

Mothers of experiences in diabetic child^a

Vivências de mães de crianças diabéticas

Experiencias de madres de niños diabéticos

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ABSTRACT

Objective: To evaluate the experience of mothers of children with *diabetes mellitus* type 1 (DM1). **Methods:** This qualitative study evaluated five mothers of children with DM1 treated at the clinic of a public hospital in October 2014. The data were analysed considering Humanistic Nursing Theory. **Results:** The following topics emerged: the behaviour of the mothers after their children were diagnosed with DM1; maternal care as a self-giving relationship (an I-You relationship); the difficulties faced by mothers in caring for children with DM1; the conflictual coexistence between children with DM1 and their mothers; the mothers' receipt of support from the family and the multi-professional team (a We relationship); and the behaviour of the mothers in the face of the fear of death. **Conclusion:** In the I-You relationship established between the researcher and the mothers, we observed that the care that they provide to their children is full of engagement, love, sensitivity, and accountability, despite the difficulties and conflicts faced.

Keywords: Children; Mothers; *Diabetes Mellitus* Type 1; Nursing.

RESUMO

Objetivo: Compreender a vivência de mães de crianças com *diabetes mellitus* tipo 1. **Métodos:** Pesquisa qualitativa, realizada com cinco mães de crianças diabéticas atendidas no ambulatório de um hospital público em outubro de 2014. Os dados foram analisados à luz da Teoria Humanística de Enfermagem. **Resultados:** Emergiram as seguintes temáticas: As mães diante do diagnóstico de *diabetes mellitus* tipo 1; O cuidado materno como relação de doação (a *relação EU-TU*); Dificuldades enfrentadas pelas mães ao cuidarem da criança diabética; Convivência conflituosa entre as crianças diabéticas e suas mães; As mães recebem o apoio da família e da equipe multiprofissional (a *relação NÓS*); As mães diante do medo da morte. **Conclusão:** Na vivência da *relação EU-TU* estabelecida entre a pesquisadora e as mães, é possível perceber que o cuidado que elas dispõem aos seus filhos é repleto de envolvimento, de amor, de sensibilidade e de responsabilização com o outro, apesar das dificuldades e dos conflitos vivenciados diuturnamente.

Palavras-chave: Criança; Mães; *Diabetes Mellitus* tipo 1; Enfermagem.

RESUMEN

Objetivo: Conocer la experiencia de las madres de niños con *diabetes mellitus* tipo 1. **Métodos:** La investigación cualitativa entre los cinco madres de niños diabéticos tratados en la clínica de un hospital público en octubre de 2014. Los datos fueron analizados a la luz de la teoría humanística de enfermería. **Resultados:** Emergiendo los siguientes temas: las madres antes del diagnóstico de la *diabetes mellitus* tipo 1; Cuidados maternos como dar a la relación (la *relación YO-TU*); Las dificultades que enfrentan las madres en el cuidado del niño diabético; convivencia conflictiva entre los niños y sus madres diabéticas; Las madres reciben apoyo de la familia y el equipo multiprofesional (la *relación NOSOTROS*); Las madres en el miedo a la muerte. **Conclusión:** En la experiencia de la *relación YO-TU* establecida entre el investigador y las madres se puede ver que el cuidado de ellos con sus hijos está lleno de compromiso, amor, la sensibilidad y la rendición de cuentas el uno al otro, a pesar de las dificultades y conflictos diuturnamente experimentados.

Palabras clave: Niño; Madres; *Diabetes mellitus* tipo 1; Enfermería.

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INTRODUCTION

Among the chronic diseases that affect children, *diabetes mellitus* type 1 (DM1) is the most common. Considering its incidence and complications, it is considered a serious public health problem worldwide.¹

The treatment of DM1 greatly affects the condition of children and their families by requiring changes in eating habits and rigorous care to maintain glycaemic control, which is done using painful procedures, including the measurement of glucose levels and insulin therapy.¹

Caring for children with DM1 is typically the role of the mother, who must pay special attention to the promotion of good eating habits, stimulate physical activity, control blood sugar levels, make frequent visits to physicians and, sometimes, long hospital stays, and offer emotional support to the child. Therefore, the mother lives almost entirely to meet the needs of the affected child.² In addition, when DM1 is diagnosed in early childhood, glycaemic control is a source of anxiety for the child, who, depending on the age, has a limited understanding of the need for painful procedures and, for this reason, in some circumstances, feels punished by the mother for something that he or she has done.

