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Perceived life satisfaction of parents raising a child with intellectual disabilities

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Abstract

Introduction and Objective. Assessment of life satisfaction is the result of comparing one's situation with the standards set by oneself. If the comparison result is satisfactory, it results in high satisfaction. Giving birth to a child with an intellectual disability significantly influences parents' assessment of satisfaction. The aim of the study was to examine the relationship between selected socio-demographic factors and the level of life satisfaction of parents of a child with intellectual disabilities.
Materials and Method. The study included families raising a child with intellectual disabilities. They were parents of students who continued their education in rehabilitation and education centres (OTEW) and special schools. A total of 1,216 parents participated in a paper and electronic survey. The questionnaires included the Satisfaction with Life Scale (SWLS) in Juczynski's Polish adaptation, and a questionnaire containing questions concerning socio-demographic data.
Results. Analysis showed that 58% of parents rated their satisfaction as low. Parents of children from special schools rated satisfaction higher. A higher level of educational correlated positively with life satisfaction. There was no relationship between the age of the child and gender on life satisfaction of the parents.
Conclusions. Integrated actions should be taken to increase the level of life satisfaction among parents of children with intellectual disabilities. Measures should include psychological support in difficult situations, financial assistance, and employment flexibility (tailored to the parent's capabilities). An important factor is to promote the acceptance and integration of people with disabilities in society, including in schools, workplaces and local communities, to reduce parents' feelings of isolation.

Key words

family, parents, life satisfaction, intellectual disability, mental health

INTRODUCTION

In the scientific literature, it is difficult to find a single definition of the term 'life satisfaction'. Depending on the theory, it is defined as satisfaction, fulfillment, and feeling of pleasure [1–2]. Scientific research on life satisfaction focuses on identifying factors that influence its level. In many studies, one can find the concept of self-satisfaction, which is seen as positive functioning and includes such areas as relationships in society, goals in life, commitment, self-esteem, and optimism. The above-mentioned levels are inextricably linked to the measures of quality of life and happiness used [3, 4]. A person may be satisfied with life as a whole, while showing dissatisfaction with certain areas and vice versa; lack of satisfaction in life does not mean dissatisfaction in every aspect. This is because people, functioning in many spheres of social and personal life, give different weights to individual areas and domains of life. The timing of the assessment of life satisfaction is not insignificant.

There is a tendency to extend the evaluation of the present into the past and future, and consequently, reality is perceived in relation to the individual's own internal time frame, creating an image that relates to the past, the current state, and future projections [5].

The authors based their research on Juczyński's questionnaire in which he defines life satisfaction as: 'the evaluation of satisfaction with life is the result of comparing one's own situation with the standards one has set. If the result of the comparison is satisfactory, it results in a feeling of high satisfaction' [6].

Six groups of factors determining the assessment of satisfaction were distinguished [7]. The first are personality factors, mainly genetically shaped-sensitivity, openness, activity level and anxiety. The second type of components are socio-demographic factors: gender, marital status, education, place of residence. Also included are such elements as economic factors (income level, inflation, unemployment rate in the area), spiritual factors related to faith, as well as individual and institutional factors. The current study focuses mainly on factors from the second group.

The birth of a child with intellectual disability causes significant changes in the family system. This new situation is often accompanied by painful and traumatic feelings that may disturb the current family structure, forcing people to find their way into previously unknown reality [8]. The parents learn a yet unknown role, defines their place, re-evaluates, and tries to adapt accordingly. The new situation causes changes in the emotional and social functioning of the family [8].

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The DSM-IV defines intellectual disability as:

> a significantly lower than average (intelligence quotient IQ 70 and below) general level of intellectual functioning accompanied by a significant limitation of adaptive functioning in at least two of the following types of abilities: communication, self-care, home life, social and interpersonal skills, the use of work security measures, ways of organizing leisure and care for health and safety. The onset of this condition must occur before the age of 18 [9].

A mild degree of intellectual disability is characterized by an IQ test score in the range of 50–69. Children with mild intellectual disabilities start speaking, reading, and writing later than their peers, they also have problems with expressing their emotions, learning, self-care, caring for health and safety, and have less adaptability. They achieve most of the competencies needed to independent functioning, but it takes more time [10].

A moderate degree of intellectual disability is usually attributed to people whose approximate IQ test result is between 35–49, which in adults means a developmental age between 6–9 years old. It is always accompanied by impaired cognition of reality, reduced motor skills, brain underdevelopment limited thought processes, reduced ability to concentrate, and memory problems [10].

