Co-operation between medical personnel, teachers, medical and social team and family for children and teenagers hospitalised with advanced cancer

Binnebesel J.[1*], Krakowiak P.[2]

[1] School of Health Education and Social Sciences in Lodz, Poland
[2] Faculty of Pedagogical Sciences Nicolaus Copernicus University in Torun, Poland

ABSTRACT

Cancer is a difficult problem not only for medical staff, but also for non-medical carers. This complexity affects the therapeutic relation to children or teenagers with cancer. Hospitalisation and the functioning of the child in a ward, as well as in hospice-palliative care system have been addressed. The problem of care provided to young patients staying in the wards or hospice-palliative care becomes an important issue for educators. The basic premise of care and therapy offered to chronically and terminally ill patients are the fact that they do not "function" in a void. Finding of this report are based on contacts with sick children in the ward and in hospice-palliative care, and with their relatives and carers during their illness and after their death. All three stages of accompanying the sick, dying or mourning child need an educator who is ready to provide assistance together with caring team of hospital or hospice-palliative care institution or social care, when supporting families in mourning. One of the qualities of teachers assisting the sick or dying child, stressed in this paper is the ability of communication with the pupil. In the past, in multigenerational families, illnesses, death and mourning were openly shared by children. Today, when dying at home is a privilege of the few and the relatives often cannot be available at the moment of death in institutions, there is a need for cooperation of educators with professionals and volunteers in order to provide valuable assistance to dying children and their relatives.

Key words: cancer, medical personnel, teachers, children, teenagers

***Corresponding author:**
School of Health Education and Social Sciences in Lodz
ul. Kamińskiego 21,
90 - 229 Łódź, Poland
Email: job@fizyka.umk.pl(Józef Binnebesel)

Received: 12.12.2012
Accepted: 15.12.2012
Progress in Health Sciences
Vol. 2(2) 2012 pp 107-115.

Hospitalisations and the hope of being cured

Cancer is an extremely difficult problem of not only a medical, but also emotional, social and educational nature. This problem also affects the therapeutic measures undertaken in relation to children with cancer. An important aspect of this condition is also the very issue of hospitalisation and the functioning of the child in a ward. The conducted studies and analyses indicate that this issue may be dealt with in the context of overall suffering, where children suffer intense trauma in all four contexts of suffering [1]. Thus, the problem of care and therapies provided to young patients staying in the wards becomes an important issue. In addition to medical procedures [2,3] and cognitive treatment [4-6], what also seems to be an crucial aspect of treatments is professional care and educational therapy, provided by educators and teachers [7-10]. The basic premise of care and treatment offered to chronically- and terminally-ill patients is the fact that they do not "function" in a void. To paraphrase one literary work, it can be said that the "patient is not an island". His or her disease affects the family, the entire environment in which the patient functions [1,11].

A significant element of a thus understood therapeutic environment is the issue of school and the role of student played by the patient. The conducted studies [1,12] clearly show that school and a day-care room operated in the hospital ward constitutes an important part of broadly-understood care and therapeutic environment [13-16]. 113 children hospitalised at 6 paediatric and oncology wards were examined. The study in essence addressed the perception of cancer. In addition to the assumed objective, the collected analytical material showed how this group perceive their home, family and their school. The following analysis is an analysis carried out by essentially contradicting the obtained results. It is based on positive factors experienced by sick children and young people in the ward. Before moving on to the analysis, it should be strongly said that the patients under study, in spite of their suffering, are still capable of finding positive aspects of their situation and treatment. This in itself could serve as a separate subject for discussion [17,18].

The issue of **parents' attitude towards me** was most often indicated by some 49% of those examined as a positive experience during hospitalisation. In this response category, the investigated persons pointed out a change in their parents' attitude towards them. Two issues were primarily stressed here. The first one concerned time spent with the child, the second one - conversations held with him or her. Instead of subjecting these findings to detailed analyses, it is suffice to quote statements representative for this issue. 8-year-old Ada said: *"Here in hospital, my mum is not in a rush to go anywhere, she has time for me"*. The issue of conversations is best illustrated by what 15-year-old Eve said: *"At home we never talked to each other that much. It is only here in hospital that we are getting to know each other - WE TALK"*. Talking about the above-mentioned issues, 16-year-old Tom said: *"Only here am I getting on well with my parents. We talk, we have time for it. We talk about everything, without masks and lies. The most important thing is that WE HAVE TIME for these conversations"*. Eve's statement, including the key phrase: **we are getting to know each other,** is the essence of the finding. Tom, in turn, demonstrates the gravity of the problem. This gravity points to the perversity of the situation and becomes fully prominent in the question: What was the situation like between parents and children at home, if only in hospital it is normal? This question will also hover over the subsequent part of the discussion.

