



THE ROLE OF FAMILIES TO DIMINISH THE SOCIAL COSTS OF DISABILITY

Loredana Adriana PĂTRĂȘCOIU

Constantin Brâncuși University

Anca LASCU

University from Bucharest

Abstract: The main aim of this study is to investigate the relationships between family functioning, parents' perceptions of quality of life and the well-being of the child with ASD. The study highlights how the perceived impact of the child's diagnosis influences family balance and how, in turn, this balance is associated with the child's well-being and the quality of life felt by the parents. The research involved 34 parents who have a child with ASD, and used: the Whoqol-Bref Scale and the PedsQL Quality of Life Inventory, the PedsQL General Well-Being Scale and the PedsQL Family Impact Module forms. The high significance of the correlations reinforce the idea that functional balance within the family system can have a favorable impact on the child's psycho-emotional well-being, especially in the context of disability conditions. This paper is also a signal for Romanian society to intervene through the appropriate services to support the family starting with the moment of receiving the diagnosis of ASD because these services can save the relations and social functions of family and also to ensure a better evolution for the child.

Keywords: ASD, family functioning, child well-being, perceived impact, quality of life

Contact details

of the author(s): Email: loredana.patrascou@e-ucb.ro

INTRODUCTION

Exploring various definitions of the family, Godeanu A. (2023) offers a systemic perspective related with multidimensional approach of family therapies as:

- Homeostasis system, a system that maintains balance and resists external changes (Don Jackson, 2004).
- Emotional relationships system- focuses on individual family members and their interactions with others (Murray Bowen, 1961-1966).



- Internalized system of relationships- describes the dynamics within a family, where members may feel included or excluded, influencing their internal representation of the family (Laing, R.D. 1994/2016).
- More than a sum of individuals, highlights interactions within the family according to explicit or implicit rules, forming a structure (Salvador Minuchin, 1998).
- Communication lens -defines the family through communication therapy, emphasizing honest and effective communication (Virginia Satir, 1972).
- Open system that features clear boundaries for the predictable exchange of information (Jay Haley, 1963 and Cloe Madanes, 1981).
- Biopsychosocial microstructure: Views the married couple as a complex interactional process (Mitrofan, N. 1989, 2011).

The same author, Godeanu A. (2023), highlights that the family is socially invested with various functions, such as:

- support function because family members understand and support each other to fulfill individual or family needs, ideals, and plans;
- communication function that involves transmitting attitudes, values, principles, and behavioral patterns, particularly to children, to assimilate a certain social group's characteristics;
- problem solving function means family members adopt strategies to resolve difficult situations and existential crises;
- continuity function- the sexual-reproductive aspect involves mutual sexual satisfaction of spouses and childbirth;
- relationship function manages intersubjective exchanges within the family and interactions with the broader community or society;
- needs satisfaction function -family members meet various needs, ranging from basic to higher-level needs;
- economic function ensures material and financial resources for the family's existence, including planning the family budget (housing, food, clothing, etc.);
- decision-making function involves making essential family life decisions, such as marriage, living arrangements, having children, and education.

From a legal point of view, parents have the right and duty to raise the child, taking care of his physical, mental and intellectual health and development, of his education, learning and professional training, according to their own beliefs, the child's characteristics and needs; they are obliged to give the child the guidance and advice necessary for the proper exercise of the rights that the law recognizes.

Sánchez Amate, J. J., & Luque de la Rosa, A. (2024) noticed that caring for a child with ASD often leads to increased stress and tension between parents, resulting in conflicts and reduced marital satisfaction. The emotional demands and responsibilities of caring for a child with ASD can cause dissatisfaction and disagreements on care strategies and necessary interventions. This stress may also impact relationships with other family members, such as siblings, who might feel neglected or resentful due to the focused attention on their sibling with ASD.

Social interactions outside the immediate family can also be affected, as caregivers may find it difficult to maintain social relationships due to the demands of caregiving. Limited time for social activities and the stigma associated with the child's behaviors in public can contribute to feelings of isolation and a diminished social support network.



Overall, caring for a child with ASD can alter family dynamics and affect interpersonal relationships, underscoring the importance of providing support at both the family and social levels to mitigate these effects and strengthen family cohesion.

MAIN TEXT

The main purpose of this study is to investigate the relationships between family functioning and parents' perceptions of quality of life, aiming to highlight how the perceived impact of the child's diagnosis influences family balance and how, in turn, this balance is associated with the child's well-being and the quality of life felt by the parents.

