

Patient-centered palliative care in pediatric cardiology: a cardiophenomenological approach

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Despite the success of pediatric cardiology and cardiac surgery in the treatment of severe heart diseases in children, a significant increase in the average life expectancy and quality of life of patients, cardiovascular diseases remain common reasons leading to the need for palliative care. A number of psychological and ethical aspects in pediatric palliative care in cardiology are not sufficiently developed. Cardiac diseases requiring palliative care affect the physiological, psychological and social aspects of patients' lives, and require special attention. It is proposed to use the second-person methods in clinical communication based on the biopsychosocial approach of cardiophenomenology in order to provide a patient-centered environment in palliative care for children with severe heart diseases. Cardiophenomenology can provide non-paternalistic relationships in palliative care for pediatric patients with cardiovascular disease to improve health-related quality of life (HRQoL).

Key words: congenital heart defects, quality of life, patient-centered care, doctor-patient relationship, palliative care for children, cardiophenomenology.

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Cardiovascular diseases are one of the leading causes of the need for pediatric palliative care. In developed countries, the incidence of severe heart disease in children is increasing [1]. At the same time, a number of psychological and ethical aspects in pediatric palliative care in cardiology cannot be called sufficiently developed, in contrast to neurological and oncological palliative care. Often the patients themselves and their parents are not ready for the end-of-life, and physicians do not take into account all aspects of mourning in such a specific context [1].

The pathophysiological and clinical features of cardiovascular diseases influence the patient's subjective experience. Modern clinical and fundamental medicine does not have sufficient tools for studying categories of experience and similar ones, i.e., phenomenological categories. In this article, we will show how you can enrich the communicative repertoire of interaction between a physician and a palliative patient in cardiology with elements and techniques of modern evidence-based humanitarian knowledge. The cardiophenomenological approach used in this article can successfully highlight the problem areas of pediatric palliative care in cardiology and help develop effective communication strategies in clinical practice.

Clinical features of severe heart disease in children

Severe cardiovascular disease often leads to the need for palliative care for children and is one of the leading causes of all-cause child mortality. Key diseases leading to severe cardiac dysfunction are cardiomyopathies and congenital heart defects. The most common severe conditions are single ventricular defects, congenital heart defects as part of genetic syndromes, pulmonary hypertension and pulmonary vein stenosis [1].

Pediatric cardiac diseases requiring palliative care have a number of clinical features due to their pathophysiology and directly impact on the subjective experience and the communication of the patient, parents and physicians. Thus, cardiovascular diseases are prone to slow steady progression with periodic decompensations with acute heart failure, after which the cardiac function is not fully restored [1]. This remitting course makes the disease unpredictable and often makes it impossible for both parents and children to prepare for death.

Also, palliative cardiac patients are more likely to die in intensive care units, rather than in a hospice or at home. Most patients undergo cardiopulmonary resuscitation. As a rule, most patients have a long history of operations and catheterizations during

their life, and at the end-of-life are sedated for intubation.

The mental status of patients varies and largely depends on whether the heart lesion is isolated or is part of a genetic disorder. In the second case, the incidence of cognitive failure is high. In both cases, the condition may worsen due to secondary organ dysfunction due to inadequate hemodynamics.

The pathophysiology and features of the clinical course specifies subjective sensations and symptoms. Fatigue, sleep disturbances, poor appetite, chest pain, shortness of breath, nausea and vomiting, and constipation are common among children with cardiac diseases over 2 years of age [1, 2]. Of mental problems, the most common among children with severe heart disease are agitation, anxiety, and decreased consciousness [2].

Patient-centered care and cardiophenomenology

The special pathophysiology and clinical course of cardiovascular diseases requires a specific approach to building relationships between doctors and patients [3]. Cardiac diseases requiring palliative care affect the physiological, psychological and social aspects of patients' lives, and, accordingly, require special attention to their lifeworld. Patient-centered medicine (PCM) is a relatively new approach in the relationship between a physician and a patient, which focus on the interests of the patient himself.

The theoretical basis for the patient-centered approach was the "biopsychosocial model", proposed by Engel GL in 1977, which involves biological, psychological and social components of a person as a single being, as opposed to the biomedical model, which can be described as disease-centered. In opposition to the disease-centered model, there are two models: person-centered (Rogers C [4]) and patient-centered.

The patient-centered approach is not yet clearly defined; in general, it can be defined as an approach to treating a patient as a unique person, taking into account his point of view and life circumstances, needs and preferences. The patient-centered approach is implemented in shifting the paradigm of the doctor-patient relationship, in participation of a patient in decision-making, in informing a patient [4].

The work by Mead N and Bower P distinguished 5 main features of patient-centredness: biopsychosocial perspective; 'patient-as-person'; sharing power and responsibility; therapeutic alliance; and 'doctor-as-person' [5]. This scheme has been successfully used in empirical studies of patient-centredness among healthcare workers [6].

