

Stomas in neonatology: recovering the mother's memory*

ESTOMAS EM NEONATOLOGIA: UM RESGATE DA MEMÓRIA MATERNA

ESTOMAS EN NEONATOLOGÍA: UN RESCATE DE LA MEMORIA MATERNA

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ABSTRACT

The scientific production overview that concerns the family and stomas urges for studies about the subject, especially about the experience in neonatal period. The present study aimed to comprehend mothers' experience about stomized children during neonatal period or the hospitalization period in Neonatal Intensive Care Unit (NICU). The methodological approach adopted in this study was Oral History, where interviews were conducted with nine mothers. The rescue of individual memories enabled construction of collective memory, organized in four themes: *dreams versus reality, lost protection, in fear's company and motherhood is needed*. The results allow a reflection about the importance of more effective actions that contribute to the autonomy and relief of suffering of the mother in NICU, where nursing care can be guided by the principles of Family Centered Care.

DESCRIPTORS

Infant, newborn
Surgical stomas
Mothers
Neonatal nursing
Family

RESUMO

O panorama da produção científica no que concerne à família e estomas é carente de estudos sobre o tema, em especial sobre a experiência no período neonatal da criança. O presente estudo teve como objetivo geral compreender a experiência da mãe que tem um filho estomizado durante o período neonatal ou durante o tempo de internação em Unidade de Terapia Intensiva Neonatal (UTIN). Utilizando a História Oral como referencial metodológico, foram realizadas entrevistas com nove mães. O resgate das memórias individuais possibilitou a construção da memória coletiva, organizada em quatro temas: *sonhos versus realidade, proteção perdida, na companhia do medo e é preciso exercer a maternidade*. Os resultados permitem uma reflexão sobre a importância de medidas mais eficazes que contribuam para autonomia e alívio do sofrimento da mãe na UTIN, em que a assistência de enfermagem possa ser orientada pelos princípios do Cuidado Centrado na Família.

DESCRITORES

Recém-nascido
Estomas cirúrgicos
Mães
Enfermagem neonatal
Família

RESUMEN

El panorama de la producción científica en lo concerniente a la familia y estomas carece de estudios sobre el tema, especialmente sobre esta experiencia en el período neonatal del niño. Se objetivó comprender la experiencia de la madre de un niño ostomizado durante la fase neonatal o durante el tiempo de internación en Unidad de Terapia Intensiva Neonatal (UTIN). Utilizando la Historia Oral como referencial metodológico, fueron realizadas entrevistas con nueve madres. El rescate de las memorias individuales permitió la construcción de la memoria colectiva, organizada en cuatro temas: *sueños versus realidad, protección perdida, acompañada por el miedo y es necesario ejercer la maternidad*. Los resultados permiten reflexionar sobre la importancia de medidas más eficaces que favorezcan la autonomía y alivio del sufrimiento maternal en la UTIN, donde la atención de enfermería pueda ser orientada por los principios del Cuidado Enfocado en la Familia.

DESCRIPTORES

Recién nacido
Estomas quirúrgicos
Madres
Enfermería neonatal
Familia

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INTRODUCTION

'Stoma', 'stomy' and 'ostomy' are words derived from the Greek language, meaning *opening* or *mouth*. They are used to refer to the externalization of any hollow viscous through an opening to the outside of the body, and this opening may be created for several reasons. Depending on the area of the body from which it originates, a stoma may be referred to more specifically as a tracheostomy, gastrostomy, esophagostomy, colostomy, jejunostomy, ileostomy and vesicostomy⁽¹⁾.

In pediatrics, stomas may be created as part of the treatment of malignant, benign, inflammatory, traumatic and/or congenital diseases of the gastrointestinal tract. However, the most common reason for the creation of stomas in this population is congenital malformation. Therefore, in most cases the children must undergo surgery to create the stoma during the first weeks of life⁽²⁾, i.e. in the neonatal period.

