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LEUKEMIA AND IMPACT ON THE DAILY LIFE OF A CHILD OF BIO - PSYCHO - SOCIAL TERMS

Białaczka i jej wpływ na życie codzienne dziecka w aspekciebio – psycho – społecznym

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A - Koncepcja i projekt badania, B - Gromadzenie i/lub zestawianie danych, C - Analiza i interpretacja danych, D - Napisanie artykułu, E - Krytyczne zrecenzowanie artykułu, F - Zatwierdzenie ostatecznej wersji artykułu

Abstract (in Polish):

Cel pracy

Celem pracy jest analiza i ocena poziomu funkcjonowania w zakresie sfery bio-psycho-społecznej dzieci chorych na białaczkę.

Materiał i metody

Za pomocą metody badawczej, jaką jest sondaż diagnostyczny, przy użyciu techniki ankietowania, z wykorzystaniem kwestionariusza ankiety własnego autorstwa badano jakość życia dzieci chorych na białaczkę. Procedura badawcza została przygotowana również na podstawie przeprowadzenia oryginalnej wersji kwestionariusza KIDSCREEN 27. Badanie przeprowadzono wśród 100 osób obojga płci - dziewcząt i chłopców. Badani to dzieci, które były pacjentami Szpitala Uniwersyteckiego im. A. Jurasza - Kliniki Pediatrii, Hematologii i Onkologii w Bydgoszczy.

Wyniki

Choroba to ciężki okres w życiu każdego człowieka. Dzieci w szczególnie ciężki sposób przeżywają każdą chorobę. Białaczka należy do chorób przewlekłych. Białaczka to najczęstsze schorzenie krwi u dzieci mimo, że nowotwory wśród dzieci występują bardzo rzadko. Proces leczenia jest długotrwały i wyczerpujący dla tak młodego człowieka. Wszystko to składa się na obniżenie jakości życia w sferze bio-psycho-społecznej dziecka. Białaczka w badanej grupie wpływa negatywnie na każdą ze sfer życia człowieka. Dochodzi do zaburzeń zdrowia fizycznego, psychicznego i relacji społecznych dziecka.

Wnioski

Jakość życia dziecka w czasie choroby jaką jest białaczka zmienia się na wielu płaszczyznach. Od czasu rozpoznania choroby zmienia się wiele aspektów dotyczących sfery bio-psycho-społecznej życia dziecka. Pogorszeniu ulega każde ze sfer życia dziecka chorego na białaczkę w większym lub mniejszym stopniu.

Abstract (in English):

Aim

The aim of the study is to analyze and evaluate the level of bio-psycho-social work in children suffering from leukemia.

Material and methods

The quality of life of children suffering from leukemia was examined with the use of the diagnostic survey method, with the use of self-authored questionnaires. The research procedure was also prepared on the basis of the original version of the KIDSCREEN 27 questionnaire. The research was conducted among 100 people. The respondents were children who were patients of the University Hospital. A.Jurasza - Department of Pediatrics', Hematology and Oncology in Bydgoszcz.

Results

Illness is a difficult period in everyone's life. Children experience any illness in a particularly difficult way. Leukemia is a chronic disease. The treatment process is long and exhausting for such a young person. All this contributes to a reduction in the quality of life in the child's bio-psycho-social sphere. With the help of the above-mentioned research tools, it has been shown that leukemia in the studied group has a negative impact on each of the spheres of human life. The child's physical and mental health and social relations are disturbed.

Conclusions

The quality of a child's life during the leukemia disease period changes on many levels. Since the diagnosis of the disease, many aspects of the child's bio-psycho-social life have changed. Each of the spheres of life of a child suffering from leukemia deteriorates to a greater or lesser extent.

Keywords (in Polish): białaczka, jakość życia, dziecko.

Keywords (in English): leukemia, quality of life, child.

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Short title

Białaczka i jej wpływ na życie codzienne dziecka

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Authors (short)

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Admission

Cancer is a fairly common disease among the human population nowadays. Leukemia is the most common blood disease in children even though cancers among children are very rare. Huge progress in treatment has not changed the fact that cancer is the first cause of death before the age of 15. Approximately 1,200 to 1,300 new cases are reported each year in Poland. The average morbidity of children from malignant tumors is approximately14/100 thou. Approximately 80% of all leukemias are lymphoblastic leukemias [Carroll, 2008; Grenda et al., 2013].