According to Piaget's theory, children of preschool age (aged three to six years) have the "magical thinking", i.e., they believe that everything that occurs is the result of their thinking. This phenomenon exposes them to a vulnerable situation in the face of events, particularly when a bad event occurs and coincides with their thinking. Therefore, because of the inability to think logically, a disease or injury event can lead these children to believe that they are being punished for something that they did or thought.³

For the mother, the condition of primary caregiver is full of meaning, which often goes unnoticed by the multidisciplinary team, whose attention is typically focused on the treatment of the child and who forgets that the relationship established between the mother and the child in the process of care directly intervenes in the health condition of the child.^{4,5} Therefore, the multidisciplinary team should support the child and his or her family, particularly the mother as the primary caregiver, and adopt an understanding, respectful, and participatory attitude by being at the disposal of mothers and understanding their experiences, which are imbued with meaning, as well as encouraging them to reflect upon their experiences.⁶

Understanding the mother's experience in the care of children with DM1 is an opportunity to improve relationships within the family and helps the multidisciplinary team increase its awareness of care and the factors that are involved in it. In addition, this understanding strengthens the care relationship between the child, the family, and the professional team, with the aim of promoting the development of an individual treatment plan that thoroughly meets the needs of children with DM1. In this context, this study considers the following topic: How do mothers of children with DM1 experience the care relationship? For this purpose, Paterson and Zderad's⁷ Humanistic Nursing Theory

is chosen as a theoretical reference because it can support the assumptions of the proposed study by addressing the existential experience of human knowledge and the relationship between the caregiver and the care recipient.⁷ Therefore, the aim of this study is to understand the experience of mothers of children with DM1 in light of Peterson and Zderad's Humanistic Nursing Theory.

This theory was proposed by the nurses Paterson and Zderad, who, in the 1960s, began working with hospital nurses to reflect on, explore, and inquire into their experiences in the field of nursing. This work allowed them to value the significance of these experiences in human existence and begin developing studies for the construction of Humanistic Theory, which was published in 1976. This theory is based on the existentialist approach (a philosophy based on phenomenological studies of reality and the analysis of human existence), with a phenomenological (the descriptive study of phenomena) focus, respecting the nurse-patient relationship. The humanistic approach of the theory proposes that nursing goes beyond the promotion of the well-being of the patient and that nurses should maintain an inter-subjective relationship with patients to enhance the human potential.⁸

For these two theorists,^{7,8} the interest of nursing "does not focus solely on the well-being of individuals but in their fullest existence, to help them be the most humane individuals possible at a particular time of their lives".

METHODS

The study was developed considering Humanistic Nursing Theory⁷ and followed the steps proposed by Phenomenological Nursing.

Humanistic Nursing Theory is the experience that exists in the I-You relationship, experienced by the researcher and the mother or by the mother and children with DM1 in the care relationship. In this sense, "the You relationship is immediate. The I-You relationship should not involve any dogmas, gimmicks, or fantasies [...]. Every means is an obstacle. The relationship occurs only to the extent that all means are abolished. Considering the immediacy of the relationship, all means become meaningless".^{9,3} The We relationship involves the relationship between the mother, the family, and the multidisciplinary team towards a common goal.

This study was guided by the five steps of Phenomenological Nursing: 1. the preparation of the nurse to come to know; 2. the nurse intuitively knows the other; 3. the nurse scientifically knows the other; 4. the nurse complementarily synthesizes the known realities; and 5. the succession within the nurse from the many to the paradoxical one.

The first step - the preparation of the nurse to come to know - suggests a condition of enquiry, in which "the researcher should be aware of her own perspectives and be willing to share them [...]". This process is painful and continuous because of the inner struggle experienced by the nurse, who starts to compare her own values with the values of the patient, which

allows her to appreciate and give meaning to the experience of investigation.^{7:119} These two theorists recommend that the nurses be prepared for this knowledge via reflective readings of literary studies in the areas of human nature, human behaviour, and their relationship with the world and establish correlations between these areas and their practice. In this context, the researcher seeks to reflect on herself, her condition in the world, and her relationship with the Other by reading the Holy Bible,¹⁰ which led her to reflect on the infinite love of God, which is available for a humanity that is full of differences. Studies on phenomenological and humanistic aspects (including Phenomenology of social relations and humanistic theory;⁹ Care: the ethics of human compassion for the Earth;¹¹ The care process, the ways of being of humans and health practices;¹² Care from the perspective of Leonardo Boff, a personality to be (re-)discovered in nursing;¹³ Alterity as a criterion for care and the education of mothers who breastfeed: philosophical reflections of practice;¹⁴ Ethics, alterity, and health: care as solidary compassion;¹⁵ and Humanization in health care: a reflective theoretical essay based on the philosophy of Emmanuel Lévinas¹⁶ also allowed the researchers to reflect on the alterity of the Other and their role as caregiver.

