

T. Gosztyła¹, A. Prokopiak²

¹ Department of Psychology, University of Rzeszów, Poland; ² Faculty of Pedagogy and Psychology, Maria Curie Skłodowska University, Lublin, Poland

Mediating role of lack of support for the relationship between extraversion and sense of loneliness in parents of children with autism spectrum disorder and parents of children with intellectual disability

Summary

Objectives

Parents of children with autism spectrum disorder (ASD) as well as parents of children with intellectual disability (ID), in addition to stress related to a child's disability, may experience loneliness and social isolation. The purpose of this study was to verify the mediating role of actually received and perceived available social support in relationship between extraversion and sense of loneliness in parents of children with ASD and parents of children with ID.

Methods

168 parents of children with ASD and 111 parents of children with ID, without autistic traits, participated in the study. The following research tools were used: De Jong Gierveld Loneliness Scale (DJGLS) in the Polish adaptation; Polish adaptation of Ten Item Personality Inventory (TIPI): TIPI-PL; Berlin Social Support Scales (BSSS) – Polish version and a survey questionnaire.

Results

It was shown in group of parents of children with ASD that extraversion weakens the sense of loneliness through the perceived available social support ($Z = -3.846$, $p = 0.001$, C.I. [-1.608; -0.496]). In this sample, the analogous, mediating role of actually received support in the relationship between the distinguished variables was also identified ($Z = -2.970$, $p = 0.003$, C.I. [-1,364; -0.249]). In turn, in the group of parents of children with ID, the existence of a mediating role of only perceived available support in the relationship between extraversion and a sense of loneliness was noticed ($Z = -2.799$, $p = 0.005$, C.I. [-1,625; -0.236]).

Conclusions

The research results indicate that extraversion participates in complex mechanisms of regulating the sense of loneliness in parents of children with ASD and parents of children with ID, in which the perceived and received support plays an important role as intermediary variables. It is advisable to sensitize parents to the importance of social support and help in building resources, and to inform about possible and available forms of assistance in the immediate environment.

Key words

Autism spectrum disorder • Intellectual disability • Parents • Sense of loneliness

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Correspondence

Tomasz Gosztyła
University of Rzeszów, Department of Psychology, Ks. J. Jałowego 24, 35-959 Rzeszów, Poland • Tel. +48 17 872 18 38
• E-mail: tomgosz@ur.edu.pl

Introduction

Sense of loneliness is a subjectively felt discomfort resulting from the unsatisfactory state of interpersonal relations^{1,2}. It does not have to be synonymous with social isolation, but it is associated with perception (indifferently, objectified or not) of being lonely and dissatisfied with the current quality of social relations³. Loneliness – as speculated – fulfills important evolutionary functions as an “alarm” against social isolation and a moti-

vating factor for establishing and nurturing social contacts⁴. At the same time, it should be emphasized that the persistent, chronic sense of loneliness has negative health consequences, such as depression and anxiety disorders, suicidal thoughts⁵, coronary heart disease⁶, and it increases mortality risk for various reasons⁷.

According to the results of many studies, the most important factors affecting the sense of loneliness are, on the one hand, the quality of social support⁸⁻¹⁰, and on the other, personality traits¹¹⁻¹². However, so far, apart from general mentions¹³⁻¹⁴ and exploratory research, which are mentioned below, these relationships were not verified in the case of parents of children with neurodevelopmental disorders, such as the autism spectrum disorder (ASD) and intellectual disability (ID). According to the DSM-5¹⁵, symptoms of ASD mainly concern deficits in the field of social communication and social interactions, as well as limited, repetitive patterns of behavior, interests or activity. The classification distinguishes three levels of depth of the disorder, based on the criterion of the severity of clinical symptoms present and – what is connected with this – the required support. ID includes deficits in the field of intellectual functioning (confirmed by both clinical assessment and standardized intelligence testing) and adaptive deficits (leading to the inability of a person to meet the developmental and sociocultural standards of personal independence and social responsibility), the beginning of which first appears in the developmental period. Raising a child with neurodevelopmental disorders is a great challenge for parents, associated with the feeling of chronic stress¹⁶⁻¹⁷ and, sometimes, the experience of social stereotypes and misunderstanding¹⁸. Parental role is often carried out at the expense of important social activities, natural for families with neurotypical children¹⁹.

