Facilitators of Multiple Myeloma Treatment: A Qualitative Study
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OBJECTIVES: To examine factors that lead to the facilitation of multiple myeloma (MM) treatment.

SAMPLE & SETTING: 29 patients who had been diagnosed with MM at Mount Sinai Hospital in New York City.

METHODS & VARIABLES: Semistructured qualitative interviews were administered by trained research staff. Interview topics included illness beliefs, illness experiences, treatment experiences, and treatment decision-making. Interviews were audio recorded and transcribed verbatim. Four coders independently coded the transcripts, and the authors analyzed data using interpretive description.

RESULTS: The following facilitators of treatment were identified: (a) healthcare team trust and support, (b) personal resilience and initiative-taking, and (c) external support (emotional/social support and instrumental/organizational support). Healthcare team trust and support were established through rapport-building and compassion, accessibility and time spent with the patient, shared decision-making, and provider reputation. Personal resilience was manifested by patients through positive attitudes, taking control of their illness, and self-advocacy.

IMPLICATIONS FOR NURSING: Understanding factors that facilitate MM treatment may lead to better patient outcomes and can potentially inform oncology nursing practice by providing a framework for tailored health education and care management practices for patients with MM.

KEYWORDS cancer; multiple myeloma; oncology; qualitative research; treatment facilitators

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Multiple myeloma (MM) is a B-cell malignancy that leads to the accumulation of malignant plasma cells and is the second most common hematologic cancer (Avet-Loiseau, 2019; van de Donk et al., 2021). The American Cancer Society estimates that in 2023 there will be almost 36,000 new cases of MM and 12,590 deaths (Siegel et al., 2023). The disease primarily affects older adults, with a median age at diagnosis of 65 years (Rajkumar, 2020). African American individuals are twice as likely to develop MM as White individuals (Rajkumar, 2020).

MM treatment has advanced in the past 20 years, with the median survival period increasing from 2–3 years to 8–10 years (Kumar et al., 2019). This improvement is, in part, because of the introduction of multiple classes of drugs that have been shown to effectively control the disease for extended periods (Kumar et al., 2019). Despite these advances, MM remains largely incurable, and many patients experience multiple relapses (Avet-Loiseau, 2019).

Because MM treatments are ever evolving, past and current research has focused largely on novel therapies and the burden of disease. Multiple studies have found that health-related quality of life is low in patients with MM (Kent et al., 2015; LeBlanc et al., 2020; Nielsen et al., 2017; Ramsenthaler et al., 2016). Individuals with MM face high treatment costs and potential job insecurity because of lengthy treatment periods that require time away from work (Goodwin et al., 2013; LeBlanc et al., 2021; Tariman et al., 2014).

Current standard treatment for eligible patients includes induction therapy with an injectable proteasome inhibitor, an oral immunomodulatory agent and dexamethasone, subsequent autologous hematopoietic stem cell transplantation, and maintenance therapy with lenalidomide (Cowan et al., 2022).

Research has shown that implementing early treatment interventions (Landgren & Iskander, 2017; Rodriguez-Otero et al., 2021) and maximizing first-line therapy allows the best opportunity to optimize long-term patient outcomes (Ninkovic & Quach,
2020). This is particularly true in patients with smoldering MM, who are at high risk for progression to active MM (Kumar et al., 2017; Lonial et al., 2020; Rodriguez-Otero et al., 2021). Despite evidence that early treatment may improve patient outcomes, research is lacking on the factors that encourage the initiation and continuation of MM treatment. To address this gap, the authors undertook this qualitative study to more deeply understand factors that facilitate MM treatment in a diverse group of patients.

**Methods**

Eligible patients were adults with a pathologically confirmed MM diagnosis who saw a clinician at Mount Sinai Hospital in New York City and had not previously completed any of the following MM treatment courses: (a) induction therapy, (b) stem cell harvest, (c) hematopoietic stem cell transplantation, or (d) maintenance therapy. Patients were excluded if they were classified as cognitively impaired by their treating physician. Eligible participants were called by a research assistant to discuss the study and determine interest in participation. Participants provided written consent, and basic demographic and clinical information were collected. Interviews took place in a private clinical setting or were conducted via telephone, according to participant preference.

