Patient Preference and Adherence

Dovepress
Taylor & Francis Group

Open Access Full Text Article

ORIGINAL RESEARCH

iPREFER: Patients' Experiences and Preference of Treatment for Multiple Myeloma Following Multiple Lines of Treatment – A Qualitative Study

Melissa Betty Perry[1], Ramsay Lochhead Devaraj[1], Kate Law[1], Fay Ashby[2], Sally Taylor[1,3]

[1]Christie Patient Centred Research, The Christie NHS Foundation Trust, Manchester, UK; [2]Clinical Operations, CellCentric Ltd, Chesterford Research Park, Cambridge, UK; [3]Division of Nursing Midwifery and Social Work, The University of Manchester, Manchester, UK

Correspondence: Melissa Betty Perry, Christie Patient Centred Research, The Christie NHS Foundation Trust, Manchester, UK, Tel +44 0161 918 2090, Email m.stanworth@nhs.net

Purpose: Each year in the United Kingdom, approximately 6000 people are diagnosed with Multiple Myeloma (MM) and treated with targeted cancer drugs. The duration and frequency of these treatments vary and include oral, intravenous (IV), and subcutaneous administration. Patients often undergo multiple lines of treatment and live with uncertainty spanning years and decades. This study (ClinicalTrials.gov Identifier: NCT06322927) explores the experiences of people receiving treatment for MM, what matters most when making treatment decisions, and what influences their treatment preference.

Patients and Methods: This was a qualitative study using semi-structured interviews. Patients were eligible if they had a confirmed MM diagnosis and received at least five lines of treatment. Interviews focused on their extensive experiences of multiple lines of oral anti-cancer and bispecific antibody treatment, or IV therapy, and were analyzed using inductive thematic analysis.

Results: Four key themes were identified from nine interviews: "Living with MM and its impact on quality of life", portrays the relentless challenges and side effects of MM; "Factors influencing treatment decision making" outlines the importance of family, shared decision-making and information needs; "Factors influencing treatment experience", including practical challenges, and self-management; and "Treatment preference" explores participants' perceptions of treatment within the context of their own circumstances. Participants showed a willingness and tolerance to accept treatments that significantly impact their everyday life, quality of life, and relationships, to achieve their goals of care.

Conclusion: The findings highlight the need for healthcare professionals to better understand individual patient circumstances and priorities, inform them of the treatment impact on their priorities to empower patients to choose the right treatment for them and improve quality of life. More research is needed to understand how to integrate this into the clinical care pathway.

Plain Language Summary: Multiple Myeloma is a type of blood cancer which often requires patients to undergo multiple lines of treatment with the intent to control the disease or improve quality of life. However, the burdens and side effects of these intensive treatments and the cancer itself can have physical, social, and emotional impacts, often causing patients to change their everyday lives and rely on informal caregivers. To improve our support and experience for patients during this time, we need to better understand their priorities and preferences surrounding treatment.

In this study, we have thoroughly explored the treatment experiences and preferences of nine patients with multiple myeloma. This study found that personal circumstances and goals of care influenced treatment decisions and preferences. Patients will endure significant side effects, impacts on their daily lives, and many lines of treatment if it helps them to achieve their goals of care. Findings from this study will support patients with multiple myeloma to make informed decisions about their treatment.

Keywords: hematologic neoplasms, quality of life, patient experience, semi-structured Interviews

https://doi.org/10.2147/PPA.S576524
Received: 1 November 2025
Accepted: 13 March 2026
Published: 28 April 2026

Introduction

Each year, over 6,000 people are diagnosed with Multiple Myeloma (MM), making it the 19th most common cancer in the United Kingdom.[1] MM is a type of blood cancer caused by malignant plasma cells impacting bone marrow function.[2] Malignant plasma cells secrete biomarkers that can be measured to indicate risk and prognosis,[3] information that can influence the type of treatment needed.[4] Over the last decade, MM survival rates have increased, with median survival extending to greater than ten years in younger individuals.[2,5,6] Despite this, MM remains a relapse-remitting disease.[2]

Patients receive multiple therapies over many years, facing numerous treatment decisions, with main treatments including targeted cancer drugs, chemotherapy, steroids, and stem cell transplants.[7] For first-line treatment, patients are often given a combination of targeted drugs such as thalidomide, lenalidomide, bortezomib, and daratumumab.[7] The administration, duration, and frequency of these treatments are variable; for example, lenalidomide is taken orally once daily for 21 days followed by a 7-day break on repeated 28-day cycles, whereas daratumumab is given in the hospital by subcutaneous injection or intravenous infusion (IV) weekly for the first eight weeks, every two weeks for 16 weeks, and once every four weeks after that.[8–10] Intensive treatments focus on effectively controlling the disease to maintain or improve quality of life (QoL).[5] Research continues to offer the potential for newer drugs with improved outcomes.[11–13] However, this may also increase treatment complexities; therefore, it is essential for clinicians to better understand patient priorities so that new and novel therapies are acceptable to patients.

From diagnosis, patients have to cope with and adapt to a constant state of uncertainty from the physical and emotional impacts of the disease and treatment.[14] The complex nature of MM, the impact of treatment lines on daily life, and the uncertainty of treatment success have wide-reaching physical, social, and emotional implications for patients and their families.[15] Physical symptoms include renal insufficiency, weakened bones, anemia, and frequent infections, which significantly impact daily activities.[16,17] Treatment sometimes relieves disease-related symptoms but may cause equally debilitating side effects such as fatigue, nausea, and peripheral neuropathy.[18,19] The substantial burden of disease and treatment side effects forces people to change their lifestyle and make major adjustments to accommodate functional changes.[14] In many cases, this includes significant life choices such as stopping work or taking early retirement, which also has a financial impact.[20] People with MM often rely on partners who become informal caregivers.[21] In addition, discussions regarding prognosis are commonplace; therefore, patients frequently consider their own mortality, adding another complexity to living life with MM.[22]

Previous research demonstrated that patients prioritize increased life expectancy, improved QoL overall, and the ability to carry out daily activities when considering treatment options.[23,24] It is further suggested that better adherence and overall survival are closely linked to treatment satisfaction in oral therapies.[25–27] Treatments are often tolerated at the expense of short-term side effects and there can be a preference for oral treatments which are perceived to be more convenient and to have higher efficacy than injectable treatments.[25,27–29] While it is suggested that efficacy has the most influence on patients' preferences, preference patterns differed based on individual patient characteristics and their approach to assessing treatment benefits and risks, which further highlights the need for shared decision-making during treatment selection.[30,31] To improve our ability to provide person-centred support during the decision-making process and throughout treatment, we need to better understand individual priorities and factors that influence treatment preferences.

