Patient Preference and Adherence

Dovepress
Taylor & Francis Group

Open Access Full Text Article

ORIGINAL RESEARCH

Multiple Myeloma Experiences and Preferences: A Mixed Methods Study of Patients and Care Partners in the United States

Darcy R Flora[1], Rachel Byrd[1], Daniel A Platt[1], Patrick Hlavacek[2], Erinn Hoag Goldman[2], Joseph C Cappelleri[3], C Todd Kennedy[4], Thomas W LeBlanc[5]

[1]Gryt Health Inc, Rochester, NY, USA; [2]Pfizer Inc, New York, NY, USA; [3]Pfizer Inc, Groton, CT, USA; [4]Independent patient and research advocate, Coto de Caza, CA, USA; [5]Division of Hematologic Malignancies and Cellular Therapy, Duke University School of Medicine, Durham, NC, USA

Correspondence: Patrick Hlavacek, HTA, Value and Evidence, Hematology, Global Access and Value – Oncology, Pfizer Inc, 66 Hudson Blvd E, New York, New York, USA, Email Patrick.Hlavacek@pfizer.com

Purpose: Multiple myeloma (MM) is characterized by treatment relapse and resistance, requiring sequential treatment decisions throughout its course. To understand how disease status and an evolving treatment landscape impact decisions made by patients and care partners, a non-interventional mixed methods study was conducted.

Patients and Methods: Patients self-reporting MM and care partners were recruited through the Gryt Health Cancer Community, social media, and snowball sampling to participate in this US-based study centered around a semi-structured interview. Patients were stratified by disease refractoriness to proteasome inhibitors, immunomodulatory drugs, and anti-CD38 antibodies.

Results: Participants included 32 patients (75.0% diagnosed before age 60 years) and 10 care partners. The treatment landscape for MM has significantly changed over the years with increased complexity leading patients to seek specialist involvement earlier in their treatment. When rating factors influencing treatment decisions, participants prioritized extending remission and survival while improving quality of life. As patients progressed further from diagnosis, treatment decision-making became more collaborative, with patients exhibiting increased self-advocacy. Given the rapidly changing treatment landscape, participants had difficulty finding accurate, trustworthy, and easy-to-understand information. Younger patients were in a different life stage than the average patient with MM and expressed unique concerns and support needs (ie, reproductive health and future earnings). Aside from MM specialists, advocacy organizations and support groups played prominent roles in dispersing information that patients trusted and found empowering.

Conclusion: MM patients and care partners played an active role in treatment decision-making. Collaborative discussions between clinicians, patients, and care partners are crucial for building trust and empowering patients. Reliable information and support resources including those for younger patients are essential for addressing the changing needs of patients and care partners. Understanding the evolving care journey is necessary to support patients with MM to optimize treatment success.

Keywords: decision-making, patient preferences, caregivers, treatment options, quality of life, qualitative research

Introduction

Multiple myeloma (MM) is a malignancy of abnormal proliferation of plasma cells in the bone marrow that disproportionately affects older adults.[1,2] In 2021, an estimated 179,063 individuals in the United States (US) were living with MM.[3] It is predicted that approximately 35,780 people will be diagnosed and 12,540 will die of the disease in 2024.[3] MM is characterized by intervals of treatment response followed by periods of relapse and refractoriness to treatment.[4,5]

Despite the disease's persistent nature, the increased availability of novel anti-myeloma agents has extended patient survival.[6] Consequently, patients with relapsed or refractory MM (RRMM) will receive many lines of therapy over the course of the disease, requiring a sequence of treatment decisions along the way. Five-year survival rates for MM increased from 34.4% (2000) to 61.1% (2020) over a span of 20 years.[3]

Received: 2 October 2024
Accepted: 16 March 2025
Published: 8 April 2025

With the introduction of increasingly effective therapies, the treatment landscape for MM has rapidly evolved, leaving the current treatment paradigm in a state of flux. However, most US clinicians generally follow the National Comprehensive Cancer Network Guidelines as a framework for disease management, as well as several well-accepted rules to help guide treatment and care decisions for their patients with MM.[2,7] In general, the sequence of decisions in a patient's treatment journey is largely guided by refractory status to standard treatments and becomes increasingly complex with each new line of therapy.[2,7]

Immunotherapies such as chimeric antigen receptor (CAR) T-cell therapies and bispecific antibodies have shown impressive outcomes in patients who have disease refractory to the 3 main MM drug classes: proteasome inhibitors (PIs), immunomodulatory drugs (IMiDs), and anti-CD38 monoclonal antibodies (mAbs). CAR T-cell therapies ciltacabtagene autoleucel and idecabtagene vicleucel have been approved for second- and third-line treatment or later in the US, respectively. The bispecific antibodies elranatamab, talquetamab, and teclistamab are currently only indicated for fifth-line treatment or later in US patients with prior exposure to at least a PI, an IMiD, and an anti-CD38 mAb (ie, triple-class exposed). However, trials are investigating the use of these immunotherapies in earlier lines of therapy.[8–14]

As new treatment options are made available, patients have more to consider in terms of assessing benefits and risks and other aspects of treatment that are most important to them. Many MM qualitative studies have sought to better understand MM treatment preferences and the decision-making process.[15–21] These studies have commonly found that increasing life expectancy is one of the most important priorities, with treatment side effects also a concern for preserving quality of life (QOL).[15,17,22] However, most studies have focused on points in time for specific patient populations, such as those with newly diagnosed MM or RRMM, or patient subgroups stratified by prior lines of therapy.[16,17,21,23] Few studies have considered the voice of MM care partners, and even fewer have looked at disease refractory status as a potential factor in treatment decision-making or educational needs that would support these decisions.[18–20,23] In this era of multiple recently approved novel therapies for MM, more studies are needed on this topic. Evaluating treatment decisions on a continuum as the disease changes over time (ie, stratifying by refractory status) may create a better understanding to adequately address the shifting challenges and needs of patients and care partners over the course of MM.

This non-interventional qualitative study was designed to explore how the MM treatment landscape in the US has impacted the experiences and preferences of patients with MM and MM care partners at different time points in the treatment journey and in varying states of disease refractoriness. This study was designed to understand the factors they consider important in their decision-making process, what influenced a change in care, and their overall educational and resource needs to better support their decisions.

Materials and Methods

Study Design

This non-interventional mixed methods study consisted of a short, cross-sectional quantitative pre-interview questionnaire and a semi-structured qualitative interview. The study was designed to yield qualitative insights from patients with MM and MM care partners, with 2 separate versions of the pre-interview questionnaire and interview guide for patients and care partners. The questions were developed and customized based on published literature,[15,17,19,21,22,24–26] previous unpublished qualitative research with patients with MM, and input from physicians, a patient advocate, and patient experience research experts. Validated questions were not included in the study. A semi-structured interview format was selected to allow for question flexibility during qualitative data collection.

The pre-interview questionnaire collected quantitative data on demographics, diagnosis and treatment history, and support. The patient interview guide contained questions for patients related to their (1) diagnosis, clinicians, and location of care; (2) treatment expectations, discussions, and decisions; (3) factors affecting treatment decisions; (4) treatment-related considerations and preferences; (5) disease and treatment education; and (6) burden of disease and support. In the care partner interview guide, care partners were asked questions about their (1) expectations and involvement, (2) knowledge of whether the patient they support had ever transitioned care (ie, changed their care team or location of care), (3) treatment decision-making support, (4) factors affecting treatment decisions, (5) medical knowledge to support the patient receiving

treatment, and (6) burdens and support needs. Patients and care partners were asked to rate 10 factors that may influence treatment decisions.[26] The study was reviewed and approved by an independent institutional review board.