The second factor which may demonstrate the experience of the family home among patients is the "**I am in the same room with a little kid**" experience. This issue was pointed out by over 45% of those examined and these were by no means only teenage girls, who could be suspected of starting to develop maternal instincts. This factor was mentioned by girls and boys alike. The essence of this experience was a desire to be needed. 14-year-old Dorothy: *"When I am in the room with Katie, I know I can help someone"*. 15-year-old Arthur: *"Everybody is all over me, I can't do anything at home 'cos I have cancer. Here in the same room with little Adam, I can give something to someone"*. 16-year-old Mark: *"Chris is for me, what I can't be for others, because they think I have cancer, so I need to be taken care of. Everybody is deciding what is good for me, everybody cares for me. They do not care, however, that I also have feelings and want to be needed. Chris KNOWS this and when I am with Chris, I KNOW this"*.

The problem of the perception of the family home among patients also manifests itself in the response shown as bar 8 on the chart: ***that I may play with other children.*** This response focuses primarily on two issues. The first issue concerns the only children. This group of patients, giving the said response, stressed that they have no siblings at home and it was only in hospital that they can meet and be with their peers. The second group are mostly "hothoused" patients.

The problem of these children is best illustrated by what 9-year-old Sylvia had to say: *"My school friends can't visit me at home, because Dad forbids me to make friends with them. Mum says that my toys are too expensive for strange kids to play with them"*. These words speak for themselves, but the words of 8-year-old Matthew reveal a real oddity: *"I can't invite my friends, because my parents say that they are simpletons and none of them is an appropriate friend for me".* Certainly, this issue could be thoroughly analysed in terms of the social group of which those friends and Matthew himself are a part. However, for sure this is not about the criminal conduct of Matthew's friends. The two responses quoted here already illustrate the actual problem of loneliness experienced in the family. This issue is aggravated by the fact that most of the children talking about being together with their peers also pointed out the above-mentioned response.

The last response category directly related to the perception of the family, one that at the same time is an element of the experience of the perception of school is response 9: ***I have time for myself***. This issue concerned primarily young people, teenagers. In order not to digress unnecessarily and to illustrate the gist of the matter, let the words of the patient illustrate the problem and serve as the only comment. 16-year-old Peter: *"Out there, there is always rush, everybody is in a hurry, so am I. Home, school, training, there's never time to ponder. Only here do I have time for myself.* 16-year-old Tatiana: *The paradox is that the hospital, and my cancer, has become the place where I meet myself. Before, I didn't have time for anything. School duties, friends. Even at home I did not have time, I didn't have time for myself, I didn't have time for my parents and my brother, They didn't have time for me, either. Paradoxically, TIME was found, despite the lack of time. I have time for THEM, for myself"* (The girl was diagnosed with chemo-resistant cancer, of which she was well aware; she died six months after saying these words). No one could have put it better, no comment is necessary here.

Other types of response are directly related to the issue of school. The way they are worded clearly shows how school is perceived by the patients where they live. Nearly 31% of those questioned considered the individual tuition they receive in the ward and the attitude of teachers as a positive factor of their hospitalisation; this shows the importance they attach to education. Their responses reveal, first of all, the problem of willingness to carry on their education and of individual contact with the teacher. Overcrowded classrooms and burnt-out teachers at public schools overshadow the school experience of a young person.

13-year-old Ala: *"It was here that I saw that a teacher is a human being, too, who has time for me, does not shout.* Tadeusz, aged 16: *It is a strange feeling to like a teacher. I even like my maths teacher here. If we don't understand something, she has time, she will sit down and explain. Even if she calls me a blockhead, she does that in a friendly way and then devotes so much time to me so I won't be a blockhead anymore".* 12-year-old Michael: *"It was the first time I saw a teacher who did not shout - here in hospital".* Many a word like these could be cited. Still, all these responses illustrate the experience of investigated children from public schools. They are surprised to see teachers smile, or show an interest in their problems. Certainly, it is unfair to say that public school teachers are sulky teaching machines, yet overcrowded classrooms and frustration, professional burnout of a sizeable section of the teaching profession is experienced by not only teachers themselves, but also students.

