

# A Qualitative Study of the Experiences of Living With Multiple Myeloma

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**PURPOSE:** To explore the ways in which multiple myeloma affects an individual's life in the modern treatment era.

**PARTICIPANTS & SETTING:** 15 individuals with multiple myeloma and 10 clinicians were recruited from two academic medical centers in the southeastern United States.

**METHODOLOGIC APPROACH:** Semistructured interviews were conducted with individuals with multiple myeloma and clinicians to explore the effect of a multiple myeloma diagnosis and treatment on individuals' lives. Transcribed interviews were analyzed using conventional content analysis.

**FINDINGS:** The following four themes emerged from the analysis: treatment without end, social impacts and isolation, ongoing financial pressure, and relationship impacts.

**IMPLICATIONS FOR NURSING:** The treatment journey for those with multiple myeloma can be lifelong and may require frequent visits to an oncologist and, potentially, many successive lines of therapy. Life effects are far-reaching and long-term. Nurses should be aware of the interprofessional resources to help meet these individuals' needs. With thorough assessment, care planning, and education, nurses can play a key role in mitigating the negative effects of multiple myeloma and its treatment.

**KEYWORDS** multiple myeloma; treatment; survival; symptom burden; quality of life

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**M**ultiple myeloma is the second most common hematologic malignancy in the United States, with 32,270 new diagnoses and 12,830 deaths estimated in 2020 (Siegel et al., 2020). Incidence is slightly higher in men than in women and almost twice as high in African Americans than in other races (National Cancer Institute, 2020). Median age of onset is 69 years, and the five-year survival rate is 53% (National Cancer Institute, 2020). Multiple myeloma's malignant plasma cells proliferate unregulated in the bone marrow, causing weakened bones, fractures, pain, anemia, hypercalcemia, and renal insufficiency (Gasparetto & Sivaraj, 2019). Multiple myeloma-directed treatment can help to reduce disease-related symptoms while introducing side effects such as fatigue, nausea, and peripheral neuropathy (McCullough et al., 2018; Raza et al., 2017).

Those living with multiple myeloma have seen median survival extend from two years in the year 2000 to more than five years currently (American Cancer Society, 2020). Younger individuals with multiple myeloma have seen median survival extend to greater than 10 years (Costa et al., 2017; Morgan & Rasche, 2017). Although long considered incurable, some have argued that cure is possible in light of the long and deep remissions experienced by some with multiple myeloma (Barlogie et al., 2014; Ravi et al., 2018). Improvements in survival have coincided with the rapid introduction of new therapies and changes in treatment patterns (Kumar, 2017). This modern treatment era began in the late 1990s and earlier 2000s with the introduction of immunomodulatory agents (thalidomide, lenalidomide) and the proteasome inhibitor bortezomib as effective anti-myeloma therapies (Kane, 2003; Singhal et al., 1999). Initial treatment often involves a three-drug induction regimen followed by high-dose chemotherapy and autologous stem cell rescue (Kumar et al., 2018). Maintenance therapy post-transplantation

is increasingly routine (Sengsayadeth et al., 2017). Relapse is common, and individuals with multiple myeloma may receive many subsequent lines of

therapy with cumulative toxicities (Kumar et al., 2018). Extended survival coupled with ongoing toxic therapy results in a difficult treatment course and can lead to significant negative effects to daily life.

Research suggests a high symptom burden and poor health-related quality of life for individuals with multiple myeloma, but important questions remain (Kent et al., 2015; Nielsen et al., 2017; Ramsenthaler et al., 2016). Much of what is known about the symptom burden of multiple myeloma and its treatment is from clinical trial reports (LeBlanc et al., 2020). Participants in clinical trials are highly selected and not representative of the wider multiple myeloma population, limiting external validity and understanding of multiple myeloma's impact across the disease trajectory (Costa et al., 2016; Rothwell, 2005). Qualitative explorations promise to provide a more complete picture of the ways in which multiple myeloma affects individuals' lives, but the qualitative multiple myeloma literature is sparse and has important limitations. The rapidly changing multiple myeloma treatment landscape means that older studies are not reflective of the current experiences of those with multiple myeloma. In addition, qualitative explorations of multiple myeloma have almost exclusively been conducted outside the United States with mostly White samples (Cormican & Dowling, 2016, 2018; Kelly & Dowling, 2011; Maher & de Vries, 2011). The purpose of this study was to explore multiple myeloma's effects on a diverse U.S.-based sample in the modern treatment era. Findings from this study will inform a more complete understanding of the negative effects of multiple myeloma.

