

ORIGINAL ARTICLE

Living with relapsed myeloma: Symptoms and self-care strategies

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Aims and Objectives: To explore which symptoms relapsed myeloma patients experience and what self-care strategies are used.

Methods: This was a qualitative study utilising focus group interviews ($n = 4$) with relapsed myeloma patients ($n = 15$) and carers ($n = 9$). The focus groups were analysed and guided by thematic analysis.

Results: Three major themes with subthemes were identified following analysis of the interview data: “difficult symptoms; “self-care” and “feeling vulnerable.” These findings indicate the challenges relapsed myeloma patients experience with ongoing symptoms and highlight the importance of continuity of care.

Conclusions: Symptom management for myeloma patients remains complex due to the array of treatments given. These patients require holistic care and thorough regular assessments to help them cope with the adverse effects on their physical and psychological health. For patients with a long-term diagnosis of myeloma, self-management workshops and regular education sessions may be of benefit.

Relevance to clinical practice: This study highlights the key role of healthcare professionals in going beyond assessment of symptoms to offering advice and support to assist relapsed myeloma patients in managing their symptoms.

KEYWORDS

carers, focus groups, myeloma, patients, qualitative, relapsed, symptoms

1 | INTRODUCTION

Multiple Myeloma is a haematological malignancy which results in a disorderly overproduction of plasma cells (Palumbo et al., 2011). Patients can experience a multitude of symptoms. Symptoms initially associated with a myeloma diagnosis include bone pain, fatigue, hypercalcaemia and renal insufficiency. In addition, cytopenias result in anaemia, infection and the increased risk of bleeding (Coleman et al., 2011). Myeloma is chronic in nature, and the symptom burden associated with a diagnosis of myeloma can be profound due to the cumulative toxicities from multiple lines of treatment (Osborne et al., 2014).

Myeloma is considered incurable and relapsing/remitting in nature. This results in intermittent episodes of symptoms requiring treatment, which are followed by episodes when treatment may not be required (Myeloma UK 2015). Relapsed or refractory disease is defined as myeloma where there has been some response to treatment but has followed with relapse and then further disease progression while on salvage therapy or disease progression within 60 days of the last treatment (Richardson et al., 2007). Patients with a myeloma diagnosis are now living longer with the introduction of novel treatment agents; however, they must learn to adapt to the many challenges posed by this illness and treatment regimens (Stephens, McKenzie, & Jordens,

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2014). Therapeutic advances have seen the introduction of disease-modifying agents resulting in increased doses of chemotherapy and novel drugs such as proteasome inhibitors (bortezomib and carfilzomib) as well as immunomodulatory agents (thalidomide, lenalidomide and pomalidomide), used alone or in combination, which have significantly improved survival rates but have increased the long-term side effects for patients (Kiely, Cran, Finnerty, & O'Brien, 2017).

The emerging challenge in modern myeloma management is matching progress with quality of life (Kiely et al., 2017). Patients with relapsed/refractory myeloma have an increased symptom burden and reduced health-related quality of life in advanced disease. In addition, in comparison with those who are newly diagnosed, these patients tend to have an increased number of symptoms (Rizzo, Xu, Panjabi, & Iheanacho, 2014). Myeloma, unlike other malignancies, does not follow a continuous course of progression in which end of life is well defined. It is suggested that this is because of its less predictable course and the ongoing neoplastic treatment associated with haematological malignancies (Sexauer et al., 2014). Moreover, the nature of the disease is characterised by periods of relapse and periods of stability. There is always the potential for rapid decline leading to death due to disease/treatment-related complications with patients in advanced disease continuing to receive and respond to treatment (Ramsenthaler, Osborne et al., 2016; Osborne et al., 2014).

Various studies have recognised pain, fatigue and breathlessness as the most common symptoms reported by myeloma patients (Kiely et al., 2017; Osborne et al., 2014; Ramsenthaler, Kane et al., 2016). Moreover, treatment-emergent neurotoxicity, gastro-intestinal side effects, infections, thromboembolic events and cytopenias result in poor performance status. These side effects can result in delays in treatment delivery and subsequent early disease progression. Despite the increasing symptom burden, patients who discontinue treatment due to increasing treatment lines remain relatively low (Yong et al., 2016). This can be somewhat explained by reports of myeloma patients being "fighters" with a courageous yearning for life; however, this may present obstacles to discussing treatment suspension with patients (Cormican & Dowling, 2016). In addition, because haematological malignancies are treated for long periods of time, patients can hold unrealistic expectations which act as a barrier to their acceptance of transition to end-of-life care (Odejide, Salas Coronado, Watts, Wright, & Abel, 2014).

