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Psychosocial and supportive care needs of individuals with advanced myeloma

by Suzanne Rowland, Robin Forbes, Doris Howell, Helen Kelly, Arta Taghavi Haghayegh, Trisha Ramnanan, and Samantha J. Mayo

ABSTRACT

Purpose: The purpose of this qualitative study is to understand, from the patient's perspective, their experience of living with advanced multiple myeloma, the psychosocial impact, and needs for support in managing and adapting to this illness.

Methods: An interpretive descriptive approach was used. Individual semi-structured telephone interviews were conducted with each participant, which focused on eliciting their descriptions of psychosocial issues and concerns, as well as the supports they use for coping with cancer. Transcripts were analyzed using interpretive description, resulting in the generation of common themes that represented the data.

Results: The sample comprised twelve adults with a diagnosis of advanced multiple myeloma who had undergone at least three lines

of treatment or were transfusion dependent. All participants were receiving ambulatory care for their myeloma in Toronto, Ontario, Canada. Four themes were generated: (1) confusion about the diagnosis and treatment options; (2) challenges in finding relevant information; (3) dealing with the chronicity of treatment side effects; (4) social support as critical for coping with the life-threat of multiple myeloma.

Conclusion: Findings suggest that the psychosocial impact of living with advanced multiple myeloma is greatly impacted by one's ability to understand the complexities of the diagnosis and access supports to cope with its physical and emotional consequences. Clinical interventions specifically tailored to meeting the information and support needs of this population are needed.

Keywords: multiple myeloma, interpretive description, qualitative, psychosocial

ABOUT THE AUTHORS



Suzanne Rowland, RN(EC), BScN, MN, Princess Margaret Cancer Centre, University Health Network



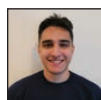
Robin Forbes, MSW, RSW, Princess Margaret Cancer Centre, University Health Network



Doris Howell, RN, PhD, Princess Margaret Cancer Centre, University Health Network



Helen Kelly, RN, MScN, Toronto General Hospital, University Health Network



Arta Taghavi Haghayegh, HBSc, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto



Maja Cardinale, RN, BScN, Princess Margaret Cancer Centre, University Health Network



Trisha Ramnanan, RN, BScN, Princess Margaret Cancer Centre, University Health Network



Samantha J. Mayo, RN, PhD, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto; Princess Margaret Cancer Centre, University Health Network

Corresponding Author: Samantha J. Mayo, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, 155 College St., Suite 130, Toronto, ON M5T 1P8

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INTRODUCTION

Individuals diagnosed with multiple myeloma often experience a host of illness and treatment-related impacts. This rare blood cancer is defined as a non-curable malignancy of the plasma cells; treatment is aimed at extending survival, with most individuals experiencing numerous relapses requiring multiple lines of therapy (van de Donk et al., 2021). However, significant decreases have been observed in early mortality and increases in five-year overall survival since the mid-2000s, with the emergence of novel therapeutic regimens that offer different combinations of chemotherapy and biological agents, as well as autologous stem cell transplantation (Binder et al., 2022). The initial introduction of the immunomodulatory agent, thalidomide, and the proteasome inhibitor, bortezomib, led to improvement in the outcomes of patients with multiple myeloma in the early 2000s. The introductions of other agents over the last decade, such as lenalidomide, carfilzomib, pomalidomide, daratumumab and belantamab mafotin, has further contributed to improved survival rates (Rajkumar, 2022). Additional new agents and approaches, including chimeric antigen receptor T-cell therapy (CAR T), are currently in clinical trials for the treatment of relapsed multiple myeloma, with potential to lead to further improvements in outcomes (Rajkumar, 2022).

Research using patient-reported outcomes suggests the importance of addressing physical symptoms that may arise from these treatments, such as dyspnea, pain, nausea, and fatigue (Boland et al., 2013; Kelly et al., 2011). All are symptoms that can be effectively monitored and addressed during clinic visits. However, there is a need to gain insight into the patient perspective, using qualitative methods, given the current context of care that is characterized by extended survival, often with multiple lines of therapy and supportive therapies such as blood transfusions.

