



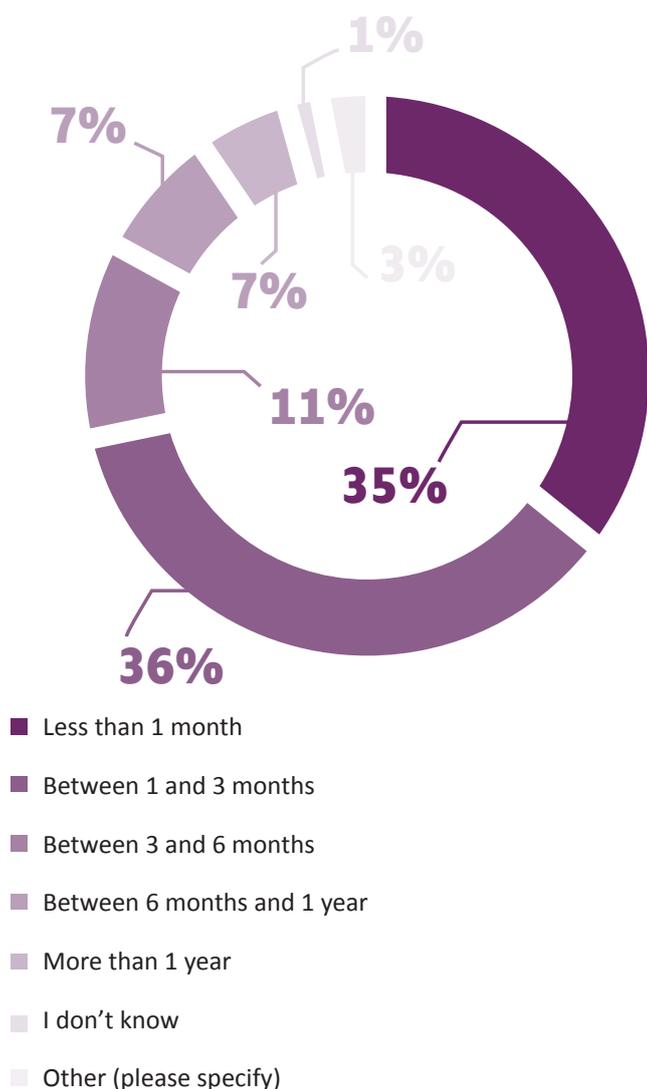
Are we all equal on terms of access to lymphoma care?

Spotlight on patients' experience

This France Lymphome Espoir survey was designed to highlight the experiences of lymphoma patients and their families. It collected 1,639 responses between 15 September and 15 November 2018. It was supplemented by a «mirror» survey of 66 specialist doctors, mostly haematologists, to compare and contrast their perceptions. It focuses on 4 main aspects of the care pathway: diagnosis; the relationship between the patient and the care team; access to care; the disease's human impact and its financial burden.

1. Lymphoma diagnosis: a vital milestone on the care pathway

Chart: Time between first visit to doctor and diagnosis (Patients)



The time that elapses between a patient's perception of persistent symptoms, consultation with a doctor and a **formal diagnosis** can vary. It may be longer for indolent lymphomas than for aggressive lymphomas. Most patients (71%) are diagnosed within 3 months of their first visit to a doctor. However, for more than 1 patient in 10 (14%) this period may exceed 6 months due to **misdiagnosis**.

