

Common knowledge of leukemia among the youth and their attitude to the diagnosed disease

Połocka-Molińska M¹, Krauss H², Ignyś I², Osmólska A¹

¹ Bydgoszcz Medical University, Poland

² Poznań Medical University, Poland

Abstract

Purpose: The aim of the study is to evaluate common knowledge shared by leukemia patients aged 12-18 yrs and to determine their attitude to the diagnosed disease.

Material and method: The study group consisted 30 of youth aged 12-18 yrs with diagnosed leukemia, which expressed agreement on participation in investigation. The study employed an own questionnaire entitled: "Common Knowledge of Leukemia among Youth and Their Attitudes to the Diagnosed Disease".

Results: Results passed of investigations one surrendered to analysis and one introduced inform of diagrams. Talked over results of investigations summed up are discussion and conclusions. Discussion achieves results of own investigations to these passed by Binnbesela's and of relating current knowledge about new-coined word disease among young people from 12 to 18 year of life, contains also considerations relating situation in which one is found young people with recognized leukemia.

Conclusions: The level of knowledge about leukemia in 12-18-year-old patients is highest in 18-year-old respondents. There is no dependence between the time lapse from the moment of diagnosis and the increase of knowledge on the subject. The attitude of young leukemia patients to their own disease does not change with the time lapse from the moment of diagnosis.

Key words: leukemia, neoplastic, chemotherapy, radiotherapy.

ADDRESS FOR CORRESPONDENCE:

dr n. med. Hanna Krauss
Katedra i Zakład Fizjologii AM w Poznaniu
ul. Świecickiego 6, 61-781 Poznań,
e-mail: hjk12@poczta.fm

Introduction

Leukemias are the most frequent neoplastic diseases that occur in children and youth. According to the literature on the subject, they constitute 30-35% of all neoplastic cases in the age group 0-19 yrs [1]. It is generally known that people are not really interested in problems that do not concern them. However, when the disease occurs among their closest family members, they look for information on the subject. Common knowledge about neoplasms is usually limited to unverified facts, overheard relations and strongly negative emotions connected with the conviction that every cancer-stricken person must die [2,3]. Hence, we can conclude that the Polish society has got little knowledge of neoplastic diseases. Basing on this knowledge, they create their own attitude to the disease and pass it on to other people. It is particularly important for children and youth who, having already got minimum knowledge of human body functions, use it to account for the causes and effects of the disease.

The diagnosis of the disease scares a young person and makes him or her think about its causes and effects, and finally about the end of life. Young patients often actively participate in treatment, want to control the situation and try to get as much information as possible to be able to cope with the treatment effects. They also expect support and understanding from both, the medical staff and their parents.

Aim of the study The aim of the study is to evaluate common knowledge shared by leukemia patients aged 12-18 yrs and to determine their attitude to the diagnosed disease.

It was assumed that the following questions would be answered by our respondents:

1. Does the lapse of time from the disease diagnosis influence the amount of knowledge about the very disease?
2. Do the age and place of living of a patient increase the interest in the disease?
3. Does the attitude of a leukemia patient change with the time that has passed since the diagnosis?

Figure 1. Age of a child at the time of diagnosis

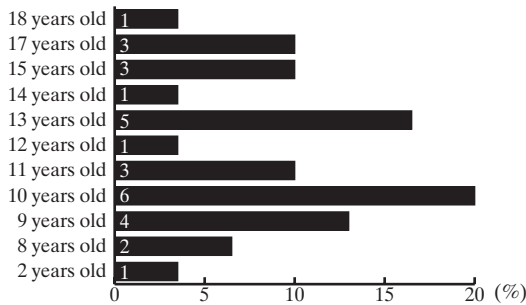
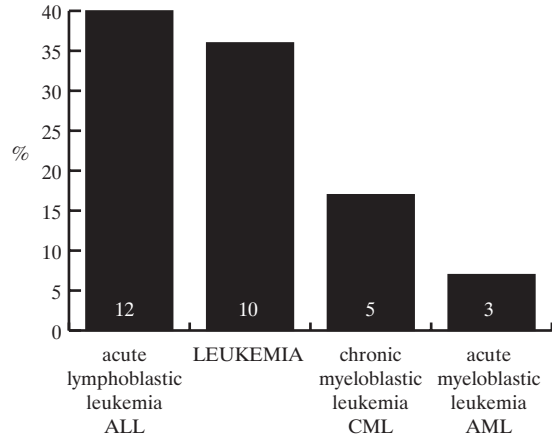


