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The impact of a chronic disease on the psychosocial development of children (based on the example of cancer)

Abstract

The problems of a child with cancer were frequently and widely reported in the scientific literature in medicine and psychology. This problem, however, rarely took place in pedagogical analyses. Studies show, however, that apart from the strict psychological issues, the upbringing and educational problems increasingly begin to get importance. The impact of the disease, treatment, and hospitalization integrally affects the child's psyche and behaviour, both during the treatment, shortly after it and what studies have shown, even many years after the finished treatment. The syndrome of learned helplessness, analyzed in social sciences, presents quite well the described problem of the, so called, constantly sick child. An essential element influencing the creation of the syndrome of the constantly sick child is the lack of knowledge and awareness about cancer, as well as its consequences among educators and teachers.

Key words: tanatopedagogy, psychooncology, cancer (neoplastic disease), education, special pedagogy

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Introduction

There is no doubt that chronic disease plays a large role in the functioning and psychosocial development of the child [1–9]. However, the concept of chronic diseases is too enigmatic and general to, in its semantic context, conduct a thorough and detailed analysis. A question therefore arises: Are there specific factors of a chronic disease affecting the said development?

The consideration, conducted below, focuses mainly on the characteristics of children and adolescents hospitalized for cancer. The obvious fact is, however, that the presented analysis has a character of a certain generalization, because the individuality of familial, care, and educational experiences generates not only the way of the child's functioning in the domestic and social environment, but also the individuality of experiencing the disease [6, 10, 11].

Thus, in the present study only one aspect of the problem of the psychosocial functioning of a child with cancer will be presented. Operatively, this aspect can be called the "syndrome of a constantly sick child". It can be compared with the "Peter Pan" syndrome. D. Kiley [12] demonstrates that this type of person wishes to be four years old through one's entire life and as a child move from one world to another whenever one wants, realizing that when one grows up, one will have to live the life

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of an adult. Therefore, one decides to be an eternal child, not grow up. In the world of Peter Pan there are no consequences or obligations, there is fun and the present day. In the interesting us case, the person wishes to always be sick, because in the illness one perceives a peculiar value and a way of life. To a certain degree it can also resemble the "Munchausen Syndrome" [13–15] where, however, not the parents, but the child itself intentionally causes or simulates the symptoms of the disease.

Material and method

In the present analysis, two research projects have been used.

The first one is dedicated to the perception of cancer of children treated against cancer. The study included in total 113 children diagnosed with cancer, being in the course of treatment in clinics and oncology and haematology wards in the whole country. The used research method is a Diagnostic survey [16]. The research techniques were: a questionnaire, observation, analysis of the products and, above all, a categorized and in-depth interview. The aim of the applied research techniques was to gather the broadest possible information concerning the perception of cancer among children.

The second research project was dedicated to the perception of cancer in the pedagogical-educational environment. The study involved 740 people, of whom 458 were students of the pedagogy specialization and the teaching specialization of continuous five-year Master's degree studies and of Master's degree studies following-up a Bachelor's degree, as well as 282 teachers of all types of schools and lecturers of higher education schools. The applied research method is a diagnostic poll, the technique a survey.

The results of two research projects were based on a qualitative-quantitative analysis, statistically elaborated through a test of statistical compliance ^{2}. Apart from statistical elaborations of research results, statements obtained with the help of a questionnaire and interview have been subjected to a qualitative analysis.

Results and discussion

To understand the essence of the analyzed problem, the traumas experienced by the children hospitalized, due to cancer, should be presented. This issue seems all the more important that it is not quite well understood among those responsible for the development, education, and upbringing of the children and youth. The following figure shows how among the studied pedagogues, teachers, and lecturers does the belief about the experience of child trauma during hospitalization and anti-cancer treatment dissolve. For 80% of the respondents, the main source of the experienced suffering was chemotherapy. In this context, important also seems the fact that among the 740 respondents, only 87 managed