Previous qualitative research documented the psychosocial impact of living with a diagnosis of multiple myeloma. For example, in a 2005 qualitative study among 20 patients, 10 months to 6 years from their diagnosis of multiple myeloma, Vlossak and Fitch found that the diagnosis can be shocking and unexpected, with psychosocial impacts that included loss of independence, concern for one's family, and "obsession with when and how the end will come" (p.144) (Vlossak & Fitch, 2008). In the context of the current treatment paradigm, where more individuals with multiple myeloma are living with advanced cancer due to multiple lines of therapy, more recent studies have reinforced the psychosocial impact of multiple myeloma over the trajectory of illness (Molassiotis et al., 2011; Potrata et al., 2011), and relapsed stages of the disease (Maher & de Vries, 2011). In 2020, Cuffe et al. (2020) interviewed patients in remission from or living with relapsed multiple myeloma and found that the experience of living with the illness is characterized by information and communication needs, treatment and symptom burden, the importance of support from family and professionals, and the psychosocial elements of survivorship (specifically, the emotional changes associated with ongoing treatment and relapse).

However, little is known about the specific psychosocial needs and concerns of patients with advanced multiple myeloma who have exhausted numerous lines of treatment and/or have become dependent on frequent and long-term transfusions of blood products. In a sample of participants receiving stem cell transplantation for multiple myeloma, Dahan and Auerbach (2006) identified the trauma related to the diagnosis of multiple myeloma, but also the personal growth that may be experienced when recovering from treatment, even if relapse remains a possibility. For patients with advanced multiple myeloma, with diminishing access to effective treatments to control the disease, understanding their experiences can inform efforts for providing tailored supportive care that can sustain quality of life.

The overall purpose of this qualitative study is to understand, from the patient's perspective, the experience of living with advanced multiple myeloma, the psychosocial impact, and needs for support in managing and adapting to this disease. Specifically, we aimed to (a) identify the psychosocial issues, concerns, and needs experienced by individuals with multiple myeloma throughout the illness trajectory, including their current status; and (b) to explore what they have learned about living with this disease, and the strategies or supports that helped them in everyday life. Insights gained from the perspective of individuals with multiple myeloma will inform the development of interventions that address their existing psychosocial concerns and needs most effectively.

METHODS

Qualitative approach and research paradigm

In this qualitative, interpretive descriptive study, semi-structured interviews were used. Interpretive description integrates qualitative methodological integrity with a focus on real-world utility, so that findings are well-suited for application and knowledge translation (Thorne, 2016; Thorne & O'Flynn-Magee, 2004).

Context and sampling strategy

The study was conducted between October 2020 and January 2021 in a tertiary cancer centre in Toronto, Canada, which sees approximately 8,000 patients with multiple myeloma annually. In 2019, there were 350 new referrals, of which 80% were planned for autologous stem cell transplantation. The multidisciplinary team of the Multiple Myeloma Clinic includes medical oncologists, nurse practitioners, and specialized oncology nurses, with access to a Psychosocial Oncology Department that includes a dedicated social worker and psychiatrist available upon referral.

Purposive sampling was used to recruit participants. Individuals were eligible if they (a) had a multiple myeloma diagnosis; b) underwent multiple (≥ 3) lines of treatment, and/or were transfusion-dependent; (c) ≥ 18 years of age; (d) not diagnosed with psychosis or delirium; and (e) able to complete questionnaires and partake in interviews over the telephone in English.

Data generation

A semi-structured interview guide was informed by the *Nursing Model for Chronic Illness Management Based on the Trajectory Framework* (Corbin & Strauss, 1991). Questions were designed to elicit an understanding of psychosocial issues, concerns, and needs experienced by these individuals throughout the illness trajectory, including their current status; and to explore what these participants learned about living with this disease and the strategies or supports that helped them in everyday life. Questions also prompted participants to recount how the disease and its treatments impacted various aspects of their lives. Examples of interview questions included: "What are your experiences with this disease?" "How has your diagnosis impacted your relationship with members of your family?" "What kinds of support do you rely on the most?" Additional prompts were used to probe deeper into the sentiments that patients shared (see supplement for interview guide). Participant characteristics were obtained using a brief demographic questionnaire, which was administered alongside the Edmonton Symptom Assessment Scale (ESAS-r) by the interviewer.

