

Psychological, physical, and social situation of patients with Hodgkin lymphoma undergoing radical chemoradiotherapy

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ABSTRACT

Purpose: To assess the physical and psychosocial situation and needs of Polish patients with Hodgkin lymphoma (HL), who had undergone radical chemoradiotherapy.

Materials and methods: 50 Hodgkin lymphoma patients were asked to complete an institution-developed questionnaire concerning their physical, emotional and social well-being, as well as their perceptions regarding the medical care they had received.

Results: The physical and psychosocial quality of life of patients with HL was diminished by the disease and its treatment. The most frequently reported side effects of both chemo- and radiotherapy were fatigue and loss of taste. The observed symptoms were slight or moderate. Although 36% of participants reported feelings of depression and 52% - were concerned about their future functioning in society, more than half of patients reported that were happy (60%). 20% of

respondents were unable to work at all, but more than half had some difficulties with their employment. 20-40% of the patients complained about having received insufficient dietary instructions and lack of information about the late adverse effects of treatment. Although the majority of respondents assessed the quality of medical care as very high emotional problems preferred to share with relatives (90%).

Conclusions: Although the physical and psychosocial situation of HL patients may be affected by the disease and its treatment, for the majority of patients, these impediments did not cause serious deterioration in functioning. Medical care was positively assessed by the HL patients, but more emotional and informative support is needed to decrease patients' anxiety regarding future functioning in society.

Key words: Hodgkin lymphoma, chemoradiotherapy, quality of life, medical care

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INTRODUCTION

Hodgkin lymphoma (HL) is a rare malignant disease which accounts for 0.5% of all new cancer cases in Poland, with more than 700 patients diagnosed annually (30 in the northeastern region) [1,2]. The majority of HL patients are diagnosed in the age group of 15-40 years – during the active period of human life. The overall 5-yr survival rate is approximately 80% (77.8% and 82.7% for men and women, respectively) and has been continuously improving, resulting in a growing population of lymphoma survivors [3, 4]. A substantial percentage of radically treated HL patients receive chemoradiotherapy. Unfortunately, both modalities are accompanied by acute and long-term adverse effects [5].

In addition, patients with Hodgkin lymphoma may present a variety of systemic or local symptoms associated with the natural course of the disease. Physical ailments and time-consuming therapy may impede patients' daily activities and limit their ability to learn, work and/or conduct their social life. Stress, irritation and feelings of insecurity during and after treatment are emotional consequences of the condition. Many studies have shown that the well-being of HL patients is significantly affected by the cancer both in the physical as well as in psychosocial area [6-8], hence Hodgkin lymphoma survivors represent a group having to manage the late and long-term effects of the disease and its treatment.

Findings indicate that lymphoma survivors may develop symptoms of posttraumatic stress disorder (PTSD), suffer from chronic fatigue and/or present worse physical and psychosocial performance in comparison to the general population [6-11].

In order to decrease the impact of the negative consequences of the "trauma" associated with cancer, the treatment process should provide not only appropriate medical care, but also emotional and social support for patients. To undertake optimal and individualized actions a more comprehensive insight into the situation of this particular subset of patients is essential.

Patients' quality of life (QoL) is currently an important consideration for Polish medical staff during the treatment process. Until recently, QoL evaluation was predominantly conducted in palliative settings [12].

Unfortunately, information concerning the impact of the cancer on Polish HL patients is limited and patients' perception of medical care is understudied.

The aim of this study was to evaluate patients' QoL in the physical and psychosocial areas shortly after treatment and their satisfaction with medical care, especially informative and emotional support.

MATERIALS AND METHODS

The current study was conducted in the Department of Clinical Oncology at the Medical University of Bialystok and in the Department of Radiotherapy of the Comprehensive Cancer Center in Bialystok, Poland. Eligible participants included 50 Hodgkin lymphoma patients (28 women, 22 men) who had undergone radical chemoradiotherapy between June 2012 and March 2014. All participants were administered 4-6 courses of ABVD regimen (doxorubicin (adriamycin), bleomycin, vinblastine, dacarbazine) chemotherapy. The number of courses depended on the stage of the lymphoma and treatment outcome. Involved field radiotherapy at a total dose of 30-36 Gy was performed after chemotherapy.

