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# Quality of Life and Awareness of the Role of Physiotherapy in Patients with Leukemia and Lymphoma

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## Abstract

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Leukemias and lymphomas are malignant tumors and leading primary haematological diseases that can significantly impair the quality of life of the affected person. The aim of this study is to gain insight into the quality of life and functioning of patients with leukemia and lymphoma and their awareness of the role of physiotherapy in the process of treatment and rehabilitation. The study was conducted on 24 patients with leukemia or lymphoma, using the Personal Wellbeing Index (PWI) and a standardized questionnaire of the European Organisation for Research and Treatment of Cancer, the EORTC QLQ-C30, for assessing certain aspects of quality of life. In addition, data were collected on the awareness and experience of patients with physiotherapy.

The assessment of quality of life showed that emotional functioning may be impaired in the long term in people with leukemia and lymphoma, while cognitive function positively correlated with the time elapsed since the diagnosis. Respondents were generally well-informed about the role of physical activity and physiotherapy in the process of leukemia and lymphoma treatment and rehabilitation. This was particularly pronounced in those respondents who reported engaging in sports activities. On the other hand, a small number of respondents got recommendations to engage in physiotherapy, which is also confirmed by their opinion that physiotherapy is not readily available to people with leukemia and lymphoma.

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## Introduction

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Leukemias and lymphomas are malignant tumors that make the predominant group among the primary hematological diseases. They develop in the bone marrow from hematopoietic stem cells when numerous genetic rearrangements and dying of a large number of cells during apoptosis take place. These processes are susceptible to the development of oncogenic changes with the development of leukemia and lymphoma (1, 2).

The primary clinical feature of leukemia is the accumulation of leukemia cells in the bone marrow and their presence in peripheral blood, while lymphomas are manifested by the increase of lymph nodes and other organs containing lymphatic tissue, such as the spleen, tonsils, gastrointestinal tract, skin, lungs and central nervous system (3).

The quality of life in people with leukemia and lymphoma is affected not only by the symptoms of the disease, but also by the side effects of the treatment, which is long-lasting and exhausting (4, 5). Due to the illness itself, the treatment (6) and the hospitalization (7), as well as the recommendations for the patients to rest and avoid physical activity (8), there is an increase of immobility and reduction of physical fitness leading to muscle atrophy (9).

Oncologic diseases can be looked upon as chronic diseases because, with the advancement of medicine, many types of tumors are successfully cured today. In addition to medical treatment, physiotherapy within oncology rehabilitation allows patients to return to their daily life activities, and it is therefore necessary in order to maintain the quality of life (10). Some research suggests that there are positive effects of physiotherapy intervention on the improvement of the quality of life of the patients (11).

Oncological rehabilitation is the rehabilitation that is concerned with achieving maximum functioning in all areas (physical, mental, social, spiritual and professional) within the constraints caused by the illness and treatment procedures (12).

It represents a complex and challenging area of rehabilitation where different professionals from the field of biomedicine, humanities, social and other sciences have their place (13).

The aim of this study was to gain insight into the quality of life and functioning of patients with leukemia and lymphoma and their awareness of the role of physiotherapy in the process of treatment and rehabilitation.

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## Methods

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### Sample description

26 patients participated in the research. Two of them were underage and due to the specific nature of childhood age they were excluded from analysis. The average age of respondents was 45 years, with the youngest being 23 and the oldest 80 years. 17 (71%) of the respondents were female and 7 (29%) male. Half of the respondents have completed college or university education. Also, 50% of the respondents were married, 20% of the respondents declared themselves as single, while the remaining 30% indicated other marital status. The average time elapsed from the diagnosis in the sample was  $7 \pm 6$  years. The most recent diagnosis was given two months before the research was carried out, and the oldest 23 years ago.

