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THE SUMMARY OF THE DOCTORAL THESIS

THE IMPACT OF PEDIATRIC NEOPLASTIC DISEASE ON THE QUALITY OF LIFE OF CHILDREN/ADOLESCENTS AND THEIR FAMILY MEMBERS - CHALLENGES AND COPING STRATEGIES

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SUMMARY:

PART ONE

Neoplastic disease in pediatrics and its psychological implications

PART TWO

Evidence-based psychology in the pediatric oncology clinic

Summary

The doctoral thesis entitled ***The impact of pediatric neoplastic disease on the quality of life of children/adolescents and their family members - challenges and coping strategies*** was carried out within the Academy of Advanced Studies (SCOOSAR) - Constantin Rădulescu-Motru Institute of Philosophy and Psychology, under the guidance of prof. univ. Dr. Camelia Popa, during the period 2018-2021.

It is structured in two related parts, respectively the first part, theoretical - *Neoplastic disease in pediatrics and its psychological implications*, with a weight of one third of the total work and the second part, of actual research - *Evidence-based psychology in pediatric oncology clinic*, accounting for two-thirds of the paper.

The first part summarizes the state of knowledge and research results in the field, and includes three chapters: Features, incidence, survival rates; Psychological levels affected by oncological disease and Modern standards of care in pediatric psycho-oncology.

The second part, the center of gravity of the paper, contains the following chapters: The experience of neoplastic disease for children, adolescents, parents and carers - a qualitative research through the biographical method; Determining the impact of cancer on the quality of life of children, adolescents and parents - a quantitative study; Development of a scale for assessing the level of suffering of children and adolescents with cancer - methodological contribution and the Conclusions.

PART ONE

Neoplastic disease in pediatrics and its psychological implications

Features, incidence, survival rates

In this chapter, the particularities of the oncological diseases of children and adolescents, their incidence, survival rates, a series of data of interest from national, European and global cancer registries, as well as the characteristics of good practices in the field of care are presented.

Statistics at European level have shown a significant increase in the incidence of pediatric oncological diseases, although part of this increase can be attributed to diagnostic performance and the optimization of national patient registration systems. The increase in the incidence of cancer in people under 19 years of age has been reported in several national and regional studies in Europe, with a common database of 1.3 billion people.

According to the global Globocan database (2021), the percentage distribution of cancer in children and adolescents in 2012 was: 10% for Europe, 48% for Asia, 23.8% for Africa, 17.6% for America and 0.6% for Oceania.

Cancer in children and adolescents has a lower frequency than in adults and a number of own characteristics. The most common cancers under the age of 18 are those of the blood and bone marrow (leukemias), as well as those of the lymphatic tissue, brain, nervous system, muscles, kidneys and bones. Each type of cancer has its own name, treatment, and chance of cure.

According to international statistics, cancer is the main cause of death from disease in children under 15 years of age.

Major advances in the diagnosis and treatment of pediatric cancers have led to a significant increase in the survival rate. Severe lymphoblastic leukemia currently has a 5-year survival rate for about 90% of cases, compared to 50% survival 30 years ago.

New approaches to cancer target two levels: intensifying research concerning the molecular basis of carcinogenesis and discovering specific therapies targeted on cancer cells (Zwaan *et al.*, 2010).

The most common forms of cancer described in Lanzkowsky's *Treaty on Pediatric Oncology* (2011) are: *leukemias*, bone marrow or white blood cell cancers, the most common malignant diseases in children, followed by *brain tumors* and *lymphomas*. Solid tumors include *neuroblastoma* and *nephroblastoma* or *Wilms Tumor*. *Retinoblastoma*, the most common intraocular malignancy in childhood, is a cancer of the developing retina. *Soft tissue sarcomas* (7% of childhood malignant tumors) are a heterogeneous group of malignant tumors derived from primitive mesenchymal cells. *Bone cancers*, with a maximum incidence around the age of 15, account for about 6% of pediatric malignant tumors. Two-thirds of these are *osteosarcomas* and one-third are *Ewing's sarcomas*.

Progresses in childhood cancer treatment have been boosted by international collaborations between researchers and practitioners. Research-based medicine has generated risk-based therapies. In developed countries, more than 80% of the children with cancer receiving modern treatments are cured (World Health Organization, 2021).

The incidence of cancer in our country is generally below the European average, both in children and adults, with the exception of cervical cancer, for which we are within the first places (30 new cases per 100,000 women), situation explained by the shortcomings of the national screening program. Approximately 60,000 new cases of cancer are detected each year, of which 165 occur under the age of 14 (Miron *et al.*, 2012).

Romanian Childhood Cancer Registry (RCCR) is a database that includes all new cases of cancer in children and young people (0-19 years) registered by pediatric-oncology centers throughout the country.

Compared to Europe, the number of cases in Romanian pediatric oncology units is significantly lower in all age groups:

Specific incidence of cancer by age groups

Romania (RCCR 2010-2015) vs. Europe (IACR 2001-2010)

Age	0-4 years	5-9 years	10-14 years	15-19 years
Romania	13.85	8.13	7.88	7.53
Europe	19.71	11.16	12.03	18.53

Note: Cases reported per 100,000 children and adolescents

About 60% of cancers diagnosed in our country are leukemias, lymphomas and tumors located in the central nervous system.

Psychological levels affected by oncological disease

In this chapter, the psychic levels affected by cancer are explored. In the psychological evaluation of the cancer patient, child or adolescent, it is always recommended to indicate the nature of the psychological factors involved, in correlation with the developed symptoms. First, we have the associated depressive symptoms, impregnated with negative cognitions and intense ruminative thoughts, which delay recovery after possible surgery and reduce compliance with the treatment (Popa & Ciobanu, 2013). Secondly, there are a number of nuclei of the personalities in formation that influence both mental representations of the disease and coping style.

