

A PRELIMINARY INVESTIGATION OF A PARENTAL STRESS MEASURE FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS AND DOWN SYNDROME

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ABSTRACT. Parents of children with disabilities were identified as presenting higher levels of negative emotions, higher risks for psychopathology and physical illness, as well as higher levels of distress, compared to parents of children with typical development. In general, more attention towards the needs of the parents who have children with disabilities in Romania is necessary, but research on the topic is scarce. Our preliminary study of parental stress is centered mainly on testing the reliability of the translated and adapted version of the Parental Stress Scale (Berry and Jones, 1995) on a Romanian sample of parents of children with ASD and Down Syndrome. Our results show that the parents of children with ASD and Down Syndrome do not report high levels of distress attached to their parental role and that the level of parental distress increases with the child's age. The scale proved to be a valid measure of parental stress in parents of ASD and Down Syndrome children, but future validation on larger samples of parents of children with disabilities is needed.

Keywords: *parental roles, assessment, parental distress, autism, Down Syndrome*

ZUSAMMENFASSUNG. Bei Eltern die Kinder mit Behinderungen erziehen, wurden erhöhte Werte an negativen Gefühlen festgestellt, ein verstärktes Risiko der Psychopathologie und der physischen Erkrankungen sowie höhere Stresswerte. Allgemein empfiehlt sich eine höhere Aufmerksamkeit gegenüber den Eltern von Kinder mit Behinderung, die in Rumänien leben, jedoch gibt es unzureichende Untersuchungen zu dem Thema. Unsere vorausgehenden Untersuchungen bezüglich des Stresses, dem die Eltern ausgesetzt sind, beziehen sich vordergründig auf das Testen der Zuverlässigkeit einer übersetzten und

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angepassten Version der Skala zur Messung von Stress-Auswirkungen bei Eltern (Berry and Jones, 1995) gegenüber Rumänischer Probanden - Eltern von Kindern die an Autismus und Down Syndrom leiden. Aus unseren Ergebnissen geht hervor, dass Eltern von Kindern mit Autismus und Down Syndrom Erkrankungen keine erhöhten Stresswerte bezüglich ihrer Elternrolle vorweisen und dass gleichzeitig die Stresswerte mit dem Heranwachsen ihrer Kinder steigen. Die Skala hat sich als zuverlässiges Instrument erwiesen, jedoch ist eine zusätzliche Bestätigung davon durch die Beobachtung einer höheren Anzahl an Probanden nötig.

Schlüsselwörter: *Eltern Rolle, Bewertung, Eltern Stress, Autismus, Down Syndrom*

Background

The challenges and emotional demands of daily life are higher in parents of children with intellectual disability which leads to difficulties in the parents' daily functioning (Norlin and Broberg, 2013) and increase of parental distress (Beck et al., 2004). Various authors reported levels of depressive symptoms below clinical relevance, showing that most parents adapt successfully to the diagnosis of their children and even place positive value on raising a child with disabilities, even though several changes in the family may occur (i.e., marital conflict, single parenthood, low quality in couple relationship). Still, studies carried out in different cultures found that parental distress is higher in parents of children with disabilities in comparison to parents of children without disabilities. Parental distress was higher in either mothers or fathers of children with developmental disabilities (Gupta, Mehrotra and Mehrotra, 2012, Huang et al., 2014), children with autism (Gika et al., 2012), and children with ADHD (Tzan, Chang and Liu, 2009, Sethi, Gandhi and Anand, 2012).

Several authors show that, in fact, the lives of people with disabilities, as well as the negative impact of disability on the family are determined by social factors, especially negative attitudes and prejudices towards disability, such as the tragedy discourse and the perspective that the family is a victim of circumstances (Broberg, 2011). Also, parental distress may be high not because of the burden that the child imposes, but because of contextual factors and circumstances that the parent experiences raising a child with disabilities. On the other hand, Baxter, Cummins and Yiolitis (2000) argued that increasingly normalized conceptualization of disability, as well as deinstitutionalization of children with disabilities during schooling, increasing access to services and facilities in the community may impact the level of parental distress and also

shift the focus of parental distress from the child to the family system and its ability to cope to life problems and challenges.

