

Combining Patients' Perspectives and Treatment / Healthcare Resource Utilization in Chronic Lymphocytic Leukemia Using a Novel Real-World Patient-Centered Database

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Objective

Chronic lymphocytic leukemia (CLL) is the most common leukemia in adults, with an estimated 20,700 new cases of CLL in 2024. Given that nearly 85% of CLL patients will survive at least 5 years, understanding patient concerns including quality of life and long-term complications is paramount. We aimed to synthesize the experiences shared by CLL patients participating in an online community with treatment and healthcare resource utilization (HCRU).

Methods

Data

- 32,738 posts from 11,200 members with CLL on Inspire's online community platform
- A subset of CLL members have linked open medical and pharmacy claims and electronic health records (EHR) through privacy-preserving tokenization

Study Population

- CLL patients on Inspire's online community platform
- Subcohort of CLL patients with linked claims/EHR were identified if they had ≥2 distinct CLL diagnoses (ICD-10 code C91.1) separated by 30–60 days, and an index date on/before 12/31/2022. CLL index date was defined as the earliest encounter date with ICD-10 code C91.1

Large Language Modelling

- Targeted review of CLL literature was conducted to establish an initial lexicon comprising primarily of medications and symptoms unique to CLL patients, which was then used to identify posts in the dataset
- A cohort of large language models (LLM) with superior capabilities in reasoning and comprehension was identified along with employing a methodical sequence of prompts to facilitate the models' understanding of examples illustrating unmet needs within user-generated posts
- Models demonstrating high proficiency in the initial phase were subsequently tasked with detecting and categorizing unmet needs as expressed by community members to enable a deeper analysis of common patterns and the frequency of expressed unmet needs
- Iterative refinement of the prompts and classification continued until an accurate correspondence was established between the labels and the detailed unmet needs delineated within the posts

Data Analysis

- Baseline patient characteristics and all-cause and CLL-related HCRU were evaluated in the subcohort with linked claims/EHR (Tables 1 & 2). Analysis was performed using descriptive statistics and conducted in R. Median and IQR are presented for continuous variables. Count and percentages are presented for categorical variables

Results

Figure 1: Illustrative Example of Using LLM to Identify Primary Unmet Needs in User Posts