The second step - the nurse intuitively knows the other - involves the knowledge of the other via the I-You relationship, when the nurse sees the world through the eyes of the patient and, for this purpose, should seek to live at the pace of the individual, allowing her to obtain the intuitive and inexpressible knowledge of the other. In this relationship, the nurse does not control the patients but considers them to be equal, respects their uniqueness and their ability to inquire about situations, and truly assists them. The decisions involved in this relationship belong only to the nurse. In this research, given that the sample investigated was known by the nurse, this phase was already being developed during the nursing visits of children with DM1 and the families.

In the third step - the nurse scientifically knows the other - the nurse reviews the knowledge about herself and the other and reflects on it, trying to synthesize, analyse, and interpret this knowledge and relate it to her previous experience in the scope of nursing. According to these theorists,⁷ "the intuitive and scientific knowledge of nursing in relation to the patient can occur simultaneously". Considering that the nurse already provided care for this group, the second and third stages were developed simultaneously.

The fourth stage - the nurse complementarily synthesizes the known realities - suggests the comparison and synthesis of the realities known by the nurse. To that end, the nurse must place herself as the object of her own knowledge and combine the known realities, interpreting, selecting, and classifying them: "[...] the differences discovered in similar realities do not compete, do not deny the other realities. Each reality can be simultaneously true and be present".^{7:123-4} Therefore, at this stage, the nurse compared and summarized the similarities and differences of the collected data to obtain a broader view.

In the fifth stage - the succession within the nurse from the many to the paradoxical one - the nurse reviews her pre-established knowledge and expands it using the knowledge that she acquires about herself and others. This new view is constructed by reflecting and analysing the many perspectives acquired during the investigation phase, in which the knowledge reflects the views of most individuals or of everyone. At this stage, the researcher seeks to reflect on the mothers' dialogues about their experience in caring for children with DM1, analysing and synthesizing them to obtain the opinion of the majority. The acquisition of this knowledge as a result of the nursing experience promotes the scientific knowledge beyond the conventional process because it helps understand the individual in the world.

The scenario of the research was the Endocrinology Clinic of a public hospital in João Pessoa, state of Paraíba, Brazil, and the study participants were five mothers who met the following inclusion criteria: being mothers with children with DM1 and who regularly attended the outpatient endocrinology service over the past year. The exclusion criteria were being mothers who did not have the cognitive ability to answer the research question.

The data were collected in October 2014 using a semi-structured interview, recorded in MP4 format, with the following question: how do you experience the care provided to your child with diabetes? These data were transcribed for analysis. There was a single meeting with the mothers; however, before the interview, the researcher talked informally with each mother, attempting to put them at ease, and then invited them to participate in the study, informing them of the purpose, benefits, and risks of the study and the freedom to discontinue the study without any harm to the mother and child. Anonymity was guaranteed by identifying each mother with names of flowers. The criterion for the termination of data collection was saturation.

The project was approved by the Research Ethics Committee (under CAAE No. 26923914.2.0000.5179), and the informed consent form was signed by the participants. The data were collected using an unstructured interview that was subsequently transcribed. For the data collection and analysis, the steps proposed by Phenomenological Nursing were followed.

RESULTS AND DISCUSSION

The participating mothers have cared for their children with DM1 for a period of three and six years. Rosa is 28 years old, and her child is 5 years old; DM1 was diagnosed when the child was aged 1 year and 6 months. Amaryllis, 25 years old, has a 7-year-old child whose disease was diagnosed at age 4. Begonia, 31 years old, has a 9-year-old child who was diagnosed at age 3. Lily, 27 years old, has a 7-year-old child who was diagnosed at age 2. Finally, Jasmine, 31 years old, has a 9-year-old child who was diagnosed at age 3.

