

Phenomenology Section

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“He is normal”: phenomenological considerations of child/adolescent’s perception of the disabled sibling

“Ele é normal”: considerações fenomenológicas da percepção da criança/adolescente do irmão com deficiência

“Él es normal”: consideraciones fenomenológicas de la percepción del niño/adolescente del hermano con discapacidad

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ABSTRACT

Objective: To understand the child/adolescent’s perception of the disabled sibling.

Method: Qualitative research, with a phenomenological approach, conducted between 2018 and 2019, in a municipality in the south of Brazil, with 20 children/adolescents who are siblings of people with disabilities, through a phenomenological interview. Respecting ethical precepts, hermeneutics was used for interpretation.

Results: The child/adolescent perceives his/her disabled sibling as a normal person, given his/her behavior, way of being and intellectual capacity. Still, it understands him as a special being, who has limitations regarding learning, but does not see him as different, thus, unlinks the idea of disability associated with the disease/abnormality.

Final considerations: The perception of the disabled sibling occurs within the perception of normality. The child identifies his sibling's lower learning capacity a way that is unique to him, a fact that does not condition him to be seen as abnormal, defining his being-in-the-world as a special way of existing.

Keywords: Adolescent. Child care. Disabled children. Siblings.

RESUMO

Objetivo: Compreender a percepção da criança/adolescente sobre o irmão com deficiência.

Método: Pesquisa qualitativa com abordagem fenomenológica, desenvolvida entre 2018 e 2019, em um município ao sul do Brasil, com 20 crianças/adolescentes irmãos de pessoas com deficiência, mediante entrevista fenomenológica. Respeitados os preceitos éticos, utilizou-se a hermenêutica para interpretação.

Resultados: A criança/adolescente percebe seu irmão com deficiência como uma pessoa normal, diante de seu comportamento, modo de ser e capacidade intelectual. Ainda, o entende como um ser especial, que possui limitações em relação à aprendizagem, porém não o vê como diferente, desvinculando a ideia da deficiência associada à doença/anormalidade.

Considerações finais: A percepção sobre o irmão com deficiência ocorre dentro da perceptiva de normalidade. A criança identifica a menor capacidade de aprendizagem do irmão ou um jeito que é só dele, fato que não o condiciona a ser visto como anormal, definindo seu ser-no-mundo como um modo especial de existir.

Palavras-chave: Adolescente. Cuidado da criança. Crianças com deficiência. Irmãos.

RESUMEN

Objetivo: Comprender la percepción del niño/adolescente sobre el hermano con discapacidad.

Método: Investigación cualitativa con enfoque fenomenológico, desarrollada, entre 2018 y 2019, en un municipio del sur de Brasil, con 20 niños/adolescentes hermanos de personas con discapacidad, a través de entrevista fenomenológica. Respetando los preceptos éticos. Para la interpretación se utilizó la hermenéutica.

Resultados: El niño/adolescente percibe a su hermano discapacitado como una persona normal, dado su comportamiento, forma de ser y capacidad intelectual. Aun así, lo entiende como un ser especial, que tiene limitaciones en aprendizaje, pero no lo ve como diferente, desvinculando así la idea de discapacidad asociada a la enfermedad/anormalidad.

Consideraciones finales: La percepción del hermano discapacitado se da dentro de la percepción de normalidad. El niño identifica la menor capacidad de aprender del hermano o una forma que le es propia, hecho que no lo condiciona a ser visto como anormal, definiendo su ser-en-el-mundo como una forma especial de existir.

Palabras clave: Adolescente. Cuidado del niño. Niños con discapacidad. Hermanos.

INTRODUCTION

Society has, over the centuries, created and followed rules that define what is normal and what is pathological, impregnating itself with its own normativity. A norm is a concept of value, which makes the existence of anything that does not correspond to it meaningless. This value makes the person normative and incapable of thinking different⁽¹⁾. The human being experiences a massification of thought, which prevents him from reflecting and questioning

what is put as “natural”, becoming vulnerable to normative models that make it impossible for him to unveil the being⁽²⁾.

