

Social Support and Quality of Life of Youth Suffering from Cerebral Palsy Temporarily Orphaned Due to Emigration of a Parent

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Abstract—The article is concerned in the issue of social support and quality of life of youth suffering from cerebral palsy, who are temporarily orphaned due to the emigration of a parent. Migration causes multi-aspect consequences in various spheres of life. They are particularly severe for the functioning of families. Temporal parting of parents and children, especially the disabled, is a difficult situation. In this case, the family structure is changed, as well as the quality of life of its members. Children can handle migration parting in a better or worse way; these can be divided into properly functioning and manifesting behaviour disorders. In conditions of the progressing phenomenon of labour migration of Poles and a wide spectrum of consequences for the whole social life, it is essential to undertake actions aimed at support of migrants and their families. This article focuses mainly on social support and quality of families members, of which, are the labour migrants perceived by youth suffering from cerebral palsy. The quantitative method was used in this study. In the study, the Satisfaction with Life Scale (SWLS) by Diener, was used. The analysed group consisted of 50 persons (37 girls and 13 boys), aged 16 years to 18 years, whose parents are labour migrants. The results indicate that the quality of life and social support for youth suffering from cerebral palsy who are temporarily orphaned is at a low and average level.

Keywords—Social support, quality of life, migration, cerebral palsy.

I. INTRODUCTION

IN a situation when a family expects a disabled child, the diagnosis itself is emotionally burdensome, while upbringing and rehabilitation would require additional expenditures and emotional support of the closest environment. Abnormalities in the development of children with cerebral palsy are visible from an early period of their lives and are confirmed by neurological tests. Initially, there occur: psychomotor underdevelopment, dysfunctions of movement and posture, pareses of limbs, involuntary movements, speaking disorders, hearing impairments, sight impairments, and epilepsy [2].

Basing on Hagberg's division, we distinguish so-called spastic (mono paretic, hemiparetic, triparetic, and tetraparetic), atactic and dyskinetic syndromes [3]. Upbringing of a child with cerebral palsy is related with a higher financial demand, necessary mainly for rehabilitation. In such cases, the chance to increase the family budget is through economic migration.

It would be too obvious to state that emigration has its

positive and negative consequences for the family life. The positive ones concern mainly its economical function. On the other hand, negative effects will be visible in disorders of realisation of the caring and emotional functions. In order to minimize the effects of temporal parting, it is essential to provide social support, which would improve quality of life [4].

Quality of life is a concept enclosing the process of meeting tangible and intangible needs, resulting from meeting standards or realising values of biological, psychological, spiritual, social, political, cultural, economic, and ecological characters of individuals, families, and communities [5].

According to Sęk, social support in the functional perspective is regarded as a type of social interaction, which is undertaken by one or both parties, which participate in a problematic, difficult, stressing, critical situation, considering that in the course of such interaction, there takes place an exchange of emotions, information, action instruments, and tangible property. Such exchange can be unilateral or bilateral, and the direction donor-recipient can be constant, but can also change. In a dynamic arrangement of interactions, we can distinguish seeking and supporting persons, receiving or donating persons. In order that such social exchange was efficient, it is essential to adjust the type of support to the needs of a recipient. The aim of supporting interactions is maintaining and decreasing a crisis or a level of stress by accompanying, exchange of emotions, creating the feeling of identity, safety and hope, and approaching to the solution of the problem and overcoming difficulties [6].

We can distinguish numerous types of social support, based on the functions addressed to them. Sęk proposes a classification of types of support depending on what is the essence of social exchange [7].

1. Emotional support consisting in relaying supporting, calming emotions, being a manifestation of concern and positive attitude towards a supported person. Supporting behaviour is aimed also at creating a feeling of membership, care and increasing self-esteem. Thanks to emotional support, suffering persons can be freed of own stresses and negative feelings, can express their fears, anxieties, and sadness. It has an influence not only on the improvement of the self-esteem of the supported person, but also on his or her state of being. Proper behaviour of the supporting person releases also the feeling of hope. Such support ensures an individual that he or she is being loved and people care about them.