A severe degree of disability often means the need for constant care, characterized by people whose IQ level is in the range of values from 20 – 34, corresponding to the developmental age range from 3 – 6 years old. The ability to communicate, perceive, focus, and react to stimuli is significantly impaired. Behavioural disorders are often present, such as hyperactivity, violent and aggressive behaviour, and withdrawal [10].

OBJECTIVE

The aim of the study was to examine the relationship between selected socio-demographic factors and the level of life satisfaction of the parents of a child with intellectual disabilities. Main research problem: **What factors influence the level of life satisfaction of parents of children with intellectual disabilities?** The significance of this issue stems from the fact that caring for a child with an intellectual disability brings numerous challenges that can impact parents' quality of life, mental health, and family relationships. Understanding the key factors determining life satisfaction will help develop more effective support systems for families and create intervention strategies to improve their functioning in various areas. These studies can also provide valuable insights for professionals in psychology, education, and social policy, contributing to the enhancement of the quality of life for this social group.

MATERIALS AND METHOD

The study included families raising a child with intellectual disabilities. They were the parents of children pursuing school education in rehabilitation, educational upbringing centres (OREW) and special schools. Inclusion criteria for the study: a parent (mother or father) with a child attending compulsory education in a rehabilitation, educational and upbringing centre, or in a public special school. Exclusion criteria: foster families, legal guardians (non-parent), grandparents, siblings, and extended family.

The study received a positive opinion from the Bioethics Committee of the Medical University of Silesia in Katowice (Approval No. KNW/0022/KB/67/19), and was conducted in Poland between April 2019-July 2020. Questionnaires were distributed at rehabilitation, educational and upbringing centres, special schools, community forums and groups for families of children with disabilities. Return of the questionnaires was time-limited (one week). Participation in the study was voluntary and anonymous. Completion of the questionnaire was tantamount to consent to participate in the study, subject to the possibility of withdrawing this consent at any stage. Respondents completed the questionnaires independently, and were completed in paper form by 563 people, and in electronic form by 664 people. A total of 1,216 questionnaires were qualified for final analysis. Questionnaires that did not meet formal qualification requirements were rejected. Only one person in the family – mother or father – was surveyed.

Research instruments. The Satisfaction with Life Scale (SWLS) by E. Diener, R.A. Emmons, R.J. Larson and S. Griffin, in the Polish adaptation by Juczyński was used. The questionnaire contains 5 statements to which the respondent answers on a 7-point scale: 1 – I completely disagree, 2 – I disagree, 3 – I rather disagree, 4 – I neither agree nor disagree, 5 – I rather agree, 6 – I agree, 7 – I completely agree. For the original version, the reliability index (Cronbach's alpha) is 0.87. The scores are added-up, and the overall result indicates the degree of satisfaction with one's life. The score range is 5–35 points. The higher the score, the greater the sense of satisfaction with life. The survey score can be compared with average scores and converted into standardized units. Results within the range of 1–4 stena were treated as low results, and those within the range of 7–10 stena as high, which corresponds to the area of approximately 33% of the lowest results and the same number of the highest on the scale. Results within 5 and 6 stena are considered average [6].

The selection of this particular research questionnaire was based on several key criteria: first, the chosen questionnaire is widely used in scientific research in Poland, ensuring its validity and reliability within the Polish-speaking population. Second, this tool has been previously validated and demonstrates strong psychometric properties, such as high internal consistency and stability over time. This ensures that the obtained results will be more reliable and comparable with previous studies. Third, the availability of norms and result interpretations which have been developed based on studies conducted in Poland. This allows for a more precise analysis of the collected data, adapted to the local socio-cultural context.

Additionally, compared to alternative questionnaires, the selected tool is more suitable for the specific nature of the studied issue, covering key aspects relevant to the research objective. It is also characterized by a user-friendly format and ease of application, minimizing the risk of errors due to respondents' misunderstanding of the questions.

Finally, metrics of the authors of the current article, including questions on socio-metric data.