Parental stress is significantly associated with the children's level of functioning (Gika et al., 2012), meaning that the lower the children's functioning the higher the parental distress, while increased levels of parental distress lead to alteration of the parents' ability to adapt and care for their children (Agazio and Buckley, 2012). Minor psychiatric problems of the parents, such as depression and anxiety are associated with the extent and frequency of behavior problems in children with intellectual disabilities (Beck et al., 2004).

Deater-Deckard (1998, cited by Hastings, 2002) investigated the association between parental distress and the behavior problems of children with developmental disabilities and found a cycle of reciprocal influence between parenting behavior and child conduct problems: parent behavior influenced children's behavior, which in turn influenced parents' level of distress. Thus, according to the authors cited, parenting behavior mediates the impact of parental distress on child outcomes.

Orsmond et al. (2003, cited by Beck et al., 2004) also found a bidirectional effect of child behavior problems on maternal well-being. Child behavior problems and lack of pro-social behavior was found to be predictive for parental distress (Beck et al., 2004). On the other hand, Lopez et al. (2008) underlined the importance of parental coping strategies on the distress level, stating that the use of adaptive coping strategies lowers the distress level. Gupta, Mehrotra and Mehrotra (2012) found that the religious coping is effective for stress management of Indian parents raising a child with developmental disabilities.

Parental distress in the context of having a child with disability was correlated to quality of life and well being. Parental quality of life was lower in fathers of children with developmental disabilities compared to fathers of healthy children (Hastings, 2002, Huang et al., 2014).

Stress in parents of children with Autism Spectrum Disorders

Autism Spectrum Disorders are lifelong severe neurodevelopmental disorders entailing a considerable functional and financial burden on the individual and family. Autism, as a prototypical disorder includes qualitative impairments in social interaction, qualitative impairments in social communication, restricted repertoire of interests, behaviors and activities, the evidence of delay or deviation being present in the first three years of life. Most of the characteristics of ASD are present early in life: limited or absent attention sharing behaviors, reduced spontaneous imitation, difficulties in understanding and using symbolic behaviors (American Psychiatric Association, 2013). Many children

with ASD have a quite difficult behavioral profile, involving self-injury, tantruming, complex rituals, which can be hard to manage and can interfere with the daily lives of their families. Disruptive behaviors, fixed schedules and the demands of daily life may also make it difficult for families to participate in activities outside the home (Bouma and Schweitzer, 1990, Fox et al. 2002, Lee et al., 2008).

A child diagnosed with ASD may represent a constant source of distress on the family unit, affecting caregivers, siblings and relationships between family members (Sanders and Morgan, 1997). Having to cope with the physical and emotional demands of caring for a child with ASD can be a threat for the psychosocial wellbeing of parents (Lee et al., 2008). Their self-confidence and self-esteem can really suffer when the family has to face the child's behavior and his special demands (Gray and Holden, 1997). It is very common for parents having a child with ASD to experience helplessness, feeling of inadequacy and failure, anger, guilt, frustration and resentment (Jones, 1997). They could refuse to give the proper medication to the child, even when the family's ability to function effectively is threatened by the child's severe behavioral problems. Stress is mostly related to the issues of ongoing dependency and the limits imposed to the family activity (Konstantareas, 1995).

It has been reported that the level of emotional distress in parents is positively associated with the level of challenging behaviors of the child (Allik et al., 2006) and it is negatively associated with the child's ability to communicate functionally (Ello and Donovan, 2005).

Other psychological problems including depression and anxiety were reported within families with children having autism and in the same time, studies have shown that a high level of distress experienced by mothers had an inverse relationship with the educational progress of the child (Robbins et al., 1991). Some caregivers of a child with ASD experience a sense of social isolation, due to the time and energy needed for the child, which severely limits their free time and ability to engage in social activities (Higgins, Bailey and Pearce, 2005).

Various authors report that the distress on families who have a child with ASD may be exacerbated because this disability is often not identifiable by physical appearance (Sanders and Morgan, 1997). There is also a lack of understanding from the community of the behaviors associated with ASD and as a result, people are often insensitive regarding the public behavior of children with ASD. Research also demonstrates that the distress associated with ASD impacts on most aspects of families' lives: recreation activities, housekeeping, emotional and mental health of members, marital relationships, sibling relations and relationships with extended family, friends and neighbors (Rodrigue et al., 1990, Benson and Dewey, 2008, Gika et al., 2012).

