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Developing the resilience of families with children with special needs

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Abstract. People frequently seek counselling at times of crisis or change. A current precipitating event such as a major life event (e.g. from married to widowed or single, have children with special needs) may spur a person to seek help. Our objectives for this paper are: the assessment of resistance and attachment levels of the families with children with neuro-developmental disorders and evaluating how the parental quality of life is perceived after applying the individualized intervention on the child with special needs.

Keywords. children with special education needs, family resilience

1. Introduction

With regard to the determinants of *family resilience*, there was a consensus that the empirical study of this construct needs to be approached from a multiple level of analysis perspective that includes genetic, epigenetic, developmental, demographic, cultural, economic, and social variables.

The empirical study of determinants of resilience will inform efforts made at fostering resilience, with the recognition that resilience may be enhanced on numerous levels: individual, family, community, culture. (Southwick S., 2013)

Bayat M. (2007) consider that “family resilience is a growing field of inquiry, investigating factors that contribute to a family's becoming stronger in spite of dealing with adversity. Despite the growing interest in studying family resilience, the topic has not been explored in families with children with disabilities.

This report is an examination of factors of family resilience in the families of children with neurodevelopmental disorders such as autism. Upon understanding that they have a child with special educational requirements, parents often change their entire life and dedicate it to the child with special educational needs. In this paper we have described some activities for the whole family, for increasing family resilience. Most of the time, the couple no longer finds ways to relax or detach from the child's problems and from here comes a multitude of problems in the couple relationship. Evidence of family resilience such as family connectedness and closeness, positive meaning-making of the disability, and spiritual and personal growth were identified and examined in this part of the study”. (Bayat M., 2007)

The autism spectrum disorders are part of the neurodevelopmental disorders.

“***The autism*** is a developmental general and early disorder which appears before the age of 3 and it is characterized by a deviant functioning, more or less tardy in each of the following fields: social interactions, verbal and nonverbal communication, and behaviour.” (Vrăsmaş E. 2008, p.189)

In 1943, Leo Kanner clearly distinguished between a specific syndrome (autism) and all other disabilities. He emphasized a series of characteristic features among which the most important are the following:

- The inability to adopt a normal position while held, even as a baby;
- An enhancement of rote memorization;
- The inability to communicate verbally;
- The inability to use abstract concepts;
- Fear and enhanced emotions;
- The inability to use imagination when playing;
- The delayed (re)production of echolalic speech/manifestations;
- The perception of a normal physical and intellectual development;
- Isolation and withdrawal;
- Unmotivated attachment to insignificant objects;
- The inability to see/understand real danger;
- The occurrence and development of ritualistic behaviors;
- The exaggeration of certain movements and their lengthy repetition;
- The existence of certain paradoxical answers to light, noise, and pain stimuli etc.
- The presence of certain stereotypical and repetitive behaviors;
- Awkward reactions to changes in the environment;
- Difficulty to communicate verbally and non-verbally, etc. (Kanner, 1943)

Lauretta Bender discussed the possibility of an early diagnosis for infants.

She described a few specific behaviors:

- Prior to 3 months of age, the feeding is very slow (the infant feeds slowly);
- The feeding time is lengthy and tiring for the mother;
- Past the age of 3 months, the infant does not smile or act alert;
- Lack of reaction to verbal stimuli;
- A lack of communication through gestures or screams;
- The infants are quiet and reserved with the people who surround them;
- They do not play with the objects and with the people who surround them;
- They play with their hands, which they watch very carefully;
- Between 7-12 months, babies do not appear to recognize their mother. (***Lauretta Bender***)

The DSM V model revealed other criteria used to **diagnose the autistic disorder:**

a. Difficulties in establishing social interactions

- Difficulties in using the nonverbal language/ behavior: a poor or absent mimicking and gesturing; an inappropriate tone or voice inflections; avoiding looking the others in the eyes; having difficulties in estimating the physical distance to other people;
- Difficulties in forming friendships with other children (or the absence of friendships): the number of friends is very small or non existant; if present, relationships are only

built around certain special interests; they are mostly friends with adults (especially family members) or with older children; they have difficulties in following the rules of the games, especially those rules that require cooperation, which leads to problems when working in groups.

- The inability to show positive emotions: happiness, achievements or interests are expressed with difficulty; they prefer individual activities (watching TV, playing by themselves).
- The inability to react to others, socially and emotionally: they do not observe the others and/or are indifferent when others are present; they do not hear the others, they 'seem deaf'; they do not react when others suffer and they lack the ability to comfort others.

b. Difficulties in Communicating

- The child uses language to communicate very little (or not at all): they do not pronounce words until they are 2 years old, or simple sentences until they are 3; if they do speak, they use the words grammatically incorrect, and the sentence is flawed.
- They have difficulties in carrying on a conversation: they lack the ability to initiate, maintain or end a dialogue; they have the tendency to speak uninterruptedly, without needing anyone's opinion, to the extent of almost carrying out a 'monologue'; they answer questions only if asked directly; if they are not interested in the topics, they speak with difficulty, and do not make any comments.
- They repeat what they say, and most of the times, they make no sense: echolalia (they repeat what they think the others are saying, what they hear on TV or radio, or from books, but this repetition only makes sense for themselves; they may speak like 'a professor', meaning they may use academic and formal language).
- They engage in games that are not suitable for their age: in imaginary (symbolical) games with few toys or scenarios; they use the toys in a concrete way (for example, a banana will never be used as a phone; they will not use blocks or lego to build; they do not engage in social games (for example, "the stone bridge"), and they show very little interest in such games.

c. Narrow fields of interest, repetitive behaviors and activities

- They show an increased interest for some topics to the detriment of others; they cannot ignore or let go of what they like easily; the topics that interest them tend to be unusual for their age (for example: astrophysics); for those subjects that interest them, the details are memorized easily;
- They engage in repetitive activities, and they insist very much (and unjustifiably so) on doing them in a specific order; they do not like any changes, and if something were to change in their routine (even minor changes), they become upset, anxious and even aggressive (for example: if there are any changes in the way home from school);
- Repetitive motor skill activities or motor tics (for example, they clap when happy or upset);
- They become very interested in different parts of certain objects (for example: the doll's eyes, the cars' doors or wheels); they use their senses to understand certain qualities of the objects (for example, they like to smell certain objects); they develop an increased interest or attachment for unusual objects.