Statistical preparation. Data from the survey questionnaires were entered into Excel. Statistical analysis of the study results was performed in IBM SPSS Statistics 26, using the following tests:

1) Pearson's Chi-2 test of independence (three levels of statistical significance were adopted: p<0.001, marked with ***; p<0.01, marked with ** and p<0.05, marked with independent groups (three levels of statistical significance were adopted: p<0.001, marked with ***; p<0.01, marked with ** and p<0.05, marked with *), one-way analysis of variance (ANOVA) (three levels of statistical significance: p<0.001, marked with ***; p<0.01, marked with ** and p<0.05, marked with *). Cramer's V correlation coefficient was used to determine how strong the correlation is between nominal variables, or between nominal and ordinal variables (expressed in categories).
2) Cramer's V coefficient – can be interpreted when the Chi-square test gives a statistically significant result. The coefficient can have values from 0–1. The closer it is to 1, the stronger the correlation between the variables. However, it does not provide information about the direction of the relationship.
3) One-way ANOVA – necessary to determine which groups were statistically significantly different from each other, as long as the test showed a significant difference, at least at the p<0.05 level. For this purpose, Tukey's multiple comparison test was performed, and its results presented using appropriate markings, i.e. specifying which groups differ statistically significantly from each other, and what is the direction of this difference (< or >).

RESULTS

More than half of the respondents (52.7%) were parents of children attending rehabilitation, education and upbringing centres (OREW). The remainder (47.3%), were parents of children attending special schools. Among the surveyed parents, the majority were women – 86%; average age of parents – 41.6 ± 7.9 years; average age of children with intellectual disabilities – 14.2 ± 5.01 years. The degree of children's disabilities was as follows: 51.2% of children had a certificate from the Psychological and Pedagogical Counseling Centre up to the age of 16; 16.9% – had a moderate degree of disability; 25.2% – significant, and 6.7% – profound degree of intellectual disability (Tab. 1).

Table 1. Degree of intellectual disability of children

Degree of child's intellectual disability	PLACE OF EDUCATION				Total	
	Special school		Rehabilitation centre educational and upbringing			
	N	%	N	%	N	%
Decision by a psychological counseling centre pedagogical until the age of 16	345	60.0	278	43.4%	623	51.2
Moderate	134	23.3	72	11.2	206	16.9
Significant	93	16.2	213	33.2	306	25.2
Profound	3	0.5	78	12.2	81	6.7
TOTAL	575	100.0	641	100.0	1216	100.0

Test Chi-2: Chi-2=139,197, p<0.001***, V Cramera=0.338

Most parents had secondary education (39.9%) or vocational education (36.3%), and slightly fewer had higher education (22%). Most parents declared that only the men worked in their families (39.4%). There were also many single people receiving benefits (22%) and people from families where both parents worked (25.1%). Full families (presence of father and mother) constituted 65.7% of respondents. At the same time, 29.6% were families in which only the mother was present and 3% were families in which only the father was present. 84.8% of respondents resided in cities.

Statistical analysis. In the analysis of the results regarding the level of life satisfaction, the standard sten norms were used, with the possible range of results: 1–10. Analysis showed that 58.4% of parents rated their life satisfaction as low, and only 18.8% as high (Tab. 2).

Table 2. Level of parents satisfaction with life and child's education

Life satisfaction	PLACE OF EDUCATION				Total	
	Special school		Rehabilitation centre educational and upbringing			
	n	%	n	%	N	%
Low	320	55.7	390	61	710	58.4
Average	141	24.5	136	21.3	277	22.8
High	114	19.8	114	17.7	228	18.8
TOTAL	575	100.0	640	100.0	1,215	100.0

At the same time, the analysis showed that the life satisfaction of parents of children with intellectual disabilities did not significantly correlate with the age of the child.

When analyzing the relationship between parents' education and their life satisfaction, those with primary and vocational education were combined into one group. This was necessary due to the small number of people with primary education. As the analysis of variance showed, the education of parents/guardians differentiated the level of their satisfaction. There is a clear tendency among the surveyed, according to which the higher the education, the higher life satisfaction. There were significant differences between all groups (Tab. 3).

When analyzing the relationship between family type and life satisfaction, people from other and single-parent families were combined into one group. This was necessary due to the small number of people in particular categories of single-parent families. Among the parents of the children, those from full families had significantly higher life satisfaction than those from single-parent or other families (Tab. 4).

As shown by the student's t-test for independent groups, on the life satisfaction scale, significantly higher results were obtained by parents of children attending Special Schools (M=4.27) than by parents of children attending OREW (M=4.00). The child's place of education was related to the level of parents' satisfaction (Tab. 5).

Analysis showed that there is a statistically significant relationship between parents' professional work and the child's place of education, although the correlation between these variables was quite weak (Tab. 6).