Interviews capture depth and nuanced information, as researchers can establish a rapport and probe participants to articulate their experiences, attitudes, and preferences.[32] Qualitative research has explored the symptoms experienced by patients and how these impact QoL and decision-making.[15,23,33] However, it is not fully understood if lived experience of the multiple treatment lines and cumulative treatment burden leads to an accumulation of side effects, shifts in preference, and priority changes as illness progresses. These are clinically important to avoid misaligning with or underestimating patients' goals, needs, and resilience. This study was informed by the Theoretical Framework of Acceptability (TFA), which explains how individuals evaluate healthcare treatments in terms of their perceived benefits, burdens, understanding, and alignment with personal values.[34] In multiple myeloma, where treatment

decisions involve trade-offs between survival, side effects, and QoL, TFA provides a structured way to understand how patients experience treatment and develop preferences. Our study (ClinicalTrials.gov Identifier: NCT06322927) will explore the experiences of people receiving treatment for MM, using the following objectives:

- Understand what matters most to people with MM when making treatment decisions.
- Explore how experiences differ across different lines of treatment.
- Determine if people with MM have any treatment preferences.

Materials and Methods

Study Design

A qualitative study was conducted at a single tertiary cancer centre in Northwest England in 2024. Semi-structured interviews were conducted with patients with MM and experience of ≥5 lines of treatment including oral anti-cancer therapy and either a bispecific antibody treatment or intravenous therapy. The target sample size was 10–15 participants based on information power and general acceptance for qualitative studies.[35,36] Recruitment was between April and September, with data collection and analysis occurring concurrently until November 2024.

Study Procedure

Participants were identified according to eligibility criteria (Table 1) and first approached by the clinical team to obtain their verbal consent to discuss the study with a researcher. Patients were given written information and the researcher ascertained their willingness to participate in person during clinic or via telephone.

Telephone interviews were conducted at a convenient time for the participant by a sole female Research Associate (MBP, Masters of Public Health) with experience in conducting qualitative interviews with oncology patients. Participants were aware that the interviewer worked within a research team at the cancer centre and was not associated with any aspect of care delivery.

Interviews were semi-structured using the pre-defined interview schedule (Figure 1), developed by the funder (CellCentric- biotechnology company) and agreed on by the research team and the patient and public involvement and engagement activities. The interview focused on their oral anti-cancer therapy followed by their experience of bispecific antibody treatment or IV therapy. Participants were given the opportunity to discuss other relevant issues that were important to them.

Table 1 The Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
Participants are eligible to be included in the study only if all of the following criteria apply.	**Participants are excluded from the study if any of the following criteria apply.**
Participants with confirmed MM (per standard disease-specific diagnostic criteria).[37]	Aged under 18
Participants must have received ≥5 lines of treatment for MM and fit into one of the following treatment categories: • Subset 1–Participants must have received an oral anti-cancer therapy and a bispecific antibody treatment. • Subset 2– Participants must have received an oral anti-cancer therapy and if they have not had a bispecific antibody treatment, they must have received at least one intravenous (IV) therapy.	Unable to understand and communicate in the English language
Aged 18 years of age or over.	Unable to provide written informed consent
Able to provide informed consent.	
Able to communicate in English.	

Data Analysis

Interviews and analysis occurred concurrently. Interviews were transcribed verbatim, and transcripts were checked for quality.[35] Qualitative data were analyzed by experienced academic researchers without a hematological clinical background and no preconceived biases towards treatment experience or preference (MBP, RLD, and KL). Transcripts were coded independently on NVivo using the six-stage thematic analysis by Braun and Clarke:[38] 1 – Familiarization of data:

Question	Prompts
1. How long ago was your <oral anti-cancer therapy /bispecific antibody treatment or other IV therapy> treatment? Replace with the specific treatment the patient has had/is having.	Was your treatment given as part of a clinical trial?
2. How would you describe your quality of life prior to starting this treatment?	What symptoms did you experience prior to starting treatment?
	How did these symptoms affect your everyday activities (eg preparing meals, walking the dog), home environment (eg interactions with people at home, physical surroundings), independence, hobbies and pastimes?
	What logistical steps did you put in place to cope with your symptoms?
	Did you feel that you were coping with these symptoms emotionally?
3. What did you know about <oral anti-cancer therapy /bispecific antibody treatment or other IV therapy> prior to receiving this treatment?	What did this knowledge make you feel about potentially receiving this treatment?
	Where did you get the information from that informed this knowledge?
4. How did you feel once you and your doctor had discussed your treatment and the potential benefits and risks?	Did the information make you feel anxious or stressed?
5. Which aspects of the treatment did you think would potentially having the largest impact on your quality of life?	Was there a discussion about how any potential issues would be managed?
	Did it make you feel that you wanted to take part/receive treatment, or did you need more information or time to think about it?
	Do you feel that the treatment would give you a greater chance of achieving your goals of care?
6. Would you have wanted more information about anything prior to starting treatment?	
7. How has being on treatment affected your ability to engage in everyday life? Please ask in follow up to discussions in question 2.	How has your treatment affected your everyday activities?
	How has your treatment affected your home environment?
	How has your treatment affected your independence?
	How has being on treatment affected you engaging with hobbies and pastimes?

