PATERNAL PARTICIPATION IN CARING FOR THE CHILD WITH DOWN SYNDROME

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ABSTRACT

Objective: to understand the paternal involvement in caring for the child with Down Syndrome. Method: it is a descriptive and exploratory study, with a qualitative approach, conducted with eight fathers between August and September 2011, through semi-structured interviews, recorded and transcribed. For information analysis, we followed in the steps of thematic analysis: sorting, grading and the analysis itself. The research project was approved by the Ethics Research Committee of the University Center of João Pessoa, under the protocol number 039/2011. Results: the fathers expressed feelings of loss by idealized child who later becomes conformism and fighting for evolution and inclusion of it. The mother assumes the role of primary caregiver and the care from the father related to the son is optional. Conclusion: the involvement of the father in the care for the son is limited and it is resulting from the cultural distribution of roles. The care is considered the domain of women, while the parent retains the role of family subsistence and playmate.

Descriptors: Down Syndrome; Fatherhood; Care;

RESUMO


Descriptors: Síndrome de Down; Paternidade; Cuidado;

ORIGINAL ARTICLE

PATERNAL PARTICIPATION NO CUIDADO AL NIÑO CON SÍNDROME DE DOWN

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RESUMO

Objetivo: compreender o envolvimento paterno no cuidado al niño con síndrome de Down. Método: estudio exploratorio-descriptivo con enfoque cualitativo realizado con ocho padres entre agosto y septiembre de 2011 por medio de entrevista semiestructurada, grabada y transcrita. Para el análisis de las informaciones fueron seguidos los pasos del análisis temático: organización, clasificación y análisis propiamente dicho. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación del Centro Universitario de João Pessoa, protocolo 039/2011. Resultados: los padres expresaron sentimiento de pérdida del hijo idealizado que posteriormente se transforma en conformismo y lucha por la evolución e inclusión del mismo. La madre asume el papel de cuidador primario y el cuidado del padre en relación al hijo es facultativo. Conclusión: la participación del padre en el cuidado al niño es limitado por la distribución cultural de papeles. El cuidado es considerado domínio de la mujer, mientras que al padre se le reserva la subsistencia familiar y el papel de compañero de juegos.

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INTRODUCTION

The Down Syndrome (DS) also known as trisomy of chromosome 21 was discovered by the English doctor John Langdon Down, who correlated it to the fact that children have an extra chromosome due to a failure in the process of cell division. The incidence of DS in Brazil is around 1 in every 650 to 700 births, and it is estimated to be about 100 thousand people affected. It should be noted a notable and distinctive set of phenotypic characteristics, being associated with mental retardation, and also to the delay of child’s motor developmental.2

Both the treatment and survival progressed remarkably over the decades due to the improvement of care provided to them, whether in the educational, multidisciplinary, family members and others ambit.3 The caring of children with DS has many repercussions due to several commitments experienced by parents. Therefore, the healthcare team must have their actions to inform, provide clearings, as well as encourage links with the child and its family, contributing to the therapeutic process and the life quality of them both.3

The birth of a child is a major event in the life of a family, requiring changings and restructuring of roles, especially from the parents, to receive a new member.4 The difficulty of acceptance with the impact of the new on the arrival of a child with pediatric dysfunctions always leaves deep marks on families, especially among parents. Commonly, five sequential stages are experienced by parents of children with disabilities: 1) impact, 2) denial, 3) mourning, 4) external focus (placing the child in an environment that is not its home), and 5) closure. Not all families experience the last two states and members of the family there is wide variation regarding the time they need to make progress in these types of stages.5 Thus, the acceptance of a child with Down Syndrome is a process of high vulnerability and emotional adjustment that takes time. The adverse reactions are varied and depend on the history of each family, their physical, social and emotional resources.6

The bond between mother and child is the more existing solid relationship between human beings, and this is due to the uniqueness of the pregnancy period and the childbirth.7 Regarding the father, it is observed his important role in the psycho-affective development of children, going beyond the role of provider and maintainer of the family, by means of its affection and its behavior, being a reference in building the personality of the children and the first transmitter of social authority.4

