



Survey of Challenges, Goals, and Interventions for Patients With Lymphoma During Aftercare Consultation: An Exploratory Cross-Sectional Study

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Abstract

This study described the challenges, personal goals, and interventions of patients with lymphoma in various domains of life that emerged from an aftercare consultation based on shared decision-making principles with a nurse practitioner. A cross-sectional exploratory design was used with a sample of 49 patients. Challenges, goals, and interventions were measured based on 4 domains of life: “my health,” “my activities,” “my environment” and “my own way.” Most challenges were experienced in the domain of “my health,” which included a loss of physical condition, reduced muscle strength, and fatigue. Patients set personal goals related to the experienced challenges, such as restoring physical condition to prediagnosis levels. Accordingly, 45 patients (84%) chose an intervention to improve physical condition and muscle strength and 33 patients (67%) chose to be referred to specialized care.

Keywords

lymphoma survivorship, aftercare, goal setting, shared decision-making

Introduction

Due to increasing survival and incidence rates, more individuals are living with adverse consequences of cancer and its treatment, such as fatigue and emotional and cognitive challenges, requiring personalized aftercare.^{1,2} In the Netherlands, despite broad cancer aftercare options, only a relatively small percentage of cancer patients are provided with appropriate cancer aftercare. The Dutch National Cancer & Life action plan² and the European Academy of Cancer Sciences³ recommend the development of tools to enhance communication and shared decision-making (SDM) about aftercare. In line with this recommendation, we developed an aftercare conversation approach based on shared goal setting and care planning that supports nurses in providing cancer patients with personalized aftercare.⁴

During an aftercare consultation, various domains of life should be addressed and goals should be set from a holistic perspective.⁵ However, little research has explored the

personal goals identified by cancer patients in various domains of life, especially by patients with hematological malignancies, such as lymphoma, and what kind of aftercare

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they choose.⁶⁻⁸ Gaining insight into these goals and planned aftercare interventions may support nurses to inform patients during aftercare consultations.

This study described the personal goals related to experienced challenges and planned aftercare interventions of patients with lymphoma in various domains of life that emerged from aftercare consultations based on SDM principles with a nurse practitioner (NP).

Methods

Study Design and Setting

A cross-sectional exploratory research design was used.

The setting was a malignant lymphoma care pathway in a 980-bed urban teaching hospital in the south of the Netherlands. On average, 80 patients are treated for malignant lymphoma within this care pathway each year.

To provide patients with personalized aftercare, an NP arranged an aftercare consultation lasting approximately 1 h between 3 and 12 weeks after treatment completion. The aftercare conversation approach was divided into 4 phases: (a) preparation, (b) shared goal setting, (c) shared care planning, and (d) evaluation.⁴ During the preparation phase, a patient-reported outcome (PROM) questionnaire was sent to the home address of the patients. This questionnaire consisted of the Dutch version of the distress thermometer (DT) and problem list (PL)⁹ and the screening inventory psychosocial problems (SIPP).¹⁰ The items of the PL and SIPP were subdivided into 4 domains: “my health” (35 items), representing the patient’s experiences with their health, healthcare challenges, and goals set within this domain; “my activities” (6 items), representing daily activities; “my environment” (10 items), representing social relations and the physical environment; and “my own way” (4 items), representing coping strategies.⁴ Patients completed the questionnaire before the aftercare consultation. Patients rated their experienced distress on the DT (range = 0 [no distress]–10 [high distress]) and their experienced challenges with the items in the questionnaire, such as fatigue, fear, and challenges with work or partner, on a 3-point scale (0 = *no*, 1 = *sometimes* and 2 = *yes*), with higher scores indicating poorer functioning. During the following aftercare consultation, the outcomes of the questionnaire were discussed and used to collaboratively set personal goals (shared goal-setting phase) and to decide on aftercare interventions (shared care planning).⁴

After the consultation, patients were asked to complete a questionnaire that asked about their experience level of SDM, which they could return anonymously to the hospital. The questionnaire included the Dutch versions of the CollaboRATE questionnaire¹¹ and the 9-item Shared Decision-Making Questionnaire (SDM-Q-9).¹² The scores on the questionnaire revealed that patients were generally satisfied with the experienced level of SDM (mean score of 84 out of 100 on the SDM-Q-9 and mean score of 91 out of 100 on the CollaboRATE).