In large part due to current technological progress, the survival of very small babies with serious birth defects and more severe health problems has become commonplace. The result of such advances means that children may become dependent for survival on lifesaving procedures⁽³⁾ such as tracheostomy and gastrostomy.

In terms of the experiences of families in Neonatal Intensive Care Units (NICUs), there is still a vast field to be explored⁽⁴⁾ regarding the family's experience with the necessity of a stoma for their infant's survival. In this context scientific production is lacking regarding this theme, especially considering this experience in the neonatal period, which is permeated by beliefs, feelings and expectations involving the birth of a new family member and the changes that this event causes in terms of family life.

The way in which families experience disease depends more on the beliefs they hold than on the disease itself, since these beliefs influence how they interpret and respond to different situations. These beliefs are the lenses through which humans view the world, and are the foundation of their behaviors and the essence of their affections. They are the basis upon which lives are built and intersect with the lives of others. Beliefs, history and disease are intrinsically interconnected⁽⁵⁾, and including families in nursing care requires being open and attentive to their interactions and to the impact of their experiences, as well as understanding their dynamics, beliefs and forms of adaptation⁽⁶⁾.

In this study, the subject was approached by focusing on the experience of mothers, who are closest to their children during the newborn period. This study was motivated by the following questions: How is it for the mother

to experience the creation of the stoma in their child during the neonatal period? How are this procedure and its implications viewed by her? Which beliefs emerge from this experience?

OBJECTIVES

This study aimed to understand the experience of the mother who has a child requiring a stoma during the neonatal period or during hospitalization in the NICU, and identify the mother's beliefs regarding the completion of the stoma in their child.

METHOD

Oral History was used as the methodological reference for research development⁽⁷⁾. This method captures accounts by means of electronic equipment, dedicated to collecting testimonies, promoting analyses of present social processes and facilitating new knowledge of the situation in question. The use of the oral history interview aims

at recording the meaning of the experience of an individual or a group, with the desire to clarify a situation being the motivation to perform work in this field. According to this method, the central and starting points for the analysis are focused in the interviews⁽⁷⁾.

Collection and analysis of data

The research was conducted according to the standards outlined in the Resolution of the National Health Council - CNS 196/96, and was approved by the Ethics Committee in Research of the School of Nursing, University of São Paulo (Case 214/2009). The inclusion criterion for the study was mothers who had gone through the experience of having a child who required some type of stoma during the neonatal period or during hospitalization in the NICU.

The study collaborators were located in a referral hospital providing multidisciplinary care to children requiring stomas in the State of São Paulo. Health professionals, with the consent of the collaborators, provided the phone numbers of potential participants to the investigator. Nine mothers of children who met the inclusion criterion participated in the study. The participants were between 24 and 36 years of age; five were college graduates, eight were married, one was widowed and, for eight of them, the child with the stoma was the first and only child.

Data collection took place between May 2009 and October 2010. The interviews were recorded with a digital recorder, following a series of questions prepared with the objective to understand the impact of the event reported in the narrative of the oral history of the woman, so as to reveal data referring to the hospitalization experience and

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the creation of the stoma, focusing on aspects related to beliefs regarding the etiology of the stoma, diagnosis and prognosis of the child, as well as aspects that weaken and strengthen the mother who lives the experience.

According to the methodology used, the post-interview stage of data analysis flowed in the following steps⁽⁷⁾: 1. Transcription: comprises the strict passage from oral to written form; 2. Textualization: questions are eliminated from the text, grammatical errors are corrected and the interview is rearranged chronologically. At this stage one chooses the vital tone, which consists of selecting a sentence that will serve as the theme for the reading of the interview 3. Transcreation: at this stage there is interference of the author in the text, where the text is redone several times seeking its improvement; and 4. Checking: this is the point in which the author delivers to the collaborator the completed text so that the collaborator authorizes the release of the work.

In Oral History, individual memory is only useful when it allows knowledge of social phenomenon. What guarantees the unity and coherence of the interviews gathered in the same set is the repetition of certain factors that ultimately characterize the collective memory⁽⁷⁾. Therefore, the analysis stage of collective memory construction was performed by means of common themes emerging from individual narratives, resulting in four thematic areas.

