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Patient Preference Studies in Hematologic Malignancies: A Systematic Review

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Background: New therapies have brought about an unprecedented expansion of treatment options for patients with hematologic malignancies that require a greater understanding patient preferences, both to inform treatment decisions and direct further patient-focused drug development. We sought to synthesize existing literature evaluating the preferences of patients with hematologic malignancies to consolidate relevant knowledge and identify future directions for research.

Methods: We conducted a systematic review in accordance with PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (PROSPERO 2022 CRD42022364647). We searched for articles published in English from PubMed and Embase. Included articles reported primary data on the preferences of patients with hematologic malignancies or patient proxies. Review articles, articles utilizing only secondary data, and abstracts without full text were excluded. Two authors independently reviewed all abstracts and assessed studies for full-text eligibility. Conflicts were resolved by group discussion. Risk of bias (quality) and conflict of interest were assessed. Data extraction included population, method of preference elicitation, attributes included, and relative strength of preferences.

Results: A total of 3,520 studies were identified, 2,960 abstracts were screened following removal of duplicates, 239 underwent full-text review, and 74 were included in data extraction. Among the 74 studies, 59 (80%) were published in the last 10 years. In total, 16,986 patients or patient proxies were represented across selected studies. Studies included patients with lymphoma (n=33, 45%), myeloma (n=25, 34%), acute myeloid (n=15, 20%) and lymphoid (n=12, 16%) leukemia, and chronic lymphoid (n=11, 15%) and myeloid leukemia (n=10, 14%). Most studies included patients from Europe (n=30), the United States (n=26), or Canada (n=10). Nearly all (n=70, 95%) included only adults. Most studies were cross-sectional (n=60, 81%), qualitative (n=13, 18%), or mixed-methods (n=13, 18%). Only 1 study was a prospective randomized trial. Preference elicitation methods included study-specific surveys (n=31, 42%), discrete choice experiments (n=28, 38%), and qualitative interviews (n=19, 26%). Most studies elicited patient preferences for treatment outcomes (n=50, 68%) followed by communication (n=14, 19%), and route of administration of therapies (n=7, 9%). Attributes included in treatment outcome studies varied but many included overall/progression free survival (n=30, 60%), side effects (n=28, 56%), route of administration (n=16, 32%), or cost (n=11, 22%). Strength of preference for outcomes was heterogeneous across studies though overall survival was frequently most important to patients. Most studies sought to inform clinical decisions (n=49, 66%), followed by policy (n=13, 18%) and regulatory decision-makers (n=6, 8%). Most studies were of high (n=44, 59%) or moderate (n=26, 35%) quality. Funding for the studies came from pharmaceutical companies (n=25, 34%), government grants (n=20, 27%), and foundations (n=18, 24%). Some studies had apparent (n=16, 22%) or likely (n=9, 12%) conflicts of interest. Only 4 studies (5%) reported implementation outcomes such as acceptability or feasibility.

Conclusions: Numerous well-designed studies have been published describing the preferences of patients with hematologic malignancies. Most of these studies were cross-sectional and relied on direct elicitation or discrete choice experiments to elicit preferences. Treatment outcome preferences varied widely across studies and patient populations. This heterogeneity supports the essential role for shared decision-making and individualization of treatment recommendations for each patient. Although many studies sought to generate data to inform clinical decisions, studies evaluating how patient preference data inform individual treatment decisions are largely absent. Future work is needed to support the clinical implementation of preference measures and to standardize relevant attributes for individual diseases and populations.

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