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Living with multiple myeloma: A focus group study of unmet needs and preferences for survivorship care

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Living With Multiple Myeloma: A Focus Group Study of Unmet Needs and Preferences for Survivorship Care

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Abstract

Purpose: To describe the unmet informational, psychological, emotional, social, practical, and physical needs and preferences for posttreatment survivorship care of individuals living with multiple myeloma to inform the development of relevant, person-centered, survivorship services. **Methods:** An exploratory, descriptive study using 2 focus groups with 14 participants, 6 to 49 months postdiagnosis. **Results:** Thematic analysis revealed 7 key themes: information needs, experience with health-care professionals, coping with side effects, communicating with family and friends, dealing with emotions, support needs, and living with the chronicity of myeloma. Participants described key characteristics of survivorship care relevant to their needs and indicated they would like a more whole of person approach to follow-up when the main treatment phases had completed. **Conclusion:** Participants in this study described unmet needs across a breadth of domains that varied over time. The development of flexible, person-centered approaches to comprehensive survivorship care is needed to address the considerable quality-of-life issues experienced by people living with multiple myeloma. Nurse-led care may offer 1 viable model to deliver enhanced patient experience—providing the vital “link” that people described as missing from their survivorship care.

Keywords

multiple myeloma, survivorship, focus groups, unmet needs, support

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Introduction

Around 1700 people are diagnosed with multiple myeloma (myeloma) each year in Australia with approximately 840 people dying from the disease annually (1). Myeloma is a malignant incurable plasma cell disorder (2). Treatment depends on disease stage, general health and age, aiming to suppress disease and control symptoms through chemotherapy, radiotherapy, immunotherapy regimens, including autologous transplantation (3,4). Symptoms of myeloma include bone pain, fractures, renal disease, anemia, infection, and fatigue, all of which have considerable impact on lifestyle, role functioning, and quality of life (5,6).

In a qualitative study of 20 people living with myeloma 5 years after diagnosis (7), the considerable impact on emotional, social, role and work-related areas of life, and fears regarding uncertainty of the future was described (7). In a survey of 113 hematological cancer survivors, including myeloma patients in the first 12 months following initial treatment (8), managing fear of recurrence was the most frequently endorsed unmet need ($n = 42$, 73%). This was followed by the need for care coordination ($n = 22$, 33%) with two-thirds ($n = 39$, 59%) reporting the opportunity to discuss diagnosis and treatment experiences with a health-care professional would have been helpful (8).

We set out to explore the experiences of a cohort of patients living with myeloma. In accordance with the definition of a cancer survivor as articulated by the National Coalition for Cancer Survivorship (9), patients recruited to this study were cancer survivors living with, through, and beyond a diagnosis of myeloma. Despite the recognized profile of chronic, complex symptoms and treatment side effects experienced by people living with myeloma, little is known about their preferences for support and survivorship care. This project aimed to establish the unmet needs and preferences for survivorship support in a cohort of patients 6 to 49 months postdiagnosis of myeloma.

Methods

Design

A descriptive, exploratory study was chosen, as it allowed for in-depth investigation of experiences and survivorship care needs of participants, while maintaining a focus on study aims, through the use of semistructured focus group prompts (10,11). Thematic content analysis was chosen as the approach to focus group data, ensuring issues of importance to participants were revealed (12). The study was undertaken in accordance with the ethical standards of the Human Research Ethics Committees of Sir Charles Gardiner Hospital (Ref. 2012-135) and the University of Notre Dame Australia (Ref. 013030F).

Sample

The local Cancer Registry recorded 248 new cases of myeloma between July 1, 2009 and December 1, 2013 from the

study site. A manual search of patient hospital records determined the date of diagnosis and treatments received to ascertain study eligibility. The Death Registry was searched to avoid contacting families of deceased patients. Sixty-three eligible participants were sent a letter of invitation from the study site hematologist; a participant information and consent form and an opt-out form to be returned within 2 weeks. Six opt-out forms were returned, 5 without indicating a reason and 1 objection to recruitment. The research assistant telephoned remaining eligible participants ($n = 57$) 1 week later to further explain the study and provide focus group location and time details.

