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905.OUTCOMES RESEARCH-LYMPHOID MALIGNANCIES

Clinical and Economic Burden Among Patients with Chronic Lymphocytic Leukemia Using a Novel Real-World Patient-Centered Database

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Introduction Chronic lymphocytic leukemia (CLL) is the most common leukemia in adults, with an estimated 18,740 new cases of CLL in 2023. This study describes current treatment patterns, healthcare resource use (HCRU) and patient voice in patients with CLL in the US using a novel patient-centered database.

Methods A retrospective study using data from the Inspire Integrated Analytical Database (IIAD), which links Inspire patient voice with electronic health records (EHR) and medical and pharmacy claims through HIPAA-compliant tokenization. Patients worldwide with various conditions join Inspire's online health community and contribute their experience through online posts and survey participation (see Figure 1). Medical and pharmacy claims in IIAD range from 2013 to present, with EHR data ranging from 2010 to present. Inspire members were included in the study if they resided in the US and had at least two diagnoses for CLL (ICD-10 codes C91.10, C91.11 or C91.12) on at least two distinct dates that were between 30 and 60 days of each other. The first observed CLL diagnosis date was considered the index date. Patients with an index date on or before 6/30/2022 were included in the analysis. Baseline patient characteristics and HCRU were evaluated. CLL treatment was identified from medical and pharmacy claims. Online posts which CLL patients have viewed at least once were evaluated. Post topics are defined as named entities recognized by Inspire's Natural Language Processing (NLP) engine from all of the discussion posts written by any Inspire members. Descriptive statistics were reported.

Results A total of 331 CLL patients were identified in the online community with linked claims and EHR data. Median follow-up time was 59 months from index date. The median age at diagnosis was 73 and 49% of patients were female. Patients were geographically represented across the US. 63% had ≥100 claims from a median of 25 care sites across 33 providers. During follow-up a median of 3 hospitalizations per patient were observed. 5% of patients experienced a Richter's transformation and 22% developed a secondary malignancy (lung, gastrointestinal or skin cancer) after their index CLL date. 104 patients (31%) of the cohort had available data for CLL treatment. Median time to first CLL treatment was 11.7 months (range: 1 day - 86.8 months). Ibrutinib was the most common medication (n = 43), followed by venetoclax (n = 30) and rituximab (n = 20). The 5 most common topics viewed by patients on the Inspire community website included: skin, side-effect, muscle, biopsy, and infection. Prior to starting therapy, searches on the Inspire platform included terms such as "imbruvica," "calquence," and "living with CLL." Searches after CLL treatment revealed that patients broadened search terms to include other cancer types such as "pelvic cancer," "liver metastasis" and "melanoma."

Conclusions This report utilized a unique dataset that integrates patient voice with EHR and claims data to describe clinical characteristics, and treatment patterns of CLL patients drawn from the patient-centered Inspire digital health community. The online population had a median age of 73 at diagnosis, consistent with the average age of CLL diagnosis (70 yrs.). Patients in our cohort initiated treatment approximately 1 year after CLL diagnosis. Online activities on the Inspire platform demonstrated that CLL patients are engaged in searching and reading discussion posts concerning the impact of side effects and treatments on quality of life, and emphasized emerging concerns about the potential impact of secondary malignancies. Future real-world studies need to integrate patient voice to fully understand the consequences of a cancer diagnosis.

Disclosures Kuk: *Roche:* Current equity holder in publicly-traded company. **Chen:** *Johnson & Johnson:* Ended employment in the past 24 months. **Samyukta:** *BeiGene:* Ended employment in the past 24 months. **Goldberg:** *Novartis Pharmaceuticals:* Consultancy; *COTA, Inc:* Current equity holder in private company, Current holder of *stock options* in a privately-held company.

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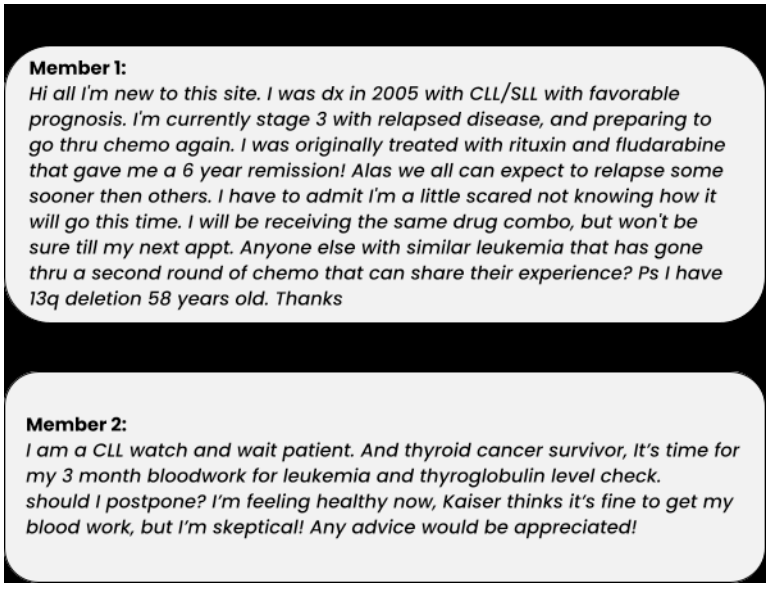

Figure 1

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