Mary, aged 15: *"My school teacher is cool, she tries, but we give her a hard time. There are 32 students in our class and she has to bring all of us under control. It is different here, there are few of us, teachers have time, they have no reason to rush, other than life, the fact that one of us will die.* 16-year-old Bartosz: *Regular school is a rat race, whoever is faster, whoever is louder. This can be best seen during breaks. Teachers are rat trainers. It is different here, a teacher is not a trainer prepping the rat for a race, but a person for whom what is important is not the race itself, but the finish line and the style of getting there. You don't have to be the first, you don't even have to reach the finish line. All you have to do is steadily move towards the goal. The problem is the goal, in our case this is a big problem. Rat trainers have no time, as they have to train the pack. Here, teachers work with the individual student, with me Bartosz M., and not with Class 2b".* The quote from Bartosz's statement strongly and deeply captures the essence. Individualism, calm and time devoted to students, all these factors are a key to success. Every teacher would like to have the comfort of working in such a setting, but according to the luminaries of education, there is no place for it in the rat race in which school takes place, as Bartek put it. You have to run, race against others, and everyone knows the consequences. After all, the patients' words also illustrate this.

Nearly 17% of them said that they consider hospitalisation as a positive development because they do not have to go to regular school. Instead of words, may the drawing by 16-year-old Ala with Hodgkin's disease speak for itself.

Describing her drawing, Ala said: *"Sometimes, after a treatment, when I lie down, I feel an atomic bomb explode inside me, everything burns me. Then, I get wounds on my skin, my face and my nose bleeds. I feel terrible and I am angry and sad. I am fed up with everything, I want it to be over, I want to die".* The very same Ala said: "*The only positive thing about being here is that I don't have to go to school".* What does "school" have to mean for her, if hospital and cancer is a salvation?

Educational activities are the most prominent area of activity of broadly-understood teaching staff. One could assume that the functions and tasks of a hospital school are obvious. However, the conducted studies indicate that this is a complex, and multifaceted problem and fulfilment of the schooling duty is just a formal platform for tasks imposed on teachers.

The first task of the school, one that is most often mentioned by doctors, nurses and psychologists, is arranging free time for hospitalised children [12]. By attending classes, young patients are able to break away for some time from the monotony of hospital life. The conducted studies show that children, who often pointed out this issue, stressed that classes help them not to get bored. Such responses are best illustrated by the words of 11-year-old Iwona: *"at least I am not bored in class, because sometimes I think that what is worst about cancer is boredom, having nothing to do here"*. Another issue directly connected with managing free time is turning the children's attention away from the disease. 13-year-old Marcin said: "*during lessons I have something to do and I don't think about my disease"*. Such statements also made up a sizeable share of responses given by young patients. Lessons offered in the ward give the children a sense of security and often increase their self-acceptance. A sense of security is connected with several issues. Firstly, the issue of normality comes to the fore in numerous statements. Let the words of 14-year-old Wojtek illustrate the problem: *"because when I go to my classes, I feel normal, because otherwise, when I am here I am fed up and I think that it will never be like it was before the disease, but when my physics teacher gives me a hard time then it's OK, because not a single normal person likes physics and it is like at a regular school, where our physics teacher also puts the squeeze on us"*. Children talking about this issue stressed that all their peers go to school and it is normal. Preventing them from attending school classes only deepens their sense of abnormality, causing additional mental burden. Another issue connected with the undermined sense of security is related to the school work backlog which builds up on the one hand, because of absence from school due to hospitalisation and on the other hand, because of poorer grades received by children hospitalised for the first time connected with their feeling unwell prior to hospitalisation. These children in particular displayed a school aversion syndrome. In their responses, these patients often stressed that when looking for reasons for their poorer grades, teachers often suspected them of laziness, and not feeling well was just an excuse. School classes given at the hospital help children to catch up on school work and not to fall behind again. In particular, the individual nature of lessons creates favourable conditions for adapting the lesson plan to the individual needs and abilities of the student. An important factor is the ability to show the students-patients that they can still learn despite their illness. The positive attitude of children towards hospital teachers makes it possible to get rid of the trauma associated with the school image, which children developed when they were suspected of laziness and aversion to school classes. The sense of security shaped by the hospital school also results from the fact that children attending classes are not afraid of facing the requirements of a regular school. The problem of not being promoted to the next grade caused by hospital stay and accumulating backlog is a significant reason for concern for some of the patients. The hospital school allows them to view with optimism what will happen to them after they leave the ward. Certainly, these issues do not concern all the patients. The conducted studies indicate that the above situation primarily affects children who are hospitalised many times, as well as those who were admitted to the ward for the first time, but have stayed there for a longer period. New patients usually use their hospital stay to have a rest from school, but with time their attitude changes. The words of 15-year-old Krzysztof can best explain what school means for a sick child: ‘*I am so often here and whenever I come it is always the same – chemotherapy, vomiting, vomiting and vomiting. I know I am going to die, just like Jagódka, Tomek and Wojtek. When I don’t know what to do I keep thinking and watching the drip medicine – drip, drip, drip. Every drip means more injuries in my mouth, pain and vomiting. My mum does not come often because she has to take care of my brothers and sisters, only the ladies from school come when I need them. We talk and laugh and however* *strange it may sound we mostly learn. Most probably I will never use this knowledge, but the fact that the maths and physics lady gets those formulas into my head and the Polish teacher makes me learn poems helps me feel normal, because anyone who is 15 years' old has to learn.'* Another important task of school in the therapy of a child who is in the paediatric-oncology ward, is to help the child intellectually to understand what cancer means. This issue seems to be obvious, but in a few cases there is some interest from the doctors and psychologists to cooperate with teachers. It is noteworthy that it is not the job of a teacher to inform a child of the prospects, the health condition or diagnosis. The core of the cooperation should be, for example, for a biology teacher to provide knowledge of the division of cells, etc. It seems natural that a biology teacher is best qualified to provide a child with the basic knowledge necessary to understand the nature of an illness through suitable content and methodology. Nobody questions the competences of a psychologist who is preparing a young patient mentally and emotionally to receive information on their illness, so it should not be surprising that a teacher may prepare the ground for a physician or psychologist to advise the child of their condition by providing the child with knowledge on the operation of the body at a level adequate to the age and intellectual potential of a child. The cooperation between a physician, and particularly a psychologist, with a teacher in this regard may better prepare a child for this difficult knowledge about him/herself.