All interviews were conducted by an RN (MC, TR), NP (SR), or social worker (RF). All interviewers had clinical experience in providing care to patients with advanced multiple myeloma and were trained in qualitative interviewing. All interviews were conducted over the telephone, due to COVID-19 restrictions limiting in-person contact at the time of the study. A total of 648 minutes of interview data were collected, with an average interview length of 54 minutes. Due to technical issues, audio files for two interviews were not captured, resulting in missing data related to demographic characteristics and verbatim responses to interview questions; however, field notes from these interviews were used to supplement the study dataset.

Data processing and analysis

Demographic characteristics were summarized using frequencies, medians, and ranges, as applicable. ESAS symptom severity and wellbeing scores on the 0–10 scale

were categorized as none, mild (1–3), moderate (4–6), or severe (7–10), as per published cut-points (Selby et al., 2010). Individual interviews were audio-recorded and transcribed verbatim. Transcripts were checked for accuracy and de-identified.

Interview transcripts were analyzed by members of the research team in accordance with Thorne et al.'s (1997) method of interpretive descriptive qualitative data analysis. Prior to coding, immersion with the interview data was achieved by listening to the audio recordings multiple times. SR and RF independently listened to all audio recordings and conducted close reading of all interview transcripts. First, codes were mapped onto categories of ideas using descriptive thematic analysis. Following this, the data were examined dynamically between its whole and in parts (Moules, 2002), in order to interpret the emerging themes and why they exist in the manner they do. Specifically, our goal was to understand better the emerging themes by moving back and forth between the larger text and its coded segments. After an independent reading and re-reading of participant interviews, themes were discussed and reviewed among investigators to ensure that (a) intimate knowledge regarding individual interviews – and meaning-making of common themes – was established; and (b) differing perspectives were considered and used constructively to derive a uniquely refined understanding of the initial themes. Analysis occurred concurrently with data collection and thematic saturation was achieved after 10 interviews, after which two more interviews were added.

Trustworthiness of the qualitative data analysis was ensured by adhering to concepts as outlined by Lincoln and Guba (1985). These concepts were operationalized in this study as (a) ensuring transparency of all data to obtain an accurate portrayal of their experiences of living with multiple myeloma; (b) the triangulation of emerging codes and themes among members of the research team (investigator triangulation); and (c) keeping a log of analytic decisions (audit trail).

Ethical Approval

The study was approved by the hospital's Institutional Research Board. Written and verbal informed consent was obtained from all participants. A \$25 gift card honorarium was mailed to participants upon completion of data collection.

RESULTS

Participant characteristics

Twelve participants were enrolled in the study, of which 10 had demographic data available (Table 1). Of the 10 participants, nine identified as Caucasian and six identified as male. The median age of participants was 62 years (range = 57–76). Interviews occurred a median 5.5 years (range = 2–20) after diagnosis of multiple myeloma, during which participants were treated with a variety of prior therapies, including autologous stem cell transplantation. At the time of the interview, all participants were currently receiving treatment. Symptom severity across the ESAS domains were mostly mild, with tiredness being most frequently reported as moderate or severe (Table 1).

