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## What can cause oncological anxiety in parents?

### Co może budzić niepokój onkologiczny u rodziców?

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#### Abstract

Early diagnosis of cancer is essential for the choice of appropriate therapy, and thus the chance of recovery. Parents play a crucial role in detecting the first signs of cancer in their children. The aim of this study was to assess parental knowledge on the early signs of leukaemia and to increase their cancer vigilance. A survey was conducted among 327 parents of 3–10-year-olds in two Polish towns: Nowa Sól and Nowe Miasteczko as well as on the Internet. Parents were asked about their responses to potential signs of leukaemia. The obtained data were analysed, considering parental education and gender, child's health status and place of residence. A total of 98% of respondents were able to provide a correct definition of leukaemia. Enlarged lymph nodes, fever, cough, headache and vomiting are the most common reasons for medical appointments. Pale skin, fatigue and apathy were a group of symptoms that did not raise parental concern. Up to three-quarters of parents associated limb pain with the process of growing, and only 7% – with cancer. It was found that parents with at most secondary education reported to the doctor due to alarming symptoms more often than those with higher education. Women were more perceptive of suspicious symptoms than men. Parents of chronically ill children are more perceptive of extravasations, fever and bruises. Although leukaemia is not a taboo, its potential symptoms do not raise parental oncological vigilance. Women, parents of chronically ill children, parents without higher education and medical graduates show the highest vigilance in childcare. The presented data indicate the need for parental education on the first signs of cancer.

**Keywords:** cancer diagnosis, early signs, leukaemia, acute lymphoblastic leukaemia, parental cancer vigilance

#### Streszczenie

Wczesne rozpoznawanie nowotworów jest zadaniem istotnym, gdyż decyduje o wyborze właściwej terapii, a tym samym o szansie na wyleczenie. Kluczową rolę w wykrywaniu pierwszych symptomów nowotworów u dzieci odgrywają rodzice. Cele pracy obejmowały ocenę stanu wiedzy opiekunów dotyczącej rozpoznawania wczesnych objawów białaczki i wzmożenie ich czujności onkologicznej. Ankietę przeprowadzono wśród 327 rodziców dzieci w wieku od 3. do 10. roku życia w dwóch miastach: Nowej Soli i Nowym Miasteczku oraz za pośrednictwem internetu. Pytano o reakcje na wystąpienie potencjalnych objawów białaczki. Uzyskane wyniki poddano analizie w zależności od wykształcenia i płci rodziców, stanu zdrowia dziecka i miejsca jego zamieszkania. 98% ankietowanych poprawnie odpowiedziało na pytanie, czym jest białaczka. Objawy, które są najczęstszą przyczyną wizyt lekarskich, to: powiększone węzły chłonne, gorączka, kaszel, ból głowy i wymioty. Wyodrębniono grupę symptomów, które nie wzbudzały niepokoju opiekunów: bladłość skóry, zmęczenie oraz apatia. Aż trzy czwarte rodziców wiąże ból kończyn ze wzrastaniem dziecka, a zaledwie 7% ankietowanych – z chorobą nowotworową. Zaobserwowano, że opiekunowie z wykształceniem co najwyżej średnim zgłaszają się do lekarza z niepokojącymi objawami częściej niż osoby z wyższym wykształceniem. Kobiety wykazują większą spostrzegawczość w rozpoznawaniu podejrzanych symptomów niż mężczyźni. Opiekunowie dzieci chorujących przewlekłe są bardziej wyczuleni na wybroczyny, gorączkę i podbiegnięcia krwawe. Białaczka nie stanowi tematu tabu, jednak jej potencjalne objawy nie wzbudzą czujności onkologicznej rodziców. Kobiety, rodzice dzieci chorych przewlekłe, osoby bez wyższego wykształcenia i absolwenci kierunków medycznych wykazują największą czujność w opiece nad dziećmi. Przedstawione dane wskazują na konieczność edukacji rodziców na temat pierwszych objawów nowotworów.