### Measuring instrument

For the purposes of data collection, an online questionnaire was created containing the questions that were grouped into four categories: general socio-demographic data, quality of life, personal wellbeing, use of physiotherapy in the treatment of leukemia and lymphoma. The European Organization for Research and Treatment of Cancer's Quality of Life Questionnaire (EORTC QLQ-C30, Version 3.0) was used to assess the quality of life (14). The questionnaire consists of five functional scales (physical, role, cognitive, emotional and social functioning), three scales of symptoms (fatigue, pain, nausea/ vomiting), scales of global health status and quality of life and six single items representing the most common symptoms of malignant diseases (loss of appetite, insomnia, dyspnea, constipation, diarrhea and financial difficulties due to the illness and treatment). All

the items were scored on a Likert scale from 1 to 4, except for the global health status / quality of life score that was scored on a linear analogue scale of seven points. The quality of life assessment refers to seven days preceding the test. All results were linearly transformed and converted into a scale from 0 to 100. A higher score on functional scales indicates better functioning, while the higher score on symptom scales indicates a greater presence of symptoms. Personal Wellbeing Index (PWI) was used to estimate personal wellbeing (15). Together with the National Wellbeing Index (NWI) it is an integral part of the International Wellbeing Index (IWI). The Personal Wellbeing Index in this study consisted of seven items that were scored on a Likert scale from 0 to 10. The results were transformed and converted into a scale from 0 to 100. A higher result means a higher degree of satisfaction with a particular area of life. Questions related to the use of physiotherapy in the treatment of leukemia and lymphoma included respondents' personal experience with physiotherapy. Satisfaction with physiotherapy was assessed on the Likert scale from 1 to 5. Furthermore, awareness of the role of physiotherapy in leukemia and lymphoma treatment and rehabilitation was investigated. Respondents expressed the degree of agreement with a series of statements about physiotherapy using a Likert scale from 1 to 5. Finally, closed single-choice questions were used to collect data on the respondents' sports activities.

## Procedure

The questionnaire was distributed and submitted online, with the help of the Croatian Leukemia and Lymphoma Society (HULL) and groups of patients with leukemia and lymphoma on social networks. Data was collected anonymously in December 2016. SPSS Statistics 17.0 was used for statistical data analysis.

## Results

### Personal wellbeing in patients with leukemia and lymphoma

Personal wellbeing of the respondents was evaluated based on the satisfaction with the items shown in Table 1. These are standard of living, health, life achievements, relationships with the loved ones and relatives, community affiliation, current sense of security and a sense of security in the future. Respondents were most satisfied with the relationship with their loved ones and relatives, while security in the future was the worst rated item.

### Quality of life of patients with leukemia and lymphoma

Quality of life was estimated based on the current degree of physical, cognitive, role, emotional and social functioning as shown in Table 2 and the occurrence of common symptoms such as fatigue, nausea and pain (Table 3).

**Table 1. Assessment of personal wellbeing of leukemia and lymphoma patients**

Factor of personal wellbeing	Average score	Standard deviation
Standard of living	68.8	20.5
Personal health	70.4	22.7
Achieving in life	72.1	22.3
Personal relationships	90.8	11.4
Personal safety	77.9	22.5
Community – connectedness	77.1	22.4
Future security	62.1	26.0

Table 2. Assessment of quality of life of leukemia and lymphoma patients

Quality of life factor	Average value	Standard deviation
Physical functioning	75.8	21.2
Role functioning	59.0	30.7
Cognitive functioning	61.1	29.8
Emotional functioning	49.3	30.3
Social functioning	57.6	32.6

Table 3. Presence of symptoms in patients with leukemia and lymphoma

Symptom	Average value	Standard deviation
Fatigue	56.9	29.5
Nausea and vomiting	55.6	32.1
Pain	39.6	38
Dyspnea	30.6	38
Insomnia	44.4	40.1
Loss of appetite	31.9	41.1
Constipation	50	33.6
Diarrhea	38.9	39.3
Financial difficulties	59.7	23.9

Physical functioning was rated as the best, while the worst rated was emotional functioning.