The characteristic feature is an abnormality in the processes of cell proliferation, maturation, and differentiation, which originate from the multipotent hematopoietic cell of the bone marrow. The development of the disease is associated with changes in hematopoietic progenitor cell genes associated with T and B cell lineage differentiation [Grenda et al., 2013]. The child's medical history is not long, being approximately 2-6 weeks before diagnosis. The most common problems reported by the child include general symptoms: stomach pain, extremity pain, enlargement of peripheral lymph nodes, and signs of thrombocytopenic diathesis [Grenda et al., 2013].

The diagnosis of lymphoblastic leukemia, like any other disease, begins with an interview with the patient. Extending the diagnosis is a complete blood cell count with differential. This examination shows the number of different types of blood cells. A diagnostic test that strictly confirms the disease is a biopsy [Hadaś, 2020].

In oncological treatment, psychological treatment is an important element. During the first stage, which is the diagnosis, parents as well as the child experience emotions such as fear, anxiety, and anger. The period of waiting for the diagnosis is a very difficult time for both the young patient and the parents. The conversation about the disease and treatment should be held before the child's stay in the hospital to minimise the child's feelings of anxiety and fear of being on the ward [Hadaś, 2020; Jeziorski, 2015; Kaufmann, 2012].

A child struggles with a change of environment and surroundings during a disease that is leukemia. Staying in a hospital is a completely new situation, not fully understood by a young child. For both the child and the adolescent, limiting contact with peers is a traumatic experience. Children who constantly feel negative emotions about themselves and their disease perceive their future with uncertainty and disbelief in their recovery. This situation shows that they lack the motivation to fight their illness. Children with the disease have a particular need for closeness to their parents. Membership in support groups for children coping with leukemia or other cancer helps them to understand their disease and their situation. Such support groups make children feel that they are not alone in this disease and that they are not the only ones struggling with such difficulties at such a young age [Hadaś, 2020; Johansson, 2009].

Aim

The aim of this study is to analyse and assess the level of bio-psycho-social functioning of children with leukemia.

Material and methods

The study was conducted among 100 children aged 8 to 18 years. The respondents were patients of the A. Jurasz University Hospital - Department of Paediatrics, Haematology, and Oncology in Bydgoszcz. For the study, consent was obtained from the Bioethics Committee, Resolution No. - INoZ.003.16.2020. The study used the following tools: self-authored questionnaires for children, KIDSCREEN- 52.

The largest number of respondents was found in the age range of 8-12 years they represent 65% of the respondents. The 16-18 age group was 20% of the respondents and 15% - 15 were in the 13-15 age group. Boys are by far the more numerous group with 60% of the respondents being 60 boys. Among the children surveyed, the majority are children living in the countryside i.e. 60%.

To check the relationship between quantitative variables which value distributions did not follow a normal distribution, Spearman's correlations were performed, and p<0.05 was taken as statistically significant.

Results

Among the children surveyed, the majority attend primary school (80%). Among the surveyed group, most children (45%) have been ill with leukemia for less than six months, 35% of the group have been ill for more than a year and 20% of the children have been ill for a year. The results show that in the surveyed group most children are in the treatment period - 65% the rest are in remission.

Of the children in the group, 75% have siblings and say that their contact with their siblings is good. The study showed a lack of opportunity for children with leukemia to spend sufficient time with their siblings - 78.57%. Seeing other family members is an issue that divided the surveyed group in half - 50% do not see other family members. The majority of respondents - 65% talk about a change in relationships with peers. The survey indicates a lack of opportunities to spend time with friends (65%) when the child wants to. Children surveyed mostly did not participate in activities at school- 55% of respondents. The survey found that children with the disease often experience anxiety - 60%. This is related to their constant fear for their life and health, only half of the children surveyed talk to their parents about their fears. The other half, on the other hand, do not talk to their parents about their worries which may make them feel more or more often anxious. Frequent feelings of fatigue accompany half of the respondents. Concentration problems among children with leukemia 55%. The survey showed that most children struggle with sleep problems. Such respondents represent 60%. Frequent physical pain is a problem for half of the children experiencing physical pain also reported that the pain does not enable them to function in everyday life. This group represents 57.14%, and the group describing pain as constant represents 37.5%.



Fig. 1. List of pain levels on a scale of 0-10).