**Słowa kluczowe:** diagnostyka nowotworów, wczesne objawy, białaczka, ostra białaczka limfoblastyczna, czujność onkologiczna rodziców

## INTRODUCTION

Cancer is the second leading cause of death in children up to 15 years old, following accidents and poisoning<sup>(1,2)</sup>. About 1,000–1,200 new cases are reported annually<sup>(2,3)</sup>. Leukaemias are the most common childhood cancers, lymphoblastic leukaemia accounting for 80% of cases in particular<sup>(4)</sup>. It is most common in children aged between 2 and 7 years<sup>(5)</sup>. Cure rates increase year by year and are currently estimated at 70–90%<sup>(1,6)</sup>. The time elapsed between the first symptoms and the diagnosis and treatment has a significant impact on prognosis<sup>(3,7)</sup>. The anamnesis of acute lymphoblastic leukaemia is short and it usually covers 2–6 weeks. It has non-specific symptoms and a very varied clinical picture. This may cause significant diagnostic difficulties and prolong the diagnosis<sup>(2,3,7)</sup>. The first symptoms of the disease (according to a decreasing incidence) include pale skin (99.5%); asthenia, apathy (85.5%), fever (70.3%), haemorrhagic lesions (36.4%), limb pain and lymphadenopathy (29.7%). Leukaemia may also manifest with more untypical symptoms, such as skin lesions or cranial nerve palsy. The aim of this study was to assess parental knowledge on the early signs of leukaemia and to increase their cancer vigilance.

## MATERIAL AND METHODS

A survey including 327 parents of 3–10-year-olds was conducted in two Polish towns: Nowa Sól and Nowe Miasteczko as well as on the Internet. Mean age of children was 6.3 years (median: 6 years). The parents were asked about their responses to the potential signs of leukaemia. The obtained data were analysed, considering parental education and gender, child's health status and place of residence (Tab. 1). Written consent to participate in the study was obtained from respondents. There were doctors, nurses and paramedics among study participants. The survey presented 14 symptoms in the form of short histories accompanied by questions about parental reactions. Increased body temperature of 37–38.5°C persisting for about 2 weeks was one of the symptoms described. The parents were asked to decide whether they would report the child to the doctor, worry about the child's condition, or take no action. The parents could also make their own suggestions in the questionnaire. Paleness of the skin was described in another example: "The mother of 4-year-old Zuzia has recently heard from several people that her daughter seemed pale although she had always had such a »ruddy complexion.«" Parents were also asked about their reactions to the presence of petechiae, which were described as tiny red spots, on their child's legs. Nose bleed and ecchymoses, commonly known as bruises, were another symptom of haemorrhagic diathesis described in the questionnaire. Parental vigilance for decreased child's activity, which could indicate increasing fatigue and apathy, was also assessed. We also evaluated parental reactions to the loss of appetite and reduced body weight in the child. We verified whether

Parental gender	Women	Men		
	291	36		
Place of residence	City	Town		
	98	229		
Education	Higher	Secondary at most		
	138	189		
		Primary	Vocational	Secondary
		14	57	118
	Non-medical	Medical		
	310	17		
		Clinical	Non-clinical	
		3	14	
Child's health status	Parents of ill children	Parents of healthy children		
	57	270		

Tab. 1. Groups of respondents

pain in the lower limbs raised parental concern and was the reason for visiting a specialist. Parental response to lymphadenopathy was also assessed. This symptom was illustrated with the following situation: "When dressing 3-year-old Kubuś, his mother noticed a small, bean-sized nodule located above the clavicle." Abdominal pain, a seemingly harmless symptom, was also analysed in the study. We also enquired about nonspecific symptoms, such as headache and vomiting. We verified whether a third recurrence of pharyngeal infection in the same month in a 4-year-old girl would be ignored by the parents. Persistent cough not responding to treatment was also included. We then asked parents about the suspected cause of the above described situations and assessed whether they could define "leukaemia."

