

THE ROLE OF A TEACHER IN EXTRACURRICULAR ACTIVITIES FOR HOSPITALIZED CHILDREN IN THE LIGHT OF REFLECTIONS ON THEORY AND PRACTICE

ROLA WYCHOWAWCY ZAJĘĆ POZALEKCYJNYCH W OPIECE NAD DZIECKIEM HOSPITALIZOWANYM W ŚWIETLE REFLEKSJI NAD TEORIĄ I PRAKTYKĄ

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ABSTRACT

Suffering from a disease and subsequent hospitalization is a stressful and frustrating phenomenon. For a child it is biopsychosocially difficult and its development is negatively affected which often-times may cause further medical issues and the need for psychological and social intervention.

In order to support the development of hospitalized children, there are hospital schools in every pediatric hospital. The schools employ qualified educators and teachers who follow the curricula implemented in regular schools. However, besides the academic part, children participate in extracurricular activities as well. Their instructors focus mainly on organizing games, artistic activities and looking after the appearance of the hospital ward.

Considering the needs of sick children for individual social support, it becomes more and more worrying that the quality of involvement of pedagogues in the process of offering psychological support to the hospitalized child and its family is deteriorated. Many specialists stress that the involvement needs to be much greater than it actually is. This, however, calls for more self-awareness of the pedagogues who work in hospital schools of their own specialist knowledge, skills and competence. On one hand, they need to be willing to do that but on the other, there must be some decisions made by their supervisors. This calls for concrete systemic solutions and directives.

KEYWORDS: child, hospitalization, pedagogue, support.

STRESZCZENIE

Choroba i związana z nią hospitalizacja jest dla dziecka zdarzeniem trudnym i źródłem frustracji. Sytuacja taka rzutuje na biopsychospołeczne funkcjonowanie dziecka i negatywnie oddziałuje na jego rozwój, przez co dziecko wymaga nie tylko interwencji medycznej, ale też interwencji natury psychologicznej i społecznej.

Na terenie dziecięcych szpitali funkcjonują szkoły przyszpitalne, których zadaniem jest wspieranie wszechstronnego rozwoju hospitalizowanego dziecka. W szkołach tych zatrudniani są odpowiednio wykwalifikowani pedagodzy – nauczyciele i wychowawcy. Nauczanie w szkołach przyszpitalnych realizowane jest przez nauczycieli i prowadzone jest według programu szkoły normalnej. Inną charakterystyką od zajęć dydaktycznych mają zajęcia prowadzone przez wychowawców zajęć pozalekcyjnych. Ich praca skupia się głównie na organizowaniu zabaw i zajęć plastycznych oraz dbaniu o wystrój oddziału szpitalnego.

Biorąc pod uwagę potrzeby chorego w zakresie indywidualnego wsparcia społecznego, coraz więcej wątpliwości budzić zaczyna jakość zaangażowania pedagogów w proces wspomagania psychologicznego hospitalizowanego dziecka i jego rodziny. Jak wskazuje wielu specjalistów, powinno być ono dużo większe niż obecnie. To jednak wymaga samoświadomości pracujących w szkołach przyszpitalnych pedagogów na temat ich specjalistycznej wiedzy, umiejętności i kompetencji. To wymaga chęci z ich strony, ogólnych ustaleń i wymagań kierowanych do nich choćby ze strony dyrektora szkoły, a więc uruchomienia konkretnych rozwiązań i dyrektyw systemowych.

SŁOWA KLUCZOWE: dziecko, hospitalizacja, pedagog, wsparcie.

Introduction – a disease in the life of a child

When analyzing the role of a disease in the life of a child, it needs to be noted that statistically, children fall ill with short term diseases, including the typical children's diseases and seasonal infections. Each of these poses an uncomfortable situation for children, yet with professional medical and nursing care provided by their close ones, a child's organism deals with these minor inconveniences fairly quickly and the little patients return to their health and normal life.

On the other hand, there is another group of diseases, including serious chronic diseases defined as 'any disorders or deviations from the norm which are either permanent, cause disability, are caused by irreversible pathological changes, require specialist rehabilitation procedures or are expected to call for long-term follow up, observation and care' [1].

These diseases include among others epilepsy, diabetes, asthma, hemophilia, cardiovascular diseases

and one of the more serious chronic diseases that children suffer from, i.e. oncological diseases.