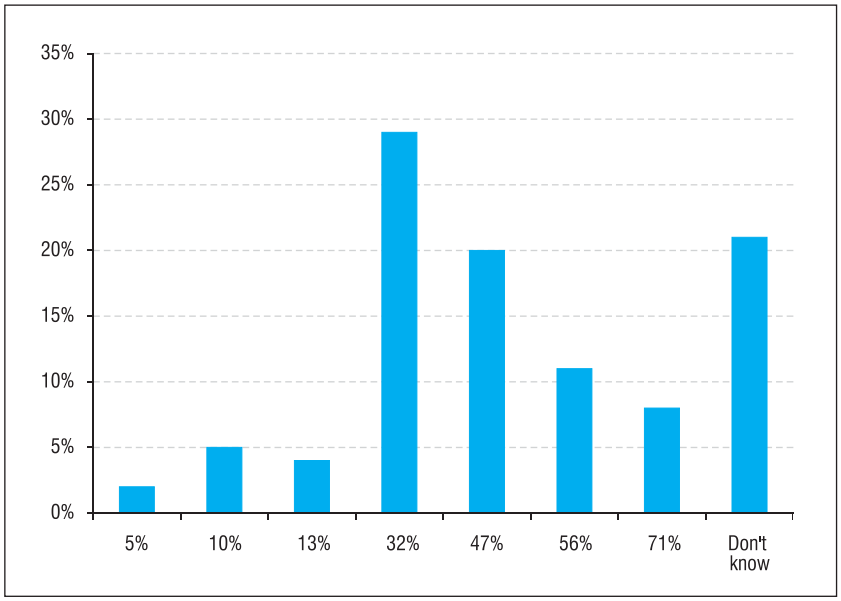

Figure 1. The distribution of percentages of indications among the pedagogical environment in the context of knowledge of cancer mortality in children

to identify correctly the meaning of the abbreviation — ALL. An interesting result, indicating the level of knowledge among the pedagogical environment, is the following graph illustrating the results of the answers to the question about the percentage of mortality from cancer among children.

The results shown in the figure above indicate that the knowledge concerning actual percentages is not significant. (Needs to say what the real figures are to compare) Most of the respondents locate the mortality rate of children affected by malignant cancer diseases in the top percentage ranges between 32% and 71%. Such perception of the disease substantially distorts its true image generating a lot of misunderstandings and negative consequences of education. The most important result from the point of the analyzed issue are the indications of the teachers concerning the evaluation of the pupils (students) included in the figure below. Besides this, it should be indicated that more than 80% of all surveyed teachers stated that they would not give a negative grade to a pupil (student), knowing that he/she has cancer. (This is very significant)

The above figure shows that for the majority of the faculty, regardless of the level of education whether it was an elementary or higher education school, the pupil's cancer constitutes a major determinant in assessing a child's knowledge during tests or answering. Teachers themselves in interviews and conversations suggest that this is unfair, but when dealing with a child that is ill they do not know how to be objective. An interesting result may be the fact that the surveyed lecturers of science, especially physics, constitute an exception. Among this group of academic teachers, only 29% indicated that a student's grade may be affected by their disease.

Research on the perception of cancer in children and adolescents [17] showed unequivocally that the young patients experience full-dimensional total suffering, not concentrating solely and primarily on the physical pain [17–20]. The figure presented below shows this problem, indicating unequivocally that the problem of physical pain does not constitute the most important element of the traumas experienced during hospitalization due to children's anti-cancer treatment.

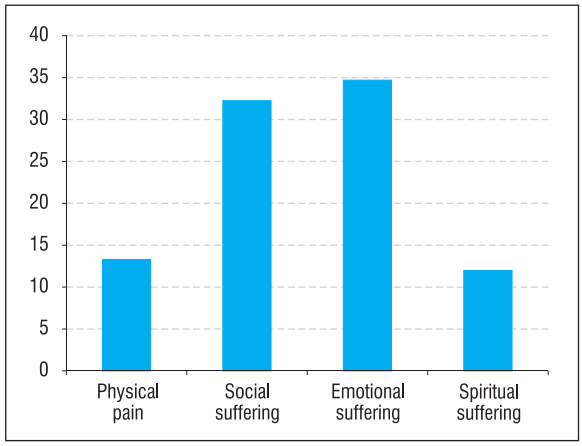

Figure 3. The distribution of average percentages of indications in the context of the experienced total suffering by the patient [17]

