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Presence of Stress in Families of People with Intellectual Disability

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Abstract: Families with people with intellectual disabilities often face certain problems and difficulties related to their mental health. They are often exposed to different levels of stress, feelings of isolation, shame, sadness, depression, helplessness and scarce physical, family and social functionality, which usually arise from the need for the care they should provide to the person with an intellectual disability. These families usually have a smaller network of formal, informal and instrumental support and this is the reason for their greater social isolation compared to other families. The purpose of this research is to determine the level of stress among family members who have a person with an intellectual disability. The level of stress will be determined in relation to the gender, age, ethnicity, level of education and place of residence of the family members. The obtained results of the research will represent a good basis for giving appropriate recommendations to the relevant institutions for developing of appropriate programs for mental health care of families who have a person with an intellectual disability. The research will cover the members of families who have a person with an intellectual disability, who are users of the daycare services for people with an intellectual disability from the Republic Center for support of people with an intellectual disability Poraka - Skopje and the rehabilitation and reintegration service for people with intellectual disability Poraka Nasha- Kumanovo. The research will use a stress index questionnaire, the Parenting Stress Index- Short Form (PSI-SF) which is designed to assess the magnitude of stress in the parent-child system, the fourth edition of the popular PSI is a 120-item inventory that focuses on three main domains of stress: child characteristics, parent characteristics, and situational/demographic life stress.

Keywords: Stress, Families, Intellectual disability, Mental health

Introduction

General about Stress

Since the second half of the last century, the word "stress" is such an everyday and common term, that everyone seems to understand what stress is, and which events are stressful and which are not, what causes stress in people. Things are not that simple though. It's well known that people experience the same situation differently and react to it differently. But the same event does not affect all people equally. A certain situation is stressful for one person, pleasant for another. Also, the level of stress tolerance is different among people. Why is that so? is a question that experts have been trying to answer for more than half a century, studying stress and ways of dealing with it. That is why the questions of what stress is, how it occurs, how it affects a person, how people react when they are under stress, how they can prevent or at least reduce the negative consequences of stress are questions that are still relevant. In the past period, several misunderstandings have been clarified, but there is still no single answer to all the questions asked.

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The term "stress" has different meanings in different scientific fields. In physics, it denotes the strong pressure that matter undergoes. In the field of medicine, this term refers to any reaction that can have a negative effect on health. In psychology, however, stress is a reaction to an unpleasant event. According to Lazarus and Folkman (2004) "psychological stress is a relationship between the individual and the environment that the person evaluates as a relationship with high demands or as a relationship that exceeds his/her capabilities and threatens his/her well-being". In fact, the assessment that the person-environment relationship is stressful depends on the individual's cognitive assessment that his relationship with the environment is disturbed.

A generally accepted opinion is that stress is a part of life, our everyday life, something we can't avoid. It is the result of the individual perception of situations that have happened, are happening or will happen. Stress affects many aspects of your life, including your emotions, behaviors, ability to think, and physical health. We all deal with stress differently, and the symptoms of stress can vary. Stress is stronger when we believe that there is no way to prevent or resolve the situation that caused it. Kaličanin and Petrović (2001) define stress as "a comprehensive psychosociobiological (or biopsychosocial) response of the organism to the influence of any stressors that seriously disturb its homeostasis, causing a general adaptive reaction".

Factors Causing Stress

A stressor can be defined as "an event that we evaluate as threatening or dangerous to our life, position in the family, society, community, material goods and which can disrupt the usual course of our life" (Arambašić, 2000). According to Kosović (2004), a stressor is any stimulus that can cause a state of stress, that is, cause an imbalance of organs and their functions. Stress factors or stressors are all potential factors that can cause stress. Regardless to their potentially diverse nature, they result in similar physiological changes in the organism. Thus, they can differ in relation to the stressogenic factor:

- Physical stress caused by energy changes or mechanical and physical effects in environment;
- Biological stress caused by biological and physiological factors such as loss of food and fluids, effects of toxic and infectious agents, biological rhythm disorders and the like;
- Psychological stress that is a consequence of unexpected threatening life events;
- Social stress as an effect of factors of a social nature such as social events, conflicts with other members of the community, wars and so on;
- Psycho-social stress, which indicates that the psychological and social components of stress often occur together

Stress is also related to certain professions. There are professions that are highly stressful, there are professional stressors in them, others are a little stressful, and some are relaxing. Stress related to or caused by work/professional obligations is called work/professional stress.