In conclusion, while myeloma is recognised as a very individual disease, patients report similar experiences regarding symptoms or adverse events (Kiely et al., 2017). There have been numerous studies reporting on measures of health-related quality of life in patients with relapsed or refractory myeloma. However, our understanding of relapsed and refractory patients' symptom experience is sparse and there is a dearth of qualitative data to describe these patients' symptom burden. This study therefore was undertaken to help address this void in the literature.

2 | METHODOLOGY

This descriptive qualitative study aimed to explore which symptoms relapsed myeloma patients were experiencing and what self-care

What does this paper contribute to the wider global clinical community?

- An understanding of relapsed myeloma patients' self-care measures to manage symptom burden from their disease and treatment.
- An insight into patients' experiences of their chronic symptom burden arising from peripheral neuropathy, fatigue and steroid-related side effects.
- Highlights that although patients' symptoms are assessed by healthcare professionals, advice and support regarding how to manage these symptoms are often not a feature of the patients' care experience.

strategies were being employed. This aim was to inform a longer-term aim of developing a self-management tool (app) for these patients.

2.1 | Ethical considerations

Ethical approval was granted by a Regional University ethics committee. Written consent was obtained prior each focus group. In addition, participants' names were not disclosed elsewhere and any information which could potentially identify a participant was removed from the interview transcripts. All participants were assigned pseudonyms to ensure anonymity.

2.2 | Inclusion/exclusion criteria

Inclusion criteria for the study were that all participants should have a diagnosis of relapsed or refractory myeloma, having had at least one treatment and failing same. Patients with newly diagnosed myeloma were not invited to participate.

2.3 | Recruitment and participants

A number of strategies were used to recruit the sample. An advertisement was placed in the clinical areas of four haematology centres nationwide; information about the study was circulated at local support group meetings nationally, haematology clinical nurse specialists informed patients of the study, and finally, a notice of the study was placed on the website of an Irish charity for myeloma patients.

Thirty-four patients attending four different haematology centres contacted the first author and expressed an interest to participate in the study. Most had made contact through the information they had received at support groups and through clinical nurse specialists. Some patients did not meet the inclusion criteria and others did not attend the focus group as planned as it clashed with personal commitments or they felt too ill on the day of the focus group to attend. Therefore, the final number of study participants was 24, which included both patients and carers. Carers were not invited to participate; however, nine patients were accompanied by a carer (spouse or child) to the focus group. These

patients requested that their relatives remain with them during the focus group for support and to help them articulate their views.

2.4 | Data collection

Four focus groups were held in hotels geographically spread around Ireland and within easy reach of public transport. Focus groups were the data method of choice as they are an efficient method of collecting large amounts of qualitative data. All four focus groups were facilitated by both authors who are experienced in focus group facilitation and the management of myeloma. One author facilitated the focus groups while the second author acted as moderator. An interview guide with five open questions was used (Appendix 1). Questions focused on participants' experiences of living with their symptoms, the toxicities and side effects they experienced and what self-management strategies were used.

2.5 | Data analysis

All interviews were audio-taped and transcribed verbatim. Interviews were on average 50–60 min in length. Data analysis was guided by thematic analysis as outlined by Braun and Clarke (2006). This method of analysis is useful for identifying, analysing and reporting themes within data, and guides researchers in undertaking six phases, that is, familiarisation with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and using vivid examples in the write-up to illustrate the themes. The approach allows for flexibility in searching for codes and themes because the six phases can be used interchangeably (Braun & Clarke, 2006).

Initial codes were generated by the first author, and from there common themes were identified within the data. Through the use of keywords, word repetitions and through comparing and contrasting data sets, codes were established from across all data sets.

Peer debriefing by the second author was completed and following discussion, agreement on the themes identified was reached. Peer debriefing involves the investigator convening with an individual or group of people to review the audit trail and emergent findings. The researcher then compares the outcomes from the individual's review with their own coding scheme. This approach enables the researcher to reflect on other competing interpretations of the data (DePoy & Gitlin, 2015).