Study Participants

Patient participants were at least 18 years of age with a self-reported diagnosis of MM for which they received treatment in the US. Care partner participants had to be a current or former primary care partner to a patient with a diagnosis of MM who met the patient eligibility criteria and was living or had been deceased for no more than 5 years. Participants were recruited through the Gryt Health Cancer Community, an online community of cancer patients, survivors, and care partners. Participants were also recruited by patient- and care partner-targeted outreach through social media platforms and snowball sampling. The aim was to recruit 40 adults, of which approximately 10 would be care partners. In addition, the target enrollment was to include an equal number of patients across 3 disease refractory subgroups: nonrefractory, single/double-class refractory, or triple-class refractory to the MM drug classes PIs, IMiDs, and/or anti-CD38 mAbs.

Data Collection

Interested individuals electronically consented to the study's information and consent document prior to answering the online screening questionnaire, in which they self-reported information on year of diagnosis, treatment(s) received, and basic demographics. The study team reviewed the screening questionnaire responses and assigned each consenting individual a study identification code. If determined eligible, participants received a link to an online pre-interview questionnaire, designed to take approximately 10 minutes. The screening and pre-interview questionnaires were housed on a Healthcare Insurance Portability and Accountability Act–compliant version of SurveyMonkey. Eligible patients and care partners who had completed the pre-interview questionnaire participated in a 90-minute, semi-structured interview. All interviews were conducted on Gryt Health's proprietary text-based online platform. Data were collected between January 2023 and June 2023.

Participants had to answer all required questions in a questionnaire section before proceeding to the next section. The questionnaire incorporated skip logic (ie, participants were only asked questions that were relevant). Range checks were included to minimize erroneous responses outside of the valid range. Completed questionnaires were checked for quality to ensure internally consistent and valid responses. Recorded interviews were also checked for completeness. Participants received compensation following the pre-interview questionnaire and interview completion.

Data Analysis

Demographic and disease information were recorded descriptively. Patients were stratified into 3 subgroups based on disease resistance to at least 1 agent in 3 drug classes (PIs, IMiDs, and/or anti-CD38 mAbs): nonrefractory, single/double-class refractory, or triple-class refractory. Refractory status was determined by clinical interpretation of a patient's self-reported disease status and medication history. Patients were defined as refractory to a specific medication only when they had stopped medication due to reported poor response and usually started a new treatment. As a disease entity, MM is conducive to assessments of this sort because of the standardized nature of the treatment algorithm and the patterns of disease progression.[2] Participant interviews were qualitatively reviewed and analyzed by refractory status.[27–30] The qualitative data analysis software NVivo (Lumivero, Denver, CO, USA) was used to organize the qualitative data. Two Gryt Health researchers independently coded the qualitative data using a codebook based on the patient and care partner interview guides. Coded data were compared, discrepancies discussed, and, as relevant, refinements made until consensus was reached. The analysis took an interpretative phenomenological, thematic approach based on the participants' own experiences, feelings, and perceptions.[30]

Results

Participant Characteristics

The study included 42 participants: 32 patients (Tables 1 and 2) and 10 care partners (Table 3). Patients were stratified into 3 groups by disease status: nonrefractory (n=12), single/double-class refractory (n=10), and triple-class refractory (n=10) (Table 4). All care partner participants were currently caring for a patient with MM who also participated in the

Table 1 Patient Demographics by Refractory Status

Demographic	Patients (n=32)	Nonrefractory (n=12)	Single/Double-Class Refractory (n=10)	Triple-Class Refractory (n=10)
Age, years				
Mean (SD)	59 (12)	54 (12)	59 (12)	66 (11)
Median	60	55	60	65
Range	32–83	32–71	38–72	49–83
Gender, n (%)				
Female	18 (56.3)	6 (50.0)	6 (60.0)	6 (60.0)
Male	14 (43.8)	6 (50.0)	4 (40.0)	4 (40.0)
Ethnicity, n (%)				
Hispanic/Latino	1 (3.1)	1 (8.3)	0	0
Not Hispanic/Latino	31 (96.9)	11 (91.7)	10 (100.0)	10 (100.0)
Race, n (%)[a]				
American Indian/Alaska Native	1 (3.1)	0	0	1 (10.0)
Asian/Asian American	3 (9.4)	1 (8.3)	2 (20.0)	0
Black/African American	5 (15.6)	4 (33.3)	1 (10.0)	0
White	24 (75.0)	7 (58.3)	8 (80.0)	9 (90.0)
US region, n (%)				
Northeast	5 (15.6)	3 (25.0)	2 (20.0)	0
Midwest	4 (12.5)	2 (16.7)	1 (10.0)	1 (10.0)
South	10 (31.3)	3 (25.0)	4 (40.0)	3 (30.0)
West	13 (40.6)	4 (33.3)	3 (30.0)	6 (60.0)
Community size, n (%)[b]				
≥500,000	9 (28.1)	1 (8.3)	3 (30.0)	5 (50.0)
100,000–499,999	8 (25.0)	4 (33.3)	3 (30.0)	1 (10.0)
30,000–99,999	9 (28.1)	5 (41.7)	2 (20.0)	2 (20.0)
<30,000	6 (18.8)	2 (16.7)	2 (20.0)	2 (20.0)
Highest level of education, n (%)				
High school diploma or GED	3 (9.4)	1 (8.3)	2 (20.0)	0
Associate degree[c]	6 (18.8)	3 (25.0)	2 (20.0)	1 (10.0)
College degree	7 (21.9)	2 (16.7)	3 (30.0)	2 (20.0)
Graduate degree	16 (50.0)	6 (50.0)	3 (30.0)	7 (70.0)
Working status, n (%)				
Full time	5 (15.6)	1 (8.3)	3 (30.0)	1 (10.0)
Part time	3 (9.4)	0	1 (10.0)	2 (20.0)
Disabled	12 (37.5)	8 (66.7)	2 (20.0)	2 (20.0)
Retired	12 (37.5)	3 (25.0)	4 (40.0)	5 (50.0)
Medical insurance, n (%)[d]				
Commercial through employer	12 (37.5)	2 (16.7)	6 (60.0)	4 (40.0)
Individual commercial	1 (3.1)	0	0	1 (10.0)
Medicaid	5 (15.6)	4 (33.3)	1 (10.0)	0
Medicare	20 (62.5)	8 (66.7)	5 (50.0)	7 (70.0)
Other[e]	5 (15.6)	2 (16.7)	1 (10.0)	2 (20.0)

(*Continued*)

Table 1 (Continued).

Demographic	Patients (n=32)	Nonrefractory (n=12)	Single/Double-Class Refractory (n=10)	Triple-Class Refractory (n=10)
Relationship to care partner, n (%)				
Spouse or partner	20 (62.5)	5 (41.7)	7 (70.0)	8 (80.0)
Friend	4 (12.5)	3 (25.0)	0	1 (10.0)
Child	1 (3.1)	1 (8.3)	0	0
Other family member	3 (9.4)	2 (16.7)	1 (10.0)	0
No care partner reported	4 (12.5)	1 (8.3)	2 (20.0)	1 (10.0)
Living situation, n (%)				
Living full time with ≥1 other person	23 (71.9)	7 (58.3)	9 (90.0)	7 (70.0)
Living part time with ≥1 other person	2 (6.3)	2 (16.7)	0	0
Living alone	7 (21.9)	3 (25.0)	1 (10.0)	3 (30.0)

Notes: [a]One participant indicated 2 races; [b]Three participant pairs in the same household selected different options; [c]Also includes trade school certificate; [d]Participants could select multiple insurance types; [e] "Other" forms of insurance included supplementary plans (eg, Medicare Supplement).
Abbreviations: GED, general education development; SD, standard deviation; US, United States.

