

Future Academy®'s Multidisciplinary Conference

Parental adjustment to disability, stress indicators and the influence of social support

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Abstract

Research into families of children and young people with disability maintain that parents or caregivers seem to experience higher levels of global stress than parents of children without disabilities, thereby presenting a high risk of developing disorders in their health and quality of life. The aim of this study is to understand the differences in parental stress and social support among groups of parents whose children have different disabilities in the context of parental adjustment to disability. Considering that adjustment is related to the effectiveness with which the family uses its resources and the support of their social network, we intend to analyse the differences of stress and social support among groups of parents of children with different problems and to clarify the relationships between the variables under study in order to adapt family intervention strategies. For this purpose a comparative, descriptive-correlational study was undertaken. The convenience sample included 152 parents of children with different disabilities (82 with intellectual disability, 37 with motor problems and 33 with autism) supported by schools and institutions in Viseu. The instruments used were: a Portuguese version of the *Parenting Stress Index* (Abidin, 1995), the *Social Support Questionnaire* – short version (Pinheiro & Ferreira, 2001) and a *Parental Questionnaire* (demographic and family data). Data were collected in schools and institutions that support people with disabilities, located in the Municipality of Viseu (Portugal). The results revealed significant differences between groups of parents in the partial results of parental stress, specifically in the *Hyperactivity/Distract* (DI), *Acceptability* (AC) and *Adaptability* (AD), dimensions of the Child Domain subscale (CD stress) and the *Role Restriction* (RO), dimension of Parent Domain subscale (PD stress). With regard to social support dimensions, we found significant differences between parents in the extent and availability of the social support network (SSQN).

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Peer-review under responsibility of Future Academy® Cognitive Trading

Keywords: parental adjustment; parental stress; social support; disability

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1. Introduction

Scientific literature has emphasized that changes and needs relating to educating children and young people with disability can affect the entire family system (Seligman & Darling, 1997). Parents or caregivers seem to experience higher levels of global stress compared to caregivers of children without disability, particularly with regard to child domain stress, constituting situations of increased risk of developing disorders on subjective well-being and mental health (Baker-Ericzén, Brookman-Frazer & Stahmer, 2005; Benson & Karlof, 2009; Felizardo, 2013; Gupta, 2007). The substantial increase in efforts of care and child education often triggers the development of signs of depression, isolation and difficulties in the marital and parental subsystems (Horton & Wallander, 2001).

In addition, some studies have shown that parents of children with Autism Spectrum Disorders (ASD) have a higher risk of depression or other mental health problems than parents of children with other problems. This may be associated with the variety of symptoms and behaviour problems of children with autism, which provides high parental stress, particularly with regard to their ability to relate to the child (Benson & Karlof, 2009).

However, despite the consistency of the results regarding the high levels of stress on the families of children and young people with disability, recent research has shown that the results are not as clear and consistent as one might think, because family adjustment to disability does not necessarily mean absence of stress, but rather the effectiveness with which the family uses their resources (intra and extra family) to deal with the stressful events (Fine & Nissenbaum, 2000). Thus, not all caregivers experience adverse consequences in the adjustment process. In some families positive perceptions and feelings are reported, which calls into question the framework that sees the families of children with disabilities in the approach that accentuates imbalance and pathology (Gupta & Singhal, 2004).

In this context, the study of the influence of social support on parental functioning in families of children with disabilities, especially the association between support and the family outcomes in health and well-being, has been at the origin of numerous theoretical and empirical analyses to identify the key dimensions of social support involved in promoting well-being and in decreasing parental stress. Thus, social support can be defined as an interpersonal transaction of emotional, psychological, informational, instrumental or material assistance with support provided by members of the social network which influences behaviour in a positive way (Dunst & Trivette, 1990; Dunst, Trivette & Deal, 1994).