The relationship of mothers with their diabetic children was based on the I-You relationship, which involves direct reciprocity and dynamic and continuous discussions.⁷ In this relationship, the

following themes emerged from the researcher's understanding of the care relationship: the behaviour of the mothers after their children were diagnosed with DM1; maternal care as a self-giving relationship (an I-You relationship); the difficulties faced by mothers in caring for children with DM1; the conflictual coexistence between children with DM1 and their mothers; the mothers' receipt of support from the family and the multi-professional team (a We relationship); and the behaviour of the mothers in the face of the fear of death.

The experience of mothers after their children were diagnosed with DM1

In the I-You relationship established between the researcher and mothers, it is possible to perceive the pain of the mothers upon receipt of the news of the diagnosis of DM1 in the child. The dream of having a healthy child collapsed and was replaced by the sadness of having a child with DM1. Living with DM1 was reported by one mother as a life of suffering, primarily because the diagnosis was presented in early childhood.

I was very sad, devastated, because I did not accept that my daughter had an incurable disease. I was desperate. (Rose)

I felt bad, very bad, because she was very young and I knew how much she was going to suffer, especially during the application of insulin. I cried a lot. (Amaryllis)

I was very sad because no mother wants her child to have an incurable disease such as this. (Begonia)

The sadness reported by the mothers and the despair described by one of them are experienced because the dream of having a healthy child with a promising future was shattered, in addition to the prospect of having a life full of pain and the uncertainty about the future. This is justified because the news of the child's illness is shocking, an unpleasant and frightening surprise for the entire family because the diagnosis leads to anxiety, uncertainty, anger, despair, and sadness about having a child with an incurable disease who needs treatment and follow-up by a multidisciplinary team.¹⁷

Maternal care as a self-giving relationship (I-You relationship)

The I-You relationship is constantly present in the care of children with DM1 by the mother. In this relationship, self-giving is the most significant construct because it is an attitude of support for promoting the welfare of the other. A deep and genuine interest permeates this relationship, and *being with* and *caring about* attitudes are evident when the mother is available to care for the needs of the child.

I have to pay close attention to my child's eating habits, insulin application, and I do not go to parties to avoid eating sweets. (Rose)

Special attention should be paid to giving the medication at the right time and avoiding the consumption of sugar. My routine has changed completely. At present, I do not work, I live only to take care of my son and my husband (who is also diabetic). (Begonia)

I have no time for other things because I need to take care of the child, constantly visit the doctor and school, and accompany her to the hospital when necessary. (Lily)

We need to pay special attention to everything, including our eating habits; we try to eat pretty much the same things as her; we rarely go to parties, the monthly shopping has also changed, and we do all we can to prevent her from feeling excluded from our lives. (Jasmine)

Faced with a chronically ill child, the family routine changes significantly, including the interruption of everyday activities and incorporation of other activities to meet the needs of the child; these include medical consultations, prolonged hospitalization, examinations, the administration of drugs, and other direct care activities. In addition, the family frequently finds it difficult to understand the diagnosis and the financial instability.¹⁸ This adaptive process can affect the family's quality of life.¹⁹

In addition, caring for a child with a chronic condition goes beyond meeting his or her physical needs. Love and affection are essential to demonstrate how important the child is to the family.²⁰ In families of children with chronic illness, the mother typically leads the care activities, which demands a considerable amount of work.²¹ Because the direct care activities make the mother realize that the child has a limited understanding of the condition, the mother tries to ease this tension with dialogue and affection.

The dedication and physical and emotional commitment of a caring mother, arising from an exhausting routine in which her own needs become secondary, in a relationship of total devotion to the sick child, typically impair the mother's health, and she experiences great psychological suffering, which often limits the accomplishment of other activities. Therefore, the welfare of the entire family is affected.^{22,23}

The difficulties faced by mothers in caring for children with DM1

In the I-You relationship experienced between the researcher and mothers, it was possible to understand the difficulties faced by the mothers in taking care of children with DM1, as demonstrated by these speeches:

[...] to apply insulin, make the routine follow-up, deprive my child of normal things such as chocolate caramel balls, the purchase of materials for insulin application when they are not available in the health centres, in addition to her diet. (Rose)

[...] to control blood sugar, diet, monitor physical activity, routine medical follow-up care at school. (Amaryllis)

It is very exhausting because I live far from the city to go to the doctor, go shopping, and purchase insulin and the materials for insulin application. In addition to the distance, the cost of all this is too high. (Begonia)