The being starts to think from what is naturalized, the thought is no longer his, and perhaps never was, what the being thinks is part of what society establishes as a rule, and he does it without questioning⁽²⁾. It is as if the being no longer thinks for himself, and even what he believes to be himself is nothing more than that impregnation of this dictatorship of the mind that prescribes the way of being-in-the-world in daily life⁽³⁾.

In the scope of existential analytics, massification can be understood as impersonality, being the category that transforms everyone into ‘impersonal’. Everyone is everyone, and therefore no one is someone. Each one is constituted only through the other, which is constituted, in turn, through another, and so on, so that no one is existentially established by themselves⁽³⁾.

In this context, one can question what would be the “normal” state of the being's body? Such questioning may be reflected on how the being sees himself, or how the other sees him, considering that, a child who is born with a disability came into the world this way, it is his way of being-in-the-world, this being his “normal”⁽⁴⁾. Besides, it is highlighted that only can be dead what can die, and only what lives can die⁽²⁾, thus only someone who was once ‘healthy’ can be/become ill, under this conception, people with disabilities are not ill, it is their existential condition, they came into the world that way, thus, they are in balance with themselves.

The ‘normal’ being is linked to the look of the other, so the look of the sibling can be constituted from the look of the family as a closer reference⁽⁵⁾. This family conception is socially influenced, from what was once created and defined as right or wrong. Thus, the concept of what is normal for a disabled person can be influenced by the whole, something built over time without questioning its validity within history.

There is evidence that the influence of a disabled sibling on siblings with typical development, often, scores between positive and negative aspects, in other words, there are difficulties/suffering in the families of people with disabilities, but also a lot of enrichment. Thus, this nuance is explicit in different ways, highlighting the repercussions on the subjectivity of these siblings, on family dynamics and concerns regarding the future, due to the fact that the disability is not understood and not accepted by society, for this reason it generates stigma and judgments⁽⁶⁾.

In this sense, it is considered necessary to foster discussion on the subject, seeking to contribute to broaden the social view about people with disabilities. Thus, the following

question was elaborated: What is the perception of the child/adolescent about the disabled sibling? And the objective was to understand the child/adolescent's perception of the disabled sibling.

METHOD

This is a qualitative research⁽⁷⁾ grounded on the hermeneutic phenomenological approach. It corresponds to an excerpt from the doctoral thesis entitled: Being-in-the-world of the child/adolescent who lives with a disabled sibling: an opening to authenticity.

Phenomenology, based on Heidegger's framework, allows us to understand the manifestation of being as it is. It understands man as a being in the world, in the situation of being released, being present and presence. From this perspective, phenomenology goes beyond the simple description of a manifestation, as it is only possible based on the showing of something⁽⁸⁾.

The study was developed in an Association of Parents and Friends of Exceptional Children (*Associação de Pais e Amigos dos Excepcionais* - APAE) in a municipality in southern Brazil. Inclusion criteria were: being a child or adolescent brother or sister of a disabled person; aged seven years or older and, at most, 18 incomplete; having a sibling aged three years or older (have experienced interaction with the disabled brother) and undergoing rehabilitation treatment at the clinic of the aforementioned institution during the period of data collection; living with a disabled sibling.

Access to the child/adolescent's families who lives with the disabled sibling was carried out by indication of APAE professionals. After the family members were invited and accepted, the interviews were scheduled, which were conducted at a date and place defined by the family, seven of which were held in the participants' own homes and 13 at APAE, in a private room. On the day of the interview, the legal guardians signed the Free and Informed Consent Form, and the Free and Informed Assent Form was also presented, which was read, then doubts resolved, then delivered and signed by the child/adolescent.

To preserve the anonymity of the interviewees, alphanumeric codes C1 to C10 ('C' for children) were used consecutively, according to the order in which the interview was carried out. In the same way, from A1 to A10 ('A' for adolescent).

At the time of the phenomenological interview, the interviewer and the child/adolescent were present. It should be noted that the interviewer has experience in qualitative research and phenomenological interviews and had previously approached the interviewee. The interviews were recorded on an MP4 device, with an average length of 40

minutes, after which they were transcribed in full by the main author. There was double checking by the interviewer and a third researcher.

