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The position of the Committee for Human Development of the Polish Academy of Sciences on family-centered pediatric treatment

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A child's illness, especially of a chronic nature, is an unplanned event that disrupts the family's regular rhythm and functioning mode, sometimes to such an extent that its entire life revolves around the illness and treatment, and other matters decline in importance. The current model of treating children with chronic diseases focuses on the family and is considered the most effective and cost-efficient because it improves the effectiveness of the patient's treatment process but also prevents the adverse effects of the child's chronic disease on the family, such as separation, crisis, and addictions, as well as increases the professional satisfaction of medical personnel. This model not only considers children's treatment using advanced biotechnological methods but also takes into account the psychosocial context of the child's development.

The significance of a family-centered pediatric care model is confirmed in both clinical practice and scientific research. Clinical observations have proven that children staying in care institutions and deprived of their mother's presence for various reasons for a long time did not develop properly and were unable to exploit their potential in full in spite of undergoing treatment and having their basic needs met. Moreover, the performed studies revealed that these children had serious psychosocial problems after returning to their family environment and later in life.

A child's convalesce depends on how their family copes with their illness and treatment, what psychosocial resources they have, what possibilities they see for adapting to chronic stress, what social and material resources, knowledge potential, and personal competence to cope with difficult situations individual family members, including the sick child's siblings, have, and what support they can count on in their environment in the broad sense. A parent's long-term stay in a hospital involves not only anxiety about their hospitalized child's health but also remoteness from their loved ones, the absence of their own place for relaxation and intimacy, social isolation, a sense of lack of financial stability, the necessity to suspend or interrupt their professional work, and fear for other family members remaining at home.

In the family-centered pediatric care model, all activities are orientated towards supporting the family's potential, as well as improving satisfaction, quality of life, and treatment results. Such a model is also the most economically effective method of treating children in both the short-term, during the hospital stay, and the long-term perspective. Day-to-day active involvement of parents in the treatment process strengthens family ties, contributes to the increase in family members' autonomy and competence in caring for the sick child, mitigates the effects of

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anxiety, pain, and negative experiences related to the stress of illness and treatment, and prevents their adverse health implications. It improves the child's health, contributes to their psychosocial development, and prevents the family from social problems caused by separation and long-lasting stress. Consequently, in the long run, it reduces costs incurred by the healthcare system. What is important, these far-reaching positive effects also enhance job satisfaction and prevent burnout of medical personnel.

Considering the information presented above, the Committee for Human Development of the Polish Academy of Sciences expresses the following position:

- 1. We appreciate the fact that the new medical staff training program of 2023 incorporates standards for communication with patients and their families carried out both directly and through social media or support groups. However, it does not fully fulfill the objectives of and the need for the widespread introduction of a family-centered pediatric treatment model. Therefore, the curriculum content should lay greater emphasis on the model of care and cooperation with the entire family of a pediatric patient, which will not only be beneficial to the treatment results of this group of patients but also profitable for the healthcare system.
- 2. The Committee for Human Development of the Polish Academy of Sciences states that a sick child's treatment, especially in the case of chronic disease, engages a treatment team that also includes, in addition to specialists in various fields, nurses, diagnosticians, therapists, psychologists, and social workers, the sick child's caregiver. It is therefore a collective patient the medical team works not only with the patient but also with their family by educating and training them in exercising nursing and therapeutic tasks, and the like, which enables the achievement of better treatment effects. We emphasize the need to extend the time for work with pediatric patients provided for by the system, precisely because of the need to communicate not only with the child but also with their caregiver. For this reason, it is necessary to consider the costs of these activities and realistically price pediatric care services.
- 3. Today, the right of a mother to be with her sick child is indisputable. However, family-centered pediatric treatment requires creating appropriate conditions for the sick child's loved ones, namely creating a "home away from home" an option of staying with the child, that is, living in a place that gives the family a space to rest, where its autonomy and intimacy is maintained and which provides the family with comfort ensuring mental balance, a sense of security, and an appropriate hygiene standard.

It is important that such conditions are available without the need to bear the long-term financial burden associated with the family's stay in the hospital. It is obvious that the creation of such conditions by a hospital requires financial outlays that the public healthcare system in Poland or many other countries is unable to incur. Therefore, the initiatives of non-governmental organizations in this field, such as the Ronald McDonald House program, should be supported. It is not always possible or necessary to provide a separate building; sometimes it is possible

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to create a makeshift home in the hospital in the form of a family room that can perform a similar function in the hospital. Here we see the role of local governments and various organizations that should become involved in initiatives aimed at improving childcare in hospitals.

The foregoing position expresses the views of the Committee for Human Development of the Polish Academy of Sciences and should not be identified with the position of the Polish Academy of Sciences.

Source: https://krc.pan.pl/stanowisko-komitetu-rozwoju-czlowieka-polskiej-akademii-nauk-w-sprawie-leczenia-pediatrycznego-skoncentrowanego-na-rodzinie/