## Methods

The authors conducted a cross-sectional, qualitative descriptive study to explore the effects of a multiple myeloma diagnosis and its treatment on individuals with multiple myeloma from multiple perspectives (i.e., patients and clinicians) via one-hour semi-structured interviews. Patients were interviewed to capture their in-depth, firsthand experience of living with multiple myeloma. Clinicians were interviewed to tap into their broad experience in caring for this population. This dual recruitment strategy helped the authors to more fully describe the experience of multiple myeloma and its treatment. The study was approved by the Duke University School of Nursing Institutional Review Board (Pro0008474).

## Eligibility and Recruitment

The authors recruited a convenience sample of individuals living with multiple myeloma from the Duke

**TABLE 1. Characteristics of Participants With Multiple Myeloma (N = 15)**

Characteristic	$\bar{X}$	SD
Age (years)	63.67	11.5
Characteristic	$\bar{X}$	Range
Months since diagnosis	71.9	8-144
Characteristic	n	
Gender		
Male	8	
Female	7	
Race		
Black	9	
White	6	
Partnered status		
Married or partnered	9	
Not married or partnered	6	
Income (\$)		
Less than 30,000	3	
30,000-59,999	3	
60,000-89,999	4	
More than 90,000	4	
No response	1	
Education		
Some college	6	
College graduate	4	
Postgraduate	5	
Employment		
Retired	7	
Disabled	5	
Employed	2	
Homemaker	1	
Stage at diagnosis		
I	4	
III	6	
Do not know	5	
Multiple myeloma treatment <sup>a</sup>		
Chemotherapy	15	
Stem cell transplantation	10	
Biotherapy	7	
Radiation therapy	7	

<sup>a</sup> Participants could choose more than one response.

Cancer Institute (DCI) in Durham, North Carolina, which provides comprehensive multiple myeloma care, including stem cell transplantation. Participants were eligible if they were aged at least 18 years, spoke English, and were diagnosed with multiple myeloma as defined by the International Myeloma Working Group (Rajkumar, 2016). Multiple myeloma clinicians helped to identify patients who would be appropriate and informative sources. The authors' study team then invited participants to join the study and obtained informed consent.

Clinician recruitment was expanded to include the University of North Carolina Lineberger Comprehensive Cancer Center (LCCC) in Chapel Hill. Like the DCI, the LCCC serves a large population of individuals with multiple myeloma and provides comprehensive multiple myeloma care. Clinicians were deemed eligible if they were involved in the care of individuals with multiple myeloma and could include physicians, physician assistants, nurse practitioners, RNs, and social workers. The authors initially anticipated 10–20 participants and made sample size decisions as a research team based on data saturation. Data saturation was considered reached when no new themes arose, and the study team considered their findings well described.

### Data Collection

The authors' interview guide was developed to explore individuals' experiences and clinicians' perceptions of the effects of living with multiple myeloma and was guided by Wilson and Cleary's (1995) health-related quality of life conceptual model. The authors' interview guide focused on symptoms, functional and social impacts, and religious/spiritual needs and was iteratively updated as interviews progressed. Interviews were conducted face to face in the outpatient clinic or via telephone. All interviews were conducted by M.R.L.