Another element of the broad activity of the teaching personnel involves care that is normally provided by common room staff. In this professional group, it is noteworthy that most of the personnel majored in early-schooling pedagogy, early teaching or caring pedagogy. The analysed group included some persons without university diplomas that had only post-secondary pedagogic education (Teaching Colleges). As with other teaching lessons, you can also observe here that the most common function of a common room is to manage the free time of young patients. However, the measures taken by the pedagogic personnel go far beyond the limitations specified by the employees of the ward. The caring-pedagogic function of the common room workers results from the nature and aims of caring and special pedagogy. The common room activities carried out according to the methodological premises of pedagogy may fulfil an important function in therapy. On the one hand, they constitute a realistic alternative to the boredom that dominates in the ward and they enable the development of a child and lessen certain psychological consequences of illnesses and hospitalization. The use of various forms of group games is conducive to relieving tension and frustration, just like creative expression with art forms may provide psychologists with rich diagnostic materials. Focusing on the abilities of a child and not just on their shortcomings, backlogs and failures, provides the affirmation of a young patient, which helps him/her deal with a disease faster and better. Being positive of their own abilities also contributes to better compensation for shortcomings, and to catching up with work. Good cooperation with a psychologist and professional pedagogic diagnosis enable the rationalization of the measures taken by the personnel of the common room, are conducive to the creative management of the free time of hospitalized children and imperceptibly turn good fun into professional and effective therapeutic activities.

Tasks of educator in the period of hospice-palliative team care

A special area of hospitalization for children and youths is palliative-hospice care. Most experts in this area strongly recommend home hospice care as the best for a child facing death [19]. However, the last stages of life of children and youths are often divided among hospital visits, rehabilitation at a hospice and home stays under the care of an interdisciplinary hospice team. In each of these cases changes occur in the child's environment, which does not affect the need of presence and psychological-pedagogic assistance during the last stages of life [1,11,15,20]. Individual tutoring replaces regular school classes in the palliative-hospice care. It is important that as far as possible in terms of strength and organization, pedagogic classes should be held at a patient's home or where he/she is staying (hospital, a permanent hospice). The palliative care team is a group of people who are experts in different disciplines that are considered equal in the integrated system of care. Apart from a physician and nurses, a team comprises a psychologist and a priest as well as a social worker and a volunteer coordinator and qualified volunteers. The medical and nursing functions as well as the psychological and spiritual care is basically similar to tasks of the members of hospital teams. A social worker and a volunteer coordinator have a special role to play and the educator and carer of a terminally ill child should cooperate with them.