Historical Development of the Teaching for Stress

Modern concepts of stress have been developing over the course of two and a half millennia. This development is still ongoing, because there is no comprehensive and generally accepted theory of stress. The development of the concept of stress begins with the observation that living organisms constantly try to protect their own harmony - internal balance, from the influence of numerous and diverse factors that disrupt it. We will only list a few concepts.

Walter Cannon (1871-1945) Cannon is counted among the first authors claiming that both physiological and psychological components participate in stress. Defining stress as an emotional and physiological response to danger, Cannon introduces the term "**fight or flight**". A critical level of stress, defined as a threat or danger, affects the organism by disrupting its homeostasis. During stress, numerous physiological changes occur in the body: strong activation of the sympathetic nervous and endocrine system, acceleration of the heart, breathing and blood circulation through the muscles, blood pressure and blood sugar increase, blood flow to the skin decreases. The secretion of catecholamines increases the speed and intensity of reactions. This overall physiological response to stress prepares the body for "fight or flight" reactions. Stress itself, according to Cannon, is potentially harmful, because it interferes with emotional and physiological functioning, and as such can lead to health problems, especially if the stress lasts for a long time, and the body is not able to respond according to the "**fight or flight**" type. ". Numerous studies in humans talk about individual, hereditary predispositions for a specific response to stress and their genetic predisposition for a certain disease.

Hans Selye (1936) developed the concept of stress. He hypothesized that stereotyped psychological and physiological changes occur as a result of difficult long-term adaptations, due to the action of various stressors, by engaging all the body's defense mechanisms. The complex of these changes marks them as **general adaptation syndrome or stress syndrome**. Essentially Selye, in this way, redefined Sydnham's concept, which speaks of the emergence of adaptation diseases. Selye, came to the conclusion that severe long-term stressful situations that can't be controlled lead to illness and even death.

The best known among these stress models is the model proposed by **Lazarus and Folkman** (1984). They define stress caused by psychosocial factors as a special relationship of the individual to the environment. They believe that stress is the result of the individual's conscious assessment that his relationship with the environment is unusual. One of the essential characteristics of that relationship is that the person assesses (realistically or unrealistically) that the new circumstances, caused by the stressors, exceed his possibilities and abilities for successful resistance. Without such an assessment, there is no stress, regardless of what the objective danger from the environment was. The cognitive component is important, that is, the individual assessment of danger and personal safety. This means that it is not just a simple reflex reaction to the influence of stressors. An event that we evaluate as threatening or dangerous for our own life, for the life of our loved ones, for material goods, position at work, in the family and community, self-respect, is called a stressor. Therefore, a stressor is an external event, and stress is an internal state or experience.

According to this model, what objectively happens to us in life can lead to a state of stress. But whether it will happen or not, that is, whether an event will be stressful or not, mostly depends on the acceptance of that event, regardless of what objectively happened. This means that the same event will not be equally stressful for all people, because they all perceive or accept what happens to them differently. According to this model, the concept of **stress** does not refer to a static relationship between an individual and the environment, they see it as a process that develops as a function of changes. According to the Lazarus model, many important elements when assessing a certain situation as stressful are:

- The characteristics of the individual (character, goals, values, gender, age, beliefs, interests...)
- Features of the environment in which the stressful situation itself occurred (demands, restrictions from other people, social support, social characteristics).