RESULTS

The presentation of collective memory is composed of four distinct themes, which are all interrelated through the series of moments that encompass the history that makes up the experience of the study participants.

By the very stage of the family life cycle in which the mothers with whom we conducted the studies are encompassed in - families with small children - the experience of having one child requiring a stoma due to a neonatal condition is closely related to another new experience: the construction of parenthood, which implies redefinition of roles, imposition of new demands and reestablishment of relationships⁽⁸⁾, demonstrating that this time in history has no isolated meaning in family life, since it is included in a much larger context. Being a mother is desired by the women who narrated their stories, representing the starting and guiding point of the whole experience of having a child with a stoma.

Dreams versus reality

The period of pregnancy is permeated by the belief that there will be a healthy pregnancy and that the newborn will be normal. Thus, the occurrence of unexpected events generates deep suffering in mothers when they realize that the reality experienced is totally different from that construed in their dreams.

Two events are considered “turning points” which remove women from their dream and place them directly into an unimagined reality: the first is the realization that their child has an abnormality, either a malformation, prematurity or illness, and the second is the need for hospitalization of the newborn in the NICU, which involves consequences such as the need for surgical intervention for the creation of the stoma.

It's usually like this: you always imagined your child as a beautiful baby, taking him/her home, breastfeeding him/her, which is what a mother does. So when I received the news that he had to have a stoma, it was hard. Very hard. My goodness! I felt sad. Very sad (E1).

Even if there is time, when it is possible to anticipate or even authorize the surgery to create the stoma, the mother is often reluctant to accept the fact. Not only does she not want the stoma to be performed, but she also hopes that there will not be any need for the intervention, even though she was aware of the possibility of its necessity in the first days of the child's life.

Two main beliefs support this denial. The first belief is that the stoma is something very unusual and difficult to live with. The second belief is that the stoma will cause pain to the child, and by fearing that the child will suffer continuously, she does not want the intervention to be performed.

(...) I imagined that she would be in pain forever. That is why it was so difficult, because I saw the gastro in a different way. It was suffering, it was very hard, and I did not want it!! I did not want it at all(E4).

The explanations and information regarding the stoma and the condition of the child show a reality that demands an understanding that gives reason to suffering. In view of the change in the course of the life dreamed of, and with the intention of seeking explanation for such suffering, the woman throws herself into an internal quest for reasons that might explain the experience of such a different story, which makes it impossible to experience that which other women, in situations considered as normal, experience when they become mothers.

When I was in the ICU I wondered: Why did this happen to me? Why was I chosen? Why must I go through this?(E2).

Lost protection

The woman believes that it is the mother's duty to take care of the child and that, being responsible for the child, it is her duty to protect him/her. This core belief makes it difficult for the mother go through the experience, since the finding of the abnormality in the child and admission in the NICU result in suffering, when she cannot perform the duty she believes is hers, and when she seeks to create conditions in which to exercise her maternal role.

After premature birth, or after finding some abnormality during the neonatal period, the woman feels she has lost the protective power she had over her child. This is true not only because the baby is no longer in her uterus, where she could ensure his/her survival, but mainly because the child is placed in an unknown and hostile environment, with all that it represents, and because she can no longer be near him/her fulfilling her duty to protect him/her:

He was constantly manipulated, he was very tiny, and he has this reflex up to this day. (...) he was in the womb, he comes out, has no contact with the mother, because he was there in the incubator, and suddenly a lot of people start to handle him(E3).

In this context, the event that culminates in the creation of the stoma in the child is perceived as something over which the mother has no control or choice, since it is the only option to keep her child alive. The creation of the stoma becomes the obstacle that the family must overcome to provide for the child's recovery, and thus has the ability to protect both child and family from suffering. Therefore, sustained by the belief that it is her duty to take care of the child, the mother tries to protect his/her life by accepting the procedure to create the stoma, not thinking about what she wants, but rather what she believes is best for the child.