It was also important to consider reflexivity. Reflexivity involves acknowledging the researcher's own assumptions and prior knowledge or opinions about the subject prior to studying it. It takes into account how the researcher's prior experiences, professional expertise and background may influence the data analysis and research process. Therefore, the first author maintained a reflexive journey throughout the data analysis process (DePoy & Gitlin, 2015).

3 | RESULTS

3.1 | Participants

Ten men and five women with relapsed/refractory myeloma participated in the focus groups. Nine carers also attended the focus

groups at the request of their relative. During the focus groups, these carers were often asked by their relative to articulate on their behalf how they were experiencing and managing symptoms. All participants were given pseudonyms to ensure anonymity (Table 1).

The most recently diagnosed patient was in 2014, and there were three patients who were diagnosed in 2002. Patients ranged in ages from 51–80 years of age (mean age 66 years of age). Nine participants were currently on treatment. Just over half of participants ($n = 8$) knew how many lines of treatment they had previously received. The average number of treatments received across all participants was three.

3.2 | Focus groups

Three main themes with subthemes were identified following analysis of the focus groups. The overarching theme identified was living with "difficult symptoms." Participants also described their "self-care" to manage these symptoms while also "feeling vulnerable". (Table 1).

3.3 | Difficult symptoms

3.3.1 | Peripheral neuropathy

The overarching major theme identified was how difficult the ongoing symptoms were for patients. Most experienced some degree of peripheral neuropathy (PN) and articulated their awareness of PN being associated with bortezomib, describing it as "pins and needles in the fingers and toes" or "numbness and a bit of burning." In addition, while PN was considered to significantly impact on sensitivity to touch and overall quality of life, many were hopeful that their experience of peripheral neuropathy would improve over time.

3.3.2 | Fatigue and steroid-induced effects

For all participants, fatigue was constantly experienced and while some accepted it as part of their treatment, others found it overwhelming. Steroid-induced symptoms were also an issue for most. Some patients described hyperactivity at night and hallucinations and reported completing excessive activity in the early hours of the morning. As well as the effect of steroids on appetite, patients also reported hiccups, facial swelling, insomnia and the "let-down" effect. Excessive diaphoresis (sweating) was another symptom experienced by some participants.

3.4 | Self-care

3.4.1 | Taking action

Discussions opened up between participants on different strategies that worked for them, and they expressed the view that this part of the focus group was beneficial to them and they felt they were not alone and "not the only one."

A number of self-care strategies to manage PN and fatigue were shared in the groups, such as the use of heat and topical cream (capsaicin cream), gel soles, acupuncture, reflexology and alternative therapies in local cancer centres. Self-care strategies for fatigue included planned rest times daily, distraction “*mind over matter*” and exercising, “*walking off the fatigue*.” Planning was also a strategy used by participants to cope with fatigue. For instance, one participant shared how he always brings a fold-up chair with him when he is out on his farm. Staying hydrated was also stressed to be of huge importance to participants, and it was emphasised as an essential part of self-care.

Other self-care initiatives used included keeping records of symptoms, paraprotein levels and bloods results at each clinic visit to monitor their myeloma. Cancer support centres were considered of benefit to some patients; however, the majority were unaware of the services they offered. Accessing other therapies was not uncommon when support networks within the hospital or the myeloma care team were not meeting patients’ needs. Complementary treatments mentioned included acupuncture, reflexology, bioenergy and reiki for ongoing symptoms such as peripheral neuropathy.

TABLE 1 Supporting quotes for study findings.