Inclusion Criteria

- Aged between 25 and 85 years.
- Fluent in English.
- No cognitive impairment (as indicated by medical record or during recruitment process).
- May be receiving oral chemotherapy considered as disease maintenance.

Exclusion Criteria

- Receiving care or follow-up at another hospital (where experiences could have potentially influenced interview data).
- Undergoing an autologous transplant (exposure to a group setting considered a potential health risk).

Focus Groups

Two 90-min focus groups were conducted at a large tertiary cancer center in Western Australia. All participants provided written informed consent prior to participation. Focus group questions were derived from a comprehensive literature review of key issues and concerns in this cohort and research team clinical experience (Table 1). They prompted participants to discuss informational, psychological, emotional, spiritual, social, practical, and physical needs, along with views about survivorship support and care.

Focus groups were facilitated by a hematology clinical psychologist experienced in facilitating focus groups with vulnerable populations, digitally recorded, and transcribed verbatim. Codes replaced participant names, and clinician identifiers were removed to ensure anonymity of responses prior to analysis. Electronic transcriptions were stored in a password-protected file on a secure server.

Data Analysis

NVivo 11 was used to manage data and undertake analysis. Transcripts were read and analyzed independently by C.B., T.M., and K.T. with content assigned to codes and themes generated from the data (12). These researchers discussed the coding and reached consensus on emerging themes. Rigor of the data analysis process was ensured by applying the criteria of credibility, auditability, and fittingness (13).

Table 1. Guiding Questions for Myeloma Focus Groups.

Theme	Questions
General introduction questions	<ul style="list-style-type: none"> • What have been your key “moments” since diagnosis and commencing treatment? • What have been the most important things you needed since you began living with myeloma? • What do you think could be put into place to support people who are living with myeloma? • What were your key concerns about finishing your first treatment phase?
Informational	<ul style="list-style-type: none"> • What have been your biggest informational needs? • How would you like to access this information? • What is the best way you could be supported now that you are living with myeloma? • What advice would you have for another patient who is living with myeloma?
Psychological	<ul style="list-style-type: none"> • What is most reassuring to you during treatment phases? • What was most distressing to you after treatment phases? • What things, if any, are you worried about now? • What things, if any, do you look forward to when you finish a particular treatment phase? • If you have experienced worry and fear about myeloma returning? • How did you need to manage this worry/fear?
Emotional/spiritual	<ul style="list-style-type: none"> • What have been your biggest emotional needs? <ul style="list-style-type: none"> – positive impact – negative impact • How did you feel at the end of each treatment phase? <ul style="list-style-type: none"> – relieved, scared, adrift? – did these feelings change over time? • How do you feel when you don’t need to see the hematologist as frequently? • Can you describe any spiritual issues or concerns since you began living with myeloma?
Social	<ul style="list-style-type: none"> • How has your life changed since you began living with myeloma? • Has your social life changed since you began living with myeloma? • How does/did your treatment affect your relationships with the people closest to you?
Practical	<ul style="list-style-type: none"> • What have been your biggest practical concerns? • How would you like your care to be handled after you complete a treatment phase? • How would you like your care to be communicated or coordinated when you complete a phase of treatment? • Have you made any plans to change your life? • Has anyone told you where to access help or support after treatment if you need it?
Physical	<ul style="list-style-type: none"> • What have been your biggest physical concerns? • Do you recall speaking to a member of the health team about the possible effects some treatments can have? • What did/do you need the most to help you with the physical side effects?
Perceptions on a survivorship model of care	<ul style="list-style-type: none"> • If you could design a model of care to best support myeloma patients, what would it look like? <ul style="list-style-type: none"> – who would be in the care team? – how would you access this care and how would they communicate with you? – what services would be provided? – how often would you like to contact/access this care model?

Independent coding and researcher checking to ensure categories accurately captured issues being discussed maintained credibility. Extensive use of examples from the data demonstrated fittingness. Auditability was maintained by documenting research planning through to analysis, and through a reflective process of discussion, and debrief with colleagues. The merging of individuals with and without hematology expertise added to the richness of interpreted data and provided a balance to the analytical process.

