Patient Preferences and Expectations regarding Leukemia and Lymphoma treatment: Improving Patient Engagement in Portugal through Quantitative and Qualitative Findings

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INTRODUCTION

For patient preferences to be effectively taken into consideration during care provision, it is important to undertake studies that explore these preferences and give the opportunity for patients to express their concerns. Subsequently, these judgments should be made known to the healthcare professionals, in order to meaningfully inform care activities.[1] In Portugal, there is a lack of evidence on leukemia and lymphoma patient preferences and expectations regarding treatment, which motivated the conduct of this study.

OBJECTIVE

To quantify the level of leukemia and lymphoma patient involvement in treatment decisions, patient preferences regarding the most valued criteria when choosing a treatment, and ascertain the main drivers of such engagement and preferences.

METHODS

An exploratory sequential mixed-methods design was implemented. This method involves the integration of quantitative and quantitative results, to provide a more comprehensive understanding of the research topic. The initial quantitative phase consisted of an online questionnaire (self-reported), to quantify the level of patient involvement and patient preferences, followed by online focus groups meetings (qualitative approach); to discuss previously collected data and explore the main drivers of engagement and preferences.

Both questionnaire and meeting invitation were shared online, with the support of **three national Patient Associations**: *Associação Portuguesa de Leucemias e Linfomas* (APLL), *Associação Portuguesa Contra a Leucemia* (APCL), *Associação de Apoio aos Doentes com Leucemia e Linfoma* (ADL);

Descriptive data analysis of the data collected in the **quantitative questionnaire** was complemented with content analysis, and **qualitative insights** from the **focus groups.**

RESULTS

1. Patient characterization

1.1 Quantitative phase

Between October to December 2022, **190 patients** currently undergoing treatment (n=73, 38%) or who have already completed treatment (n=117, 62%), answered to the quantitative questionnaire. Most participants were in the 41-55 age group (n=70, 37%), and 136 (72%) were female. The geographical distribution of participants covered 17 (of 18) districts of mainland Portugal and Islands, and the majority is followed in the public health sector (n=178, 94%).

Regarding socio-economic characteristics, a large proportion of patients have an advanced* level of education (n=81, 44%) And 36% has a gross monthly income between 500€-1000€.

ᵃ Aggregate level of education according to ISCED

Respondents by disease type

	N=190
Acute leukemia	**37 (19%)**
Acute myeloid leukemia (AML)	19 (51%)
Acute lymphocytic leukemia (ALL)	15 (41%)
n/a	3 (8%)
Chronic leukemia	**38 (20%)**
Chronic myeloid leukemia (CML)	23 (61%)
Chronic lymphocytic leukemia (CLL)	15 (39%)
Non-Hodgkin's lymphoma	**77 (41%)**
Diffuse large B-cell lymphoma	26 (34%)
Follicular lymphoma	22 (29%)
Other	29 (38%)
Hodgkin's lymphoma	**38 (20%)**

1.2 Qualitative phase

In June 2023, 10 patients currently undergoing treatment or who have already completed treatment, participated in 3 focus group meetings, with 50% being female.

Focus groups participants by disease type

Non-Hodgkin's lymphoma

Hodgkin's lymphoma

Acute myeloid Leukemia

Chronic myeloid Leukemia

2. Involvement in treatment decisions

2.1 Quantitative phase

Involvement in treatment decision, and subsequent motives, for all patients, and by disease type

Desire of being more involved	All patients N=190	Acute leukemia N=37	Chronic leukemia N=38	non-Hodgkin's lymphoma N=77	Hodgkin's lymphoma N=38
Yes	**60 (32%)**	**14 (38%)**	**11 (29%)**	**24 (31%)**	**11 (29%)**
Motives for not being involved					
Lack of disease knowledge	40 (66%)	11 (79%)	7 (64%)	12 (50%)	8 (73%)
Lack of physicians' openness	16 (26%)	2 (14%)	4 (36%)	8 (33%)	2 (36%)
Other	9 (15%)	3 (21%)	1 (9%)	4 (17%)	1 (9%)
No	**130 (68%)**	**23 (62%)**	**27 (71%)**	**53 (69%)**	**27 (71%)**
Motives for not wanting to be involved					
Trust in physician's choice	93 (72%)	17 (74%)	19 (70%)	37 (70%)	19 (70%)
Lack of disease knowledge	48 (36%)	8 (35%)	13 (48%)	18 (34%)	8 (30%)
Not wanting to have the responsibility to deal with the decision	4 (3%)	2 (9%)	-	1 (2%)	1 (4%)
Other	3 (2%)	-	-	3 (6%)	-

Note: patients were asked whether they would have liked to be more involved in the treatment decision-making process (yes/no answer). Subsequently, if they answered "yes", they were asked, "why do you think you were not involved" If they answered "no", patients were asked "why didn't you want to be involved". For both questions, patients selected among the pre-defined motives

2.1 Qualitative phase

In the focus group meetings, most participants felt fully involved in treatment choice. Content analysis revealed an additional motive for the desire of **non-wanting** to be more involved (mostly in 1L-treatment), i.e., **shock after diagnosis**

"At that moment I didn't have the ability to ask if it was my only alternative"
*"I was afraid to ask what I had"*

Moreover, some patients stated that they wanted to have been **more involved** in treatment choice to better **understand the therapeutic decision.**

3. Valued criteria when choosing a treatment

3.1 Quantitative phase

The majority of patients chose **lifespan increase** as the main criteria to choose a treatment, followed by **duration of response**. However, some differences arose by disease type. E.g., total treatment duration and frequency of administration were less relevant for patients with chronic leukemia (both in 4th place, *versus* route of administration in 3rd place). However, they were more valued in patients with acute leukemia (both in 2nd place).