To obtain the necessary information about the impact of Hodgkin lymphoma on the lives of patients suffering from the disease, an individualized two-part questionnaire was constructed, which patients were requested to complete at the end of the treatment or during the first follow-up visit (within two weeks from the last fraction of radiotherapy). Patients were included in the study after signing an informed consent form. They were asked to complete the questionnaire independently and were given the assurance that their anonymity would be preserved. Participation in the study was voluntary. The first part of the questionnaire contained questions about the patient's: age, gender, education, marital status, place of residence and financial situation. The second part was devoted to the psychosocial and physical problems encountered during treatment and to the patients' perceptions of the nursing care. The questionnaire contained closed questions with both binary and multiple-choice options.

Ethical approval for the study was obtained from the Human Care Committee of the Medical University in Bialystok, Poland.

RESULTS

The demographic characteristics of the study sample is presented in table 1.

All adverse effects of treatment were considered by respondents to be slight or moderate, so that fewer than half of the patients (44%) reported them to the medical staff. In addition, more than half of the respondents assessed their health status as good or very good and only 7 (14%) reported feeling unhealthy (all over the age of 50). One-third of the patients had difficulty in evaluating their physical condition – "they were not sure how they felt". Finally, as many as 66% of all the respondents denied feeling lack of energy.

Table 1. Demographic Characteristics, n = 50

Variable	Value	
Age (years, N (%))		
Mean (min-max)	38.6	(22-68)
18-30	12	(24)
31-40	25	(50)
41-50	3	(6)
51-60	8	(16)
61-70	2	(4)
Education (N (%))		
Primary	3	(6)
Vocational	8	(16)
Secondary	22	(44)
University or college	17	(34)
Place of residence (N(%))		
Town or city	33	(66)
Country	17	(34)
Financial status (N (%))		
Very good	2	(4)
Good	41	(82)
Unsatisfactory	5	(10)
Poor	2	(4)
Marital status (N (%))		
Single	8	(16)
Married	33	(66)
Divorced	5	(10)
Widow/er	4	(8)

