A Cross-Sectional Study Examining how Knowledge of Genetic and Biomarkers Affect the Information and Communication Experiences of Patients with CLL

L. Warwick[1], N. Dren[2] and O. Bamigbola[2] / 1. Lymphoma Coalition, Management, Mississauga, ON, Canada | 2. Lymphoma Coalition, Research, Mississauga, ON, Canada

INTRODUCTION

Chronic lymphocytic leukaemia (CLL) presents heterogeneously. As such, it is important for patients with CLL to understand the specifics of their subtype. This includes their applicable genetic markers and biomarkers, as this information directs CLL treatment according to clinical guidelines. Without this knowledge, it can be difficult for patients to source the correct information they need to understand their disease and care.

This study uses data from the 2020 Lymphoma Coalition (LC) Global Patient Survey (GPS) on Lymphomas and CLL to examine the information and communication experiences of patients with CLL who knew the markers applicable to their CLL compared to those who did not.

METHODS

Study design

- This study is a sub-analysis of the LC 2020 GPS, which is an online global survey of patients with lymphoma and CLL, carried out every two years
- The LC 2020 GPS was hosted on a third-party portal from January- March 2020 in 19 languages

Respondents

- Globally, 11,878 respondents from 90+ countries (9,179 patients and 2,699 caregivers), including **1,774 patients with CLL,** took part in LC 2020 GPS
- Patients with CLL who selected at least one marker applicable to their CLL (n=428) were compared against patients who reported not knowing if any markers were applicable (n=585).
- Both groups contained only patients who were currently in treatment, or who had been treated in the past. This is because clinical practice guidelines recommend that patients have genetic marker testing prior to first-line therapy.

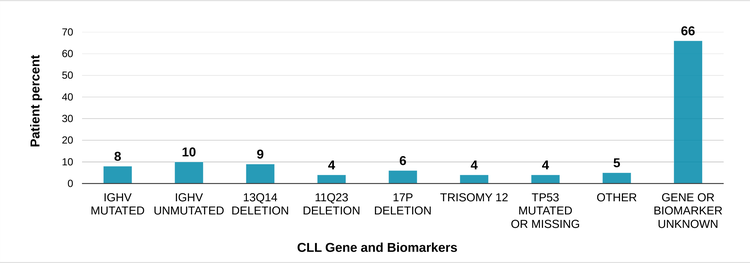

Figure 1. Gene and biomarker knowledge among patients with CLL

Statistical analysis

- Raw data was entered, merged, and cleaned in IBM SPSS v.27
- Demographics of the two patient groups were examined, and questions relating to information and communication experiences were analysed.
- Differences in proportions were tested using chi-square tests (p=0.05) and odds ratios with a 95% CI.

RESULTS

The two patient groups (marker group 'MG'; no marker group 'NMG') were similar in their distribution of sex and area of residence **(Table 1)**. However, they differed significantly in age and educational level. **(Table 1)**.

The patient groups also differed significantly (p< 0.05) in their distribution of employment status and country of residence. France was the country of residence most represented in both groups (28% MG, 37% NMG).

Table 1. Demographic comparison between the two CLL patient groups

	No Marker Group (N=585) Count (%)*	Marker group (N=428) Count (%)*	Chi square (p-value)
Age Range (years)			
18-29	7 **(1)**	**2 (0)**	20.5
30-39	8 **(1)**	10 **(2)**	**P=0.0001**
40-69	354 **(61)**	307 **(73)**	
70	209 **(36)**	99 **(24)**	
Sex			
Female	244 **(42)**	200 **(47)**	2.52
Male	341 **(58)**	228 **(53)**	**P=0.11**
Educational level			
Nome	1 **(0)**	1 **(0)**	
Primary (Elementary)	41 **(7)**	14 **(3)**	32.26
Secondary (High-school)	187 **(32)**	89 **(21)**	**P<0.001**
Post-Secondary (College/ University)	259 **(44)**	207 **(48)**	
Postgraduate (Master, PhD)	92 **(16)**	112 **(26)**	
Prefer not to say	5 **(1)**	5 **(1)**	
Area of residence			
City	255 **(44)**	215 **(50)**	**OR=1.80**
Suburban	139 **(24)**	100 **(23)**	**P=0.1**
Rural	191 **(33)**	113 **(26)**	

Relating to information and communication experiences, less than half (49%) of NMG patients were told their lymphoma subtype at diagnosis compared to 63% of MG patients (X^2=6.13, p=0.05). Compared to MG patients, NMG patients were nearly three times more likely to disagree that they are confident in their ability to find reliable information about their lymphoma (OR=2.83, p=0.0005), and that they know what each of their prescribed medications do (OR=2.94, p=0.0001) **(Table 2)**.

NMG patients were also more likely to disagree that they always understand their doctor's advice and treatment plans (OR=1.28, p=0.4778), and that they are confident in their ability to get the information they need from their doctor (OR=1.80, p=0.0947) **(Table 2)**.

Compared to NMG patients (28%), more MG patients (34%) had spoken to their doctor about changing their treatment to better meet their needs (X^2=20.39, p=0.002). Lastly, more MG patients (34%) than NMG patients (28%) reported being very confident in managing their health problems day-to-day (X^2=12.30, p=0.02).

RESULTS (cont.)

Table 2. Agreement and disagreement with statements about information and communication among patients with CLL

	No Marker Group Count (%)*	Marker group Count (%)*	OR 95% CI (p-value)
I know what each of my medications do			**OR=2.94**
Disagree +Disagree Strongly	**56 (12)**	**18 (5)**	**95% CI:1.69-5.12**
Agree +Agree Strongly	**334 (71)**	**316 (86)**	**P=0.0001**
I am confident I can find reliable information about my lymphoma			**OR=2.83**
Disagree +Disagree Strongly	50 **(9)**	16 **(4)**	**95% CI:1.58-5.07**
Agree +Agree Strongly	365 **(69)**	331 **(82)**	**P=0.0005**
I always understand my doctor's advice and treatment plans			**OR=1.28**
Disagree +Disagree Strongly	23 **(5)**	14 **(3)**	**95% CI:0.65-2.52**
Agree +Agree Strongly	460 **(85)**	358 **(88)**	**P=0.48**
I am confident in my ability to get the info I need from my doctor			**OR=1.80**
Disagree +Disagree Strongly	29 **(5)**	12 **(3)**	**95% CI:0.90-3.57**
Agree +Agree Strongly	475 **(88)**	353 **(86)**	**P=0.1**

CONCLUSION

Having adequate information is a proven key aspect to a successful patient experience. It is important to inform patients with CLL about their applicable genetic and/or biomarkers. **Compared to NMG patients, MG patients reported improved information and communication experiences across various areas.**

LC advocates not only for improved patient-doctor communication surrounding markers, but also improved access to testing for genetic mutations, markers, and chromosomal abnormalities. In the future, LC would like to examine how certain demographic differences may have confounded results.

CONTACT INFORMATION

Please direct any queries to the research department at Lymphoma Coalition:
lorna@lymphomacoalition.org or funmi@lymphomacoaliton.org.

For further details on the LC 2020 GPS, please scan the QR code or visit *https://lymphomacoalition.org/global-patient-survey/.*