulatory of the institution and, 2) that have a child carrying some type of stoma aged two (02) to ten (10) years and 3) the child has already gone home with the stoma, and 4) who agreed to participate in the survey by signing a Free and Informed Consent (FIC). From this study were excluded, the families of children who have cognitive deficits, mainly related to the neurological basis diseases, that did not heed our

inclusion criteria and those that did not accept to participate in the research.

The capture of the subjects took place through active search on the book of the surgical center of the institution; this contains information on all surgical procedures performed, including the one with stomas, which allowed the identification of children who possibly still have tracheotomies, gastrostomies, ileostomies, among others. In possession of this survey of the last twelve months, it was held a consultation in records kept in the Medical Record Service (MRS), for validation of this information and confirmation of the attendance of eligibility criteria. Later by phone, the responsible were invited to participate in the research in the next children's ambulatory appointment.

At this moment all the information about the survey were offered and clarified, and when all of them have consented to their participation. It is worth noting that the Heads of Ambulatory Nursing agreed with the research.

The research was supported by the ethical and legal principles linked to the research with human beings, contained in Resolution 196/96 of the National Health Council, which requested permission to the Research Ethics Committee (RECs) of that institution, receiving the protocol number 41/11.

Thus, it is noted that the data collection was initiated after the authorization of the RECs, where the gathering was held by an itinerary with interviews with open questions recorded in media devices and subsequently transcribed verbatim by the responsible researchers.

The subjects were addressed only by the researchers involved in this survey and informed by their anonymity, confidentiality of information, the choice of research participation by signing the FIC. The subjects were identified by pseudonyms depending on the degree of relationship with the

child, followed by a name of a children's character related to the child.

The closure of data collection happened when saturation, this is when the speeches began to repeat, the gathering ended. The interpretation of the speeches came through the Thematic Analysis, as this consists to expose the core meaning that compose a communication and its presence or frequency explain something to the analytic object used. The data were analyzed and discussed through the conceptual references from the research.

RESULTS AND DISCUSSION

Guided by the proposed methodological path, the research was followed up to the initiation of data collection with the subjects and meets the inclusion criteria established for the study.

The collection took place in the period from September to November 2011. To illustrate the subjects of this research, it was structured a framework that demonstrates a characterization of the profile, as explained below:

Framework 1: Characterization of the subjects on the research. Niterói, 2011.

Pseudonym of subjets	Child's age	Type of stoma	Time of the stoma
Sininho's mother	10 years	Colostomy	1 year
Anjinho's mother	04 years	Tracheostomy and Gastrostomy	06 months and 1 year
Bolinha's mother	10 years	Colostomy	05 years
Peter Pan's mother	07 years	Colostomy	05 months
Moranguinho's mother	06 years	Colostomy	05 years
Cebolinha's mother	04 years	Colostomy	07 months
Franjinha's mother	03 years	Tracheostomy and Gastrostomy	1 year

From the readings of the answers, the texts were collected as the core of meaning that presented, which were approximated to the

Menezes HF, Góes FGB, Maia SMA *et al.*

Subjectivity in family...

subject that contained reaching the following category.

The subjectivity of the families in the care of a child with a stoma

This category seeks to introduce an element that was evident in the speeches of the research subjects, the subjectivity that permeates child care with a stoma, in which they find support in order to overcome the difficulties of everyday life.

Subjectivity is defined as what is personal, individual, referring to interiority, what belongs to the subject of knowledge, its sensitivity. This perspective is firmed on the move of the relationships between people, which involves the feelings, expectations, hopes and anxieties present in every being, characterizing the subjectivity.¹⁴

When we discuss the subjectivity related to the field of health, it is possible to relate it as "something that is with us in the different moments of life and which can no longer be denied and excluded from the practice of a profession that, by its nature is human".¹⁴

We identified testimonials that emphasized the presence of spirituality and religiosity in the experience of mothers of children dependent on technology. Sininho's mother said that the perseverance guided by faith in God led to religious promises for the satisfactory treatment of her daughter. Moranguinho's mother asks God to give her strength and her daughter, and also claims that to face reality in a mild form, assists in the initial impact on the stoma. So, they reported:

"(...) we have to have a lot of faith, a lot of perseverance, it has to be passed for the children too and the children also pass for us to move on (...) We have many promises to pay. God wants and Virgin Mary wants, right? There in Aparecida do Norte that is her dream, she wants to go there, and we will go, as all good, right? We will finish with all this, if God helps and Virgin Aparecida wants and you will

see her all as pretty as all we want, right? (Sininho's mother, 10 years)"

"(...) and she is a blessed girl thank God (...) I ask God to give me strength to take care of her, you know? God gives strength to her, to face reality and say that this is not such a thing as fashion we think. (Moranguinho's mother, 06 years)"

Anjinho's mother shows believe in God establishing a linkage that strengthens feelings of acceptance wanting his son with her the way he is, but without suffering:

"And these times he goes to surgery, I'm too scared to lose him. Fear of losing my son, because I do not want him to suffer. And I talk to God that I want to stay with him the way he is. And I talk to God like this, but not suffering. (Anjinho's mother, 04 years)"

Another thought-provoking is the Peter Pan mother's narration. She leads us to reflect on the technological dependency that some children may use permanently, associating the religiosity, as she believes that persists is the best way to deal with this period of life:

"(...) To persevere and to have faith in God because this is going to pass. And having faith in God so I can continue, right? (Peter Pan's mother, 07 years)"

We looked for basis in Persegona, Lacerda and Zagonel when they dictate that the subjective dimensions are essential to the development of nursing and to the process of human care.¹⁴

The authors also clarify that subjectivity is understood as the expression of the emotions, of spirituality, intuition, sensitivity and also what is experienced by humans as part of themselves, in situations that require the mobilization of different feelings, which are configured as non-separable from the person and directly influence the way that conceives himself and his way of life to achieve and maintain health.¹⁴

To understand this subjectivity gives us appreciation to what we find in the analysis of the testimony of the mothers of children with special

health care needs, in which it was noticed that diverse subjective approaches were tangent to mother's care together with her son.

Scholars from various areas of knowledge, including Nursing, have been studying the religiosity and spirituality and its influences to the human existence. Nursing emphasizes the recognition of religion and spirituality as sources of empowerment to face the disease, according to the authors Paula, Nascimento and Rocha, when revising in the literature the perception of family members about religiosity and spirituality in the care the child in substitutive renal treatment¹⁵.

It can be seen that the words faith, religion and spirituality are usually used as synonyms, but do not meet the same meanings. Religion is the belief in a divine or supernatural force, which has power over everything and connected to a doctrine. Spirituality is a philosophical orientation that produces behaviors and feelings of hope, love and faith, giving a meaning to life. Spirituality and religion can strengthen the family, contributing to the formation of their beliefs and values, encouraging healthy behaviors and practices, providing social interaction, promoting recreation and helping in the confrontation of crises and transitions of life.¹⁵

The issues of religiosity and spirituality are present in the lives of these women/mothers who look after and deposit precious feelings to ensure for the life of their children. We have seen that the concepts which interact on faith, spirituality and religiosity confirm the idea of reciprocal behavior and support that strengthen the care for the child with a stoma.

Families that are feeling accomplished and comforting lead us to reflect how this chain of subjectivities seems to give them support to maintain the care, because as they feel safe, they could help in child care and stimulate the construction of the technology-dependent child autonomy in the family environment.