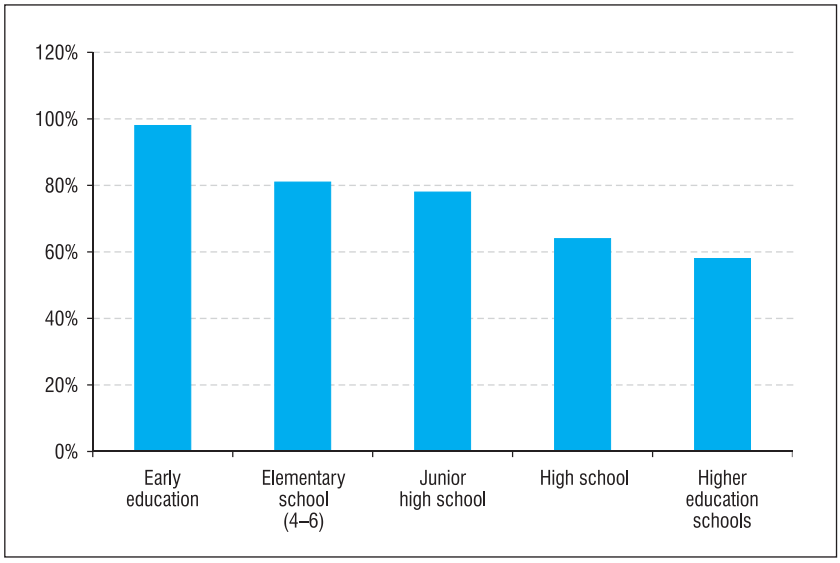

Figure 2. The distribution of percentages of indications among the pedagogical environment in giving a negative grade

According to our indications, physical pain and the issue of spiritual suffering rarely constitute a significant thread within the experienced traumas. Social suffering and emotional suffering, on the other hand, constitute, according to the respondents, the greatest problem in the course of anti-cancer treatment in the hospital.

Among the indications of social suffering, the most important issue turned out to be the social aspect manifesting itself primarily in terms of fear of the future [21]. *I fear what will happen when I leave the hospital* (13-year-old Michalina), *because all my friends from my school go to classes and I'm here and study too little* (7-year-old Iga), *because I do not go to my school like all my friends* (7-year-old Paweł), *in my school I went to classes and studied, and now certainly in my school everyone knows more than I do* (Maja 7-years-old) [21]. An important element that should also be given attention here is the issue of experiencing loneliness and otherness. *I feel lonely here, not the kind of loneliness that no one is here, but the internal kind, I feel lonely inside, abandoned. Sometimes even as mother and uncle come, I feel the loneliness even more. It is the loneliness of mine, which is here. Krzysiu, with whom I am lying here, when his mother isn't here he cries, he is sad, but when she comes he is happy, he forgets about his loneliness. I cannot, this loneliness is different* (Mariusz 16-year-old), *"I feel so lonely, lonely not physically, but spiritually abandoned, I feel that the cancer that is in me eats not only my body, but also the soul. I feel extremely LONELY, LONELY, so very, very ALONE* (Klaudia 15-years-old), *this loneliness fills me so internally, I deeply feel this sadness, with my entire self* (16-year-old Krzysztof), *my sorrow is the emptiness of my soul, it is the experience of emptiness inside of me* (17-year-old Patrycja) [22]. (It is interesting the language used here by older children. Their cognitive functioning demonstrates an ability to think more "spiritually" — the concept of the deeper loneliness, the soul. Is their anguish more real than in younger children, or are they just better able to articulate it. I would suggest the latter)

Emotional suffering is, first of all, an issue of fear of experiencing pain and suffering in the future [23]. This time also, may the children's statements on this subject be the best indicator of the problem. *I am afraid of what will be, that I will always be sick* (14-year-old Ewa), *Now I do not have such pain but I do not believe that it will always be like this, it will definitely still hurt* (9-year-old Piotr), *If someone once experienced such pain like me, it will always accompany him. It will always be standing and lurking around the corner, and I will always feel its breath behind me. I'm afraid, afraid of living with its breath, I AM TERRIFIED* (16-year-old Krzysztof). Krzysztof's statement probably quite clearly portrays the essence of the presented issue.

Issues presented above represent only a relatively small segment of the experiences of suffering by hospitalized children, but it clearly shows their way of experiencing hospitalization and themselves, and what in the analyzed problem is important, the way of looking at the future. *I do not know how it will be like when I leave this place, I do not know if I'll be fine. The disease has changed me, I do not know if I will be able live a normal life, I do not know if I will meet all the requirements* (Grzegorz 17-year-old), *when I get back from the hospital, I do not know whether it will be the same, I do not know if they'll look at me like before* (Marta 13-years-old), *the hospital has changed me completely, not only physically, but also from the inside. I do not know if they will accept it. I do not know that if when I go back to school they will be able to accept that I am different than before* (Grzegorz 16-years-old), *when I come back everyone looks at me like a freak. Women who come to the house for the lessons, also often do not know how to behave and that kind of stuff. This is not good, I do not know if it will ever be different. I do not know whether it will allow me to function normally* (Marcin 15-years-old), *because then they are all such different, I don't like this, because then it cannot be so normal* (Ania 9-years-old), *I'm no longer like before, I do not know how it will be like, I'm afraid that I will not know how to handle it all* (Iza 16-years-old) [24]. (These older children become more aware of the fact that life can never be the same again — something we are very aware of from our work with adults).