Main theme	Subthemes	
Difficult symptoms	Peripheral neuropathy	“...it’s like frost bite you know. I feel the cold and not that I would get frost bite but you get that feeling” (FG 1, Adam, patient)
		“...I got neuropathy in my feet. Which is quite severe at times, very painful...” (FG 2, Owen, patient)
		“It’s not bad enough that I’d have treatment for it but it certainly is there [PN]. I find that if I do an awful lot of walking or something during the day than it’s probably a little bit worse at night. But at the same time it’s more a discomfort than a pain.” (FG, 3, Frank, patient)
		“...it’s painful do you know. And it’s continuous.” (FG 1, Paul, patient)
Fatigue	Fatigue	“The tingling in the fourth and fifth finger and right and left hand...it’s irreversible because they told me the treatment confused it but it can’t be reversed...it means I can’t do the things I normally did properly” (FG4, Luke, patient)
		“...you’re in bed you know I find that for me anyway, if there’s something wrong and I know I’m on something that’s the cause of it. It helps. But if you’re on nothing and you’re feeling bad, it’s a bit of a worry.” (FG 1, George, patient)
		“But yeah the fatigue is, it’s unnatural really.” (FG 3, Maud, patient)
Steroid-induced effects	Steroid-induced effects	“The tiredness, you [referring to her husband] find it an awful lot too, not so much the walking because you don’t do really an awful lot of walking but standing around, we’re farmers and if someone comes into the yard at home to talk and you’re left standing, we now go around with a seat, a fold up chair over our shoulder if we’re going out because he can’t stand.” (FG 3, Eve (Carer: Wife))
		“it’s the most awful feeling, it really is, you know, you want to eat and you’re wanting and you’re not enjoying it, but at the same time you want it.” (FG, 3, Maud, patient)
		“the appetite increased and they blew me up as well.” (FG 2, Mathew, patient)
		“You’re on the roof one minute and you’re on the floor the next. Desperate.” (FG 1, Adam, patient)
		“Three o’clock in the morning I was up. I was cycling the road at six o’clock in the morning like it was crazy stuff. But I just couldn’t sleep.” (FG, 1, Paul, patient)
Self-care	Taking action	“...initially it is like a bomb when you come off them [steroids]. But after a few days and you’ll level out again. You know I think that’s worse with them, you know and they give you a lift. But now sometimes they do more than you want.” (FG1, George, patient)
		“...Don’t take the twenty [steroids] together... It isn’t as big as a belt...drink lots of water, she [consultant] keeps telling us you know two litres of water a day. So she’s talking about the kidneys.” (FG 1, Adam, patient)
		“And bio energy and you get counselling. You get several different things there and it’s free.” (FG 2, Owen, patient)
		“... It was explained to me that if [referring to temperature] it gets above a certain point, you come to the hospital. That’s, or you ring the hospital I mean, get up there.” (FG 1, Paul, patient)
		“...you know you’ve got to, what’s put in front of you, you’ve got to try and deal with it. You know or do you sit down and call on yourself worry about yourself. ‘Cos worry does do nothing. Absolutely nothing, you know... And your life it does change for sure. You know you’re not the same as you were before you got sick that’s for sure. But it’s something like you know, get on with it.” (FG1, George, patient)
Risky behaviour	Risky behaviour	“...paracetamol too kind of diffuses the temperature too... I’d probably leave you know, probably leave things on the long finger anyway you know. If the temperature starts going up...” (FG 1, Adam, patient)
		“I didn’t know how bad I was until I came in [to hospital].” (FG 1, George, patient)

(Continues)

TABLE 1 (Continued)

Main theme	Subthemes	
Feeling vulnerable	Conflicting information	<p>"I went to my own GP and told her [what drugs she was taking] and she was looking at the books and this and that." (Patient speaking about taking a new medication) (FG 2, Owen, patient)</p> <p>"That sometimes the information that you're given in one place, is completely different to the other. And if you haven't, if you didn't have anybody with you to ask questions. Because sometimes I found that you were focusing on different things... we had to poke around and look and gather information." (FG 2, Maria (carer: daughter))</p> <p>"...and there can be discrepancies do you know. Like you said, not getting straight answers. And I find that really disheartening as somebody watching it happen, do you know... There's, sometimes I feel a lack of empathy, sometimes" (FG 2, Ruth (carer: daughter))</p> <p>"Maybe they do and they're taking notes and they're processing it. And with their professional minds and all the information that they have stored. Yea that's okay, that's fine. But that needs to be relayed back to the patient, or maybe a family member, or somebody else. That can take that information and say, look this is okay, it's going to pass. If it's the cramp, it'll pass, I'm only saying, I'm taking that as an example." (Carer speaking about doctors) (FG 2, Finnuala (carer: daughter))</p>
	Need continuity	<p>"I don't think that, they [doctors] don't want to know about side effects much. That they never, they asked me once or twice about my feet like. But they offered me nothing." (FG 2, Owen, patient)</p> <p>"I don't think I've ever mentioned it [peripheral neuropathy] inside [clinic] actually, I don't know for what reason, I suppose it's because we meet different doctors every so often or whatever." (FG 3, Tom, patient)</p> <p>"And you go see the doctor and you may be seeing the six months man [doctor on rotation] you may as well be seeing your Granny and she's dead this 50 years..." (FG4, Rory, patient)</p>

3.4.2 | Risky behaviour

Some risky behaviour was also evident in self-care strategies. A few participants spoke about utilising paracetamol while simultaneously being aware that paracetamol was contraindicated as an appropriate management strategy for this group of patients. However, despite this knowledge, some continued to take it and often had deteriorated considerably by the time they were admitted to hospital.