The phenomenological interview to survey information took place between November 2018 and March 2019. This type of interview consists of a process of interaction and dialogue between researcher and participant, whose objective is for the interviewee to be able to recognize and describe their experience and the meanings given to the experienced situations related to the research topic⁽⁹⁾. For this article, in view of the full research, the following question was used: Tell me how you see your brother or sister? The number of participants consist of 20 children/adolescents and was set out based on the reach of sufficiency of meanings, and the response to the proposed goal⁽⁹⁾.

For information interpretation hermeneutics was used⁽¹⁰⁾. Two units of meaning were identified, namely: 'He is normal' and 'He is special'.

In conducting this study, the ethical precepts defined by the National Health Council were respected through Resolution No. 466/12 and 510/2016. Therefore, the study was submitted and approved by the Research Ethics Committee under CAEE No. 98.766018.2.0000.5647.

It is noteworthy that, for the elaboration of this study, the guidelines proposed by the Consolidated Criteria for Reporting Qualitative Research (COREQ)⁽¹¹⁾ were complied.

RESULTS

Study participants were 10 children and 10 adolescents, aged between seven and 18 years old, who live with siblings with disabilities (physical, mental, intellectual, or sensory).

The participants' education level was between the first year of Elementary School (ES) and High School (HS). Regarding the number of family members, it varied between three and eight people. Regarding religion, three participants said they did not know their religion, ten said they were evangelicals, two were Adventists and five were Catholics.

Regarding the age of the disabled sibling, it varied from 3 to 20 years. Regarding the type of disability, eight had a diagnosis of cerebral palsy, seven were autistic, three had Down syndrome, one had myelomeningocele and the other had unspecified mental retardation.

He is normal

In this unit of meaning, the speeches in which children/adolescents perceive their siblings as normal people are shown. In the speeches, it can be observed that the participants emphasize that the sibling is normal like other people, has a normal life and is intelligent.

I see him as a normal kid. (C1)

I am like my father and my brother like my mother. (C3)

Normal you know, he behaves, you know, like a person. (A1)

I see him as a normal person. He does everything we do. He is normal, for me he is. He is normal! We have a normal life like the others. That's it. (A6)

[...] I don't see difference from a normal child to him. He's pretty smart, all normal. I see him as a normal child, as I was saying, for me there is no difference, because that is to say, it is not even a disease. He is a very advanced person, you know, he does everything [...]. (A7)

Participant A7 highlights in his speech that there is no difference, as his brother is a very advanced person, that disability “is not even a disease”. Complementarily, in the statement of C4, it is evident that he does not perceive his brother as other people see him, but as normal:

[...] I like him, I don't see him the way his colleagues see him. I see him as normal, like me, for example, but his colleagues think he'll never learn anything inside a school.(C4)

In this statement by C4, it is possible to identify that, for colleagues, his brother does not have the same capacity as him, however, the participant does not see this difference. The speech of A5 follows in the same direction:

Ah, I see him as a normal child. For me he doesn't have nothing, he's normal. He's very smart. Now he only comes here, sometimes he even went to other schools. In this new school, these days I talked about APAE, then everyone was looking [...] I didn't even care. I don't even care about it and all, everyone thought it was weird. But to me he is a normal person. (A5)

In this statement, the participant mentions that does not care about how other people understand the fact that his brother attends APAE, that he does not ‘care about it’, because although everyone finds it strange, for him, his brother is a normal person.

Heis special

In this unit of meaning, the statements of the participants who point out the siblings as special are presented. They identify that the siblings have some difficulties, they take more time to learn, but they realize that this does not differentiate them from other people. Other participants say they see the disabled sibling as a normal child, however, they mention being a special child, who has a problem, smaller learning than the others:

She just has this problem, you know, but she's normal, she does what other children of her age do [...]. (A2)

Like a normal child, she just has a smaller learning than the others. She is very affectionate with others [...]. (A9)