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2. Informational support (cognitive), being the exchange and providing information and giving advice, which favours understanding of a situation, own situation of life, and problems. This involves also providing feedback concerning the efficiency of remedial actions of the supported persons, as well as sharing own experience by persons experiencing similar problems. Informational support meets the necessity of understanding the essence of critical events and their causes. This type of support is most often provided by persons with whom we are in sociable relations.
3. Instrumental (material) support, consisting of providing direct help in the form of loans, gifts, or services. This also includes providing information about particular ways of proceeding, and a form of modelling efficient remedial behaviour. Forms of such support can include activities to the benefit of the people in need: feeding, providing shelter, home, funds, medicines. This type of support, similarly, like informational support, is expected the most, and needed in situations of catastrophes, natural disasters, etc.
4. Evaluative support consisting in expressing acceptance, respect and acknowledging the value of the person. It is often that evaluative support can be expressed by supporting parties in non-verbal forms. It can take place in situations when such potential is appreciated and stressed, as well as are achievements in various forms of activity: social roles, artistic production, motor achievements, and sporting rivalry.

Some authors propose another division of social support, based on the structural features of support. There are distinguished:

- perceived support, resulting from convictions of a person and his/her knowledge about from who and where he/she might get support in a difficult situation, as well as the availability of the support network,
- obtained support (provided), which is objectively evaluated by a recipient as the actually obtained type and amount of support [8].

Social support contributes to limiting the negative effects of critical life events, stress, apathy, and low self-esteem. Support provided by existing various social bonds gives the feeling of closeness, acceptance and understanding coming from other people. Contact with other people result in the feeling of membership, favours social integration, shapes self-evaluation, and has an influence of increasing self-esteem. It also enables wider social contacts, at the same time revealing useful ways of coping with various problems.

Empirical studies most often include conduction of measurements of three categories of support. These include: social integration of support network, obtained social support, aimed at measuring obtained help in particular period of time, and perceived (expected) social support measuring the conviction of an individual concerning the availability of a support network when needed [9]. This work presents an analysis of social support that an individual could obtain from a social network.

II. MATERIAL AND METHODS

The research was conducted in 2015 in the area of eastern Poland (Lubelskie, Świętokrzyskie, Podkarpackie and Małopolskie voivodeship). These regions are characterised by a high rate of periodic migrations, mainly economic ones. Purposive sampling was used in the research.

The analysed group was of 50 physically disabled persons (37 girls and 13 boys), aged 16 years to 18 years, whose parents are labour migrants.

Among the adolescents with cerebral palsy, those with monoplegia constituted: 30%; paraplegia: 29%; hemiplegia: 28%; mixed form: 13% (with a division based on location scope).

Migration most often concerned fathers (64%), mothers in majority (32%) and most rarely both parents (4%). Just over half (55%) of adolescents experience long-term migrations lasting from six months to 12 months, while 45% face short-term ones, from one to three months. There were no noted migrations of over one year. Most often, the directions of economic migration of parents include United Kingdom (40%), Belgium (25%), France (15%), Italy (10%), and Germany (10%). During the absence of a parent, adolescents with cerebral palsy are cared by a parent staying in the country (80%), grandparents (15%), mature brothers and sisters (5%).

This study applied the quantitative method, utilising the following research tools: Social Support Scale by Kmiecik-Baran was used for a study on social support from the qualitative perspective. This scale allows one to distinguish four dimensions of social support: informational, instrumental, evaluative, and emotional, that an individual could obtain from a social network. The Standard Ten (STEN) was used to evaluate the obtained social support; STEN 1–4 lack of support (0–153 points), STEN 5–6 — medium support (154–198 points), STEN 7–10 — high support (199–336 points).

In order to measure the satisfaction, the SWLS by Diener, Emmons, Larson, Griffin adapted by Juczyński, was used [9]. A result of the measurement is a general rate of the satisfaction with life. The Standard Ten was used to evaluate the satisfaction with life; STEN 1–4 (5–17 points) — low satisfaction, STEN 5–6 (18–23 points) — medium satisfaction, STEN 7–10 (24–35) — high satisfaction.

III. ANALYTICAL PROBLEM

The aim of this work was to evaluate the level of social support of adolescents with cerebral palsy living in families which are temporarily parted due to migration, as well as an analysis of the dependences between the obtained social support and the level of satisfaction with life.

