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FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES: PERCEPTIONS AND EXPERIENCES OF ADOLESCENT SIBLINGS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

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Abstract

Parents of children with developmental disabilities often report increased stress compared to parents of children with typically developing children (Yazigi, & Mooney, 2005). Hence, there has been interest in whether some siblings in a family environment that includes a child with a developmental disability, and possibly a parent under considerable stress, might also be at risk for adjustment difficulties.

In terms of how siblings adjust to living and growing up with a brother or sister with developing disabilities, there are mixed findings in other countries, whether there are few studies done in Albania. Some researchers report that children with a brother or sister with developmental disabilities are at a higher risk for internalizing and externalizing behavior problems (Fisman, Wolf, Ellison, & Freeman, 2000; Hastings,2003) and for impoverished sibling and peer developing children.

The aim of the study is to explore perceptions and experiences of siblings who have a brother or sister with developmental disabilities. ***Method:*** Semi-structured interviews were used with seven typically developing siblings (age 10-16) who have e brother/sister with a developmental disabilities. Unstructured observation of siblings' interaction were made to better support findings. Also, subjects were asked to keep a diary on their every day relationship with their sibings. ***Importance of the study:*** Since there is little research done on this topic, we hope that exploratory findings will help professionals to a better understanding on what happens to adjustment and coping mechanisms in siblings of children with developmental disabilities. Also, we hope that findings will help enhancing the development of support services for siblings of children with developmental disability.

Keywords: Developmental disabilities, typically developing children, qualitative research, families, siblings

Introduction

Raising a child with developmental disabilities places new demands and challenges to the family. The arrival of a child with disabilities requires reorientation of the expectations parents once had, and it also requires developing new coping strategies from parents. Overall, the studies are based on the experiences of parents of children with developmental disabilities, but few studies focus on the impact that such experience has on typically developing siblings (Fisman, Wolf, et al. 1996). Most of the studies conduct on this issue focus on mothers of children with developmental disabilities (Dew, Balandin & Llewellyn, 2008).

Siblings influence each other within a family in a series of multiple complex ways and these relationships affect the functioning and dynamics of the family system as a whole. Adaptation and development of positive coping strategies of siblings of children with developmental disabilities are very important for the optimal functioning of the family. (Opperman, Alan, 2003).

Studies conducted on families of children with disabilities, indicate that the adjustment of typically developing siblings is influenced by different variables, such as family socioeconomic status, family size, religious beliefs etc. It seems that there is positive adjustment in large families that don’t have financial problems. In contrast to families with low socioeconomic status, which are often overloaded with care giving demands and responsibilities, families with high socioeconomic status are able to address their children needs and to turn to various professionals for help (Opperman, Alant, 2003).

Studies conducted with typically developing siblings show that, regardless of age, they are more likely to report the positive impact that having a brother/sister with disabilities has had in their lives (Dew, Balandin & Llewellyn, 2008).

Children tend to adjust better if they don’t experience feelings of rejection, blame or favoritism by their parents (Opperman, Alant, 2003). However, other studies reveal the negative impact that such experiences can have on families, or variables that jeopardize the adjustment of typically developing siblings. Thus, some studies indicate social isolation of siblings, low self-esteem, problems with adjustment and communication, or limited family interaction (Dew Balandin & Llewellyn 2008; Opperman & Alant 2003).

Siblings, often have to be patient with their brother/sister with disabilities, have to tolerate their disruptive behaviors, whether younger or older in age they report feeling sometimes embarrassed by the disruptive behavior of their siblings in public, or when friends come to visit home.

All these can make typically developing children become withdrawn and socially isolated. Prolonged stress, the burden of living with children with disabilities, care-giving responsibilities, negative coping strategies - all of these can be factors that influence the development of psychological difficulties in typically developing children (Opperman & Alant, 2003, Lainhart1999).

Some other negative effects are psychological disorders such as aggression, anxiety, somatisation, depression and behavioral problems, low self – esteem, low self concept and low social skills (Breslau, 1982; Breslau & Prabucki, 1987; Cleveland & Miller, 1977; Farber, 1960; Fowl, 1968; Gath,1974; Gold, 1993; Grossman, 1972; Lobato, Barbour, Hall, & Miller, 1987; Mc Hale& Gamble , 1989).