What is the relationship between the characteristics of the individual and the characteristics of the environment? Research shows that personality traits are related to cognitive assessment, to the choice of coping methods and through them to the immediate outcomes of stressful events. A similar role is played by values, beliefs, attitudes and interests as relatively stable characteristics of the individual. What are the consequences of stress depending on how the situation itself is experienced, that is, what the individual does in those situations, whether he fights with the stressful situation or comes to terms with his fate? When it comes to the assessment of the stressful situation, there are two types of cognitive assessments: How significant is the stressful situation itself, and here the most frequently asked question is: "Am I in trouble and what kind" and the other cognitive assessment is: the possibility of controlling the stressful situation itself, where the most frequently asked question is: "Can something be done, or to avoid a stressful situation and what to do?"

Sources of Stress

Stress is a complex reaction, that is, a syndrome - a set of symptoms. This means that stress is not caused by a single factor, but by a set of factors very different in nature and intensity, and therefore we can't determine with certainty which of them is the most important. Sometimes these are disorders that are emphasized and can be easily detected such as: a strong pain in the stomach before taking an exam, the discomfort we feel after a strong anger, or when we simply freeze (paralyze) when we are in front of a person we are afraid of. However, some mild pains, for example, pain in the waist, headache, which can be directly related to stress, and we don't bring them into relation at all. Sometimes stress quietly undermines our health, and we aren't aware of it, and it happens that we remember it only after discovering a health problem or after some loss (ulcer, some persistent skin disease, disturbed sleep), heart problems after long-term nervous tension. However, the decisive factors, "triggers" as Bensaba (2002) calls them, can be obvious, logical, such as a dispute that has been rejected several times and for which there is no prospect of being resolved in due time. Sometimes the "trigger" events are very harmless and have a silent effect, just one spoken word can cause us pain, fear or anger. It often happens in everyday life that someone gets an attack of rage in the form of an unexpected behavior or reaction, and the occasion was some small and insignificant event. In fact, that small and insignificant event served only as a trigger. It helped bring to the surface what was happening deep in the soul. Each of these reactions is the result

of the influence of some stressor who happens to be the stress source. Stress sources are multiple. Mostly their classification is derived into:

1. Physical and physiological
2. Psychological and social.

Physical and Physiological Sources of Stress

The modern way of life in humans causes sensitivity to loud noise. Noise is thought to be the root cause of 60,000 work-related injuries per year and 20% of mental hospital visits. Strong continuous light, even the light from a computer screen, causes prolonged sensory aggression. Temperature change: hot-cold; when they happen suddenly or violently, the body perceives it as aggression. It also happens during sudden changes in the outside temperature. This way of life causes changes in muscles that weaken, internal processes decrease and the body experiences stress due to accumulated toxins. Poor nutrition that is not consumed calmly and on time is another significant source of stress. Any illness, acute or chronic, initiates stress, which joins other symptoms of ill health, and an existing illness seems to cause a new illness. Example: sadness, loss of sleep, appetite, worsen pain and create bad conditions for treatment.

The way of life in the environment, the changes that happened in our life, the frequency of problems, diseases, losses are also a significant source of stress. Regarding the impact of the various changes that people are most often exposed to in life and the "dose" of stress they cause, the American psychiatrists Holmes and Roche created a stress scale on which life events are ranked from the loss of a loved one, which causes the highest dose of stress to punishments and offenses as triggers of the lowest dose of stress (Bensaba 2002). The race to achieve professional, material success, social reputation, as well as unemployment and job loss, is certainly a source of stress. Family problems and insufficient social support are also strong sources of stress. Aging brings stress for a number of reasons. The reduction of the ability to resist or adapt to changes such as: changes in physical appearance, retirement, departure of children from the home known as "empty nest", the appearance of diseases, infirmity, loss of a spouse, etc.

