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## The Relationships between Perceived Stress and Psychological Well-being Among Mothers and Fathers of Children with Down Syndrome

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### Abstract

The aim of this study was to investigate the relationship between perceived stress and psychological well-being among parents of children with Down syndrome. The relationship between perceiving one's parenthood and well-being was also studied.

The sample consisted of 126 parents (75 mothers and 51 fathers, aged 25–69) of children with Down syndrome. Our results show that ego-resiliency is a partial mediator of the relationship between perceived stress and psychological well-being. Moreover, there is a difference in well-being between parents who perceive their parenthood as a burden or challenge, and parents who report happiness and satisfaction.

**Keywords:** *children, parents, Down syndrome, stress, well-being*

### Introduction

Parenting brings happiness and satisfaction as well as sorrows and hardships. Some authors consider the relationship between parenthood and well-being to be highly complex (Nelson, Kushlev, Lyubomirsky, 2014). Parents of children with disabilities are burdened with many additional duties which affect their health and well-being (Johansen et al., 2013). Functioning and outcomes of these parents have been described by many theoretical concepts, such as quality of life and psy-

chological well-being. Quality of life has different aspects which relate to physical, emotional, cognitive and social functioning. Subjective well-being is considered in the context of two traditions: hedonistic and eudaimonistic. The first of these traditions defines well-being as finding sources of pleasure and avoiding things such as pain and inconveniences, whereas the second one relates to getting fullness of personal potential (Carr, 2009). Hills and Argyle (2002) treated well-being as personal happiness which is associated with life satisfaction and the sense of strength and control. Happiness and well-being are negatively correlated with psychological distress, which includes depression, trouble, somatic complaints, exhaustion and low self-esteem (Argyle, 2004).

Caring for a child with disability can be for its parents a source of a better understanding of the sense of life and paying attention to basic human values like love, friendship and kindness. The way in which parents of ill children perceive their own situation influences their well-being. The mothers and fathers of children with disabilities who are able to notice and appreciate the positive aspects of their situation experience more pleasant feelings than the parents who tend to focus on the negative aspects of their child's disability (Veek, van der, Kraaij, Garnefski, 2009). Pisula (2007) states that there is a connection between parents' psychological well-being and their strategies of coping with stress. Mothers who reported being more optimistic had better health than those who were less optimistic (Greenberg, Wyngaarden-Kraus, Mailick-Seltzer, Chou, Hong, 2004). The psychological well-being of mothers raising a child with a developmental disability varies according to the nature of the disability. Offspring's behavior problems are considered to be the child characteristic that most affects the maternal well-being (Blacher, McIntyre, 2006).

The majority of research has been focused on Down syndrome. Quantitative and qualitative evidence indicates that parental well-being is influenced by having a child with Down syndrome. Parents very often take care of their children throughout their whole life (Crowe, Florez, 2006). It is, therefore, not surprising that raising a child with this syndrome has been found to be connected with higher levels of parental stress and reduced well-being among parents (Dąbrowska, Pisula, 2010). They were also less content with their health, financial, social and occupational position than parents who raise children without developmental disorders (Brown, MacAdam-Crisp, Wang, Iarocci, 2006). However, there are parents that experience positive adaptation and are able to be resilient despite the risk that occurs. Brown et al. (2006) proved that parents of children with Down syndrome estimated their family life quality better than parents who raise children with autism. Children with Down syndrome and their mothers have more positive interactions than