The results of exploratory research on loneliness of parents of children with neurodevelopmental disorders²⁰ allowed to identify predictors of a sense of loneliness in the group of parents of children with ASD and parents of children with ID. In both groups, extraversion was such a role. When it comes to variables related to social support, in the group of parents of children with ASD, a statistically significant predictor appeared to be perceived available support, and in the case of parents with children with ID - actually received support.

There are premises to assume that the covariation of extraversion and sense of loneliness does not result (in whole or in part) from the direct cause-and-effect linking between them, but from the mediation of the third variable related to support. For example, it was explained that extraversion is related to loneliness through the mediation of social network variables²¹. Again, however, this problem was not analyzed in the group of parents of children with neurodevelopmental disorders. The prob-

lem is important because both parents of children with ASD²² and ID²³ experience different quality of support, and loneliness is one of the most serious aggravating factors.

Objectives

The aim of the study was to verify the mediating role of actually received and perceived social support in relationship between extraversion and sense of loneliness in parents of children with ASD and parents of children with ID.

On the basis of the considerations presented above, and above all the results of the preliminary research devoted to this problem, the following research hypotheses were formulated:

- H1: In the group of parents of children with ASD extraversion weakens the sense of loneliness through perceived available support;
- H2: In the group of parents of children with ID extraversion weakens the sense of loneliness through actually received support.

Methods

The following measures were used in the study:

1. De Jong Gierveld Loneliness Scale (DJGLS) in the Polish adaptation of Grygiel et al.²⁴, in order to diagnose the sense of loneliness of parents. The scale is one-dimensional and measures a generalized sense of loneliness. Internal consistency determined by Cronbach's α for the Polish adaptation of the scale is 0.89; the value of the average inter-position correlation $r = 0.42$; and the homogeneity coefficient H Lovinger = 0.47. The scale correlates with the UCLA loneliness scale ($r = 0.82$).
2. Polish adaptation of the Ten Item Personality Inventory (TIPI) – TIPI-PL²⁵, in order to measure personality traits included in five-factor model: extraversion, emotional stability, agreeableness, conscientiousness and openness to experience²⁶. All TIPI-PL scales are characterized by similar or higher reliability in relation to the original version (Cronbach's $\alpha = 0.44-0.83$). In order to verify the validity of TIPI-PL, the relationships of personality traits measured with the TIPI-PL and the NEO Five-Factor Inventory (NEO-FFI) were analyzed. The following values of the correlation coefficient were obtained: for extraversion $r = 0.68$ ($p < 0.001$); for agreeableness $r = 0.61$ ($p < 0.001$); for conscientiousness $r = 0.74$ ($p < 0.001$); for emotional stability $r = 0.72$ ($p < 0.001$); for openness to experience $r = 0.49$ ($p < 0.001$).
3. Berlin Social Support Scales (BSSS) – Polish version²⁷, which allow measuring: Perceived Available Support (PAS) – subjective belief, without a specific

time context, concerning availability of help from other people; Actually Received Support (ARS) – perception of help currently provided by other people; Need for Support (NFS) – the need to use support in a crisis situation; Support Seeking (SS) – the frequency and scope of seeking assistance; and Protective Buffering Support (PBS) – protecting relatives from negative news. Reliability measured by Cronbach’s α coefficient for individual scales was from 0.71 to 0.90.

- Survey questionnaire – containing questions about sex and age of the parent, education, material status, number of children and the age of the child with a specific neurodevelopmental disorder.

Participants and procedure

Ethical approval was obtained from the Research Ethics Committee of the Faculty of Pedagogy and Psychology at Maria Curie-Skłodowska University in Lublin, Poland, to conduct this study. Parents of children with ASD and ID were reached through institutions supporting the development of their children (foundations, associations, schools and kindergartens) located in four provinces of Poland: Podkarpackie, Warmian-Masurian, Gdansk and Lublin. The sets of measures were provided to the respondents and received from them by therapists and teachers working with their children. The survey was anonymous, each set was in an envelope and contained written instructions explaining the purpose of the project. Parents were informed about the possibility to withdraw from research at any time.