### Data Analysis

Descriptive statistics were used to summarize demographic characteristics of the sample. Audio-recorded interviews were transcribed verbatim by a professional service. Transcripts were verified by M.R.L. and analyzed using conventional content analysis (Hsieh & Shannon, 2005). The authors considered analyzing patient and clinician data separately but decided to analyze and report these data together because their aim was not to compare perspectives but to more completely describe the experiences of those living with multiple myeloma. To enhance

**TABLE 2. Characteristics of Multiple Myeloma Clinicians (N = 10)**

Characteristic	$\bar{X}$	SD
Age (years)	43.2	9.8
Characteristic	$\bar{X}$	Range
Years in role	7	1–17
Characteristic	n	
Gender		
Female	8	
Male	2	
Race		
White	10	
Role		
RN	4	
Nurse practitioner	2	
Physician	2	
Physician assistant	1	
Social worker	1	

rigor, three authors (M.R.L., A.L.B., and S.K.S.) coded two interviews in parallel. Discrepancies in coding were discussed through a process of code negotiation and transcript review until consensus was reached (Patton, 2015). M.R.L. applied this refined coding scheme across remaining transcripts, and results were discussed with the entire authorship team across multiple meetings. Statements were coded using a combination of a priori codes and codes that emerged from the data. Codes were then classified into categories to identify patterns and themes. Themes were developed and refined through group discussion involving all authors. The authors used NVivo, version 11.0, for data management and analysis.

### Findings

The authors interviewed 15 individuals with multiple myeloma and 10 multiple myeloma clinicians from September 2017 to September 2018. Sixty percent of the patient sample identified as African American, and participants from across the disease spectrum were included. All participants in the clinician population identified as White. Participant characteristics are further described in Tables 1 and 2. The study found that multiple myeloma and its treatment had a number of concerning effects on individuals' lives. Four themes of persistent effects emerged: treatment without end, social impacts and

isolation, ongoing financial pressure, and relationship impacts.

### Treatment Without End

The relentlessness of active treatment is what differentiates modern multiple myeloma treatment patterns from past multiple myeloma treatment patterns, as well as the treatment patterns for many other cancers. Even in periods of remission, individuals may continue maintenance therapy indefinitely to stave off relapse for as long as possible. According to a 58-year-old male participant with multiple myeloma,

I've been coming to the clinic at least once a month, no, at least once a week. For a while there, I was only on every other week, so I've been here at least once every other week since October, yeah, since August 2012.

A male multiple myeloma physician said,

This isn't the kind of thing they come in once a month, get some chemotherapy, and can forget it about the other 27, 28 days of the month. With a lot of these treatment programs, they come in twice a week, three times a week, they're taking pills at home, they're in the office at least, even when things are going well, usually at least once a month, and so there's constant reminders of the fact that they have this incurable cancer.

Multiple myeloma treatment, it seems, does not have an acute treatment phase followed by a period of recuperation. The challenges introduced by multiple myeloma and its treatment are ongoing, not to be temporarily endured and recovered from. A 46-year-old male participant with multiple myeloma shared the following:

I was getting my strength back, and I was feeling good. . . . I was thinking, it was one of those thoughts where, "Maybe I should look back at going to work now," and then right after that I relapsed again, and then that's when I went in for the third transplant. Then I relapsed again after that, so . . . before the third transplant, that was probably the worst feeling that I had.

### Social Impacts and Isolation

Multiple myeloma and its treatment have debilitating impacts on individuals' social lives and their ability to participate in activities they enjoy. Participants

described how symptoms such as fatigue or neuropathy led to physical limitations and made it difficult for them to leave their home, complete activities of daily living, or participate in activities they enjoy. According to a 63-year-old female participant with multiple myeloma,

I don't cook like I used to cook. You know, it's just difficult for me to do that. It just takes . . . you know, I just don't have the stamina to be able to do it.

A 72-year-old male participant with multiple myeloma said, "The lack of energy is the biggest bear on my back, you know. Staying in bed all day long [is what my day looks like when it's at its worst]."

Fatigue self-management often involved increasing rest at the expense of social activities or hobbies. Some participants reported that some days were better than others, limiting their ability to plan ahead. A 72-year-old male participant with multiple myeloma said,

My son, you know, they ask . . . I have two of them, and they'll ask me, "Well, what are you doing tomorrow?" or something along those lines, and I'll tell them, it depends on . . . I tell them, "I won't know until I wake up tomorrow."

Limited management strategies made fatigue particularly challenging for many. A female nurse practitioner shared the following:

I think the fatigue is the most distressing. Pain is certainly distressing, but we can usually get a pretty good handle on their pain with meds and stuff, but the fatigue is sometimes to the point where they really just can't do what they want to do because they are physically so tired.

