Original Article

Experiences of mothers of disabled children: a phenomenological study*

Vivências de mães com um filho deficiente: um estudo fenomenológico

Vivencias de las madres con un hijo deficiente: un estudio fenomenológico

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ABSTRACT

Objective: To unveil the experiences of mothers of disabled children, with a view to understand the meaning of that experience. **Methods:** This is a qualitative study using phenomenological approach based on Heidegger. The study subjects were five mothers with a disabled child. The interviews were performed at the women's homes, guided by the question "To you, what does it mean to have a disabled child? **Results:** Five categories came into focus: "meeting one's actual infant," "the impact of disability," "treading a new path with one's disabled child," "experiencing maternal altruism in the care of the disabled child," and "altering one's family daily life." **Conclusions:** The discourses revealed emotionally moved beings experiencing a painful, sorrowful manner of being-in-the-world. Mothers find themselves unprepared to deal with the experience of having a disabled child, though perceiving the situation as an opportunity for self-encounter. Changes occurred to the couple's dynamics and family members became distant. When seeking guidance from health professionals, the mothers failed to find the necessary support.

Keywords: Family relations; Disabled children; Pediatric nursing

RESUMO

Objetivo: Desvelar a vivência da mãe que tem um filho deficiente, para compreender o sentido dessa vivência. **Métodos:** Estudo qualitativo sob a perspectiva fenomenológica fundamentada em Heidegger. Os sujeitos do estudo foram cinco mulheres que experienciavam a situação de ser-mãe de uma criança deficiente. As entrevistas foram realizadas no domicílio orientadas pela questão norteadora O que é ser, para a senhora, ter um filho deficiente? **Resultados:** Emergiram cinco categorias: "encontrando-se com o bebê real", "o impacto com a deficiência", "trilhando um novo caminho com o filho deficiente", "vivenciando o altruísmo materno no cuidado do filho" e "modificando o cotidiano familiar". **Conclusões:** Os discursos revelaram seres emocionados vivenciando uma forma dolorosa e triste de estar-no-mundo. As mães se vêem despreparadas para lidar com a experiência de ter um filho deficiente, embora percebam a situação vivenciada como oportunidade de encontro consigo mesmas. No funcionamento da família, ocorreram alterações na dinâmica do casal e distanciamento entre seus membros. Ao buscarem apoio nos profissionais de saúde, as mães não encontraram a ajuda necessária.

Descritores: Relações familiares; Crianças portadoras de deficiência; Enfermagem pediátrica

RESUMEN

Objetivo: Develar la vivencia de la madre que tiene un hijo con discapacidad, para comprender el sentido de esa vivencia. **Métodos:** Estudio cualitativo realizado bajo la perspectiva fenomenológica fundamentada en Heidegger. Los sujetos del estudio fueron cinco mujeres que vivenciaban la situación de ser-madre de un niño discapacitado. Las entrevistas fueron realizadas en el domicilio orientadas por la pregunta norteadora: ¿Qué es para ud. tener un hijo con discapacidad? **Resultados:** Emergieron cinco categorías: "encontrándose con el bebé real", "el impacto con la discapacidad", "recorriendo un nuevo camino con un hijo discapacitado", "vivenciando el altruismo materno en el cuidado del hijo" y "modificando el cotidiano familiar". **Conclusiones** Los discursos revelaron seres emocionados vivenciando una forma dolorosa y triste de estar-en el-mundo. Las madres se ven sin preparación para lidiar con la experiencia de tener un hijo con discapacidad, a pesar de percibir la situación vivenciada como oportunidad de encuentro consigo mismas. En el funcionamiento de la familia, ocurrieron alteraciones en la dinámica de la pareja y distanciamiento entre sus miembros. Al buscar apoyo en los profesionales de salud, las madres no encontraron la ayuda necesaria.

Descriptores: Relaciones familiares; Niños portadores de discapacidad; Enfermería pediátrica

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INTRODUCTION

The family relationship, the mother-child involvement, and the way the family took care of the hospitalized child raised interest, but also discomfort, since the moment I completed my graduation course and started working as a nurse in a pediatric hospitalization unit.