Scientific literature has emphasized that social support has a direct and indirect effect on several aspects of parental and family functioning, including stress management and optimising resources in order to promote emotional well-being. Studies also suggest the existence of an interaction between stress and social support, so that it functions as a protective factor disrupting the influence of stressors (Cohen & Syme, 1985; Saranson, Saranson & Pierce, 1994; Dunst, Trivette & Jodry, 1997).

Following this analytical framework, parental adjustment to disability is related to the effectiveness with which the family uses its resources and the support of their social network. In this context, we formulated the following research question: Are there significant differences in the overall and partial results of parental stress and social support among groups of parents with children with different disabilities?

Thus, we intend to analyse differences in parental stress and social support among the groups of parents and to clarify the relationship between the variables under study in order to improve family intervention strategies.

2. Method

2.1. Research design

With this purpose in mind, a comparative, descriptive-correlational study was undertaken (Fortin, 2003). This

study is part of a broader line of research about the life trajectories of parents or caregivers of children with disabilities which was started in 2009 and involved samples of parents of children and young people with and without disabilities.

2.2. Participants

The selection of participants followed non-probabilistic principles. The convenience sample included 152 parents of children with permanent limitations who attended schools and institutions in the Municipality of Viseu (Portugal). Three subgroups of parents of children were formed according to the type of disability: 82 with Intellectual Disability – ID (53.9%); 37 with Motor Problems – MP (24.3%); 33 with Autism Spectrum Disorders – ASD (21.7%). Most children (65.1%, $n=99$) were male and their ages ranged from 5 to 10 years.

With regard to the parents' characterisation (age, marital status, socioeconomic level and residence), the majority ($n=132$, 86.6%) was female and 13.2% male ($n=20$), aged between 25 and 60 years ($M=38.2$, $SD=6.5$). The age groups with the highest percentage 32.2% ($n=49$) and 27% ($n=41$) were 31-35 and 36-40 respectively, followed in decreasing order by the 41-45 group (17.8%, $n=27$), ≥ 46 (14.5%, $n=22$), 26-30 (7.9%, $n=12$) and ≤ 25 (0.7%, $n=1$).

With regard to marital status, the majority (18.6%, $n=124$) was married or cohabiting, 12.5% ($n=19$) divorced, 5.3% ($n=8$) single and 0.7% ($n=1$) widow. Regarding the socioeconomic level, most (54.6%, $n=83$) were medium or medium/high level and 45.4% ($n=69$) of the lower level. As for residence, most (63.6%, $n=96$) were urban with a lower percentage (36.8%, $n=56$) rural.

2.3. Instruments for data collection

The following data collection instruments were used:

- *Parental Stress Index* – PSI is the Portuguese adaptation developed by Santos and Abidin (2003) *Parenting Stress Index* (PSI) of Abidin (1995). The author defined it as a screening and diagnosis measure providing a stress intensity measure resulting from parent-child relational system. The original scale items were subject to some changes, but the scale structure was maintained, with a new range of autonomy having been added. The items' scores in the areas as well as the criteria for listing were also respected. The scale assesses two domains that act as sources of stress: The Child Domain (CD stress) – assessing child's characteristics that may contribute to overall stress [it integrates *Hyperactivity/ Distractibility* (DI), *Reinforcement* (RE), *Mood* (MO), *Acceptability* (AC), *Adaptability* (AD), *Demandingness* (DE), dimensions of CD stress] and the Parents Domain (PD stress) – assessing the parental figure factors [which comprise *Competence* (CO), *Attachment* (AT), *Role Restriction* (RO), *Depression* (DE), *Spouse Relationships* (SP), *Isolation* (IS) and *Health* (HE) dimensions of PD stress].
- *Social Support Questionnaire – short form* (SSQ6) developed by Pinheiro and Ferreira (2001) is the Portuguese version of the *Social Support Questionnaire – short form* built by Saranson and colleagues (Saranson, Levine, Basham & Saranson, 1983). It is a widely referenced instrument in scientific literature that measures two important support dimensions: the availability perception or personal support network extension (SSQN) and overall support satisfaction (SSQS).
- *Parental Questionnaire* - an instrument built in the context of this study for collecting sociodemographic data (relating to the child and parents or caregivers) and the family system.