The results obtained by 168 parents of children with ASD and 111 by parents of children with ID, without autistic traits (in total 279 participants, including: 231 mothers and 48 fathers) were qualified for the analysis.

TABLE I. *The number of parents of children with ASD and parents of children with ID, including the sex of the respondents.*

Disorder in the child	Mothers	Fathers	In total
ASD	129	38	168
ID	96	12	111
In total	225	50	279

TABLE II. *Age of surveyed parents (n = 279).*

	Median	SD	t	df	p
Parents of children with ASD	37.95	6.789	6.320	265	.001
Parents of children with ID	43.80	8.207			

Detailed information on the number of respondents, taking into account their gender and disorders of the child, are presented in Table I.

Table II compares the average age of the parents of children with various developmental disorders, while Table III contains information on their level of education. Parents of children with ID were older than the parents of children with ASD; in their case, the average age was about 44 years, and in the group of parents of children with ASD – nearly 38 years. Both tested samples were different in this respect, as evidenced by relatively high values of standard deviations.

The group of parents of children with ASD was dominated by participants with higher and secondary education, and the group raising children with ID – by participants with vocational and secondary education.

Results

Using the Hayes’ PROCESS macro ²⁸, it was examined whether BSSS scales are mediators of the relationship between extraversion and the sense of loneliness in parents of children with ASD. The results are shown in Table IV.

On the basis of statistical analysis, the existence of a mediating role of perceived available support in the relationship between extraversion and a sense of loneliness in the parents of children with ASD was confirmed ($Z = -3.846$, $p < 0.001$, C.I. [-1.608; -0.496]). The model with the mediator explains 36.4% of the variance of the sense of loneliness. The introduction of a mediator weakens ($R^2_{med} = 0.140$) the negative relationship between extraversion and a sense of loneliness, as illustrated in Figure 1.

Subsequently, the mediation role of actually received support in the relationship between extraversion and the sense of loneliness in the parents of children with ASD was identified ($Z = -2.970$, $p = 0.003$, C.I. [-1,364; -0.249]). The model with the mediator explains 28.9% of the variance of the sense of loneliness. The introduction of a mediator weakens ($R^2_{med} = 0.112$) the negative relationship between extraversion and sense of loneliness, as illustrated in Figure 2.

In this group, there was no significant mediation role of the following variables: need for support, support seeking and protective buffering support.

Then it was examined whether BSSS scales are media-

TABLE III. Education of examined parents (n = 279).

Education	Parents of children with ASD		Parents of children with ID		Parents in total	
	N	%	N	%	N	%
Basic education	4	2,4	7	6,3	11	3,9
Vocational education	25	4,9	38	34,2	63	22,6
Secondary education	62	36,9	36	32,4	98	35,1
Higher education	77	45,8	28	25,2	105	37,6
No data	0	0,0	2	1,8	2	0,7

TABLE IV. Analysis of extraversion and loneliness regression with the mediation of BSSS scales in parents of children with ASD (n = 168).

Mediator	Model without a mediator		Model with a mediator				Bootstrap (C.I. 95%)		Sobel's Test		
	B _c	R ²	B _{c'}	B _a	B _b	B _{ab}	R ² _{med}	Lower	Upper	Z	p
PAS	-2.799***	.223	-1.861***	1.542***	-0,606***	-0.934	.140	-1.608	-0.496	-3.846	.001
NFS	-2.799***	.223	-2.871***	0.252^	0.311	0.072	-.006	-0.025	0.334	0.893	.372
SS	-2.799***	.223	-2.824***	0.678***	0.040	0.023	.016	-0.250	0.317	0.169	.866
ARS	-2.799***	.223	-2.168***	3.041***	-0.206***	-0.668	.112	-1.364	-0.249	-2.970	.003
PBS	-2.799***	.223	-2,795***	-0.163	0.027	-0.004	.001	-0.166	0.064	-0.090	.928

Note: PAS: perceived available support; NFS: need for support; SS: support seeking; ARS: actually received support; PBS: protective buffering support
 p < 0.1; ** p < 0.01; *** p < 0.001