Table 2 Patient Diagnosis and Treatment Characteristics by Refractory Status

Characteristic	Patients (n=32)	Nonrefractory (n=12)	Single/Double-Class Refractory (n=10)	Triple-Class Refractory (n=10)
Time since diagnosis, months				
Mean (SD)	90 (66)	61 (25)	88 (68)	127 (82)
Median	71	62	64	92
Range	19–296	19–94	43–271	53–296
Approximate age at diagnosis by decade, n (%)[a]				
20–29 years	1 (3.1)	1 (8.3)	0	0
30–39 years	3 (9.4)	2 (16.7)	1 (10.0)	0
40–49 years	10 (31.3)	3 (25.0)	4 (40.0)	3 (30.0)
50–59 years	10 (31.3)	4 (33.3)	3 (30.0)	3 (30.0)
60–69 years	8 (25.0)	2 (16.7)	2 (20.0)	4 (40.0)
≥1 ASCT, n (%)	29 (90.6)	11 (91.7)	9 (90.0)	9 (90.0)
≥1 allogeneic SCT, n (%)	1 (3.1)	0	0	1 (10.0)
≥1 MM clinical trial, n (%)[b]	7 (21.9)	1 (8.3)	1 (10.0)	5 (50.0)
CAR T-cell therapy, n (%)[b]	6 (18.8)	0	1 (10.0)	5 (50.0)
Bispecific antibodies, n (%)[b]	3 (9.4)	0	0	3 (30.0)[c]
On/off treatment at time of participation, n (%)				
On	21 (65.6)	7 (58.3)	9 (90.0)	5 (50.0)
Off	11 (34.4)	5 (41.7)	1 (10.0)	5 (50.0)
Cytogenic testing, n (%)				
Yes	16 (50.0)	6 (50.0)	4 (40.0)	6 (60.0)
No	4 (12.5)	2 (16.7)	2 (20.0)	0
Unsure	12 (37.5)	4 (33.3)	4 (40.0)	4 (40.0)
MRD testing, n (%)				
Yes	18 (56.3)	6 (50.0)	5 (50.0)	7 (70.0)
No	9 (28.1)	3 (25.0)	4 (40.0)	2 (20.0)
Unsure	5 (15.6)	3 (25.0)	1 (10.0)	1 (10.0)

Notes: [a]Estimates based on participant's year of MM diagnosis and age at the time of screening; [b]May have included prior and/or ongoing treatment; [c]Two participants had received 2 different bispecific antibodies.
Abbreviations: ASCT, autologous stem cell transplant; CAR, chimeric antigen receptor; MM, multiple myeloma; MRD, measurable or minimal residual disease; SCT, stem cell transplant; SD, standard deviation.

https://doi.org/10.2147/PPA.S491263

Table 3 Care Partner Demographics

Demographic	Care Partners (n=10)
Age, years	
Mean (SD)	58 (11)
Median	61
Range	42–76
Gender, n (%)	
Female	7 (70.0)
Male	3 (30.0)
Ethnicity, n (%)	
Hispanic/Latino	1 (10.0)
Not Hispanic/Latino	9 (90.0)
Race, n (%)	
American Indian/Alaska Native	0
Asian/Asian American	0
Black/African American	0
White	10 (100.0)
US region, n (%)	
Northeast	2 (20.0)
Midwest	3 (30.0)
South	2 (20.0)
West	3 (30.0)
Community size, n (%)[a]	
≥500,000	1 (10.0)
100,000–499,999	2 (20.0)
30,000–99,999	5 (50.0)
<30,000	2 (20.0)
Highest level of education, n (%)	
High school diploma or GED	0
Associate degree[b]	2 (20.0)
College degree	6 (60.0)
Graduate degree	2 (20.0)
Working status, n (%)	
Full time	6 (60.0)
Part time	0
Disabled	1 (10.0)
Retired	3 (30.0)
Relationship to patient, n (%)	
Spouse or partner	8 (80.0)
Sibling	1 (10.0)
Friend	1 (10.0)
Living situation, n (%)	
Currently living with patient	8 (80.0)
Formerly lived with patient	2 (20.0)

Notes: [a]Three paired participants in the same household selected different options; [b]Also includes trade school certificate.

Abbreviations: GED, general education development; MM, multiple myeloma; OS, overall survival; QOL, quality of life; SD, standard deviation; US, United States.

Table 4 Self-Reported Drug Exposure and Refractoriness by Refractory Status

	Patients (n=32)		Nonrefractory (n=12)		Single/Double-Class Refractory (n=10)		Triple-Class Refractory (n=10)	
Drug Exposure (E)/Refractoriness (R)	**E**	**R**	**E**	**R**	**E**	**R**	**E**	**R**
Exposed/refractory to PI, n (%)								
Bortezomib	31 (96.9)	17 (53.1)	11 (91.7)	N/A	10 (100.0)	8 (80.0)	10 (100.0)	9 (90.0)
Carfilzomib	19 (59.4)	7 (21.9)	2 (16.7)	N/A	8 (80.0)	2 (20.0)	9 (90.0)	5 (50.0)
Ixazomib	6 (18.8)	4 (12.5)	1 (8.3)	N/A	2 (20.0)	1 (10.0)	3 (30.0)	3 (30.0)
Exposed/refractory to IMiD, n (%)								
Lenalidomide	31 (96.9)	15 (46.9)	12 (100.0)	N/A	10 (100.0)	6 (60.0)	9 (90.0)	9 (90.0)
Pomalidomide	14 (43.8)	6 (18.8)	1 (8.3)	N/A	5 (50.0)	1 (10.0)	8 (80.0)	5 (50.0)
Thalidomide	4 (12.5)	2 (6.3)	1 (8.3)	N/A	1 (10.0)	0	2 (20.0)	2 (20.0)
Exposed/refractory to anti-CD38 mAb, n (%)								
Daratumumab[a]	18 (56.3)	8 (25.0)	5 (41.7)	N/A	4 (40.0)	0	9 (90.0)	8 (80.0)
Isatuximab-irfc	4 (12.5)	2 (6.3)	0	N/A	2 (20.0)	0	2 (20.0)	2 (20.0)

Notes: [a]Includes both intravenous (daratumumab) and subcutaneous (daratumumab and hyaluronidase-fihj) formulations.
Abbreviations: IMiD, immunomodulatory drug; mAb, monoclonal antibody; N/A, not applicable; PI, proteasome inhibitor.

study. Care partners were stratified based on supporting a patient with nonrefractory disease (n=3), single/double-class refractory disease (n=3), or triple-class refractory disease (n=4). Patients had been living with MM for differing lengths of time, with diagnoses occurring between 1998 and 2021. The median time since diagnosis was 71 months.

Patients and care partners had generally similar demographics (Table 1 and Table 3). Participants were predominantly non-Hispanic (95.2% [40/42]) and White (81.0% [34/42]) and mostly with a tertiary level of education (92.9% [39/42]). Patients and care partners had a median age of 60 and 61 years, respectively. All care partners had provided support since the time of MM diagnosis and for a minimum of 2 years. Most patients were disabled or retired (75.0% [24/32]), while most care partners were working full time (60.0% [6/10]). Most patients reported having at least 1 care partner (87.5% [28/32]); of these patients, the primary care partner was most commonly a spouse or partner (71.4% [20/28]). Most patients lived full time or part time with another person (78.1% [25/32]).

Diagnosis and Disease Journey Expectations

At diagnosis, most participants experienced shock, fear, and confusion. Many participants were unfamiliar with MM and did not comprehend its likely incurable nature until further in their journey. Initial expectations for the future varied widely. Some patients and care partners had an anticipation of dealing with cancer and a return to normalcy. Some patients had no expectations, while others expected significant disease progression, emotional and physical challenges, and ultimately death. Care partners expected the most difficult aspects of caregiving to be emotional support, managing the patient's QOL, and finances.