Figure 2. Types of leukemia diagnosed in the examined youth



Material and methods

The study involved leukemia patients treated in the Chair and Department of Pediatric Hematology and Oncology in Bydgoszcz and in A. Jurasz Outpatient Department of Pediatric Hematology and Oncology in Bydgoszcz. The study group consisted of youth aged 12-18 yrs; 51% of girls and 49% of boys. Patients aged 12-15 yrs constituted 67% of the subjects, and patients aged 16-18 yrs constituted 33%. There were 67% of patients from towns and 33% of patients from villages.

The patients under study were informed about the study aim, their voluntary participation and its anonymity.

The study employed an own questionnaire entitled: “Common Knowledge of Leukemia among Youth and Their Attitudes to the Diagnosed Disease”. The questionnaire was made up of three parts. The first one dealt with social-demographic data such as age, sex and place of living. The second part focused on the lapse of time from the moment of diagnosis, the type of disease and the knowledge of the disease. The last part dealt with the attitudes young people represent towards themselves and other patients with leukemia.

The questionnaire was filled in by the youth that met the following criteria:

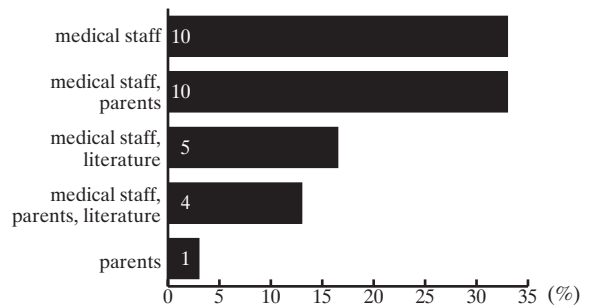
- age 12-18 years of age
- diagnosed leukemia
- their consent to take part in the study.

Results

Young patients were divided into two groups, i.e. 12-14 and 15-18 years of age, taking into consideration possible differences in their intellectual-emotional development level which is connected with the ease of acquiring knowledge about their disease. The 12-14 yrs patient group consisted of 16 subjects (53%) – 7 (23%) girls and 9 (30%) boys. There were 14 (47%) subjects in the 16-18 yrs age group – 9 (30%) girls and 5 (17%) boys. There were 20 (67%) children from towns and 10 (33%) from villages.

The analysis of the collected data showed that the highest number of respondents had the leukemia diagnosis when they were 10 years old 6 (20%). This diagnosis was made at the age

Figure 3. The source of knowledge about the disease

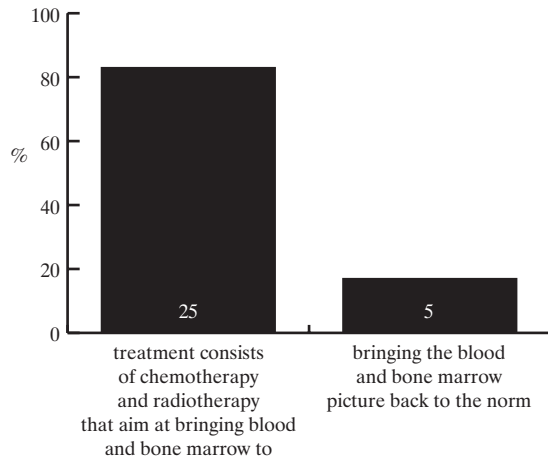


of 13 in 5 (16.7%) children and 4 (13%) were diagnosed when they were 9. There were three cases of leukemia diagnosed at the age of 17, 15 and 11 (10%) and in two (6%) children it was diagnosed when they were 8 years old. In 4 (13.3%) cases, the diagnosis was made when the patients were 18, 14, and 12 years old (Fig. 1).

Out of 30 youth under study, 12 (40%) had acute lymphoblastic leukemia (ALL). A marked group of patients – 10 (36%) did not give any answer as, particularly in the age group 12-14 they did not know the leukemia type they suffered from. They knew the general diagnosis but not the type. It resulted in non-marking the type of leukemia in the questionnaire. In 5 (17%) cases, it was chronic myeloblastic leukemia (CML), and in 3 (7%) – acute myeloblastic leukemia (AML) (Fig. 2).