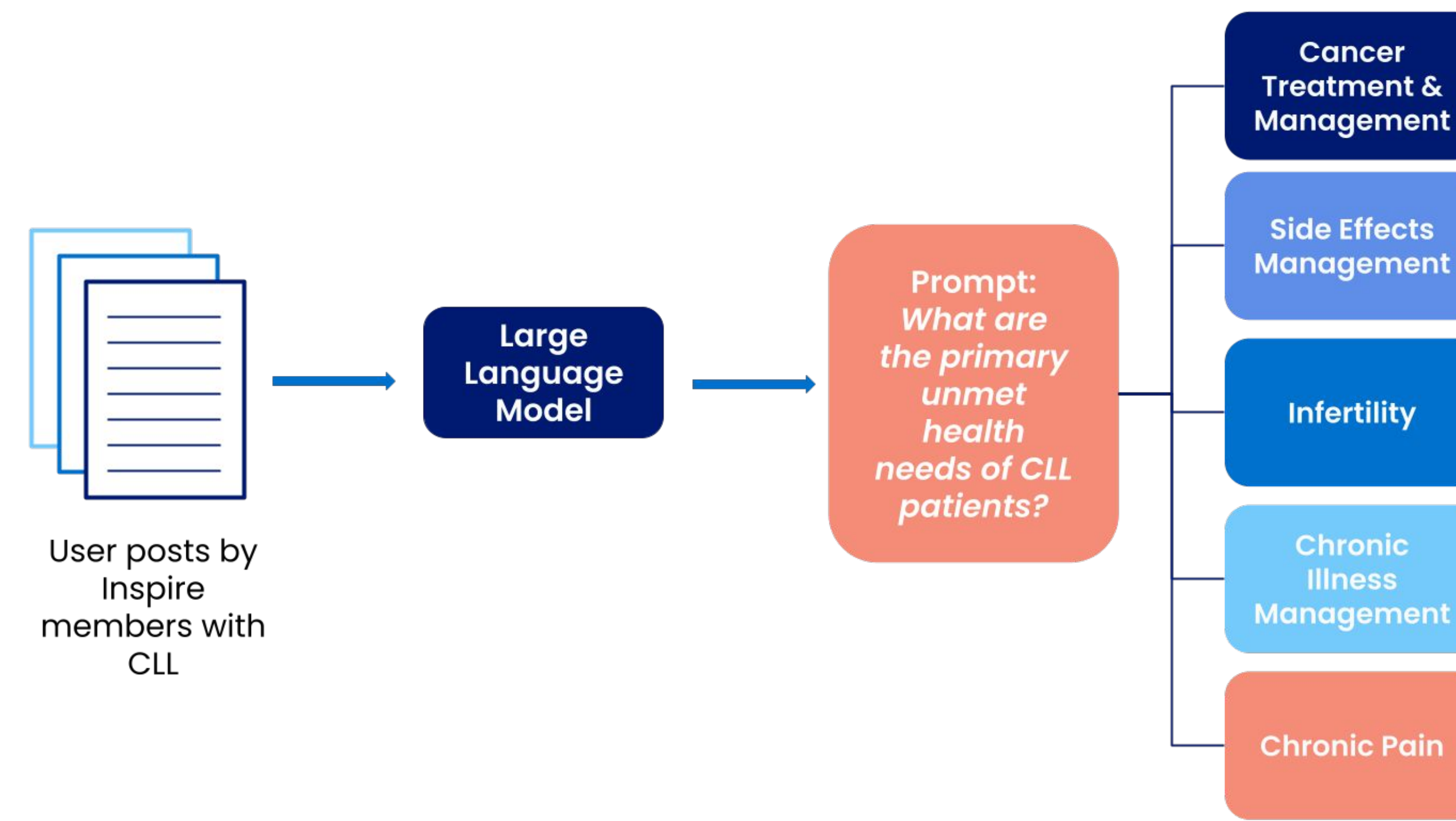


Figure 2: Unmet Needs in Chronic Illness Management

Categories of insufficient information are in the middle dark blue boxes. Coral boxes at the bottom provide details on what members were posting/searching for with respect to the insufficient information.