Figure 1 Continued.

8. How have you found the practicalities of receiving treatment?	How did you logistically manage getting to and from the hospital?
	Were the number of hospital appointments acceptable to you?
	How long was each hospital visit?
	What was your experience of the treatment procedures eg blood tests, fasting requirements, IV cannulation?
	What was your experience of the method of treatment ie taking medication orally or having an IV infusion?
	How did you logistically and emotionally manage the treatment schedule eg timings of taking oral medication at home, frequency of infusions?
9. Would you have wanted more information about anything during your treatment?	
10. How does/did your overall quality of life during your treatment compare to your quality of life prior to treatment?	How does this make you feel?
	Has your experience of treatment met your expectations?
	Do you think that the treatment has achieved your goals of care?
	Were there any other stressors you encountered during treatment that we have not discussed?
11. Would you have wanted more information about anything after your treatment?	

Figure 1 Semi-structured interview guide.

by rereading transcripts not to misunderstand the participants' context; 2 – Initial coding: inductive, with codes created from the data rather than a pre-conceived framework; 3 – Generating themes: grouping codes to form subthemes and themes; 4 – Reviewing themes: refining, merging and discarding themes in relation to the coded data; 5 – Defining and naming themes: clarifying the meaning of each theme; 6 – Producing the report – using quotes to create coherent themes. TFA informed the interpretation of themes, providing a structured way to understand how participants evaluated treatment experiences and formed preferences. Disagreements in coding were resolved by a mediator (ST).

Results

Participants and Demographics

Seventeen patients were eligible but at the time the researchers made contact four were not approached (n = 2 deceased; n = 1 aggressive behavior; n = 1 no longer eligible). Of 13 patients approached, two declined, one was ineligible (patient could not remember receiving specific treatments), one lost to follow-up, and nine participated. Demographics are presented in Table 2. Interviews lasted 47 minutes on average. Thematic analysis results are summarized in Table 3 including the four key themes: (1) Living with multiple myeloma and its impact on quality of life; (2) Factors influencing treatment decision-making; (3) Factors influencing treatment experience; and (4) Treatment preference.

Table 2 Characteristics of Interview Participants

Gender	**n (%)**				
Male	4 (44%)				
Female	5 (56%)				
Age					
Mean	60.67				
Range	36-74				
Ethnicity	**n (%)**				
British	9 (100%)				
Unknown	0 (0%)				
Current performance status	**n (%)**				
0 1 2	5 (56%) 4 (44%) 0 (0%)				
Treatment Details Discussed in Interview	**Number of Treatment Lines**	**Subset**	**Oral**	**Subcutaneous Injection**	**Intravenous Infusion**
P01	9	1	Inobrodib[a]	SAR445514[a]	
P02	13	1	Inobrodib (with Pomalidomide)[a]		ABBV-383[a]
P04	8	2	Lenalidomide (with Dexamethasone)[a]		Isatuximab (with Pomalidomide and Dexamethasone)
P05	5	1	Ixazomib (with Lenalidomide and Dexamethasone)	Talquetamab[a]	
P06	7	1	Lenalidomide (with Dexamethasone)	Teclistamab[a]	
P07	7	1	Cyclophosphamide (with Thalidomide and Dexamethasone)	Talquetamab[a]	
P09	5	1	Ixazomib (with Lenalidomide and Dexamethasone)	Talquetamab[a]	
P10	8	2	Inobrodib (with Pomalidomide and Dexamethasone)[a]		Daratumumab
P11	9	1	Inobrodib[a]	Talquetamab	

Notes: Key: [a]= treatment given as part of a clinical trial.

Theme 1: Living with Multiple Myeloma and Its Impact on Quality of Life

Participants reflected on their journey as a patient with MM alongside the relentless challenges faced from the unpredictable, long-lasting, and life-changing side effects they experienced that spanned many years and numerous treatment lines.

Attempting to maintain a sense of normality while living with an incurable disease significantly impacted individuals' daily lives:

> …it's really hard when.your brain has all the ideas of things that you want to do and achieve but then your body just doesn't have the same amount of energy to do that is…quite hard. (P04, 36, Female, Subset 2)

Aside from the physical aspects, participants described the psychological impacts and ways in which they accepted and managed their circumstances:

Table 3 Summary of Thematic Analysis Results

Themes and Subthemes	Examples of Code and Quotes	Summary of the Theme
Theme 1: Living with multiple myeloma and its impact on quality of life.	• **Maintaining normality**: "It was very important to me that I tried to keep some normality in my life, if you know what I mean". (P07, 62, Male, Subset 1) • **Supportive relationships**: "My partner's took early retirement, so she's very supportive towards me". (P06, 57, Male, Subset 1) • **Independence on bispecific treatment**: "I think it's made me more independent, before because of my breathlessness and stuff, I used to think hard about doing things but then I would think, you have got to do this, nobody else is going to do it for you, kind of thing. Whereas now, I know I can do things without having to think about it". (P11, 63, Female, Subset 1)	• Maintaining a sense of normality was important • Diagnosis of MM impacted participants psychologically • Alterations to routine, including work, travel and childcare arrangements • Changes to careers and retirement plans • Unable to plan due to symptoms • Emotional and lifestyle impact on family and friends • Demanding treatment schedules of intravenous (IV)/bispecific/clinical trials impacted parents • Infection risk required lifestyle changes and distancing • Information and consultations were a reminder of mortality • A mixed impact on independence.
Theme 2: Factors influencing treatment decision making. Sub themes: shared decision-making with family and HCPs; attitudes towards all treatment types; information needs.	• **Shared decision-making with family**: "…it was…sitting down with my wife and saying, and agreeing that the…only way that I can get over this is to…rest…" (P07, 62, Male, Subset 1) • **Attitudes towards oral treatment**: "All that plays on your mind while you are out, I just hated every minute of it but I carried on with it because at the end of the day, it was doing me good. So, you carry on with it". (P11, 63, Female, Subset 1) • **Need for information on IV therapy**: "…they were very good, they gave me a leaflet, and links to websites, and I went on myeloma.org, as well, you know, there was loads of information…" (P10, 65, Female, Subset 2)	• Reliance on family and friends to retain information • Discussion with family on treatment options • Trust in clinicians when making a treatment decision • Motivation of extension of life • Goal to reach the next transition point • Knowledge of new therapies gave hope • Willingness to endure side effects to achieve goals of care • Information sought from the internet, social media and healthcare professionals • Information given was sufficient and reassuring • Information and treatment type were sometimes irrelevant.
Theme 3: Factors influencing treatment experience. Subthemes: self-management; practicalities of treatment; expectations of treatment.	• **Emotional coping mechanisms**: "…my faith is my…strength. So, that helps me, as a person. But I did… in all honesty…struggle in it…and I got upset and I cried and things like that…So, I just release it through tears and things like that…" (P09, 58, Female, Subset 1) • **Treatment procedure on bispecific treatment**: "…I then had to go every week…I underestimated…how draining that is…So, to go from monthly, to weekly, I underestimated the impact". (P07, 62, Male, Subset 1) • **Goals of care on oral treatment**: "Again, exceeding. I never dreamt it would be this good, honestly, you know". (P10, 65, Female, Subset 2)	• Self-management was needed for oral treatment • Coping mechanisms for side effects included rest, changes to daily life, and acceptance • An awareness of one's own emotional capacity • Maintaining a positive attitude • Treatment with more frequent appointments presented logistical challenges • Reliance on family for travel to appointments • Intense initial stages of IV/bispecific/clinical trial treatments • Oral treatment gave patients more control • Oral treatment disrupted everyday life, eg. fasting requirements • Whilst some treatments exceeded expectations, not all achieved goals of care.
Theme 4: Treatment preference. Subthemes: intra-participant preference; inter-participant preference.	• **Preference of IV therapy**: "I think one of the reasons is you meet people. It might not be people on the same treatment, the same disease as you've got, but you can have conversations with them. And people give you little tips, little ideas". (P02, 66, Female, Subset 1) • **Expectations of oral treatment**: "…the ease of, like, taking it and it not taking so much time at hospital, yeah it did. But I think I didn't realise how hard the side effects would have been.half and half really". (P04, 36, Female, Subset 2) • **Bispecific treatment procedure**: "…it is very, very clunky. I could be there at half past eight, and I'm not leaving "till half past six". (P07, 62, Male, Subset 1)	• One participant preferred interaction at IV appointments over the autonomy required for oral treatment • Another participant valued oral autonomy but the fewer side effects and convenience of subcutaneous outweighed this • Most participants did not have a clear treatment preference • Evaluation of treatment was weighed up by appointments, impact on daily life, and side effects • Years of treatment experience shaped treatment preference • Overall willingness to endure and accept trade-off between treatment burden and goals of care.

https://doi.org/10.2147/PPA.S576524

…when I got diagnosed, I left the old person in that room…and I stepped out, I had to become somebody else to stay alive. I've sacrificed a lot, just to stay alive where I am ten years down the line. (P06, 57, Male, Subset 1)

Participants were also affected professionally and were forced to alter their work routine, interaction with colleagues, and travel to work:

One of the things that I do is, part of the job, I used to commute down to London on a regular basis, is not go on the Tube… (P07, 62, Male, Subset 1)

Some participants ended their careers and others reported altering their retirement plans:

I retired in about 2022…I wouldn't have been able to cope with twelve-hour shifts. (P09, 58, Female, Subset 1)

Living with MM, its symptoms, and side effects often made it difficult to plan ahead, leading to feelings of guilt when needing to cancel social events, even when others understood:

…it does impact on your day-to-day life…I think the big impact was your inability to plan. So, you couldn't say to somebody, I'll be there next week, it would be, I'll be there next week, if everything's okay. (P07, 62, Male, Subset 1)

A further consideration, highlighted by participants, was the emotional toll and lifestyle changes for their family and friends:

…I do think the actual process of having cancer, and going through treatments, and everything…I think it's much harder on my husband than it is on me, like, emotionally… (P10, 65, Female, Subset 2)

Parents of young children found it difficult adjusting to demanding treatment schedules and the necessary changes required to minimize infection risk during treatment:

…he had, like, croup...I couldn't even go anywhere near him 'cause I knew I'd get the bug myself...so my husband had to take him to hospital and you just feel like...the worst parent in the world really… (P04, 36, Female, Subset 2)

It was evident that participants were constantly reminded of their own mortality through each stage of their MM journey. This was especially prominent during consultations, when information was obtained from online sources, and at each time treatment adjustments were necessary:

…on the discharge letter, when it says prognosis, it just said, months… (P10, 65, Female, Subset 2)

There was a mixed response from participants regarding the impact of MM and treatment on their independence. Some relied on others to maintain activities of daily living, a particularly challenging change:

…I was always an independent person…It's been very difficult for me to accept help, and not be able to do things that I could do before, very difficult indeed. (P06, 57, Male, Subset 1)

Theme 2: Factors Influencing Treatment Decision Making

Many participants discussed the decision-making process and their individual information needs at each treatment transition point. Decisions were influenced by input from the clinical teams and/or family members, treatment attitudes, and goals of care.