Ever since, I noticed the importance of the family and their feelings towards the child who was kept away from their care. An immediate perception was that the mother was the core figure in the family relationships and in child care. Another perception was that not only the child, but also the family, needed care. This perception became more intense in my practice as I became aware of myself as a nurse.

This way, in my path as a nurse-being in child care, I came across disabled children and their families. The difficulties found, both by myself and by the professional team, which took care of the disabled child and the family, led me to win the right for the family members to enter the commitment unit with free schedule, since at that time they were not allowed to stay with the child during hospitalization. This permission allowed the mothers to take care of their children and ease their own anxieties.

This achievement gave me the opportunity to observe them in their disabled child's care, allowing me to perceive the affectionate relationship and the ability with which they performed it. However, I also noticed, in their speech and selfless acts, that having a disabled child was a hurtful experience for them.

The contact with disabled children raised questions about the ways of taking care and allowed me to look differently at children, disability and the families. This perception clearly unveiled the need to search for new ways and opportunities that could provide a better understanding about the emotional involvement and the family relationship with the disabled child.

This path allowed me to have more effective contact with the disabled child's family. At first, this contact was present in the mother figure, and led me to think about the question of how a family experienced having a disabled child, for I noticed the difficulties found by the family members and how the way they face those issues has great influence over the child's development.

Knowing about the child's disability is a traumatic experience, which can alter the emotional state of the family members(1). When the disability is revealed, the whole family starts an adaptation battle to recover their balance. Although only one family member is disabled, all are affected and, to a certain extent, disabled by it.

Health care professionals are often unprepared to give the diagnosis of disability to the family, which makes this a traumatizing moment for the parents(2).

The helplessness faced by the parents could be diminished if methods that are more appropriate were used to inform parents about the child's disability diagnosis. The absence of these conditions can increase the difficulties in facing the new situation, given the decisive role of informing the diagnosis, which marks the beginning of a new process of adjustment for the whole family life(3).

In fact, as studies and reflections point out, in the birth of a disabled child, the psychological state experienced by the family is one of loss, of death – "death" of the ideal, desired child. Thus, it is necessary to live the grief process for that "lost" child to then be able to receive the real child,. The individual and inter-individual contingencies, as well as family dynamics, somehow define the way and the time of elaborating this grief, as well as the associated reactions(4). If a family group, when facing previous conflicts, has once formulated joint and shared solutions, it will be more capable of finding adequate alternatives and solutions for future problems(5-6).

The family life suffers changes due to the emotional demands and living with the disabled child, which can generate conflicts and emotional instability. In this sense, I believe nurses should understand the emotional reactions that the mothers experience and the effects that the child's disability has on the family, so they can focus the attention on the family.

OBJECTIVE

To understand what having a disabled child means for a mother.

METHODS

Phenomenology makes self-encounter accessible for human beings, and, thus, it is a way to understand the mothers' experience with a disabled child. Therefore, I tried to develop themes and understand the essence of the phenomenon that I designated as "the meaning, for the mothers, of having a disabled child".

I tried to place the phenomenon in a way that it could show itself in its own language. To do this, I sought to establish a phenomenological perspective, adopting the hermeneutic perspective of Heidegger, in which the veiled sense in the description unveils itself through understanding(7).

Observing ethical aspects, the research project was approved by the Federal University of São Paulo Research Ethics Committee (Review nº 1635/98). The mothers expressed their agreement to participate in the study by providing written consent.

The study subjects were women who experienced the situation of being mother to a disabled child and who agreed to participate in the research. These women had their children enrolled in the project of disabled child care in the Special Patients Clinical Division (SPCD), of the Mato Grosso do Sul Federal University. The mothers were between 21 and 40 years old; their disabled children were between 6 and 17 years old, of which four had cerebral paralyses and one had Down's syndrome.