Positive experiences generated from growing up with a sibling with disabilities include increased sensitivity, tolerance, responsibility, high acceptance of individual differences and increased social skills (Cleveland & Miller, 1977; Graliker, Fischler, & Koch, 1962; Grossman, 1972; Wilson, Blacher, & Baker, 1989)

Studies report that positive adjustment of typically developing adolescents varies from individual patterns and family characteristics. They tend to cope better if: they live in large families with high socio economic status, if the brothers/sisters with disabilities are younger than their siblings, if there is a big difference in age between them, and if there's not a big impairment due to the disability. (Hannah ME, Midlarsky, Powell TH, Gallagher 1993.Boyce G, Barnett S. 1993)

In examining different sources of stress, Woulbroun and Gamble (1993), report stressors in siblings peer relationship, in parent – adolescent relationship, and in interaction with the wider community.

Stressors in the peer siblings relationship include care-giving responsibilities, and developing self concept.

Problematic issues in parent-child relationship are associated with inappropriate communication, unrealistic expectations, attitudes and practices of parenting and parental adjustment to the situation.

Finally, stressors related to children's peer relationship and their interaction with the wider community includes making friends, perceiving discrimination, feelings of shame, and family isolation. Of course, not all the siblings of children with disabilities experience all of the circumstances described above. However, techniques and strategies for coping or fighting stress are very important. This may explain why some children suffer more because of the family situation, while others adjust better.

A positive attitude towards disability from the parents helps their typically developing children adjust better (Gath, A. 1974).

Siblings tend to develop positive responses and adjust better if they don’t experience parental favoritism (Powell, TH, Gallagher, 1993).

Since no previous studies done in the Albanian context have included perspectives of typically developing siblings living with a brother/sister with disabilities the aim of the present study is to explore and describe siblings’ perceptions, feelings, challenges and experiences. Also, we have tried to compare the findings of this study with findings of studies done in other countries.

Methodology

Interpretive phenomenology analysis (IPA) was the chosen method of analysis in this study.

This approach was chosen for several reasons; Interpretive phenomenology fits best in studies aiming to explore and understand the lived experiences of the participants (Willing, 2002).

Interpretive phenomenology is not just a simple description of the experiences of the participants, but also a process of interpretation, where the researcher makes his own interpretations about the meanings of the lived experiences. Though interpretive phenomenology aims at exploring and describing the experiences of the participants as reported by them, it also implicates the researchers’ perspectives on the issue and on the interaction between them and the participants (Willing 2002). Researchers have their own set of expectations and their personal conceptions on the issue, which might interfere with the process of interpretation. In order to have direct access to the personal meaning offered by the participants, it is important for researchers to critically examine and reassess their perspectives and expectations.

Qualitative research authors suggest applying triangulation in studies designed on the interpretive phenomenology approach , in order to gain a more accurate picture of the phenomenon in question (Yeh & Inman 2007). In phenomenological research data are commonly collected through face-to-face interviews, diaries, notes or documentation (Creswell et.al. 2007).

In the present study we have used three different sources of data collection to ensure a true description of the siblings’ experiences: semi-structured interviews conducted with typically developing adolescents, siblings of children with disabilities, observation, and a diary recorded from adolescents on daily bases for a week.

Sampling and participants

Interpretive phenomenological analyses method involves relatively small and homogenous samples (5-25 individuals) (Creswell et al, 2007). Seven typically developing adolescents, siblings of children with disabilities, were selected to participate in the study, three of them residing in Tirana and four of them in Vlora. The selection criteria was that the participants lived with a sibling diagnosed with developmental disabilities, they were aged between 10-16 years old, and that they were aware of their sibling diagnose. Participation in the study was voluntary.

Table 1.1 gives more detailed information about the participants involved in the study. Participants are described in terms of age, sex, birth order, difference in age between them and their siblings with disabilities, etc.

Table 1.1 Demographic characteristics of Participants

Participants	Sex	Age	Birth order	Nr. Of children in family	Developmental disability diagnose of siblings	Age of the child diagnosed with developmental disabilities
1	F	10	First child in family	2	Autism	5 years old
2	F	12	Second child in family	2	Severe Mental Retardation	19 years old
3	F	15	First child in family	2	Severe Mental Retardation	10 years old
4	F	16	Second child in family	3	Autism	22 years old
5	F	10	First child in family	3	Autism	2 years old
6	F	13	First child in family	3	Moderate Mental Retardation	8 years old
7	F	14	First child in family	3	Autism	6 years old

Methods and instruments

Interviews

Semi-structured interviews were conducted with the adolescents. Since IPA approach requires the researcher to enter into the world and experiences of the participants, we included open and non-directive questions. The purpose of the questionnaire was to provide participants with the opportunity to share their experiences regarding the phenomenon we were studying. Certain questions, more specific, were included in the questionnaire in order to encourage participants to further elaborate on specific issues. The questionnaire items were generated from previous research conducted in the field and on the basis of some preliminary discussions conducted with teens. Items were organized around four main areas: 1. Teen relationship with siblings with disabilities, 2. Teen perceptions about the future, 3. Positive perceived aspects of living with siblings with disabilities, 4. Teens psychosocial adjustment.