Another problem that could affect families with ASD children is related to financial challenges because this could involve higher rates in work loss and important medical costs (Hecimovic and Gregory, 2005). Independence is a particularly important issue for children with autism as they are more likely to remain dependent on their family or services for support as they get older compared to children with other disabilities (Howlin et al. 2004).

When compared to the level of distress of parents raising children with Down syndrome, mental retardation and non-disabled children, parents of children with ASD had higher scores (Benson and Dewey, 2008), showing higher levels of distress.

Stress in parents of children with Down syndrome

Down syndrome represents a congenital chromosomal disorder due to an error in cell division which leads to an extra 21st chromosome that causes cognitive delay, impaired language and communication skills, possible sensory impairments, motor delay, associated medical conditions. Down syndrome is a lifelong impairment which determines the need to benefit of educational and rehabilitations programs for the development of language and communication, cognitive abilities, motor skills, self-help abilities, social and emotional competences. In relation with parents of children without disabilities, parents of children with Down syndrome perceive more caregiving difficulties, child-related distress regarding demandingness, the need of extra support, unacceptability and parent- related distress (Roach, Orsmond, and Barratt, 1999).

There is an abundance of literature suggesting a “Down syndrome advantage” in mothers of children with Down syndrome compared with mothers of children with other intellectual and developmental disabilities (Esbensen and Seltzer, 2011). Mothers of children with Down syndrome report lower levels of distress, have more extensive and satisfying social support and networking and perceive their child as being less difficult (Abbeduto et al. 2004). Mothers of adolescents and young adults with Down syndrome also display better psychological well being than mothers of similarly-aged children with other types of intellectual and developmental disabilities (Abbeduto et al, 2004). They also have reported less pessimism about their child's future, more closeness in the relationship with their child, and fewer depressive symptoms (Esbensen and Seltzer, 2011). After reviewing the work of several authors, Esbensen and Seltzer (2011) reached the conclusion that the Down syndrome advantage can be conferred to older maternal age at the time of the birth of the child with Down syndrome which leads to greater maturity and financial

stability. The authors also suggest that better well-being and less parental distress relate to the Down syndrome behavioral phenotype of having fewer behavior problems contributed the most to better outcomes.

Glidden, Grein and Ludwig (2014) show that Down syndrome advantage is most likely when the metric is about the child rather than the parent or family, that it may be present or absent at different ages, and it is partially explained by higher levels of adaptive behaviors, suggesting the importance of multiple measures at multiple times, and implications for family expectations and priorities across lifespan. Most, Fidler, Laforce-Boothe and Kelly (2006) sustain through their studies findings that early emergence of the Down syndrome behavioral phenotype may play an important role in shaping maternal experience. As behavioral patterns become more pronounced (cognitive delays, language delays, maladaptive behaviors) during the first 3 years of development in children with Down syndrome, maternal distress levels increase. Stronger cognitive-linguistic skills and lower levels of maladaptive behavior at all time points were associated with lower levels of distress.

In the support of the Down syndrome advantage is the fact that the condition is diagnosed and confirmed to the parents at birth or soon after or even before the child is born, thus the parents having the opportunity to begin the process of assimilating this information into their expectations, understanding their parenting role, and in many cases, beginning a coping process. (Most et al., 2006).

Van der Veek, Kraaij and Garnefski (2009) investigated the cross-sectional and prospective effects of cognitive coping strategies on the distress experienced by parents of children with Down syndrome. The results showed that using acceptance, rumination, positive refocusing, planning, and catastrophizing more often were related to increased levels of parental distress, while using positive reappraisal was associated with less parental distress.

Assessment of parental stress in parents of children with disabilities

The measurement of parental stress was not really a subject of interest for quite a long period of time. Some general stress inventories include items related to parenting, but it is impossible to differentiate the stress associated with the role of being a parent specifically in these measures.

One measure, the Parenting Stress Index (PSI) (Abidin, 1986), which is designed to measure distress in a parent-child system is used with parents of children without clinical problems. The index has been criticized because it did not measure the construct of stress, because it was considered highly invasive and because of its problems concerning the gender difference, with fathers scoring significantly lower than mothers.