Table 1

Sample Characteristics (n = 10)^a

Characteristic	n ^b			
Age (Median, Range)^c	62 (57–76)			
Gender				
Male	6			
Female	4			
Years since diagnosis (Median, Range)	5.5 (2–20)			
0–4	3			
5–10	5			
>10	2			
Level of education^c				
High school	4			
College/University	5			
Work status				
Currently working	4			
Retired	4			
Not currently working (e.g., on leave)	2			
Annual income^c				
20–39k	1			
40–59k	2			
60–79k	2			
80–99k	2			
>100k	2			
Race	9			
Caucasian	1			
Other				
Need for caregiver support for ADLs	0			
Currently receiving treatment for MM	10			
MM treatments received^c				
ASCT	8			
Lenalidomide	4			
Bortezomib	3			
Daratumabab	3			
CyBorD	2			
Other ^d	4			
Unspecified chemotherapy	3			
Co-morbidities^c				
0	1			
1–2	7			
3+	1			
ESAS scores^c				
None				
Mild				
Mod				
Severe				
Pain	3	6	0	0
Tiredness	0	5	2	2
Drowsiness	3	3	3	0
Nausea	8	1	0	0
Lack of appetite	7	2	0	0
Shortness of breath	5	2	0	1
Depression	4	4	0	1
Anxiety	6	3	0	0
Wellbeing	0	8	0	0

Note. ESAS scores are on a scale of 0–10 with higher scores indicating greater symptom severity or worse well-being (None 0, Mild 1–3, Moderate 4–6, Severe 7–10)(Selby et al., 2010). ^a Due to missing data, demographic data based on 10 of 12 participants enrolled, unless otherwise indicated. ^b Unless otherwise indicated ^c Due to missing data, based on n=9. ^d Includes carfilzomib, ixazomib, pomalidomide, and zoledronic acid. ASCT, autologous stem cell transplantation, ADLs, activities of daily living, MM, multiple myeloma; ESAS, Edmonton Symptom Assessment Scale

Themes

Four themes were generated related to the experience of living with advanced multiple myeloma: (1) Confusion about the complexities of their diagnosis; (2) Challenges in finding relevant information on what to expect; (3) Dealing with the chronicity of treatment side effects; (4) Social support as critical for coping with the life-threat of multiple myeloma.

Theme 1: Confusion about the complexities of their diagnosis

Participants expressed challenges with understanding their cancer, specifically the complexities of their individual diagnosis, disease status, prognosis, and treatment options. Feelings of confusion were particularly present when they originally received their diagnosis. This confusion was aggravated by a lack of awareness of multiple myeloma as a cancer before receiving their diagnosis, or not understanding that it was incurable. Some participants, even after having received multiple lines of treatment, described how they still did not have a good understanding of the disease and what to expect, adding to their anxiety and distress.

Confusion was particularly salient for participants who were alone when they were told the details of their diagnosis. For these participants, they experienced feeling overwhelmed and had difficulty understanding what the diagnosis was and what the treatment plan would be. As one participant reflected on what could have been different: *"If I could have had my family with me [at the time of diagnosis]. I've just been told I likely have multiple myeloma and I think I said, 'What's that?'. I sat there stunned, then I had all these documents thrust at me about treatment. It was overwhelming"* (MM004).

The feeling of being overwhelmed was also illustrated by another participant who suggested the need for, *"...someone to explain things in layman's language"* (MM003). He described an interaction with the doctor in which the need for clarification was expressed: *"There was a male doctor explaining things and I'm thinking 'it's going way over my head'. I finally said, 'In English, can we go back and just explain to me in words I can pronounce'. He drew pictures for me, and that really helped"* (MM003).

Participants also described how confused they were regarding their disease status as they proceeded through numerous lines of treatment. For example, one participant expressed that they did not understand their disease status and prognosis, despite having the diagnosis for quite some time: *"I don't know if, I am in sort of a remission, or I'm being treated, or whether I would consider myself to have cancer"* (MM011). From another participant, *"I found out months later that I was in the high-risk category because I have chromosome 17p deletion. I wasn't told that in the beginning and that was upsetting, as that changed everything as far as outcomes (prognosis and treatment) are concerned"* (MM010).

Related to treatment, one participant reflected that even though she had been treated for her cancer for several years, she did not understand that the treatment would not be effective indefinitely. *"I was shocked, I thought I would be on Velcade for the rest of my life (referring to living into old age). I never realized that there was, what I call, an expiry date"* (MM003). Similarly, in light of the few standard-of-care treatment

options available for multiple myeloma, many are presented with the possibility of participating in clinical trials. However, the limitations to clinical trial availability are not always understood. As one participant stated, *"I get on the clinical trial and when it no longer works, we just get a new clinical trial...it's no big deal"* (MM014).