The interview schedule was first piloted with one sibling whose interview is not included in this analysis. After this a question was added to the questionnaire.

Each interview lasted an average of 40 minutes.

Observation

Participants were observed by researchers on an average of 7 days. Detailed notes were recorded during interaction of participants with their siblings with disabilities, family interactions, during their leisure time, and in some cases even in the school environment (if participants and their siblings with disabilities went to the same school). Observation schedule was not structured, but it was focused on the nature of the interactions participants had during the day, like care giving, play, fights, etc, and the nature of verbal and nonverbal communication during interaction.

Particular importance was given to nonverbal communication, which provided us with more detailed information. Observation was conducted during different days within a period of 3 weeks. Average length of an observation session was 40-50 min. Observation sessions were conducted both before and after interviewing the subjects.

Diary

Participants were asked to keep a daily record for a week. They were asked to record their daily experiences related to their siblings with disabilities, feelings and thoughts about the situation that they needed to write down in order to help us understand them better.

Diaries were not structured, but teens were given some preliminary guidelines about the records they were going to keep.

Because, usually, keeping a diary is considered to be more demanding, and something very personal, we were aware that we might encounter resistance among the participants. For this reason participants were asked to keep a diary after they were interviewed. The interview enabled the establishment of a relationship between participants, creating a climate of trust and confidence between them and the researchers.

Only 4 of the participants agreed to keep a diary on daily biases.

Interpretative phenomenological analysis

Data analysis went through a few steps. We first conducted a detailed case-by-case analysis of individual transcripts and then integrated each case. Data collected from interviews, observations, and diaries was read several times. Special attention was also paid to every note and comment recorded during the interviews or observations. During the second step we shifted towards a semantic reading of the text. Reading line by line major themes characterizing each section in the text emerged. During the third step we worked with previously emerged themes, giving more structure to analysis. The previously identified themes were discussed in relation to each other.

Topics related to each other, were grouped to form main categories and issues. To ensure reliability and validity of the data coding process the two authors first worked independently to generate topics and issues out of qualitative data. Afterwards, the authors discussed on the topics they generated and compared those topics. At this point, several themes were merged or grouped, to make sure that final main themes were indeed supported by the data.

Ethical issues

During the study attention was paid to ethical issues as described below:

All the parents of the children involved in the study were informed about the aims of the study and the use of data.

Before their involvement in the study approval by both parents and children was provided.

Adolescents were not forced to participate in the study.

Parents and adolescents were informed that they would not have personal benefits from their involvement in the study.

Participants were not forced to answer any of the questions they chose to pass out. Confidentiality was ensured.

Result

After the process of data analysis, findings were arranged in several key themes and issues:

Benefits and positive aspects of the experience.

Despite difficulties siblings encounter while taking care of their brother/sister with disabilities, they reported developing positive attitudes towards a challenge that such e diagnose represents. They described the experience of living with a brother/sister with disabilities as a valuable and an enriching one. Care giving for their siblings with disabilities represented, for them, not just a difficult task to perform, but it was seen as a natural part of their strong relationship as well. They found pleasure in meeting their siblings' needs and in seeing that the relationship between them was strong and significant. A girl says:

“When I'm tired or sad, he makes me laugh. My tiredness or sadness fades away. I feel relaxed thanks to him.”

“He understands me and he just hangs out with me, he gives me lots of love.”

All participants stated that living with a brother/sister with disabilities had good impact on them in several aspects. They mentioned that this experience was a challenge in itself, a unique experience that makes them different from their peers, that makes their families different from other families. All subjects when talking about this experience, also associated it with the joy and pleasure they felt anytime an improvement took place, no matter how small it was, considering it quite rewarding in itself.

They reported that they tried to focus more on the positive aspects of their experience by keeping a positive attitude.

They talked about the positive impact that their siblings with disabilities had in the welfare and unity of their families, bringing family members together, improving their mood and their family’s mood.

A teenage girl says: "*When we’re upset, my brother is like a cure to me and to my family*".

Adolescent participants recognized that this experience helped them be more responsible, become more compassionate, altruistic, tolerant and loving toward people. They also claimed that they were sensitive to injustice or discrimination.

“The relationship with my brother helped me become more responsible than ever before. I feel more mature. By doing things for my brother I feel that what I do is worth and it has a meaning to me.”