Peripheral neuropathy, the result of multiple myeloma therapies and multiple myeloma itself, was another symptom that was difficult to manage and affected individuals' social lives and hobbies because of its effects on balance, mobility, fine motor skills, and uncomfortable sensations. According to a 76-year-old male participant with multiple myeloma, "Almost as soon as I started in the fourth round, the . . . numbness, tingling, leg pains got a lot worse."

A female nurse practitioner described a patient as follows: "He was a young guy, super active, really

outdoorsy, likes to hike, and he wasn't able to hike or do anything really because his feet were so bad."

Diarrhea was mentioned by 11 individuals with multiple myeloma and, when present, dramatically affected their lives by physically exhausting them, interrupting sleep, and making it difficult for them to leave their house out of fear of having an accident while out. An 88-year-old female participant with multiple myeloma described it as follows:

I just want to go to church and everything. I miss my fellow members and everything, but I just, I'm just afraid if I go then . . . like I said, with this diarrhea and everything, I didn't want to go and have a . . . you know . . . I don't want to be embarrassed.

Seven participants reported worry about infection keeping them from attending social gatherings and participating in activities that they enjoy, like gardening, yoga, and church. A 58-year-old male participant with multiple myeloma said,

My main problem with that was that because of it dropping my blood counts, my platelets and neutrophil so low, I had to really think about where I wanted to go and what I wanted to do and I was really totally kind of [giving] up things that I loved.

According to a 72-year-old female participant with multiple myeloma, "I wanted to see this movie so bad, but the doctor said my numbers were low and I shouldn't go to the theater. Just too many people."

### **Ongoing Financial Pressure**

The chronic nature of multiple myeloma, its ongoing treatment, and the high cost of multiple myeloma therapies placed those with multiple myeloma and their families under immense financial pressure. Multiple myeloma directly resulted in financial toxicity through medication costs, appointment co-pays, and temporarily or permanently relocating for care. Multiple myeloma made it difficult for some participants to maintain employment. Some participants reported surviving on disability income alone and relying on inconsistent financial support from foundations to afford medications. A 58-year-old male participant with multiple myeloma said,

I have no finances [laughter] anymore. Yeah, I mean it. I have no money other than what goes towards medicine. . . . I basically live on disability

income, so I can't contribute to anything other than staying alive.

Another participant, a 73-year-old woman with multiple myeloma, shared the following:

Medicare will pay for a portion of it for me, but there can be a \$500 co-pay left, and there are a number of groups out there that will fund you. I had been using one and then didn't need it for a while, and when I went back to get them, they didn't have any money left, so, but I was directed to some others to ask.

Five participants left the workforce because of their disease. For those five participants, multiple myeloma presented significant challenges to maintaining employment because of the severity of symptoms, like pain and fatigue. A 63-year-old female participant with multiple myeloma said, "Because of the pain of course, I had to stop working, but overall, I try to stay positive."

The ongoing and often intensive appointment schedule that multiple myeloma treatment requires made it difficult for individuals with multiple myeloma to maintain employment. A male multiple myeloma physician shared the following:

Even if they feel perfectly fine, they are often in clinic with us two days per week, so even if they feel OK, working on a 9–5 schedule is often challenging if they don't have flexibility.

Being forced to prematurely retire had a cascading effect on the participants' sense of self, family relationships, and financial health. According to one 46-year-old male participant with multiple myeloma,

I went into a depression, you know, because when I was released from work, I was only maybe 36, 37 years old and, you know, you tell me I can't work no more. Uh, so took a role as a stay-at-home dad, you know so, it took some getting used to, and I wasn't prepared for it.

### **Relationship Impacts**

The pressure of living with a chronic incurable illness, the severity of physical and emotional symptoms, and the financial impact resulted in altered relationship patterns and shifting roles in and out of the home. For some participants, these new stressors resulted in relationship conflict. For other relationships, the



multiple myeloma diagnosis seems to have brought families closer together.

A 54-year-old female participant with multiple myeloma shared,

I can get a little winded doing basic things. It makes me feel bad sometimes when I have to ask my husband, “Hey, can you get to the other side of the bed? Can you help me make the bed?”