Research on the internal consistency levels by Cronbach's alpha was also carried out. The parental stress and social support measuring instruments reveal moderate to high levels of reliability (Davidsholder & Murphy, 1988). Thus, the Total PSI reveals an appropriate outcome ($\alpha=0.90$), but lower than that found in studies adapted in

Portugal (Santos & Abidin, 2003). The Child Domain subscale (CD stress) shows $\alpha=0.88$ and the Parents Domain scale (PD stress) $\alpha=0.81$. On the Social Support Questionnaire (SSQ6), alpha values show high fidelity (SSQN: $\alpha=0.90$, SSQS: $\alpha=0.96$), being slightly higher than in the adaptation studies (Pinheiro, 2003).

2.4. Procedure

Permission was requested and granted by the *National Data Protection Commission* and the *Ministry of Education* of Portugal. Permission was also requested from the directors of the schools and institutions the children and their families attend, as well as from teachers (special education and regular education) and from professionals to support this research. The parents were contacted by letter in order to participate in the study; all ethical and informed consent procedures were also satisfied. No one refused to participate in the study.

3. Results

Total and partial results of parental stress and social support, and differences between groups of parents of children with different disabilities

Table 1 shows the descriptive statistics, Mean (M) and Standard Deviation (SD), of the three groups of parents regarding parental stress (total and partial) and social support measures. It also presents variance analysis (ANOVA) of parental results in stress and social support measures with respect to the type of disability.

The results regarding stress and social support indicate that there are no significant differences between the groups of parents in parental stress (Total stress PSI, CD stress and PD stress), but we found significant differences in specific stress dimensions.

Despite the overall results on CD stress, parents of children with ASD have a higher results ($M=127.7$, $SD=21.30$) than parents of children with ID ($M=123.2$, $SD=24.52$) and parents children with MP ($M=118.1$, $SD=24.13$).

In the PD stress, parents of children with MP show higher values ($M=132.7$, $SD=26.89$) than caregivers of children with ID ($M=128.5$, $SD=25.87$) and those with children with ASD ($M=118.5$, $SD=22.85$).

In Total stress PSI, parents of children with ID have higher values ($M=251.8$, $SD=45.38$) than parents of children with MP ($M=250.8$, $SD=46.08$) and those with children with ASD ($M=246.3$, $SD=40.54$).

Table 1 shows that for some parental stress dimensions, there are significant differences between groups of parents of children with ID, MP and ASD. In a more detailed analysis of the results with post-hoc comparisons (*Scheffé Test*), we found that with regards to CD stress, there are significant differences in *Hyperactivity/Distract* ($p=0.022$) and *Acceptability* ($p=0.033$), with parents of children with ID having higher results (*Hyperactivity/Distract*: $M=26.15$, $SD=6.67$ and *Acceptability*: $M=23.91$, $SD=4.67$) than parents of children with MP (*Hyperactivity/Distract*: $M=22.75$, $SD=6.13$ and *Acceptability*: $M=21.37$, $SD=5.94$). There are also significant differences in *Adaptability* dimension ($p=0.000$), with higher scores for parents of children with ASD ($M=36.09$, $SD=5.78$) than parents of children with ID ($M=30.08$, $SD=7.56$) and those with children with MP ($M=29.75$, $SD=6.88$).

In the Parent Domain subscale there are significant differences in the *Role Restriction* dimension ($p=0.020$), and the parents of children with MP have higher results ($M=23.97$, $SD=6.51$) than parents of children with ASD ($M=19.72$, $SD=6.57$).