A guide for the semistructured interviews was developed, and interviews were designed to take about 45 minutes (see Figure 1). Patients were asked about their experiences living with MM, including their care experiences and any difficulties they may have encountered related to their diagnosis, treatments, or visits. Interviewers began with questions about patients’ understanding of their illness and treatment, then asked about treatment decision-making, and finally concluded with questions about treatment experience. Experienced interviewers (N.A.B., J.J.L.) conducted all interviews, which were audio recorded and transcribed verbatim. Interviews continued until a minimum of 10 transcripts were coded and the research team concurred that thematic saturation was achieved. This study was approved by the institutional review board at the Icahn School of Medicine at Mount Sinai.

**Data Analysis**

Data analysis was completed using interpretive description (Hunt, 2009). This approach uses analytic frameworks, sample selection, data analysis, and rigor to examine human health and illness experiences (Thorne et al., 1997). To identify major themes related to facilitators of MM treatment, the authors examined participants’ diagnosis and treatment experiences and assessed how they made decisions to pursue treatment. Key concepts were coded with descriptive phrases by a team of four coders (N.A.B., R.C., J.J.L., R.Y.), and iterative content analysis occurred in parallel with recruitment (Braun & Clarke, 2006). An initial code key was established for the dataset following the coding of 10 transcripts. The coding team conducted ongoing discussions and established an agreement about the final key code. Recruitment was concluded when thematic saturation was achieved (Guest et al., 2020). The authors used Dedoose, version 9.0.46, to produce code reports.

**Results**

The authors approached 233 potentially eligible patients, 29 of whom agreed to participate. Among those who declined, reasons included not being interested and already having completed treatment. The authors did not follow up and monitor treatment uptake or disease progression in those who declined participation. Staging information was collected but was not part of the inclusion and exclusion criteria.

Twenty-nine individuals completed interviews, of whom 18 were female, and 15 self-identified as White, 9 as Black, 3 as Hispanic, and 2 as Asian. The mean age was 67 years (range = 34–83). Of the 29 participants, 29 received induction chemotherapy, 27 underwent stem cell harvest, 14 completed stem cell transplantation, 13 received maintenance therapy, and 2 delayed treatment.

The authors identified the following three themes as facilitators of treatment: (a) healthcare team trust and support, (b) personal resilience and initiative-taking, and (c) external support (emotional/social support and instrumental/organizational support).

**Healthcare Team Trust and Support**

Patients highlighted trust and comfort with their care team, particularly their oncologist, as critical in accepting treatment for MM. Comfort and trust were established in the following four ways: (a) rapport-building and compassion, (b) accessibility and time spent with the patient, (c) shared decision-making, and (d) provider reputation.

**Rapport-building and compassion:** One patient noted, “[My oncologist] is so approachable, I almost feel like she’s my friend.” Compassion and humanness were noted as traits that inspired trust, with one patient stating, “I would say that he has the ability to
be not a doctor, [but rather] just a human being. . . . I know that he genuinely cares about me like a son.”

**Accessibility and time spent with the patient:** Emphasis was also placed on the importance of healthcare team accessibility. One patient discussed reaching out to their physician following an unexpected hospitalization:

He always gave me his cell phone number . . . and he answered his phone on Easter Sunday. So I said, “Doc, I am so sorry to bother you, but this has happened.” He said, “No problem. I want you to fax the [results] to my office.”

Similarly, another patient stated, “I have everybody’s numbers—when there was a problem that I knew that I needed help with, I was actually able to call them.” When family members helped patients manage their illness, patients appreciated that provider accessibility was extended beyond just themselves. One patient stated:

My daughter actually contacted [my oncologist] and they emailed back and forth. She had a lot of questions, technical questions that she did research on . . . and he was very responsive to her, he answered all her questions. We even did conference calls . . . She would ask him questions
right in front of me and he would answer, and she
was very satisfied, too.

Finally, patients emphasized that the time their
provider and healthcare team spent reviewing their
case during each visit made them feel valued:
The nurse practitioners or the [physician
assistants] that came into the room prior to [the
doctor] would always spend 10, 15, 20 minutes
answering my questions, giving me a good idea of
expectations with the medications. . . . If I com-
plained of something, they could say to me, “Well,
that’s a normal response. This is what we would
do for diarrhea.” But they would be helpful. And
then when the doctor came in, he . . . would go
back right from the day that I was diagnosed and
all that had happened and his expectation. . . .
It gave me a sense of knowing what was
going on and that he knew what was going on . . .
[Oncologists] see so many patients a day, and to
know that he was . . . so focused on my particular
case when he was with me, I always found that
very reassuring.