Joint care in an integrated environment is not an easy task. Apart from obvious medical-nursing functions, many persons enter the lives of a sick child and their family, and their actions need coordination and supervision. It seems that a social worker or a volunteer coordinator may cooperate with the patient and his/her environment most closely. It is worth mentioning that social work in palliative-hospice care involves promoting changes and solving problems in interpersonal relations and strengthening and liberating people so that they may achieve wellness. According to the theories of human behaviour and social systems, social work is most involved where there is interaction between people and their environment. The principles of human rights and social justice are of fundamental importance for social care [21]. By analysing this definition we may notice how well it fits into the situation of care for a terminally ill child and their family. A teacher and an educator who teach an incurably ill person together with a physician, a nurse, a psychologist and a volunteer try to support a child and their family. A well-prepared social worker should work as a coordinator together with the family in all care for a seriously ill child. The intervention of social care may coordinate the care focused on the person subject to psychological and social processes. The holistic orientation of social work is universal but priorities will differ depending on culture, history and social-economic conditions where it is performed.

A social worker may provide the bond in hospital-hospice-family-school contacts, which follow different rules and rhythms of work and provide their assistance to help a young person in this dramatic period of their life. It is important that teachers and educators should take advantage of the competences of a social worker in better understanding and identifying the needs of the whole family system that is cared for. As regards an ill child, physicians and nurses are the first source of information together with other members of the inter-disciplinary caring team. An educator who gets on well with a child and whom the child trusts may even become a ‘guide’ in the last stage of life. The young patient has to choose a person they are going to trust due to their earlier experiences and the needs they formulate in their own way. This is confirmed by the comment from a general physician who cares for children at a hospice: ‘*We do not choose a patient but rather after the initial observation we are accepted and selected by a child. This privilege has to be deserved, and rejection cannot be treated as a failure, but only as the conscious choice of a child. (...) Choices made by a child in their closest environment are generally not incidental* [22].

A social worker or volunteer coordinator supervises the whole non-medical area of care. In this area there may also be a psychologist, a priest, a rehabilitant and volunteers. A very important issue for the whole team, the family and a young patient is the verbal and non-verbal communication that is transmitted and received in many different ways - see Krakowiak [23]. A seriously ill child may often make surprising choices by not following the logics of competences but rather by listening to their heart or intuition. In the event of impairment due to an illness or an inborn dysfunction, the ability of non-verbal communication becomes even more important. This is the challenge for the whole team, which can bring satisfaction if there is communication in spite of the hurdles due to the illness or disability [22].

The therapy and preparation of the family and classmates is the task fulfilled by the educator from the beginning of an illness, which is particularly important when the hospitalization comes to an end and before a child comes back to the family and class and school after hospitalization- see Binnebesel [1]. In the case of palliative-hospice care it is difficult to think of preparing a child to coming back to its peers. A teacher may discuss with a patient and their family the possible visits of closest classmates. Classes that precede such a meeting may also explain the premises of palliative-hospice care and prepare for coming death [24]. The task of an educator during hospitalization is to prepare the peers of a patient to understand the changes related to an illness (the lack of hair, deformations after procedures, amputation of limbs and other radical changes resulting from aggressive therapy) and to accept the child experienced with its suffering in the peer group [1]. During palliative-hospice care, peers should be allowed to look for ways of supporting and giving realistic hope, not related to recovery but focusing on presence and memory in any possible form. It is worth remembering that such ordinary contacts, joy, fun and humour, which are typical for children, will be the best channels of communication and providing a presence of solidarity [22]. Sometimes, modern forms of communication may be most helpful to children and youths in showing sympathy and kindness. Texts sent by peers were support for Tomek until the end of his life, when he died under the care of the hospice team and communicated until the end with his friends and classmates by his mobile phone [24].