When birth a child with disability, men in the exercise of parenthood, mostly, consciously or unconsciously reject it, as well as they may reject their wives (mothers). Fathers idealize their children, think they could be healthy, and not consider the possibility that they were born with some type of malformation.8

In paternal figure one can find the safety of home, the provision of family, its maintenance, the authority that brings respect, besides being responsible for the social factor, one that interacts with a child with special need through jokes that stimulate its better learning and, along the mother, can give care and attention to the child to develop adequately in society.9

The paternal involvement can be seen from three components: interaction, accessibility and accountability. The interaction is understood as direct contact from the father with the child, through care and activities shared and developed, whereas accessibility is the presence and availability of the father to the child, happening or not the direct interaction between them; and the accountability refers to the role that the father plays in caring for the child, such as when selecting nannies, making appointments, afford the financial costs, determine whether the child needs new clothes, that is to say, reduce the chances of raising a child outside a partnership with the child’s mother.4

In view of deepen knowledge about the experience of fatherhood before the care for a child with DS, this study has like objective:

- Understand paternal involvement in care for the child with Down Syndrome.

METHOD

This is a qualitative study that was conducted with eight fathers of children diagnosed with Down Syndrome, who were assisted in a Reference Center for treatment of children with disabilities. These fathers were selected randomly between the months of August and September 2011. The established inclusion criteria were: father who resided in the city of João Pessoa (PB), Brazil, and that could routinely accompany the child to the Activity Center. The exclusion criteria were: fathers with a kind of mental disability or problems with communication.

The technique of data collection was a semi-structured interview, which was
recorded after permission of the subjects, in order to capture the speech in its entirety to represent the context of the father in the care of children with Down Syndrome. The guiding questions of the research were: “How do you care for this child with Down syndrome?” and “What are the advantages and / or difficulties you face in caring for your child with DS?”.

The criterion for termination of the data collection was saturation and the data were analyzed based on the principles of thematic interpretation according to the following steps: sorting, grading and final analysis. From the transcription of the interviews, we proceeded to the carefully reading of the material, in order to organize the statements in the given order. Later, we reassembled the themes found, in order to build the core of meaning for the final analysis.

The subjects were informed about the purpose of the study, assuring them the right of not participating in it, with regard to the anonymity, including the publishing of data. All participants signed a Free and Informed Consent Form and received a copy with the signature of the responsible researchers.

In the presentation of the results, we used the letter “P” (Pai - Father in Portuguese) to identify the caregiver, followed by Arabic numerals that represent the sequence of the interviews.

The research project was submitted to the Ethics Research Committee of the University Center of João Pessoa / Unipê, obtaining a favorable opinion under the protocol number 039/2011.

RESULTS AND DISCUSSION

♦ Repercussion of the diagnosis of Down Syndrome for the father

The notice on the diagnosis of a child with malformation or other type of pediatric dysfunction triggers in parents several kinds of feelings. Initially, it is experienced a process of mourning, sadness, pain, worries and, even, the surprise by the diagnosis of the syndrome. Parents experience a sense of initial loss regarding the idealized child, which soon after becomes conformity for that there might be a future acceptance of the child. With this, parents blame themselves for not being prepared for such a situation.

Well, it was a surprise not very good at the beginning, so it was, actually, a shock. We did not believe it at first [...] (P1).

It was very painful [...] (Cried) [...] I just got in collapse, I just got in collapse, I cried too much, so I had to comply myself [...] (P8).

The joy from the birth of a child tends to change when it is a child with disability. Faced with the unexpected, the moment of joy goes to be a time of pain, tears, frustration, anguish, fear, insecurity and many other feelings surrounding this situation. The parents feel lost, without power and need a time to adapt themselves to the new situation.

The fact of not knowing the meaning of the name ‘Down Syndrome’ and little relate it to such experiences with other children intensify the impact of diagnosis for parents. They reported only know issues related to physical appearance as bent eyes and large tongue, most believing that it is a disease.