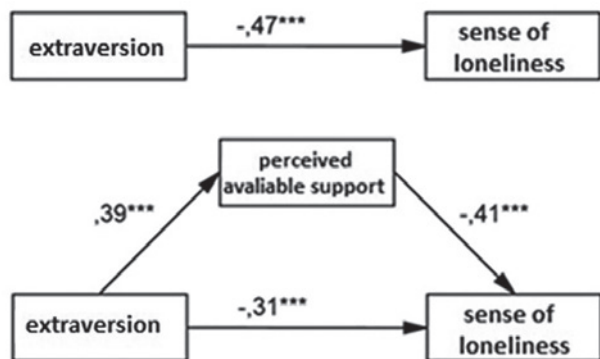


FIGURE 1. Model of extraversion and sense of loneliness regression with a mediator – perceived available support, standardized coefficients, parents of children with ASD (n = 168).
 *** p < 0.001

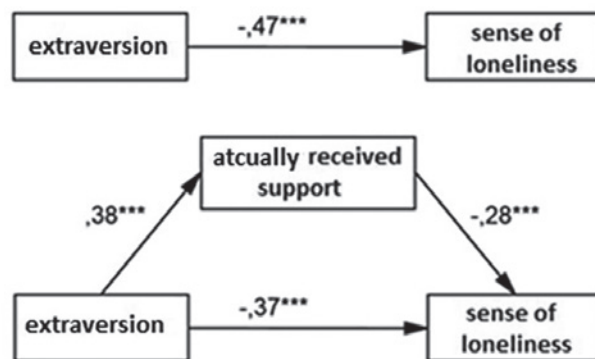


FIGURE 2. Model of extraversion and sense of loneliness regression with a mediator – actually received support, standardized coefficients, parents of children with ASD (n = 168).
 *** p < 0.001

tors of the relationship between extraversion and the sense of loneliness in the parents of children with ID. The results are shown in Table V. Significant mediating role of perceived available support was noticed in the relationship between extraversion and a sense of loneliness in the parents of children with ID (Z = -2.799, p = 0.005, C.I. [-1,625; -0.236]). The

model with the mediator explains 29.5% of the variance of the sense of loneliness. The introduction of a mediator weakens (R²_{med} = 0.099) the negative relationship between extraversion and sense of loneliness, as illustrated in Figure 3. In the group of parents of children with ID there was no significant mediation role of such variables as: need

TABLE V. Analysis of extraversion and sense of loneliness regression with the mediation of BSSS scales in parents of children with ID ($n = 111$).

Mediator	Model without a mediator		Model with a mediator				Bootstrap (C.I. 95%)		Sobel's Test		
	B_c	R^2	B_c	B_a	B_b	B_{ab}	R^2_{med}	Lower	Upper	Z	p
PAS	-1.576***	.109	-0.956*	0.864**	-0.687***	-0.813	.099	-1.625	-0.236	-2.799	.005
NFS	-1.576***	.109	-1.540***	0.039	-0.943**	-0.041	.006	-0.409	0.222	-0.258	.796
SS	-1.576***	.109	-1.511***	0.133	-0.467*	-0.120	.018	-0.518	0.030	-0.921	.357
ARS	-1.576***	.109	-1.556***	0.068	-0.318***	-0.283	.040	-0.976	0.056	-1.331	.183
PBS	-1.576***	.109	-1.609	-0.119	-0.279	-0.031	.004	-0.356	0.053	-0.375	.707

Note: PAS: perceived available support; NFS: need for support; SS: support seeking; ARS: actually received support; PBS: protective buffering support
 * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

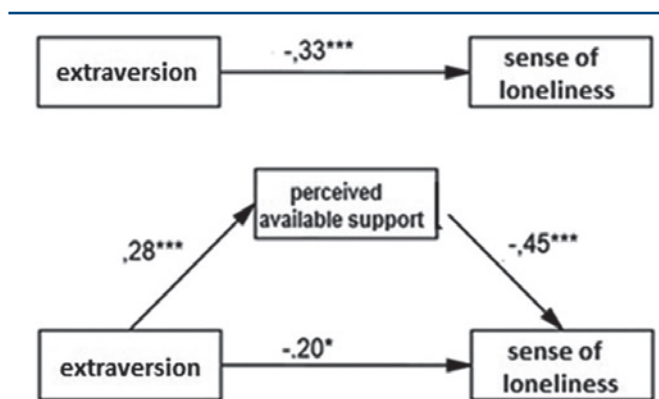


FIGURE 3. Model of extraversion and sense of loneliness regression with a mediator – perceived available support, standardized coefficients, parents of children with ID ($n = 111$).
 *** $p < 0.001$

for support, support seeking, actually received support and protective buffering support.