children with other developmental disabilities (Mitchell, Hauser-Cram, Crossman, 2015). Many studies have also reported that these parents experienced a lower level of stress and a higher level of satisfaction from received support and had a more optimistic view of their children's future than parents who raise children with other types of disability (Zasępa, 2008). Luthar and Cicchetti (2000) claim that there are both "vulnerability factors" and "protective factors" that influence one's ability to be resilient. Although there are a lot of external factors which burden parents, like the child's health problems or lack of social support (Bruno, Foerster, 2011; Cumella, Heslam, 2013), many findings indicate that they have internal resources allowing them to see the positive dimensions of raising a child with disability (King, Zwaigenbaum, Bates, Baxter, Rosenbaum, 2011). External locus of control (Lloyd, Hastings, 2009), dispositional optimism (Greenberg et al., 2004) and contentment of one's own coping strategies (Veek, van der, 2009) are considered as important protection against depressive symptoms and declining psychological well-being. There is also one other construct, ego-resiliency, which can be useful when we consider the situation of parents who face difficulties. Block and Kremen (1996) define ego-resiliency as a trait that allows individuals to cope well and have control when circumstances are changing. It allows for adapting to daily activities as well as determines functioning in traumatic situations (Şek, 2008). Some authors suggest that raising a child with disabilities is a source of processes which refer to resilience and in this way parents are able to reappraise their situation positively (King et al., 2011).

Based on the relevant literature, we assume that ego-resiliency can play a mediating role between perceived stress and psychological well-being among parents who raise children with Down syndrome. We also put forward a hypothesis that there is a difference in psychological well-being between parents who describe their parenthood in different ways. The following research questions are posed:

1. Is ego-resilience a mediator in the relationship between perceived stress and psychological well-being?
2. In which way do parents of children with Down syndrome understand their parenthood?
3. Is there any difference in psychological well-being among parents who perceive their parenthood in different ways?

## **Research Methodology**

### **Participants and procedure**

The group of participants in this study consisted of 126 parents (75 mothers and 51 fathers) of children with Down syndrome at the age of 1–39. The data was collected in a confidential and anonymous survey and questionnaires. Participation in the survey was voluntary. Initially, 140 parents (85 mothers and 55 fathers) had agreed to take part in this project. Finally, 126 of them completed questionnaires and met the terms of this project. The parents were the residents of a few Polish provinces, especially Silesian Voivodeship. Each parent received a set of questionnaires in a separate envelope and was asked to complete them. Studies were conducted both in individual contact with parents and with the help of school head-teachers, rehabilitation centres and chairmen of family associations and friends of the children with Down syndrome.

The parents' age ranged from 25 to 69 years. The mean age was 46.54 ( $SD = 10.26$ ). All the parents (100%) were married.

### **Instrument**

Perceived stress. The level of the parents' perceived stress was evaluated using the 10-item Perceived Stress Scale (PSS-10) developed by Cohen et al. (1983). The Polish adaptation was conducted by Juczyński and Ogińska-Bulik (2009). PSS-10 focuses on symptoms of negative stress which were experienced during a month. Each item has a 5-point response scale (from 0 = never to 4 = very often). The PSS-10 scores are obtained by reversing the scores on the four positive questions and then summing up across all 10 scores. Total score is the measure of chronic stress. Example questions include "In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?" Cronbach's  $\alpha$  coefficient for this scale was 0.86.

Ego-resilience. The level of ego-resiliency was measured with the help of the Ego-Resilience scale developed by Block and Kremen (1996) and adapted by Przybyła-Basista and Kołodziej (2012). This scale consists of 12 items including such ones as: "I am considered as a very energetic person", "I am more investigative than the majority of other people". The respondents rated their level of agreement with each item on a 4-grade scale, where 4 denotes "I agree very strongly" and 1 = "I do not agree at all". The scale structure consists of two factors: Optimal Regulation

(OR) and Openness to New Life Experiences (OL). Cronbach's  $\alpha$  for the total scale was 0.802, for the OR scale = 0.773 and for the OL scale = 0.59.

Psychological well-being. To measure the parents' psychological well-being we used the Oxford Happiness Questionnaire (OHQ). The original version of this questionnaire was developed by Hills and Argyle (2002). The Polish adaptation was made by Kołodziej and Przybyła-Basista (2013). The respondents rated their level of agreement with each item on a 6-grade scale, with responses ranging from 6 = "I absolutely agree" to 1 = "I absolutely disagree". The Polish version of OHQ consists of two subscales: "Life Satisfaction and Sense of Power" and "Feeling of Sense and Control". Cronbach's  $\alpha$  for the total scale was 0.902, for the first subscale = 0.882 and for the second subscale = 0.827.