Theme 2: Challenges in finding relevant information on what to expect

Participants also expressed challenges with ascertaining reliable information that was specific to multiple myeloma and that could help prepare them for what to expect as they progressed through the course of this rare and life-limiting disease. As one participant shared, *"My wife was looking up stuff (online) about multiple myeloma and I said to her, 'stop looking up stuff. Don't look here and there for stuff. If you need to find something, you need to find it from a reputable site'. We do have a couple of myeloma websites that we are members of, talking with other patients and their experiences"* (MM004).

For others, the information they find can be startling. As one participant stated, regarding information that came from a Facebook group, *"Sometimes it's very scary"* (MM006).

Educational support, as part of the intake and acclimation to the diagnosis and treatment, were suggested as offering benefits to patients throughout their treatment trajectory. As one participant expressed, *"I think there should be some kind of program where patients can find out what to expect...about everything. What happens when you get treatment? I didn't feel nearly as well informed in the beginning as I do now. I hear patients talking in the waiting area and they obviously don't know what to expect"* (MM009).

Not only was information related to the disease and treatment important to the participants, but also practical information that could help people understand the clinic processes and navigate the system. An example of the latter type of information is the expected wait time for one's chemotherapy to be ready: *"I hear people going up [to the reception desk] and giving the poor people at check-in a hard time, 'My appointment was for 11:30 and it's a quarter after 12:00 already.' I just sort of think, geez are you new here? I felt not as informed to that regard as I feel like I am now"* (MM009).

Theme 3: Dealing with the chronicity of treatment side effects

The chronicity of the treatment side effects was reflected throughout the interviews. *"So, I've been doing this for 12 years. So, my body is used to the dexamethasone...I'm one of those people that I don't sleep, but I don't get up. I stay in bed, and I close my eyes, and I rest"* (MM014).

Other side effects meriting attention include pain and decline in physical function. While patients are grateful for treatment opportunities, these treatments are coupled with changes in their abilities to engage in independent activities of daily living. *"...all the clinical trials...they've given me leg cramps; they've given me a bit of difficulty breathing"* (MM014). *"...if I do a bit of walking around. I kind of get short of breath"* (MM004).

Participants also became experts in reading their bodies for signs of disease progression as they progressed through lines of treatment and could apply this wisdom to accessing care

earlier. *“This pain nearly brought me to tears. And it’s like, ‘my God, what the hell is going on?’ And I said to myself at that point ... there’s got to be a lesion there”* (MM004).

Theme 4: Social support as critical for coping with the life-threat of multiple myeloma

The role of support and its importance to participants in coping with a life-limiting, rare cancer was a recurring theme during the interviews. In particular, participants were reliant on close friends and family members for providing emotional and practical support. Participants also expressed an appreciation for this support and acknowledged the important and beneficial role that these support persons had in their lives. One participant acknowledged the role of friendships: *“I have two girlfriends who have been wonderful”* and referred to her husband as *“My right-hand man”* (MM003).

Another said of his wife and her role in his life, *“Without her, this journey for me...it wouldn’t be the same. It would not be the same because, I don’t know, when I get information, when (the doctor) is talking to me...it kind of goes in one ear and out the other...It doesn’t really matter what you do to me because I’m going to say ‘yes.’ My wife, on the other hand, she’ll ask questions and stuff...She googles that drug right away. And she’ll see what side effects it has”* (MM004).

The theme of needing more support, and of including more information about the disease and treatment options was recurrent throughout the interviews. Participants spoke to the challenges of hearing difficult or distressing information about their disease and prognosis and cited the relationship they had with the physicians or nurse practitioners in the Myeloma Clinic as being of significance in providing informational and relational support at the time new information is received. As one participant shared, *“It’s been hard finding out that treatment wasn’t working. That’s probably been five times. Each time I hear, ‘ok your numbers (light chains and monoclonal protein) have gone up’ it’s like, oh, crap, I can’t catch a break. If there was someone to talk to (after receiving bad news), to vent a little bit, and ask questions, that would be so helpful”* (MM004).