> When my doctor said 'no cure,' I was stunned. (70-year-old patient with nonrefractory MM)

> The first 6 months I really did not understand that the MM was ongoing. I thought I'd be cured and move on with my life. […] I didn't understand that people live with cancer and try to 'manage' it. (57-year-old patient with nonrefractory MM)

> I had no idea what to expect. Because he was so young, I expected him to recover quickly. (care partner to a 55-year-old patient with triple-class refractory MM)

Clinicians and Location of Care

Most patients (78.1% [25/32]) reported current involvement of an MM specialist in their care, which could have included (1) a local specialist handling all care, (2) a specialist directing treatment provided by a local clinician, or (3) a second opinion from a specialist, either formally or informally. Nearly two-thirds of patients (65.6% [21/32]) also mentioned

involvement of a National Cancer Institute–Designated Cancer Center (NCI-DCC) in their current care, with multiple patients indicating that proximity to an NCI-DCC would influence future decision-making. Some patients who did not report current involvement with an MM specialist and/or an NCI-DCC had been under their care or advisement in the past.

Nearly half of all patients (46.9% [15/32]) mentioned seeking a second opinion at some point during their care, most often around the time of diagnosis. Most commonly, patient participants reported seeking some form of specialized care for the second opinion, including consulting an MM specialist and/or going to an NCI-DCC. Other reasons for seeking second opinions included confirmation of initial opinion, advice on disease progression, and recommendation or referral from their current clinician.

> I'm young for MM. So after doing some reading, we knew we wanted someone who was an MM-only specialist. (49-year-old patient with triple-class refractory MM)

> [The diagnosing clinician] told me to find a place or group that may work with multiple myeloma. (71-year-old patient with single-class refractory MM)

Most patient participants mentioned temporary or permanent changes to their care team (eg, switching, expanding) and/or the location of care at least once during their treatment journey. Reasons for changing care included access to a specific procedure (eg, autologous stem cell transplant [ASCT], CAR T-cell therapy), pursuit of specialized care (eg, MM specialists, NCI-DCCs), lack of a trusted relationship with their current clinician, and convenience.

> I thought [community hospital #1] was going to kill me and managed to switch to [community hospital #2]. I felt like I was being treated in a cookie-cutter manner. (72-year-old patient with triple-class refractory MM)

Various barriers made it challenging to make a change in care. These included the lack of a support system at the new location, long wait times to access care, inconvenient travel, difficulty in transferring medical records, difficulty managing personal responsibilities (eg, childcare, time off work), and the complexity of navigating insurance. Both patients and their care partners stressed the importance of building a relationship with the clinician providing care to help any transition.

> All of my medical records would be seamlessly and painlessly transitioned electronically. […] There needs to be more coordinated and purposeful communication between a patient's health teams. (36-year-old patient with nonrefractory MM)

> I would need to get to know the doctor and the facility so that I feel completely comfortable and confident in the care that they would provide. (32-year-old patient with nonrefractory MM)

Differences in the reasons for change of care were seen across the refractory groups. Patients with single/double-class refractory disease more frequently reported changing location of care due to factors unrelated to disease progression, while those with triple-class refractory disease more frequently reported changing due to the availability of different treatments, particularly novel therapies. More patient participants with triple-class refractory disease were living in larger communities or urban centers and may have had greater access to treatments.

Treatment Discussions and Decision-Making

Most patients reported discussing treatment options with their clinician. These discussions were not always routine but instead were often driven by the patients' changing needs (ie, disease progression, side effects) or initiated by the patient based on their new learnings. Because of the rapidly evolving treatment landscape, discussion of future treatments was often delayed to times of necessity to consider the latest options available.

> So we talk about [treatment options] when it's necessary, I guess. I don't get ahead of it with [my clinician], and [my clinician has] told me that new therapies come out all the time and it really depends on where a patient is so it doesn't make sense to discuss proposed treatments that may or may not be needed. [...] I'm in the midst of treatment now so we obviously have to talk about [the] next step. (38-year-old patient with single-class refractory MM)

> I haven't talked to my doctor about other options at this time. By the time I relapse, the landscape will have changed. It changes constantly. […] Yes, [treatment option discussion is] need based. […] I do not understand newly approved treatments and will look into those when the time comes. (71-year-old patient with single-class refractory MM)

Most patients thought that treatment decision-making was collaborative with their clinicians and, if applicable, care partner, but a subtle shift in the dynamics occurred over time. Discussions became more shared between patient and clinician as the patient moved further from diagnosis. For care partners, their participation in discussions differed over time, with more involvement at specific events.

> At first we were in shock and didn't understand anything so we went with whatever we were told. Now, we listen to [the clinician] and my wife asks lots of questions that he is receptive to. We haven't disagreed with any of his treatment plans, but if we did, I am sure he would discuss anything we needed to. (50-year-old patient with double-class refractory MM)

> [The patient] makes final decisions, but I'm paying attention to the doctors and making sure home care is being done properly. We do talk things when major issues come up, I definitely have a say as we ran into a situation where treatment became unworkable. (care partner to a 55-year-old patient with triple-class refractory MM)

> I think [the patient] is gonna make her own treatment decisions. I wouldn't interfere unless I thought there was a deficit in rationality. (care partner to a 52-year-old patient with nonrefractory MM)

Some patients mentioned the importance of self-advocacy and felt able to disagree with the suggestions of their care team. Personal priorities for patients included disease control, minimizing side effects, minimizing medical disruptions (eg, fewer in-person medical appointments, close location of the treatment center, easy administration), and maintaining a family/social life.

> [Personal factors] played a huge role, 'cause I've wanted to return to school for a few years now, and the side effects from treatment as well as the chronic back pain I have has made it near impossible for me to normally function. I have to always think about the potential for side effects that could cripple me even further. (32-year-old patient with nonrefractory MM)

> My oncologist understands that I want [to] live a good life with little side effects [and] that it is quality over quantity. I think because of my age that I can answer that way. (71-year-old patient with single-class refractory MM)

Participants were asked to rate the importance of 10 factors when making treatment decisions (Figure 1). Overall, the most important factors for all participants were extended remission and overall survival (OS) and improved QOL. Relief of MM symptoms and treatment side effects were also considered important factors. The lowest-rated factor was mode of treatment administration.

Factors rated as most important in treatment decisions did not vary widely by disease refractory status (Figure 1A). However, patients with nonrefractory disease rated potential impact on other medical conditions and financial burden higher than patients with triple-class refractory disease; as refractoriness increased, mean ratings decreased for financial burden, potential impact on other medical conditions, and mode of administration. The possibility of hospitalization and the location of care and/or treatment were given a lower importance rating by patients with nonrefractory and triple-class refractory disease. Patients and care partners generally rated treatment factors similarly (Figure 1B), being least aligned on the financial burden of the disease, with patients giving it a higher mean rating than the care partners did. Care partners were slightly more concerned than patients with relief of MM symptoms, treatment side effects, and the potential impact on other medical conditions.

> The idea was to have good quality of life in general and work towards it. […] If any treatment does not improve QOL, I do not think it is worth pursuing. (72-year-old patient with double-class-refractory MM)

> Over the years, treatment has become a bigger obstacle to working. I don't feel as though I can choose a treatment based on how much time off I need from work, though, so I can no longer work full time. That has had a financial impact. (61-year-old patient with triple-class refractory MM)

> You must know that reading about side effects (always including death and distant metastases) is like reading a real estate purchase document—endless and endlessly terrifying. (care partner to 78-year-old patient with triple-class refractory MM)