I see him as a special child [...]however not different from a normal child. Makes a mess like a normal child, eats junk food, plays, normal you know?! But he has his way, everyone has a way of playing, he understands everything. So, I don't see why treat him like a different kid if he understands everything. He understands when you say, no, yes, can, cannot [...]. But he's stubborn, I was stubborn (laughs), everyone was, so I don't see why treating him like a child so different, it doesn't make sense. (A8)

[...] I see him as a normal person, I don't see much difference, I don't know. But, I love him anyway. He doesn't know some things yet, he's learning, he's almost eating by himself now. Yeah, for me, I see him as a normal person. (C9)

In these speeches, it is observed that, although the participants perceive the limitations faced by the siblings, they understand that these do not differentiate them from other people. Participant A8 states that his brother “has his way, everyone has a way of playing”, in this sense, he realizes that everyone has their differences and similarities, making no sense to treat his brother “as a child that is so different”. In addition, C9 also states the love he feels for his brother and A9 highlights how affectionate his sister is.

DISCUSSION

From the participants' point of view, siblings are perceived as ‘normal’ people, who just came into the world endowed with different existential possibilities. There is no distinction, in this sense, between a child who comes into the world with a physical disability or one who comes within the standards of growth and development considered typical. All people come into the world with possibilities to constitute themselves as unique. Thus, it is defined that Dasein: being-there is being project⁽⁸⁾, is a launch into the possibilities that are given to it. Disability can be, then, an opportunity for the child or adolescent with a disability, and all those who participate in this condition through *being-with*, those who are part of their world, to firm themselves authentically, to free themselves from the massification of the impersonal.

From Heidegger's perspective^(2,3,8), the facticity of existence is never voluntary, but what is done with it, the way it is given, is always a personal decision – even if that decision is the refusal of a decision. All people come into the world with possibilities to constitute themselves as unique.

The participants' perception is that their siblings with disabilities are normal, considering that, for them, it was the way they were launched into this world, a way of being-in-the-world. It can be seen from the participants' statements that they do not see difference between them, they behave like people, they do everything that others do, and life is normal like the others.

Corroborating the results of this research, a study investigated the impact that the presence of a disabled person resulting from Cerebral Palsy has on their typically developing sibling and found out that participants see siblings with disabilities as 'normal', even with the limitations, they were normal people. However, they noticed people's stigmatizing look, and felt disrespected. The big question is based on the current biomedical model that interprets and distinguishes normality and disability, focusing on the individual body as the 'problem', a fact that stimulates exclusion and stigma in disabled people⁽¹²⁾.

Acceptance or exclusion of what is different is directly linked to the conceptions of life and values adopted by each person. So, if disability is understood as an existential facticity, through which the person exists in this world, and not as a limitation or difference, they are perceived as normality. This is reflected in the reports of children and adolescents who understand the condition of siblings with disabilities as the way they came into the world. It is worth mentioning a research that identified that siblings of children with autism spectrum disorder are empathetic and affectively connected to them⁽¹³⁾.

When the environment is favorable to individual differences and it is understood that, despite one person has limitations, he/she can carry out, develop particular and different strategies from what another person uses to perform the same tasks, even with the help of equipment, the process of inclusion is likely to be favored⁽¹⁴⁾. However, we live in a society where, generally, the impersonal prevails over the way human beings should behave.

In Heidegger's perspective "in the use of public means of transport, in the use of news entities (newspapers), each other is like the other", thus, it is as if the being completely dissolved Dasein itself, each time letting disappear its differentiation and expressiveness⁽⁸⁾.

From this point of view, society regulates the being, controls the standards, not believing in the being-able-to-do of the disabled person, unveiling a complex existential facet, in the most diverse possible dimensions. This 'abnormality' is 'unveiled' by the social mass as it is not voluntary; however, those who voluntarily choose to change of their original condition face much more social resistance, because they deliberately escape from normality⁽⁸⁾.

Some participants in this study know the sociocultural imposed normativity, in other words, due to the way other people treat and look at their disabled siblings. Thus, children/adolescents perceive, in their own way, social massification, the sociocultural constructed stigma. However, they acquire an authentic attitude towards the situation, evidenced by the way their siblings overcome the facticities to which they are exposed as beings-in-the-world. Still, anguish generates fear, apprehension, however, forces the being to be discomfort and seek its authenticity. Similarly, research conducted with families of children with Down Syndrome identified that they perceive the prejudice existing in society on a daily basis⁽¹⁵⁾.