In the above context, a further fundamental question arises: How to live with it? What coping strategies do patients adopt? It is difficult to unequivocally answer this question. What we can say with absolute certainty is that there is no universal answer. Personal experience and studies show, however, that a certain group (difficult to estimate in percentages) is characterized by the syndrome of the constantly sick child. Looking for explanations in the scientific literature of those adopting this way of functioning, we can rely on the fairly well analyzed issue of learned helplessness.

Nowakowska [20], analyzing Saligman's concepts, indicates that experiencing failure can cause a specific, pessimistic style of thinking and explaining events. She notices that we are dealing with the at-

tribution of a permanent character, manifesting itself in low self-esteem: *I'm good for nothing*. Skibińska [25] however, while delving into the theories of Saligman notes that the uncontrolled situation can evoke in a human a belief about the meaninglessness of taking actions, because he sees no connection between his conduct and the consequences that it brings. This causes a reduction in the motivation to act or the omission of new activities. Repeating Nowakowska's considerations, we can say that this situation causes a *generalized expectation of lack of control and influence on the course of events in the future, which in turn is a precondition for the emergence of negative consequences, called helplessness deficits. We distinguish three types of deficits that have a direct impact on human functioning. Cognitive deficit is the conviction by an individual that an action taken by him/her in order to achieve a desired result will be inefficient, even in a situation in which it could be effective. Motivational deficit is a decrease in the tendency to initiate new activities, and emotional deficit is characterized by aggravation of mood, depression, dejection, anxiety*. In a wider social context, this problem was also taken up by Kawula [26, 27] as well as other researchers [28, 29], noting that many situations in which a person has no control, may cause the problem of learned helplessness. It is important here, however, as the creator of the discussed Saligman's [30, 31] concept notices, that such persons adopt specific forms of responding to reality and the requirements imposed by it. They focus primarily on the avoidance of tasks and responsibilities by often adopting the pose of a helpless victim. They are addicted to outside help, often exhibit a sense of injustice, thereby aiming at the unconscious manipulation of others in order to avoid action and accountability. This problem, although not yet accurately described in the literature, is sometimes perceived in the context of the functioning of people with disabilities, which also is connected to the issue of pretentiousness [32, 33].

The presented works, which do not directly refer to children's cancer (although this problem begins to appear in psycho-oncology) [34], show clearly the direction of the search for the reasons for the materialization of the syndrome of a constantly sick child.

The previously invoked concept of Saligman translated into the situation of a child with cancer shows that the analyzed image leads to a kind of helplessness. This problem is pointed out by the patients themselves, as seen in the quoted statements. However, striking is a different fact which imposes on the experienced helplessness. The survey conducted among pedagogues and students of pedagogy research (unpublished research on the perception of cancer (neoplastic disease) in the pedagogical-educational environment) have shown, on one hand, a complete ignorance of the problems faced by young patients, and on the other hand, an absolute helplessness against them, pedagogues and future pedagogues. It turned out that over 85% of respondents would not be able to objectively evaluate the child's knowledge, knowing that he/she suffers from cancer. (This is very significant) Personal experience in dealing with these children shows that some of them are thoroughly aware of the teachers' helplessness towards their situation and state. It will be best illustrated by a statement by 12-year-old Kamil: *If I did not know something nor do I want to learn then I do such a face that the teacher will always give in. She will definitely not give an F to a bald kid, no way!!!* If this statement can be considered in the context of cunning and expediency then the words of 12-year-old Magda have to be deeply worrying: *I have cancer, don't I? The teacher has to understand that whether she likes it or not. She cannot give me an "unsatisfactory" grade because I'm sick.* Probably every therapist working with "oncology children" can cite many of these kind of statements, and probably in all of them they awake fear for their future. Teachers themselves recognize this problem, with which, however, as they say, they do not know how to deal with. *I know I'm inconsistent with Adam, I'm unfair to him and other pupils, but I cannot give him an F. He deserves it because he does nothing, he is a slacker and blames everything on the illness. I know that I hurt him, but I just cannot* (a teacher with 25 years of experience). *I remember I once had such a pupil, he was lazy, but when I remembered how he came to school with a handkerchief on his head then ... no, I could not leave him to repeat the class* (teacher with 18 years of experience). *I know that I hurt Dorota by succumbing to her. I know that she manipulated me, I should evaluate her and not the disease. I know all this, but .... I think that today I would be no wiser, I probably would not be able to be objective* (a teacher with 11 years of experience). This issue also has its bearing on family situations, parent–child relationships. *Krzysiu, since he returned from the hospital, is very pretentious. He believes he deserves everything, he wants to have everything. When I don't give him something he immediately says that he prefers to be in the hospital, because there I agreed to everything* (mother of 9-year-old Krzyś). *I do not know how I should proceed, I should*