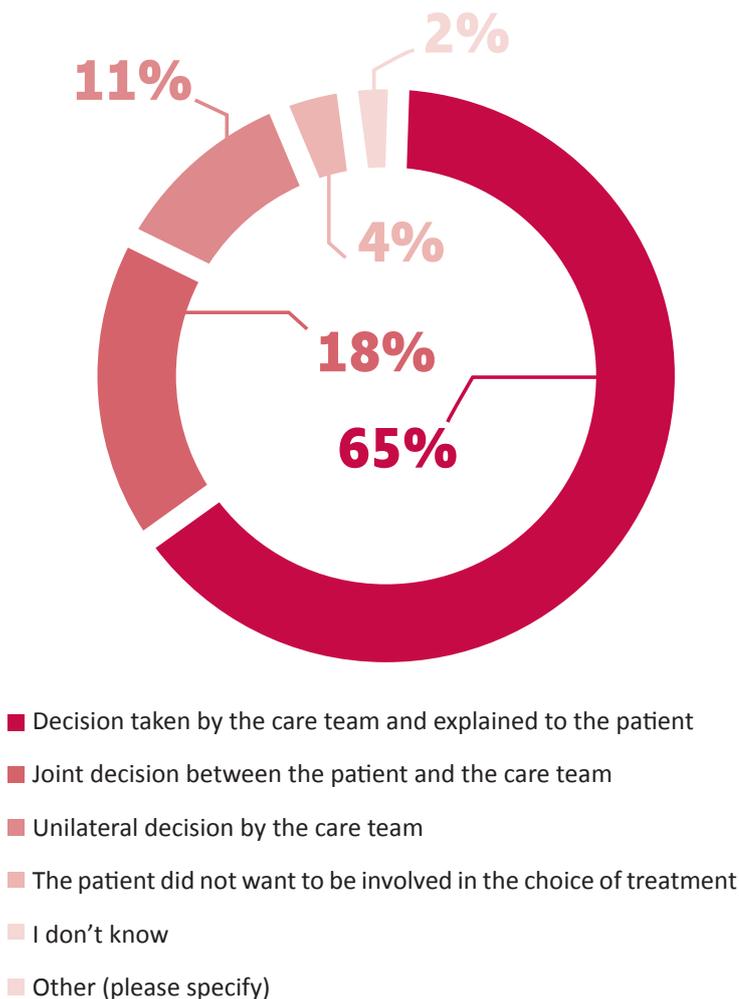
The survey identifies **2 main causes** for this: insufficient knowledge of lymphoma symptoms among general practitioners and delays in accessing diagnostic tests. Patients find this wait all the more difficult to accept because it results in reduced opportunity, especially in the case of aggressive lymphomas.

The delay between the diagnosis and the beginning of the first treatment is generally short and depends on how aggressive the lymphoma is (80% of the patients surveyed were treated within 3 months). On the other hand, support for **patients in «therapeutic abstinence»** needs to be improved with strengthened listening and supportive care facilities.

As for the **consultation dedicated to communicating the diagnosis**, not all patients benefit from it yet. The lack of haematologists' time and of dedicated professional skills, particularly among nurses and psychologists, is an issue.

2. Improving relations between patients and their care team

Chart: Patients' involvement in the choice of treatment (Patients)



Lack of haematologists' time: nearly 1 haematologist in 2 (43%) spends only 15 to 20 minutes on each patient during consultations, a situation which half of them consider insufficient. This situation, which results in particular from the scarcity of practitioners in relation to the number of patients, affects the quality of communication with and listening to patients.

Patients and their families identify **Improving comprehensive information** about the disease, the available treatments and their side effects as a top priority.

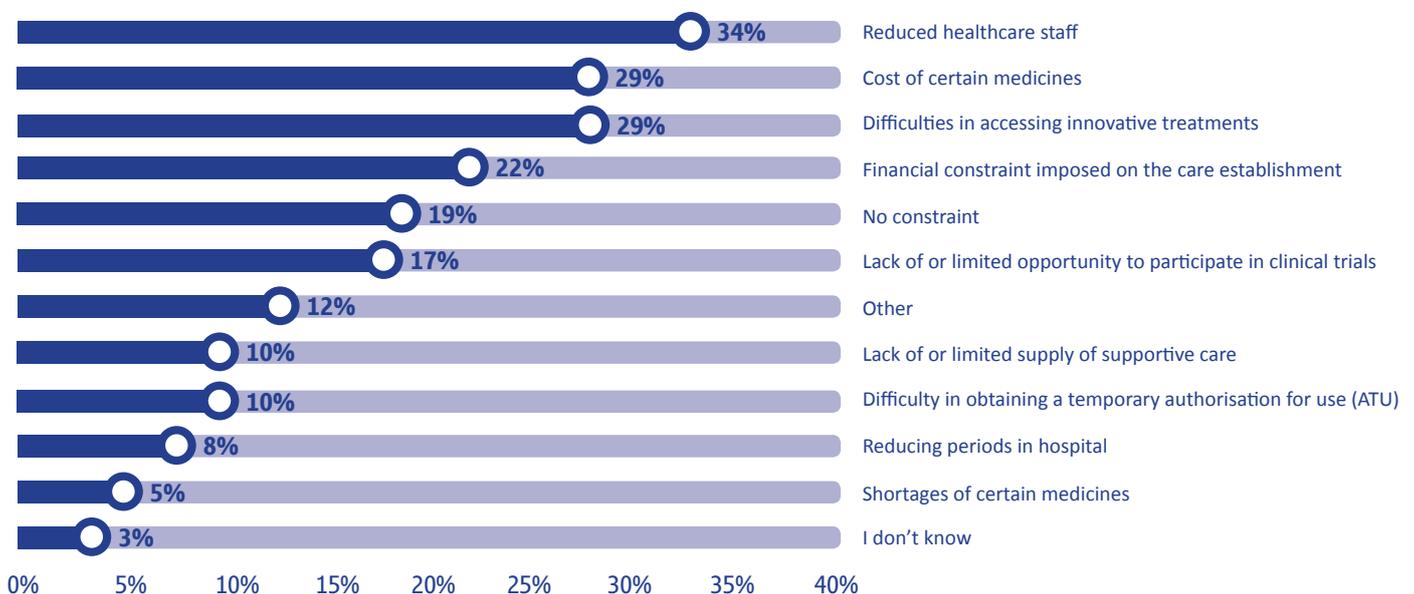
Greater involvement of patients in treatment options: under 2 patients in 10 (18%) shared the decision concerning their treatment options with their care team. Even when patients are offered the possibility of participating in a clinical trial, shared decision-making remains a minority practice (only 38% of patients in this situation report having benefited from it).

