Unfiltered Patient Insights: Commonalities and Differences in Living With Chronic Myeloid Leukemia and Multiple Myeloma

Fatima Scipione,[1,2] Kim Gibbs,[1] Christine Verini[3]

[1]Takeda Pharmaceuticals America, Inc., Lexington, MA, USA; [2]International Myeloma Foundation, Studio City, CA, USA; [3]CancerCare, New York, NY, USA.

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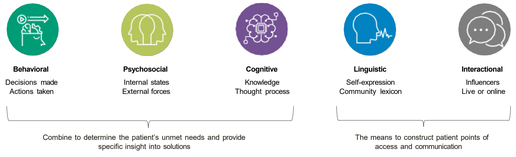
Context

- Although many studies evaluating the therapeutic efficacy of investigational cancer drugs exist, few studies have used insights directly from patients to focus on the holistic experiences of people with cancer

Objective

- To understand the multifactorial experiences of people with chronic myeloid leukemia (CML) and multiple myeloma (MM), with a focus on the behavioral, psychosocial, cognitive, linguistic, and interactional domains of patient experiences (**Figure 1**) and to use this patient-centric approach to improve care

Figure 1: Behavioral, psychosocial, cognitive, linguistic, and interactional domains of patient experiences captured in patient surveys and interviews.



The icons in this figure are shown in later figures to denote aspects of patient experiences that fall into each respective domain

Methods

- US patients with CML and MM and their care partners were interviewed (qualitative analysis) or surveyed (quantitative survey) between June 2020 and March 2021 after responding affirmatively to a request to be interviewed or surveyed

Conclusions

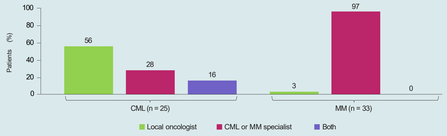
- Differences in treatment paradigms, sites of care, expectation management, and the availability of novel therapies and patient support groups resulted in drastically different experiences for patients with CML and MM across the behavioral, psychosocial, cognitive, linguistic, and interactional domains
- Patients with CML frequently felt isolated and disillusioned, while those with MM felt optimistic and supported
- Upfront education, in lay terms, regarding disease prognosis and severity, treatment side effects, and potential medication switches may improve patient experiences, particularly for those with CML
- Patient advocacy is a vital resource for both physicians and patients; greater and earlier access to reputable patient advocacy groups is desperately needed to support patients with CML
- Examples of reputable patient advocacy groups include CancerCare, the International Myeloma Foundation, and the Leukemia & Lymphoma Society

Results

- Among those qualitatively interviewed were 9 patients with CML and 1 care partner of a patient with CML; the quantitative survey population included 25 patients with CML and 9 care partners of patients with CML

- Among those qualitatively interviewed were 15 patients with MM and 10 care partners of patients with MM; the quantitative survey population included 33 patients with MM and 10 care partners of patients with MM

Figure 2: Patient experiences diverged rapidly post-diagnosis based on interactions with HCPs. In the survey, patients were asked whether they primarily received their care from a local oncologist, a CML or MM specialist, or both



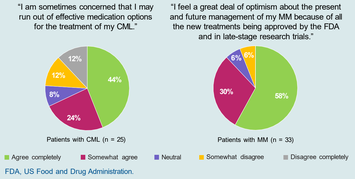
HCP, health care provider.

Patient experiences post-diagnosis and interactions with HCPs

- All patients were shocked by their diagnosis and initially felt ill-prepared to participate in discussions or decision making with their health care team (**Figure 2**)
- Patients with CML were frequently told by doctors that they had the "good cancer," leading to frustration and disillusionment
- Conversely, patients with MM felt optimistic due to the large pipeline of available treatment options and therapies under development



Figure 3: Patient experiences differed due to the availability of new and effective treatments.



FDA, US Food and Drug Administration.

Patient experiences with treatments and side effects

- Patients in both groups felt unprepared for treatment side effects and expressed a desire for more upfront preparation and education
- Patients with CML sought out alternative sources of information regarding side effect management; they experienced anxiety, concern of relapse, and fear of running out of options with each medication switch (**Figure 3**)
- Patients with CML and MM were introduced to a complex new lexicon of terminology regarding their disease and treatments (eg, "T315I positive" for CML, "RVD" [Revlimid®, Velcade®, dexamethasone] for MM)
- Those with MM were able to adapt to a "new normal" of living with their disease and treatment side effects



Figure 4: Patients with MM were more confident in the information available to them than patients with CML. In the survey, patients were asked, "How confident are you that you have all the information you need to understand and make decisions about the management and treatment for your CML or MM?"



Patient experiences with advocacy/support groups and academic sites of care

- Patients with CML noted that HCP recommendations to patient advocacy/support groups were lacking, prolonging feelings of isolation and hopelessness and leading patients to seek out alternative sources of information (**Figure 4**)
- Patients with MM, however, had greater and earlier access to both patient advocacy groups and academic sites of care with MM specialists, particularly for those who received stem cell transplants
- Among patients with MM surveyed, 76% listed online patient advocacy/support groups, 55% listed support groups, and 52% listed other individuals with MM as valuable sources of information regarding their disease and treatment options



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Disclosures

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