I will not tell you it was easy to accept (...) At the time I could not think about aesthetics, about appearance, I had to think about what was best for him; otherwise, I would not be being fair to my baby (E1).

The almost instantaneous empathy developed by the mother regarding what the child experiences brings great pain and, at the same time, feelings of impotence. The mother suffers because she believes that her child is suffering and feels impotent because she cannot perform the role of maternal protector, since there is nothing she can do to prevent her child from suffering. After creation of the stoma, the mother suffers not only because she believes that the procedures cause pain to the child, but also because of the consequent postoperative therapeutic measures, such as fasting, that makes her believe that he may be starving.

When I saw [a colostomy...] the first thing I thought was that it hurt and that it bothered her (...) So, my biggest concern was that she would suffer with it because I thought it would hurt (E6).

The overcoming of the initial shock and grief caused by the unexpected and unwanted events begins when the mother is strengthened by relying on the belief that it is her duty to care for the child, and is based on a journey of dedication to her child despite suffering. She wishes to be near the baby because exercising a vigil is a way to continue protecting her child and ensuring his/her well being, thus making her feel like a mother.

However, admission in the NICU adds other elements to the complexity of the experience of motherhood/parenthood, since it limits the mother in the exercise of her duty. This is because, even though she wants to, she feels she cannot be a full mother in this context. In the experience of the mother there is often a reversal of roles, in which the mother becomes a mere spectator in the life of her child, while the healthcare team plays the role of support and care that she believes belongs to her.

(...) this business that you can only go in a certain number of times per day is very complicated, because the child is yours and at the same time is not yours (...) For 51 days he was not our son, he was the son of the Maternity Ward. We could only pick him up at certain times; it was complicated (E3).

In the company of fear

In spite of being instilled with dreams and expectations, it is in the company of fear that the woman begins her journey into motherhood, because it is during pregnancy that she becomes afraid of having a child that will not meet her expectations, i.e. she fears that the child will not be perfect and as healthy as expected.

(...) when we learn we are pregnant, we ask: oh, I want my child to be born perfect, healthy. It's no use, all mothers say that! (E6).

The birth of a child outside the usual pattern of normality scares the mother, and the need for hospitalization in an NICU generates changes in the lives of the entire family. Believing that she is experiencing a story that does not meet the standards, accompanied by feelings of threat and fear - generated by the perception that the child has a condition and this condition is life-threatening— these negative feelings accompany the mother at the beginning of the mothering experience. Malformation, prematurity or the presence of a stoma turns the child into a different child, and the need for surgical intervention to maintain his/her life, added to admission in the NICU, are interpreted as strong threats to the child's life.

You never know what you will find, every day is a surprise, so you are afraid to go into the ICU (...) I was afraid of complications, afraid of what could have happened, I did not know how my baby had spent the night. We are very afraid of losing the baby. Very afraid, very afraid (E2).

The impact of observing the child with a stoma, experiencing a mix of denial of the new and different conditions of the child, as well as fear of the scary situation that it represents in your life is something new and unknown, which generates fear.

Of course having a child who breathes through a place that is not the usual one scares you! (E4).

For some mothers, fantasies created around the stoma are deconstructed when she sees the child. This calms her

down, since she had imagined the stoma as worse than it is. Still, she is afraid to imagine herself taking the child home with this device, and fosters hope that the stoma will be reversed before the child is discharged from the hospital. If this were to occur, she would not have to face caring for her child with a stoma.

But I thought they would take out the trash when I left there. That's what I said to the doctor: "I do not want to go home with that to take care of at home; I don't want to, I don't. I'll wait for you to take it out.(E4).

During her journey in the company of fear, faith sustains her. Religion is a demonstration of faith, and the mother uses it to make sense of and confront the story she experiences, with God as the greatest source of strength in this context.

I passed a great deal onto God. God helped me a lot (...) If you do not have something to believe in, forget it, you cannot... (E5).