Since the PCM is based on deep interaction with a patient, taking into account his personality and the

lifeworld in making medical decisions ('sharing power and responsibility', 'therapeutic alliance'), it seems necessary in order to better understand a patient and productively interact with him to use empathy-based communication methods and tools. In particular, it is proposed to use the cardiophenomenological approach.

Cardiophenomenology is an interdisciplinary patient experience methodology developed by Depraz N, et al. and combining the first- (cardiovascular) and third-person (emotional-affective) analysis [7]. The unity of mental and somatovegetative processes and their dynamic interdependence, taken into account in empirical cardiophenomenological studies, makes it possible to achieve synchronization of physiological measurements (for example, electrocardiography) and psychological fixation of the subjective states of patients.

Researchers, relying on psychophysiological data and cardiophenomenology, suggest that at the level of homeostatic self-maintenance of the organism, processes such as interoceptive and emotional-affective states, heart beats and respiratory rate should be considered as markers of the individual's unified vital activity. At the same time, the individual mental life of a patient is interpreted by them as initially involved in dynamic interactions with other people, which predetermines the psychosomatic dynamics of individual development. Thus, it is proposed to consider socio-cultural factors as important parameters of cardiovascular system, and in pediatrics, emotional-affective aspects of relations within the parent-child dyad.

It should be noted that cardiophenomenology is based on the concept that visceral sensations and reactions, primarily interception, are central to the subjective experience of emotions. It is associated with the vagus nerve, which also provides parasympathetic innervation of the heart and

lung smooth muscles [8]. Consequently, the 'third' and 'first' person (physiology and psychology, respectively) are inseparable in the case of emotion-induced visceral sensations, which, in turn, support and modify a patient's affective reactions.

From the cardiophenomenological perspective, the heart (more broadly, the cardiovascular system) functions as a recorder of emotional fluctuations in the mental life of an individual. The dynamics of heart rate from normal acceleration/deceleration to bradycardia or tachycardia, the cardiac arrhythmias and heart attacks, according to the researchers, is in a feedback relationship with the subjective emotional states of patients: the work of cardiovascular system also serves as a marker of emotional-affective states, and the factor of their intensification or deprivation in a patient's subjective life [9]. This means that the

subjective symptoms of cardiac diseases (shortness of breath, irritability, sleep disorders, fatigue) directly depend on complex psychological and sociocultural processes that affect different levels of a patient's systemic organization. Of particular interest may be the relationship of subjective (emotional-affective or cognitive [10]) symptoms caused both by systolic dysfunction and injury of pulmonary blood vessels, which is observed in pulmonary embolism [11].

Empathy and second-person methodology in palliative care for children with severe heart disease

What does this mean in the case of pediatric palliative care? It is known that one of the objectives of palliative medicine is to improve the quality of life of patients and their caregivers. This formulation of the problem distinguishes the palliative approach, aimed at filling the socio-psychological, existential lack in case of the expected end-of-life, from the conventional curative care.

Pediatric cardiology and cardiac surgery focus on curative care. In recent decades, many previously incurable diseases began to be successfully treated surgically and medically. The average life expectancy of pediatric cardiology patients, as well as its quality, has significantly increased. Therefore, the strategies of interaction between pediatric palliative care specialists, pediatric cardiologists and intensivists are still poorly developed [1].

However, this does not remove the question of creating a supportive, patient-centered environment in pediatric cardiac palliative care. Today, palliative care is a holistic, integrative approach based on the adherence of doctors and health professionals to communication, empathy, and the perception of a patient as an individual in the environment of family, society and culture.

Cardiophenomenology can provide a conceptual framework and set of communication techniques for building non-paternalistic relationships in palliative care for pediatric cardiac patients to improve health-related quality of life (HRQoL). According to the data, HRQoL in children with severe cardiac pathology is similar to that in children with other chronic diseases, but compared to healthy children, pediatric cardiology patients are a high-risk group, and interventions are required to maintain both the physical and psychosocial components of the quality of life. In this regard, it can be useful to take into account and hierarchize risk factors of several organization levels: somatic, psychological and social [12]. It is proposed to correct and define cardiophenomenology as a methodology for working with subjective symptoms and feelings in children, which are directly caused by cardiac disease.

Palliative care, based on the unity of somatovegetative and emotional-affective processes, has its own ethical offshoot, which has already found its successful application in group psychotherapy [13]. It is based on the idea of empathy — a resonance with the psychosomatic states of another person in comparison with one's own experiences. This ability can be expressed as addressing another 'in the second person'. Second person appeal, according to studies, is an elementary unit of correlation between 'I' and 'others', which provides the dynamics of interpersonal relationships within small social groups (family, community, psychotherapeutic group). In medicine, empathy works as a mechanism for a doctor's understanding of a patient's feelings and, in particular, is used by Taratukhin EO, et al. [14]. As a consequence, empathic communication is focused on dialogue, positive acceptance of a patient in a helping relationship, which in case of palliative care is not limited to a functional relationship of curative and/or palliative care.