The impact of life-limiting diseases on a child's manifestations is difficult to fully assess. Children experience a series of unpleasant events that are not experienced by their healthy friends. Hospital visits, hospitalizations, repeated absences from school, long-term treatment or palliative care, stress and discomfort related to medical procedures, side effects of treatments, ongoing episodes of pain, separation from family and friends, restriction of social interactions and isolation, they adversely affect every level of their mental system.

In very young children, serious illness during the first year of life can alter the very development of self-awareness (Brown & Warr, 2007). Young cancer patients may assume that their illness is a punishment for something they did wrong or because they had a bad thought about someone. As the child grows up, reaching the age of early schooling (18-12 years), he has an increased autonomy and his self-esteem is shaped. If the disease interferes with his own accomplishments, he may experience repulsion and failure. The approval and support of the group of the same age is extremely important and the separation from the group, as a result of the disease, is traumatic. As for adolescent patients, who are in the middle of a journey of self-discovery and at the center of major physical, intellectual and emotional changes, oncological diseases can cause them great turmoil. Unlike children, adolescents perceive death as irreversible, but accepting death is difficult because their lives are future-oriented.

From the analysis of the specialized literature, as well as from the current praxis, we consider that the psychological dysfunctions caused by oncological diseases can be systematized and analyzed on four major levels: cognitive, affective, social-relational and motivational-value (psychology of hope). We tried, within each level, to identify specific resilience factors and the corresponding coping strategies.

Influences on the cognitive level are also exerted by aggressive medical treatments that target the central nervous system. Radiation therapy (RT), for example, is part of the treatment plan for many pediatric cancers, and the impairment of the neurocognitive functioning produced by it has already been demonstrated (Rodgers *et al*., 2013; Kreitler *et al.*, 2012).

It should be noted that when exploring the cognitive level, the dynamic, nonverbal world of the child's mind can only be learned through words, so small patients should be encouraged to engage in dialogue with care team members.

On the emotional level, anxiety is a common psychiatric symptom in the acute phase of cancer diagnosis and treatment, along with acute stress disorder. In the medium and long term, depressive problems can occur. Unfortunately, clinicians lack evidence-based guidance on how to manage the anxiety of pediatric cancer patients.

Pediatric cancer is a very strong stressor, not only for patients, but also for their families. This stressor manifests itself from the moment of diagnosis, when families face the huge burden of understanding the disease, the medical terms, as well as the possibility of the death of the child at an early age.

At the social-relational level, the following were examined: family crises caused by diagnosis and illness, relationship disturbances and school failure. Social support has emerged as a first rank resilience factor.

On the *motivational value* level, the resilience factors against suffering were highlighted, in order to find the psychic resources to deal with the situation. Clear information about the disease and treatments can help both patients and families, giving them the motivation to continue fighting.

Uncertainty about the evolution and outcome of the disease is closely linked to feelings of hope and of fear. Hope, which is related to the motivational-value level of the person, can constitute an important axiological resilience factor.

It is obvious that the diagnosis of a disease such as cancer destroys the normality of life. Regardless of the prognosis, patients and their families are experiencing uncertainty, fear, despair and, together with health professionals, are struggling to understand this stage of life.

There are many challenges in developing effective assessment policies and intervention strategies, focused on hope, uniquely configured for each person.

The age-specific problems of cancer patients and the problems of their families make psychological intervention as important as medical intervention.

Modern standards of care in pediatric psycho-oncology

In this chapter I address the issue of modern standards of care in pediatric oncology, with emphasis on psychological care and the duties/competencies of the clinical psychologist. Any definition of a standard starts from the definition of public health and from the conceptual luggage of the quality of life field.

According to WHO, health refers to a complete state of well-being, physical, mental and social well-being, which involves not only the absence of disease or infirmity, but also issues related to the satisfaction of the individual's life. In a broader sense, quality of life can be defined as the sum of a person's personal values, perspectives, satisfaction, living conditions, achievements, functionality, cultural context and spirituality. Life satisfaction is a variable that defines health itself.

In the cancer clinic, the Quality of Life (QOL) can be assessed, based on questionnaires, by the patient, his carers and/or clinicians.

QOL assessment in pediatric cancer patients has important implications for clinical care, research, or social assistance. This allows the difficulties of the disease and of the treatments to be remedied.

The care of children and adolescents with neoplastic disease begins when the diagnosis is communicated.

Communicating diagnosis and treatment is a complex action that takes place within a care team. It is the first step in involving minor patients and their families in care, which lays the groundwork for obtaining parental consent and patient consent for treatment. In practice, the participation of children in care is often difficult to obtain, both because of their emotional fragility and because of the opposition of some parents, who want to limit the medical information intended for children. In turn, doctors feel uncomfortable discussing issues with the uncertainty of healing with young patients.

Evidence-based standards are those that contain essential psychosocial care recommendations for all children with cancer and their family members. General access to psychosocial support and intervention must be guaranteed for all families whose children are ill.

The clinical psychologist has a major role to play in the care team. Through different therapeutic approaches, he can help patients and families identify what aspects of the disease can be controlled, help them find sources of social support and avoid isolation, encourage them not to let the disease dominate their lives, to help them establish new routines, while continuing to meet the needs of other family members, and at the same time to encourage them to actively collaborate with the medical team.

