A Cross-Sectional Examination of Information Disclosure and Health Literacy Amongst Patients with Lymphoma

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LYMPHOMA COALITION

Introduction

Lymphoma Coalition (LC) supports over 90 member organisations across more than 55 countries. LC's overarching vision is equity in lymphoma outcomes across borders. Health literacy of patients is a requirement for shared decision making. However, little is known about the experiences of patients with lymphoma with regard to health literacy and information disclosure from their treating physicians. We sought to explore health literacy through a survey deployed across a large and diverse group of patients with lymphoma.

Methods

The 2022 Lymphoma Coalition (LC) Global Patient Survey (GPS) was completed by 7113 patients from 84 countries. We sought to understand how patients initially understood their disease. Responses to the question: "To what extent, if at all, were diagnostic tests and results explained to you?" were stratified across core demographics and tabulated. Tests for significant differences across strata were computed with JMP Pro v17.
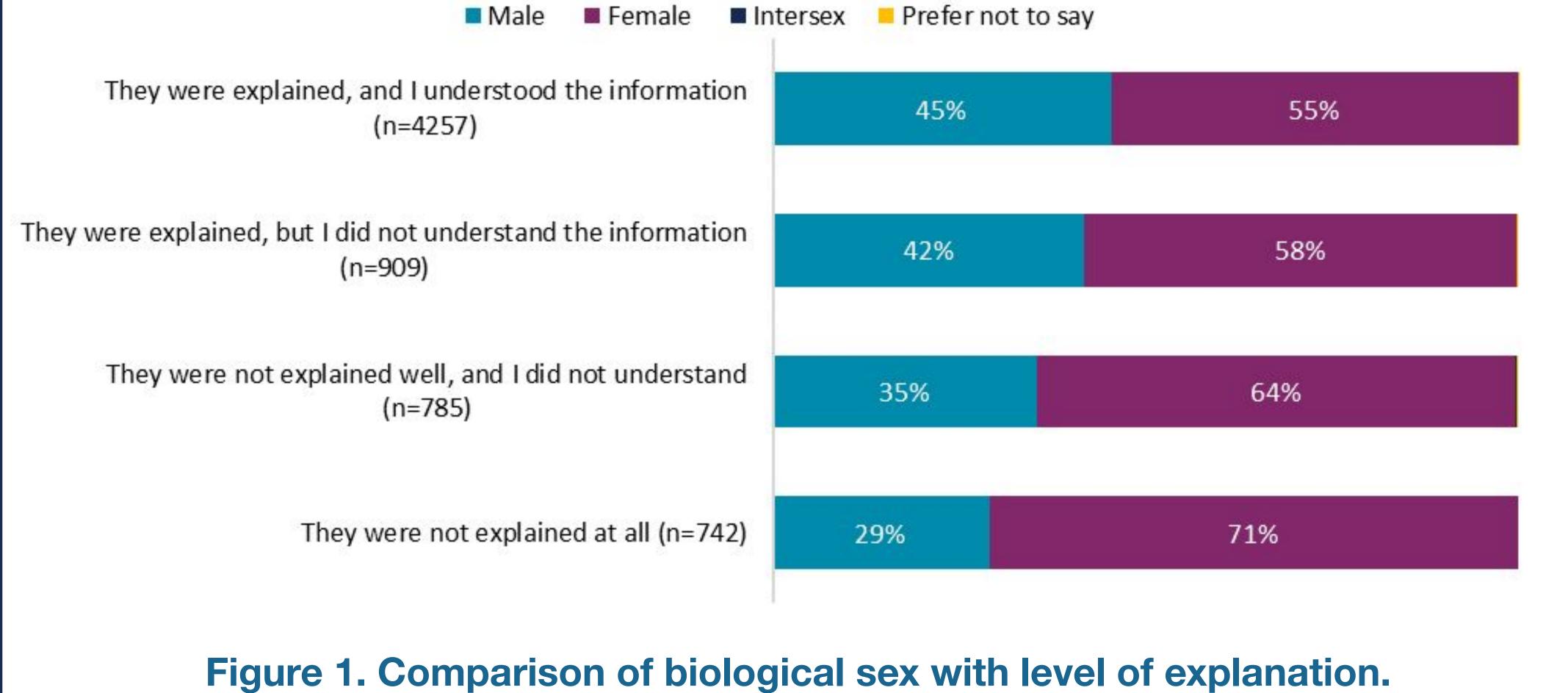
Results (Contd)

Overall, 36% of respondents reported poor comprehension. Increasing age was a significant positive predictor of health literacy with a Range OR = 6.9 [5.4 - 8.9]. Likewise, male biological sex was a significant predictor of improved comprehension OR = 1.5 [1.3 - 1.6]. Regional disparities were identified that indicated North America and Europe had the highest rates of satisfactory comprehension with 72% and 68% respectively. This was contrasted with the Asia-Pacific region at 53% (p<0.0001).