Discussion

The goal of the study was to answer the question whether perceived and actually received social support are mediators of the relationship between extraversion and a sense of loneliness in groups - respectively - of parents of children with ASD and children with ID. As a result of the analyzes carried out, the hypothesis 1 was positively verified. The mediating role of the perceived available support in the relationship between extraversion and a sense of loneliness in parents of children with ASD was confirmed. We are dealing with the situation of mediating the idea of the availability of help from others in a relationship between extraversion, as a personality trait of the parent, and the loneliness he or she feels. This group also showed the existence of a mediating

role of currently received support in the relationship between extraversion and a sense of loneliness, which was not assumed at the level of hypotheses. In the case of parents of children with ID, it was not found that extraversion weakens the sense of loneliness through the actually received support. The hypothesis 2 was not confirmed. However, the existence of a mediating role of the perceived available support in the relationship between extraversion and the sense of loneliness was noticed.

Parents of children with neurodevelopmental disorders with low intensity of extraversion (introverts), presenting greater difficulties with establishing and maintaining social relationships, may feel a greater sense of loneliness, while extroverts, having a larger social network, experience less loneliness²¹. The results of the presented study additionally indicate that extraversion participates in more complex mechanisms of regulation of the sense of loneliness, in which the perceived and received support plays an important role as intermediary variables. Stokes²⁷ came to similar conclusions, discovering that variables related to the social network significantly reduce the relationship between extraversion and loneliness. It can therefore be assumed that this is a regularity for various social groups. The results obtained prove a particularly important role of the subjective conviction about the availability of help from other people, in the case of parents of children with ASD and parents of children with ID. It can be assumed that perceived social support is an important predictor of the psychological well-being of the parent, probably of greater significance than the support actually received^{30 31} which, for example, may be inadequate to the needs, come from an inappropriate source or pose a threat to self-esteem³².

The results obtained in the group of parents of children with ASD differ from the results obtained by parents of children with ID. In the parents of children with ASD, the relationship between the sense of loneliness and extra-

version is mediated by a greater number of variables associated with social support. It can be assumed that autism as a particularly disruptive disorder, mainly due to the frequent occurrence of challenging behaviors³³, requires multifaceted and diverse forms of assistance. The most important limitation of this study is a relatively small group of examined fathers, which makes it impossible to perform analyzes with regard to the gender variable. Nevertheless, the results obtained allow for the formulation of practical conclusions regarding the support of parents of children with ASD and children with ID. It is advisable to sensitize parents to the importance of social support and help in building resources, including informing about possible available forms of assistance in the immediate environment. These goals could be implemented during workshops conducted by a psychologist or a social worker. Another important action is increasing communication skills of parents, including expressing their emotions and asking for help. Finally, support groups from the parents themselves, which can provide emotional and informational support, play an important role. It is worth initiating such activities at foundations or associations that care for the family of people with neurodevelopmental disorders. In further studies devoted to this problem, it is worth considering attributions – for example the reasons that parents of children with ASD and ID perceive as conditions of experienced loneliness³⁴. Also interesting would be a study involving parents of children with less frequent neurodevelopmental disorders, such as with

the Tourette syndrome³⁵, where the social awareness of the problem is lower, the formal support deficit is higher and, as one can assume, the loneliness of families is greater.

Conclusions

1. Extraversion, as a personality trait related to attitudes towards social contacts, sociability and assertiveness, participates in complex mechanisms of regulating the sense of loneliness in parents of children with ASD and ID, where social support variables play an important mediating role.
2. Perceived and actually received support are mediators for the extraversion relationship with a sense of loneliness in the group of parents of children with ASD.
3. Perceived social support is a mediator for the extraversion relationship with a sense of loneliness in the group of parents of children with ID.
4. Based on the results obtained, as part of the prevention of loneliness of parents of children with ASD and ID, it is recommended to sensitize the importance of social support and help in raising awareness and building resources, including by informing about possible available forms of assistance in the immediate environment.

Conflict of interest

The Authors declare to have no conflict of interest.

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