3.5 | Feeling vulnerable

3.5.1 | Conflicting information

Information provision was of utmost importance to these patients. Support networks such as the GP, clinical trial team, clinical nurse specialists and advanced nurse practitioners were mentioned as crucial to information provision regarding symptoms and side effects. The GP was mentioned as the first port of call by some. However, others expressed the view that GPs did not have sufficient knowledge about their rare condition to treat them efficiently.

The majority were informed and knowledgeable about their condition; however at times, they were overloaded with information and as a result this caused some confusion about medications and symptoms. In addition, carers, in particular, reported discrepancies in the information their relative received from different healthcare professionals. As a result, patients and carers often felt they had to complete their own research into their care.

3.5.2 | Need continuity

Continuity of care was paramount to these participants. The long-term provision of their care over years resulted in close relationships

and reliance on their consultant doctor. However, participants often felt they have to push for interventions or seek alternatives due to a lack of continuity in their care and insufficient acknowledgement for the chronic problems they experienced. Participants also stressed their need to be given adequate time at their review visits to ask questions of the consultant and seek further information. A lack of continuity of care was expressed by a number of participants, and this placed them in a vulnerable position where they believed it was pointless in mentioning their ongoing symptoms to a doctor on rotation or a locum doctor. Moreover, many relayed an acceptance of fatigue and PN as a "normal" part of treatment, so more often than not did not mention symptoms at their review clinic visits.

Participants also highlighted that documentation (on symptoms and treatments) was routinely completed by medical teams however more often than not; it was the same problems documented. It was felt that the information was collected and stored with little action taken in regard to the management of the actual problem. Participants felt isolated in their disease and at times felt an absence of acknowledgement to how they were feeling. In the case that it was an ongoing symptom which little could be done about, they just wanted reassurance that it was "normal." However, patients and carers also identified that the healthcare system as a whole was under enormous pressure and that healthcare professionals were overworked.

4 | DISCUSSION

4.1 | Peripheral neuropathy

Patients in this study considered peripheral neuropathy (PN) an expected side effect. However, they often felt frustrated because although it was a symptom that was commonly asked at clinic visits,

often very little was done about it. Peripheral neuropathy was a constant reminder of a life on treatment, and its debilitating effects resulted in participants pursuing complementary therapies and methods in their attempts to cope with the pain and nerve damage. Difficult symptoms such as PN can result in significant disability and pain (Colson, 2015). It is crucial that there is frequent assessment of neuropathic symptoms and the early detection of neuropathic pain before it gets progressively worse (Colson, 2015; Schlafer, Shah, Panjic, & Lonial, 2017).

4.2 | Fatigue

Participants also reported fatigue to be very burdensome. It is estimated that up to 63% of myeloma patients experience fatigue (Kiely et al., 2017). It most often represents both the physical and psychological burden of the disease. Participants were enthusiastic to share their self-care strategies including resting times, distraction techniques "mind over matter" and exercising or "walking off the fatigue." However, they often did not share their experience of fatigue at review clinic visits because they felt little could be done about it and it was something to be accepted. In practice, management of contributing factors to fatigue such as anaemia and depression may improve overall quality of life. In addition, patients who participate in exercise programmes of low-to-moderate intensity may benefit in reductions in fatigue (Heinrich et al., 2016).

4.3 | Steroid-induced effects

Participants were well aware of the connection between steroids and their effects; however, it left them feeling out of control at times especially regarding an increased appetite and excessive hyperactivity at night. Healthcare professionals need to acknowledge the impact of these side effects on myeloma patients. The National Cancer Institute recommends utilising the CTCAE (Common Terminology Criteria for Adverse Events) for steroid-related adverse events in practice. This helps as a guide for healthcare practitioners in determining the need and type of intervention for these patients as well as enabling consistency in the evaluation of the impact of steroids. Often there is an assumption that patients will ask about steroid-induced side effects if they need to, so HC professionals may not question about these effects as a result. In addition, because steroids assist in obtaining disease response, patients will often appear to cope well with side effects (McGrath, Patton, & James, 2009).