Psycho – Social Sources of Stress

They are significant stress generators that are contained in almost all of the previously listed sources of stress. However, they represent a specific category by themselves, which we often encounter. Fiske and Taylor (1991) tried to classify stressful events (stressors) according to their stressogenicity. They concluded that the uncontrollable events that happen in our lives are especially stressful. The importance of control over events was shown by the research of Alloy and Clements (1992). The results of the same showed that people who think they can have control over stressful events in their life are less affected by life events. This research is closely related to the phenomenon called "learned helplessness" in which people remain passive in the face of stressors that appear to be beyond their control.

The research of Fenz and Epstein (1967) in which the stress in paratroopers was examined, showed that the stressogenicity of events that are new and unknown, that is, novelty, is a strong source of stress. They concluded that the stress response of experienced skydivers is significantly weaker than that of first-time skydivers. Uncertainty, fear of the future, loneliness, lack of support on an affective level, insufficient love, newness, are strong psychological sources of stress. This means that when a person is exposed to an event that causes stress, he notices certain signs or symptoms that he actually recognizes as a consequence of stress.

Stress in Parents of Children with Intellectual Disability

Parental stress is the anxiety you feel that you just can't handle as a parent. The demands placed on you are too high. You don't have the resources to meet them. (Deater-Deckard 1998; Holly et al., 2019). Parenting stress can disrupt our well-being, and it can change the direction of a child's development. Excessive protective care, concern for the child's safety, feeling worried that something may harm the child's health. Parental stress worsens the connection with the children themselves, their emotional understanding and empathy towards them.

Can children be a cause of stress? Of course they can.
Can financial problems cause parenting stress?

Could social isolation or an inadequate support system be the cause of stress?

If it compromises your ability to care for your children—if it makes you worry about your ability to keep them safe, healthy, and thriving—then it can contribute to parenting stress.

Parental stress can also be caused by the systemic setting of society.

Are you stressed because your child suffers from excessive inconsolable crying? Are you stressed because your child often gets angry? Are you stressed because you have a child with a disability? Are you stressed because you're trying to work at home while taking care of your child?

Leutar and Štambuk (2007) state that each parent will deal with a child's difficulties in their own way, and this depends on several different factors: the parents' personality, the type, degree and time of the onset of the difficulty, parental expectations, family relations, economic and social circumstances of the family, level of education of parents, professional support, help of relatives, friends and associations, and parents' information. A parent must be ready to face everyday challenges, which requires courage and strength for continuous adaptation. Parents encounter situations that they did not plan, while the planned ones are often put aside in order to contribute to the development of their child. There are many feelings, happy, but also others: fear, worry, anger, pain, sadness and mixed feelings (Ljubešić, 2014).

Parents who have a child with an intellectual disability have to deal with the medical, social and financial needs of the child. The needs related to personal care for the child, the provision of various types of services in the field of social and health care, the inclusion of the child in the educational system, with the common goal of enabling him to have a good family and social functioning, have increased. With the increased intensity of need, parents who take care of a child are often exposed to stress and negative emotions. In the research carried out by Kishore (2011), the results show that there are no differences between the effects of intellectual disabilities and multiple difficulties on the child's burden and coping strategies, on mothers, that is, the cumulative effect of intellectual disabilities is as serious as the effect on multiple difficulties for the child (Kishore, 2011). Systems of formal, informal and instrumental support for parents who have a child with an intellectual disability should be strengthened and improved, which will enable them to reduce stressful factors that affect their mental health.

Methodology

The purpose of this research is to determine the level of stress among family members who have a person with an intellectual disability. The research covered 42 members of families who have a person with an intellectual disability, who use daycare services for people with an intellectual disability within the Republic Center for support of people with an intellectual disability Poraka - Skopje and the rehabilitation and reintegration service for people with intellectual disability Poraka Nasha- Kumanovo. The research uses a stress index questionnaire, the Parenting Stress Index- Short Form (PSI-SF) which is designed to assess the magnitude of stress in the parent-child system.

Results

Graph no.1 shows the responses of the respondents to the question about caring for their child/children, which requires more time and energy than the parent can give. The largest number of respondents, 63.4%, agree that caring for their child requires more time and energy than they can give, while 22% of respondents fully agree and 9.8% disagree.