Another participant described their experience with the bone marrow aspirate that was conducted as part of the diagnostic work-up: *“It was quite a traumatic experience and the one thing I complain vehemently about is before the results were even back, I’m told I probably have multiple myeloma. I was on my own and just sat there. The next thing I know is I am being given treatment options for cancer. I should have been told to bring someone with me for the diagnosis”* (MM011).

Later, this participant worked with a Nurse Practitioner who helped them better understand the diagnosis and treatment options, reflecting that, *“In my opinion, a nurse practitioner should be (involved) as soon as the diagnosis is made (for support and education)”* (MM011).

Despite the availability of specialized psychosocial oncology resources, participants did not describe access to, or use of psychosocial resources to help them adapt to multiple myeloma, but did describe a need to make these resources more readily available. As a participant who did make use of psychosocial support stated, *“You kind of vent a little bit. And once you vent a little bit, it feels like, ‘Oh that was great”* (MM004).

DISCUSSION

Four themes were generated related to the experience of living with advanced multiple myeloma: (1) Confusion about the complexities of their diagnosis; (2) Challenges in finding relevant information about what to expect; (3) Dealing with the chronicity of treatment side effects; and (4) Social support as critical for coping with the life-threat of multiple myeloma. By focusing on individuals who have received multiple lines of treatment and remain transfusion dependent, our study extends existing research that focused primarily on individuals at the early stages of dealing with this disease. Specifically, we identified the continued need for clear information and supportive care that attends to the medical, physical, and psychological changes these individuals experience during adjustments to the management of their cancer. Despite being many years from the time of diagnosis, these individuals continue to experience lack of clarity regarding their condition and treatment plan, as well as the need for support to manage ongoing distress and symptom management. As individuals with advanced and incurable cancer, novel treatments and clinical trials are common, adding to the complexity of their experience.

Social support, especially from family, friends, and the healthcare team, was essential to participant’s ability to cope with incurable cancer. Social support is hypothesized to buffer the adverse effects of stressful events by providing a compassionate, caring presence that bolsters the individual’s self-esteem and instrumental assistance that lessens the practical demands associated with the stressful circumstance (Cohen & Wills, 1985; Thoits, 2011). Due to treatment advances, individuals with multiple myeloma are living longer with the illness than previously, but face complications and challenges of chronicity that our findings suggest can be mitigated with emotional and instrumental support from trusted loved ones, and therapeutic interactions with healthcare providers. Dehan and Auerbach (2006) previously reported that positive outcomes among individuals newly diagnosed with multiple myeloma were rooted in strong social support and an attentive medical environment. Our current work extends these findings by supporting the sustained importance of social support from the perspective of individuals coping with advanced multiple myeloma. Our work also reinforces more recently published evidence regarding the role of social support in coping with the prognosis and incurability of the disease itself. In a qualitative study of 20 individuals with multiple myeloma, social support from family, peers, and the healthcare team was identified by participants as helping them accept their prognosis by enhancing feelings of belonging, acceptance, and safety (Hermann et al., 2021). In another study of 127 individuals with myeloma, in which 56% were classified as having high-level or maladaptive fear of cancer recurrence (FCR), greater scores of perceived social support were found to be associated with lower FCR (Hu et al., 2021).

Our findings also suggest the need for enhanced supportive care in the context of advancing disease, multiple treatments, and potentially diminishing functional and emotional capacity associated with coping with chronic symptoms. Many cancer care programs prioritize a multidisciplinary or interprofessional

