

Commentary on the article by S.B. Lazurenko et al. “Theoretical and empirical substantiation of palliative care in pediatrics”

Consolidation and cooperation are central topics of the modern stage of society development. Active interaction of education and healthcare systems is one of the components of rendering effective care to the population, increasing life quality and resource of sustainable and progressive development of the society. Theorists and practitioners, representative of different branches of science realized the need in joining efforts to solve daunting social issues. One of such issues, which is not very well-known due to its historically “closed” nature, but which is an indicator of the level of medical-social care rendered, is the problem of organizing and developing palliative pediatric service.

In this epoch of remarkable medical science achievements in operative intervention and intensive therapy, in-depth consideration of conditions and life quality of terminally ill children from the humanistic point of view and care rendering to them and their relatives is becoming more and more important. Humanism cannot be in effect during the human’s active life period. It is important that all citizens are sure that in any situation, even if a disease is incurable, they will receive full-value, individually selected medical-psychological-pedagogic and social support. Effective organization of care for children with severe chronic disease course requires a lot; particularly, pedagogues and psychologists should develop content and algorithm of care rendering in concordance with children’s and their families’ needs and prepare highly professional staff for this work. The international declaration of the World Medical Association reads: “Quality of the care rendered shall not be lower than the quality of the education received”. In view of this, continuous cooperation of theorists and practitioners with representatives of universities and training colleges is fundamental to resolution of the problem.

S.B. Lazurenko¹, N.V. Mazurova¹, L.S. Namazova-Baranova^{1,2,3}, A.K. Gevorkyan^{1,2},
L.M. Kuzenkova^{1,2}, N.D. Vashakmadze¹

¹Scientific Center of Children's Health, Moscow, Russian Federation

²The First Sechenov Moscow State Medical University, Russian Federation

³Sechenov Russian National Medical Research University, Moscow, Russian Federation

Theoretical and Empirical Substantiation of Palliative Care in Pediatrics

Author affiliation:

Mazurova Nadezhda Vladimirovna, MD, senior research scientist at the special psychology and correctional education laboratory of the FSBI "Scientific Center of Children's Health"

Address: 2, Lomonosovskiy Av., Moscow, 119991; tel.: +7 (499) 340-01-04, E-mail: mazariny-2@yandex.ru

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*The aim of the study is to study theoretical and practical basics of organizing specialized palliative pediatric service while taking into consideration the need for rendering complex medical-social help to children at the terminal stage of a disease and their parents. **Patients and study methods.** The study was conducted using the methods of theoretical literature analysis, comparison, generalization, observation, interview and polls. 252 children with severe, life-threatening diseases, and 368 parents of such children took part at the empirical stage. **Results.** It was proved that palliative help should start as soon as the diagnosis (presupposing untimely death risk) is set and may continue throughout the disease, in the moment of death and after it. Palliative help may most efficiently be rendered at healthcare institutions as they have all the necessary conditions. **Conclusions.** The following were defined as the main areas of psychological help: pedagogical and psychological work with the child to create a maximally comfortable and emotionally developing environment; psychological work with relatives to preserve their health and personal potential and prevent family breakdown.*

Keywords: *palliative help in pediatrics, rare diseases, seriously ill children, terminally ill child's family, psychological-pedagogical help, social adaptation, life quality.*

INTRODUCTION

The social changes, which have taken place in our country, and humanization of public conscience created an opportunity for a paradigm stating that human life is of utmost value and that the whole life span must be adequate and quality to form gradually. The task of the state is to provide the best possible life quality level for every citizen.

Rapid development of medicine and introduction of modern nursing technologies in the last 30 years allowed reducing children's mortality and saving lives of seriously ill newborns. However, these absolutely positive processes do not allow reducing the number of children dying of incurable diseases, suffering from daily wasting pain. All these factors conditioned the need in creating specialized palliative care in pediatrics in Russia.

Palliative care is a comprehensive complex support of patients suffering from progressive diseases with unfavorable prognosis for life when the specialized treatment resources are limited. The term "palliative" is derived from Latin "*pallium*" – "cover", "protection". In other words, it is a comprehensive care for patients, creation of conditions for maintaining their bodily and mental comfort, observance of their constitutional rights, quality improvement of the remaining life span regardless of its duration, which does not provide for a fatal outcome to draw nearer or away [1].