4.4 | Self-care: Taking action

Patients' and carers' frustration in relation to unmet symptom burden was evident in our findings. In addition to this, self-care was reported as an important aspect of the myeloma patient's journey especially when supportive care needs were felt to be unmet. Assuming autonomy over self-care appears to be an integral

aspect of the relapsed myeloma patients' journey; however, it is important to note that each new relapse brings with it an amount of debilitation and diminished morale (Stephens et al., 2014). As highlighted in our study, an increased demand on self-care extends across diagnosis, treatment and end-of-life care. Self-Management involves managing the medical characteristics of the illness, managing life roles, including changes in functions brought on by disease and managing the psychological burden of a chronic illness. However to do this, core skills are needed including problem-solving, decision-making, resource utilisation, forming health-care partnerships and taking action (McCorkle et al., 2011). Effective supportive management is crucial to both patient and carer outcomes, and previous literature suggests that myeloma patients in comparison with other haematological malignancies have the highest levels of symptoms (Colson, 2015; Johnsen, Tholstrup, Petersen, Pedersen, & Groenvold, 2009; Molassiotis, Wilson, Blair, Howe, & Cavet, 2011a). Participants in this study were taking on a pivotal role in their self-care in the absence of an organised collaboration with healthcare professionals. However, an ideal holistic plan of care which encourages patients to self-manage is often difficult to implement due to patients experiencing a very individual journey (Cormican & Dowling, 2016).

4.5 | Self-care: Risky behaviour

The study participants appeared to be well informed regarding their risk of infection. Sepsis, infection and their associated complications are the leading cause of death in patients with multiple myeloma, and many of the treatments for multiple myeloma result in immunosuppression. However, some often engaged in self-medicating a high temperature at home against medical advice and did not seem aware of the rationale behind the reasons why healthcare professionals advise against this. Low-grade pyrexia with neutropenic sepsis was frequently mentioned in the focus groups, and in addition, participants revealed that often they were unaware of how unwell they were until they were admitted to hospital. There is often an emphasis on high-grade pyrexia in practice, and perhaps, this suggests that less attention on infection and sepsis associated with low-grade pyrexia is placed in patient education.

A strong emphasis for adequate patient education is recommended especially when it is known that patients are engaging in self-care contraindicated in their care which may have implications for future practice (Colson, 2015). Nurses can provide myeloma patients with "take-home" tools that reinforce the importance of rapid care when pyrexia or infection arises. Interventions to improving the rapid response to this adverse event include using chemotherapy neutropenic fever alert magnets and wallet cards. These incorporate methods to follow for symptomatic patients presenting at emergency departments including prompt triage, standard neutropenic fever admission orders and adding a rule-out-sepsis track for those presenting with neutropenic fever to the ED triage sheet (Hawley, Loney, & Wiece, 2011).

4.6 | Feeling vulnerable

In contrast to patients feeling empowered to manage their condition, a sense of vulnerability is evident in their comments. The findings suggest that information provision remains a primary concern for patients and their carers, but discrepancies between different healthcare professionals are a feature of their experience. Furthermore, carers in the focus groups particularly emphasised the issues relating to inaccuracies received from healthcare professionals as well as inadequate follow-up. This highlights the perceived needs of the carer being based around the patient's own needs. Similar findings were reported in a cross-sectional survey of myeloma patients and their partners in the UK suggesting that carers may be neglecting their own self-care to meet the needs of the patient (Molassiotis, Wilson, Blair, Howe, & Cavet, 2011b). Participants in this study also highlighted the central role of their consultant physician to their care. The role of the physician in prioritising quality of life, and supportive care for myeloma patients has also been highlighted elsewhere (Cömert, Güneş, Şahin, & Saydam, 2013). It appears that this reliance on healthcare professionals opens patients to more vulnerability but also the need for a "support team" as recently suggested by Hulin et al. (2017).