Motherhood is needed

Because she wants to be free to exercise her maternal role, the greatest expectation of the mother is to take her child home. Taking him home symbolizes the conquest of the objective that led her to desire this whole experience: being a mother. Believing that she needs to exercise her motherhood generates in the mother the strength to live day to day, overcoming fears and challenges and looking forward to the day she leaves the hospital with her child in her arms.

When I was there I thought of the day I would leave; I wanted to go home. My expectation was to bring him home, knowing that this would end one day, knowing that I would take my son home in my arms and would live a new life(E2).

Because she wanted so much to take her child home, the reality of the stoma is seen by the mother as the opportunity to make her wish come true. She thinks of the welfare of the child and, because she judges that the best course for her child is to have him/her at home under her protection - and stoma represents the fastest way to get the baby out of the NICU – thus she authorizes or requests the surgery.

(...)in talking, we thought that going ahead with the gastro would be the easiest, quickest way to take him home, so we opted to do the gastro, to get out of the hospital, despite it not being very nice for him, but it was better. It was we that communicated the time to perform the gastrotomy. It was we who asked for it, it was not something imposed on us, it was something that originated a lot more from us(E3).

However, despite the urge to remove the child from the NICU, the mother is not exempt from concerns. Because she is aware that when she takes the child home

the responsibility for the child's care will be entirely hers - while during the hospitalization period that function belongs to the team - fear once again follows her. The life waiting outside the hospital environment is also reason for concern, whether it is related to the near or distant future.

(...) what I really want is for my child to become a normal kid. Have you thought about if the doctor came to me and said: your daughter will be using this little bag? How would that be? How could she play using that little bag? And her adolescence? It would be sort of complicated. I'd have to learn how to deal with the situation(E6).

Even filled with concerns and fears the mother takes action. With the child still hospitalized in the ICU, she prepares and seeks out resources that will be needed to keep the child out of the hospital environment. She also gets involved in training to be able to care for her child at home, learning to perform technical activities and overcoming her fears and limitations.

I remember I had to learn how to do everything there in the ICU, to change equipment, to do everything. My goodness! It was so hard for me at first. God almighty! How we suffer from the unknown. I remember, gee! I trembled, I trembled! The first time I went to touch Carol's gastro, my God! I cried, I cried (E4).

Acceptance of the surgical procedure for the creation of the stoma is not synonymous with accepting the new condition of the child, since she had not imagined this to be her child's life. There are beliefs that strengthen the mother and help her embrace this new story as hers; one of them is to believe that the stoma is temporary and that, therefore, at some point in the future her life will be normal.

What gives strength for the mother to go on is hope. She moves on, believing and waiting for the day when the stoma will be closed, hoping that in the future she can experience a different story from that experienced thus far. She dreams of a future governed by normality.

The mother always thinks about what is best for the child. Thus, acceptance of the *different* child actually occurs when the mother begins to believe that the stoma was the best course of action for him/her. What builds that belief is to see her son alive and witness his improvement. The woman realizes that, thanks to surgery, she can finally take the child home and take on the role of mother with autonomy. She starts to conceive that what really matters is being a mother, regardless of the child's situation.

(...) this procedure [stoma]... is not the best thing in the world, but it is a way for you to see that your son is alive, that your child may develop, and you're there with him (E2).

DISCUSSION

Since mothers were the focus of the study, the construction of motherhood within the investigated experience stood out in the stories told. The narratives reveal the difficulties experienced during this transition, which should occur in the NICU. Results show that the health condition of the child at birth - with consequent hospitalization in an NICU and performance of a stoma - interfere with the construction of maternal identity, since it deconstructs both the idealized image of the child, as well as that of the mother role. The belief that every newborn is healthy⁽⁹⁾, also revealed in this work, has great potential to make the experience of having a child with a health condition one of suffering.

The NICU is seen by the mother as a threatening and scary environment, since it compromises the construction of the maternal role. In addition, it generates fear by implying the possibility of losing the child. Other studies also demonstrate that the admission of the newborn in the NICU frightens parents and arouses fear of losing their child, especially because they are living unknown experiences in an environment foreign to them⁽⁹⁻¹¹⁾.

