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## Quality of life attributes in individuals with life-threatening illness in the context of special pedagogy in Slovakia

**Abstract.** Contribution deal with quality of life of individuals with life threatening illness in Slovakia. Targeted focused on the category of children with oncological illness. In recent years, we focused on research activities at individuals with life threatening illness in Slovakia within special pedagogy. In conjunction with quality of life and with education of these individuals. In these contexts, we can talk about the context of special pedagogy.

**Keywords:** quality of life, life-threatening illness, cancer, special educator, emotion, pre-school age, education.



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Activities focused on upbringing and education of children with life threatening illness realized by a special educator, are one of the areas of support for improving the quality of life of such children and their families. Symptoms of illness and treatment are seriously interfering with all areas of quality of life and family life, including physical health, psychological health, sexuality, spirituality, social area, emotional area, self-sufficiency, cognitive area, economic background and so on. Each family is unique, its functioning is influenced by several factors: the number and characteristics of its members, the education and employment of parents, values, cultural traditions, religious beliefs, etc. Adaptation can have a different course and depends mainly on the age at which the child be-



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comes disabled [10]. From the view of special pedagogy, such care is primarily focused on removing or reduction the impact of an illness on a psycho-social, emotional, and cognitive personality areas. The perception of the quality of life from a psychological point of view is very subjective and overall satisfaction with the individual's life is very closely connected to emotional dealing with it [2]. Positive effects such as the short-term positive emotions and long-term dealing with happiness affects short- and long-term positive evaluation of life events. On the other hand, negative effects as short-term negative accumulated emotions and long-term dealing with sadness, anger, frustration, leading to short and long-term negative evidence of life events [7]. Special educator through game activities with children or together with their families and adequate communication strategies, helps to create positively survived living situations and thus contributes to a positively experienced difficult period of life. Another important area of quality of life is the area of socialization. The child naturally longs for follow-up contacts, after somewhere to belong to, be useful and the illness and the resulting long-term hospitalization and isolation from social contacts, may cause various psychological disorders and social deviations and overall threatening the quality of the child's and its family's life. The most important aspects of social dimension of quality of life considers [8] to interact the individual with the surroundings and the need to self-realize an individual to perform a social role for which it is intended. Child in pre-school age with illness loses the opportunity to develop relationships with their peers in a natural environment such as a kindergarten and is limited to obtaining contacts in the hospital environment. The involvement of such a child in common activities, together with other children can help to develop social skills and emotional abilities and can lead to the creation of a sense of belonging and satisfaction of self-realization needs. It is important to note that a family of such a child is going through a very difficult period of life and often focuses attention only to a child with illness and forget their own needs. As a result of a child orientation with illness and freight treatments, the family can lose his socio-economic status, comes to social contacts and employment, which can cause the emergence of inferiority, apathy, depression, or loss of life perspective. High importance, in the ability of an individual to achieve well-being and satisfaction they also have individual personality traits, such as positive affectivity that are most often associated with dealing with feelings of well-being, confidence, emotional stability, self-control, resilience

and other features, which is becoming more commonly referred to as emotional intelligence [1]. With a psycho-social and emotional experience of the child, the cognitive concept of subjective quality of life assessment is also related. Life-threatening illness and treatment can also negatively affect the cognitive part of personality, for example, at the level of imagination, memory, or attention. These specificities in cognitive abilities can interfere with different areas of the individual's life, from the ability to address common conflicts, communication or acquiring new knowledge in upbringing and education and so on. The illness can reactivate previous unresolved difficulties and can create such stress that its coping skills are limited. Kübler Ross [3] assumed that children to a high stress burden as a life-threatening illness, passes a series of five (now well known) stages: denial, anger, bargaining, depression, and acceptance. Rational - cognitive acceptance of the illness directly affects emotional and behavioural reactions aimed at handling illness, with this relationship is reciprocal. Among ideas, emotions, behaviour, and physical reactions there is a complex interplay in which no area has a primacy and in common involved in the overall quality of the life of an individual with the illness [5]. It is important to remind that in Slovakia, a special educator has its representation in the educational activities of children with a life limiting illness during hospitalization, but not after release to the child in palliative care. However, in terms of improving the quality of life of such children and their families in palliative care, it is important to support the continuous education of special educators in the field of physical disabled, sick and disabled with the accent for the pedagogy of sick and also promote their palliative care education what should be in practice - to extend such care for special-pedagogical support.

Quality of life is the subject of the interest of several research in the world and in Slovakia. In recent years, research in Slovakia began to focus on the quality of life of individuals with life-threatening illness in conjunction with education, we can say about a special-pedagogy context, as child, pupil, teenage and adult with life threatening illness is the subject of the pedagogy of physically disabled, sick and health impaired. Progress in modern medicine has increased survival chances and opportunities to improve the health importantly, these children and students can return to school, school groups, and their normal lives [9].