just give him a decent ass-whooping, but whenever I get angry at him I feel guilty because he suffered so much already. The worst part is that he badly takes advantage of this (father of 14-year-old Marcin). *Iza is a golden child, but since the disease our relations have really, really changed. I cannot refuse her anything and she knows it. It saddens me that it is a game. How many times has she hurt me by saying that the hospital was better, that in the hospital when she wanted something I did not refuse her that ..., it hurts me, and I cannot refuse her anything* (mother of 13-year-old Iza). Already these statements show the problem of disturbed family relations. In all of these statements, also evident is the fact of the adoption of children of pretentiousness attitudes and the use of situations. Saligman's early studies already pointed to the danger of maintaining the behaviours, described by him, and transferring them to the bigger areas. May the most recent example be the words of Magda, a girlfriend of 17-year-old Łukasz ailing for several years with cancer. *I do not know what to do. I love Łukasz, but I do not agree on what He wants. He demands from me that I go to bed with him. He said that he has cancer and that he may have no more opportunities in life. You know what's going on, he said that he might die at any moment... I'm afraid, I do not know what to do. I do not want to hurt Him, but I do not want this yet, but I also do not know how to tell him, as He is so sick... ."*

Conclusions

I think the situation described above in a rather dramatic way shows the problem. Often, it starts with forcing the small things, submissiveness to parents already on the ward, *My mom has never yet refused to buy me a toy when I'm lying here* (8-year-old Patryk), then moves to a more complex issue of "settling" the goodwill of teachers towards more or less justified backlogs in knowledge, *It always works, even in Nutria when I remind her that I have cancer, always. None of them had yet given me an F* (16-year-old Kuba), then it's time for "setting up" other issues. At some point, the majority of cases it "dealt with" in this way, *How can you deny something to someone who has experienced so much in childhood as I have. I have already suffered my share, I did not have chances for a lot of things, because I was sick, I was sick and that's it* (a fragment of an interview with currently 26-year-old Michał, at the ages from 9 to 16, many times hospitalized due to cancer). *Exactly the I was sick, and that's it* may constitute one of the main problems of the psychosocial development of children with chronic illness. In some of them, through the experienced traumas during the illness and a specific infirmity of the environment, it can lead to specific pretentiousness, where cancer, on one side, can justify almost anything, on the other hand, it can open the door, which leads to the fact that it really becomes a certain kind of value, a way of life. Let the words of a 32-year-old man suffering from cancer in childhood be the best summary: *The biggest problem for me was when I learned that I am healthy, that I'll live. Quite frankly I was 17 years old then and through all the years of the disease I have always had a great excuse for everything: I have cancer. Then, as I learned about the poor prognosis, I lived like on suitcases, I did care about anything. One day they told me that it was OK, there is a remission, I will live. O fu.... (Sorry) I broke down. I had to start living without an easy tariff. I had to start studying, pass the final exams and all, live without the disease. It was tough*.

Andrzej found support in his family, wise teachers, and friends.

Comments

The article raises some real issues about educating teachers and parents to continue to adopt normal rules and discipline to prevent these problems occurring. We always instruct parents of bereaved children to be sensitive to them, but follow the normal household rules and to maintain good discipline despite their sadness and difficulties. We have seen too often problems created by the effects of parents 'going soft' on their children because they feel sorry for them after a traumatic event. It leads to some of the problems outlined in this article such as behaviour difficulties and manipulation. I was very moved by the sense of the children recognising they will never be the same again and the lack of understanding of this by adults. I was also moved by the terrible loneliness experienced by these children. Ruth was hospitalised when she was 4 years old. She didn't realise what a traumatic impact it had had on her life until 3 years ago. I think it is a very interesting article. It may not tell us many new things, but it certainly reinforces powerfully the things we know and highlights the part educators can play in helping to prevent problems like this occurring. We have similar problems with the way educators deal with bereaved children. They frequently do not under-

stand their needs and this leads to loneliness. They also often experience peer isolation. Not being able to talk to anyone about their feelings often deepens the problem, especially if a parent is grieving and cannot listen to the needs of their child. I wonder if these sick children experience bullying in their peer settings or whether they use their sickness to deter bullies? It would be interesting to know.

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