In majority, the young patients marked medical staff or medical staff and parents – 10 cases each (33% each) as the source of information about the disease. There was only one person (3.3%) who obtained this information from the parents (Fig. 3).

The analysis concerning the knowledge of the youth as to what the disease really is showed that 27 (90%) of respondents described it as a proliferation of leukocytes (white blood cells) of one type in the human organism. None of them pointed at proliferation of red blood cells which proves they have got good knowledge of the disease. Only 3 (10%) patients marked the answer which was atrophy of leukocytes.

Figure 4. The knowledge of chemotherapy purpose

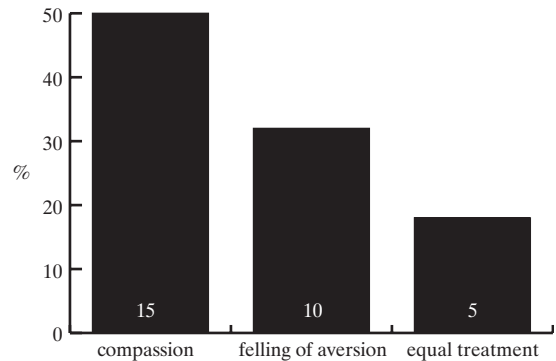
The respondents have good orientation about the causes of the disease they suffer from. 28 (93.4%) patients answered that the most important factors in the development of the disease were some viral infections, bone marrow damage caused by chemical substances (benzene), ionizing radiation or genetic factors. Only 1 (3.3%) child thinks that the disease is caused by the loss of a big amount of blood and diseases of unknown etiology.

The question about the most frequent initial symptoms was answered correctly by the majority of respondents – 24 (80%) who marked correct answers given by medical literature: pallor, dyspnea, weakness, susceptibility to infections, fever, lymph nodes swelling. It was very rare for them to mark the symptoms characteristic for leukemia and other diseases. It has been very important for the study that the young patients know and realize the purpose of anti-neoplastic treatment i.e. the application of chemotherapy in acute leukemic conditions.

The analysis of questionnaires shows that 25 (83.3%) of respondents know that the treatment of acute conditions consists in chemotherapy, mainly and its primary aim is to reach remission i.e. to bring the blood and bone marrow picture back to the norm and to reduce the number of neoplastic cells by at least 1000 times. They have sufficient knowledge to understand that application of remission maintenance treatment is necessary. None of the respondents thinks that the aim of remission is to bring the blood and bone marrow picture back to normal without the change in the number of neoplastic cells. They also know that, beside chemotherapy and radiotherapy, there is also a possibility of bone marrow transplantation (*Fig. 4*).

All respondents say they fight and do not give in. During a casual conversation they all say they fight, do not give in do not feel pity for themselves and do not like pity or exaggerated emotions from their closest relatives.

The analysis of data on the attitude of the youth to other leukemia patients lets us state that about 50% of all respondents – leukemia sufferers feel compassion to the others suffering from the same disease. It is surprising, however, that 10 (33%) patients, males mostly, aged 12-15 feel aversion to patients that are in the same departments and suffer from the same disease.

Figure 5. Attitudes of the youth to other leukemia patients

Only 5 respondents, when speaking about other leukemia patients, say that “they are exactly the same like us and should be treated identically, no matter if they are ill or not” (*Fig. 5*).

Discussion

Appropriate knowledge about neoplastic diseases causes the decrease of the fear level which is closely connected with emotional suffering. According to Chojnacka-Szawłowska [1] the knowledge of leukemias possessed by the Polish society can be described as common knowledge. Unverified facts are treated as information and they usually make people think that a cancer patient must die.

Available, although limited, literature [2,4] distinguishes three sources of common knowledge about diseases:

- own experience of a person providing fragmentary knowledge only, but it seems to be the most important source
- information, opinions and attitudes that come from actual sufferers and those who have contact with such patients or claim to have had it
- knowledge acquired from mass media.

Having talked to the examined youth, we can conclude that the most information about their disease comes from physicians and nurses who work in the department. The same amount of information is given to them by parents who learn it from medical staff and literature. Moreover, the young patients often get information from other patients who have the same kind of leukemia and stay together in the same department.

According to the studies by Świerczak-Bażańska et al. [5], 78.75% of youth suffering from a neoplasm have got sufficient knowledge of their disease.

