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FATHERS' PERCEPTIONS OF THEIR EXPECTATIONS ABOUT THE FUTURE OF CHILDREN WITH MENTAL DISABILITY

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ABSTRACT

This study aimed to reveal the paternal perceptions about their expectations for the future of children with mental disability. The data was collected from semi-structured interviews from August to November 2011. Phenomenology, in the hermeneutic perspective of Heidegger, was the theoretical reference chosen. Reaching the phenomenon, twelve subjects participated in the study, men, fathers of children with mental disabilities. Themes emerged from the phenomenon investigated: 'designing the future of the child from the news of disability', 'reflecting about the future in daily life', 'realizing that the child with disability has his own development time', 'realizing the child´s dependency' and 'having hope and faith as the future'. The birth of children with disabilities allowed the father reflect front the fact, giving new meaning to their perceptions and expectations about being a father. It is concluded that in face of having a child with disability experienced by the father, being heard is a therapeutic process and should be an intervention proportionate by a healthcare professional. It is therefore suggested the training of professionals who provide assistance to this population, so that better care be provided to individuals having this experience.

Keywords: Future Expectations. Father-Child Relations. Disable Children. Phenomenology.

INTRODUCTION

The literature review about the expectations for the birth of a child covers several facets of this event related almost exclusively to maternal experience(1-4). However, there are still gaps in parental experience and the process of being a father and their interactions after the child´s birth.

Parenthood is consolidated on father´s imagination with the arrival of a child. Before contact with the child, father and mother go through an imaginary relationship with the baby. The image, result of parental imagination, is called baby or imaginary child(2). The development of the relationship with the imaginary child is very important to the creation of the maternal/parent and child bond(5).

However, the deficiency in a child, in the imaginary of the population in general is related to limitation and imperfection(6). In this sense, the birth of a child with a disability is able to deconstruct the previously idealized formulation in relation to children and their future, rising feelings of disappointment, despair, sadness, shame, and especially mothers, because there is the death of the imaginary baby(3,7).

Grief comes with the loss, representing the breakup of a relationship(4). Grief is an emotional and cognitive challenge that makes the person reorganize and reconstruct with the loss(3,4).

Although there are studies on this experience in the mother's perspective(3,4,7,8), how this event would experienced in the parental perspective? How the father of a child with a disability is perceived in family dynamics? These are questions that need better understanding so that professional approaches are developed in a more congruent way with the situation experienced by parents of children with disabilities and help in handling everyday situations.

Considering the phenomenon of having a child with disabilities has the potential to impact the structures and family interactions, and taking into account the gaps in studies about paternal perspective of their experience and expectations about the future of the child, this study aimed to reveal the paternal perceptions as their expectations about the future of the child with mental disabilities and the consequences of this event in the family under the fatherhood perspective.

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METHODOLOGY

The phenomenology is the theoretical approach chosen for the development of the study. This perspective is not about the idea that there is a problem needing to be solved and explained, but rather, a question that needs to be understood. The question becomes a phenomenon at the time that encourages the researcher to unveil it(9). In this way, this study aimed to understand the essence of the phenomenon, which is designated as the fathers´ perceptions about the future of a mental disability child. The hermeneutic perspective of Heidegger was adopted, in which the meaning hidden in the description is unveiled through understanding(8,10).

Regarding to the ethical aspects, the research project was approved by the Ethics Committee in Research with Human Beings of the Federal University of Mato Grosso do Sul (Opinion Number 1913); and parents expressed their willingness to voluntarily participate in the study by signing the informed consent term (TCLE).

This study was performed with men, fathers of children with mental disabilities enrolled in Special Education Center Girassol (CEDEG) of the Association of Parents and Friends of Exceptional (APAE) of Campo Grande, MS. The researchers went to the social service CEDEG-APAE, explaining the research and requesting to be contacted with parents who had telephone registration at the institution. The social service of the institution schedule the interviews with about 16 parents, according to its convenience. Only 12 parents attended the dates scheduled for the interviews; the other two refused to participate and two did not attend the scheduled dates.

The speeches were collected by the lead author, from August to November 2011, through individual interviews held in a private room offered by the institution. To better understand the phenomenon, the following guiding question was used: “How do you see the future of your child?” In most of the interviews the word “son” has been replaced by the child´s name. The speeches were recorded on digital media with an average duration of 45 minutes and fully transcribed, keeping the original lines. When asked about the child´s disability diagnosis, the researcher opted the original speech of the parents, as it is believed that the way the fathers mean to their child´s disability affects the design of the future. Table 1 shows the relationship of the parents of the study.

Table 1. Record of fathers interviewed.