Perceived parenthood. To investigate the ways in which parents perceive their own parenthood, we had developed a Questionnaire for Mothers and a Questionnaire for Fathers. With the help of these questionnaires, quantitative and qualitative data was collected. Exemplary items were as follows: "Being a parent of a child with Down syndrome is for me: ..." (Przybyła-Basista, Kózka, 2016, in print).

## **Research Results**

To examine the extent to which ego-resilience affects the relationship between perceived stress and psychological well-being, we used regression analyses and the Sobel test (1982). This procedure includes the criteria defined by Baron and Kenny (1986).

The first phase of mediation analyses among the parents of children with Down syndrome confirmed that perceived stress predicted psychological well-being ( $\beta = -.616$ ;  $t(124) = -8.703$ ;  $p < .001$ ). The second phase of the analyses proved a negative relationship between perceived stress and ego-resilience ( $\beta = -.455$ ;  $t(124) = -5.691$ ;  $p < .001$ ). In the third phase, an independent variable and a mediator were introduced to the model at the same time. As a consequence, the role of perceived stress in predicting psychological well-being decreased ( $\beta = -.499$ ;  $t(123) = -6.539$ ;  $p < .001$ ). The mediator was positively related to the dependent variable ( $\beta = .256$ ;  $t(123) = 3.346$ ;  $p < .001$ ). Hence, the first three conditions were met. The outcome of the Sobel test was statistically significant ( $z = -3.132$ ;  $p = .001$ ). It indicates that the fourth condition, i.e., the significant reduction of the effect of the independent variable (perceived stress) on the criterion (psychological well-being) when the mediator (ego-resilience) is added, is also met. In other words, the occurrence of partial mediation has been confirmed (cf., Figure 1).

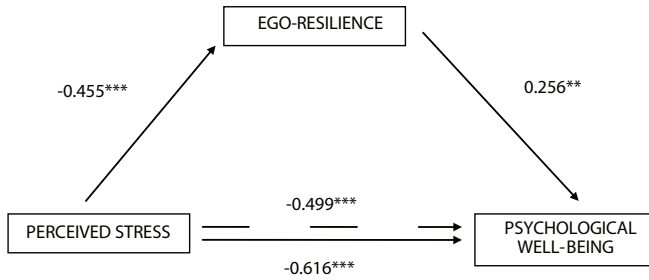


Figure 1. Illustration of the simple mediation model: Ego-resilience mediates the relationship between perceived stress and psychological well-being

The second objective of this study was to investigate the way in which the parents of children with Down syndrome understood their parenthood. 111 parents (70 mothers and 41 fathers) from the total sample of 126 parents answered the question which concerned the perception of their parenthood. Qualitative analysis showed that the parents (both mothers and fathers) understood their parenthood in such categories as: burden ( $n = 20$ ), challenge ( $n = 49$ ), ordinariness ( $n = 13$ ) and satisfaction-happiness ( $n = 29$ ).

The third objective of this study was to probe into the question whether there was any difference in the level of psychological well-being between the parents who understood their parenthood in different categories. The results obtained with the use of the ANOVA test and Scheffe test showed that there was a significant difference in psychological well-being between the parents who perceived their parenthood as a burden or as a challenge and the parents who described their parenthood as satisfaction-happiness ( $p = .001$ ). The parents who described their parenthood as satisfaction-happiness ( $M = 111.86$ ;  $SD = 11.94$ ) had a higher level of psychological well-being than the parents who declared that their parenthood was a burden ( $M = 91.75$ ;  $SD = 16.46$ ) or challenge ( $M = 95.85$ ;  $SD = 17.67$ ). The results of the analysis are shown in Table 1 and Table 2.