Results

Participants

Eighteen (31.5%) of 57 eligible individuals agreed to participate. Fourteen participants attended on the scheduled day (Figure 1). On average, 31 months (standard deviation [SD]:

13.8; range: 6-49 months) had elapsed since diagnosis. Thirteen participants had a partner and 5 indicated at least 1 child <20 years of age living at home. Participants in focus group 1 had received 1 line of treatment and an autologous transplant (n = 5). Seven participants in focus group 2 had received at least 2 lines of treatment. Five participants had received 1 autologous transplant, and 1 participant had received a second autologous transplant.

Age range and time since diagnosis were comparable with those who did participate. The majority of nonresponders preferred to not provide a reason (Figure 1).

Main Themes

The following 7 themes emerged and reflect data from both groups: information needs, experience with health-care

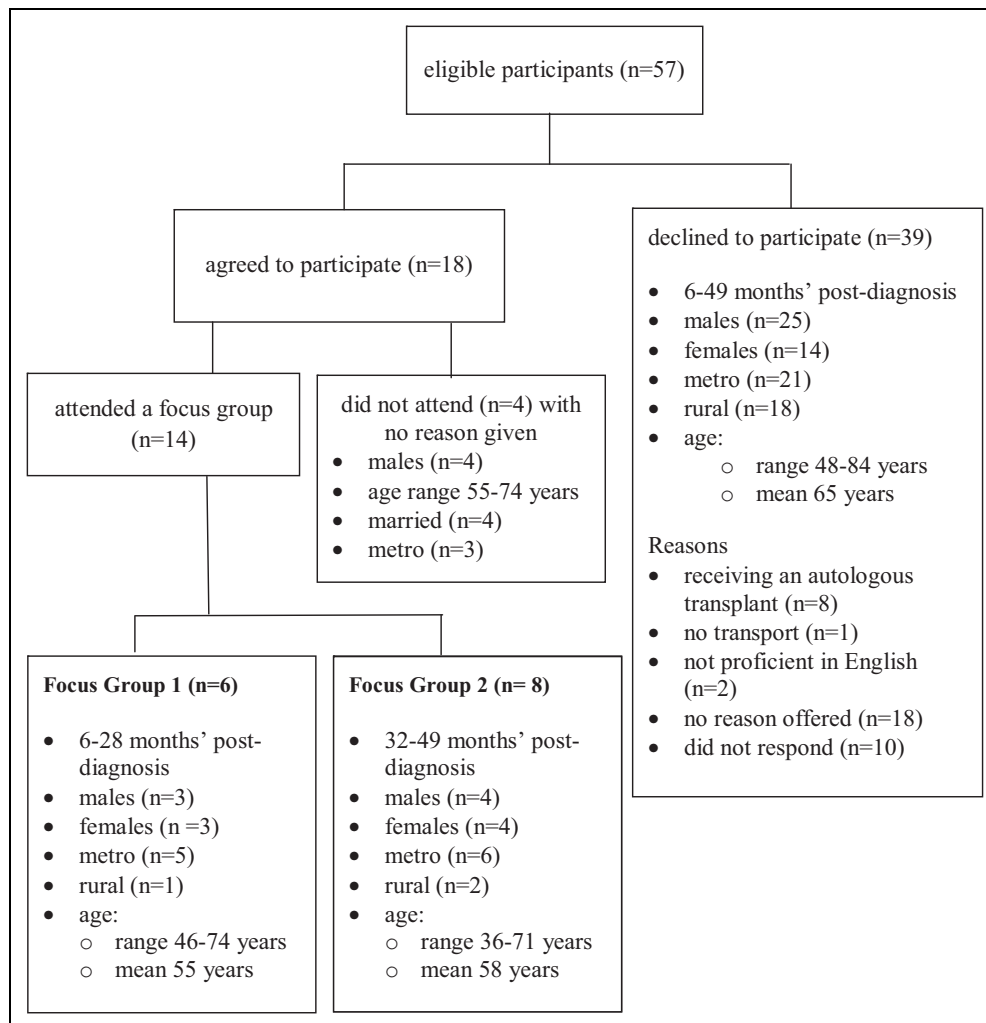


Figure 1. Recruitment and participant characteristics.

professionals, coping with side effects, communicating with family and friends, dealing with emotions, support needs, and living with the chronicity of myeloma.