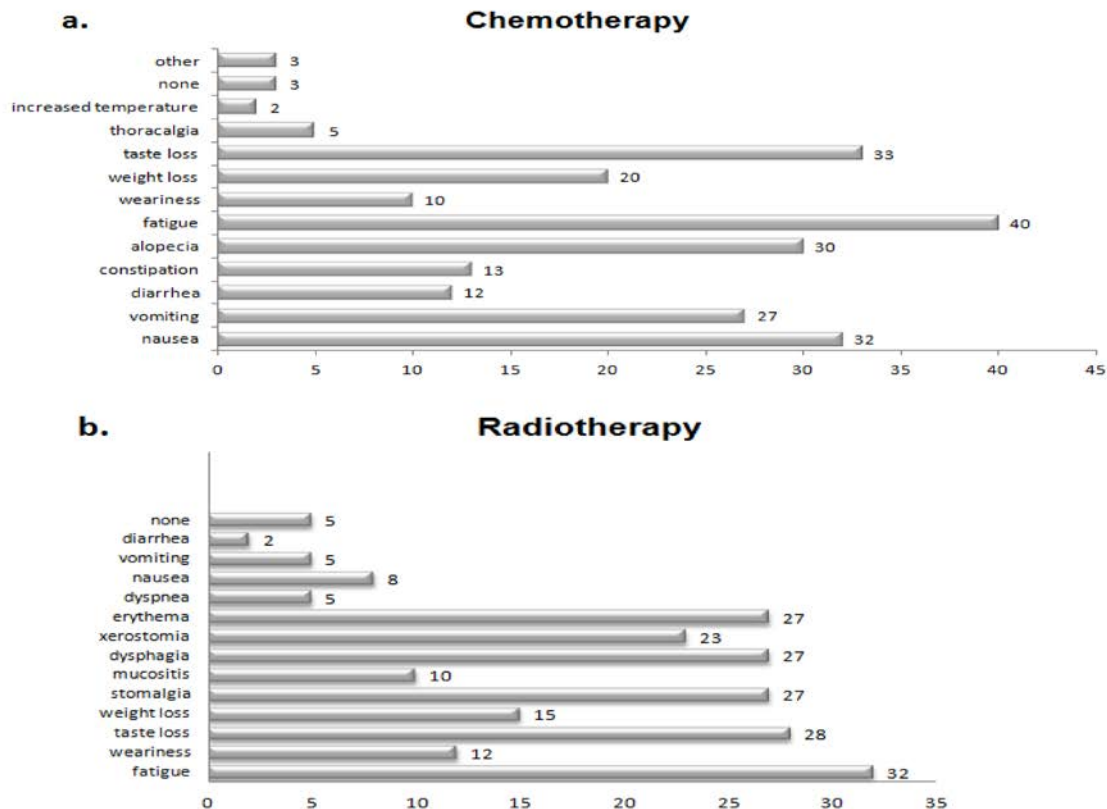


Figure 1. Adverse effects of chemotherapy (a) and radiotherapy (b) reported by Hodgkin lymphoma patients treated with radical intention. Multiple answers were possible. Other symptoms (3 patients) were headache, myalgia and neuropathy

Physical well-being

The most frequently reported adverse effects of both treatment modalities were fatigue, loss of taste and weight loss. During chemotherapy patients often also suffered from nausea, vomiting and alopecia, whilst during radiotherapy they were affected by mucositis, dysphagia and skin rash. The entire range of symptoms presented by the HL patients during oncological treatment is presented in Fig. 1.

Psychological well-being

We found that the diagnosis of Hodgkin lymphoma affected the psychological status of approximately 60% of patients. Approximately one-third of them felt depressed (36%) and/or nervous/irritated (24%). An even larger percentage of respondents described anxiety or fear during therapy. The most frequent causes of these feelings were: uncertainty regarding treatment outcome (60%) and fear of side effects (44%) (Fig. 2).

Furthermore, they were apprehensive about their future functioning in society (52%). With regard to external appearance, very few patients (n=7) perceived their appearance as unattractive.

More than half of patients felt reconciled with the disease (56%) and despite the illness, reported feeling happy overall (60%). 38/50 respondents (76%) felt they were coping with the disease and 1/3 expressed a need to talk about the illness with a healthcare professional. Of particular importance in terms of psychological and spiritual well-being was the fact that the majority of respondents (80%) regarded themselves as fully-valued individuals, able to play an active and useful role in society.

Social well-being

The family, social and professional life of Hodgkin lymphoma patients was also affected by the disease and its treatment.

More than half of the patients (38/50) admitted that they had been forced to change their previous lifestyle as a result of the disease (Fig. 3).

All of them had informed close relatives about their disease and the majority of respondents (90%) had received emotional support from their family. The majority of patients (80%) felt that the disease had not affected the quality of their relationships with family and friends negatively, and in some cases (20%) they even felt that their relationships had improved in the context of the illness. 64% of patients were satisfied with their sexual life.

The patients also complained about the negative impact of the disease on their professional activities. Every 5th patient had had to resign from work and more than half were unable to fully complete their duties.

Medical care – informative and emotional support

All patients felt they had been fully informed about their diagnosis and oncological treatment schedule. 90% considered they had been informed about medical procedures and potential (acute) side effects associated with therapy. 80% of the respondents reported that they had received advice from the medical staff about rules of hygiene and methods of dealing with adverse effects, both during and after treatment. They were familiar with preparations for the treatment of erythema and oral cavity hygiene during radiotherapy and knew the basic rules of management for nausea, vomiting, diarrhea and constipation. Of greater concern is the fact that a high percentage of patients reported that they had not been informed about diet (20%) and the late effects of chemoradiotherapy (40%), notably its influence on fertility.

Moreover, participants reported having insufficient knowledge about the effects of oncological treatment on their sex lives and had doubts about the necessity of using contraception during and after treatment (40%).

Also, as many as 40% of patients had difficulties in answering a question about whether they were “dangerous” in relation to other people during treatment and/or whether they should take special precautions in relation to contact with children, in particular.