**Table 1.** Psychological well-being among parents of children with Down syndrome who perceive their parenthood in different categories

Psychological well-being	Categories of perceived parenthood	<i>n</i>	<i>M</i>	<i>SD</i>	<i>SE</i>	ANOVA <i>F</i>	<i>p</i>
total score	burden	20	91.75	16.46	0.51	7.826	<b>0.001</b>
total score	challenge	49	95.85	17.67	0.34		
total score	ordinariness	13	99.70	19.34	0.62		
total score	satisfaction-happiness	29	111.86	11.94	0.43		

**Table 2.** Multiple comparisons with the use of the Scheffe test

Psychological well-being	Categories of perceived parenthood	Categories of perceived parenthood	<i>p</i>
total score	burden	challenge	0.83
total score	burden	ordinariness	0,60
total score	burden	satisfaction-happiness	<b>0.001</b>
total score	challenge	ordinariness	0.90
total score	challenge	satisfaction-happiness	<b>0.001</b>
total score	ordinariness	satisfaction-happiness	0.18

## **Discussion and conclusions**

Ego-resilience has turned out to be a partial mediator between perceived stress and psychological well-being among the parents of children with Down syndrome. It means that the stress perceived by the parents has a weaker effect on their well-being when they have such a resource like ego-resilience. This resource makes their functioning in difficult situations more optimal (Kaczmarek, Sęk, Ziarko, 2011). Every difficult situation is in some way a source of stress and has a negative impact on the psychological well-being and also life satisfaction, the sense of strength, and the sense of control. Our findings suggest that ego-resilience is a resource that has beneficial effects.

The other important thing is to investigate not only if the resources exist or not, but also how parents perceive them. The findings of such studies can contribute to a better understanding of the adaptation process of parents who raise children with Down syndrome. The findings of this study provide support for the argument that many families are able to respond to the experience of raising a child with disability, such as Down syndrome, with resilience and adaptive functioning. A lot of parents perceive their parenthood as satisfaction (happiness). In our opinion, these families have adapted to their situation of raising a child with disability better than the parents who perceive their parenthood as a burden or challenge. It is possible that parents who struggle with many stressful hardships and demands have difficulties achieving satisfaction and an optimal level of psychological well-being and adaptation. This suggests that the parents who are able to view the contributions of their child more positively can experience relief from the parenting stress connected with raising their child. It offers protection against a negative sense of well-being and allows parents to take good care of their children. What

is more, the parents' perception of their situation and the sort of the problems which they face can be changed. It is important to remember that adaptation is a dynamic process occurring across the lifespan (Levinson, 1986) and to update the knowledge about factors and processes associated with the functioning of families of children with Down syndrome.

The findings of this study are subject to several limitations. Firstly, the use of self-report measures should be pointed out. Another bias might be that the parents who decided to participate in this study might have differed significantly from the parents that did not. Most of the participants in this study were members of family associations and friends of children with Down syndrome. What is more, the parents were highly diversified with regard to their age and the age of their children. It means that the obtained results should be generalized with caution. Finally, there are some limitations as to the analyses conducted in this study. We divided the parents' answers into four categories, but this division should be a subject of further research.

Despite these limitations, the present study holds implications for researchers and practitioners, which might be promising. The mediating effect of ego-resilience is an important finding that may guide the design of interventions. Practically, it can be suggested that programs to support families with children with Down syndrome should investigate parents' adaptation process, emotions which are connected with it, and the way in which they perceive their parenthood. Nelson et al. (2014) indicate the type of experienced emotions as a mediator between parenthood and well-being. The perspectives of the parents' perceiving parenthood found in the present study may then be used to recognize the current situation of parents who face responsibility for caring for children with the Down syndrome.

In conclusion, there is a need for further research on the psychological well-being in parents of children with Down syndrome to improve their psychological functioning and also their children's well-being. Still much remains unknown in the area of the functioning of these families. Increased research attention is needed to understand the life-span needs of parents and persons with Down syndrome and their family and social functioning. Further research should include objective data, like detailed descriptions of children's development, and should be based on larger samples and longitudinal study designs. Understanding more fully how individuals handle lifelong caregiving challenges will open the door to new forms of help.



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