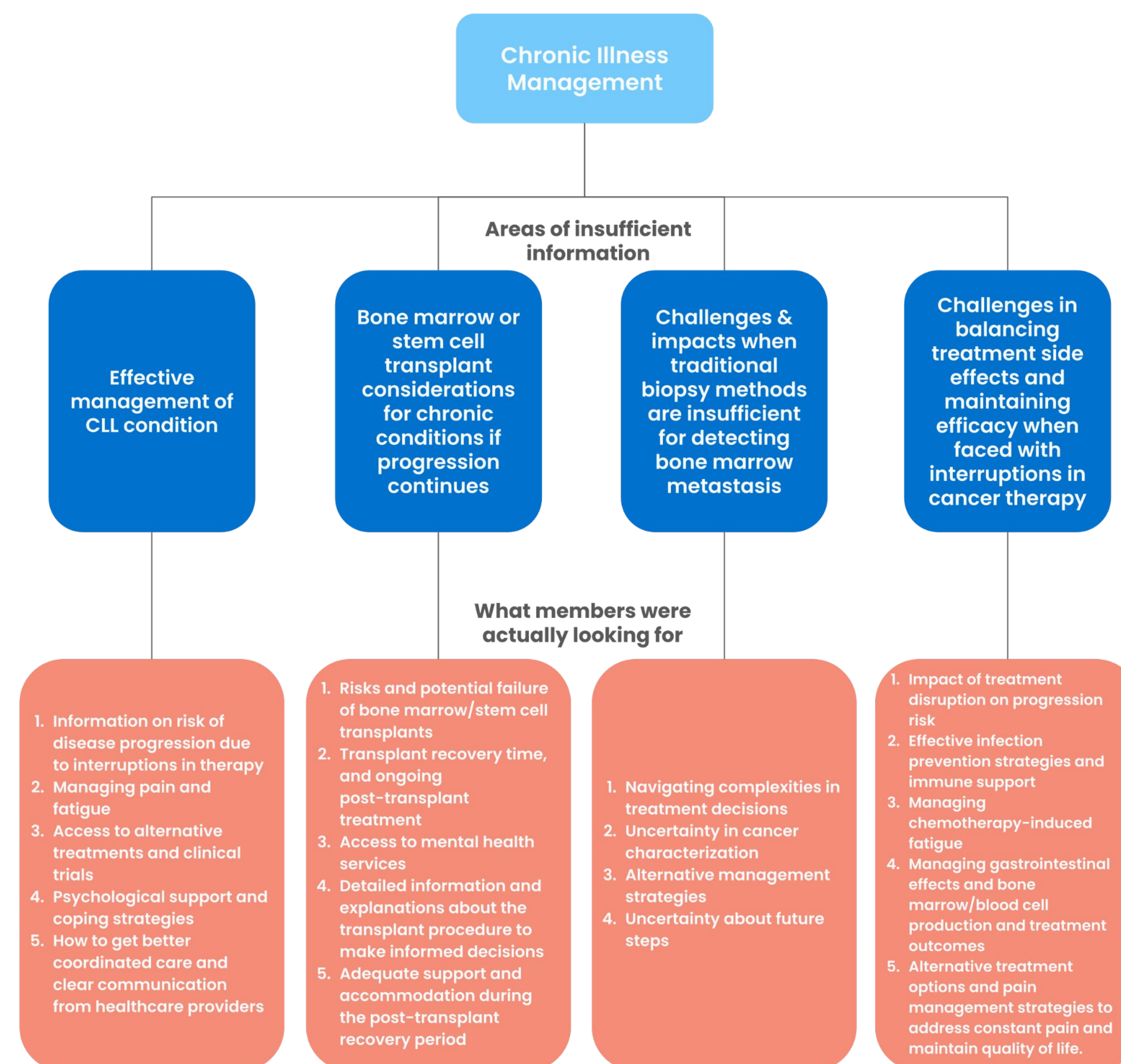


Figure 3: Secondary Unmet Need in Cancer Treatment & Management

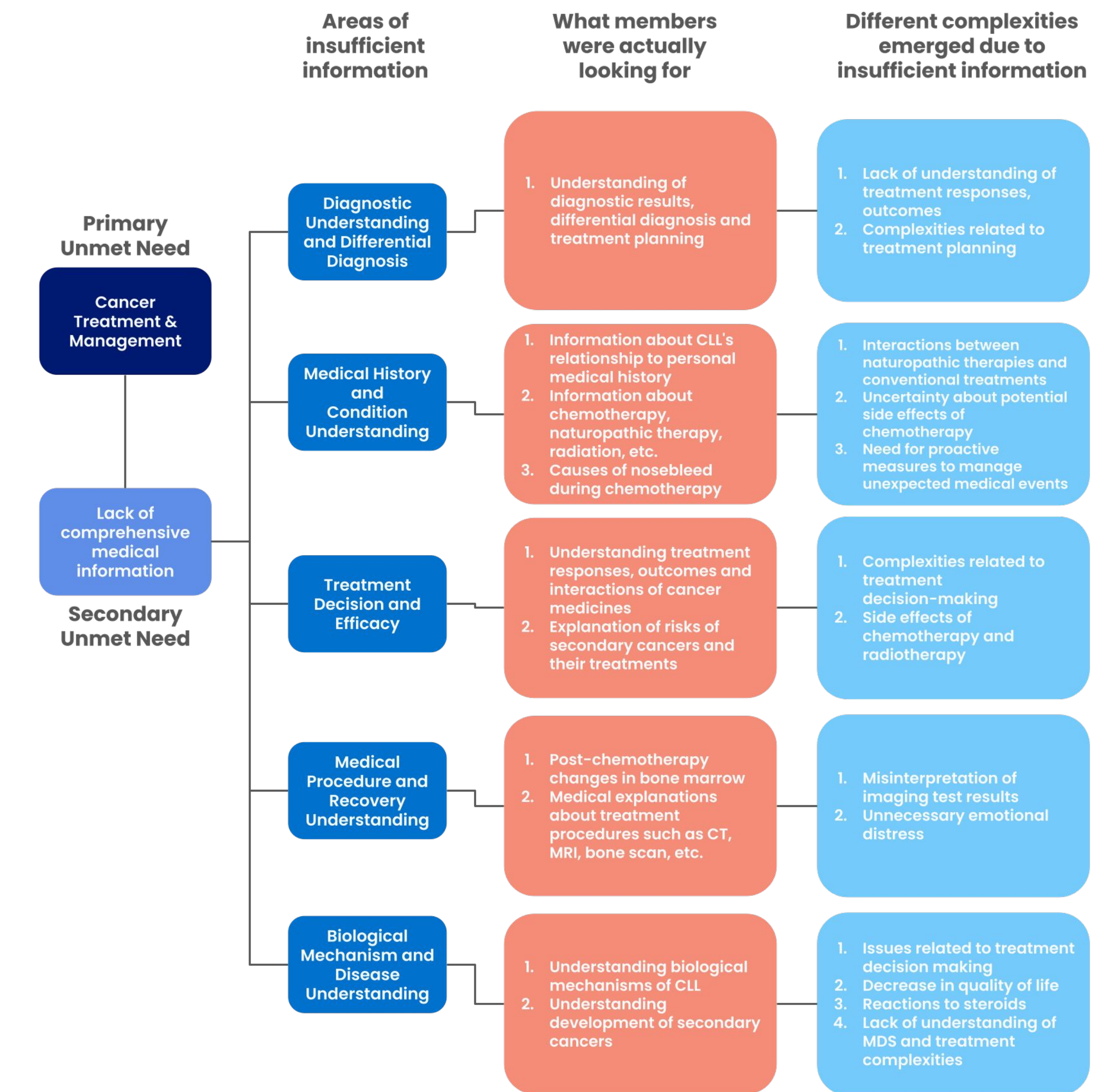


Table 1: Patient and Disease Characteristics in Subset with Linked Claims/EHR

Characteristic	Patients with Linked Claims / EHR N = 426
Gender	
Female	231 (54%)
Male	159 (37%)
Unknown	36 (9%)
Region	
Midwest	88 (21%)
Northeast	85 (20%)
South	147 (35%)
West	81 (19%)
Unknown	25 (6%)
Age at CLL Diagnosis (Dx)	69 (62, 76)
No. of claims per patient	143 (78, 245)
Follow-up time from CLL Dx, months	65 (36, 87)
No. of hospitalizations per patient after CLL Dx ¹	3 (1, 5)
No. of ER visits per patient after CLL Dx ²	2 (1, 4)
Experienced Richter's transformation	19 (4.5%)
Developed a secondary malignancy (lung, GI, skin cancer) ³	99 (23%)

Notes: 1. 170 patients had ≥ 1 claims with a hospitalization. 2. 123 patients had ≥ 1 claims with an ER visit. 3. Patients were included if they had an ICD-10 code for C34, C43, C44, or C15 - C26 after their CLL index date. A high rate of secondary malignancies was noted in our cohort; possibly a marker of patients who are seeking additional online information

Table 2: CLL Treatments in Subset with Linked Claims/EHR

Regimen Name ¹	Patients with CLL Medication in Records N = 134		
	First Therapy After Index CLL Date N = 134	Second Therapy After Index CLL Date N = 58	Third Therapy After Index CLL Date N = 20
acalabrutinib	13 (9.7%)	15 (26%)	2 (10%)
acalabrutinib, obinutuzumab	3 (2.2%)	0 (0%)	1 (5.0%)
bendamustine	2 (1.5%)	0 (0%)	0 (0%)
bendamustine, obinutuzumab	0 (0%)	0 (0%)	1 (5.0%)
bendamustine, rituximab	8 (6.0%)	1 (1.7%)	0 (0%)
chlorambucil	0 (0%)	3 (5.2%)	0 (0%)
chlorambucil, obinutuzumab	1 (0.7%)	0 (0%)	0 (0%)