Subjec	Age	Years of study	Relation with the child´s mother	Disability diagnosis of the child	Child´s age
FATHER 1	23 years old	11 years	Married	Down's syndrome	6 months
FATHER 2	34 years old	11 years	Married	Down's syndrome	1 year and 9 months
FATHER 3	27 years old	9 years	Divorced	Not defined	1 year and 3 months
FATHER 4	22 years old	5 years	Married	Down's syndrome	5 months
FATHER 5	31 years old	16 years	Married	Moebius Syndrome	2 years old
FATHER 6	73 years old	4 years	Married	They did not know	31 years old
FATHER 7	43 years old	3 years	Married	Down's syndrome	2 years and 7 months
				They did not know	19 years old
FATHER 8	42 years old	9 years	Married	Cerebral palsy	8 years old
FATHER 9	39 years old	7 years	Married	They did not know	4 years old
FATHER 10	34 years old	14 years	Married	Sequels of prematurity	2 years and 3 months
FATHER 11	60 years old	5 years	Married	Degenerative disease	27 years old
FATHER 12	38 years old	14 years	Married	Innate Metabolism error	8 years old

A close reading of the speeches was held to better familiarize with the statements and know how they perceive the phenomenon of having a child with mental disabilities. After this step, the units representing meanings of father´s experience were highlighted. The next step was to transcribe the units of meaning to the language of the researcher, approaching the speech to a research language. The units of meaning were grouped into themes and then in an open category by the phenomenological reduction performed. It can be said that these groups form a synthesis of judgments consistent from naive descriptions of the subjects(11).

RESULTS AND DISCUSSION

From the narrative and analysis of the study subjects´ speeches, it was possible to understand that parents, facing the diagnosis of mental disability of their sons, rebuild their expectations about their role and about the uncertain future of the child. Representative category of father´s experience in this context, “Rebuilding the paternity and the future of the child”, representative of the father´s experience with a child with disabilities is divided into five themes: “designing the future of the child from the new disability”, “reflecting on the future in everyday life”, “realizing that the disabled child has his own development time”, “realizing the child´s dependency” and “having hope and faith as the future”.

Since the communication about the child´s disability, the father goes through intense reflections in order to understand the reality experienced and how life would be and the future of childcare that inspires and managements to which he did not feel ready. He still reflects on being a father as something new, challenging and unknown to him. With the fact that the child has a disability, all that was previously made before the child´s arrival is deconstructed, appearing fear, insecurity, uncertainties and misunderstanding of the event. Preconceived ideas about disability as a condition that limits a person´s life, mix with new concepts generated for the child in an exercise to seek other possibilities not thought. However, even against the effort to envision future possibilities for the child, the father experience in his imagination the image of a sick baby, dependent on complex care or simply possessed of a condition that frightens and leaves no expectations.

The reflection that the father makes about the future of the child has different questions, such as if the child will develop, how will his day-to-day and what to expect of school education. The father questioned about how the child will develop in society, if he will be accepted and will accept himself. He inquires about the future, if he will date somebody and will work when grows up. Before all these questions, the father gradually realizes that the child may depend on his care forever, having to redesign his own conceptions and family life 're-building the future of paternity and child' in daily life with him.

Although the father´s concepts on child deficiency are modified as he experiences his being-Father-of-a-child-with-disabilities, expectations regarding the improvement of health and child´s condition, and even healing his disability, make him have hope and faith that his child will always have a future to be designed according to his real possibilities. Hope that the child may have a future with better conditions drives the father to create opportunities he can reach to develop the best possible way and thus have chances of a future that includes education, work or family.

The themes are presented below along with the narratives of the parents of the study to further illustrate the paternal experience.

Designing the future of the child from the new disability

Receiving the child´s disability news or the perception that the child is different from others, makes the father feel helplessness and disappointed. Impotence emerges against the uncertain and unknown, because the child´s condition takes the father not know how to handle and cannot envision his future and to question his own conduct in society.

The birth of a child is the possibility of the father as a man to do and give his best for the child. When realizing this is not the way he imagined, disappointment appears. The future of the child before thought of as something promising, is deconstructed and becoming something uncertain for the father, causing him to deconstruct dreams imagined before.

> I already had a position to give something, do a better future, but ... it did not work ... I often found myself thinking like this: oh boy, I wanted so badly to do good and God gave me this, right... (Father 6)

> I like to study and everything, then you want a child to teach him ... it gives a frustration. Because the father arrives, 'Oh, what did you do at school, homework, I do not know what ...' With us, we do not have it (Father 12).

