

Delivering high-quality care to patients with a non-Hodgkin's lymphoma: barriers perceived by patients and physicians

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ABSTRACT

Background: Despite the presence of non-Hodgkin's lymphoma (NHL) guidelines, there are still gaps between best evidence as described in guidelines and quality of care in daily practice. Little is known about factors that affect this discrepancy. We aim to identify barriers that influence the delivery of care and to explore differences between patients' and physicians' experiences, as well as between the different disciplines involved.

Methods: Patients and physicians involved in NHL care were interviewed about their experiences with NHL care. The barriers identified in these interviews were quantified in a web-based survey. Differences were tested using Chi-square tests.

Results: Barriers frequently perceived by patients concerned lack of patient information and empathic contact (12-43%), long waiting times (19-35%) and lack of guidance and support (39%). Most barriers mentioned by physicians concerned the unavailability of the guideline (32%), lack of an up-to-date guideline (66%), lack of standardised forms for diagnostics (56-70%) and of multidisciplinary meetings (56%). Perceived barriers concerning the guideline and standardised forms significantly varied between the disciplines involved (range 14-84%, $p < 0.05$).

Conclusion: Patients and physicians experienced different barriers for high-quality NHL care. A tailored strategy to optimise guideline adherence and daily NHL care, based on these barriers, has to be developed and tested.

KEYWORDS

Barriers, implementation, non-Hodgkin's lymphoma, qualitative analyses, quality of care, quantitative analyses

INTRODUCTION

The incidence of malignant lymphoma has increased significantly over the past years.^{1,2} Malignant lymphomas can be classified into Hodgkin's lymphoma (HL) and non-Hodgkin's lymphoma (NHL). The latter is the most common haematological neoplasm in adults worldwide.³ Multidisciplinary evidence-based guidelines for NHL have been developed, both nationally and internationally, to assist physicians and patients in their decisions regarding appropriate diagnostics, treatment and follow-up.⁴⁻⁷ Unfortunately, just the publication and dissemination of guidelines is often not enough to close the existing gap between guidelines and daily practice.⁸ We believe that better guideline adherence can lead to a higher quality of care. Therefore, the first step in improving quality of care is getting insight into current daily practice and the factors that influence the delivery of high quality of care.⁹ For NHL, several studies have demonstrated that the patient care is suboptimal.¹⁰⁻¹² Wennekes *et al.*,¹² for example, described lack of guideline adherence concerning diagnostics, therapy and follow-up. However, less is known about barriers that influence delivery of high-quality NHL care experienced by patients and physicians. The aim of

this study is to identify the most important barriers that influence daily NHL care as perceived by patients and physicians.¹³

METHODS

Study design

We qualitatively explored barriers of delivering NHL care by performing semi-structured interviews among patients and physicians. In order to assess the importance of the barriers found, we quantified the barriers in a web-based survey.

Participants and recruitment

Patients. Patients were recruited for the interviews through the website of the Dutch Lymphoma Organisation (patient association (LVN)), or by their attending physician. For the surveys, Twitter and the online forum of the LVN were used for recruitment. Patients diagnosed before 2008 were excluded to ensure information on current quality of care (2008–2011). Patients were reminded to complete the survey by an updated news item on the LVN website and by another tweet. Consent for the interview and survey was presumed if patients responded positively.

Physicians. Physicians involved in NHL care, including haemato-oncologists, pathologists, radiation oncologists, radiologists and nuclear medicine physicians, were included in the study. For the interviews, physicians from 22 hospitals involved in an NHL study in 2006¹² were invited to participate. Additionally, physicians involved in the Lymphoma Working Party of the Haemato-Oncology Foundation for adults in the Netherlands (HOVON) were invited by e-mail. For the surveys, the Dutch Societies of Internal Medicine (NIV), Pathology (NVvP), Radiology (NVvR), Nuclear Medicine (NVNG), and Radiation Oncology (NVRO) were consulted for contact information. Based on this, physicians were contacted either via a call in the newsletter (NVvP, NVvR), by email (NVNG, NVRO), or by post (NIV). Since no additional registration exists for physicians specialised in NHL, all members of the Dutch Societies were contacted. A reminder was sent to all, two to four weeks after the initial mailing. The surveys were independently tested by two project members before fielding the questionnaires. Consent for the surveys was presumed if the questionnaire was completed.