Table 1. Results of Parental Stress Measures - PSI (Child Domain Stress - CD; Parental Domain Stress - PD; Overall Stress), obtained by parents (children: Intellectual Disability – ID; Motor Problems – MP; Autism Spectrum Disorders – ASD)

Measures	Parents: ID (n=82)		Parents: MP (n=37)		Parents: ASD (n=33)		F	P value
	Mean	SD	Mean	SD	Mean	SD		
PSI – Child Domain (CD)								
<i>Hyperactivity/Distract (DI)</i>	26.15	6.67	22.75	6.13	25.84	5.25	3.940	0.022
<i>Reinforcement (RE)</i>	10.36	3.50	10.13	4.09	11.27	3.14	1.015	0.365
<i>Mood (MO)</i>	9.45	3.42	8.35	3.26	8.78	3.91	1.369	0.258
<i>Acceptability (AC)</i>	23.91	4.67	21.37	5.94	23.15	3.75	3.500	0.033
<i>Adaptability (AD)</i>	30.08	7.56	29.75	6.88	36.09	5.78	9.718	0.000
<i>Demandingness (DE)</i>	23.28	6.34	25.81	6.01	22.63	5.67	2.878	0.059
CD stress - total	123.2	24.52	118.1	24.13	127.7	21.30	1.449	0.238
<i>Scheffé Test – Hyperactivity: ID > MP; Acceptability: ID > MP; Adaptability: ASD > ID; ASD > MP</i>								
PSI – Parental Domain (PD)								
<i>Competence (CO)</i>	29.79	6.21	29.97	5.94	27.24	5.92	2.380	0.096
<i>Attachment (AT)</i>	12.89	3.47	12.24	4.24	12.21	3.24	0.628	0.535
<i>Role Restriction (RO)</i>	21.18	6.43	23.97	6.51	19.72	6.57	4.015	0.020
<i>Depression (DE)</i>	20.21	6.50	22.32	7.28	19.63	6.47	1.701	0.186
<i>Spouse Relationship (SP)</i>	17.20	6.44	17.29	6.72	15.33	5.62	1.163	0.315
<i>Isolation (IS)</i>	14.68	5.59	13.05	4.39	12.30	4.48	3.049	0.050
<i>Health (HE)</i>	12.59	3.81	13.86	4.09	12.06	3.11	2.256	0.108
PD stress - total	128.5	25.87	132.7	26.89	118.5	22.85	2.867	0.060
Total Stress - PSI	251.8	45.38	250.8	46.08	246.3	40.54	0.180	0.836
<i>Scheffé Test – Role Restriction: MP > ASD</i>								

Table 2 shows the results of groups of parents in perceived social support. In the availability subscale (SSQN) there are significant differences ($p=0.000$) among parents of children with ASD, with higher results for social support ($M=19.51$, $SD=8.74$), and parents of children with ID ($M=13.37$, $SD=7.92$). There are also significant differences between the parents of children with ASD and parents of children with MP ($M=13.27$, $SD=6.35$).

Table 2. Results of Social Support Measures – SSQ6 (availability – SSQN; satisfaction – SSQ6S), obtained by parents (children: Intellectual Disability – ID; Motor Problems – MP; Autism Spectrum Disorders – ASD)

Measures	Parents – ID n=82		Parents: MP n=37		Parents: ASD (n=33)		F	P value
	Mean	SD	Mean	SD	Mean	SD		
Social Support Questionnaire (SSQ6)								
SSQN (Availability/ extension)	13.37	7.92	13.27	6.35	19.51	8.74	8.157	0.000
SSQS (satisfaction)	25.41	8.50	26.62	5.86	29.12	6.41	2.869	0.060
<i>Scheffé Test – SSQN: ASD>ID; ASD>MP</i>								

Research of relationship between parental stress and social support variables

A Pearson correlation coefficients were used to find the relationship between perceived social support and parental

stress dimensions (we added another sample of 149 parents of children without disabilities to the sample of 152 parents of children with disabilities). As shown in Table 3, Total stress PSI, CD stress and PD stress have significant and negative correlations with social support and its dimensions: availability of support and satisfaction with support (Total stress PSI/SSQN: $r = -0.372$; Total stress PSI/SSQS: $r = -0.499$; DC stress/SSQN and SSQS: $r = -0.243$ and $r = -0.380$; DP stress/SSQN and SSQS: $r = -0.447$ and $r = -0.543$; $p < 0.001$). The lowest correlations emerge between parental stress (Total stress PSI and CD stress) and the availability of social support. The highest correlations are found between parental stress (Total stress PSI and PD stress) and satisfaction with social support.