The average score for pain levels is 3.95.





Through surveys, quality of life before the disease was shown to be high. The average is 9.80.





Surveys show a decrease in quality of life after diagnosis. The average is 4.60.





The largest number of children i. e. 40% described their health as 'so-so'.



Fig. 5. Distribution of the results on determining your well-being and physical activity.



Distribution of the results shows that most people described their well-being as average 35%.



The surveys showed that the largest number of respondents had been a little or medium active in the last week - 30%.



Fig. 7. Distribution of responses to running ability in the last week.

The surveys showed that most children questioned 40% when asked if they had been able to run in the last week answered 'a little'.



Fig. 8. List of answers about being full of energy.

Thinking back to last week, 45% of respondents were rarely full of energy.



Fig. 9. List of answers about feeling full of joy in life in the last week.

The surveys show that the most frequently chosen answer regarding feeling full of joy in life is a little - 40% of respondents.







In the past week, only 20% of respondents felt good mood very often.



The surveys show that most respondents 70% rarely felt good fun.



Fig. 12. List of feeling sad.

The surveys showed that the largest number of people i. e. 45% felt sadness rarely in the last week.





40 30 70 70 70

30 00%

dość często

The surveys showed that most respondents quite often feel lonely - 50% .

35,03%

rzadko



10,00%

zawsze

25 00%

bardzo często

The surveys showed that 35% of respondents rarely felt satisfied with the way they were.



Fig. 15. A list of how often you have enough time for yourself.

The surveys show that most respondents, 45%, feel they have enough time for themselves.



Fig. 16. A list of how often you could do what you wanted in your spare time.

The surveys show a wide variation among the respondents in terms of how often they could do what they wanted in their spare time. Among the respondents there are 30% - 30 people who could very often do what they wanted to do.



Fig. 17. Check how often your parents had enough time for you.

The surveys show quite often that parents spend enough time with their child among 45%.



Fig. 18. Check how often did you spend time with your friends?

The surveys show that the majority i. e. 40% of those surveyed have never spent time with their peers.



Fig. 19. List of how often you and your colleagues helped each other.

The surveys showed 30% rarely helped each other with their colleagues.



Fig. 20. List of how often you could rely on your friends.

The research shows that most often respondents described the frequency of reliance on their colleagues as rare or very frequent.



Fig. 21. A list of whether you were satisfied will be at school.

Respondents mostly 35% answered very in terms of how satisfied they were with being at school. KIDSCREEN-27 statistical analysis.

Report						
Gender		KIDSCREEN - physical health	KIDSCREEN - mental well- being	KIDSCREEN - independence and relationship with parents	KIDSCREEN - social support and colleagues	KIDSCREEN - school environment
	Average	2,8000	3,0357	3,6250	2,9062	3,4063
	Ν	40	40	40	40	40
Girl	Standard deviation	0,61603	0,43853	0,84711	1,17354	0,63217
	Median	2,9000	3,1429	3,4167	3,3750	3,6250
	Minimum	1,60	2,43	2,33	1,00	2,00
	Maximum	3,60	3,57	5,00	4,00	4,00
	Average	2,5500	2,7024	3,4306	2,2500	2,5833
	N	60	60	60	60	60
Boy	Standard deviation	0,53441	0,47584	0,26090	1,15072	0,70810
	Median	2,5000	2,7143	3,5000	2,0000	2,5000
	Minimum	1,80	1,71	3,00	1,00	1,75
	Maximum	3,60	3,43	4,00	4,25	3,75
	Average	2,6500	2,8357	3,5083	2,5125	2,9125
	N	100	100	100	100	100
Total	Standard deviation	0,57866	0,48747	0,57656	1,19837	0,78767
	Median	2,7000	2,7143	3,5000	2,0000	2,8750
	Minimum	1,60	1,71	2,33	1,00	1,75
	Maximum	3,60	3,57	5,00	4,25	4,00

Table 1. Descriptive statistics for the individual subscales of the KIDSCREEN questionnaire, taking into account gender.