Patients consistently complain about the frequent change of interns during their treatment. They consider the **referring haematologist's follow-up** for the duration of the treatment necessary to establish a relationship of trust between the patient and the care team.

Better training in the psychological and relational dimension could also help haematologists to be better able to respond to patients' concerns.

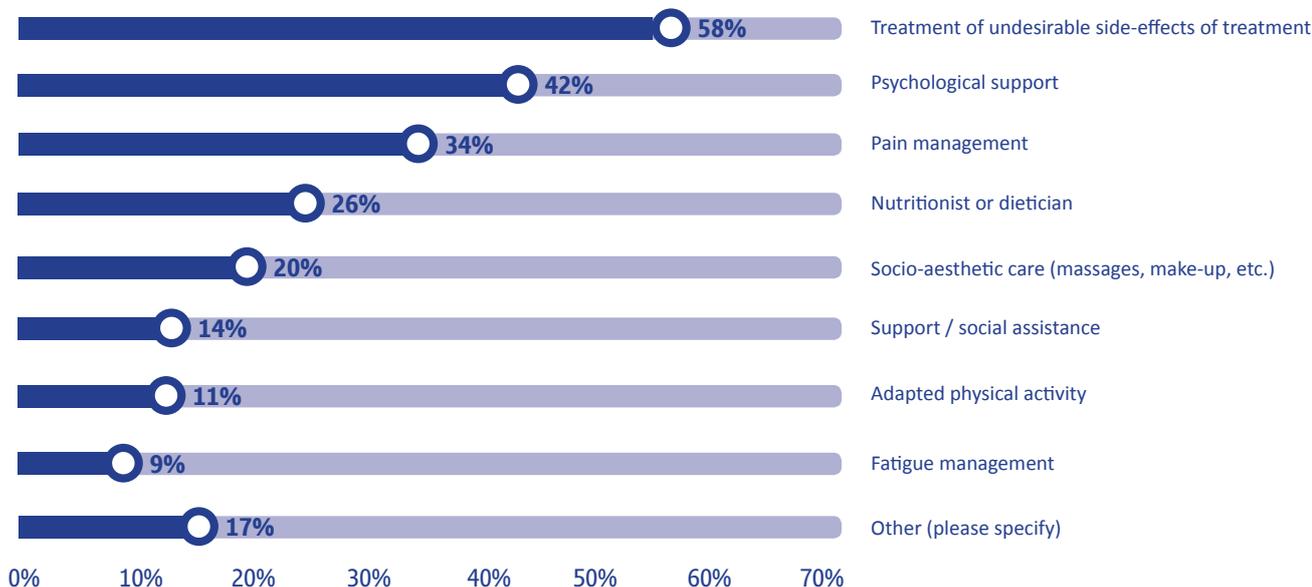
3. Access to treatment: patient priorities and constraints experienced by Haematologists

Chart: Constraints on the care pathway (Haematologists)



One-third of the haematologists (34%) identify the **decreasing number of healthcare staff** as the primary constraint on the care pathway. Patients also consider that the insufficient number of healthcare professionals affects the quality of the care they receive. While nearly a third of haematologists (29%) report **difficulties in accessing some innovative treatments**, only a small minority of patients (6%) report that they have experienced barriers to accessing the treatment or care prescribed for their condition. **Inequalities in access to clinical trials:** 1 patient in 4 was offered the possibility of participating in a clinical trial, but this proportion varies according to the type of facility where the patient is treated.