A substantial percentage of patients were aware that, should any symptoms arise during treatment, they ought to inform their nurse or doctor. However, fewer than half of the respondents (44%) had actually done so. A common reason for this was that the patients considered that their ailments were not serious enough to inform medical staff about them and/or they did not want to “bother” them.

All patients confirmed that the nurses and doctors talked with them during medical procedures and a significant majority (96%) described the staff as “empathic” and “friendly”. None of the respondents complained about communication with the medical staff. The majority described the nurses’ and doctors’ language as simple and easy to understand.

Furthermore, the nurses and doctors were regarded by patients (80% and 72%, respectively) as the appropriate persons to ask for help in the event of medical problems arising. In contrast, for emotional support, the patients turned, in particular, to members of their family (45/50) (30% mentioned also doctors or nurses).

Finally, as many as 96% of respondents assessed the medical help they received as sufficient and satisfactory and affirmed that they felt safe in hospital.

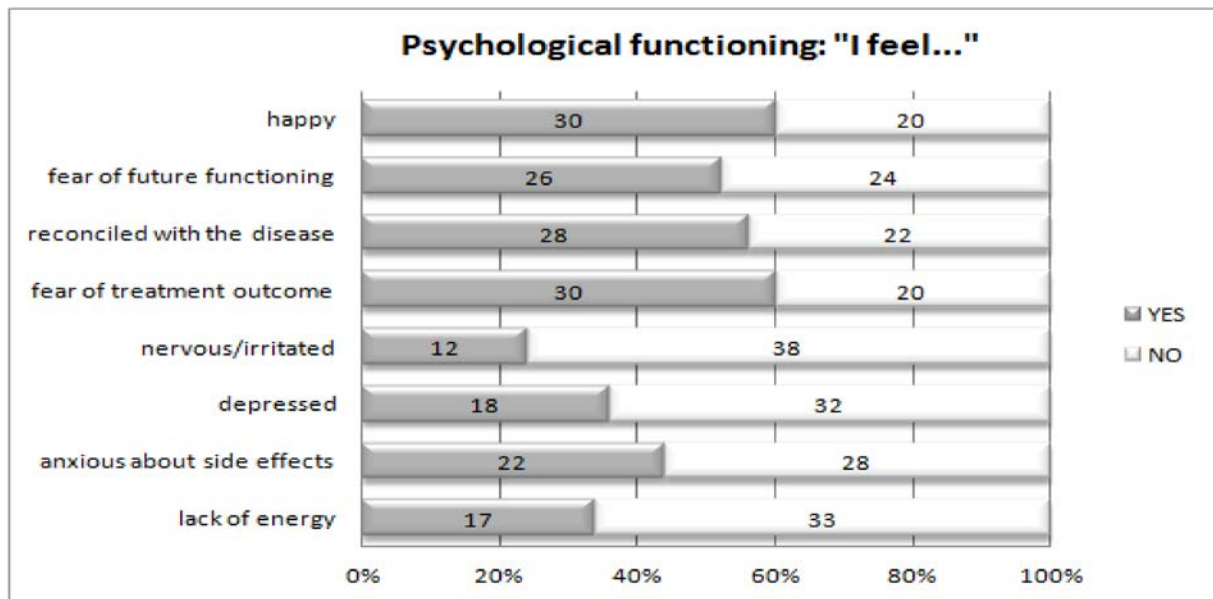


Figure 2. The psychological impact of Hodgkin lymphoma on patients' lives (n = 50)