In the modern world, palliate care for children is a separate medical specialty or area of medical-social activity [2-6]. In Russia it is only beginning to develop. A complex of theoretical-methodological, empirical and practical measures is required to create and effective system of pediatric palliative care in our country. This process should involve a multidisciplinary approach, which allows joining effort of doctors, social workers, psychologists, pedagogues and representatives of other "caring" professions. It is necessary to understand that pediatric palliative care is considerably different from similar care for adults; peculiarities of Russian healthcare, dominant macrosocial (cultural) ideas, ethnic and national traditions of the country should also be taken into account [7-9].

Study aim: theoretical analysis of palliative care state in our country, study of interconnection of personality, micro- and macrosocial parameters determining peculiarities of parents' reaction to their children's severe diseases in order to outline the main risk factors

of losing personality and labor potential of parents. Given the study aims, we obtained information on individual personality peculiarities and emotional state of adults nearest to terminally ill children, on the most frequent mechanisms of adapting to life-threatening diseases, social conditions of their work and personality needs of family members (social circle, work availability, third-party help and need in this help, free time activity, time spent on caring of a child etc.). Presenting psychological-pedagogic and social (in the broad sense of the word) care we demonstrate the main results of this study in this article.

PATIENTS AND METHODS

Study participants

252 children with severe, life-threatening diseases (causing death before reproductive age or requiring urgent medical intervention in order to save a child's life; incapacitating, aggravating a patient's life quality) took part in the study. These diseases included mucopolysaccharidoses, mucoviscidosis, glycogen storage disease, tyrosinemia, rheumatoid arthritis, systemic lupus erythematosus, dermatomyositis, cardiomyopathy, Duchenne's disease and liver cirrhosis. Age of children – 1 month to 16 years.

368 parents of these children also took part in the study: 252 mothers and 116 fathers. Age of parents – 18-48 years.

The families lived in Moscow and Moscow Region (n=199); in other regions of the Russian Federation: in cities (n=122), in the country (n=47).

Study methods

Given the common logic of a theoretical-empirical study, we used the following methods: theoretical analysis of medical, pedagogical, sociological and historical literature, normative documents and acts, comparison, generalization, classification based on studying real practice of state institutions' work, logical, comparative-contrastive and retrospective analysis and systematization of the obtained results. Conducting empirical study, we used such methods as observation, interview and polling.

RESULTS AND DISCUSSION

Theoretical analysis of the issue of palliative care allowed defining its main stages and peculiarities of development.

Progressive humanistic ideas have always originated in the sphere of the most educated members of society, such as ministers of religion. That is why the first asylums for seriously ill people were organized by religious institutions: Roman Catholic churches and monasteries. Later, churches started building spitals and almshouses (as one structural unit). The division of godly asylums and religious institutions took place only in the beginning of the XX century. At present, most institutions rendering palliative care and medical-social-psychological support of terminally ill patients are parts of medical inpatient hospitals.

Thus, realization of goals and objectives of palliative care, its essence, meaning and content had initially taken 2 directions: medical and spiritual. Russia was not exclusion. Order of Tsar Fedor Alexeyevich of 1682 of organizing 2 hospitals with new European customs in Moscow may be considered the first document referring to the creation of first asylums for seriously ill people in Russia: one at Znamenskii Monastyr (in Kitai-gorod) and another at Granatnyy Dvor (behind Nikitskiye Vorota). This decision was grounded on the ideas of English philosopher Francis Bacon, which spread across Europe, on the responsibility of strong and healthy part of society for weak, seriously or incurably ill people [10]. A network of institutions (asylums) for seriously ill patients had been created in the 3 following centuries in most European and Asian countries. Goals, objectives, directions and methods of supporting seriously ill people in concordance with the disease course character were defined, algorithms of relieving pain syndrome, caring of open nidi and wounds, regulations of asepsis and patient's diet and personal hygiene were developed, types of social security, psychological support, spiritual and cultural aspects were determined during that period.

By the beginning of the XX century, palliative care had already had theoretical foundation, methodology and scientifically substantiated system. However, it had become an independent scientific medical area, received official international recognition and legislative security only by the end of the century. The first international normative act to consolidate goals, regulations, principles and rights of seriously ill patients was approved by the World Health Organization in 1981 [11]. Right of a seriously ill patient to anesthesia was secured later, in 1986. By 2002 8 countries had created and introduced into practices standards of rendering palliative care. "Code of Patients' Rights" was passed in 2003; in compliance with it, patients gained a right to information on their health condition and disease development prognosis, possible complications, available therapy methods, to make a decision on the treatment program for their disease, to participating in therapy selection and definition of life conditions.