team approach, as it acknowledges the unique and specific expertise that different disciplines can add to the patient journey to ensure the most positive outcomes. However, access to supportive care resources and specialists can be inconsistent, leaving needs of patients unaddressed. Standardized psychosocial assessments with processes for linkage to early psychosocial intervention have been developed in hematological cancer populations (Antes et al., 2019; Pai et al., 2019; Rosati & Tarquini, 2015) and may offer a means by which to ensure equal access to resources that can improve quality of life. More broadly, in the context of hematological malignancies such as multiple myeloma, where a discrete “end-of-life” stage is often not apparent, a shift to integrated palliative care that ensures symptom control, psychological care and advanced care planning in conjunction with specialized medical management of the disease itself can reduce the physical and psychological distress of patients and families from the time of diagnosis (Zimmermann, 2016). To facilitate this, individuals diagnosed with multiple myeloma should be informed on the benefits of a supportive palliative care approach to enhance quality of life while continuing medical treatments, and various care teams should aim to collaborate on providing such care from the moment a patient is diagnosed, as opposed to anticipated final weeks or days of life.

Multiple myeloma is a complex illness and those affected may have very distinct experiences. For example, patients with “high-risk cytogenetics” often have a poorer prognosis (Sonneveld et al., 2016; van de Donk et al., 2021), requiring different information than those patients with low-risk disease. However, any life-limiting diagnosis can be devastating to patients and families, and it is vitally important that they receive information that is not only accurate, but is presented in a way that they can comprehend. Development of interventions to meet patients’ information needs throughout the cancer trajectory would be beneficial to reducing the experience of confusion and improving individuals’ ability to engage in treatment planning and decision-making. For example, the use of a multiple myeloma-specific survivorship care plan could be used throughout the cancer continuum as a tool to share information and facilitate dialogue regarding areas requiring clarification (Kurtin, 2017). Based on our study findings, such care plans should emphasize details of the individual’s diagnosis and treatment history, plan for monitoring and surveillance, as well as resources for symptom management. To ensure information is well understood, healthcare providers may consider assessing the availability of social supports and encouraging the presence of a support person when key information is shared, such as at the time of diagnosis. Moreover, as health literacy among individuals with multiple myeloma also increases self-efficacy in shared decision making (Nejati et al., 2019), screening for poor health literacy can help clinicians further tailor their approach to patient education and inform linkages to appropriate resources.

Our study has some limitations. Since interviews were conducted with each participant in a single point in time, our findings are limited to participants’ recollection of their experiences, and we were unable to evaluate fluctuations in their experiences over time. Additionally, all study interviews

were conducted by telephone where non-verbal gestures and expressions were not captured. Our findings reflect the experiences of a study sample that was English-speaking, mostly Caucasian, experiencing mild symptoms overall, and receiving care in a tertiary cancer centre with access to specialized psychosocial services. Thus, the transferability of our findings to other settings or circumstances in which patients may experience unique challenges to accessing supportive care (e.g., language barriers, high symptom severity, lack of specialized services), may be limited. Additional research is needed to understand the needs of individuals from diverse backgrounds, as well as those who are more highly symptomatic or receive care in less resource intensive clinical settings.

SUMMARY AND IMPLICATIONS FOR PRACTICE AND RESEARCH

Individuals with advanced multiple myeloma have specific needs related to information, symptom management, and psychosocial support that require attention from the time of diagnosis and throughout the continuum of care. Special attention ought to be paid to patients who lack family support and/or struggle with medical literacy, from diagnosis onward. Attention from the multidisciplinary team is necessary to ensure patients’ needs for information and support throughout the trajectory of their illness are met. This requires individual assessment at each clinical encounter to ensure that the care plan is optimized to meet the patient’s needs. Tools and guidelines for the assessment of psychosocial needs are available (Howell et al., 2012), which can help with the proactive identification of needs and timely access to appropriate supports. However, expanding access to appropriate and effective interventions to address any concerns identified through such assessment is also needed. This may include myeloma-specific patient education, self-management support, or supportive care services to address physical and psychological issues including symptom control, physical fitness, emotional health, and social well-being (Jeevanantham et al., 2020; Shapiro et al., 2021; Snowden et al., 2017). Specialized oncology nurses and nurse practitioners may be well positioned to lead innovations in this area.

DECLARATIONS

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Ethics Approval: *This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University Health Network (#19-6037)*

Consent to participate: *Written informed consent was obtained from all individual participants included in the study.*

Data Availability: *The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.*

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