Responsibilities and care for the needs of the brother / sister

All participants admitted that taking care of siblings with disabilities meant a lot of responsibilities to them. Although none of the participants was the primary caregiver for the sibling with disabilities, they reported being involved in different tasks like responding to their siblings’ physical and emotional needs, helping them in their education, watching over them, and walking them to school or to the kindergarten. According to participants, involvement in care giving is as a result of the family collaboration and of the the pleasure they find in taking care of their sibling with disabilities.

A teenager claims *“I love to help my brother. Me and my family, we are all one for my brother; we all work in group for one purpose, like the fingers of a hand.”*

As reported by participants, not only parents actively ask them to take care of their sibling with disabilities, but they themselves have developed an inner sense of responsibility toward their siblings as well. They report taking care of their siblings as something that comes naturally, as a responsibility that is part of them now, which even if they were tired or would like to do something else could not be avoided. Thus, one participant said that she took care of her brother almost all day long and added that:

"*The only difference between me and my mother when it comes to my brother is that she is the one who gave birth to him*."

However, the burden of numerous tasks during the day and numerous needs of their siblings put different restrictions to the participants' lives. They could not attend all the social activities they wanted to and didn't have much time for themselves or their personal interests because of the lack of time. Sometimes they could not attend certain places where they could not bring their siblings with them, and other times they just felt exhausted to do anything else. Care giving was a consuming work. One of the participants said:

"Very often I can not get out or do something that I like, because I have to look after my brother."

Another one said: *"Some desires I can not meet, because we can't take the brother along with us"*

During the interviews, the negative emotions that arise in such situations were expressed in a limited way, followed immediately by the expression of positive feelings toward the brother / sister just to balance the negative emotions. A 12- year- old says:

" l get bored, sometimes he drives me crazy, tears my books (the brother), but can not get angry with him because he is sick, and ... I love him, he is my brother".

In the diaries recorded from the subjects, the latter were more likely to talk about nervousness, anger, frustration, physical and psychological exhaustion caused by involvement in the care of brother / sister with the disorder.

Young people consistently exhibited an ambivalent position between the desire to provide care, rewards and pleasures that had in caring for the brother, as well as the difficulty of this assignment.

Implications on the social circle of the adolescents

This topic describes the social relations of youth, the impact brother / sister with disabilities has on their social lives and their feelings and experiences in their social group.

All young people said they enjoyed good relations with lots of close friends at school and in the community where they live. However, they say their time is limited and that they have already abandoned many social activities, due to the hyperactive behavior of brother / sister and in some cases they experience shame from the others' response. This, in some cases, has led to the isolation of some young people who find difficulties in holding social relations.

When it comes to their social circle, the subjects reported that due to the disruption of brother / sister, they often feel prejudiced, misunderstood or rejected, and the disturbance of the brother / sister can easily become subject to harassment and ridicule in class. Subjects feel that others do not easily accept people with disorders or disabilities. They claim they do not talk to others about the disorder of the brother / sister, and if someone asks about it they tend to avoid it. Even less do they share with their friends the negative emotions (like anger, frustration) they may have towards the parents or the brother / sister with disability, when they are constrained to limit their time and activities to care for brother / sister. One interviewee agrees:

“If I have an argument with my classmates, they laugh at me and say - your brother is crazy, you're a family of freaks”

They described feelings of shame, embarrassment, anger, anxiety and loneliness in such situations created by their peers.

A 13- year-old says :*"I feel very lonely in class when they mention my brother to tease me, I feel like crying."*

This constitutes an explanation of the reason all the subjects admitted they do not like to talk about the brother / sister with disabilities in company of their friends and avoided the argument whenever they could. During the observations, R. which studies at the same school with her brother, seemed embarrassed from him, wanted to avoid or reduce contact with him , felt angry and frustrated by the taking care of her brother when in school.

Another challenging situation is the difficulty to manage the strange behaviors of the brother / sister in social environments, the shame of others and a strong desire to protect the brother / sister. A girl studying in a school with the brother says:

"He disturbs me during classes, does not let me learn and even nag my classmates"

However, among more mature siblings an improvement of social relations and greater appreciation from others was observed. This came as a result of the commitment toward their brother, or because they had a more positive perception of adolescents who are ready to make sacrifices for brothers / sisters. A 16 - year-old participant says:

“My friends praise me a lot saying your brother couldn’t have a better sister. They keep even closer to me. ”

Family interactions

This topic describes the role of parental treatment and attitudes of parents toward their own brother / sister regarding the adaptation, the feelings and attitudes of young people to the situation.