Shared Decision-Making with Family and Healthcare Professionals (HCPs)

Participants acknowledged the difficulties in retaining large amounts of information discussed during consultations. Family members gave individuals the opportunity to discuss thoughts, gain different perspectives, and help remember information:

…they gave me information beforehand, and both my daughters read it and they said everything looked alright… (P11, 63, Female, Subset 1)

Clinicians actively involved participants in their treatment plan, however participants' trust in their clinical team also influenced decision-making:

> …these are experts in their field…I completely trust the team, and I think you have to, to go forward with it. (P10, 65, Female, Subset 2)

Attitudes Towards All Treatment Types

Participants' treatment motivations mostly centred around keeping the cancer at bay and extending life:

> …I was doing anything that I could possibly do to eradicate the cancer in my body. And if it meant that this was the treatment that...the next line of treatment that I was offered then I'm taking it. (P09, 58, Female, Subset 1)

While remission was the main goal for most participants, some viewed treatment as a way of delaying things until the next transition point:

> …if I can get 18 months out of all of this, then that's 18 months further down, that I don't have to start another treatment. (P07, 62, Male, Subset 1)

These participants leaned into their knowledge of therapies in development, taking hope from it when their current lines of treatment failed to reach their goals of care:

> And knowing how this condition operates, then it's another time game…it allows for the pipeline of treatments that are currently coming through…it's just another factor in the strategy of playing, maximizing every treatment. (P07, 62, Male, Subset 1)

If there were side effects from treatment, participants considered the idea that they were living on "borrowed time", and were willing to endure this to achieve their goals, be it remission or otherwise:

> …if they'd said, oh, you've got a 99 per cent chance of croaking very shortly, or you've got a one per cent chance of living a bit longer, I would have taken that one per cent chance…. (P05, 64, Male, Subset 1)

Information Needs

Most participants felt they received sufficient and reassuring information throughout all treatment types. Participants sought information from the internet, social media, and HCPs. However, for some, there was little time to think about what was happening between each treatment line:

> And I felt quite reassured that everything was meticulously planned for every eventuality. (P06, 57, Male, Subset 1)

Interestingly, while participants did consider and appreciate the information provided, some felt they would have gone ahead regardless of this information or treatment type:

> …I would have gone ahead with it anyway. (P05, 64, Male, Subset 1)

Theme 3: Factors Influencing Treatment Experience

The practicalities and logistics of all treatment types proved challenging at times depending on the individuals' geographical location, family commitments, mindset towards and experiences of appointments and treatment Participants used various self-management techniques to cope with these challenges, in conjunction with family and clinician support.

Self-Management

Each participant's situation varied in complexity, and those with more autonomy over their treatment (eg oral) needed to rely on their own self-management in order to adhere to their treatment schedule:

> …I have, like, a tablet box that I put my medications into so that I make sure that I take everything. 'Cause even as a nurse sometimes it can be difficult remembering, especially the amount that I have. I think I'm currently on 17 medications. (P04, 36, Female, Subset 2)

All treatment regimens had different side effects. Participants developed personalized coping mechanisms and resilience that ranged from understanding the need for rest, altering daily routines, and accepting their current reality:

> I manage it myself with eyeliners and stuff like that. The eyebrows were thinner and I just put eyebrow pencil on. So, it's nothing that can't be fixed, you know. (P09, 58, Female, Subset 1)

Aside from physical challenges, participants were aware of their own emotional capacity and established boundaries when necessary:

> So, I try not to take too much information in… (P11, 63, Female, Subset 1)

Participants echoed the need to keep calm, stay positive, and maintain a sense of normality:

> …you can really over-think things sometimes. I think that trying to stay level-headed, and if you've got a problem embrace it… (P06, 57, Male, Subset 1)

Practicalities of Treatment

Logistical challenges surrounding appointments (travel; childcare; family commitments) had a greater impact on those with more frequent appointments (IV; bispecific treatment; clinical trial), further to travel, or no access to their own transport. Some participants relied on family to support with travel to and from appointments:

> …it's a 75 mile round trip…so I'm more reliant on my partner to do things now, which is difficult for me. (P06, 57, Male, Subset 1)

Initial stages of treatment were intense, particularly for IV/bispecific/clinical trial treatments. Participants on oral treatment reported greater control:

> …that's the good thing about oral,you're not in the hospital as long. And you've got, like, a little bit of...you've got autonomy… you're the one who's controlling the tablets… (P09, 58, Female, Subset 1)

Though oral treatment did come with its own challenges that disrupted everyday life:

> …there's the fasting bit…you have to sort of, not eat for two hours, then you take your tablets, then you can't eat for an hour afterwards. And at the time…they had to be 12 hours apart…it was tricky…when you've got to sort of, plan your day…and logistically work out things. (P10, 65, Female, Subset 2)

Expectations of Treatment

Participants had varying expectations of the different treatment types. In some cases, treatment exceeded expectations, whereas in others, treatment did not achieve their goals of care which were ultimately to reach remission:

> Well, if you're not responding to the treatment, it's not reaching your goals, is it? (P01, 74, Male, Subset 1)

Theme 4: Treatment Preference

Some participants expressed a preference between their own different treatment types (intra-participant preference) and favored subcutaneous or IV over oral treatments. We also compared the experiences of the same treatment types between participants (inter-participant preference). Those without a particular preference still highlighted the various challenges of different treatment lines (fasting; tiredness; waiting times).

Intra-Participant Preference

Only two participants explicitly expressed a treatment preference. One participant preferred IV therapy due to the interaction at appointments, and felt the autonomy required for oral treatment would be challenging:

> I would prefer infusion. Because at least you got sometimes to speak to somebody… (P02, 66, Female, Subset 1)

The other participant valued the autonomy aspect of oral treatment but the convenience of subcutaneous treatment and fewer side effects outweighed this:

> …I would prefer an injection rather than tablets because I feel, like, it's just quicker, and I've experienced less side effects… (P09, 58, Female, Subset 1)

Inter-Participant Preference

Most participants did not have a clear treatment preference but evaluated their treatment via a range of factors including frequency and length of appointments, the impact on daily life and treatment procedures (eg the requirement to fast on some oral treatments), method, schedule and experience (eg side effects):

> It was awful, it was absolutely awful, only because it was a treatment where you had to fast for three hours before… (P11, 63, Female, Subset 1)

Participants drew on their years of previous treatment experience when considering different treatment lines:

> The injections are fine. I've had a similar procedure…So I knew, reasonably what to expect… (P06, 57, Male, Subset 1)