cyclophosphamide	2 (1.5%)	0 (0%)	0 (0%)
cyclophosphamide, fludarabine, rituximab	4 (3.0%)	0 (0%)	0 (0%)
cyclophosphamide, rituximab	0 (0%)	0 (0%)	1 (5.0%)
ibrutinib	51 (38%)	19 (33%)	5 (25%)
ibrutinib, obinutuzumab	1 (0.7%)	0 (0%)	0 (0%)
ibrutinib, rituximab	2 (1.5%)	0 (0%)	1 (5.0%)
ibrutinib, rituximab, venetoclax	0 (0%)	0 (0%)	1 (5.0%)
ibrutinib, venetoclax	0 (0%)	1 (1.7%)	0 (0%)
idelalisib	3 (2.2%)	0 (0%)	0 (0%)
obinutuzumab	5 (3.7%)	2 (3.4%)	1 (5.0%)
obinutuzumab, venetoclax	1 (0.7%)	1 (1.7%)	0 (0%)
rituximab	19 (14%)	7 (12%)	1 (5.0%)
rituximab, venetoclax	1 (0.7%)	0 (0%)	0 (0%)
venetoclax	16 (12%)	9 (16%)	5 (25%)
venetoclax, zanubrutinib	1 (0.7%)	0 (0%)	0 (0%)
zanubrutinib	1 (0.7%)	0 (0%)	1 (5.0%)

Notes: 1. Treatments initiated within 30 days of each other were considered as a single regimen. Gaps > 120 days between treatments were considered as separate lines of therapy.

Conclusion

Combining a patient-centered online community database with EHR/claims data may provide unique insights into the cancer journey. Online activities on the Inspire platform demonstrated that CLL patients are engaged in searching and reading discussion posts concerning management of their cancer, chronic illness and side effects and their effects on quality of life. We identified high rates of secondary malignancies, possibly uncovering a CLL cohort seeking additional information about long-term complications. Future real-world studies must integrate patient voice to fully understand the consequences of a cancer diagnosis.

Limitations Medical and pharmacy claims may not provide a patient's complete medical journey as there may be gaps in insurance coverage. Findings from this study may not be generalizable to the broader CLL population.