The preconceptions that the father of the study has about disability appear when he sees his child with this condition. The image of a sick child, dependent of his parents and suffering rejection by society permeates his imagination, leading him to reflect on the uncertain future. Deficiency raised the fear that people in this condition could become wanderers, or be institutionalized if they not receive the care and rehabilitation required for their social inclusion.

Although the future is part of the imaginary of all of us, the conception with more detail could not be held by the parents of the study, being understood as something to be expected without many expectations. For these parents, the future of the child cannot be made, because they should give freedom to the child to be what he wants and achieve it. That future is also imagined as something different just for the child, according to the following speech:

> If he was a normal child, you think: I'll put him in school, then college, marriage, children. In a special child, you have to think differently, you have to plan differently, see differently, create a different basis because he will also be different. (Father 10)

The lack of completion of a clinical diagnosis for the disability of the child or of a likely prognosis of growth and development was a great limiter for the paternal conceptions about the future. The lack of information and clarity as to what was happening with his son did not allow his father to formulate opinions about his development. This situation brings the feeling of anguish and anxiety that permeate the father´s conception for the future of the child.

> I do not know what she has actually, you know? No one knows what she has, if she will walk, she will talk or if she will have whatever ... I want to know what she actually has ... (Father 3)

> When you have a disease, you have the instructions of what to do: changing the diet, changing the routine, changing the medicine here and there, and resolving. In his case, it was like that... (Father 12)

To understand why the magnitude of the impact of disability on parents´ lives, we must bear in mind the hegemony of the biomedical model in society, with an approach based primarily on human biology and pathophysiology, discarding the power of human relations in the health-disease(12), leading the disability to be seen as a failure and a problem(6). The hegemony of this model in society associated with the culture that preaches the same in relation to disability was evident in the paternal speeches about the child´s condition, when at the moment of knowing about it, professional paused to report that the child was deficient. The impact of this phenomenon in the life of the father marks his existence and seems to see the word disability related to the child, causing him to have to reframe his reality. Heidegger, when describing on the dialogue, says that this is the way the subject means his reality(10). However, hearing that the child has a disability and be-father-of-a-child-with-disabilities is not enough, it is necessary to know the disabilities of his son to formulate an expectation about their future and how will be his existence.

Reflecting on the future in everyday life

The daily life of children with disabilities has an agenda of rehabilitation activities and few opportunities to play like other children. For the parents of the study, the possibilities of the common daily activities of a child such as riding a bicycle, playing, discussing and claiming emerge as a future yearning for the child, especially those with several mental disabilities and delay in neuro-motor development:

> My dream is to see her picking up, dropping the TV control and stirring in things, messing up ... (Father 9)

> I see my friends complaining, 'Oh, my son broke it, stepped in I do not know where ...' Sometimes even say, 'Gee, I wish my son was doing this, you are complaining too much ...' (Father 12)

After the initial impact with the child´s disability news, the father seeks to reorganize his expectations regarding the achievements of children and their future. Among them, there is the desire for independence and, in the paternal conception, it can be achieved through education and inclusion in the labor market. For parents, the independence and autonomy would be a great achievement for the child and the family, it would be through them that the child would feel most closely to the conception of normality and inclusion in society.

For the parents of the study, the sexuality of adolescents and young people with disabilities is a source of conflict in family relationships, as there are differences of opinion between the couple when it comes to the loving future of their son. Parents believe that the child has no information and do not know how to handle their sexuality in a healthy and secure manner. They fear that the child seeks get what he wants through aggression and impositions.

Talking about sexuality of the child in the family result in discussions by the divergence of beliefs and subject management, especially between spouses. There are fears that he can engage with people who do not respect him. Some members of the family, especially the mother, has difficulty seeing the child as someone who could have active sex life:

> My wife gets mad at me: you are very silly, the kid is not old enough and you're talking about dating. I say: it is a logical thing, is it the physiological, not the people who will determine, we have to be prepared for that. (Father 8)

Although the father wants the autonomy of his son, the speeches reveal the father´s fear of his son´s sexuality expression, which sometimes takes the father to seek ways to suppress their sexual behavior.

A study of literature review about adolescent sexuality with mental disabilities shows that this subject brings great concern to parents, especially the mother, translated by repressive and discriminatory attitudes that prevent adolescent development. In addition, there is prejudice around the sexuality of people with disabilities, as an eyesore and abnormality and should be controlled by the family(13).

In the phenomenological perspective, by suppressing the essence of the other there is the annulment of being. This fact allows reflecting on what Heidegger approaches for co-existence, that when the other is not for me, the co-existence becomes inauthentic because co-exist is to relate to the other seeing as being.