Another group of diseases are traumas of various types, poisonings which call for intensive treatment, diseases which require surgical procedures. These medical problems as well as the above mentioned chronic diseases usually call for hospitalization.

From the medical point of view, a disease is 'an impaired function of the organism and its regulatory mechanisms' [2]. Psychological concepts which refer to the effect of the serious chronic disease on a child's life stress that it is the source of frustration, an event in the life that prevents the child's most basic needs from being satisfied [3]. Moreover, specialists believe that diseases which require a long-time and intensive therapy constitute a lengthy change in the child's habits as well as in the lifestyle of his/her family. They always have negative biopsychosocial results which also has a negative impact on the child's development. Therefore, not only the child's organism is affected, but his/her psychological wellbeing, cognitive activity and functioning within the society. The situation of such a child burdened with a serious and chronic disease and complex therapy he/she must undergo, oftentimes distorts the child's emotional balance and lowers the threshold of his/her psychological resilience [4]. Invasive treatment exposes the child to prolonged suffering not only of their body, but in the spiritual, psychological and social realm as well.

Interestingly, a serious chronic disease may initiate a particular crisis in the child's life. The crisis defined by Adamczak as 'a traumatic event caused by an unpredictable situation to which it is impossible to prepare, accept, experience or apply any necessary remedies' [5]. It is, however, assumed that a crisis evoked by a disease is a particular type of crisis as it jeopardizes all the major values in the patient's life.

Hospitalization as a hardship in the life of a child

Treating a patient with an acute or chronic disease normally involves hospitalization, i.e. 'putting them in a health care institution where specialist treatment and nursing care are provided using appropriate medical equipment and coordinated consultations of specialist of various medical areas' [6].

Słowik stresses the fact that the need to hospitalize a child is an element of clinical practice which makes the patient's situation even more unpleasant and complex [7]. The inconveniences related to the disease itself are accompanied by unfavorable external factors such as helplessness, difficulty in accepting the schedule of treatment and rehabilitation, unconditional dependence upon the decisions made by the medical personnel as well as the isolation from the child's natural environment

of his/her family and peers. A child that has been hospitalized several times is exposed to numerous situations related to medical procedures, changed conditions and organization of everyday life, sometimes the unpleasant healthcare personnel and other staff that take care of the little patient as well as the difficult situations related to poor or inadequate results of treatment or the lack of any positive results whatsoever. The sick child must assume a new role in life, the role of a patient which enforces substantial changes and limitations to his/her lifestyle. Tojza points to the fact that all these might deprive the children of their needs, initiate the feeling of insecurity and a deep permanent stress, emotional as well as physical strain [8]. Additionally, as it is indicated by Zimbardo, 'such a situation may favour the occurrence of any potential disease' [9].

Considering the above, it needs to be noted that the child's reaction to its disease and hospitalization is always individual; it depends on many factors, such as the child's age, intellectual development, previous experience, the course of treatment and rehabilitation, the severity of the symptoms, the child's awareness as to the nature of the disease, its course and prognosis as well as the support it gets from its close ones and from medical and nursing team [10, 11].

The author's own studies [12] point to the fact that younger children experience hospitalization stress with more difficulty than the stress caused by the occurrence of the disease itself. Older children realize their situation and are aware of the fact that their plans for the near future have to be cancelled. They feel helpless; they are in despair. The emotions of a hospitalized child, especially when the hospitalization takes a long time, are tangled, they are impulsive, fearful, labile, they frequently lose their temper, they find it hard to show their feelings and they become dangerously depressive. A child like this becomes emotionally unstable or hypersensitive, its psychological resilience is lowered, it is easily disoriented, tired and annoyed. Pecyna points to the fact that these strong emotions may lead to secondary changes in cognitive processes such as difficulty to focus their attention, impaired visual and auditory perception, memory problems, impaired thinking, making associations and reluctance to undertake any intellectual effort [13]. Additionally, there may be vegetative symptoms such as headaches, lack of appetite, nausea, diarrhea or obstruction.

Regardless of the child's age, it may be that it cannot cope with its disease and hospitalization and with time it starts to develop the reactions of withdrawal which are frequently interpreted by the medical staff as an expression of having adjusted to the disease. Meanwhile, this is a dangerous maladaptive reaction [14].