Instrument development and content

Interviews. The interviews were scheduled according to the participants' preferences concerning date and setting (face-to-face or by telephone). Participants were asked about their experiences with clinical practice regarding NHL care. The structure of the interviews was based

on previously developed quality indicators¹² and two theoretical models.^{14,15} These models facilitate description of potential barriers using five domains: factors related to the guideline (I), to physicians (II) and patients (III) and factors concerning the organisational (IV) and social (V) context. Data collection was finished when no new influencing factors were found and saturation was reached. All interviews were audiotaped and transcribed verbatim for analysis with Atlas.ti® (version 6.2.23, Atlas.ti Scientific Software Development GmbH; Berlin, Germany). The results of the interviews were used for the surveys.

Surveys. Because patients and physicians have different perspectives in NHL care, two different surveys were developed. The surveys were converted into a web-based survey using LimeSurvey (version 1.91, Boston, MA). The online survey did not accept unanswered questions and adaptive questioning was used. A modified version of the 'Consumer Quality Index (CQI) for cancer patients' was used.¹⁶ The CQI, based on the American Consumer Assessment of Health Providers and Systems (CAHPS) instrument, is a standardised method to measure experiences of patients concerning quality of care. Permission to use this survey was obtained.

The patients were asked about their experiences regarding the organisation of NHL care, competence of physicians, information provision and communication, collaboration in NHL care, guidance and support, and after care. Questions were scored using closed questions with four answer possibilities, including never (1), sometimes (2), most of the time (3) and always (4). When relevant, 'I don't know' or 'not applicable' were included. The first part of the survey contained 11 questions about characteristics of the patients, including age, gender and type of NHL.

The surveys developed for physicians consisted of 85 questions for haemato-oncologists, 52 for pathologists, 63 for radiologists and nuclear medicine physicians, and 59 for radiation oncologists. The first part of the survey contained eight questions about characteristics of the physicians and their clinical setting, including age, gender and the type of hospital. The surveys were divided into the same five domains as the interviews,^{14,15} and concerned statements about the Dutch NHL guideline and local protocols, working according to the recommendations, the organisation of NHL care and the social context. The statements were scored on a five-point Likert scale (1=strongly agree, 5=strongly disagree).

Data analysis

Interviews. The interview transcripts were analysed using qualitative content analyses, taking into account the direct as well as the underlying meaning of the text.¹⁷ Potential

barriers were identified independently by two members of the project team. Any discrepancies were discussed until consensus was attained. Two other members of the project team randomly choose two transcripts to verify the qualitative analyses. After extraction, the established barriers were categorised into the above-mentioned domains and their frequency was scored.

Surveys. SPSS (version 16.0, Chicago, IL) was used for the analyses of the survey results. The answer possibilities of the patient survey were dichotomised as disagreement (score 1 or 2) and agreement (score 3 or 4). For physicians, the Likert scores were classified as agreement (score 1 or 2), neutral (score 3) and disagreement (4 and 5). Differences between patients and physicians were descriptively reported. Chi-square tests (statistical significance set at two-sided $p < 0.05$) were performed to get insight into differences in perceived barriers between the four disciplines involved in NHL care.

RESULTS

Participants and recruitment

Seventeen patients and 33 physicians from hospitals spread over the Netherlands were interviewed. *Table 1* shows the

characteristics of 28 patients and 132 physicians who filled in the survey. Patients and physicians from all age groups were represented and the two sexes were equally divided in both patients and physicians. Most patients (19 out of 28) in our study population had a diffuse large B-cell lymphoma or follicular lymphoma.

Barriers perceived by patients and physicians

The interviews resulted in barriers in all five predefined domains. In total, during the interviews 62 unique barriers were identified by patients (24 barriers) and physicians (47 barriers). They mainly indicated barriers in the physician (24 barriers) and organisational domain (15 barriers). Physicians also mentioned 13 barriers concerning the guideline. Eight unique barriers in the social context and two barriers related to the patient were identified.