Palliative communication from the cardiophenomenology perspective should take into account the tendency of cardiac diseases to slow progression with periodic decompensations, after which the heart function is not fully restored. In this case, it is the constitutional feature of the cardiovascular system and its functions that directly substantiates the experiences of a patient and his parents: the anticipatory grief can be prolonged due to the impossibility of predicting the disease course, which increases the severity of psychological trauma in caregivers. This means that communication with palliative patients should be based on empathy not only for a patient, but also for the experiences of his family.

Talking about a child patient in the third person is ethically unacceptable. The "second person" provides an effective tool for communication with both a patient and his parents, who often act as intermediaries from doctor to patient.

The doctor does not have direct access to a patient's experience, his subjective feelings. Sometimes this gives a reason to treat his body as an object with defective functions or organs. A curative understanding of health care committed to the idea of survival can be realized in an objectified and dehumanized attitude towards the patient. The prospect of expected death may also contribute to this. Nevertheless, in palliative communication, one should pay tribute to the personal, subjective states of patients. In the case of pediatric cardiology, one should address him directly, saying that this is "your" disease, "your" experience, which, despite its privacy, can be shared.

A patient's suffering and complaints are not just signals of internal dysfunctions of the body, they are

also markers that activate empathy and compassion. On the physician's part, non-paternalistic and non-hierarchical communication begins with second person appeal. 'You' may die, but we will do everything to improve your quality of life. Curative medicine, due to its focus on patient survival, may neglect the patient's subjective quality of life in order to prolong his life. On the contrary, palliative care is based on the needs of a patient himself and his relatives, who together make a decision. Second person appeal may prompt a patient to make an existentially significant decision to prolong or stop treatment in case of end-stage disease.

It is known that anticipatory grief in palliative has nosological specificity, since different degrees of incurability sets different expectations. In addition, the assessment of incurability and the decision to provide palliative care depends on who expresses it — a "traditional", curative or palliative physician.

The disease course is often unpredictable and the prognosis is difficult. Long periods of compensation are replaced by acute decompensations, after which treatment and prognosis are revised [1]. Because of this, parents are less and later aware of the proximity of the child's death, and cardiologists overestimate their readiness for it. This means that one should also take into account the temporal specifics of end-stage cardiovascular diseases and build communication from the perspective of a patient's sudden death, informing the parents about the likelihood of such an outcome.

The dynamics of cardiovascular system in the cardiophenomenological perspective presupposes its openness to the future, including one's own death, as well as the death of another. To achieve joint readiness for the dying of a child requires work with stereotyped ideas about death, carried out by psychologists both with a patient himself and with his relatives [15].

Study limitations. Within the pediatric palliative care in cardiology, the limitations of the cardiophenomenological approach are manifested. Like any other humanitarian methodology, cardiophenomenology cannot be universally applicable to all categories of patients, as a result of which the measurement of the 'second person' is implemented in different ways. In particular, it is worth noting that autonomic patients are very difficult to treat with empathy — just like cognitively intact patients with intact personal autonomy and basic cognitive functions. Similarly, empathy and interpersonal correlation in the 'second person' perspective is not universal, but depends on local socio-cultural contexts. In some cultures, the child's autonomy is neglected in favor of the dyad, while in others, on the contrary, the patient is endowed with personal

Table 1
Comparison of curative and palliative approaches in pediatric cardiology

Curative care	Palliative care
survival	quality of life
"add days to life"	"add life to days"
paternalism	dialog
physiology	phenomenology, psychosomatics
biology	culture
third person	second person
"brain"	"heart"

autonomy from the earliest life periods. All these input parameters must be taken into account in the practical palliative care in cardiology within the cardiophenomenological approach.

Conclusion

In this article, we have shown how the 'second person' methodology based on the cardiophenomenology can be implemented within the patient-

centered care in the context of palliative care for children with severe heart disease. In palliative communication, one should refer directly to a patient himself as a subject experiencing the disease. Second person appeal means the recognition of his personal autonomy and possession of existential, emotional-affective characteristics.

Taking into account a patient's subjective sensations and experiences caused by endogenous (psychosomatic) and exogenous (socio-cultural) factors of his lifeworld can help to improve the quality of life of a patient and caregivers.

Patient-centered palliative care is aimed at making up for the socio-psychological, existential lack in the situation of the expected end-of-life, which distinguishes it from the more traditional curative approach (Table 1). Cardiophenomenology, which emphasizes the biopsychosocial unity of an individual, presupposes an empathic attitude towards the patient, built on the basis of 'second person' communication.

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