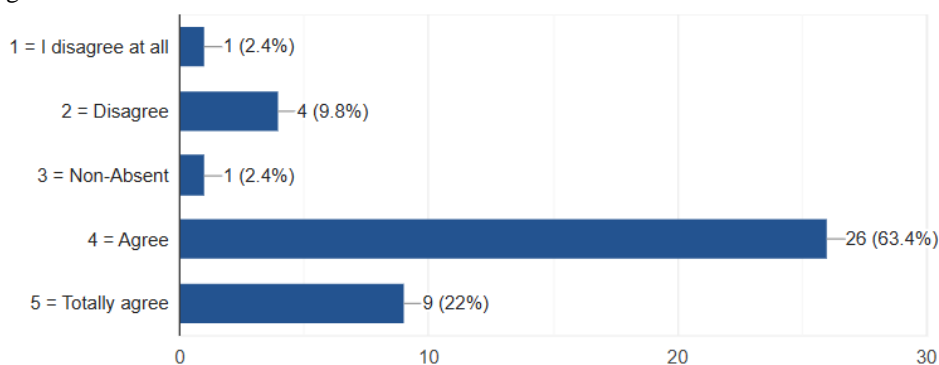


Figure 1. Care for the child/children by the respondents

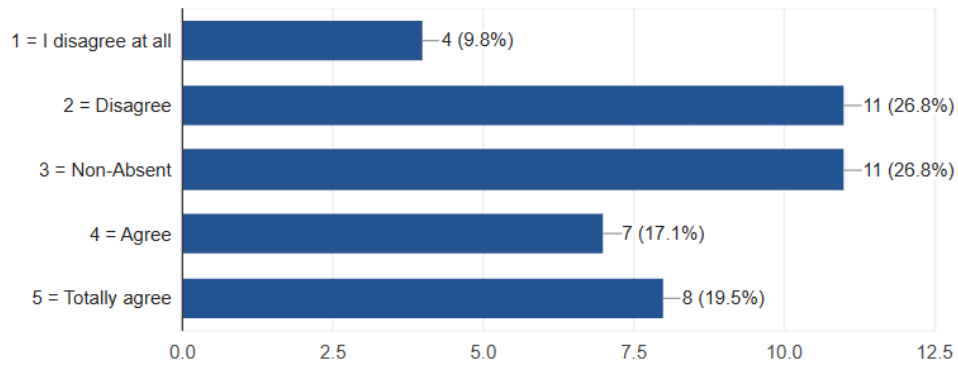


Figure 2. Sources of stress among respondents

The results analyzed according to the main sources of stress in the respondent's life from the condition of the child's disability are presented in graph number 2. The largest number of respondents, 26,8%, disagree that the greatest source of stress in their lives is caused by the condition of their child. Total 19,5% of the respondents completely agree that the condition of their child/children is the biggest source of stress. There is a smaller number of respondents, 17,1 % who agree, and 9,8% who disagree at all.

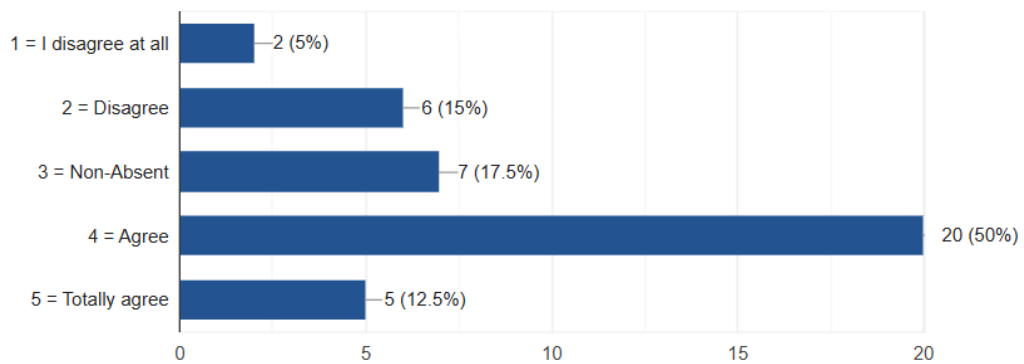


Figure 3. Balancing of respondents of different responsibilities due to the needs of the child/children