R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3731-39

The nursing professional, taking care of these families, need to understand that if the belief produces beneficial practices, the nurse could encourage, reaffirm and incorporate these practices in the care for health promotion.¹⁵

Another subjective approach to the care of child with a stoma refers to the act of overcoming from mothers and coincidentally their children. When they express their speeches, Sininho's mother says that she believes that the acceptance of the chronicity of her daughter, gave impetus to her daughter to accept the path imposed by the treatment, linking in this context, the presence of the religion aspect. She said:

“(...) She has accepted everything in a good way, without complaining, right? And we are passing all the strength that we can, without asking anything from her (...) Now, we're getting there, and with God's willing we will finish her treatment and get back all normal again and the hope is that it will be back everything to normal. (Sininho's mother, 10 years)”

Bolinha's mother, living far from the research scenario, does not discourage the desire to help in the care of her child, however she reports some difficulties:

“(...) it is a lot of courage, a lot of fight, right? Is what I do, right? Because, sometimes we come here and we have people here complaining, but we come far from here. We wake up at 01:00 a.m.! We stay here all day long when we come to the doctor's appointment, and so ... take care with affection, with love.(...) In the beginning was difficult, right? Now that he's more active, smarter ... he has a normal life, right? But, like this, he can't make effort in certain things. (Bolinha's mother, 10 years)”

Feeling alone and having to solve all the problems of everyday life, regarding to the treatment of her son, she feels rewarded by seeing his development through health service access, even away from her residence.

From the health access and guidance in health practices, the mother accepted her child's situation better and provides care that can

facilitate the understanding of the incentive observing the autonomy of the child.

The new demands of child care with technological dependence require mobilization and reorganization of the family dynamics to give a new meaning to family bonds. Thus, to strengthen the family in demand of overcoming the impact caused by the diagnosis of a child, this requires the union of all its members, as well as a social network that can be use during difficulties that may arise.

We should not complete this category, to express the reflections of happiness that these mothers show us and thus understand that the adversities from the trajectory of life of a child caring with technological needs, that reach objective and subjective results that overflow emotion senses that help in quality of life. Expressing this emotion, mothers tell us that their children are happy, regardless of physical limitations imposed:

“And if also the child that cannot return to normal be happy along with the physical limitations(...). We are so happy, all I've been passing with her, the better, is a very good thing. (Sininho´s mother, 10 years)”

“(...) He is very "kind", smiling, he is very happy. (Anjinho´s mother, 04 years)”

It is clear the feelings of mothers showing their welfare when they see that their children are living their lives, with the imposition of a technological device. We resume having a meaning for breaking of negative senses that are linked in the initial daily life of the clinical diagnosis.

Understanding this subjectivity gives us support to realize the context of care provided to children technology dependent and its performance in children development. In awakens us to this subjectivity that interacts to a process of respect in the environment for the personal choices of the individual and their capabilities.

R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3731-39

We could not leave aside in this work the matter of subjectivity and lose these valuable testimonies describing the interlacing of the living and that permeate the process of care and serves as a tool for human lapping process and supportive care, that has been the great search of nursing throughout its history. To talk about this human dimension is a process that requires study, reading and especially critical thinking to understand the concepts involved, as well as the way to articulate them to professional practice, enriching the nursing knowledge.¹⁴

The message that we want to give is that the family needs to be seen as powerful and consistent in the contribution of the incentive to the autonomy of the child with a stoma and the nurse, with his unique and specific assistance to the family, understands the real needs relating to child development in children with a stoma.

CONCLUSION

This study allowed the knowledge of care experienced by the family caregiver of children with a stoma, in this case, the mothers. The family experience in a new reality imposed by treatment shows reflections of sensations, that we consider as subjectivity, which leads the family to seek strategies facing new difficulties.

The maternal senses in relation to care and child development are based on subjectivity, in which are involved the cultural nuances inherent in every being, becoming important the alliance of knowledge between professional and client. The double via of reciprocity between mother and son allows the experiences to be propelling for the child's development.

We have seen that the religiosity permeates the daily lives of these families and brings with it the ability of mobilization that modifies the attitudes and behavior of each one. Hope in God allows the therapist to be accepted

Menezes HF, Góes FGB, Maia SMA *et al.*

Subjectivity in family...

calmly, strengthening family bonds, as well as the family-professional. The spiritual needs of each person must be taken into consideration in nursing care.

We believe that the link facilitates the care as gives confidence in the relationship established and allows to understand the acceptance of the chronicity of the son. The link can be on accountability, from the professional commitment and involvement with the individual.

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