Study hypotheses

Hypothesis 1: Parents who perceive a lower impact of the child's disorder on family life tend to report a higher quality of life.

Hypothesis 2: Parents who perceive a more balanced family functioning tend to report a higher state of well-being for their child.

Hypothesis 3: Parents who benefit from quality social relationships and social support perceive a more balanced family functioning.

A total of 34 respondents participated in the present study, representing parents who have a child diagnosed with ASD. Participants were selected based on the eligibility criteria (to be parent of an ASD diagnosed child) and completed a series of validated psychometric instruments, which assess the impact of the child's diagnosis on the family, the child's well-being and the quality of life felt at the individual level. In terms of gender distribution, 91.2% of the respondents were female (n = 31), and 8.8% were male (n = 3). All participants are parents of children with ASD, all coming from urban areas. The average age of the respondents is between 30 and 45 years, and the level of education is predominantly higher (bachelor's and postgraduate studies).

All participants were informed about the purpose, procedure and confidentiality of the study, and participation was only based on informed consent, signed in advance. Each person completed an agreement on the processing of personal data, in accordance with Regulation (EU) 2016/679 (GDPR). The study was conducted in accordance with the ethical norms of the Code of Ethics for the Psychologist Profession. No material rewards were offered to participants, but explanations of the results were provided upon request. All adult subjects gave their consent to participate in the study.

The Whoqol-Bref Quality of Life Scale and the PedsQL Quality of Life Inventory were completed during individual sessions. Parents were informed and assured of the confidentiality of the data and information provided by completing the questionnaires. They also acknowledged that there were no right or wrong answers, that there was no time limit and that they could ask questions if they did not understand an item. To facilitate the completion of the questionnaires, they were transposed into Google Forms.

The WHOQOL-BREF (World Health Organization Quality of Life - Brief) is a questionnaire with 26 self-report items. It assesses an individual's perceived quality of life across four major domains:

- physical health,
- psychological well-being,
- social relationships, and
- environment.

This tool provides a quick and culturally relevant measure of health and well-being, making it useful for both clinical and research purposes.



The PedsQL instrument is a set of questionnaires developed by Varni et al. (1999) to assess the quality of life of children and adolescents, from their own and parents/legal guardians' perspectives. Two forms were used in this study:

- A) PedsQL General Well-Being Scale is a questionnaire addressed to parents regarding the quality of life of their children. The questionnaire consists of 6 items that refer to the child's perception of himself from the parents' perspective and a general item, referring to the child's health status.
- B) The PedsQL Family Impact Module is a questionnaire addressed to parents who have a child with health difficulties and problems and assesses the impact of the child's diagnosis on family members. Responses are provided from the perspective of how much aspects of the parents' lives have been affected by the child's health condition in the last month.

The PedsQL Family Impact Module includes 36 items, distributed across 8 dimensions. The 8 dimensions are: physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worries, daily activities and relationships between family members.

Discussion of the results

Hypothesis 1: Parents who perceive a lower impact of the child's disorder/diagnosis on family life tend to report a higher quality of life.

There is a significant positive relationship between the perceived level of family functioning and adaptation (total impact score) and general quality of life and health. To examine the relationship between the perceived impact on the family (assessed by the total impact score from the PedsQL Family Impact module) and the global perception of quality of life and general health (assessed by the specific subscore from the WHOQOL-BREF), the Spearman correlation coefficient (rho), suitable for non-normal distributions, was applied.

Table 1

Spearman correlation between total family impact score and overall quality of life and health

Correlations

Spearman'srho	<i>Total family impact score</i>	<i>Overall</i>		
		<i>Total family impact score</i>	<i>quality of life and health</i>	
		CorrelationCoefficient	1,000	,364*
		Sig. (2-tailed)	.	,034
		N	34	34
		CorrelationCoefficient	,364*	1,000
		Sig. (2-tailed)	,034	.
		N	34	34

*. Correlation is significant at the 0.05 level (2-tailed).