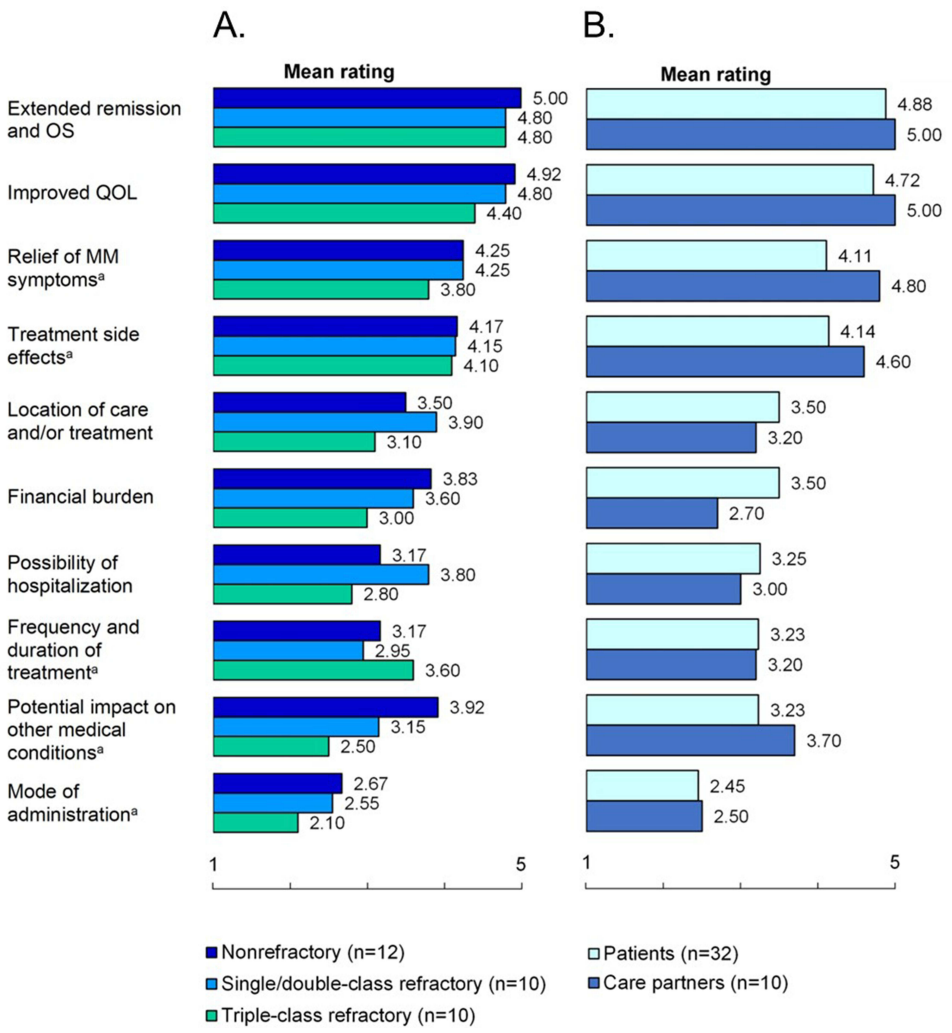

Figure 1 Treatment decision priorities of patients (n=32) by refractory group (**A**) and all patients and care partners (**B**) (mean rating). Participants were presented with 10 factors that might influence their treatment decisions and asked to rate them based on the following scale: (5) very important, (4) fairly important, (3) important, (2) slightly important, and (1) not at all important.

Notes: [a]One single/double-class refractory participant reported a "2 to 1" rating, which was averaged to 1.5.

Abbreviations: MM, multiple myeloma; OS, overall survival; QOL, quality of life.

Treatment Adherence and Burdens

At the time of this study, 34.4% of patients (11/32) were not receiving treatment for MM, including 6 with refractory disease who most recently received CAR T-cell therapy to treat MM. Among the 5 patients with nonrefractory disease who were not receiving treatment, 1 patient was guided to stop treatment based on measurable or minimal residual disease (MRD) status. Reasons for treatment discontinuation among the other 4 patients, all of whom had had an ASCT, included taking a "break" from maintenance therapy and/or its associated toxicities.

> So, we have created an individual treatment plan that will continue to put me into a place of stability so I can have 'breaks' from ongoing chemo. The chemo is very hard on me, and it takes a lot out of me and I don't want to live that way. So treatment for [me] is about knocking the MM back so I can get off of [treatment] and feel better and live more fully for a period of time. (57-year-old patient with nonrefractory MM)

Patients faced disruptions in daily living due to MM symptoms, treatment side effects, medical appointments, and the awareness and uncertainty of having a likely incurable disease. Patients had different ways of coping with these burdens, including medicines and supplements, diet and exercise, and supportive care (eg, physical therapy). Patients also relied on emotional coping methods, including therapy, social support (eg, family, friends, support groups), spirituality, pets,

hobbies, and a positive mindset. The nature of MM led to sacrifices from both patients and care partners, including interfering with career plans, limiting travel, changes in financial security, social isolation, and modifications to long-term goals.

Education and Support Resources

All patients reported engaging in research about MM and its treatment, listing MM-specific advocacy groups, medical/research experts, and support groups as trustworthy sources of information. Many indicated that advocacy groups provided the most helpful resources and disseminated current, trusted information, while support groups provided a connection to others who had similar experiences and created a sense of community. However, some participants acknowledged that incorrect information was given in these support groups. As the disease progressed, patients became more focused on research around addressing side effects and understanding potential future treatment options. Over time, both patients and care partners indicated that their research became more "efficient" as they learned what sources to seek out and had a better understanding of the disease space.

> I just feel like you don't know what you don't know, so it's hard at least at the beginning to even know what to try and learn about. Plus treatments and trials are constantly changing. (50-year-old patient with single-class refractory MM)

> The support group leader is great at guiding to resources. Fliers at the doctor's office led me to the support group. (72-year-old patient with triple-class refractory MM)

Patients mentioned difficulty in finding and understanding information on new treatment options. Information gaps included how therapies work, their side effects and management, treatment-specific pros and cons, individual-specific information (eg, comorbidities, genetics), new research (eg, clinical trial data, impact of treatment order), and resources (eg, financial support, second opinions). Barriers to finding information included too much being available and outdated or inaccurate material. Information was also hard to access publicly or difficult to understand, with the use of complicated medical terms and acronyms. The cognitive effects of both disease and treatment served as additional barriers to seeking and understanding information.

> We don't want to 'Google' and get wrong info. (care partner to a 55-year-old patient with triple-class refractory MM)

> I think that a lot [of information] is out there. My foggy brain can only take so much content. I alternate between wanting more and wanting to escape. (60-year-old patient with double-class refractory MM)

Information that patients wish they had known sooner fell into 4 distinct categories: prevention and early detection, treatment (eg, options, efficacy data, side effects, order of treatment), general MM education (eg, prognosis, "honest" description of the disease's chronic nature), and the mental and emotional impact of living with the disease.

> So the only information that would have helped was if there were some tests as part of routine checkups that could have indicated MM—by the time I was diagnosed, I think my MM had progressed. (72-year-old patient with double-class refractory MM)

> Side effects and efficacy. I never really asked questions about it, and it wasn't offered to me. (50-year-old patient with double-class refractory MM)

> I wish that I had understood at the outset that I would basically be in ongoing treatment indefinitely. (56-year-old patient with nonrefractory MM)

> One thing not mentioned much is the mental and emotional aspects of the cancer, treatment, and maintenance. (62-year-old patient with nonrefractory MM)

All patient participants indicated that they had interacted with other patients with MM in some way, frequently in support groups. Social media platforms and MM coaching, either having a coach or being a coach to other patients, were additional ways participants connected to other patients with MM. These connections assisted participants in learning about living with MM, the experiences of other patients, and helpful resources. They also enabled participants to receive

or provide emotional support and encouragement. However, some patients and care partners did not want another MM-related commitment and participation in support groups caused negative emotions. Overall, care partners expressed more hesitancy with support groups than patients.

> [I] belong to several online blogs and chats. [...] I have in the past [attended a support group] but not for quite some time. I pretty much have support groups on my Facebook, and we all share and talk and encourage each other. Social media can be a good thing at times. (60-year-old patient with single-class refractory MM)

> I did not have the benefit of guidance from others as to resources. That would have been great. I now serve as a MM coach for others through Healthtree.org and I offer that kind of support to new MM patients. (56-year-old patient with nonrefractory MM)

> I'm not interested in a support group. Life is so much about this I don't want to have more about it! (care partner to a 55-year-old patient with triple-class refractory MM)

Younger Patients with MM

Compared with the US MM population, this study included patients who were younger (median age at study participation, 60 years; Table 1). Forty-four percent of patients (14/32) were diagnosed before the age of 50 years, and 75.0% (24/32) before the age of 60 years (Table 2). These younger patients were at a different stage of life and, therefore, expressed different challenges and support needs than the typical US patient with MM. Notably, younger patients often felt isolated and unable to relate to both available MM-related data and other patients with MM.