Also in this chapter of the thesis I examined the stage of death of the child/adolescent with cancer and the issue of survivors.

Thus, the palliative care team, consisting of medical and psychosocial personnel, must be extremely present during the last weeks, days and hours of the life of the sick child/adolescent. Even if the team cannot avoid approaching death, it is responsible for making death as peaceful and pain-free as possible, by controlling physical symptoms and meeting the existential, emotional and social demands of both the patient and his family members.

The support must be directed according to the cognitive and emotional resources of the dying child/adolescent, the physical manifestations he/she is facing.

As for the survivors, they may experience physical complications, have difficulty in school and access to long-term career opportunities, may face problems in social relationships, chronic fatigue, anxiety and depression. All these affect the quality of their life, impairing their ability to perform their daily tasks, their ability to start a family, and their ability to plan for the future (they are not sure that the disease will not recur).

On the other hand, family members are also cancer survivors. Parents and siblings continue to have symptoms of post-traumatic stress disorder, feelings of loneliness and isolation after treatment, even when things are going well - the child/sibling does not die (Brown, 2006).

Increasing the quality of life of pediatric cancer survivors and their families is a priority in the policies of developed countries. The factors that increase the quality of life provided by the practice of evidence-based research include psychological support and medical care following the oncological treatment.

PART TWO

Evidence-based psychology in the pediatric oncology clinic

Preamble

The second part of the paper, the research itself, includes three related studies, one qualitative and two quantitative, with their own methodologies and subjects, which can provide practitioners with new tools to assess the quality of life of patients and family members and can outline psychological strategies for action in fighting cancer.

Study 1. The experience of neoplastic disease

The first study of the second part of the paper, entitled ***The experience of neoplastic disease for children, adolescents, parents and carers - a qualitative research through the biographical method***, complies with the theoretical rigors of the qualitative research in the socio-human sciences and paves the way for the quantitative methods in the next study. The biographies of 50 children and adolescents with cancer and 50 parents were researched, to look at how their emotions and cognitions were structured as a result of trauma, and which coping strategies and resilience factors were activated. In addition, 20 hospital teachers and carers were included as part of the oncological therapeutic alliances.

This study involved collecting a large and detailed volume of data on: *the emotional and cognitive* problems of children and adolescents with cancer and their parents; *perceived quality of life indicators*; *their adaptive*, functional *behaviors and resilience factors*.

Several ways in which threats to the validity of qualitative research can be fought (Yin, 2011) were used in the study, namely:

- my involvement, as an investigator, in the researched environment;
- obtaining a large volume of data in detail from the subjects, during 2 years;
- choosing the most reliable information and corroborating it with information from different sources, on the analyzed topics and
- permanent reporting on the results of international research in the field.

This type of qualitative research is recommended, moreover, in the preliminary phase of a larger research (Popa, 2011).

The short biographies collected have allowed highlighting the life trajectories of people affected by the disease, their thoughts and emotions, as well as a series of quality of life needs, in correlation with a series of individual psychosocial resilience factors, which can be raised to the level of coping strategies to cope with the stress of the disease.

These narratives, with a profound significance for their authors, highlighted a series of psychic levels modified by the disease, from which we could later deduce:

- the uniqueness of individual experiences;
- a series of common characteristics of the studied subgroups;
- a set of personal and group needs, related to the quality of life, as well as
- appropriate coping methods, reflected in the adaptive behaviors of the subjects.

We examined all these aspects in terms of their strength, according to a categorical grid of analysis and, to increase the validity of the study, we compared them to studies conducted in other countries.

The material subjected to the qualitative analysis was presented in the form of Testimonials (paper’s annex) of those involved in the study - children, adolescents, parents, hospital school teachers and carers.

Experiencing anxiety and depression

Experiencing high levels of anxiety and depression, after the diagnosis of a life-limiting cancer, is ubiquitous among cancer patients and their family members. We have extracted from the Testimonials countless evidence of the high intensity of the anxious and depressive symptoms they faced:

- *"I'm scared when they change my cannula, I want it to last as long as possible" (patient A.M., 10 years old);*
- *"I have recently had some health problems. Without being able to control myself, I induced one of the strongest stresses I have felt since I knew myself, which resulted in fear. I also had a lot of other negative states. I felt like a stranger in my body, I felt like these negative states lead to a battle with me that they easily win, without me retaliating, leaving me easily defeated" (patient I. L., 16 years old);*
- *"I was and am afraid of my future, of how I will live" (patient A.J., 17 years old);*
- *"Apart from the fact that my former colleagues and friends are behaving strangely with me, I am afraid to be left alone in a room" (patient A. P., 14 years old);*
- *"I cried a lot and didn't communicate for a few days" (patient S. M., 10 years old);*

The analysis of Testimonials has shown us that children, especially adolescents, express intense fear, stress, and despair. Crying, depersonalization, uncontrollable negative feelings are present in most of their compositions. Fear of the future, fear of isolation, fear of losing touch with others, perceiving oneself as powerless in this state of ill-health, lack of courage, blocked communication, low self-esteem, thoughts of death, death seen as a relief from pain, the cry for help, reaching one's limits, helplessness - are mentioned as such by adolescents. Younger children, on the other hand, refer to altered relationships with friends and more limited fears - of injections, of treatments, of the hospital in general, of the way they look after the treatments, as well as of the permanent fatigue they feel.

Dysfunctional cognitions

Negative, fatalistic thinking, in terms of black and white, long analysis of the phenomenon of death and other dysfunctional cognitions, such as awareness of one's own helplessness, futility, exaggeration of difficulties, distrust of people, act to a point, after which other thoughts replace them, more realistic, adaptive, such as redefining relationships with people, reasoning about a better understanding of oneself, meditations on the deep meaning of life.