The factuality understood as the situations that define the existence of a being(10) and here it is the event of having a child with disabilities, affect the initial expectations of the father as being a father and from that shapes his way of being in daily life, leading to his existence to gain new insights and realities, as well as their experiences of being-with-son-in-the-world. Therefore, being a father is modified due to the new requirement of reality. This fact is similar of the one described by Heidegger, by pointing out that it is necessary to break with the idea that man determines the world and the world determines man, as if they were separated. On the other hand, for this philosopher, man and world complement each other in a constitutive ideal(14).

In this context, where the world and man complement each other, the future for the father with a disabled child, is renewed with the possibility to transcend and understand himself in a reflexive movement, allowing to be a father.

Although the future of the child is not clear to the father, it is being built in their daily lives as the child develops and as soon as the father would be understanding the context and the real possibilities of the child.

Realizing that the disabled child has his own development time

The understanding that parents of the study are acquiring, about each child having their own learning and development time, enables to believe in a more optimistic perspective for the future. The yearning for his son´s improvement makes the father seek all the ways out of their way to help in the stimulation, development and children´s social inclusion. However, sometimes the lack of immediate results or the delay of the reach of new skills for the child, causes the father seek other alternatives and treatments in hopes of accelerating the rehabilitation process. This perception of the father leads him to understand that the child has his own individual rhythm, which must be respected.

> There are things that you will have to be slower, because there is not your time, it is her time ... and

> I tried ... I tried to speed up the process, I gave more antibiotics, more medicine, looking for more doctors, all medicine he passed I gave her. I looked for another one passing other medicine option, I gave ... It was then that I realized that I wanted to speed up a process that nature itself would deal ... (Father 10)

Realizing the child´s dependency

The disabled children requires a lot of care and an intense demand for stimulation and rehabilitation activities so they can reach a certain autonomy and independence. However, even if the desire for independence and self-care are present in the imaginary of the father, he is still afraid that in the future, the child can continue depending on family care.

In this sence, although the father has expectations of a future in which the child can develop activities with greater autonomy, he fears to not happening and seems to keep the image of a child who does not grow dependent on nursing care and will always be among parents until his death.

When parents get older, they fear for their death and for the care of the child with disabilities to be delegated to another family member, usually the brother.

> The other children will take care of him, it is what I think, give him what he needs. I think they will surely take good care of him. (Father 6)

Realizing that the child remains dependent on family care, the father suffers and sorrow, as evaluates as if all the effort made for the child having a more autonomous life was possible the way they imagined.

> The other children were everything but Junior was not ... it's complicated ... (Father 11)

This fact leads his father to reflect on the reality and to narrate the feeling of sadness at the fact that the other children have developed and this child does not, feeling helpless to the situation.

The autonomy of the child is a constant concern by the father. This fact leads us to think about how his father´s insertion in institutions specializing in the care and rehabilitation of people with disabilities, intensifies their desire for independence of the child, including strengthening hopes, since some studies relate the speeches on the importance of the child´s autonomy with disabilities to professionals in these institutions(15). IN this way, if the child does not reach the independence given by both parents as the institution, there is a great frustration within the family(16).

Having hope and faith as a future

The father of the study walks seeking the best for the child and have hope and faith that he can have his health condition improved. He believes in normal child development through all the resources made available by science, and he hopes the medical healing and divine. Sometimes, when there are no conditions for the parent to perform the appropriate medical treatment for the child, as in cases of associated pathologies, the way is the hope in God that nothing worse could happen to his son.

> In the future of Junior, I first think of God helping doctors to give a good recovery for him, for him to return to normal, cure this disease, right ... (Father 11)

However, even in the daily achievements of the child, father´s expectations should be dosed, since they can lead to disappointment if the child does not reach what he expected:

> We have a faith that he will develop, we see every day he is wining, but I cannot have so much expectation, down to earth and we will ... (Father 12)

According to Hopkins, “"hope is to desire or crave for anything that brings us satisfaction”(17), but there is also a school of thought(18) referred to this feeling, not as a conviction that something will occur, but being assured that whatever happens makes sense, regardless of how happen. For parents of the study, hope is an inner strength, and that strength allows transcending what is laid and seek a new awareness of being(19).

The cure, in the father´s conception, is close to what Heidegger meant by cure: a care act. Care in this sense would be present with each other, next to each other and to the other in search of the meaning of their existence. Thus, the study leads us to understand the father´s hopes on his son´s cure, much more than a desire for the disappearance of the disability, being a father´s way to make sense of being a father, making sure that everything will be right regardless the child develops or not.