I did not know. I knew there was such a disease, not now know by name, [...] Then I was told that DS is a disease that occurs in people and the features are identical. The little face, you notice immediately that the child is DS [...] (P8).

I did not know about it. Really, you say the daughter of so and so is Down Syndrome, but you do not concern to read, to know. You think it only happens with your neighbor, your friend, there when it happens in your family, you start to worry (P6).

In line with the results, one study points out that the need to cope with this situation makes parents seek information about the syndrome. Many of them consider that the prior knowledge about the trisomy 21 is insufficient, little clear and / or objective, showing that there is a lot of lack of information. This fact contributes to the parents feel lost before the diagnosis obtained.

They reported that the perception that they had before the child with Down Syndrome is of a child with limitations and weaknesses, but they saw it like any other child, i.e., “normal”. They expressed knowing the need that they had more attention, dedication and care for the purpose of having a deficiency in the development, thus favoring a greater dependence.

For me he is normal. I have two children and I see him as a normal child. He gives a little more work because we have to dedicate more. [...] I do not think there’s much difference than a normal child, there are things that are later and takes longer (P1).
Paternal participation in caring for the child...

After the impact of diagnosis, parents initiate a phase of conformation to accept the new reality and begin to fight for the development of the child. The awakening of feelings different from those experienced previously is very common. In this process, the parents start to consider the child as special or as a blessing from God, putting in them the central focus of their care and reason for living.

At this stage, parents live contradictory moments, because while they are experiencing the joy of fatherhood, show some fear with regard to the future of the child. In order to overcome the limitations imposed by the disease, parents mobilize themselves to make the child more independent as for the cares in daily living activities. Concomitant to these feelings, they verbalize the fear of death and the accountability of the family before the child with DS.

Regarding his future, what we plan is for everybody is teaching all people that it is possible to face it, for example, do the tasks in the house, even cooking. Because we think he needs to be as independent as possible for that in the future if we are not here anymore and he is living with someone else it does not require so much care (P1).

I prepare my children, the youngest who is 10 years old and the other who has 25. I always say this: the day I pass away, go to another world A. (son) will stay under the responsibility of you (cried and took a deep breath and got silenced) (P6).

In accordance with another study\(^8\), the findings of this research show a constant concern of parents of children with Down Syndrome about who, in case of their death, would be responsible for their kid. However, it was noted in their speeches the possibility of care and accountability remain with relatives and siblings.

♦ Involvement of father in the care for the child with Down Syndrome

In the study, we identified that the mother assumes the role of primary caregiver, whose focus of organization of its life and everyday dynamics goes through the cares for her son with Down Syndrome. It was observed that the care of the father regarding the son is optional, because he needs working to provide the livelihood for his family, so, takes care of the child when it is possible.

I do not participate at all times of day, but I participate when I can, [...] So who prepares milk usually it is me, matter of bath and tasks like this, most are from the mother (P2).
I can say that my participation is less than that from the mother. Because I wake up early and go to work, [...] But when I'm at home, play with her and sometimes I put on the uniform of school (P5).

The father's role of provider of the livelihood of the family makes him put the care activities with a child with DS in the background, so the caregiver role is firstly assigned to the mother, as well as the household tasks. There is a distance from father when he realizes the great involvement of his wife in child care.  

Regarding facilities and difficulties in caring for children with Down Syndrome, parents report greater emphasis on the first, since these children have a good neuropsychological motor development and this facilitates the daily care:

- It is very easy to dress up her, bath, she eats very well [...] This is a facility that we have. Regarding to watch, she turn on the television by herself, she puts the DVD, sweep the house, helps her Mom (P5).
- He is easy in his tasks. Bathing sometimes he is too lazy to go, but when I say he will do it. Bathing is quiet! He alone brush their teeth, [...] He is independent [...] (P7).

Authors claim that one can never predict the level of intelligence that a child with Down Syndrome can reach. Most of them are competent and know to perform daily activities without supervision and others get much bigger advances, for example: study and work.  