The phenomenon can be noticed especially in adolescents, with a well-developed abstract thinking and in parents. Some explicitly point to the dysfunction of their thinking in the context of the disease and the depressive rumination that affects their judgments.

- *"I cannot succeed, I can't, I'm too weak" (patient E.M., 8 years old);*
- *"Thinking in the tunnel ... I blame myself for everything that happens to me, I make a big deal out of it, my thinking is in black and white" (patient A.E., 18 years old);*
- *"I can't say I've always been a good person. I have made many mistakes, I have put*

wrong labels on people, and sometimes I have caused suffering to those who deserve love, and I have given my heart to those who deserve ignorance, without caring that I will not receive love back. I haven't always been who I am today. In fact, even today I am not who I want to be, but I fight every day to get to the best version of myself. Fight for yourself and don't allow people to humiliate you, don't let them look down on you! They are not better than you, but they see you in disbelief and that is why they are walking all over you" (patient M. I., 17 years old).

Experiencing positive emotions and realistic cognitions

Even patients and their family members nominate as an arsenal in the fight against cancer gratitude, love, closeness to loved ones, good thoughts, finding happiness in the little things of life, with family and colleagues at the hospital school, nature observation, friendship, acceptance the situation or the discovery of simple living:

- *"I feel contentment, love, I spend more time with my loved ones" (patient D. A., 11 years old);*
- *"My positive thoughts have always existed because I knew I was going to get over it ... well, and that's how it was" (patient I. L., 16);*
- *"One of the emotions I experienced was the happiness that I prepared some gifts for some family members, and they really appreciated it. Another emotion is the love for family and friends, knowing that they are always with me, they encourage me, they make me feel loved" (patient B. M., 17 years old);*
- *"I am glad that I was able to continue the school during this period and I thank everyone for all the understanding and good thoughts offered. I feel happy when I open the door of my home and my puppies jump on me and they are very happy. I am very happy because almost all my vertebrae in my spine have regenerated" (patient M. I., 15 years old).*

Coping strategies and needs to increase the quality of life

A Psychological assistance is one of the quality of life needs identified in the subjects. This has a proven positive impact on both behaviors and the outcomes of care plans.

- *"I need peace, support and trust" (patient L.V., 10 years old);*
- *"The moments in the hospital are painful and scary, but you have to keep thinking that this experience is a short part of your life. But, remain optimistic. And have a little realism to realize and accept your current situation. And communicate as much as possible with your friends! Tell yourself << I will succeed! >>. Courage*

and hope are vital in this fierce war. Do not hesitate to use these weapons against evil! As long as you hope, everything will be fine" (patient S., 18 years old);

- *"You have to be strong, optimistic, and full of hope in order to attract the good. No matter how you feel, always try to find an activity to pass your time faster" (patient C.B., 14 years old).*

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In another study on the psychomechanics of the language of adolescents with cancer, conducted together with prof. Univ. Maria-Magdalena Jianu and prof. Univ. Camelia Popa, we reconfirmed the optimism/positive emotions of adolescents with terminal cancer as significant factors of resilience.

The study was presented during the doctoral training at the international conference *Individual, family, society - contemporary challenges*, fourth edition, organized by the Institute of Anthropology "Francisc Rainer", in the fall of 2021. In the study (N = 30, 16 boys and 14 girls) we analyzed the psychomechanics of the subjects' language - we selected the words from their last ten posts on social networks. The method was also a biographical one - we phenomenologically assessed the nature/meaning of everyday experiences. At the time of the research, all subjects were deceased. Adolescents whose last ten posts were analyzed had been previously known to us in the hospital.

With the help of prof. Univ. Maria-Magdalena Jianu (Romanian language) the words in the texts of the posts were classified according to their general lexical meaning and their morphological characteristics. The study found a 2:1 ratio in favor of terms with positive emotional connotations, compared to those with negative emotional connotations.

Adolescents with cancer have focused, over the last part of their lives, on topics that have helped them to understand and value life, religion, and family, which has helped reduce anxiety and depression about death or even the cancellation of the terrifying thoughts they had about their disappearance, even though their physical condition was in a visible and very rapid deterioration.

Study 2. Determining the impact of cancer on quality of life

Obiectives

By this quantitative study we aimed to enter, with the help of methods adapted and standardized on the Romanian population, the world of children and adolescents with cancer, hospitalized in the country, and their family members, to identify, on the one hand, the most important features of their psychological profiles and on the other hand - the needs of psychological, psychosocial and educational assistance/care, which can increase their quality of life. Practically, the results of the study will help us achieve an important goal - the validation of our own clinical scale for assessing the suffering of children and adolescents with cancer, an approach that we have designed in this extensive research and which has already done the subject of BDI article.

Hypotheses

• It is assumed that there are significant differences between children and adolescents with cancer in terms of quality of life, level of depression and irrational cognitions that they internalize. Thus, children may develop greater anxiety about procedures and treatment than adolescents (which lowers their overall quality of life score), a range of more severe depressive symptoms, and stronger irrational cognitions, such as intolerance to frustration. given the rules.

• It is assumed that there are statistically significant correlations between the items of depression and irrationality scales. Some of the variability in the total quality of life score for children and adolescents with cancer can be explained by the variable given by the total score on the CASI irrationality scale.

• There are significant differences between the behavioral, emotional, and social issues reported by adolescents with cancer and those reported by their parents and educators / caregivers. Patients' self-reports may be more optimistic than those of parents and caregivers regarding depressive and anxious symptoms, ADHD, provocative opposition, or conduct disorder.

