

A Cross-Sectional Study Examining the Diagnosis and Psychosocial Experiences of Patients with Cutaneous Lymphomas

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INTRODUCTION:

Cutaneous lymphomas are not easily diagnosed; many people will live through periods of severe discomfort without effective treatment. Once diagnosed, patients must manage flare-ups that can be painful and embarrassing. As such, cutaneous lymphomas may impact patients' quality of life. Using data from the Lymphoma Coalition (LC) 2020 Global Patient Survey (GPS) on Lymphomas and CLL, this study examines the diagnosis and psychosocial experiences of patients with cutaneous lymphoma compared to patients with other lymphoma subtypes.

METHODS:

Globally, 11,878 respondents (9,179 patients, 2,699 caregivers) responded to the LC 2020 GPS. Patients with cutaneous lymphoma ('CL patients') (n=470) were compared against patients globally (all other subtypes) ('global patients') (n=8,709). Demographics of the two patient groups were examined, and descriptive analyses for questions relating to initial diagnosis experience and psychosocial issues were performed in IBM SPSS v27.

RESULTS:

The two patient groups differed significantly ($p < 0.05$) in all the demographic categories examined, including country and area of residence, age, sex, education level, and employment and household status. Relating to initial diagnosis experience, while 52% of global patients received their diagnosis within less than three months of their first doctor's appointment, this was true for only a quarter (25%) of CL patients. Nearly half (46%) of CL patients reported it took more than 12 months to get a diagnosis compared to only 11% of global patients ($X^2 = 509.98$, $p < 0.001$).

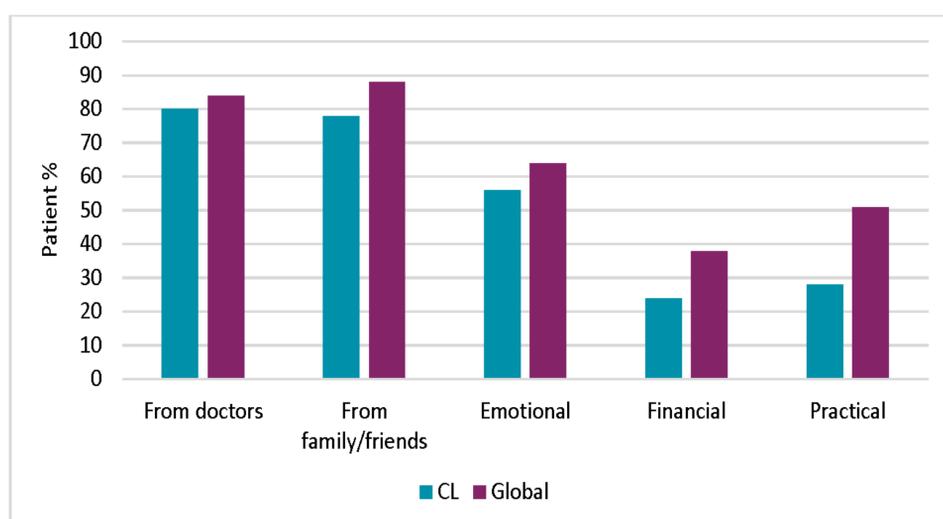


Figure 1. Patients who reported receiving enough support in different areas

RESULTS (continued)

Compared to global patients (78%), fewer CL patients (69%) reported receiving and understanding information on the stages of their care at diagnosis. A quarter (26%) of CL patients reported not receiving this information, compared to only 13% of global patients ($X^2 = 26.31$, $p < 0.001$). Compared to global patients (72%), fewer CL patients (53%) reported receiving and understanding information on side effect management at diagnosis. 39% of CL patients reported not receiving this information, compared to 20% of global patients ($X^2 = 36.94$, $p < 0.001$). Fewer CL patients (52%) reported receiving the right amount of information generally at diagnosis compared to global patients (57%) ($X^2 = 20.79$, $p < 0.001$). Compared to global patients, CL patients reported receiving less support across all areas listed (figure 1); the differences were significant ($p < 0.05$) in all cases except for support from doctors. Relating to psychosocial issues, compared to global patients, a greater proportion of CL patients reported experiencing concerns about body image (26% vs 44%, respectively) and fear of lymphoma progression (38% vs 58%) ($p < 0.001$ in both cases).

CONCLUSIONS:

- Time to diagnosis remains unacceptably long for many patients with cutaneous lymphoma (12+ months)
- Many patients with cutaneous lymphoma are not receiving enough information at diagnosis
- Patients with cutaneous lymphoma are disproportionately affected by certain psychosocial issues specific to their disease, and require more support across various areas

DISCLOSURE:

Dren, N., Bamigbola, O. A. & Warwick, L. have the following financial relationships to disclose:

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