Palliative care is an integral part of healthcare system. The advanced high-technology kinds of medical care are used to improve patients' life quality, such as operative and pharmacological influence, hormonal and radiation therapy, anesthesia, conventional technologies, means and methods of reflex therapy, physiotherapy, integrative and complementary medicine. The program of therapeutic measures is defined given the patient's clinical indications and individual wishes. Volume of medical care and character of its realization at healthcare institutions may be different: palliative care department with round-the-clock stay at the medical institution's inpatient department, palliative care department fulfilling outpatient service at the hospital's day care facility, operations' (emergency) field service or domiciliary care for patients by specialists of the hospital's palliative care department, patient's sojourn centers and day-off services. Differentiated approach to its organization provides for reality of fulfilling in practice the main regulations, principles and objectives of palliative care and allows taking into consideration individual requests and needs of a patient in medical-social support.

Principles and content of adult palliative care cannot simply be transferred to the care system for children. There is a range of distinctive features both in the structure of diseases causing untimely death and in physical reaction to pain, psychological disease experience and compensation capabilities of a child's body. This determined the need in distinguishing pediatric palliative care as an independent branch of science.

The following classification of conditions requiring pediatric palliative care is adopted at present [12]:

- life-threatening diseases with a risk of unsuccessful curative therapy and untimely death (malignant neoplasms, irreversible/malignant cardiac, hepatic and renal failure);
- conditions resulting in unavoidable untimely death, though long-term intensive treatment may prolong children's life span and preserve their physical and social activity (cystic lung hypoplasia, polycystic lung disease);
- progressive conditions continuing for many years; only palliative therapy is possible (Batten-Mayou and Tay-Sachs diseases, mucopolysaccharidoses, muscular dystrophy);
- irreversible and incurable, but not progressive conditions causing in a child severe incapacitation, susceptibility to frequent complications and possible untimely death (severe cerebral palsy, incapacitating consequences of diseases and traumas (in particular, brain and spinal cord traumas)).

Such a classification provides a possibility of individual selection of methods and volume of specialized medical care rendering to children with incurable diseases. Use of high-technology types of action at this form of medical service allows protecting parents from the situation of impossible choice: between treating their children's disease and creating conditions only for alleviating their condition, maintaining and improving their life quality (which is possible in seriously ill adult patients).

The World Health Organization defined pediatric palliative care in 2002 as follows: "Palliative care for children with various nosologic forms of life-threatening diseases/conditions which, as a rule, cause children's untimely death or severe incapacitation is active total care for children's body, mind and spirit and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate children's physical and psychological distress and provide social support to their families. Care can be provided in tertiary care facilities, in community health centers and even in children's homes" [13, 14].

According to the statistical data of the Ministry of Health, 6,000 children under 17 years of age required palliative care in 2010. Palliative care was for the first time in healthcare history defined in November 2011 by the new Federal Law #323-FL "On the principles of health protection of the RF citizens" (article 36). It is recognized as a type of medical care rendered in the framework of the state-guaranteed free medical care program. A draft order "On adopting the algorithm of rendering pediatric palliative medical care" of 15 February 2012 was published in the beginning of 2012; it supplemented children's rights secured in legislation by article 11 "Individual program of rehabilitation of disabled people" of the RF Federal Law #181-FL "On the social protection of disabled people in the Russian Federation" of 24 November 1995, by the Family Code (articles 55, 66 and 67), Education Act and the RF Healthcare Act (articles 30 and 61) [3, 5, 10]. Governing body of the Ministry had promised that hospices and palliative care units would be introduced in 74 regions throughout 2012. Their objective is to render medical care to children in order to relieve pain and alleviate other severe disease manifestations and provide care for child's mind and spirit in order to improve life quality and support family members in a difficult life situation.

Pediatric palliative care rendering algorithm is given in the order's appendix. In addition, the guidelines list rules of drug prescription and usage, clinical nutrition and care, list of hardware and rooms for care rendering, specialization and number of care providers.

Thus, the issue is more or less resolved in legislation. However, content of psychological-pedagogic support of children and parents remain an open question. The issue's specific character is that even a dying child continues developing as a personality and in terms of cognition, which is why all conditions for the realization of child's needs in novelty of impressions, cognition, acceptance and support of the adult milieu must be created.

When a child is severely (terminally) ill and a family is to experience grief of a loss, an issue of adapting parents to an upcoming loss and care rendering after a child's death comes up. Adaptation process peculiarities are determined by person's psychological qualities, personality development level characterized by the perfection of personality behavior and activity regulation mechanisms. Not only survivability and finding a place in social structure may be deemed adjustment criteria, but also the general level of personality integrity, ability to develop in concordance with life potential, subjective self-esteem and life meaningfulness. Psychological adaptation on the biological level depends on the nervous system condition and its ability to regulate inhibitory and excitative processes. Continuous emotional distress, no possibility to rest and recover end up, as a rule, with physiological regulation resource depletion and decrease in nervous system's adaptive qualities. Social buffer has an important role in psychological adaptation issues – these are resources and capabilities provided by social environment that a person uses to adapt.