Attitudes like this are from an authentic being, as they circumscribe the real of existence. It is the choosing itself that projects, being able to provide a vision of the totality of Dasein (being-there), allowing self-understanding that is its self-realization-in-being. It is to realize oneself on an ontological level⁽⁸⁾.

Existential phenomenology understands the body as a way in which the being is constituted in the world. However, dealing with social massification is a challenge for families of disabled children. Uncovering such universe, a study identified that the family has been socially excluded due to the stigma surrounding disability. It is exposed that this fact is negative, both for them and for their children, being affected by the context of exclusion⁽¹⁶⁾.

On the other side to the findings of the study, in social imaginary, the disabled person is still seen and perceived as ill. Disability brings with it a strong emotional burden for parents, children, and other family members. Thus, when analyzing the health perception of caregivers of children with intellectual disability, it is noticed that they see their health in a negative way. Moreover, the use of the nomenclature “disabled person” is full of reckless meanings, since it is usually loaded with prejudice, stigma, stereotype⁽¹⁷⁾.

In this context, the family plays a fundamental role in the development of their children, as it is through them that their perspectives are constituted, they acquire their experiences, form their self-esteem, learn to make their own decisions, their perceptions of how to see the other and themselves and also how to face and overcome challenges⁽¹⁸⁾. In view of this, the conceptions of families can influence the perception of their children, including their perspective regarding the way of being-in-the-world of the disabled person.

Research has identified that older siblings of disabled children find it difficult to talk to parents about their sibling’s existential condition, making it difficult for them to understand their situation, as well as the need to (re)organize their way of being-in-the-world⁽¹⁹⁾.

In the inauthentic existence, one fears the opinion of the others, of the unknown, for not being in the standards constructed by society, the man denies himself and dives into an individual himself⁽⁸⁾. Thus, when A5 stated to not “pay attention” to the others finding it strange that his brother attends APAE, he overcame the existential facticity of having a disabled brother, overcame the barrier of being and achieved the existence. On the other hand, a study with younger siblings of a person with a mental disability identified that the siblings do not find it difficult to be socially accepted because they are siblings of disabled person⁽²⁰⁾.

In this context, perhaps the way of seeing it as normal, however, with some problem, may be related to the fact that parents also say that to their children. It is understood that such a view is rooted in society, which builds and disseminates a standard of normativity and thus replicates it, often unconsciously, without reflecting on what it really means to be normal. The impersonal ‘takes over’ the being, and the latter begins to act in this way, since the impersonal prescribes the way of being in everyday life⁽⁸⁾. It is in this impersonal that the being is leveled with others, letting themselves be carried away only by the conceptions of “we”, without questioning such conceptions⁽²¹⁾.

The ‘normal’, therefore, is to be always according to others, never to be authentic. In this vertiginous concatenation of personal (in)constitution, in which no one is him/herself, those who show themselves differently, in an authentic way, stand out⁽⁸⁾. Even if this difference is involuntary, as in disability, the different is highlighted in the everyone-who-is-equal-to-everyone mesh. Although involuntary, the disability can be a trigger for the person to constitute himself from it, that is, from what is his own, from what does not come from others. Assuming who you are, the way you were released into the world.

One cannot properly conceive the essence of being ill without a determination of being healthy⁽⁸⁾. Thus, the disabled person exists with a certain existential condition, which can only be compared to him/herself, with no ‘normality standard’ to return to.

From Heidegger’s perspective, it can be understood that the disabled person came into the world with an existential condition and his sibling knew him from the beginning with this condition. Thus, there is no other normality standard for the child/adolescent, as he or she met and related to the sibling with this existential condition.

Therefore, in the normative standards, the biological sciences only consider as normal what can be measured, thus reverberating a certain ‘control’ of the phenomena of existence⁽¹⁾. The norm measures, especially with regard to the normal and to the pathological, thus, the human being enters this social massification and becomes incapable of thinking other way,

which makes it impossible to unveil his own being. Moreover, to be in a pathological state, the human being must have been normal before.