In the following section, we would like to present research focused on emotionalism as one of the attributes of quality of life in children of pre-school age.

Pre-school age represents a significant period for the development and forming of the child's emotional world. The quality of emotional life in this period is an important precondition for further emotional development of child. Impulsivity, lability, and suggestibility of child emotion creates its own emotional world of a child in which the emotions are as a filter of all knowledge, increasing and expanding the needs and interests of the child, affect the quality and durability of acquired knowledge. All the child is experiencing, raises various experiences, motives, desires in his soul, and they affect his emotional attitude to people and the world and decide on a dominating pallet of his future emotional life [4]. The defence of the child against a negative emotional experience is their suppression that, according to psychologists just transforms into other forms that will continue to be harmful in the form of scary dreams, anxiety, depression, psychosomatic difficulties [4]. The oncological ill child of pre-school age is aware of the presence of its illness and intensively experiencing it - a physical and mental burden significantly affects the emotional world of the child. The emotional burden can also lead to inappropriate manifestations in the field of children's behaviour, which significantly increases the demands on professional and personal competences of a special pedagogue. Inappropriate manifestations of behaviour in the child are affecting the psychological well-being of other children and disturb a positive socio-emotional climate in the kindergarten.

The aim of combined research, which was implemented in cooperation with Drienova, was encouraged and stimulating the development of the emotionality of oncological ill children and equally to direct their emotional growth. We were based on the knowledge that the emotional skills will increase the emotional resistance and stability of the child. What the oncological ill child will become more stable, the better to be able to balance with difficulty, failure and various stress situations that brings oncological illness, demanding treatment, and long-term hospitalization. In addition to the intention, we assumed that the implementation of the proposed set of activities in the education of oncological ill children will allow us to achieve positive changes in socio-emotional climate in the kindergarten class at the medical facility, reduce or reduce emotional problems or behaviour problems and improve the cooperative functioning of the child in education. We used a standardized questionnaire behavioural children's pre-school ages from McGuire and Richman, direct observation, and case to the realization of research.

Through that questionnaire, we have identified the occurrence of emotional problems and problems in behaviour in oncological ill children in kindergartens in health facilities and in children who attend ordinary kindergarten. After processing data and evaluation of the overall scoring in the children from the ordinary kindergarten, we compared the occurrence of emotional problems and problems in healthy children and in children with oncological illness undergoing intensive treatment in children. Based on a detailed analysis of the score in the individual questionnaire items in the oncological ill children from the kindergarten, we detected the frequency of the occurrence of specific manifestations, manifesting emotional problems and problems in behaviour. Following application of the created stimulating program for the development of emotional intelligence, we have also implemented the output diagnosis of behaviour in the selected group of oncological ill children with several serious emotional problems and / or problems in behaviour. The questionnaire method was also used when assessing the effectiveness of the stimulus program created. The research sample consisted of 6 children with an oncological illness between the ages of 4.5 years to 6 years attending the kindergarten in a healthcare facility, which, at the time of research, undergoes long-term intensive treatment in the clinic of children's haematology and oncology in Bratislava. A group of children selected for the research sample was in terms of their age, determined by medical diagnosis and ordered protocol method of therapy heterogeneous. When choosing a research sample, we have determined the following criteria:

1. Personal emotional problems and/or behaviour problems were identified in the child's input diagnostics.
2. The child undergoes intense treatment of oncological illness requiring continuous long-term hospitalization.
3. The child is 4-6 years old.

The set of activities to stimulate and stimulate the development of the emotionality of a child with cancer consists of 35 specific proposals for activities supporting the development of the emotionality of a child with cancer in the intrapersonal as well as interpersonal level. The goals of our proposed activities are:

- create and support a favourable socio-emotional climate in the group of children;
- stimulate children's emotionality and direct their emotional growth;

- to develop the child's personality as a whole on the intrapersonal and interpersonal level in terms of cognitive, affective and psychomotor;
- to enable children to gain the experience of "themselves", to experience pleasant feelings and emotions necessary for their personal development;
- express their own thoughts, feelings, feelings, experiences and desires through verbal and non-verbal communication;
- to form and develop empathy at the elementary level;
- create fluent relationships with children and adults based on mutually maintained emotional attachment.

We examined whether emotional and / or behavioural problems were more common in children with cancer in kindergartens in hospital undergoing intensive anticancer treatment in primary schools than in children attending regular primary schools.