Chart : Provision of supportive care (Patients)



Need for comprehensive patient care: slightly more than 1 in 2 patients (58%) has benefited from medical care for treatment-related adverse events. In addition, coordination between lymphoma treatment and other medical care is often lacking.

The supply of supportive care is still inadequate: the 4 supportive care services that the French National Cancer Institute (INCA) considers essential are offered to less than a half of patients, and some even to under 1 in 5 patients: psychological care (42%), pain management (34%), nutritional follow-up (26%) and social care (14%). Complementary supportive care, such as adapted physical activity or fatigue management, is offered to only 1 in 10 patients. An almost total lack of support following the end of treatment is also reported.

4. The disease’s human impact and financial burden

Geographical distance: 1 patient in 5 has to travel more than one hour (20%) or more than 50 km (23%) to the health centre where they are being treated. These distances have a significant impact on the fatigue of patients who are already weakened by the disease and their treatment.

Inadequate system for reimbursing transport costs: transport costs to the care facility are residual costs that are borne by the largest number of patients. In addition, there are often travel and accommodation costs for relatives, especially when the distances between the place of residence and the care centre are significant.

Chart : Expenses paid by patients after reimbursement (Patients)



Residual charges can vary considerably, according to patients: for 1 patient in 2 (45%), the residual charge that has to be met by the patient for lymphoma care is less than 500 euros. Nevertheless, 1 patient in 4 pays an annual cost of 500 euros or more, and 1 patient in 10 pays even more than 5,000 euros.

Poor coverage of supportive care: supportive care is poorly covered by the social security system. The costs most often mentioned by respondents are: onco-aesthetic care, including the cost of wigs; customised nutrition; the use of complementary medicines; psychological follow-up and adapted physical activity.

The limits of the long-term / major illness (ALD – Affection de Longue Durée) exemption: While the ALD system allows most patients to be 100% covered for all care directly related to lymphoma, it does not apply to health costs that are an indirect consequence of the disease or treatment. In addition, reimbursement is calculated on the basis of social security tariffs, which do not always represent 100% of the costs incurred by patients. Lastly, the fact that ALD exemption is not retroactive can lead to significant costs when the diagnosis is made late and/or when the procedure for granting the ALD exemption is lengthy.

Conclusions

The survey results suggest that although access to available medical treatments for lymphoma is generally ensured, there are significant inequalities in the access to complementary but necessary care. The financial costs borne by patients are also a source of inequality. It would appear that the quality of the care pathway is largely determined by the human relationship between the patient and the healthcare team, which is itself affected by the lack of staff and resources.

Priorities arising from the survey

1. Improving information for general practitioners on lymphoma symptoms.
2. Accelerating access to diagnostic tests in cases of suspected lymphoma.
3. Ensuring the presence of healthcare staff dedicated to communicating the diagnosis to the patients in all health centres.
4. Ensuring that fertility preservation is systematically addressed.
5. Making haematologists aware of patients' expectations in terms of information.
6. Adapting the length of the consultation to patients' individual needs.
7. Involving the patient in deciding on treatment options, whatever the extent of these options.
8. Ensuring that the patient is followed by a referring haematologist throughout the care process.
9. Training haematologists to listen.
10. Ensuring equal access to innovative therapies.
11. Promoting equal access to clinical trials.
12. Offering patients a comprehensive care plan.
13. Expanding the supply of supportive care before, during and after the end of treatment.
14. Systematising the supply of supportive care for patients who are in therapeutic abstention.
15. Improving the supportive care provided outside the hospital setting.
16. Improving and facilitating the reimbursement of transport costs.
17. Extending to 100% the coverage for the care of the consequences of the disease or of its treatment.
18. Establishing the principle of full coverage retroactivity in the case of long-term / major illness (ALD).