Although parents reported that the facilities are more prominent, others reported some generalized difficulties in their testimonies, primarily related to complications of the syndrome as difficulties relating to the language, learning and autonomy.

- There is difficulty only in her learning, at school which is a bit slow [...] Just read and write that she is slow (P5).
- Today the difficulty I have with my daughter is in speech. Oh my God, it will come up a light, a miracle; she will speak (P6).

The delay in the acquisition of speech and language is one of the biggest problems faced by parents of children with Down Syndrome. The development of speech, as well as the entire communication process, depends on several organic, environmental and psychological factors which are present from the first day of life. Accordingly, the staff must be aware and guide parents as for the search for resources and professionals to minimize such problems.

♦ Multidisciplinary team in the care for children with DS

Health professionals are important in the care for children with DS, since the transmission process of diagnosis for the family until the monitoring and providing of information on the neuropsychological motor development.

The way of establishment of the relationship of health professionals with the child with DS and its family, in view of the father, makes a difference in caring, maximizing performance in the activities established by each health professional.

- She likes it too much; she knows the name of the phono (therapist) and everything [...]. And the phono also likes very much of her (P5).
- I think yes he likes, because he likes to go (P4).

Patient satisfaction with the multidisciplinary treatment is more associated with the interaction with the professional, with the time used during treatment, communication skills and clear explanations about the child development.  

By questioning parents about their perceptions regarding the multidisciplinary intervention, they realize that their children are having a good outcome in the multidisciplinary treatment, favoring a better development.

- Today A. is too different than she was; I owe it to the treatments. The development of A. is growing at the edge of her, but we see reactions, [...] So, for me it is great (P6).
- I see her developing herself, because she was pretty weak [...] (P3).

The multidisciplinary treatment is essential for the growth and development of children with DS, because, between rights and wrongs, the child will develop skills and abilities. For that to occur, it takes discipline in the treatment proposed by health professionals.

Another relevant aspect is the research is related to the bond with the scholar pedagogical team. The school has provided to the children with Down a major global development that will be the foundation for all other improvements. Parents believe that the school has favored a greater performance of the son.

- Today he does well, he interacts with everybody of the school, plays, and he also has battery class [...] He likes a lot, always talk of the school, including vacation, he is talking about wanting to go to school [...] (P7).
She loves going to school, on the day that she will not she gets irritated. [...] She interacts with everybody of the school, she until began to socialize herself through music lessons [...] (P6).

Attending school will allow the child with Down Syndrome acquire, progressively, knowledge increasingly complex that will be required from society and whose bases are indispensable for the formation of any child. Despite all pedagogical favoring for insertion of special children in school, some parents reported feelings of exclusion and negative feelings experienced in the process of school inclusion:

[...] So in this school I felt the rejection and discrimination of special children. They receive the children, but do not have a job addressed to them (P6).

I feel that the teachers at the school are just playing, dancing with J. Because they do not send any homework for he does [...] (P8).

The teacher cannot forget, or even ignore, it is the duty of the school to welcome and educate all students, as well as seeking ways to conduct this task. It should be alerted to the need to rethink this reality in schools and training courses for teachers, for they can be prepared to meet the specific needs of these children so that they have a proper socialization.

Several decrees in Brazil and around the world have been drawn up to ensure the right of school inclusion, however, there is a missing of conditions that ensure not only access to schools, but the permanence and success of these students enrolled in regular classes, with specialized and able professionals to meet the needs of these children.

In view of the father, the process of acceptance of the child in school is not very easy. Some of them noted that their children were well accepted, other report that there were other difficulties, having to go to more than one school and, even those ones who before the obstacles chose to put their children in special schools.

The teachers do not want to do it; I had to go to several schools (P2).

She was very well accepted in school for special children [...] (P6).

 [...] He was accepted because I was paying [...] So all that is paid the school accept, there is no problem of not having vague (P8).