Of the typical problems, the respondents were most affected by financial difficulties caused by illness and treatment, fatigue, nausea and vomiting. The average satisfaction of the respondents with their general health condition at the time of the study was 73 out of the possible 100 points. Statistical analysis has shown that cognitive function correlated positively with the time elapsed since the diagnosis ( $r = 0.493$ ,  $p = 0.014$ ). In other words, the cognitive function improved with time elapsed since the diagnosis was established. Time elapsed since the diagnosis was not statistically significantly related to other aspects of functioning. Also, those who reported sporting activities ( $N = 10$ ) have statistically significantly better rated their role functioning ( $t = 2.062$ ;  $p = 0.051$ ). On the other hand, the presence of characteristic symptoms did not show correlation with the time elapsed since the diagnosis. Age was not significantly related to any single aspect of functioning or frequency of symptoms.

### Use of physiotherapy in rehabilitation of people with leukemia and lymphoma

When asked if they had any personal experience with physiotherapy, 10 (42%) respondents responded positively. Four reported leukemia or lymphoma related complications as the reason, while the remaining six reported some other reason unrelated to the primary disease and the treatment did not take place at the same time as the treatment for leukemia or lymphoma. Among the respondents whose physiotherapy was associated with primary disease, one reported the use of physiotherapy for the duration of therapy, one for both during and after the completion of the therapy, and two after the completion of the treatment for leukemia or lymphoma. Therapeutic exercises were the main therapeutic modality. They were reported by all four respondents. Breathing exercises were reported by two respondents out of four. Also, one person reported the use of lymph drainage. The average satisfaction with physiotherapy, regardless of the duration and the reason for the use of physiotherapy, was  $3.7 \pm 1.2$ . When asked whether physiotherapy was recommended or prescribed to them during the treatment and rehabilitation, three (13%) respondents responded positively.

The availability of physiotherapy was generally estimated as low ( $M = 2.1$ ;  $SD = 0.9$ ). Examining the awareness of the role of physiotherapy in the treatment and rehabilitation in patients with leukemia and lymphoma showed that respondents felt that physiotherapy could alleviate the side effects of therapy and contribute to the recovery from the disease and rehabilitation in patients with leukemia and lymphoma. An overview of the level of information on the role of physiotherapy is presented in detail in Table 4. No statistically significant difference was found between respondents who do and do not have personal experience of physiotherapy in terms of agreeing with any of the statements as well as the availability of physiotherapy ( $t = -0.983$ ;  $p = 0.330$ ).

Respondents generally consider engaging in physical activity as desirable. 42% of the respondents were recreationally involved in some sporting activities. None of the respondents reported being involved in competitive sports. They mostly reported aerobic exercises such as walking, running, swimming and cycling.

Respondents who reported being engaged in sports activities were statistically significantly better informed about the following physiotherapy-related statements: "Physiotherapy can alleviate unwanted side effects of leukemia and lymphoma treatment" ( $t=2.093$ ;  $p=0.048$ ) and "People with leukemia and lymphoma should avoid physical activity to maintain their strength" ( $t=-2.756$ ,  $p=0.012$ ). For the statement "Physiotherapy is an integral part of the treatment and rehabilitation of people with leukemia and lymphoma" ( $t=2.003$ ;  $p=0.058$ ), the level of statistical significance ( $p<0.05$ ) was not reached, but the tendency to agree with that statement is still slightly higher among those who are engaged in sports. The results of the connection between sporting activities and awareness of the role of physiotherapy in the process of treatment and rehabilitation of people with leukemia and lymphoma are given in detail in Table 5.

**Table 4. Awareness of patients about the role of physiotherapy in leukemia and lymphoma treatment and rehabilitation**

Statement	Average score	Standard deviation
"Physiotherapy is an integral part of the treatment and rehabilitation of people with leukemia and lymphoma"	3.5	1.3
"Physiotherapy can contribute to the recovery and rehabilitation of people with leukemia and lymphoma"	3.8	1.3
"Physiotherapy can alleviate unwanted side effects of leukemia and lymphoma treatment"	3.7	1.0
"People with leukemia and lymphoma should avoid physical activity to maintain their strength"	1.9	0.9

**Table 5. Relationship between sports activities and awareness on the role of physiotherapy in the process of treatment and rehabilitation of people with leukemia and lymphoma**