The family, the school and social workers in the period of loss and mourning

In the event of death preceded by a long illness, there is often a tendency to isolate children from the sight of a dying person. However, in order to understand more fully the fact of the death of a loved one, each person from the close circle should have contact with the dying so as to say goodbye. This is easier when children participate in visits to a sick person in the earlier stages, or when they help a relative at home. We must understand the fear, or even repulsion, children may express to the changing body of a loved one, especially in the case of ravaging diseases. Following our common sense and intuition, as well as a thorough analysis of the situation, we should allow children and adolescents to say goodbye to the dying person, and if possible, to participate in watching over them in the last hours of their life. In the case of older children and adolescents, it is best to talk about it, explaining the reasons of the changed appearance, smell or other side effects concomitant with the last phase of life. We should not urge children's presence at the bedside of the dying person if they clearly do not wish that, or if they express, in their own way, discouragement or repulsion. In the case of long death throes at home, we should save children from prolonged presence at the bedside of the dying relative by organizing their activities in a separate room and inviting them to participate in the after-death vigil. It is very important that children and teenagers have the company of older, trusted people at the times of farewells, to which children should be carefully prepared by means of talks about the appearance of the deceased and the reactions of the adults present at the vigil. The point is that they should feel safe and that their feelings could be heard out with attention. If they react with fear or reluctance, we shouldn't act against the child's will, but we should try to dispel their fear or doubt in conversation. Children may want to bid the deceased farewell in a specific manner, by writing a letter, leaving a toy, or drawing a picture or other form of art [23].

Adults are also open to doubt about the question of the participation of children and adolescents in a funeral ceremony. In the case of schools, usually a delegation from the class goes to the funeral. The teacher should consult the family of the deceased child on this matter, and then - according to the arrangements made - devote time for discussion with the pupils on their participation in the funeral ceremony. In some cases, the whole class, or even more classes or the entire school participates in the funeral. The class tutors and the guidance counsellor must be very tactful in order to read correctly the pupils' needs at such a time and not to burden a family overcome with sadness [20] Children's participation in the funeral must also involve their parents' consent. If there is a decision for children's participation in the ceremony, they must be under the care of an adult ready to dedicate his or her attention to the children, their emotions and concerns, preparing them beforehand for what they will see and hear. Participation in the funeral may have a salutary impact on how the children will deal with sorrow and the loss of a close friend. If the parents decide that their child will not participate in the funeral, we should recount its course to the child, devoting time for any questions or doubts, illustrating the event with pictures from the ceremony or a visit to the cemetery at a later time. In the case of elder siblings of the deceased child, a social worker or a teacher should encourage their participation in the funeral, since separating them from the family will make it more difficult for them to go through their mourning. We should give them the freedom of decision, as autonomy is very important to older children and adolescents. If they do not want to take part in the funeral, we should talk to them about the reasons for their decision, without forcing them to change it. The reason why young people are afraid to participate in such ceremonies is often anxiety or fear of humiliation and tears. A request for assistance in the preparation of one of the elements of the funeral can often break the adolescent's resistance against the religious ceremony or a situation in which the teenager will be exposed to "public view" [23].

A responsible teacher should be aware of the fact that the orphaned family may still be under the care of a palliative or hospice institution and, as far as possible, he or she should stay in contact with its personnel. Cooperation established during an illness should be continued, which will help prevent many misunderstandings in the child's education and the entire context of their return to the group and everyday activities. Often, a child's drama following the loss of a loved one (a parent, a sibling, or other important people) arises from ignorance of the pupil's situation. Both teachers and members of the social care team (a social worker, a psychologist, a chaplain or volunteers) can help effectively in diagnosing and solving the child's emotional or social problems. For an orphaned child, school can be a source of additional stress. That is why it is so important for the parents, the teachers and the hospice team to work together. Their aim should be to create an atmosphere of understanding, to find ways to help the child if it has problems with concentration in learning, with classmates, or on more difficult days of deeper dejection. Often, such a simple task as presence by their side after a loss, dedicating time to them, helping with their homework or listening to their story and accepting the tears are enough to show support and help. Often, one phone call by the teacher to a social worker from the palliative or hospice institution can help understand the pupil's educational problems in the context of the dynamics of a family in mourning [25].