**Provider reputation:** Patients’ treatment decisions
were also guided by the reputations of providers and
institutions. When asked what advice they would give
to someone newly diagnosed with MM, one survivor
noted, “Go to [provider’s name]. They are experts in
multiple myeloma, they will make sure that you’re
well taken care of. And I guarantee you will get the
right treatment.” Another patient commented, “Go to
a doctor that deals just with multiple myeloma, don’t
go to just a general oncologist; that’s why I ended up
at [provider’s name]. He was the multiple myeloma
guru, so to speak.”

**Personal Resilience and Initiative-Taking**
Personal resilience and initiative-taking were patient
qualities that facilitated getting treatment.

**Positive attitude:** A focus on regaining normalcy
and adopting a positive attitude was described as a
means to stay strong. A patient reflected, “Sometimes
you get negative. That’s very usual. Why did this
happen? . . . But I don’t allow it to stay. The optimism,
you have to look at the light, the light side of life.”
Patients acknowledged that a positive attitude was
also necessary for managing unexpected outcomes of
treatment response and cancer progression. As one
patient recommended,

Set your goals and stay as positive as possible.
When you’re positive and you get hit with a set-
back it’s not devastating. The other thing I used to
always [say] to myself is “Make sure you’re taking
two steps forward, so in case you get knocked
back, you’re only going one step back and you’re
still ahead of the game.” So always get the small
victories and then eventually they become a big
victory. The worst thing you can see is people that
get down on themselves and you see them sink
very quickly.

In addition, a positive outlook on treatment
options and illness management was a motivating
factor in pursuing treatment. A patient described
their comfort in likening MM management to that of
a chronic illness:

Knowing that I’m not going to be taking the old
dirt nap tomorrow, you know . . . they told me
we’re going to treat this like it’s a chronic disease.
Like if you had high blood pressure, diabetes, you are going to take a pill, and Dr. [provider’s name] likes to use the [phrase] “take a pill.”

Another patient commented on the hope brought on by the advance of medical science: “Every day, they’re making new discoveries. And they’ve come such a long way from 30, 40 years ago, when it was a death sentence.”

**Taking control:** Resilience also came in the form of patients feeling as though they had some control over treatment rather than feeling as though the disease controlled them. One patient took comfort in monitoring their treatment results, stating they spent time learning more about . . . the importance of what the blood tests mean and what they are all about. And what I did there was just research it. And [I] went to one of the real websites. I got definitions, and I set up a little glossary with each one, and I track[ed] all of my data. And for me again, and as a control person and a data person, that helped me get a sense of control over things . . . watching the numbers go down.

However, patients cautioned against focusing solely on the illness. One individual stated,

There are people that dwell on it and that’s all—they become their disease. And I didn’t want to . . . I don’t want to be thinking, I want to be out working and busy worrying about other people and not me. So I think the fact that I was able to get back to work and be vital and vibrant and alive and caring, you know, and that’s the thing that probably saved me.

Others described finding a sense of control by focusing on fulfilling desires they may not have previously prioritized. As one patient described,

In fact, having myeloma’s pretty good. I mean, living the way I am, and I can go on living. . . . What it’s done is, it’s made me want to travel as much as I can. . . . Now I can enjoy myself. I always thought I was so directed toward [my career] that I didn’t really have enough time to read other things and experience the world and all that, but now I’m doing it.

In a similar vein, some patients sought to detract focus from the negative aspects of their treatment by planning events around hospital or doctor visits. As one patient detailed,

I hold my breath every time I come. . . . When [I] have to look at the results with the doctor. . . . Is [it] going to be there this time? . . . So, what we have done is, we make a day out of [the doctor’s appointment]. . . . Do we go to Chinatown? Do we go to the Italian side? Do we go to Macy’s? . . . It’s always about something else. Not just this.

**Self-advocacy:** Patients also advised information-seeking and self-advocacy. Coming prepared with outside information was a practical way to get the most out of one’s oncologist visit. One patient commented, “I understand the medical system and that you can’t go in and talk for two hours. You have to be able to be prepared for your visit.” Another emphasized that emotions during oncologist visits sometimes hindered information processing and advised as follows:

Do a little reading on your own, on the internet. . . . Because what I found when we initially would talk to the doctor, he’s saying words at you. And you may be writing them down, but your handwriting is terrible. So you need time to process. So having the outside time to process it, think it through in my own terms, come up with additional questions.

MM survivors also noted that gaining more knowledge informed how they interacted with their physician and how they approached treatment options. As one patient stated when reflecting on their treatment history,

I didn’t know anything about it [initially]. So I just took the doctor at his word. But now if I had to do it over again, we could sit down and we would say, “Why [this treatment], why not another treatment?”