I need to control his diet when he leaves home because he wants to eat sweets and snacks at school, which he should not eat, and make sure he eats at the right time. I also find that the food he needs is expensive; sometimes, I have difficulty buying it. (Lily)

The routine of constantly visiting the doctor and taking daily injections is very tiring and sad because I know that she suffers a lot. (Jasmine)

The mothers reported the many difficulties that they face as caregivers of children with DM1, particularly having to maintain a diet low in sugars and lipids, in addition to glycaemic control, which is performed by blood glucose monitoring and insulin application. For the mothers, it is difficult to assimilate these new techniques and incorporate them into the new routine, primarily because of the young age of the children, which makes them very dependent on the mothers. Other problems such as the cost of dietary food and the materials used to measure glucose levels were also reported by the mothers.

Studies^{24,25} conducted with parents of children with DM1 have shown that families can be affected by professional, financial, and social factors because of the parents' work overload, which requires them to modify the social and family routine to meet the demands of caring for children with DM1. In addition to the daily care, the mothers in this study reported an exhausting routine of having frequent medical appointments and hospitalizations as well as purchasing materials for blood glucose measurement, insulin therapy, and dietary products.

The Unified Health System (*Sistema Único de Saúde - SUS*) restricts the specialized care of individuals with DM1 to large health centres, which limits public access to these services because not all of the smaller cities have ambulances to transport families to the major centres. For this reason, they need to afford these expenses. In addition, the materials used for insulin therapy (needles, syringes, and insulin) and blood glucose measurement (the measurement instrument and tape) are not always provided by local governments, and families are forced to resort to public prosecution (Public Ministry) to be entitled to these materials. However, until the determination of the prosecutor, the families are responsible for the costs. This exhausting condition triggers conflicts and financial instability in the family and directly interferes with the control of blood sugar in the child.

The conflictual coexistence between children with DM1 and their mothers

In the I-You relationship experienced between the researcher and mothers, it was possible to understand the daily struggle of the family, which involves feelings not only of love and affection

but also of sadness and anguish on the part of the mother and the children with DM1.

She is still too young, she does not understand everything that happens on a daily basis. Sometimes, she cries because she does not want to take her insulin or wants sweets. I'm devastated, but I talk to her, give affection, invent things so that she does not suffer so much. It is lovely. It's not easy for me. (Rose)

I try to be strong, especially in front of my son. I do not let him perceive that I suffer from all this so he does not feel guilty. Although he is a child, he already understands. I try to have a peaceful and caring coexistence in order to compensate for other things that were taken from him. I really want to see my son become a successful adult. (Begonia)

It is very difficult because, sometimes, his disobedience stresses me, and he goes over the top, especially when measuring blood sugar and eating on time. When I complain, he says I do not like him because he is ill and that I only like the other children. I become angry because I think I have more feelings for him, considering the greater care and attention provided to him compared to the attention given to the other children. (Lily)

[...] I try to talk a lot with her, although she often gets upset and says she will not take insulin, that she is tired of needles, and this makes me devastated because I want to see my daughter well. I try to understand her small world because I know she is only a child. (Jasmine)

The I-You relationship experienced between the mother and children with DM1 is sometimes confrontational because the children do not understand their condition and the determination of the mother to maintain adequate glycaemic control, and it can generate anger and sadness in the child and distress in the mother.

A previous study²⁴ also notes that conflicts between children with DM1 and their mothers are common and that the younger the child, the greater the incidence of conflicts. This may be because children do not understand their condition and therefore feel that glucose measurement and insulin therapy are a punishment for something that they have done.³

The mothers' receipt of support from the family and multidisciplinary team during childcare (the We relationship)

The mothers reported receiving support from the family and the multidisciplinary team in the care of children with DM1.

My husband and my mother help me in everything. (Rose)

My husband and my family help me. (Amaryllis)

I share the care responsibilities with my husband and the whole family. All of them help us a lot. (Jasmine)

The grandfather also cares, and he is already a little too grown up, he helps me remember things. Now, I feel more relaxed because I know how to administer insulin, the diabetes is under control, and the doctor informed me about the disease "[...]" (Lily)

The family was reported to be a source of support in child care; however, one mother reported that the activity of the multi-professional team, particularly the physician, was poor. The support of the medical team, by providing technical assistance and encouragement for changes in behaviour, is essential for properly managing the disease and providing care. It is imperative that in the child care, the mothers feel encouraged by the family and the multidisciplinary team. With the guidance of professionals and the sharing of responsibilities with the family, the mothers can perform their duties with more reassurance and ease, which helps improve the interaction between the mother and the child and promotes the success of therapy.