> My prognosis according to the doctor is very fluid because I am so young. […] I was seeking information about other young people dealing with MM. […] I'm still looking for more information on younger individuals dealing with MM and their life expectancy. (32-year-old patient with nonrefractory MM)

> I do [attend MM support groups], but I really haven't connected with [the members] outside of the groups. To be honest, they are all old enough to be my grandparents. So the only thing we have in common is MM. (43-year-old patient with nonrefractory MM)

A major age-specific burden the younger patients highlighted was parenting challenges. Twenty-five percent of patients (8/32) had minors in their household at some point since diagnosis, and 18.8% (6/32) still had minors in the household at the time of the study. Some challenges mentioned included needing help with childcare, being present in a child's life, normalizing their lives as much as possible, and learning how to talk to children about MM. Participants also expressed fears about not being around for their children.

> Really, my main concern is my daughter and being able to parent her well and be there for her. […] I wish there was some help for single parents. […] I think child care help for single parents would be huge. (50-year-old patient with single-class refractory MM)

> I was very scared at diagnosis and if I would live to see my daughter grow up. (50-year-old patient with double-class refractory MM)

> Early on, it was hard to find info about talking with children about cancer/myeloma. (56-year-old patient with nonrefractory MM)

> I am so proud of the ways that I continued to love my children and teach them to move through fear and grief rather than pretend it doesn't exist. (care partner to 43-year-old patient with nonrefractory MM)

Other frequently cited challenges were around sexual and reproductive health and the impact on current and future financial earnings. Of the participants diagnosed before the age of 50 years, only 35.7% (5/14) were working either full or part time at the time of this study. Reproductive health considerations were also not frequently discussed between the care team and patients leading to gaps in knowledge and uncertainty around fertility, given the lack of individual-specific information for younger patients.

> No one talks about sexual challenges. All are scared to talk about it. It is normal, all [people who receive chemotherapy] have that problem. (52-year-old patient with nonrefractory MM)

> The only sacrifice that I made that I do not like is the fact that I had to retire from my career. […] I am on social security disability and unfortunately that does not pay enough for me to live exactly comfortable. (54-year-old patient with nonrefractory MM)

> The exhaustion, fatigue, mental fatigue has been the most disruptive along with how much administrative work it takes to cover costs and keep medical coverage while on disability as a younger person with MM. (49-year-old patient with triple-class refractory MM)

Discussion

This mixed methods analysis examined patient and care partner preferences and decision-making at different points throughout the MM treatment journey. This study is unique in that participant results were stratified by disease refractory status to the 3 main anti-myeloma drug classes (ie, PIs, IMiDs, and anti-CD38 mAbs), which is an important consideration for choosing subsequent therapies.[7,17,18,21] Patient participants had a broad diagnosis window (1998–2021), spanning more than 2 decades of treatment landscape progress, as well as changing patterns of access to expert care.

Extended remission and OS and improved QOL were the most important decision-making priorities for both patients and care partners, echoing findings of other studies and emphasizing the need for continued patient engagement on these factors.[19,22,31,32] Overall, ratings were not highly influenced by disease refractory status, although the potential impact on other medical conditions had the largest difference between refractory group ratings. The possibility of hospitalization and the location of care may have been less important factors in making treatment decisions for patients with nonrefractory disease, since they often had recently received ASCT and were familiar with a hospital setting, or for patients with triple-class refractory disease, since these patients were often already seeking novel treatments in that setting. Nonetheless, these correlations were small and may not be fully due to disease refractory status but rather influenced by external factors. In general, ratings were likely impacted by each participant's lived experience and thus may change as their circumstances and experiences change. In addition, this may not be representative of the population due to the small size of each refractory group (n=10-12).

Patients and care partners were generally aligned on priorities in this study, although the rating of financial burden was higher in patients than in care partners, and care partners were slightly more concerned than patients with relief of symptoms, treatment side effects, and the potential impact on other medical conditions. A discrete choice experiment by Fifer et al,[19] which included patients with MM at various stages of treatment, carers, nurses, and physicians, and a study by Auclair et al,[20] which included patients with MM and caregivers from the US, Canada, and Europe, also found that care partners were less concerned with the financial burden of treatment than patients.[19,20]

Globally, survival remains the most important factor for patients with MM.[17,19,22] Side effects of treatment are also an important factor. In a United Kingdom discrete choice experiment, patients living with others and those more recently diagnosed placed greater importance on average survival and mild to moderate side effects.[31] Those patients who were receiving treatment longer were likely to place more importance on the mode and frequency of treatment. In this study, frequency or duration of treatment was also prioritized more by patients with triple-class refractory disease. Furthermore, He et al[17] found that treatment duration was cited most frequently as a major treatment burden by patients in a qualitative study in European patients with newly diagnosed MM or RRMM.

QOL was also rated highly as a decision-making factor for all participants regardless of the patient's disease refractory status. This is not surprising since MM is now more widely viewed as a chronic disease that patients will be living with for a long time.[33] As a result, patients are more likely to make treatment decisions based on QOL versus potential OS, taking into account how cumulative symptoms and side effects will impact their emotional state and their ability to participate in the activities of daily living.[33,34]

An interesting observation was the high percentage of patients with nonrefractory disease who indicated that they were currently not receiving any therapy, even though current guidelines recommend maintenance therapy after primary therapy for MM.[35] Patients cited discontinuation of maintenance therapy due to toxic side effects of the treatment or simply to give themselves a treatment break. The decision made by patients and their clinicians to discontinue maintenance therapy indicated that they were potentially placing short-term QOL above better long-term outcomes. In a retrospective study by Nunnelee et al,[36] patients were divided into groups of those who discontinued maintenance early

(≤3 years post ASCT) or late (>3 years post ASCT). The most common reasons for stopping treatment early were adverse events and patient preference. However, the patients who discontinued maintenance late were more likely to have longer progression-free survival and OS.[36]

MRD status has shown significant prognostic value, with MRD negativity associated with prolonged progression-free survival.[37] More than half of the patients (56.3% [18/32]) in this study were aware of having had MRD testing at some point during their care. At least 4 patients, with different refractory statuses, indicated that they were actively monitoring their MRD status, with 2 patients indicating that MRD status had guided their treatment decisions. One patient in this study did discontinue all treatment based on MRD status. Indeed, patients and clinicians will often weigh the risks (eg, short remission) and benefits (eg, lower side effects burden, QOL) of discontinuing therapy after achieving sustained disease control. While MRD status may become a useful tool for making these clinical decisions as indicated in a retrospective study,[37] it remains a prognostic factor in clinical guidelines.[35,38] MRD negativity continues to be explored in clinical trials as a decision-making tool, but the results have been mixed, depending on other disease factors. Patients in the GEM2014MAIN trial who achieved negative MRD status after maintenance for 24 months discontinued maintenance and had low progression rates, including those patients with high-risk features, while the MASTER trial demonstrated higher recurrence rates among patients with high-risk cytogenetics who discontinued maintenance therapy based on MRD negativity.[39,40]

In this study, patients recognized the importance of involving an MM specialist early in their treatment journey. The sequence of decisions in a patient's treatment journey has historically been guided by refractory status to standard treatments, becoming increasingly complex with each new line of therapy and necessitating the involvement of a specialist.[6,41] Finding a specialist can be challenging in MM, particularly in rural or medically underserved areas.[41] This study also showed that as patients moved further from diagnosis, they felt more comfortable questioning treatment options as decisions became more complex and personalized. This may be because they had more MM-related knowledge and experience as they moved further from diagnosis. The trust relationship between patient and care team was also found to be important in this study. While some factors are out of the patient's or clinician's control, Whitney et al[41] suggested that this trust relationship evolves throughout the treatment journey, is vital for the decision-making process, and could be enhanced through communication and shared decision-making tools.