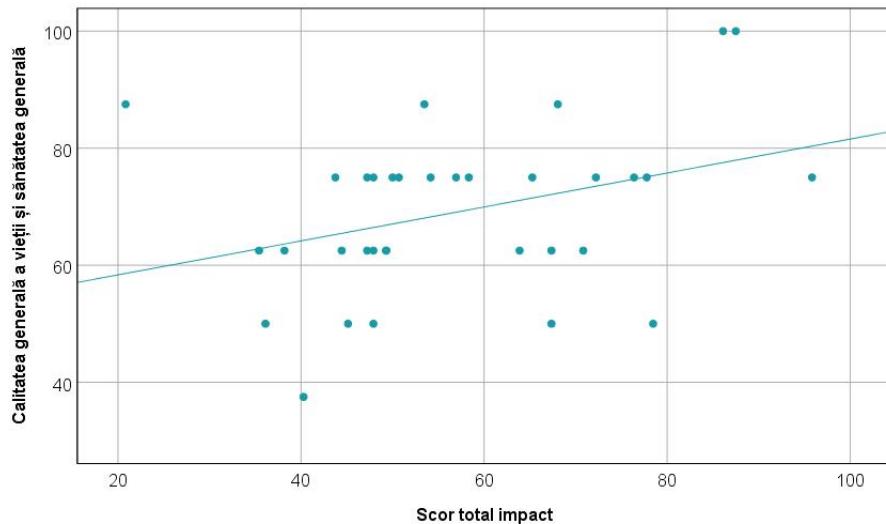


Figure 1 Scatterplot illustrating the relationship between perceived family impact (PedsQLFamily Impact Module) and overall quality of life and general health (WHOQOL-BREF)

The results indicate a statistically significant positive correlation between the two variables, with a correlation coefficient value of $\rho = 0.364$, at a significance level of $p = 0.034$ ($N = 34$). This means that as the total impact score increases (i.e. the negative impact on the family is reduced), the parents' perception of their own quality of life and general health improves.

Although the magnitude of the correlation is moderate, the result is statistically significant and supports the hypothesis that family well-being is associated with a positive assessment of their own quality of life among parents of children with medical needs.

Hypothesis 2: Parents who perceive more balanced family functioning tend to report higher wellbeing for their child.

There is a significant positive relationship between the level of family functioning and child well-being. To explore the relationship between general family functioning and child well-being, Spearman's correlation coefficient was used, given the possible non-parametric nature of the data. The variables were assessed by the “Family Functioning” subscale of the PedsQLFamily Impact Module and the child well-being score of the PedsQL General Well-Being Scale.

The results indicate a statistically significant positive correlation, with a coefficient $\rho = 0.546$, at a significance level of $p = 0.001$ ($N = 34$). This result suggests that more effective family functioning is associated with higher child well-being, as perceived by parents.

Table 2

Spearman's correlation between family functioning and child wellbeing

Correlations

			Family functioning	Child wellbeing
Spearman'srho	Family functioning	CorrelationCoefficient	1,000	,546**
		Sig. (2-tailed)	.	,001
	N		34	34
Child wellbeing		CorrelationCoefficient	,546**	1,000
		Sig. (2-tailed)	,001	.

**. Correlation is significant at the 0.01 level (2-tailed).

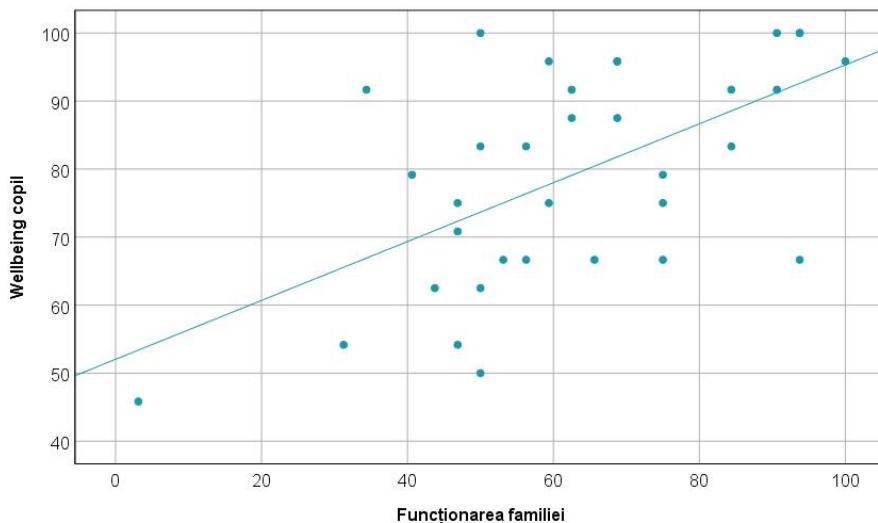


Figure 2 Scatter plot illustrating the relationship between family functioning (PedsQL Family Impact Module) and child well-being (PedsQL General Well-Being Scale)

Hypothesis 3: Parents who benefit from quality social relationships and social support perceive more balanced family functioning.