Crisis intervention with children and adolescents can be provided by the parents, relatives, teachers, or a priest, and the support they provide is usually enough to cope with the grief. At every stage, the best "specialist" for the child or a young person is the person closest to them. This person should be the one to talk about death, about feelings and explain any doubts. However, some children's reactions may appear alarming to us. We need to know what kind of behaviour requires specialist advice and assistance. We should not be too hasty with such a decision – it should not be taken right after the loss has occurred. Then, the reactions may be very violent and diverse. Whether the child or teenager needs specialist help depends on the intensity, and above all, prolonged nature of the condition. We can talk about alarming signals if after a few months the following behaviours can still be observed: long-lasting sadness, depressive behaviours; living at full speed, with no time to relax among friends; lack of interest in one's appearance, clothing, environment, toys; constant fatigue and problems with sleeping; constant and raised level of aggression; long-lasting physical complaints; avoiding contact with the environment; seeking solitude; indifference to school and the activities the child used to like; feelings of guilt and lack of self-esteem; seeking consolation in alcohol, drugs or sex; changing moods and lack of control over them; direct or indirect threats of suicide.

Before we ask for psychological or psychiatric help, we must prepare the child or the adolescent for such a meeting. We must emphasise the specific situation and the fact that trained people are able to help anyone in such a situation. It is also worthwhile to show the child that this is not the result or symptom of helplessness, but wisdom of life that requires us to look for help wherever it is possible. Teenagers need to be told of the need for psychological intervention, the aim of which is to assist their growth, having been disturbed by a loss that triggers a whole range of difficult experiences. In both cases, using language adequate for their age, we must convince them that this is not due to their "insanity". A child's therapy should be as limited as possible, so that parents and other close persons could resume their task of assisting the child in its process of mourning. Also psychological assistance provided for teenagers must be adapted to the stage of their development and consulted with them in order to obtain the expected results. Please keep in mind that the presence and involvement of a teacher the child knows and trusts may be more effective than the highly specialized therapeutic aid of a person unknown to the child [23].

CONCLUSIONS

All three stages of accompanying the sick, dying or mourning child or teenager, presented in this paper, require a teacher or an educator who, being aware of his or her fears and attitudes to illness and death, is ready to provide assistance with the help of the personnel of the hospital, the palliative or hospice institution or the social care unit, and to support the child in mourning. Our assistance may be hindered due to psycho-emotional barriers resulting from our own traumatic experiences and the adopted model of thinking or avoiding thought about a serious illness and death. This is connected with the fear of passing time and avoidance of subjects related to suffering and death [26]. One of the elements of the emotional maturity of the teacher who is to assist the sick or dying child is the ability to establish real communication with the pupil. Only by getting to know ourselves and our fears of illness and dying, can we assist effectively the patient as well as other children entrusted to our care [27]. In the past, in multigenerational family communities, concerns, illnesses, as well as death and mourning were shared by children and adolescents as full members of the family. Today, when dying at home is a privilege of the few and the relatives often cannot be present at the moment of death in hospitals, there is need for cooperation between teachers, educators, the medical staff and the social workers in order to provide effective assistance to the sick or dying child and his or her relatives [28].

REFERENCES

1. Binnebesel J. Opieka na dziećmi i młodzieżą z chorobą nowotworową w doświadczeniu pacjentów, UMK, Toruń, 2003. (Polish)
2. Bożka J. Nowotwory wieku dziecięcego, PZWL, Warszawa, 1989. (Polish)
3. Matysiak M. Hematologia w praktyce pediatrycznej, PZWL, Warszawa, 2002. (Polish)
4. Kowalczyk J, Samardakiewicz M. Dziecko z chorobą nowotworową, PZWL, Warszawa, 1998. (Polish)
5. Rogiewicz M. Problemy psychoonkologiczne dzieci i młodzieży [w:] Psychoonkologia, de Walden-Gałuszko K.(red), PTP, Kraków, 2000, pp 101-106 (Polish)
6. Samardakiewicz M. Optymalizacja metod wspomagania biopsychospołecznego dzieci leczonych z powodu choroby nowotworowej, Wydawnictwo Polihymnia, Lublin, 2008. (Polish)
7. Binnebesel J. Miejsce oraz rola pedagoga i terapii pedagogicznej na oddziale pediatryczno-onkologicznym. Psychoonkologia, 2001 Jul-Dec; 9:3-12. (Polish)
8. Binnebesel J. Szkoła elementem normalności w oddziale pediatryczno-onkologicznym [w] Wielowymiarowość integracji w teorii i praktyce edukacyjnej, Chodkowska M.(red), UMCS, Lublin, 2002, pp 87-97. (Polish)
9. Binnebesel J. Aspekty pomocy i opieki pedagogicznej nad dzieckiem z chorobą nowotworową [w:] Forum pomocy dziecku i rodzinie w środowisku lokalnym B. Matyjas (red) t. II, Kielce, 2002, pp 51-60. (Polish)
10. Binnebesel J. Relacyjne aspekty terapii dzieci terminalnie chorych, [w] Edukacja jako proces socjalizacji osób niepełno-sprawnych, Klink, A. Kraków, IMPULS, pp. 73-77 (Polish)
11. Buczyński F. Rodzina z dzieckiem chorym na białaczkę, KUL, Lublin, 1999. (Polish)
12. Binnebesel J. Opieka nad dzieckiem z chorobą nowotworową. Aspekt pozamedyczny, UMK, Toruń, 2000. (Polish)