Subjects

Our study is exploratory, quantitative. We carried it out between February and August 2020, in the university pediatric oncology clinics in Bucharest, Constanța, Cluj-Napoca, Timișoara and Iași. The study included:

- 100 patients, divided into two equal sublots, respectively children (N = 50) aged between 8 and 12 years and adolescents (N = 50) aged between 13 and 17 years;
- 100 parents also distributed in two equal sublots, respectively parents of children (N = 50) and parents of adolescents (N = 50);
- a batch of 100 carers/teachers.

The inclusion of human subjects in the research was done based on the informed consent of the parents and with the consent of the subjects to complete the questionnaires. The research documentation and the consent form were approved by the Ethics Commission of the Institute of Philosophy and Psychology Constantin Rădulescu Motru - School of Advanced Studies of the Romanian Academy.

Methodology

We applied eight questionnaires - seven for which we purchased the licenses for and one that we adapted to the Romanian population, with the help of the owner of the license, which we present briefly below:

1. ***PedsQL quality of life assessment questionnaire* –** assesses dimensions such as suffering/pain, anxiety about procedures and treatment, concern, cognitive problems, perception of physical appearance and communication;
2. ***Children's Depression Inventory* (CDI)** – provides information on the severity of depressive symptoms in children and adolescents aged 7 to 17 years;
3. ***Child Symptom Inventory* – 4 (CSI4)** – a screening tool that assesses the symptoms of children's emotional and behavioral disorders;
4. ***Adolescent Psychopathology Scale Short Form (APS-SF)*** – assesses adolescent psychopathology (identifies six specific disorders and six psychological and behavioral problems);
5. ***CASI irrationality scale for children and adolescents*** – measures internalized irrational cognitions, behavioral problems, and emotional problems;
6. ***Scale of post-traumatic development (SRGS)***, which assesses the post-traumatic perception caused by the confrontation with a negative event;
7. ***School Motivation and Learning Strategies (SMALSI)* –** a questionnaire to assess learning strategies and school motivation, highlighting the student's strengths and weaknesses;
8. ***Achenbach's System of Empirically Based Assessment (ASEBA)*** – measures skills, adaptive school functioning of children and adolescents aged 6 to 18 years.

Research strategy

We designed to explore the multitude of data obtained on several levels of depth and complexity, respectively:

- *primary analysis* (average scores, T scores, standard average deviations, significance of differences between averages), for all questionnaires applied to the subjects. We highlighted the dimensions in the area of clinical scales, as well as the differentiating aspects between batches and sublots;

- *correlational analysis* - for the major areas investigated, namely quality of life, clinical pathology and school functioning. We presented the high correlations between the variables of different instruments (interdimensional level) and between the variables of the same scale (intradimensional level);
- *factorial analysis*, which allowed us a deeper understanding of this population of subjects. We performed factorial analyzes for the groups of patients, parents and teachers/carers, as well as for the subgroups based on age (children and adolescents) and gender (girls and boys);
- *analysis of variance*, for testing research hypotheses and
- *linear regressions*, for the selection of those dimensions - predictors that we have included in our own scale for assessing cancer stress.

PedsQL quality of life assessment questionnaire however, it showed that the sublot of children reacted better to *suffering and pain* (score 72.3) than that of adolescents (66.7) and their parents (66), which we also find in the case of adolescents, who react better in suffering than their own parents (score of 66.7, compared to 61.3), as well as in the aspects related to *nausea, worry, communication*. The quality of life related to the health perceived by children has a score of 65, while that reported by their parents - a score of 60.2. For adolescents, the ratio between the self-perceived quality of life and that perceived by their parents is 69.6, compared to 66.4. The fear of doctors and hospitals, as well as the fear of needles, is also more terrifying for those up to 12 years old, compared to those over 12 years old. In the case of sublots by gender and age, there are statistically significant differences in all dimensions related to the quality of life of the cancer patient. Girls have more physical discomfort, suffer more from the disease, and are more anxious about hospitals and treatments.

Children's Depression Inventory (CDI)

In the research we used:

- short version of CDI (CDI: S) for children/adolescents, with 10 items, which ensures a fast screening of the vulnerable population of cancer patients;
- version for parents (CDI: P), with 17 items and
- version for teachers (CDI: T) with 12 items.

For almost all the variables included in the analysis, we obtained scores lower or equal to the limit scores of the CDI, from the tests standards, which means that our group of children and adolescents does not have depression, despite its somatic condition affected by cancer. In the case of the variable *functional problem*, we have a *first clinical significance* - our averages exceed the standard by more than 2 points: 9.68 in children, compared to 7.20, the standard score and 9.96 in adolescents, compared to 7.96. The variable *functional problems* refers, at its clinical significance pole , to the fact that the evaluated subject must force himself/herself for school activities. Through the research with the help of the CDI Inventory we detect first of all the symptomatic persons from a group and secondly we investigate the presence/absence of depression symptoms in a group.

The higher standard deviations, obtained by us at some indicators of the self-assessment scale, give us the basis to appreciate that in our groups of children and adolescents - where the range of scores is very wide - we also have highly symptomatic people.

Child Symptom Inventory – 4 (CSI4)

To complete the diagnosis of the studied population with other clinical scales, complementary to CDI, we resorted to the Child Symptom Inventory 4 (CSI4), applicable only to the sublot of children (7-12 years). The severity scores of the symptoms, evaluated by the children's family members and the teachers of the hospital school where the children are enrolled, therefore show the presence of symptoms of moderate and high severity for some individuals of the group, but not for the group as a whole. Symptoms include characteristic attention deficit disorder, challenging opposition, conduct disorder, major depressive disorder, dysthymic disorder, and generalized anxiety disorder. These require the holistic care team to focus on the problems of the child affected by the oncological medical condition.