Table 3. Parental education and life satisfaction

SWLS	EDUCATION OF PARENT/GUARDIAN						ANOVA		Tukey's test
	basic / professional (1)		secondary education (2)		higher education (3)				
	M	SD	M	SD	M	SD	F	p	
Special school	3.45	2.04	4.46	2.19	5.45	2.41	35.439	<0.001***	3>2>1
OREW	3.34	2.31	3.94	1.97	5.21	2.50	31.189	<0.001***	3>2>1

Table 4. Family type and life satisfaction of parents'

SWLS	FAMILY TYPE				T-student Test	
	Complete family		Another			
	M	SD	M	SD	t	p
Special school	4.52	2.33	3.68	2.16	4.067	<0.001***
OREW	4.58	2.23	3.08	2.17	8.323	<0.001***

Table 5. Child's place of education and parents' life satisfaction

SWLS	Child's place of education	Min	Maks	M	Me	SD	t-student test
Life satisfaction	Special school	1	10	4.27	4.00	2.31	t=2.038 p=0.042*
	OREW	1	10	4.00	4.00	2.33	
	TOTAL	1	10	4.13	4.00	2.32	

Table 6. Employment of parents and child's education

Respondent's type of work	Child's place of education				Total	
	Special school		Rehabilitation centre educational and upbringing			
	N	%	N	%	N	%
both work	175	30.4	130	20.3	305	25.1
only the woman works	47	8.2	29	4.5	76	6.3
only the man works	211	36.7	268	41.8	479	39.4
neither work	47	8.2	41	6.4	88	7.2
one claims benefit	95	16.5	173	27.0	268	22.0
TOTAL	575	100.0	641	100.0	1216	100.0

Test Chi-2: Chi-2=37,324; p<0,001***, V Cramera=0.175

DISCUSSION

The situation of the birth of a child with intellectual disability is one example of structural changes in the family. Family members evaluate and experience these changes individually. Crises are often a source of negative evaluation of life satisfaction, and one of them is raising a child with intellectual disabilities. Such a situation can significantly disrupt relationships between family members and change the quality of functioning of the entire family system. Parents who do not find themselves fulfilling their role often withdraw from social life, feel a sense of injustice, and submit to negative emotions, which consequently affect their relationships with others and their sense of satisfaction. Parents who accept the situation also accept difficult parenting and see the positive components. Such relationships are characterized by mutual understanding, support, and cooperation [11].

The life satisfaction of parents of children with intellectual disabilities is largely influenced by difficult behaviour in daily life, most often: tantrums, destruction of property, physical aggression towards oneself or others, and failure to comply with regulations. Difficult behaviour occurs in 25% of children with intellectual disabilities, with the main factor being difficult communication, which limits the ability to express frustration and explain the circumstances and other external factors that are the basis for suffering [12].

Research by Stelter and other researchers on the meaning of the lives of parents of children with intellectual disabilities shows that variables such as gender, education and professional activity, influence the sense of meaning, which is an important element of life satisfaction [11, 13, 14]. In such families, parents who work and have a higher level of education show a greater sense of meaning. The current study also confirmed the importance of these factors for the sense of life satisfaction. It can be assumed that working parents achieve their life goals and find fulfillment in their professional work. They can also perceive the meaning of life in working and realizing ambitions. Work can be a kind of escape from difficult everyday life.

The general level of understanding of the rules and phenomena in the environment in which one functions often increases with the level of education. Moreover, a longer education process may have a significant impact on the development of interpersonal skills, self-discipline and stress management, which may also contribute to better coping with life's challenges and increased life satisfaction. People with higher education are often more aware of their needs and rights, which makes them take care of their needs. All of this can have a positive impact on the feeling of satisfaction, despite the difficulties experienced.

At the same time, own research also showed that there was no relationship between parental satisfaction and the age of the child with intellectual disability. This type of disability is characterized by limited cognitive-behavioural development in the child, which results in the achievement of certain skills and characteristics. The rate of development is an individual feature, which gives therapists working with the child a basis for determining the area of assistance. On this basis, regardless of the biological age, a programme of work with the child is established. Therefore, it is not the age, but the rate of progress of the child that may determine the level of satisfaction [15].

Additionally, the current analysis showed that parents of children attending Special Schools rate their life satisfaction higher than parents of children attending OREW. Rehabilitation, education, and upbringing centres (OREW) have been established by the Polish Association for Persons with Intellectual Disabilities. The Centres provide educational and rehabilitative activities for participants aged 3–25 years of age, with various degrees of intellectual disability and multiple disabilities, for whom everyday activities constitute a significant barrier. The centres are intended for people who have a certificate identifying the need for rehabilitation and educational classes (children and adolescents with profound disabilities), or with opinions on the need for special education (children and adolescents with multiple disabilities, including intellectual disabilities).