Table 2. Mann-Whitney test

Tested value						
	KIDSCREEN - physical health	KIDSCREEN - mental well- being	KIDSCREEN - independence and relationship with parents	KIDSCREEN - social support and colleagues	KIDSCREEN - school environment /	
U Manna-Whitneya	887,500	725,000	1125,000	912,500	487,500	
W Wilcoxona	2717,500	2555,000	2955,000	2742,500	2317,500	
Z	-2,219	-3,373	-0,535	-2,055	-5,059	
р	0,026	0,001	0,593	0,040	<0,001	

Statistically significant differences (p=0.026) were found between genders on the KIDSCREEN physical health subscale. Girls showed a higher self-assessment of physical health than boys. Statistically significant differences (p=0.001) were found between genders for the KIDSCREEN subscale of mental well-being. Girls showed a higher self-assessment of mental well-being than boys. There were no statistically

significant differences (p=0.593) between genders on the KIDSCREEN subscale independence and relationship with parents. Gender did not differentiate the score obtained on this subscale. Statistically significant differences (p=0.04) were found between genders on the KIDSCREEN subscale social support and colleagues. Girls scored higher on this subscale than boys. There were statistically significant differences (p<0.001) between genders on the KIDSCREEN subscale school environment. Girls scored higher on this subscale than boys.

Table 3. Spearman's correlation between the variables: age and KIDSCREEN - physical health

Correlations						
			Age	KIDSCREEN - physical health		
Spearman's rank correlation coefficient	Age	Correlation coefficient	1,000	0,634		
		р	•	<0,001		
		Ν	100	100		
	KIDSCREEN - physical health	Correlation coefficient	0,634	1,000		
		р	<0,001	•		
		N	100	100		

Table 4. Spearman's correlation between the variables: age and KIDSCREEN - mental well-being

Correlations						
			Age	KIDSCREEN - mental well-being		
Spearman's rank correlation coefficient	Age	Correlation coefficient	1,000	0,749		
		р	•	<0,001		
		Ν	100	100		
	KIDSCREEN - mental well-being	Correlation coefficient	0,749	1,000		
		р	<0,001	•		
		N	100	100		

 $There \, was a \, statistically \, significant \, (p < 0.001) \, positive \, correlation \, between \, the \, variables. \, KIDSCREEN \, subscale \, physical \, health \, score \, increases \, with \, age.$

There was a statistically significant (p<0.001) positive correlation between variables. The score of the KIDSCREEN subscale - mental well-being increases with age.

Correlations					
			Age	KIDSCREEN - independence and relationship with parents	
Spearman's rank correlation coefficient	Age	Correlation coefficient	1,000	0,295	
		р	•	0,003	
		Ν	100	100	
	KIDSCREEN - independence and relationship with parents	Correlation coefficient	0,295	1,000	
		р	0,003	•	
		N	100	100	

Table 5. Spearman's correlation between the variables: age and KIDSCREEN- independence and relationship with parents

There was a statistically significant (p=0.003) positive correlation between the variables. The KIDSCREEN subscale score of independence and relationship with parents increases with age.

social support and concegues						
Correlations						
			Age	KIDSCREEN - social support and colleagues		
Spearman's rank correlation coefficient	Age	Correlation coefficient	1,000	0,809		
		р	•	<0,001		
		Ν	100	100		
	KIDSCREEN - social support and colleagues	Correlation coefficient	0,809	1,000		
		р	<0,001			
		N	100	100		

Table 6. Spearman's correlation between the variables: age and KIDSCREEN- social support and colleagues

There was a statistically significant (p<0.001) positive correlation between the variables. The score for the KIDSCREEN subscale - social support and colleagues - increases with age.

Correlations					
			Age	KIDSCREEN - school environment	
Spearman's rank correlation coefficient	Age	Correlation coefficient	1,000	0,663	
		р	•	<0,001	
		N	100	100	
	KIDSCREEN - school environment	Correlation coefficient	0,663	1,000	
		р	<0,001	•	
		N	100	100	

Table 7. Spearman's correlation between the variables: age and KIDSCREEN - school environment

There was a statistically significant (p<0.001) positive correlation between the variables. The score obtained for the KIDSCREEN subscale - school environment - increases with age.

Table 8. Spearman's correlation between the variables: disease duration and KIDSCREEN - physical health

Correlations						
			Since when have you had leukemia?	KIDSCREEN - physical health		
Spearman's rank correlation coefficient	Since when have you had leukemia?	Correlation coefficient	1,000	0,379		
		р	•	<0,001		
		Ν	100	100		
	KIDSCREEN - physical health	Correlation coefficient	0,379	1,000		
		р	<0,001	•		
		Ν	100	100		

There was a statistically significant (p<0.001) positive correlation between the variables. The KIDSCREEN physical health subscale score increased with duration of disease.