Information Needs (Box 1)

Participants had differing views about the amount of information they had received at diagnosis and most had never heard of myeloma before. Some were overwhelmed and felt they couldn't absorb the information, others felt they were not given enough. All participants reported using the Internet. Many felt a list of reputable and reliable sites to search would have been helpful and may have made the diagnosis less confronting.

[I] typed in multiple myeloma and read something about 'it's not curable' and turned the computer off and went 'no!'. . . . the average person out there who goes online doesn't get the full medical details. . . . that's the information you want. (MM2-7)

Experiences with Health-Care Professionals (Box 1)

Participants suggest, in the main, their experiences of medical care were positive, but some said it was difficult to obtain "holistic support." Participants discussed ways to maximize the value of their consultation appointments. Some indicated they would have liked to review blood results prior to appointments, to process the information and determine the "right questions to ask," agreeing this would help reduce anxiety.

. . . but if you're told that [out of remission] at an appointment, you're just in shock, you're useless. So yes [before appointment] it does make a much better consultation. (MM2-2)

Participants spoke positively about general practitioners (GP) when cancer symptoms were recognized and communicated effectively. Negative experiences were described as those where a GP had not recognized symptoms of a serious illness resulting in a delayed diagnosis.

Box 1. Information Needs and Experiences of Health-Care Professionals.

Information needs	<p>“You get a package of books and stuff. There’s a limit to how much you can absorb I think, especially initially you know, you’re kind of reeling.” MMI -1</p> <p>“I think in a way, because [the consultant] didn’t say I never got around to asking some things that I would’ve [liked to].” MMI-4</p>
Experiences of health-care professionals	<p>“I think the nurses are quite knowledgeable . . . but a lot of them don’t have the time to sit with you, I mean while they’re in the room they’ll talk a little bit like that’s how the one nurse told me about the plastic knife and fork when I said everything tastes like metal.” MM2-7</p> <p>“I don’t know if the doctors realize how anxious we get waiting for these result . . . I just couldn’t wait, I was just a bit of a wreck, because you never know—it’s like waiting to find out if you’re sick again, so I got them to send the results to my house.” MM2-7</p> <p>“My GP actually picked mine up . . . and she’s very good, I was very fortunate to have that doctor.” MMI-4</p> <p>“My GP didn’t pick anything up! And I’d been having these symptoms for about a year and a half, I’ve had a broken rib and it don’t heal . . .” MMI-5</p>

Box 2. Coping With Side Effects.

Side effects	“I can’t just go out and kick a footy, do all those hard sorts of sports that I loved to do, but now I just can’t do those sorts of things, too much of a risk.” MM2-3
Others expectations	<p>“ . . . all of a sudden you look good, you look normal, you know. People look at me and think ‘you can’t possibly be sick.’” MMI-6</p> <p>“I feel tired a lot . . . My muscles have all gone. Whereas, I was working manually, I would spend a half hour doing office work in the day, then 10 hours of lifting and stuff . . . I’m trying to swim every day and walk and things and people say, “you’ve got a good life, going to the beach every day.” MMI -5</p>
Hair loss	<p>“I’m proud of it, you know, I’d always say “I’ll never be bald, I’ll never be bald” and, I’d no control over it. And waking up and seeing your pillow covered with hair just absolutely ruined my mind, and I was just really really impacted by that.” MMI -1</p> <p>“You are someone who has cancer, from that point [losing hair] onwards. I found it very confrontational.” MM2-2</p> <p>“ . . . I’m a hairdresser by trade, so for me to have no hair it’s like “I can’t possibly have no hair!” M1-2</p>
Peripheral neuropathy	<p>“I couldn’t even get toothpaste out of a tube, it affected my strength in my hands and feet. I was driving along 1 day, and I couldn’t feel the controls, the pedals, so, I’ve given up driving, which, again, is a very frustrating thing to do.” MMI-4</p> <p>“And with the feet problem, exercising is tough, because I get to the point where I don’t trust my feet anymore, you know . . . Even making a run to cross the road, the green man . . . you think “will I go? will I go? will my feet listen to what my brain’s telling them to do?” MMI -1</p>
Fatigue	“I think that’s the most frustrating thing, when you’ve had some sort of treatment, or when your whole system’s down, when you’re really weary and tired, and you can’t do . . . even simple chores are a real hassle. And you’re so frustrated that you can’t do . . . just the normal things.” MMI-4