In *table 2a and 2b*, the most important barriers perceived according to patients and physicians, as quantified by the surveys, are summarised. Barriers are included if at least 15% of the responders classified that item as a barrier and if ≥ 15 responders answered the question concerned. Barriers among patients, physicians, and differences between them are described below. Some illustrative quotations from the interviews are included in *figure 1*.

Table 1. Characteristics of patients and physicians who filled out the survey

Patients (n=28)			Physicians (n=132)		
Characteristics	N	%	Characteristics	N	%
Gender			Gender		
Male	14	50	Male	72	55
Female	14	50	Female	60	45
Age groups			Age groups		
25-44	8	29	25-44	62	47
45-64	18	64	45-64	67	52
≥ 65	2	7	≥ 65	2	2
NHL classification			Discipline		
Follicular lymphoma	9	32	Haematology/Oncology	50	38
DLBCL	10	36	Pathology	31	24
Marginal zone B-cell lymphoma	2	7	Radiation oncology	36	27
Other classification	7	25	Radiology/Nuclear medicine	15	11
Region of hospital			Region of hospital^a		
North	3	12	North	14	11
East	2	8	East	25	19
South	3	12	South	7	5
West	18	69	West	82	62
			Abroad	4	3
Type of hospital^b			Type of hospital		
University	10	38	University	45	34
Non-university	21	81	Non-university	87	66
Level of education			Years of experience		
Low	13	48	0-5 year	49	37
Middle	10	37	6-15 year	49	37
High	4	15	16-25 year	26	20
			>25 year	8	6

DLBCL = diffuse large B-cell lymphoma; ^a physicians were asked in which region they were trained; ^b five patients were under treatment in more than one hospital.

(I) *Guideline-related barriers*. No barriers related to the guideline (developed for and by physicians) were mentioned by the patients. Physicians pointed out barriers mainly regarding the lack of availability of local NHL protocols (47%) and lack of an up-to-date version of the NHL guideline (66%). They agreed about the need to have

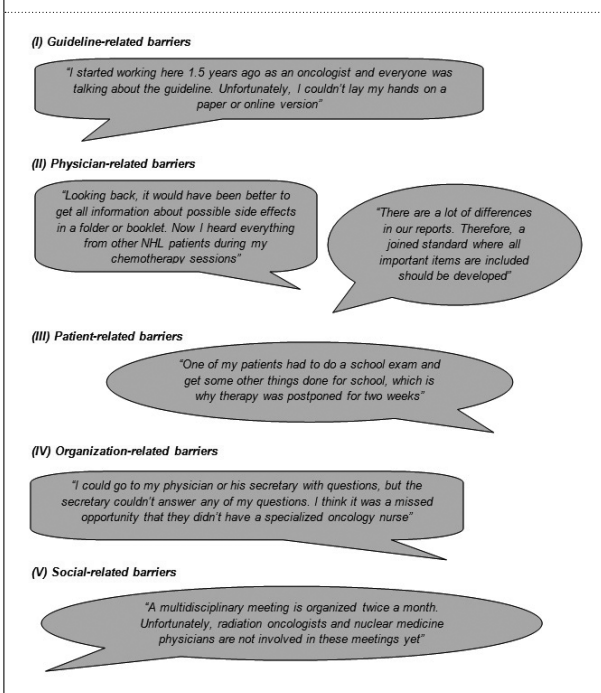
Table 2a. Most important perceived barriers that influence daily NHL care according to patients