Statement	t-test	
	t-value	p-value
"Physiotherapy is an integral part of the treatment and rehabilitation of people with leukemia and lymphoma"	2.003	0.058
"Physiotherapy can contribute to the recovery and rehabilitation of people with leukemia and lymphoma"	1.022	0.318
"Physiotherapy can alleviate unwanted side effects of leukemia and lymphoma treatment"	2.093	<b>0.048</b>
"People with leukemia and lymphoma should avoid physical activity to maintain their strength"	-2.756	<b>0.012</b>

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## Discussion

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Rehabilitation of patients with leukemia and lymphoma is a relatively new and unexplored area. The current medical knowledge focuses mainly on primary therapy and recovery, which are becoming more and more successful. However, we should not neglect the quality of life and the functioning of people, which can be significantly impaired in the process.

The data obtained by this research are based on a relatively small number of respondents who make a very heterogeneous group with regard to the time of the diagnosis and treatment of the disease. Only three respondents were diagnosed with leukemia or lymphoma within a year with regards to the time of the study. It would be of interest to identify the reasons for the low turnout of the newly diagnosed. Some of the possible reasons are their own psychological barriers in publicly acknowledging their illness and lack of awareness of a support system in the form of a patient association, which was the main source of respondents for this research. It is important to strengthen the connection between healthcare professionals and associations whose activities are aimed at people with leukemia and lymphoma in the future. In addition to the wellbeing of the patients, it also enhances the monitoring of their functioning and quality of life, which is the basis for creating future health guidelines for this population. Furthermore, it would be advisable to distinguish between patients with leukemia and lymphoma in future studies in order to detect the possible difference between these two populations.

When it comes to personal wellbeing of the respondents, the item that has proved to be the most critical is uncertainty in what the future brings. Without a healthy control group, it is difficult to ascertain to what extent this insecurity is the consequence of the illness and how much of the general state of the society. Research on a sample of healthy Croatian citizens has also shown that they are on average the least satisfied with the security in the future and their standard of living, and most satisfied with relationships with their family and friends (16). In any case, it would be desirable to involve patients in transdisciplinary rehabilitation programs that will contribute to the preservation and enhancement of

both physical and psychological functions that may be affected by the disease. In support of this is the fact that emotional functioning has shown to be the worst of all evaluated functions. It is followed by social functioning, while the physical functioning has been rated as the best by far. Similar results were obtained in women with breast cancer (17) and laryngectomized persons (18) where the area of emotional functioning was identified as the worst. It should be taken into account that the respondents in this study are people whose acute phase of treatment and rehabilitation, associated with the greatest physical difficulties, is mainly behind them. It is therefore logical that the prevailing problems are psychological problems. An important determinant of their psychological state is the financial burden of a disease whose effect can be felt even a certain amount of time after the treatment is over. In the examined sample, financial difficulties are the ones defined as the greatest accompanying burden of the disease. Accordingly, the standard of living is also estimated as relatively low. On the other hand, relations with the loved ones and relatives were most satisfying for the patients, which is encouraging given the important role of family and friends in the process of treatment and rehabilitation. Based on the meta-analysis, Allart-Vorelli et al. concluded that the quality of life of the people with hematological tumors is significantly impaired, with the most pronounced symptoms of tiredness, pain and reduced overall vitality due to illness and treatment, which is consistent with the results of our research (19).

Data relating to the role of physiotherapy in the treatment and rehabilitation of patients with leukemia and lymphoma is difficult to comment as fewer than 50% of respondents have experience with physiotherapy, and only four (17%) used physiotherapy in the context of the primary disease. What is certainly a devastating fact is that only three (13%) of the respondents were referred to some form of physiotherapy in the process of their treatment and rehabilitation. What would be of interest to find out in the future, and is not covered by this questionnaire, is the source of recommendation. Are they health professionals, families and friends or patient associations who have the greatest influence on inclusion of physiotherapy in the treatment process?

It is encouraging that respondents are generally well-informed about the role of physiotherapy in the context of treatment of leukemia and lymphoma.