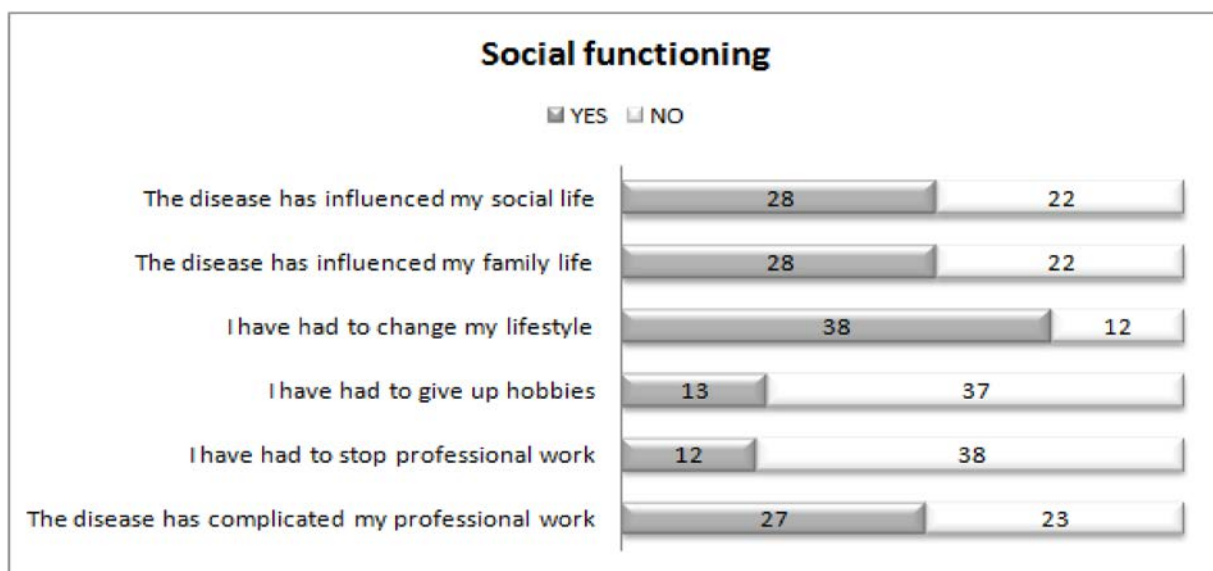


Figure 3. The social impact of Hodgkin lymphoma on patients' lives (n = 50)

DISCUSSION

Cancer diagnosis and oncological treatment can affect patients' present and future life [13-16]. Identification of the factors contributing to the well-being of individuals with HL may help to provide a more patient-directed approach. Thus, better quality of healthcare could decrease the negative impact of the cancer on HL survivors.

The most frequently reported adverse effects of both treatment modalities were fatigue, loss of taste and weight loss. The observation that fatigue is a prevalent symptom during chemo- or radiotherapy (40/50 and 32/50, respectively) is in accordance with data from the literature – as many

as 96% of oncological patients may suffer from it [6,8,15,17,18].

Furthermore, fatigue at the end of treatment is a predictive variable for persistent fatigue among HL survivors, and this, in turn, may be a serious cause of maladaptive responses [6,8,10,11,19-22].

Miltényi et al. [7] have revealed that fatigue is significantly higher in patients who had been treated more than 20 years before than in those who were undergoing treatment suggesting that the intensity of this ailment may be enhancing in the course of time.

Importantly as regards patients' physical status, all side effects of treatment (including

fatigue) were assessed by respondents as being only slight or moderate. This was reflected in the frequency that patients reported these symptoms to the medical staff (only 44%) and by the fact that none of the patients required hospitalization during the course of treatment. These findings show that HL patients did not experience a significant decline in physical well-being. Additional support for this conclusion comes from the fact that as many as 66% of all respondents denied experiencing “lack of energy” and more than half assessed their health status as good or very good. Unfortunately the situation may change in the course of time – findings noted that HL survivors treated with chemo- or radiotherapy presented a lack of energy many years after treatment [8].

Furthermore, 64% of patients were satisfied with their sexual life, which also confirms good functional well-being shortly after treatment [16].

Data from literature indicate that contrary to fatigue the sexual functioning improves during follow-up, except for patients ≥ 50 years [23].

It may be the case that the functional status of the individuals with HL is associated with the young age of the patients. The majority of respondents were less than 50 years old. This age group is typical for Hodgkin Lymphoma [3]. In the present study, those patients who made a negative assessment of their health were more than 50 years old. Many studies have shown an association between the age of the patient and physical quality of life [6,13,14,24]. As regards side effects, younger patients generally report weaker symptoms and faster recovery [6,8].

The psychological functioning of HL patients appeared to be affected more significantly than their physical performance, though still not as seriously as expected. More than half of respondents managed to cope with the disease (38/50) and to feel happy in spite of it (30/50). More importantly, in terms of human spiritual well-being, as many as 80% of respondents felt that they were fully valued as people, able to play a useful role in society. They were hopeful and interested in life. Possibly, the younger age of the HL individuals and the generally good prognosis for the disease contributed to the more positive emotional attitude of the patients, without detriment to their self-evaluation.