13. Binnebesel J. Nowe aspekty pedagogiki specjalnej, [w] Rehabilitacja, opieka i edukacja specjalna w perspektywie zmian, Cz. Kosakowski, A. Krause (red.) UWM, Olsztyn, 2004, pp 122-8. (Polish)
14. Binnebesel J. Zapomniani niepełnosprawni pacjenci [w] Problemy edukacji, rehabilitacji i socjalizacji osób niepełnosprawnych. Rottermund J. (red.):, t. 2, IMPULS, Kraków, 2007, pp 37-46 (Polish)
15. Binnebesel J. Pedagogical therapy of chronically and terminally ill children, [w] Edukace zaku se specialnimi vzdelavacimi potrebami, Sbornik příspěvků z mezinárodní conference. Ostravská univerzita v Ostravě, Ostrawa, 2007 pp 64-72.
16. Binnebesel J. Odczuwane doświadczanie choroby nowotworowej przez dzieci hospitalizowane na oddziałach pediatryczno-onkologicznych [w] By człowiek nie musiał cierpieć, Nowicka A. Zych A. (red.), DSzW, Wrocław, 2007, pp 52-59. (Polish)
17. Binnebesel J. Opieka nad dzieckiem przewlekle i terminalnie chorym – wyzwania dla pedagogiki specjalnej [w:] Dyskursy pedagogiki specjalnej. Od tradycjonalizmu do ponowoczesności. Górniewicz E, A. Krause A. (red.), UWM, Olsztyn, 2002, pp 365-74. (Polish)
18. Binnebesel J. Percepcja czynników wspierających i utrudniających hospitalizację dziecka z chorobą nowotworową na oddziale pediatryczno-onkologicznym (w) Pedagogika specjalna szansą na realizację potrzeb osób niepełnosprawnych, Dykcie W, Kosakowski Cz, Kuczyńska-Kwapisz J (red): PTP, Olsztyn, 2002 , pp 597-599. (Polish)
19. Dangel T. Domowa opieka paliatywna nad dziećmi w Polsce — model potrzeby, możliwości i ich ocena, SCHOLAR, Warszawa, 2001. (Polish)
20. Binnebebesel J. Odczuwane doświadczanie choroby nowotworowej przez dzieci Hosnitalizowane na oddziałach pediatryczno onkologicznych [w] By człowiek nie musiał cierpieć, Zych AA, Nowicka A, DSzW, Wrocław, 2007.
21. Payne M. Know your colleagues: role of social work in end-of-life care. End of Life Care, 2007, 1(1): 69-73.
22. Bohdan Z. Wolontariat hospicyjny wśród dzieci - szczególne wyzwanie i zobowiązanie [w:] Podręcznik koordynatora wolontariatu Hosnicyjnego, Krakowiak P, Modlińska A, Binnebesel J. (red.) ViaMedica, Gdańsk, 2008, pp 63-9. (Polish)
23. Krakowiak P. Strata, osierocenie i żałoba, ViaMedica, Gdańsk, 2007. (Polish)
24. Świtała M., Kławsiuć P. Podróż za horyzont. Pięć lat później, ViaMedica, Gdańsk, 2009. (Polish)
25. Keirse M. Smutek dziecka. Jak pomóc dziecku przeżyć stratę i żałobę, Polskie Wydawnictwo Encyklopedyczne, Radom, 2005. (Polish)
26. Dolto F. Rozmowy z dzieckiem o śmierci, PWN, Warszawa, 2002. (Polish)
27. Formella Z. L'educatore maturo nella comunicazione relazionale. LAS, Roma, 2009.
28. Binnebesel J, Bohdan Z., Krakowiak P, Krzyżanowski D, Paczkowska A., Stolarczyk A. (red.). Przewlekle chore dziecko w domu. Poradnik dla rodziny i opiekunów, ViaMedica, Gdańsk, 2012. (Polish)