Regarding the norm, it is necessary to recognize that the disease is still a biological norm, thus the pathological state cannot absolutely be abnormal, but abnormal in relation to a given situation⁽¹⁾. However, being healthy and being normal are not equivalent, since pathological is a type of normal. What characterizes health is the capacity to go beyond the norm that defines the instantaneous normal.

Under the same point of view, it is exposed that the norms consider the individuality of people, considering that man seeks to re-signify himself. So, the process of (re)normalization is used as subjective, for each subject in face of his individuality and in face of perceptions of the environment in which he lives in a different way; and, likewise, each medium will relate differently to this man⁽¹⁴⁾.

The disease can be considered a biological norm, in this context, therefore, the pathological state does not characterize an abnormality in the absolute sense, abnormal only to a given situation. However, being healthy and normal are not equivalent in their totality, on the premise that the pathological can be a type of normal. In this premise, health is characterized by the possibility of going beyond the norm that defines the instant normal, tolerating violations of the usual norm, establishing new norms in new situations⁽¹⁾.

Given the above, it is understood that when the person is released into the world with a disability and starts to exist in a different way than expected, he is normal, in his condition.

In this context, the child/adolescent who sees the sibling as normal, has overcome the barriers of a controlling understanding of averages, which are considered a normality standard, with a stigmatizing and limiting view based on values, beliefs, and social expectations that translate it as an incapable, fragile and vulnerable being. Thus, it shows the freedom of *becoming* of the disabled sibling, who shows himself how to be authentic, using his own lenses to see the other.

Faced with the vicissitudes that permeate the existence of the child or adolescent of a disabled sibling, this person is influenced by their own culture. In this context, disability does not seem to be understood and accepted by society, which ends up generating stigmas and judgments in the face of what is unknown and this fact affects the sibling⁽⁶⁾. It should be noted that there is a social construction of what it is to be a disabled person and this influences the conception of the family and the sibling⁽²²⁾. However, networking would enable support and understanding for the child/adolescent and insertion of this population in social environments.

Thus, the child/adolescent is a *being-in-the-world* under construction, which is why he/she is not free from the stigmatizing facts of everyday life that can cause anguish - a privileged source of reflections. The possibility of reflecting on everyday situations and taking a stand in the face of existential facticity allows these children/adolescents an openness to authenticity.

FINAL CONSIDERATIONS

This study allowed us to understand the child/adolescent's perception of the disabled sibling, evidencing their vision regarding their sibling's life condition, regarding their behavior, their way of being, their intellectual capacity, of being a normal person. In addition, it is identified that, in the view of children and adolescents, a lower learning capacity of the sibling or a way that is unique to them, in a special way, does not make them different from other people, considering them the normal, segregating the idea that disability is linked to abnormality, being a matter of perspective of what is imposed as normal, that is, accepting their way of being in the world.

It is important to highlight that the subjectivity of the person, the family and social context are what will guide their thinking, their perceptions about life; about the others, issues related to normality; about disabled people, their perspective and relationship with them. In addition, understanding that differences in being-there constitute their way of being-in-the-world, thus understanding and accepting them is essential to conceive that the condition of disability is not associated with abnormality, but rather, it is an existential facticity.

New research and debates are suggested that allow to advance to an increasingly inclusive society, in this sense, separating the concepts of health, illness, and living conditions is important for advancing on the subject. It is believed that such studies allow discussion about stigma, and minimize judgment in the face of the unknown, the different or what is not understood.

As a limit of the study, it is evident that its object of study was the sibling, as the research could be expanded to other family members, it is also believed that other spaces can be explored with a view to know different cultures and to expand the knowledge on the theme.

However, the study brings important contributions/implications for the practice of health care and education, as from the perspectives of these children/adolescents it is possible to develop strategies for empowerment and appreciation of the potentialities and possibilities of disabled people. In addition, this way of seeing the other in the world is essential for social

inclusion and minimizing stigma and discrimination, as well as enabling other people, who do not experience disability in the family, to reflect and understand the way of being in the world of disabled child/adolescent.

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