Correlations						
			Since when have you had leukemia?	KIDSCREEN mental well-being		
Spearman's rank correlation coefficient	Since when have you had leukemia?	Correlation coefficient	1,000	0,253		
		р	•	0,011		
		Ν	100	100		
	KIDSCREEN mental well-being	Correlation coefficient	0,253	1,000		
		р	0,011	•		
		N	100	100		

Table 9. Spearman's correlation between the variables: disease duration and KIDSCREEN -- mental well-being

There was a statistically significant (p=0.011) positive correlation between the variables. The scores of the KIDSCREEN subscale - psychological well-being - increased with the duration of the disease.

Correlations					
			Since when have you had leukemia?	KIDSCREEN- school environment	
Spearman's rank correlation coefficient	Since when have you had leukemia?	Correlation coefficient	1,000	0,462	
		р	•	<0,001	
		Ν	100	100	
	KIDSCREEN- school environment	Correlation coefficient	0,462	1,000	
		р	<0,001	•	
		Ν	100	100	

Table 10. Spearman's correlation between the variables: disease duration and KIDSCREEN- school environment

There was a statistically significant (p<0.001) positive correlation between the variables. The KIDSCREEN subscale score - school environment - increased with the duration of the disease.

Discussion

A child is a vulnerable and helpless being in the adversity they may encounter. The difficulty they will encounter may be illness. Leukemia is a disease that burdens not only the physical health but also the mental and emotional health of the child. During a child's diagnosis and treatment, their whole life changes. Key elements of their sense of security are disrupted. Parents help their child through the most difficult times, but this is not always enough, as they cannot always give their child the attention they would like.

This paper considers the negative impact of leukemia on a child's biological life. Leukemia is a disease that burdens the entire human body. Children are by nature very mobile, they like to run, and ride a bike, unfortunately, the disease takes away this opportunity by making them feel weak, feel pain, and lack the strength to move. Treatment is very taxing on the body. This is linked to children often feeling tired and in pain. This sensation is completely new and foreign to them. The pain makes it difficult to function in everyday life, something they have never experienced before. The lack of physical fitness also affects other spheres of a person's life, e.g.: emotional and social spheres.

The work of Szkudlarek et al. concerns fitness deficits in children after childhood cancer. An early developmental physicality programme is proposed. Fitness classes are proposed that should counteract the low fitness levels of children after cancer[Szkudlarek et al. 2014].

The results of our study show in 57.14% of cases children had difficulties in functioning in daily life due to the disease. Fatigue and feelings of physical pain were reported in half of the respondents. Continuous pain was experienced by 37%. Results from the KIDSCREEN-27 sheet on the overall health assessment show that 40% of the children felt "so-so". Only 15% of respondents were fully physically fit. Most children described their physical fitness as average (35%).

A child is a being still forming its character and emotional zone. Illness disrupts its functioning through fear for its health and life and a sense of dissatisfaction with who it is at any given time. Children enduring illness primarily struggle with fear. Fear for their lives accompanies them every day, this causes a decrease in their sense of joy and good mood. Children stop enjoying the things that used to make them smile. The change in appearance during the illness translates into a lack of self-acceptance and reduced satisfaction with who they are. Reduced contact with other children and less time for oneself induces feelings of sadness. Feelings of loneliness and sadness are quite common among young patients in Oncology departments. The child's psyche changes and sets them up for constant fear for their health and life. Loneliness and lack of contact with peers can cause feelings of rejection and exclusion from the group. Children may become withdrawn and less and less involved in life, e.g. at school. Problems of daily life also impinge on sleep disturbances among children with leukemia. Sleep problems are associated with feelings of pain and all worries about life, as well as exclusion from the group among peers. The older the child is, the better it is for them to understand the situations present in their life. Mess findings suggest that the intensity of anxiety as a trait and other negative emotions is linked to the number of complications after treatment. Numerous somatic complaints favour the expression of negative emotions and also increase anxiety in children. Nowak reports on the findings of the study, based on an analysis of drawings of young patients. The drawings show anxiety and concern about the situation in young patients. The drawings show the emotions of anxiety and sadness accompanying children in illness [Hadaś, 2020; Malinowska et al., 2017].