Research questions

1. What is the social support for adolescents with cerebral palsy living in temporarily single parent families due to migration?
2. What is the relation between social support and quality of life of adolescents with cerebral palsy living in temporarily single parent families due to migration?

Hypothesis

- H1.** Social support of temporarily parted adolescents is at a medium level.
- H2.** Dependence exists between the level of social support and quality of life of adolescents with cerebral palsy from temporarily single parent families due to migration.

IV. STUDY RESULTS

The statistical analysis was aimed to determine the social support and mutual dependences between the social support and quality of life of adolescents with cerebral palsy living in partially parted families due to migration. For that aim, statistical analyses were conducted.

A general analysis of data according to the Social Support Scale revealed that a major group of respondents (72%) had results below 1999 points (4-1 STEN), what indicates a lack of social support. A high social support concerned only 4% of respondents. The remaining group (24%) had a result of 5-6 STEN, i.e. support at a medium level (Table I). A detailed analysis of provided support shows that respondents did not obtain help in the scope of informational support (74%), emotional support (70%), and evaluative support (69%), (Table I, Fig. 1).

TABLE I
SOCIAL SUPPORT COMPARED TO LIFE SATISFACTION

Amount of obtained support	Types of social support			
	Informational Structure rate (%)	Instrumental Structure rate (%)	Evaluative Structure rate (%)	Emotional Structure rate (%)
Lack of support	74.00	50.00	69.00	70.00
Medium support	15.00	28.00	20.00	26.00
High support	11.00	24.00	11.00	4.00
Overall	100	100	100	100

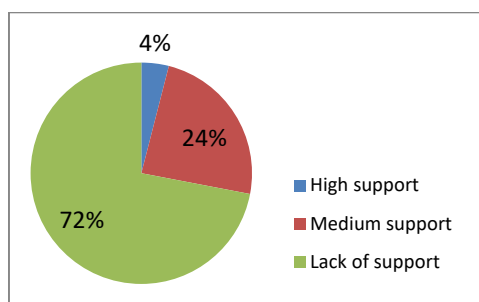


Fig. 1 Social support – overall result (%)

A majority of respondents (63%) experience a low satisfaction with life, while 30% state medium satisfaction, while high satisfaction was revealed by only 7% (Table II).

TABLE II
LIFE SATISFACTION

Level of life satisfaction	Structure rate (%)
Low	63
Medium	30
High	7

A statistical analysis showed that both analysed variables

are statistically significantly related with each other at the level of $p < 0.05$. The relation between them is of a weak strength and positive mark (Table III).

Generalising obtained data, we must stress the fact that the lower social support, the lower satisfaction with life. It is acknowledged also by results presenting social support, where as much as 72% of respondents do not experience social support, while 24% has medium support and only 4% has high support.

TABLE III
LIFE SATISFACTION COMPARED TO FELT SOCIAL SUPPORT

Life satisfaction	Social support	
	Pearson correlation efficient	0.24
Two-tailed significance	0.022	
N	50	

V. CONCLUSIONS

The obtained study results show that there is a necessity of prophylaxis actions. The role of social support became a subject of numerous scientific researches relatively recently. The reason of such strong interest were observations indicating that persons surrounded by many family members, having many friends, and being a member of various organisations, coped with everyday difficulties and stress much better, and also have better health. The results show:

1. Nearly 75% of respondents declared a lack of social support. The main form of their support was instrumental support.
2. The level of life satisfaction of the analysed group is classified with the majority at the low level.
3. There exists a positive correlation between social support and life satisfaction (low, positive).

Disabled adolescents experiencing migration of a parent experience negative consequences related with the temporal parting with the parent. The difficulties should be neutralised by proper actions, such as:

- determining, presenting and fast diagnosing of changes in functioning of families;
- psychological and educational help provided to families and parents on emigration;
- social and institutional support (e.g. a family assistant, financial, legal, and informational assistance);
- necessity of a deeper cooperation between institutions offering support: school – social welfare centre – psychological and pedagogical counselling centre, in the scope of diagnosing functionality of families;
- support and help of clergymen (religious communities and societies); and,
- activation of extended family, acquaintances, friends, neighbours, in order to provide support to families bringing up adolescents with cerebral palsy, experiencing parting due to migration.

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