Numerous patients lauded the Multiple Myeloma Research Foundation as a reliable and comprehensive source for research studies, general information, and support resources. Conversely, they discouraged the impulse to “google multiple myeloma and go into any different sites, it’s like going into like a Pandora’s box. There is too much conflicting [information], and there’s a lot of crazy stuff out there.”
Self-advocacy was also recommended as a tool for navigating treatment. One patient advised that you “have to be involved. You have to be a part of your medical team. . . . You have to listen to what the doctor is saying and give [your] input.” Patients encouraged others to speak up about treatment options, clarification of medical information, and any concerns or worries. As one patient stated,

I am paying attention to every little thing. . . . I keep it in my head to ask whatever doctor that I will be seeing. . . . [Multiple myeloma] makes me more aware of what is going on [in my body]. If my toes don’t feel right [for example], I told them, “There is something wrong with my toes.” And I think sometimes I get on their nerves. For me, it’s best to talk to them about it.

**External Support**

Patients reported that receiving external support promoted emotional well-being and enhanced their ability to navigate challenges related to seeking and undergoing treatment. Support was defined as emotional/social (friends and family) and instrumental (organizational).

**Emotional/social support:** Support from loved ones included accompanying patients to visits, aiding patients in carrying out research on MM and treatment options, and providing emotional solace. One patient’s spouse explained that they approached the disease together, stating, “Every single doctor’s appointment he had, we went together as a team.” In addition to finding strength in the support of a loved one, patients felt motivated to fight their illness to be present for their families. As one patient commented,

I’m always a strong believer in not letting people down. And when people help you, you want to be there for them. . . . We have nieces and nephews and their kids and we’re all very close. So we’re always around them. So I think that’s what keeps you going.

Some individuals purposefully sought support from those outside of their family to reduce the burden on family members and to seek opinions unbiased by emotional ties. As one patient described,

Well, my family was kind of in a state of shock because I’m like the matriarch. So, I mean, not only was it impacting me, it impacted my family. . . . So the family was too emotionally involved. . . .

But one of the women I did my undergrad with, her mother died from multiple myeloma. . . . So she had been through it and it had been enough time for her to heal. . . . She was the one that I was able to bounce information off of. And help for my decisions.

Others found it helpful to attend formal support groups, which offered emotional and informational support. One patient described their local support group, saying, “We average 20, 25 people a month . . . and we have people from the insurance companies. We have a social worker come. It’s like a group therapy session.”

**Instrumental support:** Organizational and instrumental support facilitated MM treatment accessibility and aided patients logistically. The cost of medications and treatments was often cited as prohibitive without coverage by insurance or other means. One patient described the ongoing cost of treatment as “paying a membership [fee] to keep myself alive.” Patients discussed participation in clinical studies as a common way to obtain free treatment. Others cited receiving aid from various grants or funds. One patient noted,

Recently I have been a little concerned because after . . . my medical coverage changed and I was no longer covered, then it became an issue of whether my [lenalidomide] was going to be covered. It was a very large co-pay, which I could
never afford. But the pharmacy was great. They were able to quickly look into and obtain a grant to cover that so I wouldn’t have to.

Other forms of logistic support were car services such as Access-a-Ride, hotel stays provided near treatment sites, and wigs supplied by the American Cancer Society for those who had lost their hair following treatment.

Discussion
The current study identified three primary facilitators for acceptance of MM treatment: (a) healthcare team trust and support; (b) personal resilience and initiative-taking; and (c) outside support provided by family, friends, and formal organizations. This study adds to the literature by identifying the importance of internal factors, specifically patient resilience and sense of control, in accepting MM treatment. In addition, it reaffirms the importance of trust in the patient–provider relationship and external factors including financial, social, and organizational support previously found to facilitate treatment completion.

Like research by Tariman et al. (2014) and Goodwin et al. (2013), this study found that external factors such as financial and social support are an important part of MM treatment decision-making. The availability of external support from family, friends, and formal organizations influenced treatment decisions by providing logistic support, including accompanying patients to visits (Tariman et al., 2014), as well as emotional support. Making caregivers and family members welcome at medical visits and involving them in treatment discussions may also facilitate treatment initiation.

Patients with MM incur significant financial strain because of out-of-pocket treatment and medication costs, patient and/or caregiver housing, travel and food expenses for treatment received at MM treatment centers, and loss or pause in employment status because of extended inpatient treatment or physical limitations brought on by pain and fatigue (Goodwin et al., 2013). In addition, as treatment options advance and patient survival increases, so does the financial burden of ongoing treatment (Goodwin et al., 2013).