A lengthy hospitalization might cause a disorder called hospitalism which is defined as 'group of symptoms caused by prolonged hospitalization which include emotional and intellectual numbness, listlessness, depression and losing interest in social contact' [15]. Hospitalism is usually accompanied by iatrogeny which negatively affects the patient's emotions and which is initiated by three groups of factors [16]. The first are the objective external factors, that is the material conditions, the limitations of movement, the diagnostic and therapeutic activities which the patient must give in to, a different organization of life, unfriendly attitudes of others toward a sick person, dependence upon other people and isolation from the society and the nature. The second group involves objective internal factors such as fear, insecurity about the course of the disease and treatment. The third group are subjective factors, especially the pain which is experienced differently by different patients.

Although the above factors have not been thoroughly examined as to their objective traumatic action, the author's own studies [17] point to the fact that they do negatively influence the hospitalized child.

The little patient finds it very hard to put up with all the organizational and institutional aspects of the hospital ward (the standards, habits and prohibitions). The material aspects (the rooms and furnishing) and those pertaining to the medical care as well as the poor quality of clinical communication – all these make the hospitalized child miserable.

No child is ever prepared for the disease or hospitalization appearing in its life. A child cannot cope with all these on its own. Since there is a strong connection between the ability to cope with hardships, emotional support and social assistance, it is extremely important that a hospitalized child and its parents get support which is adequate to their needs, especially emotional support which should be provided by well-educated specialists.

The role of hospital school in the educational process of hospitalized children and its basic tasks

In Poland there are hospital schools at each pediatric clinical hospital. The schools are to support a multisided development of their students. Pursuant to the Decision of the Minister of Education and Sport of 10 September 2002 on detailed qualifications of teachers, stipulating the schools and conditions on which teachers without university degrees or other qualifications issued by a special educational institution for teachers could be employed (Journal of laws No 155, point 1288), these schools employ qualified teachers and educators.

The work of each hospital school is carried out according to certain guidelines received from educational authorities which are documented in the Curriculum, Prophylaxis Program and the Schools Statute. The Curriculum defines legal basis of the operation of the school, its tasks and educational aims, as well as teachers' responsibilities. It also includes the timetable of school events, the rights and responsibilities of students and their characteristics. The Prophylaxis Program includes a diagnosis of needs and difficulties which constitute the starting point for all the tasks and activities which are to support and remedy the difficult situations that hospitalized children need to cope with. This document specifies the academic and educational activities which are to strengthen and promote the positive social stance of the students. In the Statute, general conditions of the school operation are included, along with information of the staff, their aims, tasks as well as the bodies which are responsible for the organization of work. There are the rights and the responsibilities of students and the manner of documenting the academic work, educational work and caretaking work.

Among the basic responsibilities of teachers and educators, which are also specified in the Teacher's Charter and the Act on the Educational System, the most important is extending pedagogical care over the sick children which calls for some knowledge of these children with whom the educators work. It is also important to be able to adapt the curriculum to the current possibilities of each child.

Teacher in a hospital school – the work and tasks

In hospital schools, teaching is carried out by qualified teachers and educators according to the curriculum of a regular school. However, due to the nature of students (sick children) and the place where the classes take place (a hospital ward) it must be noted that teaching needs to take account of the current possibilities of the students, their resilience to physical effort, their mobility, etc. The pace of lessons is usually slower, the students are not overly burdened with homework and the requirements and expectations are adjusted to their individual possibilities. Classes are carried out on a one to one principle, sometimes they need to be carried out as team work and then it is possible that at the same time different material is covered with different members of the group. The most important principle of school work is to 'rationally manage the strain, the effort of sick children, to keep balance between making the student work and taking it easy, depending on the child's psychological needs and physical abilities' [18].

Considering the importance of academic work in the life of a hospitalized child, it needs to be noted that the topics and methods as well as the stance of teachers themselves play a very important therapeutic role which supports the medical treatment. School work activates the sick child, distracts it from the disease and the hospital which makes it an important form of therapy [19]. What is important, the continuation of the educational process offers the children a chance to continue their studies and obtain grades, it gives them faith in their own abilities, keeps up school readiness and satisfies cognitive and social needs, at least partially. The prospect of returning to their regular schools offers some stability in the emotional sphere of the sick children, offers them security and self-esteem [20].