Coping With Side Effects (Box 2)

Most participants struggled with treatment side effects, described as “the most difficult part of their experience.” Participants felt health professional support and guidance in preparing for, coping with, and managing side effects were inadequate.

I found one of the challenging things is understanding and dealing with the side effects. My issue is about coping . . . so I never

quite know if it’s an important side effect or not. I don’t want to waste the doctor’s time on unimportant things. (MM2 -1)

A number of side effects were mentioned; however, hair loss, peripheral neuropathy, and fatigue were most widely experienced and discussed. All participants described hair loss as difficult; besides the emotional impact to self-image and identity, it labeled them as having cancer. Peripheral neuropathy impacted day-to-day functioning and well-being. Fatigue was described as

Box 3. Communicating With Family and Friends and Dealing With Emotions.

Family support	“But it’s the after, once you look OK—don’t get me wrong, my family’s still there and they still know I’m sick . . . but people look at you and go ‘you look fantastic’ you know, and you do, you look good, you’ve got your hair back. So people don’t assume you’re sick, they don’t know your journey, and it’s a physical thing.” MM1-2
Children	“My grandchildren didn’t recognize me, they don’t think I’m the same person (laughs) . . . we were so close, you know they did everything with me and after I spent 5 weeks in hospital I’m like a stranger and I think like they’ve just got to get to know me again.” MM2-4 “You know, how many birthdays have I got left? How many things like teaching them how to drive? Basic things like that.” MM2-3
Hope and positivity	“So although you always want to have hope and you always try and find some bit of hope, there’s this massive expectation of people with cancer to be constantly positive.” MM2-5 “If I don’t find something positive out of it . . . it’ll come to an end much quicker than I want it to—even though there’s maybe an inevitable thing for us. So I try to live on ok, there’s a reality, but there’s a little bit of hope about having positivity about it.” MM2-8 “. . . you’ve really got to seize the moment all these other people are just dawdling through life and we’re able to actually focus more on making sure that it’s a good day, and we all have to go about that different ways of managing risks, accepting we’ve got limitations, but if you can keep that positive focus to try and make every day a really good day, then I think life’s brilliant.” MM2-1

excessive and long lasting; however, some found physical exercise beneficial.

Participants described a sense of loss, as the disease and treatment had changed their life. They discussed the difficulty of appearing “well on the outside,” while dealing with challenging side effects not physically obvious to others. In a sense, the cancer was viewed as “forgotten,” and there was an expectation to resume normal duties and roles. Support from loved ones wavered when participants began to improve and look better.

Communicating with Family and Friends (Box 3)

Families were supportive; however, at times the ways in which they tried to help was not useful or even wanted. There was a sense that family and friends were uncomfortable or unable to cope when the participant was “down” or wanted to talk about prognosis. One participant spoke of the difficulty in having to refuse advice perceived as helpful.

. . . and in the end with all the herbal things and stuff I just had to say, ‘I’ve chosen conventional treatment, I’m happy, it’s working for me, just leave me alone’ . . . you’re trying to manage yourself but also all those people around you so it’s really hard work. (MM2-2)

Participants described talking to their children about myeloma as a key difficulty and “stressful.” Regardless of children’s ages, participants wanted to talk honestly using age-appropriate language during conversations without frightening them.