Available research provides general support for the conclusion that parenthood may have negative consequences on psychological well-being and that children exert negative influence on the quality of other family relationships (McLanahan & Adams, 1987). For sure, there is a need for better understanding of the connections between parental distress, on one side, and well-being and the quality of other relationships such as couple, on the other side, taking into account both the rewards and demands of parenthood. One step ahead was the development of a more direct measure of individual differences in the level of stress associated with raising children.

Compared to other measures for parental stress, Oronoz, Alonso-Arbiol and Balluerka (2007) consider the Parental Stress Scale (Berry and Jones, 1995) appropriate because of its wide applicability, as well as for the accessible formulation of the items. The measure is designed to assess the level of stress associated with child rearing and generated by the parenting role itself.

The Parental Stress Scale was originally tested for validity on several groups of parents with at least one child under the age of 18 living at home; the samples were generally well educated and many held managerial and professional occupational positions (Berry and Jones, 1995). Relevant literature on stress and parenting was surveyed by the authors in order to identify potential themes and concepts involved in parental stress. The item selection aimed to consider the dichotomy of parenthood, source both of pleasure and strain. Positive themes include emotional benefits (love, happiness, fun) and sense of self-enrichment and personal development. Negative components include demands on resources such as time, energy and money and opportunity costs and restrictions. Half of the items indicate higher stress and the others indicate lower stress (Berry and Jones, 1995). The measure proved to be a reliable instrument for the assessment of parental stress on Romanian populations of parents of children without clinical problems or disabilities aged between 2 and 17 years (Gavița et al., 2011a, b, Gavița, David and DiGiuseppe, 2014).

Though research focusing on the stress of parents raising children with disabilities is vast, the findings are contradictory and so far the dilemma regarding positive and negative impact of the presence of a child with disabilities in the family system has not been concluded. Research regarding Romanian population has been scarce, although the legal and social changes for children with disabilities require more attention in research and practice on the parents and families of these children.

In order to approach this need, the current study has as objectives:

- a) the adaptation and preliminary testing of reliability on Romanian population of a scale that assesses parental stress;
- b) the investigation of the levels of parental stress experienced by parents of children with ASD and Down syndrome and

- c) the exploration of some demographic characteristics associated with differences in the stress levels reported.

Method

Participants

Thirty-two biological parents of children with ASD and Down syndrome were recruited from several agencies addressing the needs of children with disabilities, as well as several special schools in Cluj-Napoca, Romania. All the participants volunteered to participate in the present preliminary study of parental stress. One of the participants did not understand the procedure and therefore we considered that the results given could bias the whole analysis and therefore were eliminated from the database.

Measure

The 18-item version of the Parental Stress Scale was found to have adequate reliability (Berry and Jones, 1995) as a measure of the distress attached to parenting, an alpha Cronbach coefficient of .83, on a total sample of 125 parents of children without disabilities. There were several administrations of the scale in order to assess the validity of the instrument, as the authors reported. Also, good reliability of the measure was found on Romanian populations of parents raising typically developing children (Gavița et al., 2011a, b, Gavița, David and DiGiuseppe, 2014), Cronbach alpha values ranging between .83 and .85.

Following two analyses with the purpose to observe the ability of the scale to discriminate between parents of typically developing children and parents of children with both developmental and behavioral problems, the results of the discriminant analyses showed that the scale is able to differentiate between the two samples of parents (Berry and Jones, 1995).

In addition to the PSS, the parents also completed measures of loneliness, anxiety, marital satisfaction, job satisfaction, state guilt, trait guilt, social support satisfaction and the dimension the social support network. Parental Stress Scales scores were significantly related to all measures in the expected direction, with one exception – number of people in the social support network for fathers (Berry and Jones, 1995).

Also, results from the factor analysis suggested the relevance of considering specific components of parental stress (rewards, stressors, control). The authors suggested that additional data are needed to assess the co variation between the PSS and other measures of interpersonal functioning, attitudes and emotions and to determine if the PSS is an appropriate measure for larger

socioeconomic groups, for single parents, for different clinical populations and for fathers of children with special needs. Nevertheless all the data suggest the utility of the Parental Stress Scale as a brief, valid and reliable measure of the important construct of parental stress.