The reports were collected in January 2000, through non-structured, non-directive individual interviews carried out at the participants' homes. The interviews were conducted by the guiding question: "What does it mean, for you, to have a disabled child?".

Five reports were collected, with which the repetition of the unveiling of the phenomenon was reached. The five reports, numbered from R1 to R5, were fully transcribed, in order to maintain their uniqueness.

After a careful reading of the transcriptions, I tried to become familiar with the mothers' reports as a whole, in a global and intuitive understanding of the way the subject exists in the situation of having a disabled child. This way, I could later emphasize the meaning units (MU) in each of these reports.

The meaning units were described in the researcher's language, searching for convergences and divergences, which were grouped in themes. The themes that emerged pointed to the essential aspects of the phenomenon, leading to the existential understanding of this being-there with a disabled child. Such understanding allowed the identification of categories that, together, express the essence of the subjects' original experiences.

RESULTS

The categories apprehended, derived from the mothers' experiences were: "meeting one's actual infant," "the impact of disability," "treading a new path with one's disabled child," "experiencing maternal altruism in the care of the disabled child," and "altering one's family daily life."

According to the reports, the expectation of the birth of an ideal and desired child's is destroyed by the encounter with the actual infant. This moment is permeated by feelings of sadness, disappointment, inferiority and rage , leading the mother to not understanding the experienced situation and, later, the experience of grief for the loss of the desired child.

The meanings unveiled in the reports regarding the social representations of maternity show that the mothers perceive the child as a way of continuing their own existence and even as a possibility of assigning new meanings to life. However, these representations change when the mother meets the actual infant:

> *"So all that you, the mother, were expecting… was not reached, not accomplished" (R5 MU5).*

Mothers described the feelings and emotions they experienced with the disabled child's birth with great suffering and grief. An abrupt disturbance strikes their emotional balance. They live a unique and non-transferable experience, permeated by crying, loneliness, helplessness and a great anxiety to escape this situation.

Therefore, the mother lives a great emotional and existential conflict, feeling abandoned and powerless to continue living. She wishes to give up the struggle, which, at that moment, feels too painful. She shows herself vulnerable in face of the situation, not being able to grasp the reality of having a disabled child.

The mother feels unhappy, showing feelings of disbelief and hopelessness. Having a disabled child brings great suffering, reported by her as death:

> *"… we feel that…, and the actual feeling of death…" (R5 MU45).*

The mother struggles with her own feelings, opposite and contradictory, first feeling a very strong physical and emotional aversion to the child, which makes it impossible for her to get involved in affection and care, not being able to establish a maternal link and connection with the infant.

Anger appears and reflects toward the child through rejection and dislike. This feeling, however, is also directed to herself, for feeling responsible for generating a disabled child.

The encounter with the actual infant is permeated by feelings of disappointment, leading to a feeling of disconnection to the child. This emotional disconnection and the affective breakage with the child make the mother incapable of taking care of her infant and breastfeed. Thus, she later experiences a feeling of guilt for her actions and for their consequences:

> *"At that moment I could not see her as a child, I could only see her disability, and for this reason, I felt very strong aversion" (R5 MU21).*

Facing this moment puts the mother's emotions and feelings at stake, and, despite experiencing a difficult situation, she wishes to continue being the mother of a disabled child, searching for alternatives of adaptation to this reality in the middle of this turmoil of feelings. She perceives herself as needing to live through a period of grief to be able to overcome the loss of the ideal infant and, by doing so, accept the disabled child.