The principles of operation of Special Schools are regulated by the Regulation of the Minister of Education of 9 August 2017. The Education Law has been adopting in European Union countries, including trends in education, aimed at teaching disabled people together with their healthy peers and siblings. Students requiring special organization and working methods, i.e. students with disabilities: deaf, hard of hearing, blind, visually impaired, with physical disabilities, with mild, moderate or severe intellectual disabilities, with autism, including Asperger's syndrome, and with multiple disabilities, having a decision for the need for special education, they can attend primary schools, schools with integration classes, schools with special classes, and other centres dedicated to disabled youth. Schools organize classes for young people to prepare them for work in professions that do not require high qualifications, e.g. baker, confectioner, gardener, painter, which take place in specially prepared rooms, or in workplaces [15].

The place of education of a child with an intellectual disability is closely related to his or her health condition and the degree of disability – the greater the deficits and the higher the degree of intellectual disability, the greater the likelihood that parents will decide to use the possibilities of a rehabilitation, education and upbringing centre. Due to the greater difficulties in the functioning of a child with a significant and profound disability, parents of children under the care of the centres may show lower life satisfaction than parents of children attending special schools. It should also be noted that the results of the current indicate that in the families of children studying at OREW, more parents raise the child alone, and therefore do not work.

At the same time, there are fewer families in which both parents work. As previously emphasized, professional work is associated with a sense of life satisfaction. Research on life satisfaction emphasizes the important role of social support [8, 16–18]. In families where both parents are present, it can be assumed that this support will be greater than in families where one parent is absent. In complete families, the members complement each other, creating a system that responds adequately and flexibly for their needs. This is especially important in difficult and crisis moments. A child whose upbringing requires many resources: financial, health, time and mental, is a burden on this system. An incomplete family means taking over daily the role of a spouse who is absent, which in turn leads to an overload with responsibilities and a feeling of loneliness in the face of emerging problems [19–20]. Own research confirmed that parents raising a child with intellectual disability in intact families experienced higher life satisfaction.

Practical implications supporting parents of children with intellectual disabilities:

1. *Access to professional psychological assistance* – regular psychological and therapeutic consultations for parents, organizing support groups where parents can share experiences and coping strategies.
2. *Education and training for parents* – workshops on methods to support the development of a child with an intellectual disability, training on managing difficult emotions, and stress reduction techniques.
3. *Strengthening the social support system* – creating local and online communities for families in similar situations, promoting integrative activities, such as family meetings, events, and recreational programmes.
4. *Improving access to healthcare and rehabilitation* – increasing the number of specialists (psychologists, therapists, special educators) available to families, facilitating access to therapies that support development of the child, such as occupational therapy, speech therapy, and behavioural therapy.
5. *Financial and legal support* – simplifying procedures for obtaining financial aid and support services, providing legal counselling regarding the rights of parents and children with disabilities.
6. *Flexible employment solutions* – promoting flexible work arrangements for parents of children with intellectual disabilities (e.g., remote working, reduced working hours); introducing support programmes for working parents, such as additional leave days for caregiving.

Limitations of the study. The authors are aware of the limitations of the study. It was not possible to conduct research on a larger number of parents, due primarily to the COVID-19 pandemic, which affected, among other things:

- difficulties in recruiting participants, especially in studies requiring direct contact;
- the necessity to conduct research remotely, which may have affected the representativeness of the sample;
- remote data collection (e.g., online surveys, telephone interviews) may have influenced the quality and reliability of responses;
- a high level of stress and uncertainty related to the pandemic may have affected participants' subjective responses;
- possible distortion of results due to situational variables (e.g., isolation, limited access to social support);
- limited operation of educational, therapeutic, and medical institutions may have affected parents' well-being and their level of life satisfaction;
- reduced availability of support services may have increased the burden of caregivers, potentially impacting research outcomes.

CONCLUSIONS

1. Parents raising a child with an intellectual disability rate their life satisfaction as low.
2. The higher the education level of the respondents, the higher their life satisfaction.
3. The age of the child is not related to the level of parents' satisfaction.
4. Parents of children attending special schools rate their life satisfaction higher than parents of children from OREW.

In future research, it is worth including parents of students living in social welfare homes and other 24-hour educational facilities. The authors also want to examine the impact of the child's disability on the parents' life satisfaction.

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