According to the DSM 5-TR definition, to diagnose a child with autism, he/she needs to lack in 3 big developmental areas: “*a poor social interaction, difficulties in communication, narrow interests and repetitive behaviors*”. (**Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR), 2022**)

If a child shows at least 6 of the 12 symptoms previously discussed, he/she is autistic. To identify each symptom, we need to carefully analyze each of their behaviors. To be considered autistic, a child needs to present 2 symptoms for social interaction, at least one communication-related symptom, and at least one symptom related to repetitive behaviors or narrow fields of interest. *The family system* represents a critical context within which children develop. Although raising a child with a disability may represent a challenge to this dynamic system, research demonstrates that families have the capacity to demonstrate both maladaptation and resilience in the face of related stressors.

For example, in a study, Gardiner, Mâsse, and Iarocci (2019) examined “the psychometric properties of the Family Resilience Assessment Scale (FRAS) among families of children with autism spectrum disorder (ASD).

This tool is the only measure of family resilience that seeks to identify within-family protective factors, including the extent to which they rely on adaptive belief systems, organizational patterns, and communication processes.

Identifying protective processes utilized by those who show resilience is critical within both clinical practice and research, as it aligns with a strength-based perspective that builds on what families are doing well.” (*Gardiner, Mâsse, and Iarocci, 2019*)

2. The experimental research

2.1. The goals of the research

1. Evaluating the resistance and attachment levels of the families with children with neuro-developmental disorders
2. Evaluating how the parental quality of life is perceived after applying the individualized intervention on the child with special needs

2.2. Methods of the research

The researchers used the following instruments in this study:

1. **The Global Quality of Life Test (QOLI), Michael B. Frisch, Ph.D.**
2. **Resilience assessment questionnaire (RAQ, Siebert, 2005)**

2.3. The research results

The researchers hypothesize that there will be a positive correlation between the level of resilience and the parental quality of life after the implementation of the intervention on children with neurodevelopmental disorders.

There were 40 participants in this study; they were all parents of children with neurodevelopmental disorders from Constanta County, Romania. In this paper, we chose to talk about the families of children with autism, as we know autism imposes special educational requirements, but we also leaned on family, couple, couple strapping, attachment style, quality of lifestyle, and couple satisfaction.

We next compare the samples, using the T Test for the independent samples.

Group Statistics

	Intervention plan	N	Mean	Std. Deviation	Std. Error Mean
Attachment	Before applying the experiential program	40	120.20	10.471	1.656
	After applying the experimental program	40	128.50	9.441	1.493
Resilience	Before applying the experiential program	40	58.25	10.157	1.606
	After applying the experimental program	40	68.55	11.059	1.749

Fig. no.1 Comparison of the averages of the variables before and after the psychological intervention for family

There is an increase in the average of the attachment variable (DAS) after the intervention: this is now 128.50, compared to 120.20 – its initial value, before the intervention.

The average of the resilience variable shows an increase in the average from 58. 25 (the average at the initial testing) to 68.55 after the individualized intervention.

Independent Samples Test

	Levene's Test for Equality of Variances	t-test for Equality of Means									
		F	Sig.								
									Lower	Upper	
Attachment	Equal variances assumed	.532	.468	-3.723	78	.000	-8.300	2.229	12.738	-3.862	
	Equal variances not assumed			-3.723	77.1	.000	-8.300	2.229	12.739	-3.861	
Resilience	Equal variances assumed	.007	.933	-4.338	78	.000	-10.300	2.374	15.027	-5.573	
	Equal variances not assumed			-4.338	77.4	.000	-10.300	2.374	15.027	-5.573	

Fig.no.2. T-test for Equality of Means

The above findings show a significant statistical difference for both the attachment variable, as well as the resilience variable, for both variables this difference being under 0.05.

After implementing the individualized intervention plan, we can confirm that the parents of the children show a higher degree of resilience, and there is an increase in the quality of the couple adaptation, the averages of both variables being higher after the intervention, than before it.

3. Conclusions

It should be noted that the parents and the siblings of the children with special needs, also need therapy in order to better understand the situation and to be able to adapt to a new life, because in the end everything changes for a family. By changing a family, we are actually talking about changing the lives of its members.

Lately more and more couples have shown a low resilience to the problems they face. They fail to find strategies to increase resilience and most of the time, upon learning that they have a child with disabilities, autism, neurodevelopmental problems or other associated problems, they often end up divorcing. A diagnosis puts a lot of pressure on the partners of the couple, most of the time they end up blaming each other for it then the family falls apart.

At the same time, we focused on the couple with children who have special needs, applying profile tests before and after implementing an individual therapy plan for the child, which has led to remarkable results both within the couple and for the child. We applied tests depriving the quality of life as well as the diadic consensus in the couple, attachment, cohesion in the couple, affective expression and satisfaction in the couple.

This paper aims to continue in the future by finding, shaping and implementing more comprehensive strategies and therapeutic plans on each couple.

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