The Romanian translation of the measure attempted to preserve the meaning of each item in order to maintain the equivalence with regard to the underlying construct. Three versions of the translation of the instrument were compared and the most appropriate wording for each of the items was chosen based on mutual agreement. The three researchers that translated independently the measure hold expertise in the field of special education and family systems psychotherapy. None of the 18 items of the original measure was eliminated.

Procedure

Permission to recruit the participants was requested from all the institutions involved in the present research. After the informed consent to volunteer was obtained from all the participants, the questionnaires were given to them to complete at home and to be returned in about one week time. The parents who needed further clarifications could ask for advice from the contact persons in each institution, who were instructed to respond to such requests from the participants.

Results and discussion

Demographic characteristics of the sample

The parents that volunteered to participate in our study ranged in age from 31 to 55 years ($M=40.1$, $SD=6.08$), most were from urban areas (58.1%) and most of them were mothers (64.5%). Of the total number who answered, 86.2% were married, 6.9% not married and 6.9% divorced, most were highly educated persons with graduate and postgraduate studies (54.9% of the total number). Still, a large part of the participant parents were employed as personal assistants for their child (45.2% of the total number).

The age range of the children with disabilities was between 4 and 16 years ($M=9.8$, $SD=3.04$), most of them were diagnosed with ASD (71% of the total number) and the rest with Down syndrome. A percentage of 29% of the children were the only ones that the parents had, while most of them (48.4%) had another sibling, 9.7% had two other siblings and 6.5% had 6 other siblings. Of the total number of children, 41.9% were first born.

Reliability of the Parental Stress scale

The Parental Stress Scale (Berry and Jones, 1995) used in our research was tested for reliability, by computing the alpha Cronbach coefficient. We obtained adequate values for the measure of scale reliability, namely an alpha Cronbach of .84, which shows that the Romanian translation and adaptation of the scale is a reliable measure of parental stress in parents of children with ASD and Down Syndrome, as indicated by the results obtained in our preliminary study. The values are similar to the ones reported by the authors of the instrument (Berry and Jones, 1995), but should be treated with caution given our small sample of participants.

Severity of parental distress and factors that influence the distress level

On the total sample of parents, the mean score we obtained for parental stress was 38.55 (SD=9.2), meaning that the parents in our sample did not seem to experience increased levels of distress. All the parents in our sample were recruited from institutions in which the child's with disabilities needs were appropriately approached and answered, which can be a reason why the parents did not experience high levels of distress in their role as parents. Still, a number of parents did experience higher levels of distress (the range of the scores was between 24 and 59) and even if a significant number of parents had scores below 40, we consider that several of them may be at risk, as 9 of the total number of 31 parents scored between 40 and 50 points and two had scores above 50 points, as shown in figure 1. As professionals, we cannot ignore that there are parents for whom raising a child with disabilities means high levels of distress and who are at risk because of this.

On the other hand, most of the parents included in our study asserted that they received support in raising their child with disabilities (a percentage of 54.8% of those who answered the question). The social support is indeed an important factor in the management of stress derived from the tasks that a parent normally has with respect to his/her child. Most of the support identified by the parents comes from the nuclear family (husband/ partner), but also from the extended family (grandparents, in particular) and from the larger system (teachers, child protection services and professionals, the state, NGOs). Reliable sources of support from a large network are important for the parents in their process to adjust to their children's needs.

The level of parental distress significantly correlated with the child's age ($r=.45, p<.05$), meaning that the higher the age of the child with disabilities is, the level of parental distress increases. This result is in line with theoretical assumptions and empirical evidence showing that with age, the child's disability

and limitations become more obvious, as he or she advances in schooling, while the parent’s vulnerabilities become more explicit with age, leading to the increase of worry for the child’s future. Also, as the child becomes older, the parent’s ability to manage problem behavior decreases, leading to the increase of the parent’s anxieties. All the parents and children were recruited from institutions offering special education services and therapies for children. In time, the efforts that the parents involve in various interventions, generating frustration in case the child’s situation does not improve, seem to increase the distress level that the parent reports. The parents’ age alone was not significantly associated with the level of parental distress.