## RESULTS

The questionnaire asked parents what leukaemia was. The available options included blood cancer, skin paleness and a heart disease. The correct answer was provided by 322/327 parents; 3 parents associated leukaemia with skin paleness, and 2 parents provided no answer to the question. The parents were asked to choose potential causes of lower limb pain in children in the questionnaire. The answers are summarised in Tab. 2. Up to three-quarters of parents, both mothers and fathers, associated limb pain with the process of growing. One in three parents pointed to mechanical trauma as the cause of the symptom. This answer was statistically significantly more common among city residents ( $p = 0.0018$ ). Changes in the weather were the third leading cause of pain in the lower limbs. This option was selected statistically significantly more often by the residents of towns vs. cities ( $p = 0.0196$ ). One in ten respondents pointed to cancer as the cause of limb pain in the child. This response was statistically significantly more common among parents with higher education ( $p = 0.0084$ ) and city residents ( $p = 0.0461$ ) compared to those with at most secondary education and town residents.

	Total group n = 327	Parental gender		City		Education			
		Women n = 291	Men n = 36	Large n = 98	Small n = 229	Higher n = 138	Secondary at most n = 189	Medical n = 17	Non-medical n = 310
Growth process	245	218	27	78	167	109	136	12	233
Mechanical trauma	114	97	17	47	67	54	60	5	109
Weather changes	56	48	8	9	47	20	36	5	51
Cancer	32	27	5	15	17	21	11	2	30

Tab. 2. Causes of limb pain in children – parental responses depending on their gender, place of residence and education

	Total group n = 327	Parental gender		City		Education			
		Women n = 291	Men n = 36	Large n = 98	Small n = 229	Higher n = 138	Secondary at most n = 189	Medical n = 17	Non-medical n = 310
Enlarged lymph nodes	311	280	31	93	218	129	182	16	295
Fever	306	274	32	96	210	129	177	15	291
Cough	303	271	32	90	213	125	178	14	289
Headaches and vomiting	303	271	32	90	213	125	178	15	288
Nosebleeds	287	255	32	80	207	113	174	15	272
Abdominal pain	277	246	31	87	190	116	161	13	264
Infection	273	246	27	82	191	110	163	13	260
Petechiae	262	235	27	68	194	97	165	12	250
Lack of appetite and weight loss	223	201	22	70	153	87	136	13	210

Tab. 3. Symptoms leading to medical consultations

Symptoms that are the most common reason for visiting the doctor are summarised in Tab. 3. Almost all parents pointed to enlarged lymph nodes in their child. This symptom was significantly more often indicated by women ( $p = 0.0249$ ). Fever was another reason for visiting the doctor. It was more common among women, city residents and respondents without medical education. Almost all parents (92.7%) find persistent cough, headache and vomiting in the child to be alarming signs. These symptoms were predominantly pointed out as the reasons for a specialist consultation by women, town residents and respondents without medical education. The group of parents who would decide for a medical appointment due to a nosebleed was dominated by town residents ( $p = 0.0423$ ) and parents with at most secondary education ( $p = 0.092$ ). More than three-quarters of respondents (80.1%) pointed to petechiae as the reason for a medical appointment. This symptom was statistically significantly more common among town residents ( $p = 0.0024$ ) and respondents with at most secondary education ( $p = 0.0002$ ).

Home remedies appear to be more commonly used for apathy, bruises, fatigue, pale skin, lack of appetite, weight loss and petechiae. The level of parental education had no significant influence on the decision to use one's own treatment methods. The most common methods used by respondents included changes in the child's diet and activities, rest, vitamin supplementation and ointments. The most surprising parental responses were reported for petechiae. One of the parents suggested that "it may be skin irritation caused by

wearing trousers made of some sort of fabric causing irritation." Other respondents eliminate symptoms of haemorrhagic diathesis with oily creams, Alantan, or calcium preparations. Fatigue also caused unusual reactions: "Perhaps it is not my son who is the problem; maybe his schoolmates have ADHD."