The feeling of rejection shown by the mother is represented in attitudes of abandonment, overprotection and denial of the disability, configuring a state of fear and anxiety. The attitude of abandonment is characterized by non-investment, either of love, of dedication or child care. The mother reacts to the situation by expressing a right to not desire and not want the disabled child. This feeling is confronted with the guilt and worry of hiding this desire, once she perceives herself as misunderstood by the other people who surround her and, therefore, she often prefers not to show it:

"I think, that it is even a right the mother has of not wanting this child, because people don't understand why you don't like the child, but it is her right not to like it at this moment, because it is not the child she wanted to have…[tears]*" (R5 MU13).*

When confronted with this context of intense emotions, the mother demonstrates the difficulty to love the disabled child and suffers for believing that this feeling is not proper for a mother. She lives a routine of anguish from the disabled child's birth and perceives the possibility of having her suffering diminished in this child's termination. This perception comes filled with the feeling of guilt for not having been able to love the child and for having wished for its termination:

"… she was born with a heart condition… There was a night… that she had some crises and I…, I thought a lot…, who knows, if she died…, then our problems would be over [tears]*… I was feeling very guilty…, I was feeling very…, like a… very bad person…" (R5 MU26)*

The birth of a disabled child had destroyed the dream of the ideal infant and, with it, the woman's expectation to be a mother was completely lost. The non-satisfaction of her desire to have an infant as she had idealized is perceived by her as a hollow area in her being, and a feeling of not having become a mother emerges.

While being-there, the mother is launched in a world of uncertainties and insecurities, which lead her to feel without possibilities of relations with herself and the world she is in.

She faces the impact and the rejection from people regarding the child's disability and suffers with the curiosity manifested by the looks, comments and attitudes in face of her and her child's presence in the different environments she visits. When she notices that society does not accept and does not offer space for the different, the mother adopts the same attitudes found and the imposed standard of normality , reinforcing her own feelings of shame of the child's differences and, thus, preferring not to expose the child publicly.

Family conflicts emerge as a source of concern and angst for the mother, which are experienced due to the difficulty in perceiving the child as a being with possibilities and in accepting its disability. As she goes through this intense suffering, the mother feels lonely and distanced from the real situation and from her family members. This distancing and loneliness makes it difficult for her to become involved in the situation and, consequently, impairs her understanding, or attributing of a meaning in her existence.

She experiences the guilt of having generated a disabled child and of having feelings and attitudes of rejection towards that child. This guilt comes with suffering, for the mother perceives herself as being the only person with feelings of rejection and non-acceptance:

"Many times we, besides having this feeling, [tears] *don't want this child, we blame ourselves a lot too…, thinking that you're the only one who doesn't want it" (D5 US14).*

Following her path in this experience, the mother faces the fact that she does not know and does not have information about her child's disability. The lack of information means not knowing how to act. She perceives in the professional's attitude the lack of involvement and support necessary for her adaptation to the situation and for the adoption of actions regarding child care. For the mother, it is disturbing to find a discrepancy between her own emotional turmoil and the insensibility of the professionals:

"… the doctor didn't come to me, didn't say: your child will have a problem, your child has a problem; he didn't tell me" (D1 US26).

Although the mother searches for sources of support from health care professionals to face this moment and for becoming able to take care of her child with more safety, she does not find any. For the mother, not receiving the necessary information regarding the child's disability means not being seen and respected as a person and, as a human being, not being respected in her feelings. This, in turn, leads to experiencing feelings of disbelief and hopelessness.

The mother looks for some kind of explanation for why this happened to her, worrying about the exact cause for the disability. This fact is frustrating, for it is not always possible to determine the reason for the child's disability:

"I have this, I don't know, as God's test for me, if I will take good care of him…" (R4 MU3).

The mother's affliction and experience bring out the need to look for answers to her questions from the spiritual point of view. In religion, they find the help to be able to understand and, this way, facing and accepting its veracity.

The mother wins over the disability gradually, trying to build the bases of a relationship in which the disability is not the child's existence axis. The mother shows the feeling of love and affection flourished in the overcoming of pain and suffering:

"But it is something we carry with a lot of love, a lot of tenderness. I love my son very much, he is everything to me, you know…" (R1 MU11).

Following the path in this experience, the mother faces the fear and possibility of the beloved child's death and perceives this loss as a failure in her function as a mother, for she would feel robbed in her role as a provider:

"I dread that one day God may take my child… You know, some nights I don't even sleep…" (R1 MU23).