Adolescent Psychopathology Scale Short Form (APS-SF)

We used this test to deepen the psychological knowledge of our adolescent subjects, because even those with mild disorders or subclinical symptoms have problems with adaptability and daily functioning, dimensions already affected by extremely traumatic cancer, which involves a radical change in lifestyle.

However, the results suggest that adolescents with cancer have a school-related problem or that their medical condition may significantly interfere with their learning tasks, which is often noted in child psycho-oncology studies.

Surprisingly, however, in the context of low scores for depression and anxiety, is obtaining of the clinical score for *suicide* - 2.50, compared to 2.33 - the score of the clinical sample in the test standard. However, given the specific nature of cancer, with the constant threat of relapse and fatal prognosis, it is possible that this indicator is not related to a major depression of adolescents with cancer - we have already seen that they get low scores for depression - but their excessive preoccupation with death, transposed cognitively and permanently analyzed, but not emotionally invested (death is a central thought). As we have shown in the theoretical part of the paper, cancer patients often have thoughts about their own disappearance and its moment. They conceptualize death according to their age and level of understanding, have recurring thoughts about death, think about its imminence and irreversibility, and raise a number of ethical issues, such as medically assisted euthanasia, termination of pregnancy, and so on. Also, those hospitalized are constantly facing disappearance when they see their friends in the hospital dying.

From this perspective, we do not believe that suicide appears in the profiles of subjects as a depressive symptom, as a serious and imminent complication of major depressive disorder, but rather as a constant concern, reflexive-cognitive, of these young people who see their lives threatened by disease.

CASI irrationality scale for children and adolescents

The absolutist requirement for justice is the only dimension in which our batches and sublots obtain scores of over 20 and exceed the average of the CASI standard, of 18.88. This is a strong maladaptive cognition associated with anger and other behaviour destabilizing emotions.

Children and adolescents with high scores on the *absolutist requirement for justice* perceive the things that happen to them as terrible and put many imperative conditions, such as *must*. In the context of the oncological diseases they suffer from - and which mainly affects their lives, pleasures, friendships -, frequent and long hospital stays, harsh treatment, they were expected to feel painfully these events, to consider them unfair and to design their solution at the cognitive level through the demand for justice, by claiming justice and the reparations that are due to them.

The differences between girls and boys are statistically significant for all scale sizes.

Stress-Related Growth Scale (SRGS)

Our scores show that neither children nor adolescents with cancer develop significantly post-traumatic. There are also no significant differences in the developmental trauma by gender and age.

SMALSI questionnaire for *School Motivation and Learning Strategies*

In the case of the children's sublot, we obtained scores below the standard (below 20.9) in the size of the *study strategies*, both for girls (18.76) and for boys (17.72). These strategies involve: the use of efficient memorizing techniques, good coding of information, optimal storage and prompt updating/retrieval. The study consists, in fact, in organizing the information, making the connections between the information, making the conceptual pyramids, etc.

Students with lower scores on the *study strategies* scale may have difficulties learning as a whole, as the authors of the test note.

The averages obtained, both for girls and boys, indicate a problematic demotivation of children with oncological problems, probably inherent in the context of their disease. The severely affected somatic condition results in repeated absences from school, frequent admissions, long hospitalizations and a motivational effort focused mainly on the goals related to care and treatment plans.

As with other studies that used SMALSI, we note that girls have fewer problems adapting to school requirements, more developed study skills, and an adequate focus on learning tasks. Differences from boys are significant in all dimensions of students' strengths. Instead, boys score high on the student's weaknesses, which means higher school-related difficulties, mostly in test-related motivation and anxiety areas.

ASEBA - Achenbach's System of Empirically Based Assessment

The averages of our sublots of children over 11 years of age and adolescents indicate a normal level of functioning, with no sublinical or clinical intensity at any of the scale sizes. These results confirm what we obtained previously, by applying the other evaluation questionnaires, both in terms of psychopathology and in terms of school functioning. Thus, dimensions such as depression, anxiety, loneliness, attention problems and cognitive problems are placed in the area of clinical normality, at the group level. Even for the variable *somatic symptoms* (nightmares, fatigue, dizziness, nausea, headache, vomiting, stomach ache, etc.), where we would have expected an approach close to the clinical level, the scores are in the normal range.

Associating the evaluated dimensions

We examined the correlations on two levels: *intradimensional* - variables from the same scale and *interdimensional* - variables of different scales, taking into account the tasks included in the methodology and according to the criterion of the psychological fields/areas researched.

In the field of *quality of life*, the variable *suffering/pain* establishes high correlations with the variables PedsQL *anxiety about procedures, anxiety about treatment* and *nausea*, both in the case of the whole group of patients (N = 100) and in those of sublots by gender.

Anxiety about procedure reflects the fear of needles, tests and drips, and *anxiety about treatment* refers to the fear of doctors and hospitals, justified fears in the case of our subjects.

The variable *nausea* establishes high correlations with *suffering*, as we have previously shown, and medium-high correlations with:

- other PedsQL variables - *anxiety and cognitive problems*;
- variables of the SMALSI Assessment Questionnaire for School Motivation and Learning Strategies - strategies used in organizing tests, study strategies;
- CDI depression inventory variables - *dysthymic disorder and major depressive disorder*.