When comparing answers provided by parents with higher education and at most secondary education, we found that the latter ones were statistically significantly more likely to report to the doctor with alarming symptoms, such as petechiae ( $p = 0.0002$ ), bruises ( $p = 0.0022$ ) and nosebleeds ( $p = 0.0092$ ). It was only fatigue in the child that was of greater concern for parents with higher education ( $p = 0.042$ ) (Tab. 4).

Medical education (or its lack) was also considered when analysing parental responses. Respondents in the first group were more vigilant for the lack of appetite, weight loss and apathy in their children. Petechiae were an alarming symptom in the other group. In other cases, the respondents' answers were similar.

Furthermore, we compared responses to disease symptoms in the child between men and women. Women are more likely to report to the doctor with alarming symptoms. They spend significantly more time looking after children, as evidenced by their 89% participation in the questionnaire. Mothers are significantly more likely to report to the doctor due to enlarged lymph nodes ( $p = 0.0249$ ). Fathers are more likely to visit specialists only in the case of apathy, nosebleed and abdominal pain in their children.

	Education			
	Higher <i>n</i> = 138	Secondary at most <i>n</i> = 189		
		Secondary <i>n</i> = 118	Vocational <i>n</i> = 57	Primary <i>n</i> = 14
Weight loss	87	86	42	8
Petechiae	97	102	51	12
Nosebleed	113	111	50	13
Bruises	50	67	29	6
Infections	110	105	46	12
Pale skin	68	69	32	8
Fatigue	72	52	20	4

Tab. 4. The frequency of medical appointments depending on parental education

Parents of chronically ill children are more observant of petechiae, fever and bruises compared to those with potentially healthy children.

We also assessed parental reactions to the first symptoms of leukaemia considering the place of residence. Higher vigilance for fatigue in the child was observed among city residents ( $p = 0.0139$ ). Respondents with higher and non-medical education prevailed in this group. Petechiae were found to be an alarming symptom for parents living in towns ( $p = 0.0024$ ). In this group, such responses were statistically significantly more common among respondents with at most secondary education ( $p = 0.003$ ). The vast majority of parents did not have medical education. The questionnaire also asked parents to link the symptoms of leukaemia with specific diseases, the clinical picture of which could be composed of. The results are shown in Tab. 5. More than two-thirds of respondents pointed to pharyngeal infections as a disease corresponding to the symptoms listed. One in two parents opted for food allergy, which was chosen significantly more often by city residents ( $p = 0.0028$ ). Cancer was the third most common answer. City residents ( $p = 0.0028$ ), respondents with higher ( $p = 0.0129$ ) and medical ( $p = 0.036$ ) education statistically significantly more often opted for cancer. City residents ( $p = 0.0002$ ) and those with higher education ( $p = 0.0054$ ) significantly more frequently

pointed to a parasitic disease as an entity with a clinical picture consisting of the above mentioned symptoms. One in three parents linked the described symptoms with poisoning. This answer was more common in parents with medical education ( $p = 0.0366$ ). Pneumonia, which was suggested by city residents ( $p = 0.0056$ ) and parents with higher education ( $p = 0.0049$ ) was another mentioned entity. Almost one in four parents pointed to mechanical trauma. This answer was statistically significantly more common among respondents with higher education ( $p = 0.0118$ ). One in six respondents chose urinary tract infection, with a significant predominance of parents from cities ( $p = 0.0224$ ) and those with higher education ( $p = 0.0448$ ). Otitis was selected as the cause of the symptoms listed by the smallest percentage of parents.

## DISCUSSION

The literature contains numerous reports of rare cases of leukaemia and diagnostic guidelines for acute lymphoblastic leukaemia in children. However, only few papers are devoted to the initial symptoms of leukaemia, which are first noticed by the parents, and have a chance to be diagnosed by a general practitioner or a paediatrician only at a later stage. Therefore, we conducted a study to evaluate parental knowledge on the first signs of leukaemia to look through their eyes at the affected children before they attend specialists.