There is a significant positive relationship between the quality of social relationships and family functioning. To assess the relationship between the quality of social relationships and general family functioning, the Pearson correlation coefficient was used, given that both variables are continuous and according to normality tests. The results indicate a statistically significant positive correlation between the two variables, with a coefficient of $r = 0.490$, at a significance level of $p = 0.003$ ($N = 34$). This indicates that people who report a better quality of social relationships (e.g. social support, close relationships, satisfaction in interpersonal interactions) tend to perceive a more efficient family functioning in everyday life, including in the context of managing the child's diagnosis.

This relationship is of practical significance, as it suggests that external relational resources can contribute to maintaining a functional balance within the family, by reducing parental stress and increasing resilience in the face of difficulties.

Table 3

Pearson Correlation Between Social Relationships and Family Functioning
Correlations

		Social relationship	Family functioning
Social relationship	PearsonCorrelation	1	,490**
	Sig. (2-tailed)		,003
	N	34	34
Family functioning	PearsonCorrelation	,490**	1
	Sig. (2-tailed)		,003

**. Correlation is significant at the 0.01 level (2-tailed).

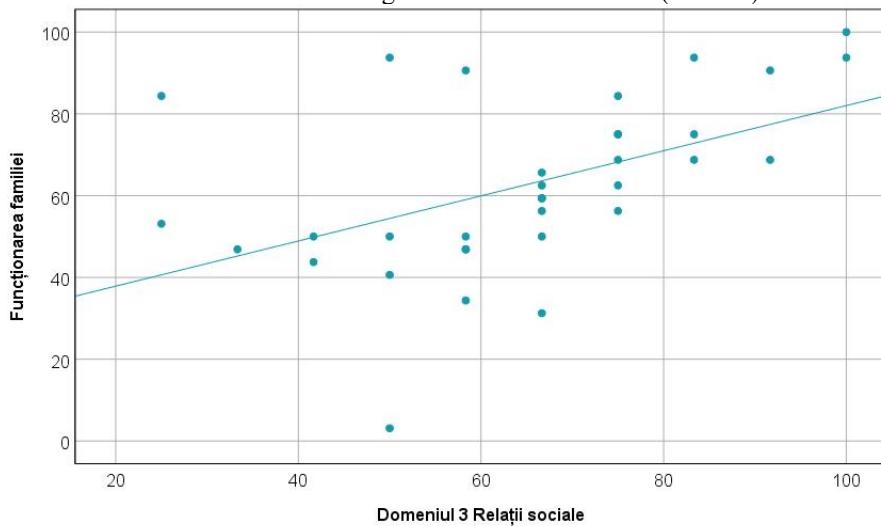


Figure 3

Scatterplot illustrating the relationship between the score for social relationships (Domain 3 – WHOQOL-BREF) and family functioning (PedsQL Family Impact Module)

CONCLUSION

Even though our research is conducted with a sample of parents who use private therapies for their children with ASD, this fact indicates the financial stability of the family. This paper excluded the poverty variable that significantly affects family relationships and that we want to investigate in a future study.

This paper draws attention to the need for intervention at the social and community level so that the family of the child with ASD receives the social support that it needs to be able to support a positive evolution of the child with special needs. We know that only few families survive the test of ASD diagnosis without falling apart. Awareness by parents, but also by society / community about the results highlighted by the study, as well as the preparation of medical and psychological services can bring significant positive developments both in the couple's relationships and in the positive evolution of the child with ASD (the family being the most important space of belonging that provides stability and harmonization).



REFERENCES

Bronfenbrenner, U. (2005). Making Human Beings Human: Bio-ecological Perspectives on Human Development. Thousand Oaks: Sage. (us.sagepub.com)

Godeanu A. S.,(2023). Manual de psihologia cuplului și a familiei. București: Editura Sper

Sánchez Amate, J. J., & Luque de la Rosa, A. (2024). The Effect of Autism Spectrum Disorder on Family Mental Health: Challenges, Emotional Impact, and Coping Strategies. *Brain Sciences*, 14(11), 1116. <https://doi.org/10.3390/brainsci14111116>

Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial

Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL: Measurement model for the pediatric quality of life inventory

Varni, J. W., Sherman, S. A., Burwinkle, T. M., Dickinson, P. E., & Dixon, P. (2004). The PedsQL Family Impact Module: Preliminary reliability and validity

Rusnac, V. (coord.) & Curilov, S., Guzun, O. (et al.). (2017). Incluziunea educațională a copiilor cu tulburări din spectrul autist: Ghid metodologic. Chișinău: Tipografia Centrală

Winnicott, D.W. (2013). Copilul, familia și lumea exterioară. București: Editura Trei