Even when all negative aspects were considered, participants would endure and accept this trade-off between treatment burden and their goals of care:

> …as always with these drugs, and everything, it's a trade-off. So, would you trade-off part of your loss of taste to be in complete remission – yeah. (P07, 62, Male, Subset 1)

> …anything is worth a shot… (P10, 65, Female, Subset 2)

Discussion

This study explored the experiences and preferences of people receiving treatment for MM. Our results highlight patients' tumultuous experiences and their extraordinary resilience to tolerate not just the cancer but multiple treatment lines that caused significant and sometimes life-threatening side effects and disrupted everyday life and future plans. Although this supports current evidence,[14,15,19,21] our study extends this, showing the importance of family and information when making a treatment decision, the challenges and management of each treatment type, and how personal perception and circumstance can impact preference. These findings can be interpreted through the TFA, which considers how patients evaluate treatments in terms of emotional impact, perceived burden, understanding of options, and alignment with personal values, providing a structure to understand experiences and preferences.[34] Mapping our four themes onto TFA shows how patients consider emotional impact, practical challenges, understanding of options, and personal values when evaluating treatments.

Participants described the demanding nature of IV/subcutaneous/clinical trial treatment and the autonomy provided by oral treatment lines, which reinforces previous findings.[29,30] Arranging childcare was a constant worry as IV/subcutaneous treatment regimens were often long and required hospital time, while oral treatment regimens were regularly associated with unpredictable side effects that could occur at any time. Although not generalizable, two participants explicitly reported their preference for IV and subcutaneous administration which contradicts previous evidence[29] of preference for oral therapies. This may have been related to the fasting requirement of those particular agents.

Any change in treatment represented another time to face the incurable nature of the disease and the challenge to maintain a sense of normality and positivity. Participants mentioned the importance of discussing treatment options with HCPs and family members, alongside receiving sufficient information surrounding these treatment lines. While personal

circumstances influenced preferences for treatments, remission and extending life were the biggest influencing factors in participants' decision-making. This reinforces previous research,[23,24] where importance was placed primarily on treatment efficacy to increase life expectancy and progression-free survival. The main factor that influenced willingness to try new treatments and tolerate resulting side-effects was the hope of remission or buying time to get to the next treatment which might offer that goal. Prior work[39] has identified similar factors influencing decision-making though our data illustrates how the frequent reminder of the prognosis serves as a motivating factor to persist with treatment regardless of the side effects or where remission chances were poor.

Previous research[23,39] highlights how patients understand and prioritize the key aspects of treatment such as side effects and treatment features (eg mode of administration) but also their willingness to trade the burden and side effects for treatment outcomes. In addition, some participants were aware of the development of novel treatments and incorporated this knowledge into their attitudes towards treatment. Our study demonstrates how participants adopt the perspective that time on treatment lines is a gateway to newer treatments which may achieve their goals of care. While remission was a hope, and hope was a goal of care for some, extension of life was always the priority.

Treatment experience varied based on personal circumstances and over many years of treatment, each participant developed individualized self-management mechanisms alongside general coping strategies. Mirroring previous research,[28,31,39] while patients with MM become experienced in managing the multifaceted impact of treatment, it was still apparent how their personal circumstances, treatment history, side effects, and logistical issues influenced their treatment preference. Participants appreciated clinical support and valued a holistic approach including recognition of the mental health burden of treatment which was previously identified as an unmet need.[21]

Those who relied on family support described the detrimental effect on their independence as well as the emotional toll and lifestyle changes their family members experienced. The intense treatment regimens across the administration methods also impacted participants with young children. This enhances prior literature[14,21] by providing further insight into the myriad of challenges faced by patients and their families.

The burden of numerous treatment lines that patients with MM experience can negatively impact their QoL. Advances in precision medicine may offer the potential to reduce the treatment burden by tailoring treatment based on genetic, environmental, and lifestyle factors.[40] Further research is needed to generate evidence to support the widespread implementation of precision medicine into clinical practice for all patients with MM.[4]

This study emphasizes the importance of understanding individuals' personal routines and how these may influence treatment decisions. In addition, it is important to understand individuals' priorities and personal circumstances which may add to the burden of treatment and impact their ability to self-manage symptoms in order to tailor clinical support.

Implications for Practice

Given the length of time patients with MM may be on treatment, the wide-ranging side-effects and symptoms, and the significant impact on QoL, HCPs must regularly assess and re-evaluate patients' needs. This will ensure they have access to medication; holistic support that reflects the multi-dimensional nature of side effects, and effective resources to self-manage symptoms. To provide person-centred care, the individual's unique circumstances must be recognized. This will allow treating centres, where possible, to be flexible when allocating appointments which are appreciated by patients and ease the burden of treatment. HCPs will also be able to better understand the personal pressures and priorities that affect treatment decisions and allow better support during this process. Additionally, providing patients with information detailing the intensity of different treatment lines will allow them to prepare themselves for the significant impact the treatment may have.

Participants demonstrated their tolerance to treatment regardless of the side effects, chance of success, and administration route. Routine assessment of needs and QoL on all patients with MM will provide HCPs with current evidence on how well-tolerated treatments are. This information can be presented to patients so they are aware of the potential impacts of treatment on their QoL and can make an informed decision based on this knowledge but balanced with the hope of successful treatment.

Limitations

Only nine patients were recruited from a single cancer centre, limiting generalizability of findings. All participants identified as British hence these experiences, preferences, and coping mechanisms may not reflect the cultural or racial differences of all patients with MM.[41] However, the small sample size and demographics were reflective of clinic attendance as all appropriate eligible patients were approached. Albeit the findings do not fully explore all treatment options available to this population due to limitations on recruitment.

A further limitation was the degree to which we can attribute the experiences and side effects to different treatment lines and administration methods. Although interview questions were specific to each treatment, participants would often talk in general about their experiences and impact. Some patients are often on treatment for many years and participants acknowledged the difficulties in discerning the differences between treatments. Some of the information lacked clarity but as researchers we have, where possible, associated individuals' experiences with specific treatments.