Moved with love and the desire of giving the child the opportunity to develop his or her responsibilities, the mother seeks treatments, rehabilitation, education and returns to religion or belief, among other resources, certain that she is doing what must be done, even if this takes a physical and emotional toll on her.

Considering that other mothers experience a similar situation, or maybe worse, and comparing herself to them, the mother launches herself into living and doing things for the disabled child. She perceives herself as having to adopt the characteristics of the perfect, ideal mother and, for that, she acts towards accepting all the requirements of the outside world, coping with the situations she experiences with resignation.

By doing so, she establishes an affectionate relationship of helpfulness and patience, surrendering to the child's care. These actions, however, reveal the idea, already introjected by the mother, that the child's care is her responsibility, considering herself the main provider of his or her needs. This way, she perceives herself living the experience of being a mother in different and adverse situations, which demand constant mobilization to provide the child and the family with the necessary conditions for acquaintanceship and development.

She experiences a non-authentic way of living with the nurse team, not being able to show her feelings and attitudes towards her experience and suffering.

"The nurse insisted: you have to do it, you will breastfeed this child. So I don't know to which extent it was good or bad, but from then on I was breastfeeding, at least for the first three months, so, I felt really bad". (R5 NU23).

By living the experience of being the mother of a disabled child, one observes the process of maternity and nurturing being built gradually. However, until this process is established, the mother experiences a period of distancing from the child, in order to be able to elaborate and re-organize her feelings:

"Actually, this mother instinct, of maternity, was established around the fifth month and on" (R5 MU30).

In this sense, the mother approaches the child and her feelings flourish, making it possible to develop the affective connection with the child. She, therefore, starts to love and respect the child:

From the moment I had a change in this view and in the feeling, you start to see the child, to waken the feeling and like it, you know?" (R5 MU 43).

Being able to overcome the obstacles that make the involvement difficult and distanced her from the child led the mother to see the possibilities of this child and establish a rich acquaintanceship of emotions and positive feelings.

During her journey, the mother faces herself and her conditions to provide the attention and care that the child needs, developing in practice and in her routine with this child ways and forms to meet his or her needs:

"But it is an experience that we have too…, it is a very big experience…! (R1 MU2).

Feeling confident and safe leads the mother to provide the physical and emotional care of the child in her own way, once she cannot find the support and counseling necessary to develop her tasks:

"… I think there is nothing else to do besides the care that the mother should have, feeding, hygiene, love and affection, you can't even get mad with a child like this, you can't have a fight with the child, she doesn't misbehave…, she doesn't bring you worries, on the very contrary.! (R2 MU13)

The family's ways are transformed with the child's disability, initially showing vulnerability to everyday activities and, in other moments, re-organizing themselves and showing a disposition based on what is to come. The mother feels the need of family support and the attitude of listening as emotional and practical support for her acquaintanceship and care with the disabled child:

"These situations, most of the times, we don't have this exchange with others. With the doctors…, I would go, talk, I went to a lot of appointments with the pediatrician, but not because she asked, more because I decided to" (R5 MU38).

For the mother, the father's participation and involvement in child care is a fundamental factor for her emotional balance. Complicity from the father provides her with confidence and calmness, and makes her feel supported and understood. This attitude is perceived as complicity and absolution of a probable feeling of guilt. She feels that she can share the experience and make joint decisions regarding the child. She perceives the father as a partner, and his companionship configures a possibility of winning the conflicts. Thus, she foresees a future for the family:

"From the moment that the father has the same love and affection for the child, it gets easier, it easier for two people to win a battle together than alone" (R2 MU18).

The mother sees herself in face of the need to leave her job to meet the demands of the disabled child's care, and due to the initial difficulty in dealing with the feelings and conflicts. She feels incapable of leading a life as the one she had before her child arrived, and, therefore, she launches herself to the demands imposed by the situation experienced in the family and regarding the child's care:

"… I couldn't lead a normal… life as I did before… I worked two shifts, but I stopped working…" (R5 MU35).