Analysis of results of the empirical study of psychological condition and adaptation mechanisms in parents of terminally ill children showed that external manifestations of the distress suffered depends on the individual personality peculiarities: from external calmness and even indifference to dramatic affective episodes. Both responses result from defense reactions caused by continuous mental overstrain. Most parents were depressed or stressed when talking with specialists and other parents. They paid the most attention to discussing child's urgent medical issues and physical needs, health condition. They described their own condition and interests to a psychologist, looked for support and reassurance that it is possible to find a way to cure their child briefly and less readily. Many of them mentioned the feeling of stupor, lack of understanding of what was happening, feeling of "acute physical pain inside", uselessness of existence and struggle, their own powerlessness and cruelty of the

world around. Change in parents' perception of themselves and their life was noted in connection with crisis of accepting the disease and upcoming loss. Almost all of them expressed thoughts and blamed themselves of the disease, said that they had to prevent it somehow, wished to cure their children, but realized their powerlessness and felt desperate. This caused depression, self-humiliation and self-esteem decrease. The parents spoke of their own global incompetence in past, present and future, doubted their abilities and capabilities of managing any life and everyday situation, as they are not able to help their own children. These changes were especially difficult for fathers who got used to always control the situation at work, "be at their best" and provide the family. Some parents tended to shift the blame for what had happened to other people, including doctors. In this case their actions and outlook were aimed at fighting circumstances, fighting for justice and creating an imaginary model of the perfect world.

Regardless of their emotional state, mothers or fathers had to continue exercising parental responsibilities. In 83.5% of cases, ill children were the only in families (sometimes parents were unable to have other children). In families with 2 or more children the other children were born before the ill child in 76% of cases, i.e. siblings of seriously ill children are, as a rule, older brothers and sisters. Most parents reported no wish and thought of giving birth and raising another child due to lack of time and psychological resources and depressed emotional state. Significant material expenses for treatment and care for a broken and requiring constant attention child meant that one of the parents had to leave work and fully and selflessly devote oneself to care about life and development of son or daughter (on the average, parents spend 6-12 hours per day for care). Ca. 70% of parents expressed complaints about difficult financial standing and restrained living conditions due to their children's disease. Both parents managed to remain working full-time only in 15% of families. In this case children were taken care by immediate relatives or hired employees, who worked for money. According to the data obtained, abrupt social network reduction happened in all families after children contracted a disease. Only 1 out of 5 parents mentioned that they retained a big number of friends and acquaintances who they keep in touch with. The question about the organization of free time caused sincere astonishment. It appeared that only an insignificant number of respondents (less than 10%) could allot 0-4.5 hours per week (2.3 hours on the average) to their hobbies, to satisfy their personal needs and wishes. Along with the need in constant care and concern for child's life and health, in 76% of distressed parents mentioned an ability to calmly communicate with a child. Thus, one of the parents told about his

daughter: "I cannot see her. I see only her pain. I loved her very much when she was alright, but now, when she is so seriously ill, I am angry and annoyed". Such mixed feelings significantly influenced parents' behavior and, thus, worsened the process of their communication with children, decreasing life quality of all subjects of interaction. In such a life situation parents appeared to be unable to draw a border between their child's image and disease. All respondents mentioned the inability to talk with children about their condition, plans for life and future. Thoughts about the upcoming outcome, despair and repeatability hindered displaying their feelings and emotions; that deprived children of feeling of parental trust and spiritual affinity, necessary emotional support.

The aforementioned indicates that family as an integrated systemic formation experiences an influence of severe stress. In our study we recorded frequent failures of family structure and functions, and sometimes even marital crisis. It appears that family as a comprehensive whole functions worse when grief befalls. We obtained data on the intensification of psychological and social issues in brothers and sister along with the ill child's condition aggravation. They become more irritable and irate, envy parents or feel guilty, study badly, have low self-esteem and intense anxiety. The problem of disturbed or destroyed social connections, especially with parents, and feeling of not being needed in comparison with the ill child appears to be the most significant. Matrimonial relationship may fail because of continuous, difficult and unpromising treatment of children and their subsequent loss. People who sincerely love each other not always can cope with the loss of their child and keep on living together. What parents of the dying child encounter psychologically lies beyond the possible images of the world. Their paradigm suddenly becomes untenable, as the world around has changed dramatically. Adaptation to this life situation cannot be fast, as the changes touch upon deep levels of consciousness. According to our data, in the vast majority of situations the adaption cannot complete without professional, individually selected care, which may most effectively be organized at the healthcare institution when medical care is rendered to the ill child. Almost all parents (98.6%) felt need in psychological-pedagogic support of specialists, and only 54.34% of them receive it. Preventing family fragmentation and maintaining mental health of its member are important areas of work of psychologists and pedagogues in palliative pediatrics.