Clarke et al.<sup>(8)</sup> showed that the speed of diagnosis depends, among other things, on disease-related factors, such as the lack of specific symptoms that could indicate the disease, and the lack of early, alarming symptoms. The second group of (disease-unrelated) factors is divided into three subgroups: parental factors, doctor-related factors and factors related to the healthcare system. Parental response to the symptoms of leukaemia depends on the ability to accurately interpret the symptoms. The most common parental behaviours include a failure to link the symptoms with a serious disease (cancer) and associating these symptoms with "harmless" conditions instead. The symptoms of leukaemia mentioned by respondents included all

	Total group <i>n</i> = 327	Parental gender		City		Education			
		Women <i>n</i> = 291	Men <i>n</i> = 36	Large <i>n</i> = 98	Small <i>n</i> = 229	Higher <i>n</i> = 138	Secondary at most <i>n</i> = 189	Medical <i>n</i> = 17	Non-medical <i>n</i> = 310
Pharyngeal infection	222	195	27	70	152	101	121	11	211
Food allergy	154	135	19	59	95	74	80	9	145
Cancer	141	124	17	55	86	71	70	12	129
Parasitic disease	122	107	15	52	70	64	58	8	114
Poisoning	107	97	10	38	69	46	61	10	97
Pneumonia	106	90	16	43	63	57	49	6	100
Mechanical trauma	78	65	13	30	48	43	35	4	74
Urinary tract infection	52	42	10	23	29	29	23	4	48
Otitis	45	36	9	14	31	18	27	2	43

Tab. 5. Potential diseases the clinical picture of which includes symptoms asked in the questionnaire

those indicated by the authors in the questionnaire except for enlarged lymph nodes and headache. A change in the child's behaviour worried parents most. The respondents interpreted these symptoms as a result of their child's excessive activity, e.g. they linked limb pain with physical exercise or growing pains. Although most parents had little or no knowledge on leukaemia, they intuitively excluded the disease when the child's behaviour was normal and usual disease symptoms were present. Only persistent or exacerbated symptoms, such as fever or bruises, prompted parents to consult a doctor.

Woodgate et al.<sup>(9)</sup> described the way young patients and their parents perceived cancer symptoms. The authors emphasise that children and parents fail to report some of the symptoms as they consider them unimportant or non-specific for cancer. This should prompt doctors to ask more detailed questions. The authors underline the importance of seeking the meaning that patients and their families attribute to the symptoms of cancer due to the implications, including the assessment of the severity of the symptoms and further diagnostic and therapeutic management. They show how different the way of describing the symptoms of the same disease, but experienced by different children and their parents, is<sup>(9)</sup>. In the described study, fatigue and apathy in a child, as one of the first symptoms of leukaemia, indicate the need for close listening to the patient and their family as these symptoms may be easily overlooked or underestimated.

Papers describing the incidence of the first signs of cancer in a child are available in the literature. Bernbeck et al.<sup>(10)</sup> described "red flags" in the diagnosis of leukaemia in daily medical practice. A total of 96% of patients consulted at least one cancer symptom with a specialist; no symptoms occurred in others. Mucosal or skin bleeding, recurrent infections and fatigue are the most common symptoms leading to medical appointments. Weight loss and headache are rarely consulted with specialists. The study presented in this paper showed that enlarged lymph nodes, fever and cough were the most common symptoms reported by parents during medical appointments. Pale skin, fatigue and apathy, on the other hand, do not raise parental concern.

## CONCLUSIONS

Although leukaemia is not a taboo, its potential symptoms do not raise parental oncological vigilance. Women, parents of chronically ill children, parents without higher education and medical graduates show the highest vigilance in childcare. It is advisable to educate parents on the first signs of cancer.

### Conflict of interest

*The authors do not report any financial or personal connections with other persons or organisations, which might negatively affect the contents of this publication and/or claim authorship rights to this publication.*

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