The school has a duty to provide to the children with the same opportunities that the people considered “normal” have, in order to perform their potentialities through appropriate educational conditions. The possibilities of transformation underlie up in cases where students actually find, in the regular school system, a favorable environment, for the childhood development. However, the tasks proposed by the school, from the perception of parents, are ludic activities without cognitive purposes. Actions of this nature are limiting and do not involve the welcoming and the full care, which are essential to the children with DS.

When inserted into the regular school, the parents said that there are many difficulties, since schools receive children with DS because it is a right that is guaranteed in law, but they are not prepared or not having trained human resources and nor appropriate environment that can enhance the development of each child in its uniqueness.

They did not treat A. well [...] They did not care of her [...] So, I took off A. from that school [...] (P6).

The literature suggests that the degree of development and socialization of children with Down Syndrome can be very satisfying when it come to be seen as individual who can be part of a world designed for skilled and competent people. This happens when these children are introduced in school without difficulty, i.e., without prejudice and without distinction. The child is able to understand its limitations and live with its difficulties for the rest of life.

Health professionals involved in caring for children with DS should keep in mind that the child is potentially able to overcome their difficulties when it encounters an integrated team and a family that endeavor and optimize the individual needs of the child relating it to the social context.

CONCLUSION

In the care for the children with DS, the parents reported that the notice of the diagnosis triggered feelings and reactions, such as: fear and anguish. One factor that greatly increases the impact of the diagnosis for these parents is that many of them have mentioned not knowing how would be the DS; we noted an absence of information. Therefore, it is necessary to create information policies in the media and inclusion of children with disabilities in society and, so, before a diagnosis of such type, parents would not feel so uninformed and desperate.
Parents have the perception that their children are like any normal child, although they have limitations and weaknesses due to a deficiency in development. They know that their children have a higher dependency and, therefore, need to have more dedication, attention to the child and be close to it. In this process, it is for health professionals support parents and prepare them for the coping according to the degree of dependence of the child. If parents are qualified for the care and instructed about the importance of continuity of treatment at home, they may also properly stimulate the development of the child in an ongoing manner.

The feelings of love and affection of parents for children with Down Syndrome are present, but even realizing that they have a child that requires closer monitoring and attention, the care from the father is still sporadic. This usually occurs because the father works to provide the livelihood of his family, but at other times because the mother assumes the cares and not the delegates them to the division of family roles, overloading herself. Help families to understand the importance of building the shared care of children with DS at home contributes to a better life quality for all family members as it helps to minimize the impact of changes in the everyday.

By exposing their bond with the child, the parents emphasize the facilities in the care for the child, since even with delay, they reach milestones of neuropsychological motor development and this facilitates the daily care. The difficulties were little highlighted and they are related to communication problems, language, autonomy and the schooling process. Therefore, the professionals of the rehabilitation team are essential to conduct the process of stimulating and maximizing the child's development while minimizing the difficulties in caring. The children with Down syndrome will have forever any limitation due to the genetic changes, but that does not mean they cannot perform and/or have some skill, it will take a little longer, but, with proper stimulation and monitoring of a team of prepared professionals, they have a great chance to become a more independent person.

By establishing relationships with affective and effective bond and to be responsible, together with the family, by the care and stimulation of children, the health professionals contribute, on the one hand, to maximize the development potential of children, improving its life quality, on the other hand, to help the family to keep a positive coping on changes that are triggered in the everyday after the birth of a child with DS.

The process of acceptance of the child with DS in school is not very easy. The idea of inclusion is not new, but it still needs to be built in the minds of educators, governors and all of the society. Firstly of all, we must stop ignoring the existence of the problem and make it part of the accountability of the society to these families in caring for these children.

It claims for the mobilization for more effective insertions of the fathers in caring for the child with DS, thus minimizing the difficulties of overhead faced by the mother, as well as the symptoms of the syndrome, favoring the development of the child, and strengthens the process of inclusion of it into society.

It is hoped from this study, further researches should be subsidized on the selected theme and there is an awake of reflection of academic students and health professionals to develop facilitating strategies for coping the weaknesses found in the fathers, maximizing the life quality of family and the children with Down Syndrome.

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