Perceived barriers per domain	Number of patients ^a	
	N	%
(I) Guideline		
-		
(II) Physicians	N	%
Patient communication/information		
In my hospital, physicians do not...		
... provide written information about diagnostics and/or therapy	5	22
... provide information about patient associations	10	44
Emphatic contact		
In my hospital, most physicians do not...		
... listen carefully to their patient	4	16
... show personal interest in their patient	7	28
... show attention for emotions and coping of the patients' relatives	8	35
(III) Patients	N	%
In my hospital...		
... patients may not always participate in decision-making	3	13
(IV) Organisational context	N	%
Waiting times		
In my hospital...		
... time between referral and first diagnostics was >10 weekdays	5	19
... time between first diagnostics and final diagnosis was >15 weekdays	9	35
... treatment could not be started as soon as possible after diagnosis	8	31
... hospital appointments for diagnostics/therapy were not planned on one day	13	50
... my own physician is not available in case of urgent problems	4	15
(V) Social context	N	%
Teamwork and personalised care		
In my hospital...		
... physicians are not informed about agreements made with other physicians	4	17
... there is no central contact person for making appointments	5	22
... patients often see different physicians for diagnostics and treatment	4	17
Guidance and support		
In my hospital...		
... no help was offered for dealing with emotions and practical problems	8	35
... no psychological help was offered after breaking bad news	9	39
^a Not all questions were answered by all patients. Therefore the results do not always relate to the total study population (n=28).		

Table 2b. Most important perceived barriers that influence daily NHL care according to physicians

Perceived barriers per domain	Number of physicians ^a	
	N	%
(I) Guideline		
The NHL guideline...		
... is not really known to me	27	24
... is not easily accessible for me	35	32
... is not extensively read by me	35	32
... is not used as a reference	46	42
... does not give enough room for including patient preferences	18	16
... is not clear enough for my profession	35	32
... is not up-to-date for my profession	71	66
... is hard to update because of lack of consensus	34	31
... <i>should be updated</i>	72	66
... <i>should be available online</i>	91	83
A local NHL protocol...		
... is not available at our hospital	52	47
... is not clear enough for my profession	9	15
... is not up-to-date for my profession	13	22
... <i>should be available online</i>	35	63
... <i>is not necessary because we use protocols of other hospitals</i>	29	58
(II) Physicians	N	%
Working according to the NHL guideline/protocol		
In our hospital...		
... the IPI score is not routinely calculated for NHL	6	15
... indicator lesions are not routinely measured	14	21
... the Cheson response criteria are not routinely used	22	40
Standardised forms		
In our hospital no standardised forms		
... for pathology requests are available	41	70
... for pathology reports are available	32	56
... for radiology/nuclear medicine requests are available	39	59
... for radiology/nuclear medicine reports are available	43	65
... no integrated reports are accomplished for radiology and nuclear medicine	20	32
(III) Patients	N	%
-		
(IV) Organisational context	N	%
Materials and facilities		
In our hospital...		
... no standard NHL patient information is available	13	22
... no standard procedure for after care is available	9	15
... no compulsory training days for NHL care are established	34	32
... no specialised oncology nurse is present	15	24
Waiting times		
In our hospital...		
... diagnostics can usually not be done in 15 weekdays	9	16
(V) Social context	N	%
Multidisciplinary meetings...		
... do not include all professions involved	53	56
... <i>with all professions involved would improve NHL care</i>	52	64
^a Not all questions are applicable to all five professions or are answered by all physicians. Therefore the results do not always relate to the total study population (n=132). ^b Based on multiple choice questions where more than one answer could be checked. Items in italics are perceived as facilitators.		

Figure 1. Illustrative quotations from patients and physicians concerning barriers of quality of NHL care delivered



an up-to-date, online version of the guideline (66% and 83%, respectively) and an online version of the local NHL protocol (63%). Of note, 24% of the physicians were not familiar with the guideline.

(II) Physician-related barriers. The most frequently mentioned barrier by patients concerned physicians providing insufficient information about patient associations (44%), the lack of attention for coping of the patients' relatives (35%) and not showing personal interest in a patient (28%). Insufficient written information provided by physicians was mentioned frequently during the interviews and 22% agreed on this in the survey. Physicians did not mention barriers regarding information provision and communication, but mainly focused on the lack of standardised forms for diagnostic requests and reports (ranging from 56-70%) and the not routinely used Cheson response criteria (40%).

Physicians did not mention barriers regarding information provision and communication, but mainly focused on the lack of standardised forms for diagnostic requests and reports (ranging from 56-70%) and the not routinely used Cheson response criteria (40%).

(III) Patient-related barriers. Concerning patient self-reflection, some patients mentioned a lack of participation in decision-making (13%); physicians did not mention barriers in this domain. In the interviews, a few patients and physicians mentioned patients' preferences concerning postponement of diagnostics or treatment as impeding factor.