The results obtained in own research confirm the problem of the continuing impact of negative emotions related to the child's illness and treatment. This is confirmed by the fact that 50% of the children surveyed rarely experience a sense of well-being. Among the children surveyed, up to 70% rarely feel like having fun. A sense of loneliness is quite common for 50% of the children surveyed. When it comes to time for themselves, 45% of the children rarely have enough of it. Research on anxiety shows that 60% of those surveyed confirm it. Children talk to their parents about their fears in 50% of cases. Sleep problems are experienced by as many as 60% of all respondents.

The human social sphere is a fundamental part of a child's development during adolescence. Children have limited contact with their peers and even with family members especially during the period of treatment, i.e. during hospitalisation. Contact with siblings is very important, it is the closest environment right after parents. This contact is often limited to phone calls. Playing with siblings or peers is impossible due to hospitalisation, reduced immunity, and general weakness. Siblings, because of their young age, often do not fully understand what is going on and why their parents are so often not at home. Therefore, parents are often torn between a healthy child at home and a sick child in hospital. All these elements add up to a deterioration of social relationships, which are one of the foundations of human life. The contact that children also have limited is with grandparents, who alternately keep vigil at the sick child's bedside. Adults try to talk to and keep up the little patient's spirits. Nowak presents the illness as a problem that puts the parents between siblings, i.e. a healthy child and a sick child. Children can only understand the seriousness of the situation at the right age. Younger children may feel rejected and neglected by their parents in favour of their sick sibling [Malinowska et al. ,2017].

The results of the survey indicate a high limitation of spending time with siblings (78.57%). Regarding general contact with siblings, 57.14% have this contact, due to today's technology such as mobile phones and the Internet. Relationships with peers have changed for 65% of the respondents. Spending time with friends was impossible for 85% of the respondents. Attending school was impossible for 55% of the children surveyed. Relying on colleagues was only possible for 35% of the respondents.

Reference literature indicates a higher incidence of leukemia among boys. Children become ill most often at school age - primary school. The length of the illness does not affect changes in the previously discussed spheres of life. The duration of the illness does not affect the return to daily life from before the illness was diagnosed during remission. An illness is an undesirable event in a person's life, and certainly in the life of a child. The length of the illness, i.e. the duration of the social, emotional, and biological disturbances, does not affect the return to "normality" of everyday life after treatment. Lost contact with peers, and returning to school after a longer or shorter break is another challenge for such a young person. The older the child is, the better it is for him to understand the situations present in their life. Mess's findings also indicate that the duration of the course of the disease does not affect the level of anxiety as a trait, nor the expression of negative emotions in various social situations [Hadaś, 2020].

The results of the own research confirm the fact that boys are more frequently affected - 60%. As many as 80% of those surveyed are in primary school. The duration of the illness was examined in the period of less than one year, one year, and more than one year. Most respondents had been ill for less than a year with leukemia (45%). More than a year ill with leukemia was 35% among all children surveyed.

Conclusions

- Leukemia disrupts the child's normal physical functioning. The extent of the child's mobility. and the decrease in quality of health has a negative impact on the child's general well-being. The child is physically restricted due to experiencing frequent pain and deterioration in fitness. The lack of sports opportunities also results in a decrease in the child's sense of full enjoyment of life.
- 2. Leukemia negatively affects the child's emotional zone. This is caused by feelings of anxiety and pain and loneliness. The lack of time for oneself and the constant accompanying anxiety are not conducive to the child's well-being. Visual changes in the child's appearance result in a lack of acceptance and satisfaction with who they are.
- 3. The social sphere is disturbed by exclusion from various social groups e.g.: class. The change in daily life, which is based on being in hospital for examinations and treatment, makes the children feel a sense of exclusion from participating in school life and also partly in family life. Limited contact with siblings and peers negatively affects the formation of social bonds.
- 4. In the surveyed group, boys are more likely to be affected by leukemia than girls and children aged 8 to 12 years.

Recommendations for nursing practice

The care of a child with leukemia should take into account many aspects, such as the child's age, psycho-emotional development, family and peer relationships, the stage of the disease, and the treatment models used. Other aspects must also be taken into account when caring for a child in the early stages of the disease, or the terminal period. This makes it extremely challenging for the nurse and at the same time requires the ability to modify actions. Periodic analysis of the quality of life assessment of the child and their parents can be helpful.

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