Conclusion

The experiences of people receiving treatment for MM have been represented, giving a better understanding of what matters most to participants. Their individual experiences highlight how personal circumstances, family and social support, challenges, and goals of care influence treatment decisions and preferences. Although intra-participant preference was marginally divulged, participant experience highlighted a willingness and tolerance to accept treatments that significantly impact all aspects of their everyday life, QoL, and relationships, in order to achieve their goals of care.

Future research should complement qualitative data on patient preference with measurable outcomes such as QoL and patient-reported experience measures and include an inclusive sampling strategy to explore the preferences and experiences of all patients with MM including a diverse spread of age, ethnicity, race and gender. To improve patient experience, clinical staff need to be aware of individual circumstances when considering treatment options, inform patients of the treatment impact relevant to their needs, incorporate time for shared decision-making with family and friends, enabling patients to choose the right treatment for them, improving QoL, and facilitating personalized care.

Abbreviations

HCP, healthcare professionals; IV, intravenous infusion; MM, Multiple Myeloma; QoL, quality of life.

Ethical Considerations

Ethical approval for this study was granted by The North of Scotland Research Ethics Committee (1) (11/03/2024, ref: 24/NS/0028) and was carried out in accordance with the Declaration of Helsinki. Informed consent was obtained from all individual participants verbally, recorded by a trained researcher, and a paper copy was also sent to the participants to complete. Participants consented to the data collected, including anonymized quotes from interviews, being published as part of the research project. No identifiable information is included; however, the authors confirm that the data supporting the findings of this study are available within the article.

Acknowledgments

The authors would like to acknowledge and thank all participants in this study for providing their invaluable experience during interviews. We would also like to express our thanks and appreciation to our Research Nurses Vanessa Ellis and Eleanor Pearce for their continued support of our team. This study has been delivered through the National Institute for Health and Care Research (NIHR) Manchester Biomedical Research Centre (BRC) (NIHR203308). The views expressed are those of the authors and not necessarily those of CellCentric Limited, the NIHR or the Department of Health and Social Care.

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 CellCentric Limited.

Disclosure

Author Fay Ashby is employed by the funders and was part of the study conceptualization and reviewing of this manuscript. Author Melissa Betty Perry was funded by CellCentric to attend the British Psychosocial Oncology Society conference to present the abstract of this paper as a poster presentation with interim findings. The poster's abstract was published in "Supplement Abstracts" in a special issue of the Psycho-Oncology Journal (2025 conference abstract: https://airdrive.eventsair.com/eventsairwesteuprod/production-delegatereg-public/9c8815d0cb264e339ce307df4406ad28). All other authors have no relevant financial or non-financial interests to disclose.

References

1. Cancer Research UK. Myeloma incidence statistics; 2024. Available from: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/myeloma/incidence#heading-Zero. Accessed November 4, 2024.
2. Myeloma UK. What is myeloma? 2023. Available from: https://www.myeloma.org.uk/understanding-myeloma/what-is-myeloma/. Accessed October 30, 2024.
3. Nandra TK, Devi A, Jones JR. Multiple myeloma: what a non-haematologist should know. *Clin Med*. 2022;22(3):230–233. doi:10.7861/clinmed.2022-0144
4. González-Calle V, Keane N, Braggio E, Fonseca R. Precision medicine in myeloma: challenges in defining an actionable approach. *Clin Lymphoma Myeloma Leuk*. 2017;17(10):621–630. doi:10.1016/j.clml.2017.06.021
5. Myeloma UK. Treating myeloma; 2023. Available from: https://www.myeloma.org.uk/understanding-myeloma/treating-myeloma/. Accessed October 30, 2024.
6. Myeloma UK. Treatment for relapsed myeloma; 2024. Available from: https://www.myeloma.org.uk/understanding-myeloma/treating-myeloma/treatment-for-relapsed-myeloma/. Accessed October 30, 2024.
7. Cancer Research UK. Treatment options for myeloma; 2023. Available from: https://www.cancerresearchuk.org/about-cancer/myeloma/treatment/treatment-decisions. Accessed November 8, 2024.
8. National Institute for Health and Care Excellence. Lenalidomide plus dexamethasone for previously untreated multiple myeloma; 2019. Available from: https://www.nice.org.uk/guidance/ta587/chapter/2-Information-about-lenalidomide. Accessed March 6, 2026.
9. Janssen-Cilag Ltd. DARZALEX 1800 mg solution for injection PIL; 2025. Available from: https://www.medicines.org.uk/emc/product/11488/pil. Accessed March 6, 2026.
10. Janssen-Cilag Ltd. DARZALEX 20 mg/mL concentrate for solution for infusion PIL; 2026. Available from: https://www.medicines.org.uk/emc/product/7250/pil. Accessed March 6, 2026.
11. ClinicalTrials.gov. Study Assessing Activity of Intravenous (IV) Etentamig Monotherapy Versus Standard Available Therapies in Adult Participants With Relapsed or Refractory Multiple Myeloma (CERVINO); 2026. Available from: https://clinicaltrials.gov/study/NCT06158841. Accessed February 20, 2026.
12. ClinicalTrials.gov. MagnetisMM-32: a study to learn about the study medicine called elranatamab in people with multiple myeloma (MM) that has come back after taking other treatments (including prior treatment with an anti-CD38 antibody and lenalidomide); 2026. Available from: https://clinicaltrials.gov/study/NCT06152575. Accessed February 20, 2026.
13. ClinicalTrials.gov. Study to evaluate CCS1477 (Inobrodib) in haematological malignancies; 2025. Available from: https://clinicaltrials.gov/study/NCT04068597. Accessed February 20, 2026.
14. Rubins Z, Gibson BJ, Chantry A. What can patient narratives reveal to us about the experience of a diagnosis of myeloma? A qualitative scoping review. *J Patient Exp*. 2022;9:1–11. doi:10.1177/23743735221079133
15. LeBlanc MR, Hirschey R, Leak Bryant A, LeBlanc TW, Smith SK. How are patient-reported outcomes and symptoms being measured in adults with relapsed/refractory multiple myeloma? A systematic review. *Qual Life Res*. 2020;29(6):1419–1431. doi:10.1007/s11136-019-02392-6
16. Gasparetto C, Sivaraj D. *Understanding Multiple Myeloma*. 1st ed. Jones and Bartlett Learning; 2019.
17. Nucci M, Anaissie E. Infections in patients with multiple myeloma in the era of high-dose therapy and novel agents. *Clinl Infect Dis*. 2009;49(8):1211–1225. doi:10.1086/605664
18. Raza S, Safyan R, Suzanne L. Immunomodulatory drugs (IMiDs) in multiple myeloma. *Curr Cancer Drug Targets*. 2017;17(9):846–857. doi:10.2174/1568009617666170214104426
19. McCullough KB, Hobbs MA, Abeykoon JP, Kapoor P. Common adverse effects of novel therapies for multiple myeloma (MM) and their management strategies. *Curr Hematol Malig Rep*. 2018;13(2):114–124. doi:10.1007/s11899-018-0443-0
20. Myeloma UK HCP Hub. Financial concerns; 2024. Available from: https://hcp.myeloma.org.uk/courses/myeloma-nurse-learning-programme/lessons/module-10-living-well-with-myeloma/topics/financial-concerns/. Accessed November 5, 2024.
21. Lyall M, Crawford R, Bell T, et al. Characterizing the patient journey in multiple myeloma: qualitative review. *JMIR Cancer*. 2022;8(3):e39068. doi:10.2196/39068
22. Molassiotis A, Wilson B, Blair S, Howe T, Cavet J. Living with multiple myeloma: experiences of patients and their informal caregivers. *Support Care Cancer*. 2011;19(1):101–111. doi:10.1007/s00520-009-0793-1