4.7 | Need continuity

Myeloma was once considered life-limiting but is now one where patients live for many years on an unpredictable journey with ever-increasing treatment options. Myeloma patients are seen as champions in their fight against their disease and often, as evident in this study, learn to adapt to their disease by their attempts to live with a new "normal." They are also acknowledged by healthcare professionals as well informed and educated about their illness (Cormican & Dowling, 2016).

Participants in this study were determined to stay as well as possible. Web-based resources and complementary therapies were often accessed when patients felt that their concerns were not being listened to. However, educational and support tools/resources targeted at healthcare professionals and patients are needed to facilitate communication and to help patients and carers journey through the burden of living with an incurable disease (Hulin et al., 2017).

The majority of care for the myeloma patient is undertaken in an outpatient setting where they must learn to self-manage their disease (Kurtin, Lilleby, & Spong, 2013). However, although symptoms and adverse events were often acknowledged on clinic visits, participants felt that at times, there was a lack of intervention, continuity of care and empathy. Myeloma is an uncertain illness, and therefore, patients need to be provided with adequate time on clinic reviews to explore their symptoms and appropriate management strategies. There was a sense of resignation among the study participants that some of their symptoms could not be well managed, and as a result, they did not continue to mention them at medical consultations. It is therefore imperative that long-term

issues are attended to in a more proactive manner at review visits. Patients tend to adjust to their diagnosis over time when compared to their initial experiences from treatments such as stem cell transplants (Molassiotis et al., 2011a) and want to get on with their lives (Molassiotis et al., 2011b).

Improved survival means that healthcare teams must consider effective supportive care and health maintenance to ensure that patients have a maximum quality of life. The treatment goal for myeloma is to prolong survival and improve quality of life; however, quantity of life is commonly given higher priority than quality of life (Colson, 2015; McGrath, 2002). Tools such as the adverse event checklist for monitoring patients with multiple myeloma developed by Colson (2015) can be used to structure assessment at review visits. Such a checklist could be incorporated with the data collected in this study to guide the development of a symptom management app for smartphone devices. As myeloma is now being considered a chronic illness, self-management is a crucial element to the patient's illness experience and health technology presents an opportunity to improve continuity in symptom management monitoring and intervention.

5 | LIMITATIONS

This study has a number of limitations. The participants were self-selecting and may have been better able to manage their symptoms than those who chose not to participate. A number of patients who had planned to participate were too unwell on the day of the focus group to attend which may suggest that those who declined to attend might have had more acute symptoms and concerns than those who participated.

The inclusion of carers may have impacted on the interaction within the groups, and it may be possible that more information from the patients regarding their experience and concerns could have been gleaned had carers not been present. The presence of others in a group might limit the interaction of others participating (Acocella, 2012). However, it must be acknowledged that the presence of carers highlighted their role in helping patients manage their disease. Furthermore, the focus groups were beneficial in this setting as the group interaction enabled ideas or thoughts to be provoked in others; however, focus groups can also make people feel uncomfortable discussing sensitive issues.

6 | CONCLUSION

This study identifies the need for a more structured approach to managing symptoms and adverse events among relapsed myeloma patients. The implementation of such a system in practice would prioritise crucial patient information and ongoing assessment of each patient's experience. If myeloma is to be viewed as a chronic disease, it is essential that patients feel empowered in their efforts to manage their symptoms.

Moreover, future research needs to explore the influence of health technology as an opportunity to improve symptom management monitoring and intervention for relapsed myeloma patients.

7 | RELEVANCE TO CLINICAL PRACTICE

Myeloma patients are living longer, but they also must self-manage a range of unpleasant and challenging ongoing symptoms. Regular assessment of symptoms by healthcare professionals is essential, but also important is the need to explore patients' self-care strategies and provide feedback on these strategies. Self-management workshops and regular group education sessions facilitated by specialist haematology nurses may benefit these patients in empowering them as they negotiate their symptom journey.

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CONTRIBUTIONS

Study design OC, MD; data collection and analysis OC, MD; and manuscript preparation OC, MD.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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APPENDIX 1

FOCUS GROUP QUESTIONS

1. In relation to symptoms, could you tell me about any long-term symptoms you are currently experiencing?
2. Could you describe how you manage your symptoms?
3. What impact do your symptoms have on your daily lives?
4. What do you find is helpful from healthcare professionals in providing advice or support in how best to manage the symptoms you have described?
5. Is there anything else you would like to say about living with your symptoms?