(IV) Organisation-related barriers. Patients pointed out waiting times as a barrier, with hospital appointments not planned on one day (50%) being the most common issue. Physicians mentioned the lack of compulsory training days for NHL care (32%) and the absence of a specialised oncology nurse (24%) as a barrier. The latter was also mentioned frequently during the interviews.

(V) Social-related barriers. Barriers perceived by patients included items on teamwork and guidance & support; for example, the lack of help offered after breaking bad news (39%). Physicians pointed out barriers concerning structural multidisciplinary meetings. Especially, the lack of participation of all involved disciplines in the multidisciplinary meetings (56%) was seen as a barrier. They agreed that the involvement of all disciplines participating in NHL care in multidisciplinary meetings would improve NHL care (64%).

Differences in perceived barriers between the disciplines involved

Significant differences ($p < 0.05$) in perceived barriers between the four disciplines involved in NHL care are found (table 3). Pathologists more often perceived barriers according to accessibility of the guideline, (57%) its use (52%), and clarity of a local protocol (63%) compared with other disciplines; radiation oncologists perceived these barriers in only 14%, 14% and 0%, correspondingly. Regarding standardised forms, haemato-oncologists less often perceived barriers concerning standardised pathology forms (42%) than pathologists (84%) and 21% of the haemato-oncologists perceived the lack of integrated forms as a barrier compared with 48% of the radiologists/nuclear medicine physicians. In the organisational context, standardised patient information about NHL seems less often available for radiation oncologists than haemato-oncologists (classified as barrier in 50% versus 15%) and the absence of compulsory training days for NHL was most rated as barrier by radiation oncologists (71%).

DISCUSSION

This is the first study to identify barriers for delivering good quality of care to NHL patients. The interviews and survey showed considerable differences in focus between patients and physicians involved in NHL care. Patients pointed out more barriers regarding patient communication, guidance and waiting times, whereas physicians focused on guideline-related barriers and standardisation of forms and procedures. Among the physicians from the four disciplines involved in NHL care significant differences were encountered in lack of guideline use, standardised forms, patient information and compulsory training days.

Table 3. Differences in perceived barriers between physicians of the disciplines involved in NHL care

Perceived barriers per domain	Haemato-oncologists		Pathologists		Radiologists/ nuclear med. physicians		Radiation oncologists		P value
(I) Guideline	N	%	N	%	N	%	N	%	
The NHL guideline...									
... is not easily accessible for me	11	24	12	57	10	33	2	14	0.02
... is not extensively read by me	9	20	11	52	13	43	2	14	0.01
... is not up-to-date for my profession	34	74	7	35	22	73	9	64	0.01
... should be updated	32	71	10	50	17	57	13	93	0.04
A local NHL protocol...									
... is not clear enough for my profession	3	13	5	63	1	7	0	0	0.00
(II) Physicians									
Standardised forms									
In our hospital...									
... no standardised forms for pathology reports are available	16	42	16	84	n.a.	n.a.	n.a.	n.a.	0.00
... no integrated reports are accomplished for radiology and nuclear medicine	8	21	n.a.	n.a.	12	48	n.a.	n.a.	0.03
(IV) Organisational context									
Materials and facilities									
In our hospital...									
... no standard NHL patient information is available	7	15	n.a.	n.a.	n.a.	n.a.	6	50	0.01
... no compulsory training days for NHL care are established	11	23	5	26	8	31	10	71	0.01

n.a. = not applicable to this profession.