Patients reported that they were more likely to seek treatment when they had comprehensive health insurance, access to study opportunities that provided free treatment options, and access to grants and organizations that covered direct and indirect expenses associated with treatment. To ensure that patients do not delay or refuse treatment because of financial burden, MM treatment teams and institutions should provide care coordination that connects patients with financial aid resources from the onset of diagnosis during the initial treatment discussion.

Echoing findings from Tariman et al. (2014), this study’s results suggest that trust in the healthcare team is influential in treatment decisions. However, unlike previous research that focused solely on the role of provider trust as a treatment facilitator, this study also specifically examined factors that led to the establishment of patient trust in the healthcare team. The authors found that patients expressed trust in providers and healthcare teams who were accessible and who communicated in clear and approachable language. Thus, healthcare teams should ensure that they communicate clearly, set expectations, and are accessible to their patients with MM. Programs such as Oncotalk (Arnold et al., 2017; Back et al., 2003), which provides communication skills training to oncologists, may increase the effectiveness of provider communication. Other techniques that can be implemented to improve the clarity and effectiveness of communication include using everyday analogies to describe biologic processes and using diagrams and pictures for visual learners (Friedman & Wolchok, 2016).

Assessing patient understanding may be done by implementing teach-back techniques following a discussion and asking questions such as “Can you tell me, in your own words, what we talked about?” (Davis et al., 2002). At a more fundamental level, coursework in medical and nursing school curricula that teaches effective communication may provide students with a framework they can continue to build upon as they advance in their medical careers (Gilligan et al., 2021). Increasing accessibility may be accomplished by using an on-call screening center, which allows trained medical staff to triage telephone calls, answer questions, and transfer calls to the patient’s team as needed (Wong et al., 2010). These services allow patients to feel connected to their provider team outside of appointments while also respecting provider teams’ work-life balance (Wong et al., 2010).

The unique takeaway of this study’s findings is the acknowledgment of patient-specific qualities, specifically resilience and a personal sense of control, in facilitating MM treatment. Although Tariman et al. (2014) found that patients sought treatment because of self-reported descriptions of identity and character, such as their job or personality, they did not explore specific patient characteristics and qualities. The authors of the current study found that resilience
facilitated MM treatment, as reflected in patients' active choices to regain normalcy in everyday life, retain a positive outlook, celebrate small victories, and view their MM as a manageable chronic illness. In addition, establishing a sense of personal control over elements of MM facilitated treatment. This was exemplified by patients who actively monitored their laboratory results to track their progress or who took control of their personal lives by taking time to prioritize desires such as travel and hobbies.

In a narrative review of 22 studies, Ludolph et al. (2019) recommend that all newly diagnosed patients with cancer be offered the opportunity to participate in a resilience-enhancing intervention alongside their cancer treatment. Following such an intervention, the enhancement of resilience remained stable or increased for one year, and it was more effective if the intervention occurred across a minimum of 12 sessions and 24 cumulative hours (Ludolph et al., 2019). Examples of resilience-enhancing interventions include participating in meditation exercises, increasing optimism through group discussions, and increasing cognitive flexibility by positive reevaluation of negative thinking patterns (Ludolph et al., 2019). Similarly, Rosenberg et al. (2018) found that providing patients with cancer with a brief skills-based intervention targeting resilience resources (stress management, goal setting, positive reframing) improved resilience and reduced psychological distress. Implementing similar low-cost therapeutic interventions upon diagnosis may further promote the facilitation of MM treatment.

Limitations
All study participants were recruited from Mount Sinai Hospital in New York City. This is an academic tertiary health center in a major metropolitan city, so these findings may not be generalizable to the larger population. Given that interviews were conducted with English-speaking participants, this study may not account for how language barriers affect the facilitation of treatment. Although this study provides preliminary data on the significance of healthcare team trust and communication, personal resilience, and external support in facilitating MM treatment, additional studies carried out across the United States in different care settings are needed to comprehensively investigate potential facilitators.

Implications for Nursing and Conclusion
This study's findings can potentially inform oncology nursing by illustrating the unique factors that facilitate treatment acceptance by patients with MM. Findings underscore the importance of healthcare team trust and communication, personal resilience and sense of control, and external support. Actionable changes that may be implemented by nurses to promote these facilitators include encouraging the use of clear and everyday language by the healthcare team, increasing healthcare team accessibility, providing financial education resources at the onset and throughout MM treatment, and employing resilience-enhancing interventions throughout MM treatment.

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