Rank of criteria, all patients (n=190)
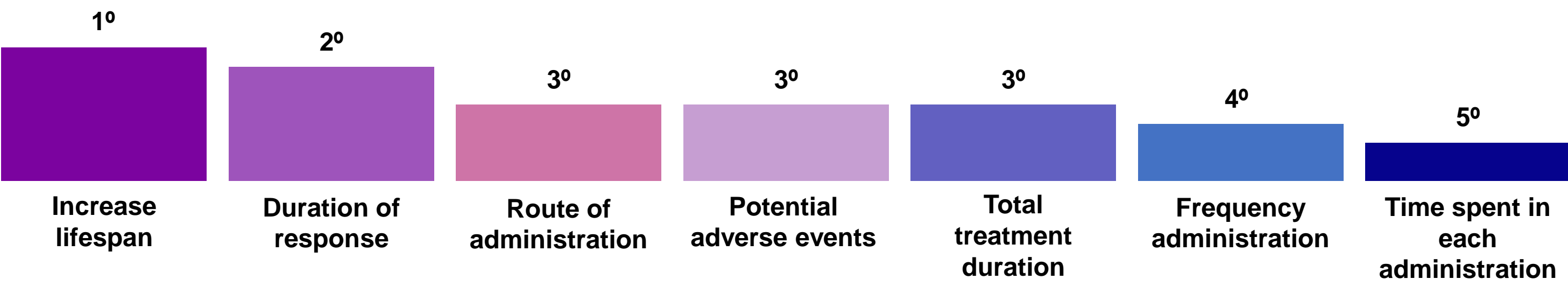
Note: patients were asked to rank seven pre-defined criteria, by their level of importance (1=most important; 7=less important), when choosing a treatment

3.2 Qualitative phase

Even though these results were corroborated in the focus group meetings, two more criteria were mentioned as being relevant for treatment choice: **success rate of therapy** and **distance from the patient's home to the hospital.**

4. Route of administration preference

4.1 Quantitative phase
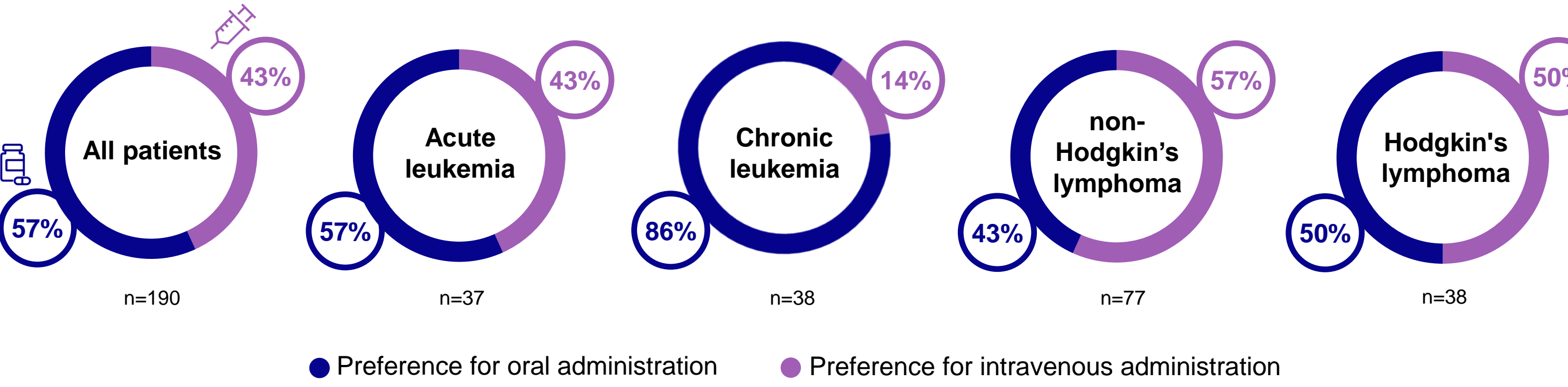
Overall, 57% (n=109) of patients stated **oral administration preference** over intravenous. An even more detailed analysis, based on the disease subtype, shows that this preference increases to 91% (n=21) in CML; 80% (n=12) in CLL and 79% (n=11) in AML.

4.2 Qualitative phase

Preference for oral administration was essentially associated with **easiness and practicality**:

"it´s simpler and furthermore the intravenous route can be very painful"

whereas preference for intravenous administration was associated with a sense of greater proximity to healthcare professionals:

"I feel a closer follow-up by the nursing teams and physicians"

Additionally, it was stated that the treatment phase might be determinant for this preference. It is important to note that for some diseases, those for which there is no therapeutic options with different routes of administration, stating this preference is quite hypothetical.

Limitations

- This is an exploratory study, based on an online questionnaire and online focus groups. This methodology may have contributed for a selection bias, since patients from lower socio-economic levels have a lower probability of enrollment;

- Leukemias and Lymphomas include several diseases with different clinical profiles and available treatments, and therefore further studies, with a larger number of participants per disease subtype, should be conducted to better explore patient needs and preferences.

TAKE HOME MESSAGES

- **This exploratory study reinforces that some patients want to be more involved in the treatment decision, and that patient perceptions on lack of knowledge regarding their disease can influence their level of involvement. Improving health literacy may contribute to a greater patient involvement during all treatment stages.**

- **While all patients value the most the lifespan increase and duration of response when choosing a treatment, other criteria, such as the route of administration can also play an important role for some patients, with oral administration being mostly preferred over intravenous administration.**

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References
[1] Tringale et al (2022), Integrating patient values and preferences in healthcare: a systematic review of qualitative evidence. BMJ Open 2022;12:e067268. doi:10.1136/bmjopen-2022-067268