Patients and care partners used multiple resources to do their own research on MM and its treatment options to help them make more informed decisions. However, many patients and care partners had difficulty finding the desired information because the amount of information available was overwhelming, resources were outdated due to the rapidly changing treatment landscape, and public access to the latest data was limited. The information was also often hard to understand, and some patients mentioned that cognitive effects of their disease and treatment made it even more difficult. Due to the chronic nature of MM, sustained support and educational efforts of various kinds were required. MM specialists, NCI-DCCs, advocacy organizations, and support groups played key roles in the pursuit of personalized care, dispersing trusted information, and empowering patients to advocate for themselves. Only a portion of the patients knew whether they had cytogenic (50.0%) or MRD (56.3%) testing done. This is an area in which patient education could be improved.

MM is predominantly a disease of the elderly; the median age of diagnosis in the US is 69 years.[3] Patients in this analysis were comparatively younger, with 75.0% being diagnosed before the age of 60 years. However, these younger patients provided unique insights to challenges faced, including the prospect of living with the disease for a longer time and therefore the likelihood of multiple lines of therapy and exposure to novel therapies that are currently reserved for later in the disease cycle. Younger patients are diagnosed in their most productive years and experience significantly higher personal, professional, familial, and financial burdens compared with older patients.[42] This patient subgroup needs attention and support, given their long disease journey with multiple potential complications. Although younger patients tend to have a better prognosis, there is not much literature on the unique challenges experienced by this patient group.[43]

This study had certain known limitations. Participants in this study may not be representative of the general US population of patients with MM and their care partners due to the nature of the sampling. There may have been sampling bias due to the digital nature of recruitment, unintentionally excluding participants lacking technological skills or resources or those who were too ill to participate. As such, this study may have been more likely to recruit younger

participants who were more informed and involved in MM care, either for themselves or the patient with MM they were supporting. This study also relied on participants to self-report medical-related information, such as their MM treatment history, with disease refractory status classification fully reliant on this information. A participant's ability to recall details from the past may have varied and may be subject to recall bias. Taken together, the composition of the study population and how it relates to the general US population of patients with MM and their care partners should be considered when interpreting the results from this study. Despite these limitations, the primary objective of this research was to obtain experiences and understand perceptions and preferences directly from patients with MM and their care partners.

Conclusion

This mixed methods study identified how disease status and an evolving treatment landscape affected treatment decisions among patients with MM and MM care partners. The treatment landscape for MM in the US has changed significantly in the last 2 decades, with many more treatment options now available. This complexity has resulted in patients seeking specialist involvement earlier in their disease journey. Patients and care partners are becoming increasingly involved in decision-making and rated extended remission and OS and improved QOL as the most important treatment decision priorities in this study. Importantly, ratings for certain factors may change throughout their treatment journey. Collaborative discussions between clinicians, patients, and care partners may help to promote trust and improve patient empowerment. This study also highlights the importance of support resources such as MM-specific organizations and the need for trusted information that can supplement the conversations patients and care partners have with their care teams. These findings will help the MM community to better address the shifting challenges and needs of patients and care partners over the course of the disease, having practical implications for treatment adherence and outcomes.

Ethics Approval

The study was conducted in accordance with the Good Practices for Outcomes Research issued by the Professional Society for Health Economics and Outcomes Research and in the consolidated criteria for reporting qualitative research (COREQ).[44] The study was approved by WCG Institutional Review Board (#20226876) and was conducted in accordance with the principles of the Declaration of Helsinki.

Consent to Participate

All participants consented to participate through an electronic information and consent document, which included consent to publish anonymized responses, direct quotes, and summaries of the research results.

Acknowledgment

The authors thank the patients and care partners who participated in this study. Medical writing support was provided by Robyn Roth, PhD, of Nucleus Global and funded by Pfizer. Parts of this paper were submitted as abstracts to the 65th ASH Annual Meeting and Exposition and presented at the EHA2024 Hybrid Congress. These abstracts were published in Blood 2023;142 (Supplement 1): 7357: https://doi.org/10.1182/blood-2023-180951, Blood 2023;142 (Supplement 1): 7383: https://doi.org/10.1182/blood-2023-179554, and HemaSphere 2024;8(S1): https://doi.org/10.1002/hem3.104.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This study was funded by Pfizer Inc.

Disclosure

Darcy R Flora, Rachel Byrd, and Daniel A Platt were employees of Gryt Health Inc at the time of the study. Flora reports research funding from Amgen Inc, Seagen Inc, Pfizer Inc, and Syneos Health. Byrd reports research funding from Seagen Inc, Pfizer Inc, and Syneos Health. Platt reports research funding from Bristol Myers Squibb, Pfizer Inc, Syneos Health, and Amgen Inc. Hlavacek, Goldman and Cappelleri are employees of Pfizer Inc and hold equities. Kennedy reports speakers bureau for Bristol Myers Squibb and Janssen; consultancy for AbbVie, Genentech Inc, Adaptive Biotechnologies, and Pfizer Inc; non-financial support from Johnson and Johnson/Janssen for consulting, speaking and travel; honoraria for single meeting- ended Dec 31,2022 from Premier, Inc. LeBlanc reports consultancy and/ research for and honoraria from Flatiron, CareVive, BMS/Celgene, Duke University, Deverra Therapeutics, GSK, Genentech, Gilead, Menarini/Stemline, Incyte, Rigel, Seattle Genetics, Lilly, Meter Health, American Cancer Society, BlueNote, Jazz Pharmaceuticals, Incyte, Novartis, Pfizer, BeiGene, AstraZeneca, Astellas, Agios, Agilix, AbbVie, Leukemia and Lymphoma Society, National Institute of Nursing Research/National Institutes of Health, Seagen, and Servier; patents and royalties from UpToDate; current equity holder of Dosentrx and ThymeCare.