When comparing the results of the total score in the questionnaire in oncological children attending kindergartens in hospital at the time of our research and in children attending regular kindergartens, we found that in oncological children in kindergartens in hospital undergoing intensive treatment of cancer in behaviour than in children from a regular kindergarten. After evaluating the results of the total score in the questionnaire in children with cancer in kindergartens in hospital, we found that most of the observed children with cancer undergoing intensive anticancer treatment who attended kindergartens in hospital at the time of our research and / or behavioural problems. After evaluating the results of the score in the questionnaire for children with cancer in, we found that difficulties with concentration of attention and inappropriate level of activity kindergartens in hospital that affect the overall functioning of the child in the educational process occur in most children with cancer visiting kindergarten in hospital. After applying the set of activities proposed by us, we performed output diagnostics of behaviour in children from a selected research sample who participated in the implementation of our activities. We investigated whether the application of a set of activities in a selected group of children had a positive effect on the emotional and social behaviour of a child with cancer undergoing intensive anticancer treatment, on the overall functioning of the child in the educational process.

The results of our research showed that by applying the set of activities created by us aimed at supporting and stimulating the development

of the child's emotionality, we managed to reduce or alleviate the manifestations manifesting emotional and behavioural problems in all children from our selected research sample. We managed to achieve positive changes in the level of attention concentration and level in some children from the selected research sample. Positive changes in the level of attention concentration were achieved by applying a set of activities to one child from the research sample and positive changes in the level of activity were achieved by applying activities to three children from the selected research sample. From the results of the research, we can state that the implementation of the set of activities created by us effectively influenced the socio-emotional side of the personality of a child with cancer. When comparing the results of the score in the questionnaire achieved in the input and output diagnostics of the child's behaviour, we found that children from the selected research sample, after applying a set of activities, achieved positive changes in the category of emotional and behavioural problems. This means that the behaviour of children with cancer has been alleviated or reduced by manifestations of emotional and / or behavioural problems. When comparing the scores in the questionnaire achieved in the input and output diagnostics of the child's behaviour from a selected research sample, we found that in the category of overall functioning of the child in the educational process, we achieved positive changes in several children. Specifically, in four children, positive changes in the child's functioning in the educational process were confirmed; in two children, no changes occurred in the given area. In a deeper analysis of the score results in this category of problems, we found that positive changes in the level of attention concentration were demonstrated in one child from the research sample after the application of the set of activities. We achieved positive changes in the level of activity in 3 children from a selected research sample.

After the implementation and evaluation of research, the aim of which was to verify the effectiveness of our set of activities stimulating and stimulating the development of emotion of a child with cancer, we allow to formulate recommendations ourselves based on our research findings and empirical experience gained in implementing activities with a selected group of children with cancer. Recommendations:

- we recommend regular implementation of play activities using the method of emotional inventory in order to strengthen the positive feeling in children with cancer so that they pay more attention to positive things, learn self-control;

- regularly include emotional retuning in the daily routine through fairy tales, listening to music, dancing, singing, etc.;
- regularly include activities with elements of art therapy, music therapy, creative drama in education;
- make creative use of the world of stories and fairy tales;
- regularly implement relaxation games and exercises to regenerate the body, defend against stress and to experience positive feelings in children;
- alternate activities requiring a longer focus of attention with relaxation moments and activities to release the accumulated tension;
- create opportunities for children to control their emotional discharge;
- to provide children with a space for artistic expression of emotional experience using art techniques, musical movement expression;
- include games and activities aimed at developing cooperation, first games and activities in pairs, gradually in a group with a smaller number of children;
- often include interactive games and exercises using verbal and non-verbal communication (role-playing exercises, active listening exercises, problem-solving exercises);
- specially to provide psychological support to children - to approach children with love, with a great deal of patience, empathy, and acceptance.

The results of our research showed that by applying our set of activities aimed at supporting and stimulating the development of the child's emotionality, we managed to achieve positive changes in all children from the selected research sample – alleviation or reduction of manifestations manifesting emotional and behavioural problems. We achieved positive changes in the level of attention concentration and activity level in some oncological children from a selected research sample.

Working with children with cancer requires a thorough knowledge of the specifics of education, close cooperation with medical and health staff, parents of children and other professionals involved in the care of children with cancer. The implementation of the research was hampered for us by the fact that we do not currently work directly in this department and the organizational management of the research was very demanding due to the rapidly changing health status of children undergoing cancer treatment. These changes in children's health required situational decision-making. Despite the complications, we managed to



implement the proposed activities with all the children selected for our research sample. The results of the research proved the effectiveness of the activities we created, which we managed to alleviate or reduce the manifestations manifesting emotional problems, problems in social relationships in all observed children and we also achieved positive changes in the overall functioning of the child in educational process.

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