We note the moderate correlations of this variable with the variable *cognitive problems,* in boys (0.40) and with the writing/research skills, in both genders. Nausea and vomiting are common side effects of cancer treatment, which consists of chemotherapy and radiation therapy.

Anxiety about procedures, which reflects the fear of needles, tests and painful perfusion, is a very active variable that is highly correlated with *anxiety about treatment, concern* and with *physical appearance*.

These dimensions reflect: the fear of hospitals and doctors, the worry that the treatment will fail, that it will have side effects, as well as the self-perception problems of the patient (who thinks he does not look good, is ashamed of his body, deformities, scars, hair loss, weight loss or weight gain or any amputations).

In the field of emotional and behavioral issues, we examined the correlation of the variables of the CDI Depression inventory and the CASI Irrationality scale for children and adolescents. In the correlation table of the variable *general depressive mood* we notice that it establishes high associations with the other scales of CDI such as *negative mood, self-esteem* (measures self-efficacy, *devaluation, physical self-perception*), *anhedonia* (psychological loneliness of the subject, lack of joy that derives from it, the lack of pleasure for previously valued activities) and moderate correlations with the perceived inefficiency (wrong execution of some activities). Even if we do not have psychiatric disorders of clinical intensity in the whole study group, some depressive symptoms are present and, as we see, they correlate significantly with self-esteem and other levels of functioning of the patient, which is perceived globally as *ineffective*.

In the field of school activities, we found high correlations both between the SMALSI variables and between them and those of the CDI Depression inventory. The *study strategies* variable correlates highly with affective variables such as *negative mood, depressive mood,* and *self-esteem*, and establishes an average association with self-perceived *inefficiency*. In the correlation pictures of the batch and sublots, the variable *note-taking/listening skills* is associated with the CDI variables - *negative mood, depressive mood, inefficiency* and *self-esteem*, as well as other variables of SMALSI, respectively: *reading and understanding strategies, organizing techniques, writing and research skills,* and *test strategies*, and the variable *reading/understanding strategies* is associated with *organizing techniques, test strategies, writing/research skills, depression, negative mood,* and *self-esteem*.

A profile of the pediatric oncology patient

We resorted to factorial analysis in the main components (Hotteling), keeping as a minimum proportion for the relevance of a factor 10% of the total variance, and as a minimum level of saturation of the variable in factor 0.35 (Popa, 2011).

This approach takes into account the total variance of the data and turns the original variables into a smaller set of linear combinations. The task of the main components analysis is to identify the patterns in the data and to direct the data, by highlighting their similarities and differences.

For the entire group of children and adolescents with cancer, the first factor, with its own variance of 18%, is par excellence a ***factor of school skills***. It encompasses five dimensions with high saturation (>70), respectively *organizing techniques* (0.87), *note-taking/listening skills* (0.86), *reading/understanding strategies* (0.84), *writing/research skills* (0.78), *study strategies* (0.72) and a dimension of 0.67 - *the strategies used in organizing the tests*. All these dimensions outline to the first extracted factor the identity of school abilities factor.

The second factor extracted, with its own variance of 15%, has an interesting configuration, with high saturations for three dimensions related to quality of life, respectively *cognitive problems* (0.94), *physical appearance* (0.94), *communication* (0.84) and with moderate saturations for the other three, respectively *the strategies used in* *organizing the tests* (0.59), the *study strategies* (0.58), the *writing-research skills* (0.43). We appreciate that we could have, therefore, ***a quality factor of life related to school***.

The third factor, with its own variance of 12%, is a ***factor of depressive affective mood***, because in its structure it is associated with high saturation *depressive mood* (0.98), *negative mood* (0.77), *self-esteem* (0.75) and with medium-high saturations - *anhedonia* (0.68) and *inefficiency* (0.61).

The fourth factor, with its own variance of 11%, includes, with average saturation, dimensions related to: *worry* (0.60), *global self-assessment* (0.56), *anxiety about treatment* (0.54), *low academic motivation* (0.55), *anxiety about tests* (0.49), irrational cognition, respectively *intolerance to work frustration* (0.40) and *anxiety about procedures* (0.39). *Intolerance to frustration about rules* (0.39) and suffering/pain (0.37) are also part of the factor. We called this composite picture a ***distress factor***.

However, we should not generalize this factorial structure to all cancer patients, because our own set of intercorrelated variables was obtained based on our tests and variables that we selected. If other tests are used, the picture may change. However, the selection of the evidence included in the research was based on a judgment of its application, based on relevant clinical experience in working with children and adolescents with cancer.

Returning to our factorial picture, we must show that school is an element of normality in the lives of these children, and the fact that they can continue their courses during cancer treatment, in the hospital school, is welcome.

Going to school is vital for children and adolescents with cancer. School not only helps them feel normal, but also drives them away from loneliness, reduces the stress of illness, forces them out of isolation and to regain interest in activities they used to like. For young patients, attending classes after the episode of intense suffering can be a sign that life itself is returning to normal, that they can have fun with others like them, and that they can make new friends.

Statistical testing of hypotheses

The testing of the first hypothesis made in the research, according to which *there are differences between children and adolescents with cancer in terms of quality of life, level of depression, irrational cognition and the level of post-traumatic stress they interiorize*, was performed using the test statistic Z, after calculating the variance on each item for children and adolescents (child variant = 1.68 / adolescent variant = 1.74).

The result was statistically significant (p<0.05), which led to the rejection of the null hypothesis that there would be no differences between children and adolescents with cancer in terms of mentioned sizes.

