

SATISFACTION WITH LIFE OF THE SIBLINGS OF PEOPLE WITH DISABILITIES IN EARLY ADULTHOOD

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Abstract

The topic of the article is the issue of achieving satisfaction and life contentedness by the siblings of people with disabilities in early adulthood and the impact of their siblings' disability on their quality of life. The paper discusses the terminology as well as contemporary concepts of the quality of life and family and personality factors affecting it. The methodological part presents the problems, hypotheses and research tools, and characterizes the studied group. The final section presents research findings and their interpretation.

Keywords:

disability, family, sibling, satisfaction, adulthood

Satisfaction with life from the perspective of various research approaches

Satisfaction with life is an ambiguous, multidimensional and interdisciplinary notion. In the subject literature this term is defined interchangeably with the quality of life, life contentedness, wellbeing, prosperity, happiness.

A breakthrough in the development of life satisfaction research in the field of social sciences was made by A. Campbell's study who in the 1970s defined the quality of life as a life experience expressed by the level of life satisfaction and happiness. Under its influence, human life started to be considered holistically (Sadowska, 2006, p. 15).

In the 1990s Australian researcher R. A. Cummins delved into the issue of identifying the areas of life quality and he successfully identified seven areas of the quality of life: material well-being, health, work/activity,

intimacy (close relationships), safety, social well-being, emotional well-being. The researcher assumed that the quality of life is both objective and subjective, and the defined areas constitute each of them. In the subjective dimension the cultural values are vital whereas within the subjective dimension – the personal values are essential. The subjective areas refer to the satisfaction with each of the areas with respect to their significance to a particular person (Sadowska, 2006, p.36).

Positive psychology binds satisfaction and the good quality of life with well-being and its measure is mental well-being, a positive affection, satisfaction. The role of happiness in the contemporary concepts of good life is the criterion of relevance of other concepts considered as indicators of good life, such as a sense of life, autonomy, purposeful pursuit, optimism, etc. Are all happy lives good? According

to Aristotle's concept a more complex satisfaction associated with cultivating and developing virtues, i.e. eudemony, is an alternative to hedonism or a life full of pleasure. A hedonistic pleasure is a completely subjective state whereas eudemony corresponds to more objective standards that can be observed (King, Eells, & Burton, 2007, p. 22).

The close relationship between the quality of human life and happiness shows the happiness theory by J. Czapiński. Czapiński's psychological well-being scheme has three levels. The first level is the will of life - the deepest and the most basic level which is least susceptible to external influences and is a necessary condition for the survival of a man. The second level is the overall psychological well-being or aspects of satisfaction with one's own life as a whole. It constitutes an intermediate layer built upon the previous one. The third level, the most outer one, related to the objective events of the world and the conditions of life, consists of partial satisfactions, i.e. the judgments and feelings that pertain to particular areas of life.

An example of a contemporary view of life satisfaction is also the personalist and existentialist concept. It assumes that the psychic life takes place in four dimensions:

1. psychophysical,
2. psychosocial,
3. subjective,
4. metaphysical.

According to this assumption, the quality of life can be defined as a way of life, i.e. a type of life problems and a way of solving them which is characteristic of

each dimension. The sense of the quality of life is made up by a subjective assessment of the way of life and the accompanying feelings (Struś – Romanowska, & Frąckowiak, 2007, p. 17).

In defining life satisfaction, norms and values which are imprinted in human consciousness play an important role and show their desire for a specific state or purpose that affects the particular behavior of people. The achievement of life satisfaction by a person is influenced by the factors independent of them as well as the factors dependent on their activity. The human-independent factors can be divided into the external ones, e.g. the place of birth, and the internal ones, e.g. health or personality traits.

These theories are some of many functioning and present in the social sciences. Not all of the works are part of the research tradition of experiencing and living a life. An example of that is the approach presented by D. Rybczyńska according to which “the quality of life is an integrated system of motivation and pursuit factors which underlie human needs and values. The level of the quality of life depends on personal and social expectations, the type of activity of an individual and their choices in life. These attributes have an impact on the sense of life, and in turn, on the quality of life”

Family and personality factors influencing the emotional development of the siblings of people with disabilities

The birth of a disabled child is one of the determinants of a sense of life satisfaction independent of a human being. Both parents and siblings of a child with a disability are placed in a situation which is

not only completely beyond their control but also extremely difficult. Some parents use defensive mechanisms such as resignation, negation, aggression, rejection, contact avoidance. The parents go through various periods of emotional experiences after diagnosing the child with disabilities. A. Twardowski lists four periods of such experiences:

- Shock period – where there is regret, despair, fear, feeling of harm, helplessness, hopelessness. During this period one usually deals with a total mental imbalance of the parents.
- Emotional crises (depression or despair) – emotions are not as turbulent as they used to be, but the sense of loneliness, life disaster, helplessness are still dominant. The parents are not reconciled with the fact of their child's disability.
- Period of apparent adaptation to the new situation – it is characterized by the use of defensive mechanisms such as unreasonable ways of adapting to the child's disability. The parents still deny this fact, show an unreasonable faith in cure, take numerous ineffective but tedious and expensive treatments, they look for other professionals and centers.
- Period of constructive adaptation – a complete real adaptation to the child's disability. Action strategies undertaken by the parents become coherent and effective. They seek solutions that ensure normal living conditions and fulfill the needs of all the family members (Twardowski, 1991, pp. 22 – 26).

Not all the parents reach the period of constructive adaptation which has a direct impact on their relationship with the disabled children and the relationship between the healthy and the disabled siblings.

The issue of the functioning of parents of children with disabilities is relatively often discussed by researchers. The problems, the development and course of life of the siblings of people with disabilities are treated marginally (Žyta, 2010, & Twardowski, 1991). They perform various roles and face various tasks and problems at different stages of their life. As the parents age, their responsibility and involvement in caring for their disabled siblings increases, often after the death of their parents they are burdened with caring for and deciding about the fate of their disabled siblings. The relationship between the disabled siblings and the healthy ones is primarily influenced by: the parental attitude, the degree of the disability of the siblings, the visibility, the disability, the behavior of the person with a disability, the order of birth, the difference of age, the sex, the parental self-esteem, the illness or death of the parents and other factors (Sidor, 2005, p. 31).

The parents play the most important role in developing self-awareness and adaptive processes in the siblings of people with disabilities. It depends on them how the healthy children in the family will perceive their situation and themselves against the background of the family. Their accepting attitude is conducive to positive relationships between the siblings. The way the parents work with the disabled child affects how the sibling sees his or her situation and how well he or she deals with

it. Negative parental emotions affect the other children and influence the emotional environment in the family. Positively oriented parents shape in their children hope, optimism and resilience in difficult situations (Twardowski, 1991, p. 97).

The baggage of experience and the emotional experiences gained in the childhood and through the period growing up with the disabled siblings cannot remain with no impact on the adult life of the healthy sibling. The research shows that many people having disabled siblings encountered negative attitudes and many a form of discrimination on the part of both peers and adults. As a consequence of such experiences, their self-esteem may be lowered or there might arise a conviction of being inferior, which negatively influences the development of satisfactory interpersonal relationships. Yet, the research also indicates that having a disabled sibling can have positive aspects; owing to a disabled brother or sister, the respondents learned sensitivity, tolerance, responsibility (Jankowska, & Wójcik, 2008, p. 210 - 211).

Entering adulthood and early adulthood is by nature considered to be particularly difficult in a human life. Such a person experiences the peak of their physical abilities, motivation for action, activity, life energy, creativity, on the other hand, this person is exposed to numerous stressful situations and conflicts resulting from taking on new tasks and social roles. The difficult situation of such people is deepened by the fact that their siblings are affected by a disability. Young people want to become independent from their parents, which is related to living up to their own challenges all by themselves or with a limited parental support. At the

same time, the young person is forced to take decisions and take responsibility for themselves simultaneously realizing that they will affect not only their own life but also the life of other people related to them, including the lives of their disabled siblings (Mailna, 2014, p. 27).

Can the burden of having a disabled sibling affect the feeling of satisfaction in early adulthood? This is undoubtedly a difficult and stressful situation. In order to adapt to a difficult situation, a young adult must demonstrate certain competences and have personal qualities that are conducive to a successful exit from a crisis. These qualities comprise the characteristics of the Big Five personality model (neuroticism, extraversion, openness to experience, conscientiousness, compromise), the sense of control placement, the self-esteem level and the evaluation of the importance of development tasks (Mailna, 2014, p. 45)

The studies show that close relationships with parents and family are associated with an increased self-esteem (Baldwin, Hoffmann, 2002; Greene, Way, 1995). It can be assumed that a high self-esteem will be associated with the efficiency of implementing the developmental tasks of the period of early adulthood (Mailna, 2014, p. 57).