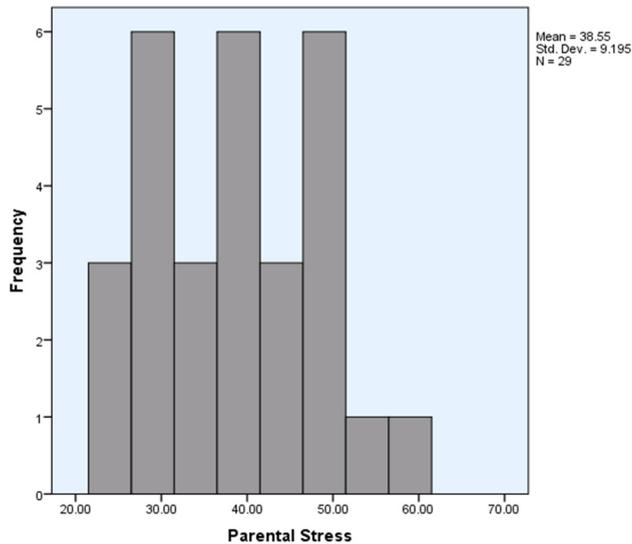


Figure 1. The distribution of the parental stress scores

As shown in table 1, other demographic characteristics were not relevant for the level of parental stress that the parents in our study reported.

Table 1.

The mean level of parental stress, depending on demographic characteristics

Characteristic	mean	t
Child’s diagnosis		
Down Syndrome	37.86	.24
ASD	38.81	
Parent’s gender		
Masculine	35.4	.84
Feminine	39	

Characteristic	mean	t
Origin		
Urban area	35.88	1.43
Rural area	41.67	
Parent's work status		
Unemployed	43	1.53
Employed	36.79	

Interestingly, our preliminary investigation did not find any significant differences between the levels of parental distress of the participants raising children with ASD and those of children with Down Syndrome, as other studies found, though a slightly higher level of distress was found for parents of children with ASD (table 1). Parents' gender did not account for significant differences in the levels of distress, though mothers in our study did report higher levels of distress compared to the fathers. Though not statistically significant, participants from rural areas were more stressed than those from urban areas and participants who did not work outside the home reported slightly higher levels of distress compared to those who were employed. As the size of our sample is very small, these results need to be further tested in other researches on larger samples.

Conclusions

Our results showed that the parents of children with ASD and Down Syndrome may not experience higher levels of distress, compared to the results reported in other studies. The mean scores reported by the authors of the scale (Berry and Jones, 1995) on a group of mothers of children with behavior problems was 43.2 (with a SD of 9.1), the mean scores of mothers who had children with developmental disabilities receiving special education services were slightly lower ($M=40.1$, $SD=9.3$) and the mean score of the mothers of children without clinical problems was significantly lower than both the previous ones, a mean of 37.1 with a SD of 8.1, which shows that the scores for the parental stress on the group of parents included in our research were not significantly different from the scores that the authors obtained for parents of children without disabilities.

Our preliminary investigation of parental stress adds important contributions to the development of the field of parenting children with disabilities, though given the small sample size our results should be treated with caution and tested on larger samples. The Parental Stress Scale (Berry and Jones, 1995) proves to be a reliable instrument for the assessment of stress levels in Romanian parents raising children with ASD and Down

Syndrome, as our preliminary investigation shows. The Romanian translation and adaptation of the scale was easy to understand for the parents and also easy to complete, so its use in future studies is recommended. The instrument itself needs further testing in order to become a valid assessment for practitioners working with children with disabilities and their parents.

In our study, the level of stress that the parents of children with disabilities experienced was not overall high, with some notable exceptions that our data emphasized, some of the participants experiencing stress levels much higher than the average. As practitioners, we have the duty to identify and provide the care that these parents may need, in order to reduce the potential risks.

The only demographic characteristic relevant for the stress level was the age of the child with disabilities, the older the child, the higher the distress that the parent reports. With time, the parents as caregivers of a child with disabilities may become tired and even experience symptoms of burnout. Also, with time, other risks and losses may add to those inherent to the specific characteristics of the child with disabilities. A possible direction for further research would be to differentiate between various sources of distress that the parents are exposed to, besides the difficulties arising from raising a child with ASD or Down Syndrome.

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