It’s very hard, she was only 9 when I was diagnosed, so, to try and tell her what was going to happen to me, we have to sort of tread lightly, because she’s known cancer to be deadly . . . both

her grandparents [died] . . . to say those words that her mum had it, would’ve been just traumatic. I had to try and find ways to explain it to her, that I wasn’t going to end up in a coffin, you know? (MM1-2)

Dealing With Emotions (Box 3)

Many participants perceived stress was a contributing factor to their diagnosis and response to treatment.

. . . stress, I think that’s a massive part of my diagnosis, I was separated [at] diagnosis . . . I have noticed that when it’s stressful . . . that’s when my levels go up. (MM2-3)

Similarly, participants talked about their emotional response to diagnosis and how emotions fluctuated with disease status. There was the feeling they should be able to express the good and bad aspects without pressure to be continually positive. Coping strategies were discussed generally and specifically, especially those that helped maintain hope for the future such as better treatment options or having something to look forward to. Exercise, a positive frame of mind, and not “giving in” were identified as helpful strategies.

Food and exercise. Book a holiday. Always have something to look forward to. (MM2-3)

For many participants, there was a sense that living with myeloma had a positive impact on their well-being, forcing them to “live in the now” and “appreciate the moment.”

A reluctance to accept professional psychological support was described and a few felt by the time they had an appointment the need had passed. Participants who had accessed an

Box 4. Support Needs and Living With the Chronicity of the Disease.

Support needs	"It's not that you want to go and see a psychologist out in the suburbs cos maybe they've never dealt with somebody [with cancer] like that." MM2-7
Peer support	"You don't want to upset anybody and that's why I started going to the meetings . . . because you actually got to talk about it! With your family you don't sit like this and have a discussion. I mean initially I found it a bit sort of "oh my god" but then once you start talking it's like here, I mean everybody's in the same boat. I think it's a great opportunity for us to get our story out." MMI-2 "And you wanted empathy not sympathy . . . But you could only get empathy from someone who was exactly where you are." MMI-6 "Well maybe if there was a contact register . . . specific to people who did want to help, and you could be told 'this person is more than happy for you to contact them, you know, please do' or 'would you like us to get them to contact you?' Because sometimes . . . if X had've rung me, I would've been perfect with that, but I just couldn't do it myself." MMI-6 "I know of other people at other hospitals and I've said 'you done that?' and they're saying 'no, haven't done that, what's that all about?' and I'm thinking surely there's got to be a common path that we tread down, with slight branches off depending on individuals, but there's got to be a common path—is that right or not?" MM2-8
Link person	"One thing I have thought about that I would really have liked is one person that I had the phone number of that I knew that I could ring if my appointment was wrong, if I was feeling depressed and wanted to arrange counseling, just one person. That was mine in this hospital somewhere." MM2-2 "Yeah, just knowing that at any point you can ring up and you know, not get a message press this press that and get through to someone who couldn't help you anyway." MM2-3
Living with myeloma	"I don't think any of us really forget about it, there's not a day that goes by that I don't anyway!" MMI-2
Remission	"I feel fantastic. Everything's back to normal, apart from still having the disease, obviously. But I'm back at work, I'm back with the girls training for netball . . . So that is good, not being on anything." MMI-2

experienced cancer care psychologist at the hospital found it beneficial.

Support Needs (Box 4)

Gaps in service provision were identified during discussions, and participants made suggestions on what they would have found helpful. Participants described changing needs with regard to individual or group support at different stages in their cancer journey. They recognized individual differences existed in the types of support they may choose to access or want provided. Some found support groups useful to share experiences and gain informational, emotional, and social support. Others felt the group environment would be intimidating, or they would be unable to connect with others. Another issue was hearing about different treatment regimens, making them feel insecure about their treatment. However, for most there was a longing to be connected with others of a similar age and life stage.

I found it really hard to go to the clinic and have my treatment because I didn't want to be sitting next to people who were quite a bit older than me. I couldn't talk to them because I felt like I didn't have anything in common. Obviously I did, because I had the disease . . . MMI-2

The suggestion was made that a contact register in the hospital could be beneficial, where individuals could approach others who had myeloma to talk through their shared experiences. Although, participants felt those overwhelmed by negative experiences would be unhelpful to connect with.