Explanation level	They were not explained at all	They were not explained well, and I did not understand	They were explained, but I did not understand the information	They were explained, and I understood the information
Average Age	55	51	53	59

Table 1. Average age of patient by explanation level.

Results

Figure 1. Comparison of biological sex with level of explanation.

Of the 6684 respondents who indicated a level of satisfaction or dissatisfaction with regard to the comprehension of diagnostic and laboratory tests, 58% and 42% were males and females respectively with a median age of 60 and range of 18 - 97 years.
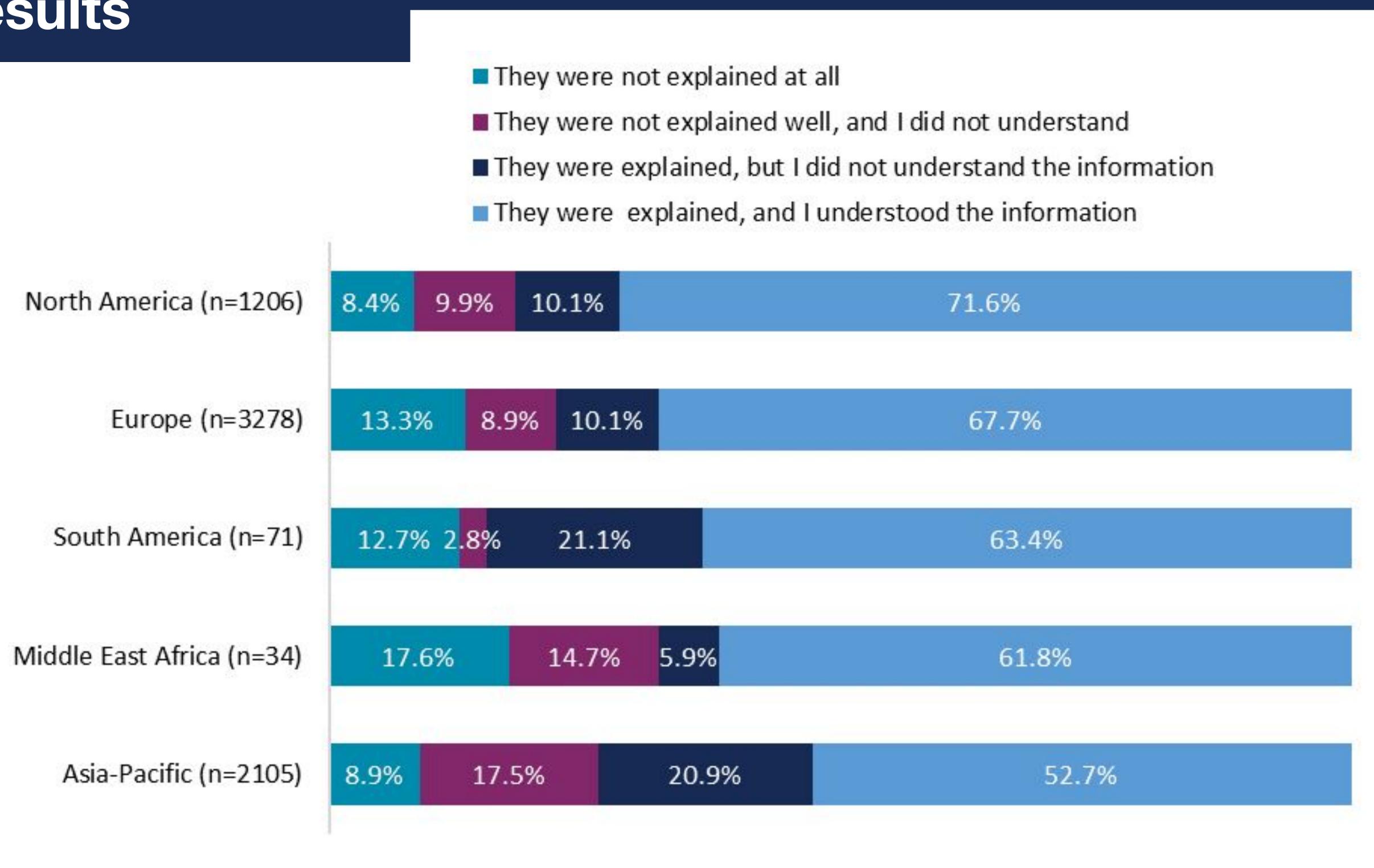

Figure 2. Comparison of region of residence by explanation level. Ordered by most complete understanding to least.

Conclusion

One of the goals of precision medicine is to deliver the right therapeutics to the right patient at the right time. Shared decision making has the ability for patients to provide valuable feedback to their treating physicians. However, a lack of health literacy essentially excludes patients from participating in the decision making process. All three demographics examined above indicated highly significant disparities that can have adverse ramifications on healthcare equity. We feel that patients should understand their disease and the available treatment options which will yield increased participation in their care.

Disclosure

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