References

1. Cowan AJ, Allen C, Barac A. et al. Global burden of multiple myeloma: a systematic analysis for the global burden of disease study 2016. *JAMA Oncol*. 2018;4(9):1221–1227. doi:10.1001/jamaoncol.2018.2128
2. Kumar SK, Callander NS, Adekola K, et al. Multiple myeloma, version 2.2024, NCCN Clinical Practice Guidelines in Oncology. *J Natl Compr Canc Netw*. 2023;21(12):1281–1301. doi:10.6004/jnccn.2023.0061
3. Surveillance, Epidemiology, and End Results. Cancer Stat Facts: myeloma. Bethesda, MD: SEER. Available from: https://seer.cancer.gov/statfacts/html/mulmy.html. Accessed April 19, 2024.
4. Moreau P, Touzeau C, Vij R, Goldsmith SR, Rosko AE. Newly diagnosed myeloma in 2020. *Am Soc Clin Oncol Educ Book*. 2020;40:e144–e158.
5. Rajkumar SV, Kumar S. Multiple myeloma current treatment algorithms. *Blood Cancer J*. 2020;10(9):94. doi:10.1038/s41408-020-00359-2
6. Maples KT, Scott SA, Lonial S. Novel approaches to the treatment of multiple myeloma. *Clin Adv Hematol Oncol*. 2023;21(5):247–256.
7. Moreau P, Kumar SK, San Miguel J, et al. Treatment of relapsed and refractory multiple myeloma: recommendations from the International Myeloma Working Group. *Lancet Oncol*. 2021;22(3):e105–e118. doi:10.1016/S1470-2045(20)30756-7
8. Abecma (idecabtagene vicleucel). Summit, NJ: Celgene. April. 2024.
9. Carvykti (ciltacabtagene autoleucel). Horsham, PA: Janssen Biotech, Inc. April. 2024.
10. Elrexfio (elranatamab-bcmm). New York, NY: Pfizer Labs. August. 2023.
11. Tecvayli (teclistamab-cqyv). Horsham, PA: Janssen Biotech, Inc. May. 2024.
12. Talvey (talquetamab-tgvs). Horsham, PA: Janssen Biotech, Inc. August. 2023.
13. Lee H, Neri P, Bahlis NJ. Current use of bispecific antibodies to treat multiple myeloma. *Hematology Am Soc Hematol Educ Program*. 2023;2023(1):332–339. doi:10.1182/hematology.2023000433
14. Firestone RS, Mailankody S. Current use of CAR T cells to treat multiple myeloma. *Hematology Am Soc Hematol Educ Program*. 2023;2023(1):340–347. doi:10.1182/hematology.2023000434
15. Parsons JA, Greenspan NR, Baker NA, McKillop C, Hicks LK, Chan O. Treatment preferences of patients with relapsed and refractory multiple myeloma: a qualitative study. *BMC Cancer*. 2019;19(1):264. doi:10.1186/s12885-019-5467-x
16. Crawford R, Gries KS, Valluri S, et al. The patient experience of relapsed refractory multiple myeloma and perspectives on emerging therapies. *Cancer Rep*. 2022;5(11):e1603. doi:10.1002/cnr2.1603
17. He J, Duenas A, Collacott H, et al. Patient perceptions regarding multiple myeloma and its treatment: qualitative evidence from interviews with patients in the United Kingdom, France, and Germany. *Patient*. 2021;14(5):613–623. doi:10.1007/s40271-021-00501-7
18. O'Donnell EK, Shapiro YN, Yee AJ, et al. Quality of life, psychological distress, and prognostic perceptions in caregivers of patients with multiple myeloma. *Blood Adv*. 2022;6(17):4967–4974. doi:10.1182/bloodadvances.2022007127
19. Fifer SJ, Ho KA, Lybrand S, Axford LJ, Roach S. Alignment of preferences in the treatment of multiple myeloma–a discrete choice experiment of patient, carer, physician, and nurse preferences. *BMC Cancer*. 2020;20(1):546. doi:10.1186/s12885-020-07018-6
20. Auclair D, Mansfield C, Fiala MA, et al. Preferences and priorities for relapsed multiple myeloma treatments among patients and caregivers in the United States. *Patient Prefer Adherence*. 2022;16:573–585. doi:10.2147/PPA.S345906
21. O'Donnell EK, Shapiro YN, Yee AJ, et al. Quality of life, psychological distress, and prognostic perceptions in patients with multiple myeloma. *Cancer*. 2022;128(10):1996–2004. doi:10.1002/cncr.34134
22. Janssens R, Lang T, Vallejo A, et al. Patient preferences for multiple myeloma treatments: a multinational qualitative study. *Front Med Lausanne*. 2021;8:686165. doi:10.3389/fmed.2021.686165
23. Jen WY, Yoong J, Liu X, Tan MSY, Chng WJ, Chee YL. Qualitative study of factors affecting patient, caregiver and physician preferences for treatment of myeloma and indolent lymphoma. *Patient Prefer Adherence*. 2020;14:301–308. doi:10.2147/PPA.S241340
24. LeBlanc MR, LeBlanc TW, Leak Bryant A, Pollak KI, Bailey DE, Smith SK. A qualitative study of the experiences of living with multiple myeloma. *Oncol Nurs Forum*. 2021;48(2):151–160. doi:10.1188/21.ONF.151-160
25. Nathwani N, Bell J, Cherepanov D, et al. Patient perspectives on symptoms, health-related quality of life, and treatment experience associated with relapsed/refractory multiple myeloma. *Support Care Cancer*. 2022;30(7):5859–5869. doi:10.1007/s00520-022-06979-7
26. LeBlanc TW, Russell NH, Hernandez-Aldama L, et al. Patient, family member and physician perspectives and experiences with AML treatment decision-making. *Oncol Ther*. 2022;10(2):421–440. doi:10.1007/s40487-022-00200-9

27. Tashakkori A, Teddlie C. *Mixed Methodology: Combining Qualitative and Quantitative Approaches*. Thousand Oaks, CA: Sage Publications, Inc; 1998.
28. Krippendorff K. *Content Analysis: An Introduction to Its Methodology*. 4th ed. Thousand Oaks, CA: SAGE Publications, Inc; 2022.
29. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nurs Health Sci*. 2013;15(3):398–405. doi:10.1111/nhs.12048
30. Braun V, Clarke V. *Thematic Analysis: A Practical Guide*. 1st ed. London: SAGE Publications, Ltd; 2021.
31. Fifer S, Galinsky J, Richard S. Myeloma patient value mapping: a discrete choice experiment on myeloma treatment preferences in the UK. *Patient Prefer Adherence*. 2020;14:12831293.
32. Batchelder L, Philpott S, Divino V, et al. Physician treatment preferences for relapsed/refractory multiple myeloma: a discrete choice experiment. *Future Oncol*. 2022;18(25):2843–2856. doi:10.2217/fon-2022-0378
33. Monteith BE, Sandhu I, Lee AS. Management of multiple myeloma: a review for general practitioners in oncology. *Curr Oncol*. 2023;30 (5):4382–4401. doi:10.3390/curroncol30050334
34. Osborne TR, Ramsenthaler C, de Wolf-Linder S, et al. Understanding what matters most to people with multiple myeloma: a qualitative study of views on quality of life. *BMC Cancer*. 2014;14:496. doi:10.1186/1471-2407-14-496
35. Rajkumar SV. Multiple myeloma: 2022 update on diagnosis, risk stratification, and management. *Am J Hematol*. 2022;97(8):1086–1107. doi:10.1002/ajh.26590
36. Nunnelee J, Cottini F, Zhao Q, et al. Early versus late discontinuation of maintenance therapy in multiple myeloma. *J Clin Med*. 2022;11(19):5794. doi:10.3390/jcm11195794
37. Martinez-Lopez J, Alonso R, Wong SW, et al. Making clinical decisions based on measurable residual disease improves the outcome in multiple myeloma. *J Hematol Oncol*. 2021;14(1):126. doi:10.1186/s13045-021-01135-w
38. Dimopoulos MA, Moreau P, Terpos E, et al. Multiple myeloma: EHA-ESMO clinical practice guidelines for diagnosis, treatment and follow-up. *Ann Oncol*. 2021;32(3):309–322. doi:10.1016/j.annonc.2020.11.014
39. Rosiñol L, Oriol A, Ríos R, et al. Lenalidomide and dexamethasone maintenance with or without ixazomib, tailored by residual disease status in myeloma. *Blood*. 2023;142(18):1518–1528. doi:10.1182/blood.2022019531
40. Costa LJ, Chhabra S, Medvedova E, et al. Daratumumab, carfilzomib, lenalidomide, and dexamethasone with minimal residual disease response-adapted therapy in newly diagnosed multiple myeloma. *J Clin Oncol*. 2022;40(25):2901–2912. doi:10.1200/JCO.21.01935
41. Whitney RL, White AEC, Rosenberg AS, Kravitz RL, Kim KK. Trust and shared decision-making among individuals with multiple myeloma: a qualitative study. *Cancer Med*. 2021;10(22):8040–8057. doi:10.1002/cam4.4322
42. Tanguay M, Dagenais C, LeBlanc R, Ahmad I, Claveau JS, Roy J. Young myeloma patients: a systematic review of manifestations and outcomes. *Curr Oncol*. 2023;30(6):5214–5226. doi:10.3390/curroncol30060396
43. Steinbach M, Neupane K, Aziz M, et al. Multiple myeloma in young Patients: a scoping review. *Clin Lymphoma Myeloma Leuk*. 2024;24(1):15–22. doi:10.1016/j.clml.2023.08.019
44. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357. doi:10.1093/intqhc/mzm042