The testing the second hypothesis, according to which *there are statistically significant associations between: items of the CDI (Child Depression Inventory) depression scale - short version; of the CASI Irrationality scale for children and adolescents and of the SRGS Scale of post-traumatic development*, was performed both in the correlational analysis (interdimensional correlations) and with the help of logistic regression. We analyzed the interaction between the dependent variable (biological gender), seven independent variables represented by items of the CASI Irrationality scale for children and adolescents and the Stress-Related Growth Scale (SRGS).

According to the data, the two items *I cannot stand to follow the rules and also to be necessary to well behave* and *I learned how I can help others* are risk factors, and the risk factor with the best confidence interval is the item from Scale of post-traumatic development *I learned how I can help others*.

We further analyzed, using linear regression, the interaction between the dependent variable given by the total score of the Quality of life scale for children and adolescents with cancer (Total Ped-QL) and the independent variable, represented by the total score of the Irrationality scale for children and adolescents with cancer (CASI_total). Thus, using the average level of the variable, the total score of 9.4783 of the Irrationality scale, we obtained the following value to estimate the evolution of the criterion Ped-QL_total = 9.4783 * 0.330 + 11.575 = 14.702.

The correlation coefficient indicated that 9% (r = 0.3) of the variability in the total quality of life score for children and adolescents with cancer can be explained by the variable given by the total score of the CASI Irrationality scale.

The testing *of the third hypothesis*, according to which *there are significant differences between the behavioral, emotional and social problems self-reported by adolescents with cancer and those reported by their family members, as well as by teachers/carers*, was performed by analysis of variance (ANOVA), which showed that there are statistically significant differences (p <0.05) between the three groups of subjects.

The differences between the self-assessments and the assessments of the parents/teachers were revealed to us even from the primary analysis of the data, in the case of the tests that have answers for them.

Thus, in the PedsQL Quality of life questionnaire, children and adolescents generally make more optimistic self-reports than their parents.

Study 3. Development of a scale to assess the level of suffering of children and adolescents with cancer

In this research, we aimed to substantiate a short scale for assessing the level of distress of children and adolescents with cancer, easy to be applied in the cancer clinic.

Some of our results were published in the fall of 2021 in an BDI journal. This is the study *Development of a scale for assessing the level of distress for children and adolescents with cancer*, International Research Journal of Public and Environmental Health Vol.8 (5), pp. 293-298 (Popa, 2021), to which I worked with the PhD supervisor.

First, starting from the previously presented results, we used linear regression to identify variables - significant predictors of distress and to explain the relationship between a dependent variable and one or more independent variables. Regression analysis helps us understand how much the dependent variable changes with a change in one or more independent variables. Some examples:

»A statistically significant association has been established between the item *I am concerned about the side effects of medical treatments* in the PedsQL Quality of life scale and the item in the same test *Pain at needle sting* (injections, blood tests, drips). (probability p <0.05, chi-squared test, df-degree of freedom);

»A statistically significant association was found between the item *I am concerned about the side effects of medical treatments* in the PedsQL Quality of life scale and the item in the same test. , chi-squared = 44.88, df = 16).

»A statistically significant association has been established between the item *I am concerned that cancer will return or recur* in the PedsQL Quality of life scale for children and adolescents with cancer and the item on the same scale *Pain at Needle Sting* (i.e. injections, blood tests, perfusions) (p = 0.0468, chi-squared = 25.55, df = 16).

»A statistically significant association has been established between the item *Has a poorer school performance than in the past* on the CDI:T depression scale for hospital school specialists where are enrolled the children and adolescents with cancer participating in the study, and the item from the same scale *They have to force themselves to do their school activities* (p = 0.000, chi-squared = 79.38, df = 9).

The six items that constitute the short distress assessment scale we have obtained are:

1. I have a poorer school performance than last year;
2. I have to force myself to do school activities;
3. As I am close to start working on homeworks, I think that I need more time in order to have the necessary mood;
4. I worry about my medical treatments;
5. I worry about the side effects of my medical treatments;
6. I worry about the pain at needle sting (injections, tests, drips, etc.).

For answers, we use a Likert psychometric scale with the following answers: 1. Strongly disagree 2. Disagree 3. Neither agree nor disagree 4. Agree 5. Strongly agree. The resulting average level of distress is 17.6.

We calculated the internal consistency (α Cronbach) of the scale. It has a value of 0.7, a limit result for the reliability of the internal consistency, which indicates, however, that the items in the test are correlated with each other. However, we need a new study with this scale, with a larger number of respondents, possibly on an international group of patients.

Conclusions

Knowing the constants of pediatric oncology patient profiles offered by research, we can make both complex psychological assessments of this specific clinical population and predictions on individual and group behaviors, without ignoring situational variability and changes within individuals, which inevitably occur in the context of life-threatening illness. Also, through the scientific knowledge of the profiles, we will identify those vulnerable points on which the clinical psychologist will work, in order to activate the appropriate coping strategies of the patients. Last but not least, in correlation with the quality of life perceived by the subjects, we will be able to formulate, in a future study, proposals based on psychosocial standards of care for Romanian children and adolescents suffering from cancer.

We aimed, by applying a set consisting of eight validated questionnaires, to capture those sets of psychological variables that are likely to manifest themselves during the disease and that may facilitate or, where appropriate, hinder patients' compliance with treatment.

The fact that we managed to test a significant number of 100 children and adolescents hospitalized in major cancer clinics in Romania, the same number of parents - plus another

100 carers and teachers who reported about patients - is one of the strengths of the research conducted.

We mark, through this approach, a premiere in the Romanian psycho-oncology research, which allows a better knowledge of the clinical population in pediatric oncology and its needs.

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