Participants

A total population sampling technique was used, and 120 patients were invited for an aftercare consultation with the NP. All patients met the following inclusion criteria: (a) Diagnosed with non-Hodgkin or Hodgkin lymphoma; (b) treated with chemotherapy combined with other therapy; and (c) in remission after medical treatment of newly diagnosed or relapsed patients with lymphoma.

Variables and Data Collection

Experienced distress and challenges were retrieved from the PROM questionnaire, which patients filled out before attending the aftercare appointment. The NP and patients discussed the outcomes to set personal goals and plan interventions during the aftercare consultation. At this time, the NP registered the set personal goals and planned interventions in the patients’ files structured according to the 4 domains of life. Afterward, the data on goals and interventions were extracted by auditing all patients’ files.

Analysis

Descriptive analysis was performed using the IBM Statistical Package for the Social Sciences version 27.¹³ Missing data were coded as such and omitted from the analysis. The mean, median, and standard deviation scores on the DT and the frequencies of the reported challenges (answers of *yes* and *sometimes* in

Table 1. Patient Characteristics.

Patient characteristics (n = 49)	
Age (Mean/range)	65 (18-82)
Gender (n/%)	
Male	37/75.5
Marital status (n/%)*	
Married or cohabiting	39/86.6
Single	4 /8.8
Widowed	2/4.4
Diagnosis (n/%)	
Diffuse large B-cell lymphoma	26/53.0
Follicular non-Hodgkin lymphoma	6/12.2
M. Waldenström	6/12.2
Hodgkin lymphoma	3/6.1
Other Non-Hodgkin lymphomas	8/16.3
Treatment (n/%)	
R-CHOP ^a (up to 8x)	34/69.3
Combination chemo-immunotherapy + ASCT ^b	2/4.0
8x R-CVP ^c	6/12.2
4–8x ABVD ^d	2/4.0
DRC ^e or R-Bendamustin	5/10.2

*Missing values: 4. Percent = valid percent.

^aRituximab, cyclophosphamide, doxorubicin, vincristine, and prednisolone.

^bAutologous stem-cell transplantation.

^cRituximab, cyclophosphamide, vincristine, and prednisolone.

^dAdriamycin, bleomycin, vinblastine, and dacarbazine.

^eDexamethasone, rituximab, cyclophosphamide.

the PROM questionnaire were calculated as experiencing the challenge), set goals and planned interventions were calculated.

Results

Of the 120 patients invited for an aftercare consultation, 49 gave informed consent to participate. Patients gave several reasons for not responding, such as already being provided with sufficient support.

See Table 1 for patient characteristics.

Distress Thermometer and Experienced Challenges

The scores on the DT ($N=49$) indicated a mean of 4.6 ($SD=2.2$) and a median of 5.0 on a range from 0–10, with 0 representing no experienced distress and 10 indicating high distress. The 3 most frequently experienced challenges across all domains (Table 2) were all physical challenges within the domain of “my health”: loss of physical condition ($n=48$, 98%), reduced muscle strength ($n=46$, 94%) and fatigue ($n=43$, 88%). In the domain “my health,” emotional challenges were also experienced, with pondering mentioned by more than half of the patients ($n=25$, 51%), followed by fear ($n=20$, 41%). Cognitive challenges were experienced by more than 40% of the patients. The most frequently experienced challenges in the domain of “my activities” were related to daily

functioning ($n=35$, 71%) and household activities ($n=18$, 37%). In the domain “my environment,” patients experienced a loss of libido ($n=20$, 41%), for which they expressed no need for professional care. Patients reported no challenges in the domain of “my own way.”

Personal Goals

Patients set a total of 94 personal goals with the NP during the aftercare consultations (Table 2). Most goals fell within the domain of “my health”: 45 patients (92%) set goals related to physical challenges, such as restoring physical condition to prediagnosis levels, and 7 patients (14%) set goals related to emotional and cognitive challenges, such as being able to enjoy life and experiencing less fear or pondering and being able to focus on a television program or playing a game. In the domain of “my activities,” 15 patients (31%) set goals in relation to practical challenges, such as performing household chores and gardening, and 8 patients (16%) set goals to resume work, such as resuming all activities on the farm or returning to work as a school principal or volunteer. In the domain of “my environment,” 8 patients (16%) set goals to resume their social activities, including playing golf, walking, dancing, and making love.

Table 2. Frequency of Experienced Challenges, Goals, and Interventions.