Siblings reported that the positive attitude of parents and their acceptance of the situation had a direct impact on their personal attitudes. In the cases where parents had already accepted the brother / sister disorder and were optimistic about his/her performance, the siblings themselves felt more comfortable, cooperative and were positive.

The perceived impact that a child with developmental disorders has within the families, varied in different subjects. Thus, four of the subjects claimed to not speak with their parents on the disorder of the brother / sister, and even less about those negative emotions towards the situation. They claim that there is not much to say about this, and avoid asking parents about the disorder of the brother / sister.

A 13- year-old says:

"I do not have much time to talk about these things at home, D. is ill and that is all. What is there to talk about with my mother? Plus she gets upset when asked about this. "

The fear siblings had they might hurt the feelings of their parents, or say something wrong was another sub-topic discussed by these young people. It can also be an explanation why they avoided conversations about the brother /sister disorder, as well as negative feelings towards them.

All subjects claimed to feel no difference in their parents' love for them or their sister and brother with disorder, but claimed that there were changes in the attitudes and behaviors of parents. They showed more tolerance towards the child with disabilities, by increasing their demands for them and on the other hand paying more attention to the children with disabilities. But everything was justifiable from the special needs the brother / sister had. All subjects said that they happened to feel jealous of brother / sister with a disability, but that these feelings quickly faded away, just reminding themselves the brother / sister has special needs and that parents cherish the same love and affection for both of them.

One participant accepts:

“I feel bad because I'm the only girl and l would like more attention. I understand that my brother has stronger needs than me and I ‘m sure they love me just as much as him. If I have any desires, they are always there for me.”

Meanwhile, during the observation sessions, there were no signs of jealousy observed from the subjects.

Discussion Of Results

The study aimed at exploring and describing the experience of having a brother / sister with disabilities, focusing on the relationship among children, the positive aspects of experience, the role of parents, taking care of them and the difficulties of youth in society.

As revealed by the existing literature siblings of children with disabilities are much involved in caring for children with disabilities (WC Gamble, Woulbroun, 1993). They are involved in caring for their physical needs, socializing, walking, supervision, entertainment and education. However, previous studies show that young people are more involved and have more responsibility in the families with a low socio - economic level (Opperman, Alan, 2003). While in our study, young people, who are not the primary care-takers of children, have a more significant role and the extent of their commitment is very high, so the nature of their duties is similar to many parental duties. Previous studies also provided social constraints, stress, and psychological difficulties associated with the increased workload. (Opperman & Alan 2003, Lainhart 1999). However taking care of the brother / sister is not considered a burden, and many of the subjects accomplished these tasks related to the brother / sister with pleasure. This stemmed from the strong relations between family members and the close significant relationship between children. It seems that the young subjects are taught to care for the brother / sister with disabilities and this has now become a natural part of their daily life. They even assume atypical roles sometimes.

Also, even though building a relationship with a person with mental disabilities may present challenges due to difficult communications and different interests, cognitive problems and limited opportunities, the subjects in this study had managed to establish a close relationship with the brother / sister. They spend a lot of time playing, working or just hanging out together. They felt satisfied and rewarded by this relationship, overcoming innumerable challenges related to health problems.

On the other, the study shows that even though caring for a child with disabilities was a family effort, the burden of tasks, fell more on girls than boys. This is a unique finding that deserves further research.

The study showed that subjects appreciate the positive impact that brother / sister had in their life and family. Previous studies emphasized the personal benefits and positive qualities that young people had developed. (Cleveland & Miller, 1977; Graliker, Fischler, & Koch, 1962; Grossman, 1972; Wilson, Blacher, & Baker, 1989).

The study however confirmed that also the family had many benefits, they had become more united and co-operative, and the teamwork was strengthened within the family. Also, the disabled child had a good effect on mood and positive feelings of the teenager and the whole family. Even this finding requires further study to explore the impact on cohesion and family dynamics.

According to Gamble and Woulbroun siblings of children with disabilities may suffer discrimination, feelings of shame and isolation of the family. In fact, even though all agreed that care for the brother / sister was consuming and straining, the most stressful experiences and episodes of adolescents related to discrimination, stigma and prejudice from the peers and other important people. Strong desire to protect, the compassion they felt toward toward their siblings when others treated them badly and embarrassing behavior in social environments provoke avoidance of these situations, in normal social conversations, and the avoidance of activities and different social environments. Even this situation in many cases has had a significant impact on the type of social interactions, leading in some cases in isolation of adolescents and limiting their social commitments.

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