The health condition of the child threatens the construction of motherhood, since the mother tries unsuccessfully to play her role within the hospital environment. This is because the team itself and the institution - with its protocols and routines regarding family presence in the environment - prevent her from exercising her function. It has already been found that the relationship between nurses and mothers can significantly affect how women perceive their experience of motherhood, since the establishment of these interactions may facilitate or restrict their ability to take on the role of mother⁽¹²⁾. Inhibitory actions performed by nurses, either consciously or unconsciously, place them in the role of 'experts', cementing their power over the child by means of care routines, while mothers are relegated to the role of mere spectators of the care provided⁽¹²⁻¹³⁾.

The study revealed that the mother feels threatened and subverted, and therefore waives personal, social and family life in order to be able to be a mother to the extent possible while the child is hospitalized. This posture makes her live the experience leveraging as much of the space given to her as possible during a limited period of time. She wants to be free to stay close to her child at all times, but circumstances allow her to be close to him/her only during certain times. Because she is seen as a visitor by the hospital, she starts to feel as though the child is not hers. Other studies also show that parents feel like visitors of their child⁽¹⁴⁻¹⁵⁾ and wish to stay 24 hours a day in the Neonatal ICU⁽⁵⁾.

Although parents indicate the relationship developed with the nurse as being the most significant factor with regard to their experience in the NICU⁽¹⁶⁾, they are tied to

institutional and professional standards that end up inhibiting their experience as parents during the hospitalization of the child⁽¹⁷⁻¹⁸⁾. Such rules make them feel excluded from the child's care.

Regarding coming to terms with the need for a stoma, some aspects intensify the suffering and the concern of the mother. Among these is the belief that the procedure will mean an abnormal appearance of the child throughout its life. Other aspects that cause worry and suffering for mothers in advance are associated with the distorted image she has of the stoma - before the procedure - and the belief that the child will feel pain continuously after the creation of the opening, which may be related to insufficient information and clarification of concerns regarding the procedure on the part of the health team.

A study conducted with parents of children who underwent gastrostomy found that the parents identified lack of information from professionals and judged that the information that had been given was inadequate regarding the procedure that would be performed⁽²⁰⁾. Many felt that more information could have been provided when gastrostomy was suggested, considering also that information could have been provided regularly during the entire process of making the decision and repeated after consent had been obtained⁽²⁰⁻²¹⁾.

Upon completion of the stoma the mother believes that the opening will be closed and goes on with the hope that one day she will be able to experience a normal story. A study conducted with parents of children with intestinal stomas⁽²²⁾ also found that the stoma is much simpler to face when viewed as a temporary condition, because this gives parents hope that there will be an end to the period of abnormality and the beginning of a new *normal* period in family life.

CONCLUSIONS

Understanding the experience of a mother who has a child requiring a stoma as a consequence of a neonatal condition - the question that this study aimed at revealing - has been unexplored in the area of Neonatology, as the exploration of this experience within the birth event has not been investigated by other studies.

It is the duty of the mother to care for her child and exert motherhood. These are the two beliefs that empower women who live the experience of having a child with a stoma as a consequence of a neonatal condition, but also weaken them when the mothers cannot realize them. They configure themselves, therefore, as evidence of studies that expand knowledge on the subject.

These beliefs provide the necessary strength for the mother to face the daily adversities that she encounters during living with the disease, hospitalization and performance of the stoma. They drive her to overcome negative

feelings - such as fear, suffering, distress and denial of the condition of her child - and mobilize her to pursue motherhood to the extent that it is possible within the lived context, toward an unknown future.

This study was limited to understanding the experience of a single family member; however, research is needed that focuses on the experience of other family members and can describe in more detail the interactions between the family and the healthcare team.

The initial responses to questions brought up by this study may enable nursing interventions grounded on beliefs, feelings and needs revealed in the maternal narratives, thus the evidence brought forth could be used in healthcare practice, leveraging unveiled data in interactions undertaken with mothers that are going through similar situations.

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