The analysis of own research, particularly of the questionnaires' Part II, 57% of patients from the 12-18 age group have got good or very good knowledge of leukemia. The best knowledge is represented by the oldest participants of the study – those aged 18, irregardless of sex, place of living and time lapse from the moment of diagnosis. Boys aged 12-13 (57%) show the

lowest level of knowledge. They have got very little information about their disease. Taking into consideration the division into 12-14 and 15-18 age groups and their intellectual abilities, the study shows that 44% in the first group and 64% of respondents in the second group have satisfactory knowledge of leukemia. The remaining 56% from the 12-14 age group did not have even basic knowledge about the disease. It can be assumed that this lack of knowledge may result from the lack of interest in the disease, no access to information or the leukemia stage at the time of the study. It has been noticed that the amount of knowledge of leukemia among the youth with diagnosed leukemia is much bigger in older participants of the study.

Another factor analyzed statistically was the comparison of leukemia knowledge and the lapse of time from the moment of diagnosis. According to literature [1,2,6], the level of knowledge about the disease increases with the lapse of time from the diagnosis. Our study does not confirm this statement. The analysis of our results shows that in 10 (33%) cases of patients with the disease diagnosed 8-13 years ago, the knowledge about leukemia is lower than in the remaining 20 (67%) respondents. The answers given by these patients may not reflect the actual knowledge about the disease. Having observed them and talked to them, one can say they already feel tired by the whole situation, i.e. by continuous hospital stays, diagnostics and the very treatment the started to dominate their lives. They are not really willing to talk about the disease and become nervous when this subject is brought up. They are keen on talking about any other subject of interest to them.

The attitude of leukemia patients to the disease itself is a very important element of the therapeutic-nursing process. Hence, the answer to the question "does this attitude change and when" was looked for. It turns out that the study results are unequivocal. All respondents fight with the disease and do not give in. The respondents do have breakdowns, go through very difficult moments, and sometimes are fed up with it. Such situations take place in the moments that take them aback. Here, they most often speak about adverse effects of the first chemotherapy such as changes in appearance, constant nausea, vomiting, or chronic mucous membrane inflammation. As they say, they were aware of chemotherapy side effects, but there is a difference about knowing about them and actually going through them. The attitudes of leukemia patients that can be

described as hope, fight and not giving in are not dependant on anything at all. Sex, age, and place of living or the time lapse from the moment of diagnosis does not affect these attitudes. Their fight with leukemia is surely supported by those who consciously or unconsciously do not let them give in.

Carrying out a survey with the application of own questionnaire has allowed to evaluate the level of knowledge and types of attitudes to the disease among leukemia patients who are aged 12 to 18 years.

Each disease, particularly a neoplastic one, ruins the external and internal order in the life of every human being. Everything must be subordinated to many hospital stays and treatment cycles. The youth suffering from leukemia go through experiences they have not known so far, experiences they neither understand nor they want to understand.

Conclusions

The analysis of the collected material has let formulate the following conclusions:

1. The level of knowledge about leukemia in 12-18-year-old patients is highest in 18-year-old respondents;
2. There is no dependence between the time lapse from the moment of diagnosis and the increase of knowledge on the subject;
3. The attitude of young leukemia patients to their own disease does not change with the time lapse from the moment of diagnosis.

References

1. Chojnacka-Szawłowska G. Rozpoznanie choroby nowotworowej. PZWL, Warszawa 1998; 14-21.
2. Binnbesel J. Opieka nad dzieckiem i młodzieżą z chorobą nowotworową w doświadczeniu pacjentów. Wydawnictwo Uniwersytetu Mikołaja Kopernika, Toruń 2003; 7-16.
3. Skotnicki A. Białaczka nie jest dziś wyrokiem śmierci. *Służba Zdrowia*, 1997(103-104); 10: 14.
4. Twycross RG. Care of the terminally ill patient. *Triangle*, 1992; 31, 1, 1-7.
5. Świerczak-Bażańska I, Skotnicki A. Bądź dobrą „towarzyszką podróży” w walce z chorobą. *Magazyn Pielęgniarki i Położnej*, 2003(9); 28-9.
6. Samordakiewicz M, Kowalczyk JR. Rekomendacje dotyczące opieki psychospołecznej nad dziećmi. *Pediatra Polska*, N° 2000.