Another important aspect of didactic work in a hospital school involves the grades which evaluate not only the achievements but also the involvement and effort perceived through the child's current abilities and possibilities. The grades are not only valuable for the academic process, they constitute a therapeutic value as they strengthen the energetic resources which are necessary to fight the disease [21].

An after class educator in the structure of hospital school

After class educators and pedagogues have a different set of tasks from the responsibilities of subject teachers.

As is evident in the school documentation, the teaching staff need to be familiar with the living conditions of their students, their current state of health, they have to contact their parents, their regular school regarding the promotion to the next level, the medical personnel and the psychologist in order to obtain information on the physical and psychological development of their students, they have to prepare school reports and comments on how the child was doing while in hospital.

The after class educators' work is of a completely different nature. While the subject teachers have fixed hours of work in various wards and their contact with children is very superficial, the after class educators work permanently in particular wards, they meet the same children every day and they belong to the cross-disciplinary team of specialists looking after the sick child.

The documentation of after school classes points to the fact that they are mostly spent on catching up with the school work, helping the children with their homework, looking after the appearance of the ward, organizing school events and building up the atmosphere of mutual understanding and shaping the self-awareness of the child. What is interesting, in the documents published on hospital school websites, the tasks of after school educators are defined with great precision as to

organizing leisure time for children, therapeutic activities during after school classes, namely games, art and various types of team work which offers support and motivates the patients' activity. All of these have to fulfill some therapeutic function. They keep the children from being bored, they let them develop and relieve stress or frustration.

By analyzing the educators' tasks as specified in the documentation, one finds it difficult to come across precise notes on any work carried out on a one to one basis, offering emotional support to a child or its parents, which was stressed by Kopczyńska-Sikorska as early as in the 1980s [22]. Even though there are some very general remarks and guidelines of the kind in the documentation, they are not really detailed and it is not very clear who exactly is responsible for following them. There is no mention that it is the educator who is responsible for keeping in touch with the child and offering support, that such a person should accompany the child in its quest for its own place in life and battling with difficulties and that this type of relationship can be particularly valuable to sick children. There is no mention of the fact that the educator, present daily on the ward, is the person who should actively cooperate with the child's parents, offering support not only to the child itself but to its parents as well.

Based on the author's own studies [23], as well as the experience of several educators working in hospital schools and the author's observations made during a month long practice in a children's hospital, it can be said that the educators do carry out the above type of work and that the work is carried out in cooperation with a psychologist. Regretfully, this can only be said about children with acute or very serious chronic diseases, that is on the wards where children have to stay for several weeks or even months. The educators working on those pediatric wards where children stay for a relatively short time do not seem to implement these aspects of work. On these wards, the work of the educator – pedagogue involves organizing games, including board games, artistic activities and looking after the appearance of the ward.

This is surprising and worrying. Firstly, it is popular knowledge that supporting a sick child, satisfying its needs in all areas is one of the essential factors that facilitate the recovery and bring the child back to the society. It is clear that a hospitalized child (and its parents) has to cope with hardships regardless of the type of the disease and the length of the hospital stay. Thus, even a child who stays in hospital for a relatively short time, just like its parents, may need emotional support or concrete psychological assistance with elements of crisis intervention. Secondly, pedagogues who get qualifica-

tions for working with a hospitalized child, according to the decision of the Minister of Education and Sport (10 September 2002) acquire very specific knowledge, skills and competence which make it possible for them to take such actions. Having analyzed the curricula of pedagogical studies with a major in Hospital Pedagogy, it is clear that the graduates are well prepared for doing their tasks. They learn Psychology of health, Sociology of health and illness, Psychological and medical foundations of pedagogical work and revalidation of chronically ill children, Interpersonal behavior, Intervention and psychological assistance at the time of illness, Upbringing and care in the family burdened with a chronic disease, Upbringing and care in a medical institution, Systems of social support, Psychoeducation, The basics of palliative care. These courses point to the areas which should not be problematic for educators and where it is expected that they take up some activity, including individual work, psychological intervention and offering emotional support to the little patients and their parents. Thirdly, on these wards where the hospitalization is not prolonged, psychological assistance is offered only in some cases and based on very concrete recommendations. On these wards, psychologists' visits are rare. The only person, besides the medical personnel of course, who can observe the child, recognize its needs, as well as the needs of its parents is the after school educator. Unfortunately, as it has been said above, that person mostly deals with organizing artistic work for children but does not get involved in concrete individualized activities which could offer the children emotional support.