FINAL CONSIDERATIONS

The birth of a child with mental disability in the family context causes a serious imbalance in the family way of living. The primary perceptions of misunderstanding of the situation, feelings of anguish, despair and grief are gradually transmuted by new ways of living and thinking of this reality.

The child with mental disabilities allows the father to perform his fatherhood in a way he never imagined, and reflect on their way of being-there-in-the-world, reframe concepts, beliefs and ideas about his own son and being a father. The phenomenon unveiled in this study leads us to the understanding that the father perceives Being-there or Dasein, from his experience with being-father-of-a-child-with-disabilities. This perception leads him to keep the hope for the child´s cure and to take care of him the best way as possible and with the resources available, despite the sense of frustration that emerges in his career with his son.

We believe that the experience of having a child with disabilities experienced by the father is rich and disturbing at the same time, bringing many possibilities in paternal imagery and mess everything his father believed while being a human being. In this sense, the health professional in the approach to family disability experience, should provide environments and spaces where everyone can express feelings and anxieties, and especially the father, who has historically been neglected and not heard. We believe that in this way, through an open environment to hear everyone, care these parents, families and children with disabilities can be exercised in an authentic way.

We suggest that future research seek among the professionals who provide care to children with disabilities their conceptions about being the father, for greater discussion on the topic.

PERCEPÇÕES PATERNAS QUANTO AS SUAS EXPECTATIVAS SOBRE O FUTURO DO FILHO COM DEFICIÊNCIA MENTAL

RESUMO

Objetivou-se desvelar as percepções paternas quanto as suas expectativas em relação ao futuro do filho com deficiência mental. A coleta de dados ocorreu a partir de entrevistas semiestruturadas, nos meses de agosto a novembro de 2011. Para tanto, a fenomenologia, sob a perspectiva hermenêutica de Heidegger, foi o referencial teórico escolhido. Mediante o alcance do fenômeno, participaram do estudo doze sujeitos, homens, pais de crianças com deficiência mental. Dos discursos, os temas que emergiram diante do fenômeno investigado foram: 'concebendo o futuro do filho a partir da notícia da deficiência', 'refletindo sobre o futuro no cotidiano', 'percebendo que a criança com deficiência tem seu próprio tempo de desenvolvimento', 'percebendo a dependência do filho' e 'tendo a esperança e a fé como futuro'. O nascimento da criança com deficiência permitiu ao pai uma reflexão diante do fato, ressignificando suas percepções e expectativas quanto ao seu ser-pai. Conclui-se que diante da experiência de ter um filho com deficiência vivenciada pelo pai, ser ouvido é um processo terapêutico, devendo ser uma intervenção proporcionada pelo profissional de saúde. Sugere-se, assim, a capacitação do profissional que presta assistência a essa população, para que seja proporcionado um melhor atendimento aos indivíduos que vivenciam essa experiência.

Palavras-chave: Expectativa de Futuro. Relações Pai-Filho. Crianças com Deficiência. Fenomenologia.

PERCEPCIONES PATERNAS EN CUANTO A SUS EXPECTATIVAS SOBRE EL FUTURO DEL HIJO CON DISCAPACIDAD MENTAL

Resumen

Este estudio tuvo como objetivo desvelar las percepciones paternas, según sus expectativas para el futuro de su hijo con discapacidad mental. Los datos fueron recogidos a partir de entrevistas semiestructuradas en los meses de agosto a noviembre de 2011. Para ello, el marco teórico elegido fue la fenomenología, según la perspectiva hermenéutica de Heidegger. Los sujetos del estudio fueron doce, siendo hombres y padres de niños con discapacidad mental. De los discursos, los temas emergidos sobre el fenómeno investigado fueron: 'concibiendo el futuro del hijo desde la noticia de la discapacidad', 'reflexionando sobre el futuro en la vida cotidiana', 'comprendiendo que el niño con discapacidad tiene su propio tiempo de desarrollo', 'entendiendo la dependencia del hijo' y 'teniendo la esperanza y la fe como futuro'. El nacimiento del niño con discapacidad permitió al padre una reflexión delante del hecho, re-significando sus percepciones y expectativas en cuanto a su ser-padre. Se concluye que, delante de la experiencia de tener un niño con discapacidad experimentada por el padre, ser oído es un proceso terapéutico y debe ser una intervención proporcionada por un profesional de salud. Por lo tanto, se sugiere la capacitación de profesionales que prestan atención a esta población, para que un mejor cuidado sea proveído a las personas con esta experiencia.

Palabras clave: Expectativa del Futuro. Relaciones Padre-Hijo. Niños con Discapacidad. Fenomenología.

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