Own research methodology

To determine whether the degree of satisfaction with life and the related level of the quality of life of the siblings of people with different types of disability in early adulthood differs significantly from the level of satisfaction with life of the people of similar age having siblings with no disabilities, I conducted a study on a group of 48 subjects having siblings.

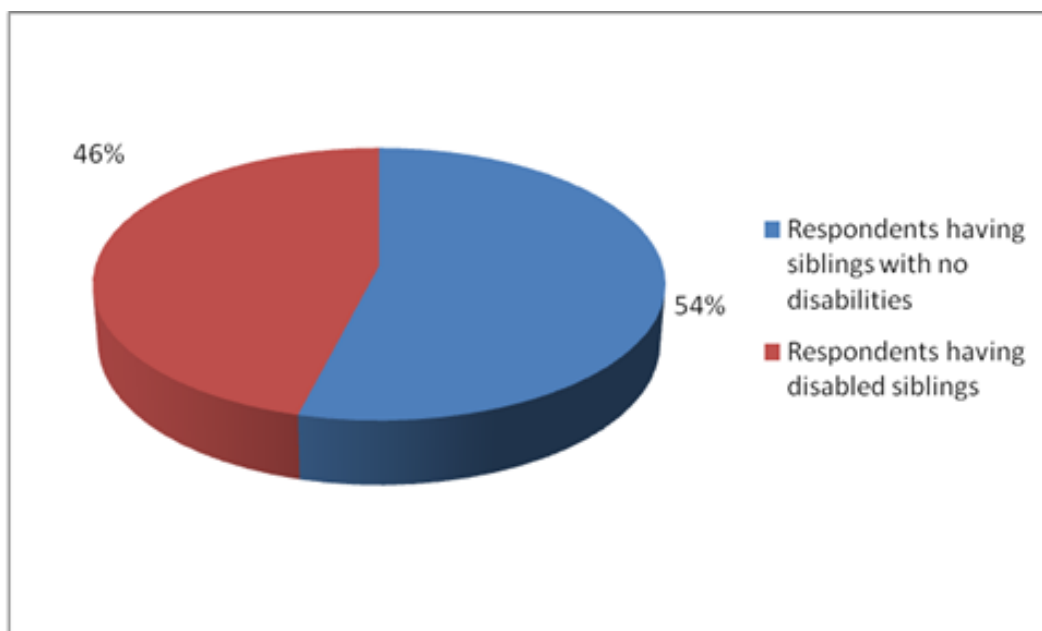


Figure 1 Distribution of the respondents according to the occurrence of disability in their siblings

Among the respondents, 54% had siblings with no disabilities, while 46% had brothers and sisters suffering from various disabilities.

The siblings of people with disabilities were contained in one of the four research groups.

Table 1 Distribution of the respondents having siblings with disabilities with reference to the type of disability

Group	Size	Group percentage
Siblings of people with autism	6	27,27
Siblings of people with cerebral palsy	5	22,73
Siblings of people with visual impairment	6	27,27
Siblings of people with Down syndrome	5	22,73

For the purposes of the research I formulated the following research problems:

- How do the adult siblings of people with disabilities assess satisfaction and the level of life contentedness compared to those having siblings with no disabilities?

- How do the adult siblings of people with disabilities evaluate their quality of life compared to those having siblings with no disabilities?

Based on the literature analysis of the research subject and the presented research

problems, the following hypotheses were made:

Hypothesis 1: *In the early adulthood the siblings of people with disabilities can have equally satisfactory lives as their peers having siblings with no disabilities.*

Hypothesis 2: *The adult siblings of people with different types of disabilities evaluate their quality of life as lower compared to those having siblings with no disabilities.*

The method used in the study was the diagnostic survey method and the technique applied – the questionnaire survey.

The following research tools were used to determine the degree of satisfaction with life and life contentedness of the siblings of people with disabilities in the early adulthood period:

- Satisfaction With Life Scale (SWLS) by E. Diner, R.A.Emons
- own adaptation of the Quality of Life Scale based on A. Campbell's scale.

The Satisfaction With Life Scale (SWLS) is made up of five life satisfaction statements. The task of the respondents is to refer to these statements on a seven-point scale (I totally disagree, I disagree, I rather disagree, I neither agree nor disagree, I rather agree, I agree, I

completely agree). The more points, the greater the satisfaction with life.