Thus, child's life-threatening disease dramatically changes social life situation of the whole family. The stressor's operating zone covers not only children themselves and their parents, but also ill child's brothers and sisters, grandparents, and sometimes other relatives.

The need in rendering care to the family is conditioned by a range of circumstances. Firstly, by a difficult life situation child's relatives find themselves in for a long period of time. This is connected with the fact that identification of health derangement cause and diagnosis verification allow the doctor to start treatment, jugulate or dispose of disease and at least alleviate child's suffering. Both disease and diagnosis itself become life emergency for the ill child's parents. Parents regard information on causes and character of a severe disease as death sentence passed by medicine in whole and a certain doctor in particular. Unfavorable prognosis of child's life means the collapse of their life plans and hopes, while continuous severe emotional pain results in deep distress.

Secondly, high emotional stress, deep traumatizing emotional pain along with the exhaustion of bodily adaptation reserves lead to the development of apathy and indifference. If this condition continues for a long time, it results in the reduction in needs, simplification and flattening of emotions and interests, compulsive thoughts and overvalued ideas, leads to depreciation of life and simplification of activity and escapism. Specialized psychological care may help parents cope with severe emotional state, psychological, physical and moral stress, retain mental and physical health, go through all stress stages and start functioning efficiently.

Goal of the psychologist's professional activity in relation to seriously ill child's family members is to render help to parents in the difficult life situation in rational realization and perception of the situation, in the realization of a real possibility and search for ways of controlling the situation, in retaining their and their child's dignity and the main life interests, values, goals and motives, in building the model of the future, planning various kinds of activity (mental, professional and social) in concordance with new life circumstances, support in revealing and realizing new meaning of life. This work may be conducted individually, with all family members at the same time or in a group of parents having children with severe incurable diseases.

Thirdly, psychological support of a family in an especially difficult period of care and concern for a terminally ill baby will allow preventing its possible disintegration, retaining psychological, personality and labor potential of parents and providing a child with optimal social life conditions.

As the disease negatively influences and distorts psychological relationship of a child with the world around, a separate sphere of pedagogue-psychologist's activity is a creation of special

emotionally developing environment conditions to activate psychological capabilities and realize child's individual needs. Considerable differences in disease pathogenesis and course and the level of mental development determine the need in individual approach to the selection of content, methods and measures of psychological-pedagogic work. Content of psychological-pedagogic care depends on the health and mind condition and mental activity of children at the moment of care rendering. Thus, psychological care should be aimed at providing social conditions for satisfying a need in interaction with the environment and developing the main kinds of activity (communicative, object, play and academic) in the children with gradual slow health decline, clear consciousness and active mental activity. In case health is rapidly declining and mental activity is sharply reduced, a pedagogue-psychologist determines social conditions to satisfy child's needs in emotional and physical comfort, novelty, feeling and perception of sensory stimuli and orientation in the environment.

A separate area of psychologist's activity is the conduct of psychological measures aiding to alleviate psychological stress and prevention of the medical staff's emotional burnout.

CONCLUSION

Definition and satisfaction of seriously ill children's and their family members' physical, mental, social and spiritual needs should start from the moment of diagnosis verification and continue throughout the disease, at the moment of bereavement and after it. 2 main activity areas of a pediatric palliative care unit psychologist may be defined: work with small patients and with their families.

Palliative care may mostly effectively be rendered at healthcare system institutions, where all the necessary conditions are created. Interdisciplinary interaction of specialists will allow exerting complex and comprehensive influence on both bodies and souls of patients, all their social environment.

Giving right of palliative care to seriously ill patients, the society splits responsibility for their life and care quality with relatives. At the same time, medical care system implements its direct functional responsibility for the development and realization of an individual treatment program, especially in the view of parents and relatives who do not have necessary knowledge and experience. We may affirm that palliative care is one of the conditions of real

enforcement of constitutional right of the parents in a difficult life situation to active life and realization of their personality potential, professional and personality growth.

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