This is due to the fact that many pedagogues do not feel competent to undertake this sort of activities. They lack the charisma which makes it possible to address individual needs of their students, even those which have not been fully verbalized. Teachers lack sensitivity and openness to the needs of sick children and their parents. Perhaps there are some guidelines which limit the role of pedagogues to teaching, which decide that the after school work's only aim is to organize the leisure time that little patients have so much on their hands.

This issue must be treated as a problem which is very pressing, yet not really new. Many specialists have been discussing it for a long time. A renowned pedagogue, professor Józef Binnebesel, based on his own studies has been pointing to that fact that pedagogy with its theoretical and practical tools can support psychology especially in the period of hospitalization [24]. Professor Binnebesel adds that not only the cooperation between a psychologist and a pedagogue, but also individual work of the pedagogue can minimize the traumatizing effects of the disease and the hospitalization.

The role of pedagogues in hospitals should not be limited to the question of teaching and organizing artistic activities or games. Pedagogues have full qualifications to cooperate closely with psychologists and the work with the sick child and its parents might include not only strictly educative activities but the therapeutic ones as well.

Professor Ewa Kantowicz suggests a wider involvement of pedagogues in the process of supporting the little patient and its family and stresses the fact that social support needs to fulfill a precisely defined role [25]. Professor Kantowicz believes that each pedagogue of today, not only the one working in a hospital school, should be prepared to act as an advisor, councilor and therapist who can directly help students in a difficult life situation, a consultant who can help parents out and an intermediary between the child's environment and the institutions which offer support in difficult situations.

It is clear that the involvement of pedagogues in the process of psychological assistance offered to hospitalized children and their families should be much bigger than it actually is. This, however, calls for self-awareness of hospital school pedagogues with respect to the skills, abilities, competence and specialist knowledge which they already have. On the one hand, they just need to be willing to take up concrete activities but on the other, there must be some guidelines and requirements from the head teacher, thus some systemic changes need to be introduced.

Summary – conclusions and recommendations

Illness and hospitalization are extremely difficult situations in a child's life. For the time being a new role must be assumed, the role of a patient, who distorts all the areas of the child's activity, including cognitive activity, social and kinesthetic activity. The internal balance is impaired, so is the balance between the organism and the external world. Thus, a hospitalized child does not only require medical intervention but one of a psychological and social nature [26].

Considering that 'satisfying the biopsychosocial needs which goes in line with the conditions in which the child finds itself, is the starting point for recovery' [27], it is equally important that the hospitalized child needs to carry on with its academic program and at the same point, it must have its psychological needs satisfied by the hospital school personnel. It is equally important that a pedagogue should make an effort and offer the little patients and their family individualized emotional support which does not only involve organizing games and artistic activities. They are important as they involve children, they bring back the feeling of normalcy and distract children from thinking of their diseases which fulfills an important psychotherapeutic

aim [28]. Yet, what is needed is more thoughtfulness, more reflection and openness to the emotional needs of patients and their parents. What is needed is individual work with the elements of psychological intervention and emotional support offered to little patients and their families. Needless to say, these activities must not be part of some carefully planned strategy, but they must react to difficult situations which might come along, they must address the needs emerging from the situation of the patients and their parents.

The recommendations for pedagogues working in hospital schools, and first of all, for the after school educators are well grounded as their knowledge, skills and competence acquired during their studies make it possible for them to understand the emotional condition of the patient and to take up activities which can improve that condition. The social role that is assumed by a hospital school pedagogue should be considered not only in the context of systemic solutions, but it should be treated as an ethical duty with respect to the child and its parents.

To sum up, the issue of undertaking individualized work with a sick child in order to offer them emotional support that is expected of a pedagogue and educator working in a hospital school is very important not only to the child, but to the society as well. In some respect, the issue is related to the quality of the contemporary health care, but also involves the rights of the little patients and their parents.

From the pedagogical point of view, it is also very important as the child continuously experiences the world and the information; the stimuli which reach it even during the hospital stay shall shape its future attitudes towards difficult situations, towards people and life. The conviction that one can always count on somebody's helping hand and support shall be an element upon which the child's security might depend. Experiencing real support is extremely valid for such a child and their parents. This support will convince the child that whenever it comes to real trouble in their life, another human being constitutes the greatest value.

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