The chronic condition of the child enhances the relationship between the family and the health care team in the search for resources to meet the demands that are imposed by the disease. The need for child care using the health network and other resources is on-going, particularly for those in situations of vulnerability.¹⁶ The relationship between the parties is the We relationship, which occurs among the mother, the family, and the multidisciplinary team in the search for the same goal, the well-being of the child.

In a study with parents of children with DM1, family and friends were noted as being important sources of support, although African-American and Hispanic low-income parents did not receive any professional or social support.²⁶ The participation of the family and the multidisciplinary team in the care of children with DM1 is essential for the mother because she feels encouraged during an exhausting routine. Happy mothers take better care of their children. With this collaboration, she can be stimulated to promote the well-being of the child and to develop the human potential in them.

Parents who feel stressed because of the chronic condition of the child are unable to provide the support that is necessary to maintain the metabolic control of the child. The reverse is also true.²⁷ In this sense, the multidisciplinary team must focus its care on the family because the family cares for the child on a daily basis; therefore, the family must be supported to manage DM1 with a minimal impact.²⁸

The relationship between the mother and the multidisciplinary team should involve support, trust, and safety, which are reflected in the multidisciplinary team's recognition of the mother's care for the child. Therefore, the team should clarify and guide the mother on the child's health condition, valuing the mother's achievements and involving her in the therapeutic plan because this type of relationship helps manage conflicts.²⁹

Mothers in the face of fear of death

In the I-You relationship established with the researcher, the mothers expressed their helplessness regarding the severity of the disease and the fear of death.

All this affects me a lot, to see my daughter very sick and being unable to do anything. I often think that she is alive by a miracle. I am convinced of that because the blood glucose levels reached 600, and the doctor said he could not do anything. (Amaryllis)

I'm afraid this unfortunate disease will kill my son and my husband. (Begonia)

The daily care makes mothers fear the loss and end of a relationship based on love, affection, and devotion established between them and the affected children in the I-You relationship. They feel powerless and suffer from the possibility of being separated from their beloved children. In this situation, the multidisciplinary team should support them through attentive listening, touching, and sharing information to ensure their well-being and to overcome this condition.

A study²⁹ reports that mothers of children and adolescents with DM1 have a multifaceted stress condition associated with the daily care of the child, the management of chronic diseases, the level of responsibility, commitment to the care provided to children with DM1, and the fear of losing them in cases of extremely high glucose levels.

The multidisciplinary team that provides assistance to children and their families should acknowledge that the adjustment to diabetes therapy is a dynamic and on-going process. In different stages, families begin to have new demands, and for this reason, they must be induced to incorporate these requirements and consider their new psychosocial contexts.³⁰

When the I-You relationship occurs between caring mothers and the multidisciplinary team, each, in their own way, is open to the way of being of the other to care for their needs. In this interaction, professional practice suffers a relational change between those who offer or provide care and those who receive care, and this relationship is permeated with commitment and solidarity, which are necessary to establish bonding in comprehensive care.²¹

CONCLUSIONS AND PRACTICAL IMPLICATIONS

In the I-You relationship established between the researcher and the mothers, it was observed that the mothers' care for their children is full of engagement, love, sensitivity, accountability, and self-giving. The care occurs on a daily basis in response to the needs of children with DM1, who express themselves by crying, being angry, and being silent. In this relationship, conflicts are experienced by mothers and their children because of the need to restrict the diet and to perform painful procedures daily, which the child does not accept because of his or her lack of maturity.

The We relationship is present when mothers request the support for child care from family members and those who have become part of their coexistence (the multidisciplinary team), which connects to ensuring the well-being of children with DM1 via shared care.

This study indicates the importance of the uniqueness of the relationship between the mother and children with DM1. This relationship is full of not only love and self-giving but also conflicts that are experienced on a daily basis owing to the difficulties developed from the lack of materials and financial resources necessary for quality care.

Therefore, the care provided to children with DM1 and their families must ensure well-being and health, with a view to understanding the children in their singularities and to involving them in building an individual treatment plan that encourages them as citizens and rights holders.

In this process, the activities of the multidisciplinary team that cares for children with DM1 and their families were not very evident. This result indicates that further studies are necessary to promote the debate over the involvement of the multidisciplinary team in the care of children with DM1.

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