Table 3. Pearson correlation coefficients between social support and parental stress (Total PSI; CD; PD)

Measures	PSI global stress	CD stress	PD stress
SSQN (availability)	- 0.372**	- 0.243**	- 0.447**
SSQS (satisfaction)	- 0.499**	- 0.380**	- 0.543**

** $p < 0.001$

These results show coherence with validity studies of social support (Saranson et al., 1983) which found significant negative correlations with anxiety and depression measures and significant positive correlations with psychological well-being variables.

4. Discussion

The results converge with the majority of studies in this area, because they enhance the high levels of stress parents or caregivers of children with disabilities feel, particularly in Child Domain stress (Baker-Ericzén, Brookman-Frazier, & Stahmer, 2005; Felizardo, 2013; Gupta, 2007; Santos & Abidin, 2003).

Parents of children with ID have more expressive stress values in *Hyperactivity/Distract* and *Acceptability* dimensions compared to parents of children with MP. On other hand, the latter showed higher stress on *Role Restriction*. These data report that stress resulting from intellectual problems is largely associated with inadequate behaviour of the child, as well as the level of the mismatch between the actual child's characteristics and parental expectations. In this context, the type of intervention should include parental counseling components, in order to promote a greater awareness and involvement for a better adjustment to disability. Measures that focus on the management and control of behaviour should also be included. It should be noted that this group of parents concomitantly had the lowest levels of social support, so intervention should focus on streamlining the formal and informal social support network.

With regard to parents of children with MP, the most significant differences in stress occur in the *Role Restriction* dimension of the CD stress subscale. Data suggest that parents may experience a significant level of stress related to changes involved in care and changes in daily routines, which influence parental and family functioning (Marvin & Pianta, 1996).

Parents of children with ASD showed significantly higher values in *Adaptability* compared to the other groups of parents. This dimension highlights parental problems in dealing with the child's difficulties in adapting to new situations, which is expected taking into account the difficulties of children with autism in adjusting to changes and life routines.

These results are partly in line with the study by Gupta (2007), which found distinct parental stress values according to the type of disability. The literature emphasizes that parents of children with autism appear to have specific sources of stress associated with the variety of symptoms and behavioural problems of students with autism (Benson & Karlof, 2009). However, it is interesting that it is precisely this group that shows higher values in perceived support (availability of support and satisfaction with support). These results will not be unconnected with

the fact that these parents are linked to a support institution that children and young people with autism and families attend, the APPDA of Viseu, and benefit from specialized monitoring of existing Structured Teaching Units in schools. The APPDA of Viseu works very closely with parents or caregivers and, in this case, the peer support groups work particularly well. Similarly, studies by Heiman (2002) on resilient families of children with disabilities stressed the importance of social resources and the effects of various types of support in response to family needs. These results lead us to the importance of rethinking the forms and formats of intervention in this field, particularly with regards to the type of support to be provided, and should be more suited to families' needs and resources. The literature also highlights the role of informal support, which will have to be optimised in the intervention context (Felizardo, 2013).

In this framework, intervention programs should include ways to support the adaptation of families, seeing them as the most important context of a child's development, and therefore deserve special attention. Thus, measures and actions should include topics at the level of knowledge about the specific nature of autism disorders, as well as on issues related to learning and behaviour control, preventing inappropriate behaviour. This work could be developed in the context of counselling and family therapy, but the social support provided by groups of parents, especially in the early stages of adjustment is particularly important promoting positive but realistic expectations of children (Gupta & Singhal, 2004, cited by Felizardo, 2013).

Acknowledgments

The Portuguese Foundation for Science and Technology (FCT) through the project PEst-OE/CED/UI4016/2014, and the Center for Studies in Education, Technologies and Health (CI&DETS).

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