A 46-year-old male participant with multiple myeloma said,

If I didn’t have myeloma, then I probably . . . I know I’d still be working, I might still be married, raising my children within the household. . . . I think that was the hardest part, trying to, . . . trying to still be a father figure for the household. Still be supportive for my wife because a lot of that burden fell on her. Where we was in this together, financially. Uh, so a lot of the burden fell on her.

A 58-year-old male participant with multiple myeloma described the “paradoxical guilt” his partner felt as they navigated the reality of his multiple myeloma diagnosis as follows:

She has this . . . kind of paradoxical sort of guilt. She wants to be more helpful, but she doesn’t want to be more helpful because she wants her own life. I don’t want her help because I don’t want to be a burden on her life, but when I don’t want her help, it hurts her feelings because she feels guilty because . . . you can see how it can all feed on itself in weird ways. And so, it has made for a very, very complicated relationship.

## Discussion

This article described the experiences of individuals living with multiple myeloma and the ways in which the disease and its ongoing treatment affected their lives. This study included a racially diverse sample of individuals with multiple myeloma from across the disease trajectory and was further strengthened by the inclusion of clinician voices. The authors uniquely described these life effects in the context of the ongoing nature of multiple myeloma treatment. The findings suggest important effects of multiple myeloma treatment on individuals’ social activities,

financial health, and relationships, from which they may not get a chance to recover from but which must be endured. These findings represent new and expanded understandings of the effect of multiple myeloma on individuals’ lives.

This study is the first qualitative exploration that documents the unrelenting nature of multiple myeloma therapy and its effects on individuals’ lives. Earlier studies by Dahan and Auerbach (2006), Vlossak and Fitch (2008), and Molassiotis et al. (2011) echo these findings of serious life effects but lack discussion of the ongoing nature of modern multiple myeloma treatment patterns. The current study adds significantly to the literature by identifying and discussing never-ending treatment as an important factor in individuals’ experiences with multiple myeloma. Additional studies are needed to identify and describe disease and treatment trajectories to better understand their contribution to negative outcomes and life effects. The authors of the current study also recognize that the pattern they describe of treatment without end may not be entirely unique to multiple myeloma, as many with incurable cancers are living longer because of expanding treatment options (e.g., stage IV breast cancer, stage IV colon cancer, stage IV lung cancer) (Takano et al., 2019; Waks & Winer, 2019; Wu, 2018). Increased focus on this treatment pattern and its effects on individuals’ lives should extend beyond multiple myeloma where applicable.

The authors identified fatigue, diarrhea, and peripheral neuropathy as common and difficult-to-manage symptoms in multiple myeloma and highlighted the serious effects these symptoms have on individuals’ ability to fulfill social and occupational roles and participate in activities they enjoy. Breaks from active treatment often improve symptoms as individuals recuperate from the difficulties of enduring toxic therapies (Richardson et al., 2017). These treatment breaks may not be available for some, increasing the urgency to address symptoms effectively. Symptoms like fatigue and peripheral neuropathy are multifactorial and are difficult to manage and treat effectively. Strategies that help individuals live fulfilling lives in the face of difficult symptoms should be increasingly looked to for this population. Possibilities for treatment may include increased referrals to physical medicine and rehabilitation services or psychotherapeutic approaches that help individuals live with chronic illnesses (e.g., cognitive behavioral therapy, acceptance and commitment therapy) (McNeely et al., 2016; Yu et al., 2017). Integrated

specialist palliative care should also have a role, given its significant effect in improving symptoms and quality of life among those with advanced cancer (Fulton et al., 2019; Samala et al., 2019).

To the authors' knowledge, this study is the first qualitative description of the financial burden multiple myeloma places on individuals and families, and some of the downstream effects this has on other aspects of individuals' lives. The serious impact of multiple myeloma on participants' finances is not surprising considering the high cost of many common multiple myeloma therapies (Dusetzina et al., 2019; National Comprehensive Cancer Network, 2020). The high costs of multiple myeloma care are part of a broader trend of increasing cancer care costs but are particularly salient for this population whose care often involves stem cell transplantation, many lines of therapy, and indefinite maintenance therapy (Laviana et al., 2020; Rajkumar, 2018). Emerging treatment strategies include four-drug induction regimens and chimeric antigen receptor T-cell therapies, promising to further increase the costs of multiple myeloma care (Lin et al., 2019; Voorhees et al., 2020). Financial counseling and the use of foundation or pharmaceutical company grants to cover costs may not work for everyone and may become less effective as costs continue to rise. The nature of the financial costs in cancer will ultimately require a health policy response. Further research is needed to describe the financial burden of living with multiple myeloma and how it may compare to other cancer populations, and to find new strategies to address the high cost of cancer care.