Unfortunately, the availability of physiotherapy is considered lacking, which is consistent with a small number of recommendations for its implementation. Engaging in a sport activity is associated with greater awareness of the role of physiotherapy in treatment, which can be interpreted as a result of personal experience of beneficial effect of physical activity. More research suggests that physical activity can have a significant effect on different aspects of functioning and diminishing the occurrence of symptoms in people with tumors (19). Thus, effective exercise has been shown to improve the quality of life, cardiorespiratory functions, physical functioning and fatigue in breast cancer patients (20). Taking into account the impaired emotional functioning of our respondents, the impact of physical activity on mental health should also not be neglected. A possible reason for that is the contribution of social interactions involving group exercising as well as the effect of distracting attention from the disease and treatment, which helps to reduce the negative impact (21). Mishra et al. found in their meta-analysis the positive effects of exercise on health-related quality of life in different domains of functioning in cancer patients after the treatment was completed (22). This points to the importance of systematically involving different physical activity programs in clinical guidelines or recommendations for work in phases of rehabilitation and inclusion of a physiotherapist as a mandatory member of a multidisciplinary team.

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## Conclusion

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This research has shown that psychological and emotional functioning can be impaired in the long term in people treated for leukemia and lymphoma. Consideration should be given to the possibility of active inclusion of patients in some form of organized psychological support. Regular physical activity is also a significant factor in psychological wellbeing and it should be adapted to the specifics of this population in order to prevent injuries and further damage to the health status. In this sense physiotherapy is certainly the method of choice.

Respondents are generally well-informed about the role of physical activity and physiotherapy in the

process of leukemia and lymphoma treatment and rehabilitation. This was particularly pronounced in those respondents who reported engaging in sports activities. On the other hand, few respondents got recommendations to engage in a physiotherapy process, which is also confirmed by their opinion that physiotherapy is not readily available to people with leukemia and lymphoma.

The availability of physiotherapy is directly related to the awareness of all participants in the treatment process about its contribution. That is why the first step in better implementation of physiotherapy in the treatment of people with leukemia and lymphoma is the education of the patients and their families, as well as health professionals. Important links in this process are patient associations in which the experiences of patients and members of the health team come together. Additionally, it is important to continue research on a greater number of respondents with an emphasis on people who are in the process of treatment or have just completed it.

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## KVALITETA ŽIVOTA I INFORMIRANOST O FIZIOTERAPIJI MEĐU OSOBAMA OBOLJELIMA OD LEUKEMIJE I LIMFOMA

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### Sažetak

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Leukemije i limfomi zloćudni su tumori i vodeće primarne hematološke bolesti koje mogu znatno narušiti kvalitetu života oboljelih osoba. Cilj je ovog istraživanja dobiti uvid u kvalitetu života i funkcioniranje osoba oboljelih od leukemije i limfoma te njihovu informiranost o ulozi fizioterapije u procesu liječenja i rehabilitacije. Istraživanje je provedeno na 24 osobe oboljele od leukemija ili limfoma, pri čemu je primijenjen Indeks osobne dobrobiti (PWI) te standardizirani upitnik Europske organizacije za istraživanje i liječenje raka EORTC QLQ-C30 za procjenu pojedinih aspekata kvalitete života. Također, prikupljeni su podaci o informiranosti i iskustvu pacijenata s fizioterapijom.

Procjena kvalitete života pokazala je da emocionalno funkcioniranje može biti dugoročno narušeno u osoba oboljelih od leukemije i limfoma, dok je kognitivna funkcija pozitivno korelirala s vremenom proteklom od postavljanja dijagnoze. Ispitanici su uglavnom dobro informirani o ulozi tjelesne aktivnosti i fizioterapije u procesu liječenja i rehabilitacije kod leukemije i limfoma. To je bilo posebno izraženo u onih ispitanika koji su prijavili bavljenje sportskom aktivnošću. S druge strane, mali broj ispitanika dobiva preporuke da se uključe u fizioterapijski proces, što potvrđuje i njihovo mišljenje da fizioterapija nije lako dostupna osobama oboljelim od leukemije i limfoma.

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**Cljučne riječi:** fizioterapija, kvaliteta života, leukemija, limfom, tjelesna aktivnost

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