23. 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
24. Dombeck C, Swezey T, Gonzalez Sepulveda JM, et al. Patient perspectives on considerations, tradeoffs, and experiences with multiple myeloma treatment selection: a qualitative descriptive study. *BMC Cancer*. 2023;23(65):1–10. doi:10.1186/s12885-022-10458-x
25. Jacobs JM, Pensak NA, Sporn NJ, et al. Treatment satisfaction and adherence to oral chemotherapy in patients with cancer. *J Oncol Pract*. 2017;13 (5):e474–e485. doi:10.1200/JOP.2016.019729
26. Wilke T, Mueller S, Bauer S, et al. Treatment of relapsed refractory multiple myeloma: which new PI-based combination treatments do patients prefer? *Patient Prefer Adherence*. 2018;12:2387–2396. doi:10.2147/PPA.S183187
27. Ayto R, Annibali O, Biedermann P, Roset M, Sánchez E, Kotb R. The EASEMENT study: a multicentre, observational, cross-sectional study to evaluate patient preferences, treatment satisfaction, quality of life, and healthcare resource use in patients with multiple myeloma receiving injectable-containing or fully oral therapies. *Eur J Haematol*. 2024;112(6):889–899. doi:10.1111/ejh.14180
28. Dhakal P, Wichman CS, Pozehl B, et al. Preferences of adults with cancer for systemic cancer treatment: do preferences differ based on age? *Future Oncol*. 2022;18(3):311–321. doi:10.2217/fon-2021-0260
29. Eek D, Krohe M, Mazar I, et al. Patient-reported preferences for oral versus intravenous administration for the treatment of cancer: a review of the literature. *Patient Prefer Adherence*. 2016;10:1609–1621. doi:10.2147/PPA.S106629
30. Thomas C, Ailawadhi S, Popat R, et al. Treatment preferences of patients with relapsed or refractory multiple myeloma in the United States, United Kingdom, Italy, Germany, France, and Spain: results from a discrete choice experiment. *Front Med*. 2023;10(1271657):1–12. doi:10.3389/fmed.2023.1271657
31. McKay C, Maiese EM, Chiarappa J, et al. Patient preferences for multiple myeloma (MM) treatment: interim analysis of a discrete choice experiment. *Blood*. 2018;132(Supplement 1):3586. doi:10.1182/blood-2018-99-112921
32. Xu Z, Wang Y, Qian Y. The design and application of in-depth interviews in primary care research. *Chin Gen Pract*. 2025;2(2):100062. doi:10.1016/j.cgpj.2025.100062
33. Rifkin RM, Bell JA, DasMahapatra P, et al. Treatment satisfaction and burden of illness in patients with newly diagnosed multiple myeloma. *Pharmacoecon Open*. 2020;4(3):473–483. doi:10.1007/s41669-019-00184-9
34. Sekhon M, Cartwright M, Francis JJ. Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Serv Res*. 2017;17(1):88. doi:10.1186/s12913-017-2031-8
35. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. 2016;26 (13):1753–1760. doi:10.1177/1049732315617444
36. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: a systematic review of empirical tests. *Soc Sci Med*. 2022;292 (114523):114523. doi:10.1016/j.socscimed.2021.114523
37. National Institute for Health and Care Excellence (NICE). Myeloma: diagnosis and management (NG35); 2016. Available from: https://www.nice.org.uk/guidance/ng35. Accessed February 20, 2026.
38. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101. doi:10.1191/1478088706qp063oa
39. 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(264):1–10. doi:10.1186/s12885-019-5467-x
40. NHS England. Precision medicine; 2020. Available from: https://transform.england.nhs.uk/ai-lab/explore-all-resources/understand-ai/precision-medicine/. Accessed November 1, 2024.
41. Althubaiti A. Information bias in health research: definition, pitfalls, and adjustment methods. *J Multidiscip Healthc*. 2016;9:211–217. doi:10.2147/JMDH.S104807