Regarding the question, is it difficult to balance different responsibilities due to the needs of my child/children, which are presented in graph number 3, the largest number of respondents, 50%, think that it is difficult for them to balance the different responsibilities for the child/children, while 17,5 of the respondents are not excellent in answering the question, 15% disagree, 12,5 of the respondents totally agree, and an insignificant number of 5% don't agree at all.

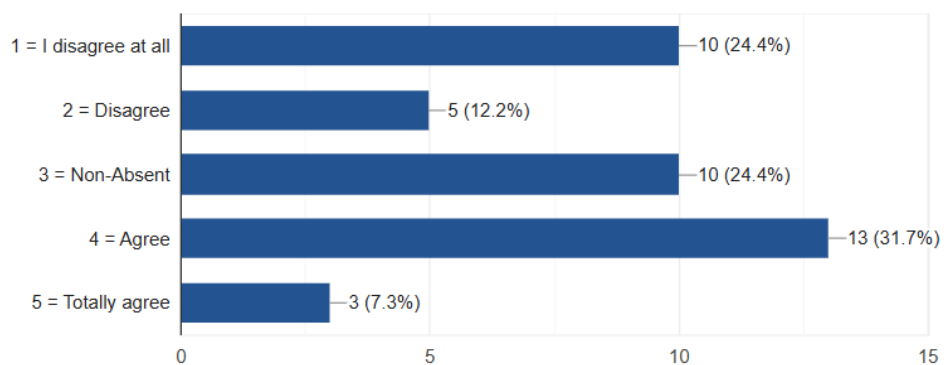


Figure 4. Having choices and control in the respondents' lives

Regarding this question, having a child/children with a disability means having too few choices and too little control over my life, from graph number 4, we can notice that the largest number of respondents 31,7% agree, 24,4% don't agree at all, as well as 24,4% who declared themselves undecided regarding this issue. The number of respondents or a total of 12,2% who agree is smaller.

Conclusion

The impact of stress is manifested in many aspects of our lives; they have a direct impact on our emotions, behavior, ability to think and on physical and mental health. Each person deals with stress differently, and the symptoms of stress can also vary. Caring for a child with an intellectual disability in a family is a great stress, which is reflected in many spheres of the parents' and the extended family's life, thus reducing their quality of life. Parents need functional ways of dealing with stress, because they represent the most important social support they provide for their child. The social, economic, health situation, the pace of life, the needs and challenges in everyday life that need to be answered, lead to an increase in the level of stress among parents. Therefore, it is necessary to take appropriate actions aimed at increasing the resources in the community, which would give families more support in dealing with the daily problems and difficulties they face, and which would reduce the stress all members of the family face. Adequate stress prevention programs, information and education of parents, and the involvement of experts from various fields and service providers who would contribute to preventing and overcoming stressful factors among parents who have children with intellectual disabilities are needed. From the conducted research, we came to the conclusion that parents of children with intellectual disabilities who use the daycare services for temporary stay in Republic Center for support of people with an intellectual disability Poraka - Skopje and the rehabilitation and reintegration service for people with intellectual disability Poraka Nasha- Kumanovo, face a series of difficulties related to the care of their child, in the use of their time spend with the children, in dealing with financial difficulties, in balancing the various responsibilities due to the needs of the children and in terms of the choices and control they establish in their lives. From the research itself, we came to the realization that for the largest number of respondents, the biggest source of stress in their lives is caused by the condition of their child/children.

Scientific Ethics Declaration

The authors declare that the scientific ethical and legal responsibility of this article published in EPESS Journal belongs to the authors.

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