This study also highlights the impact multiple myeloma has on close relationships. Participants described being less able to care for themselves and to maintain previous roles and responsibilities, shifting burdens to caregivers or partners. One participant reported that the shifting burdens imposed by multiple myeloma caused relationship stress and led to divorce. Although caregiver burden in multiple myeloma has been explored in other work, this article is the first to report conflict and divorce as a result of multiple myeloma's life effects (Molassiotis et al., 2011). Large national studies in the United States, Korea, and Denmark have identified risk factors for divorce among cancer survivors to include female gender and lower socioeconomic status, but these samples did not include multiple myeloma survivors (Carlsen et al., 2007; Stephens et al., 2016). Conflict in close relationships from the stresses of living with multiple myeloma is a topic that should be explored further.

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## KNOWLEDGE TRANSLATION

- For many individuals with multiple myeloma, treatment continues for many years, requiring ongoing education and symptom management.
  - Multiple lines of therapy present multiple opportunities for informed decision making, and nurses have a vital role in educating and supporting individuals and families through these decisions.
  - Long-term effects of these treatment patterns cascade beyond physical and emotional effects to include social, financial, and relationship effects, highlighting the need for thorough assessment and interprofessional coordination and management.
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## Limitations

The current study has important limitations to consider. It is a qualitative exploration with a modest sample size of 15 patients and 10 clinicians, so the findings may not generalize to other populations. Individuals with multiple myeloma in this study were all recruited from a single academic medical center in the southeastern United States, were on treatment at the time of the interview, and were younger at diagnosis than the national population of those with multiple myeloma. Clinicians were similarly recruited from two academic medical centers where treatment patterns may be different from other settings. Therefore, the authors may be missing important facets of the experiences of those living with multiple myeloma. For example, these findings likely do not represent the experiences of those in remission and off treatment and those treated in rural or community cancer centers. Despite these limitations, the authors believe this study significantly adds to the understanding of multiple myeloma's effects on individuals' lives in a rapidly changing treatment environment.

## Implications for Nursing

Findings from the current study highlight three features of modern multiple myeloma treatment that call for nursing intervention. First, the ongoing nature of multiple myeloma treatment highlights the need for nurses to educate those with multiple myeloma that their treatment journey could be lifelong and require frequent visits to their oncologist and, potentially, many successive lines of therapy. Ongoing treatment can bring ongoing treatment-related symptoms, underscoring the need for nurses to proactively identify and manage these symptoms. Second, multiple lines of therapy present multiple opportunities for informed decision making. Individuals actively decide

whether to continue, pause, or discontinue treatment, and nurses have a vital role in educating and supporting them through these decisions. Third, the multidimensional nature of the life effects highlighted in this article call on nurses to carefully assess these issues and coordinate care among the interprofessional team available at their institution and in their communities. This study highlights not only the physical and emotional symptoms experienced by those living with multiple myeloma, but also the cascading effects multiple myeloma has on individuals' financial and personal lives. Through thorough assessment, care planning, and education, nurses can play a key role in mitigating the negative effects of multiple myeloma and its treatment.

## Conclusion

For many cancers, the effects of active treatment are intense but time limited. For some living with multiple myeloma, these effects are intense and unrelenting. The current study sheds new light on this concerning reality and details serious effects on individuals' ability to participate in social and vocational activities, their financial health, and their relationships. Further research is needed to describe multiple myeloma treatment patterns and the ways in which these patterns negatively affect individuals' lives. Targeted interventions are needed to address the serious life effects reported in this article and could include assistance of individuals to live well in the face of difficult and burdensome symptoms, shared decision making, health policy advocacy, and relationship support.

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