When living with the disabled child, the family discovers that there are no formulas or specific ways for the relationship with him or her, unless that it is necessary to be patient, strong, persistent and affectionate. Through the daily routines with the child, the family members discover new ways, learning in the self-discoveries a way to live together as a family. Hence, the acceptance of the family members is reached by allowing themselves the dignity of experiencing and expressing strengths and personal limitations, respecting themselves and their individual potentials.

The mother understands that the emotional situation generated by the child's disability also affects the closest family members and that such experience cooperates with the family union, which mobilizes itself towards helping to provide care. The mother perceives this fact as a facilitating integration attitude toward the disabled child in the family unit:

"Then it involves a very big process, you having a disabled child in your home. It involves the family, it involves the grandmother, it involves maternal and paternal grandparents" (R3 MU3).

As the mother overcomes the obstacles that emerge with the disability of the child, sadness and grief are replaced with the feeling of joy and happiness. She intensely lives the successes for her personal and family achievements and growth. The mother perceives in this child the lever for the continuous accomplishments of her being:

"But there is also another side… we live like this… a world of…, of much joy too…, of much success…" (R5 MU49).

The mother understands that her alternatives are possibilities that lie within, and she needs to fragment old concepts to be able to find these possibilities, recognize them, and put them into practice. This way, she allows the new possibilities of being-there-with-the-disabled-child to flow and emerge.

DISCUSSION

The impact of the child's disability showed to be a painful and conflicting process for the mother, who sees herself unprepared to face or deal with this way of being a mother. She still experiences the feeling of guilt for having generated a disabled child and for having the inherent emotions and feelings.

For the mother, having a disabled child represented the failure to meet her expectations towards maternity. Thus, she faces the need to change her role as a mother and with the non-continuity of the family, whose history was modified by the child's disability.

She shows pain, sadness and angst in her speech, which often push her away from family members and from her own child, in an attitude of non-attachment and rejection, which Heidegger also considers a form of concern.

The mother also unveiled herself through feelings of disbelief and helplessness when facing the inability to change the situation. She experiences a time of uncertainty, of feelings of angst and fear in face of the threat perceived in the child's impossibilities, questioning herself about the reason why this happened. The family life suffers great changes in view of the emotional demands and the acquaintanceship with the disabled child, bringing about conflicts.

CONCLUSIONS

According to my practice with the mothers and the families of disabled children, I notice the vulnerability of the family in this experience. If the family does not receive proper care, and, if we are indifferent to their feelings and needs, they tend not to collaborate with child care, and the search for possibilities to establish a relationship with the child will happen belatedly.

The failure to establish a bond between the health care professional and the family members, in cases of disability diagnoses, will affect the posterior family attitudes towards the disabled child, her interaction with the family and the adaptations to come(8).

The unveiled meaning showed that the family needs help to rebuild the goals and objectives and to deal with the feelings that arise in the routine of family experiences with the disabled child. It is necessary to understand that, as for the mother and the family, the disability also generates conflicting feelings for the health care team, who experiences feelings of defeat and of not knowing what to do or how to act.

The nurses' actions also depend on their personal disposition to conduce themselves through the ways of understanding the situation these families experience. It is possible that we fail to consider that, although painful, depressing, and suffering, working with families who experience this situation constitutes an aspect of nursing care(9).

The knowledge of emotional reactions that these mothers experience and the effects that the child's disability has on the family favors nurses to focus his or her attention on the family in which this child is inserted.

Providing care to a family in such a confusing moment requires an environment where everyone can express their fears, difficulties and conflicts. This should be a space where they feel they are respected in their truest feelings and their rhythm of adaptation to this new reality of being-family-with-a-disabled-child.

The nurse is a professional who takes care of human beings and interacts with him or her. Therefore, it is urgent that we consider the family who experiences having a disabled child as an object of our care. By understanding the way this family lives, we can see different and individualized ways of providing them with care and attend to their needs.

This fact requires further studies to develop intervention strategies in order to equip the nurse for providing family care.

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