$N=49$	N (%)	N (%)	N (%)
Challenges experienced in the domain:		Goals set in the domain:	Interventions in the domain:
<i>My health</i>		<i>My health</i>	<i>My health</i>
Physical challenges		Physical challenges	Physical challenges
Loss of physical condition	48 (98)	Emotional challenges	7 (14)
Reduced muscle strength	46 (94)	Cognitive challenges	7 (14)
Fatigue	43 (88)	<i>My Activities</i>	<i>My Activities</i>
Nerve sensations of feet and hands	28 (57)	Practical challenges	15 (31)
Sleep disorder	26 (53)	Social challenges	4 (8)
Weight loss	13 (27)	Work or school-related challenges	8 (16)
Dry skin	19 (39)	<i>My environment</i>	<i>My environment</i>
<i>Emotional challenges</i>		Dealing with loved ones	8 (16)
Pondering	25 (51)	<i>Referral</i>	<i>Referral</i>
Restlessness	17 (35)	Oncological physical therapy	17 (35)
Grieve	14 (29)	Oncological rehabilitation	16 (33)
Less emotional control	21 (43)	Physically active	12 (24)
Fear of disease or treatment	20 (41)	(walking, visiting a sports club, cycling)	
Feelings of depression	15 (31)		
<i>Cognitive challenges</i>			
Memory loss	23 (47)		
Problems with concentrating	21 (43)		
<i>My activities</i>			
<i>Practical challenges</i>			
Problems with daily functioning	35 (71)		
Problems with household activities	18 (37)		
<i>My environment</i>			
<i>Social challenges</i>			
Loss of libido	20 (41)		

Planned Interventions

Most interventions were planned in the domain of “my health” (Table 2), with most patients ($n = 41$, 84%) choosing an intervention to improve their physical condition and muscle strength. A majority of patients ($n = 33$, 67%) chose to be referred to specialized care, of which 17 (35%) opted for oncological physical therapy and 16 (33%) opted for multidisciplinary oncological rehabilitation. A total of 12 patients (24%) chose to be physically active themselves, for example, by walking or visiting a sports club.

Discussion

This study aimed to describe the personal goals related to experienced challenges and planned aftercare interventions of patients with lymphoma in various domains of life that emerged from aftercare consultations based on SDM principles with an NP. The majority of the patients experienced physical challenges within the domain of “my health.” Accordingly, most goals and interventions were related to these challenges. To cope with these challenges, two-thirds of patients chose a referral to specialized care.

Our study adds knowledge to cancer research agenda's^{2,3} in giving insight into set personal goals and planned interventions related to experienced challenges in various domains of life, that were formulated by patients with lymphoma. Furthermore, it may support nurses to better inform patients and facilitate personal care planning. As each patient is unique, it is important that nurses facilitate a discussion based on SDM principles.

Our study is in line with former studies in which patients reported impaired physical functioning and fatigue as major challenges after treatment of malignant lymphoma.¹⁴⁻¹⁶ Challenges in the physical domain are frequent and easily addressed by both patients and health professionals.^{6,17} Approximately one-third of the patients chose referral to multidisciplinary oncological rehabilitation, which addresses interrelated challenges concerning physical, cognitive, emotional, social, and spiritual levels and/or role functioning.¹⁸ However, according to the literature, patients seem to make little use of aftercare possibilities.² Thus, it is worthwhile to further explore which patients completed the aftercare interventions that they planned during their consultation. Furthermore, more research is needed about the benefits that patients experienced from support or specialized care during and after treatment.

Limitations

A limitation of this study is that only patients who perceived the need for the aftercare consultation participated. Accordingly, we may have selected a group that experienced the most challenges after treatment and, therefore, the results may not be generalizable to all patients with lymphoma. Another limitation is the lack of diversity of characteristics because of the small total number of patients—predominantly older male patients

with diffuse large B-cell lymphoma. Although diffuse large B-cell lymphoma has the highest incidence, is diagnosed more in men than in women and the mean age of the patients in our study corresponds with the reported age of this type of lymphoma,¹⁸ our results may not be generalizable to other groups of patients with lymphoma.

Conclusion

The results of this study provide insight into experienced challenges, set goals, and planned interventions by patients with lymphoma after chemo-(immuno)therapy. Physical challenges in the domain of “my health” were reported most frequently. Accordingly, most goals and interventions were set within this domain.

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Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the Ethical Standards of the Institutional and National Research Committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Ethical approval for this study was obtained from the Medical Ethics Committee Zuyderland Medical Center (METCZ20190001).


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Informed Consent

Informed consent was obtained from all individual participants included in this study.

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