Participants felt a health professional link/support person was required, who had expert knowledge, be able to offer information, advice, and provide reassurance. This person could also act as the contact between participants and the wider support team and help facilitate communication.

Living With the Chronicity of the Disease (Box 4)

Participants discussed the chronicity of myeloma, living with an incurable disease and inevitability of relapse.

Well, they say 'it's going to come back, it's not curable, it's treatable, but don't kid yourself because we can't cure you', so there's always this 'oh my gosh'. It's tough because you know you've got to go through it all again [treatment]. (MM1-6)

Many participants had experienced a relapse and spoke about dealing with recurrence. For some, the recurrence was as devastating as the initial diagnosis.

I'm not on drugs, I'm on a roll, and then you get symptomatic again and it was confirmed it was bad. It was devastating. (MM2-2)

Death and dying was not discussed in depth during the focus groups. Conversely, participants discussed periods of remission as a time when life returned to a sense of normality. This was expressed as comforting and liberating.

Discussion

Reports of the experiences of people living with myeloma and a description of their unmet needs are limited in published literature (14,15). Our study contributes to an understanding of the experiences of care and treatment for this group of people. Consistent with recent work (16,17), our findings indicate that support is required for people to adjust to living with an incurable disease has an unpredictable trajectory of remission, relapse, and refractory disease (18,19). This is an important area for future intervention. Most of the people in our study had never heard of myeloma before their own diagnosis, and as such, the need to ensure that patients and their support networks are well informed about the disease and what they can do to keep themselves well is an important consideration for enhancing survivorship experience (20,21).

Treatment side effects were described as one of the worst aspects of the experience, with many people reporting feeling unprepared to recognize or cope with them (20,22). Preparation and strategies for self-management of side effects were identified as a priority area where more intervention is required. Fatigue and peripheral neuropathy were reported as particularly challenging, as they impact negatively on daily functioning and the quality of life (16). These present important areas for future multidisciplinary, survivorship research. Developing effective, feasible resources that enable prompt, access to information about the disease, its treatments, and side effects is an important focus for survivorship innovation to minimize or ameliorate these unmet and highly burdensome needs. Survivorship research to minimize the physical and psychological impact of the complex symptoms and side effects of myeloma is urgently needed.

System issues highlighted as opportunities to improve posttreatment experiences included knowing blood results prior to an appointment, as a way of reducing anxiety and maximizing time for discussions at hospital appointments (16), and ensuring a focus on addressing emotional needs as well as medical issues.

Participants spoke about having to manage family's feelings and reactions while they tried to cope with their own. Development of survivorship services or resources targeted at family members/support networks may enhance posttreatment experiences for all affected by this disabling and complex disease.

Given the rarity and incurability of myeloma (23), some patients identified myeloma support groups as an important component of their survivorship care, providing information,

emotional support, and a venue for shared understanding of their experience. A health professional "link" person was consistently identified as an important component of supportive survivorship care.

Limitations

This study reflects the views of a specific cohort of myeloma patients who self-selected to participate in our qualitative, exploratory study. The intent was to offer deeper understanding of the experiences of an underresearched group of people about whom we know little about their experiences. Given the intent of the work, the small number of people who took part and the heterogeneity across participants does not present methodological limitations as they would in a quantitative study. The findings are offered as an opportunity to build further research informed by patients' experiences. We acknowledge that disclosure by the focus group facilitator of her role as a psychologist may have influenced the content participants chose to share and issues discussed, but the similarity of our data with that reported from other studies undertaken with this group of patients indicates that this did not influence the information shared.

Conclusion

Participants in this study described unmet needs across a breadth of domains that varied over time. The development of flexible, person-centered approaches to comprehensive survivorship care is needed to address the considerable quality-of-life issues experienced by people living with multiple myeloma. Nurse-led care may offer 1 viable model to deliver enhanced patient experiences—providing the vital "link" that people described as missing from their survivorship care.

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