The adapted Quality of Life Scale based on A. Campbell's scale consists of 9 questions:

1. Are you satisfied with your family life?
2. Are you satisfied with your health?
3. Are you satisfied with your contacts with friends and acquaintances?
4. Are you satisfied with your professional career?
5. Are you satisfied with the way you spend your free time?
6. Are you satisfied with the place you live in?
7. Are you satisfied with your and your family's housing conditions?
8. Are you satisfied with your own and your family's financial situation?
9. Are you satisfied with yourself?

The task of the respondents was to define their own feelings on a five-point scale.

Research findings

The analysis of the results of the study conducted with the Satisfaction With Life Scale did not show statistically significant differences between the siblings of the disabled people and the siblings of people with no disabilities.

Table 2 Life satisfaction level of the adult siblings of people with no disabilities and with disabilities

Variable	Group	M	SD	T-test result	Validity level
Satisfaction With Life Scale(SWLS)	Respondents having siblings with no disabilities	22,35	4,44	0,07	0,943
	Respondents having disabled siblings	22,45	5,93		

This means that the adult life of the siblings of people with different disabilities does need not to be less satisfying than those with the healthy siblings. With an adequate parental support they can from an early age realize their passions, aspirations, and the fact of having a disabled person in the family does not have to be the cause of limitations.

On the other hand, the analysis of the Quality of Life Scale results shows statistically significant differences between the people having healthy siblings and the siblings of people with different disabilities, thus indicating that the people having siblings with disabilities evaluated their quality of life as lower than those having siblings with no disabilities.

Table 3 Life satisfaction level of the adult siblings of people with no disabilities and with disabilities

Variable	Group	M	SD	T-test result	Validity level
Quality of Life Scale	Respondents having siblings with no disabilities	37,38	3,14	2,43	0,022
	Respondents having disabled siblings	33,86	6,17		

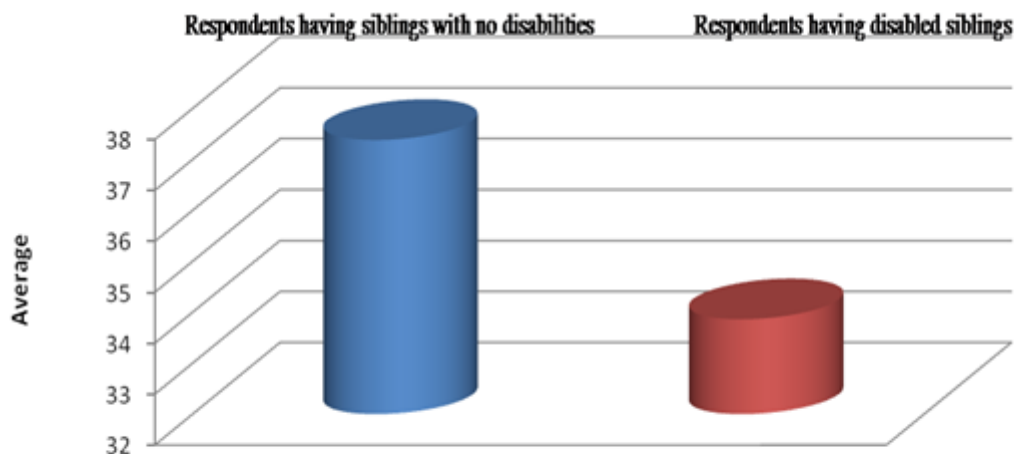


Figure 2 The occurrence of disability in siblings vs. the level of the Quality of Life Scale obtained by the surveyed respondents

The research findings show that the siblings of people with disabilities experience a lower quality of life in early adulthood than their peers having siblings with no disabilities. Yet, it does not have to go hand in hand with lower satisfaction

with life and life contentedness. In order to make the siblings of people with disabilities grow up to be happy adults who have a positive relationship with the disabled sibling, they need to be supported by parents from the earliest years of life as

well as they require institutional support. Based on the American experiences, one may conclude that the development of systemic solutions for integrating the siblings into the idea of supporting and normalizing the living conditions of people with disabilities is essential. This is a group of people who have the longest contact with their disabled siblings and should therefore be supported so that this fact does not affect the quality of their adult life and their satisfaction with life, contentedness and happiness.

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