On the other hand, 36% of patients reported feelings of depression and 60% described their emotional status as fearful. This finding cannot be ignored by medical staff. In the light of findings suggesting that 8% of lymphoma survivors may suffer from PTSD (prevalence in general population – 2.4%) and heightened physiological and psychological stress [11,25], the emotional support during treatment is of paramount importance. In the present study, 56% of patients

felt they had reconciled themselves with the disease but only 1/3 wanted to talk about it. It may be the case that young adults, burdened with domestic and professional duties, do not have the time or the inclination to analyze the disease and discuss personal matters. On the other hand, their unwillingness to discuss the illness may reflect ways of coping based on avoidance and denial, related, for example, to a fear of hearing bad news (60% of patients expressed fear of lymphoma recurrence). They may also have felt that the appropriate conditions did not exist to discuss their concerns with the medical staff.

Our findings showed that HL influenced social functioning in more than half of the patients. Interestingly, the observed impact was both positive and negative. All patients had informed close relatives about the disease and the majority of them (90%) felt they had received emotional support from their family (66% of respondents were married). The quality of interpersonal relationships did not change for the majority of patients (80%) and in some cases (20%) it had even improved. These results are in line with the literature, which suggests that lymphoma patients experience a great deal of support from different sources [26,27].

A serious life event, which beyond all doubt is that of malignant disease, in the majority of cases positively verifies the quality of relationships [26]. In contrast, the disease had a deleterious effect on the professional sphere of the patients' lives. In the present study, every 5th patient had to resign from work and more than half were unable to fully complete their duties.

Many studies have shown that up to 40-60% of cancer patients have difficulties at work [8,27]. These problems may lead to financial difficulties and evoke feelings of instability [8,27]. Fortunately, in the present study, 84% of respondents assessed their financial situation as good. One paper [8] showed that Hodgkin's lymphoma survivors mentioned the topics of finance less frequently than controls. However, there is evidence that the financial situation of HL patients has a tendency to worsen and impede re-integration even years after a return to full health [4,10,25,28].

The data derived from the EORTC-GELA H8 trial [5] revealed that impairment in patients' QoL early after treatment occurs mainly in the social and psychological domain and to a lesser extent in physical status. There is evidence that quality of medical care (e.g. meeting the needs of cancer patients, time devoted to patients) can influence patients' emotional well-being [12,29].

Our findings have shown that the discussion which precedes treatment is of the essence in shaping HL patients' feelings of security. Insufficient information concerning aspects of patients' sexual lives, contraception and fertility

(vital issues for young adults) was the source of patients' apprehension associated with future functioning in their family and in society. Another important consideration is that only 30% of respondents expected emotional support from the medical staff. This perception may be caused by a shortage of patient-allotted time and inappropriate working conditions hampering building of close relationships between nurses and patients [30].

Another explanation might be inadequate psychological skills among the medical staff. Therefore, more effort should be made to train nurses and doctors in the psychological skills required to communicate with patients.

The present study has numerous limitations. The relatively small number of patients available due to the low prevalence of the disease made the statistical evaluation impossible. To investigate more thoroughly patients' opinion about some aspects of treatment as well as quality of medical care an institution-developed no validated questionnaire was used.

Moreover the single-institution study provides only a regional picture. There is need to carry out such an analysis across the country to yield more reliable and accurate data that may then be incorporated into a greater whole. Despite its shortcomings and relatively small scale, this study is of great importance because brings about additional improvements in the local healthcare system of HL patients and provides basis to multi-institution investigation.

CONCLUSIONS

The physical and psychosocial functioning of HL patients may be deteriorated by the disease and its treatment. It would seem that simple measures like extended discussions and detailed advice about disease-associated issues could decrease HL patients' distress and feelings of insecurity and improve their general well-being. Ultimately, a multidisciplinary team would be required to meet the needs of patients with HL undergoing radiochemotherapy.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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The authors have no funding to disclose.

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