In this study, an important barrier pointed out by patients was the need for clear information from physicians. Studies in other areas of healthcare have also pointed out the lack of information provided by physicians.^{18,19} However, the ability of patients to recall the information provided might not always be optimal as well.²⁰ Next to good communication, emphatic contact is often put forward when experienced care is evaluated. Our results and those of other studies^{21,22} show that these two topics are important issues of concern for patients. Physicians, on the other hand, did not pay special attention to barriers regarding information provision and communication to patients. Research shows, however, that emphatic communication can influence patient satisfaction, quality of life and even medical outcome.^{23,24}

Interestingly, a barrier frequently mentioned by physicians concerned the lack of an up-to-date guideline. In general, clinical guidelines aim to promote evidence-based practice and improve patient outcomes.²⁵ It is hence necessary to update guidelines on a regular basis. The Dutch NHL guideline⁶ was developed in 2004 and has not been updated since. However, several web-based protocols were initiated²⁶ and international evidence-based guidelines are available online.^{5,7} The use of such protocols is associated with better patient outcomes.^{27,28} We therefore believe that the implementation of an updated national NHL guideline could help to reduce perceived barriers and may result in improved quality of NHL care.

In several cancer studies guideline adherence was associated with better overall survival or progression-free survival.^{29,30} Our study showed several barriers resulting from not working according to guidelines, for example lack of assessing the Cheson therapy response criteria (table 2b). Recently, a national imaging working group developed recommendations for the standardisation of PET-CT scan requests and reports.³¹ Another important barrier is the lack of well-organised multidisciplinary meetings. Guidelines for optimal functioning of multidisciplinary meetings have recently been formulated.³² The dissemination of these recommendations is definitely an important step towards improved care.

With regard to the strengths of this study, a unique setting was created to obtain a broad overview of perceived barriers in current NHL care. First of all, physicians of all disciplines involved in NHL care were approached to participate in our study. This gave us the opportunity to compare barriers perceived between the four disciplines involved. Our results indicate differences in perceived barriers among physicians involved in NHL care, which is valuable for subsequent research.

Second, we incorporated the patients' perspective in the study. The inclusion of NHL patients in our study is in line with the increasingly important role of patients in managing their own hospital care. This study clearly shows the added value of incorporating patients' points

of view: barriers concerning patient communication and information provision were not experienced by physicians, whereas this was a main concern for patients. To our knowledge, this is the first study that looks at such a wide-ranging study population, including patients as well as physicians from all disciplines involved.

Third, identification of the barriers perceived was based on both qualitative and quantitative research. Interviews were used to qualitatively explore barriers perceived by patients and physicians, after which these results were quantified in a survey. This thorough overview is not only applicable on a national level, but might also be valuable internationally since recommendations on NHL care in the Dutch guidelines and protocols largely conform to international guidelines.^{4-7,26}

There are also some limitations in this study that should be addressed. First, we were not able to calculate the survey participation rates. LVN and the Dutch Societies do not provide home addresses of patients or physicians for study purposes and there is no registration for physicians specialised in NHL care. Based on these restrictions, we do believe the best possible way to approach participants was utilised.

Second, the recruitment method used is possibly also responsible for the relatively low number of responses and could have introduced underreporting. We think that highly motivated persons might participate more often in research than less motivated/involved ones. For example, the percentage of physicians who do not really know the content of the NHL guideline might be even lower in the non-responder group. Another possible explanation for the low number of responses might be that NHL patients are often older patients who may not be familiar with the Internet. Our responders, however, represented NHL patients and physicians of all age groups and our total study population was diverse (table 1).

Third, the surveys applied were not validated before use. However, to ensure that they truly represent the complete spectrum of NHL care, the surveys were based on the barriers identified in the prior interviews. In addition to this, the patient survey was derived from the standardised CQI questionnaire for cancer patients. For this reason four answer possibilities were used in the patient survey, instead of the frequently used five-point Likert scale. To the best of our knowledge, no validated questionnaires were available that could have been used in our study.

In conclusion, this study gives a broad overview of barriers that influence NHL practice, as perceived by patients and physicians. Barriers most mentioned by patients were lack of guidance & support, long waiting times and lack of clear communication and emphatic contact. Physicians most often stated lack of an up-to-date, online NHL

guideline, lack of standardised forms for diagnostics and the absence of multidisciplinary meetings with all physicians involved. Among the four disciplines involved in NHL care significant differences were encountered in guideline use and the lack of standardised forms, patient information and compulsory training days. Together with the gaps found in quality of care by Wennekes *et al.*,¹² our results form a solid basis to develop a tailored implementation strategy to increase the quality of NHL care and to test this strategy on effectiveness and costs.

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