

Patients' experiences of living with multiple myeloma

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Multiple myeloma is a malignant proliferation of plasma cells. Its clinical manifestations include bone pain due to lytic lesions (soft spots in the bones that can increase the risks of painful fractures), anaemia, renal insufficiency, hypercalcaemia, immunodeficiency and increased susceptibility to infection (Colson, 2015). Each year about 5700 cases are diagnosed in the UK (Cancer Research UK, 2020), 32 000 cases in the USA (American Cancer Society, 2018), and 352 in the Republic of Ireland (National Cancer Registry Ireland (NCRI), 2018). It is a relapsing–remitting cancer resulting in periods during which symptoms need to be treated, followed by intervals during which treatment is not necessary (Rajkumar and Kumar, 2016; Multiple Myeloma Ireland, 2017).

There are several treatment options for patients diagnosed with multiple myeloma. In most cases, these can induce long intervals without any symptoms of the disease, allowing patients to have a reasonable quality of life. Consequently, multiple myeloma can be considered to be a chronic condition, where the aim of treatment is not to cure the disease but to control its symptoms (Anticancer Fund and the European Society for Medical Oncology, 2017). Survivorship has become a reality for some patients, with the overall survival at 5 years reaching more than 53% (National Cancer Registry Ireland, 2018).

However, there are particularly onerous toxicities related to the novel therapies used to treat multiple myeloma (Sonneveld et al, 2013; Stephens et al, 2014; Dowling et al, 2016; Moreau et al, 2017; Cancer.net, 2019). Late effects (such as peripheral neuropathy, weight gain, heart failure, psychosocial issues, pain, secondary malignancies, fatigue) are increasingly relevant to patients with multiple myeloma because they are now living more than a decade following diagnosis and have repeated lines of complex therapies throughout the course of the disease (Snowden et al, 2017).

The overall goals in managing multiple myeloma are to prolong survival, control disease progression, and enhance quality of life (Kelly et al, 2010). However, knowledge and understanding of the individual's perspective and experiences of living with the condition, along with the burden of treatment, play a central role in providing effective, patient-centred care (Kelly and Dowling, 2011; Maher and DeVries, 2011; Cormican and Dowling, 2016). The purpose of the current study was to explore individuals' experiences of living with multiple myeloma for more than 1 year.

ABSTRACT

Background: Multiple myeloma is a B-cell haematological malignancy characterised by uncontrolled plasma cell proliferation. Patients with the disease often undergo periods of remission followed by multiple relapses. Understanding patients' experience of living with this chronic condition is key to providing effective patient-centred care. **Aims:** This qualitative descriptive study explored the experiences of patients living with multiple myeloma. **Methods:** A purposive sample of 6 patients was used. Data were collected using in-depth unstructured interviews and analysed using Colaizzi's (1978) thematic framework. **Findings:** The emergent themes included: information and communication; treatment and symptom burden; the importance of support from family/friends and professional help; psychosocial elements of survivorship. **Conclusion:** The complex symptoms of multiple myeloma need to be treated holistically to manage the unpredictable nature of this disease.

Key words: Multiple myeloma ■ Patient experience ■ Oncology nursing ■ Haematological malignancy

Methods

To achieve the aim of the study a qualitative exploratory design was used; this was because it permitted an insight into the experiences of people from their perspectives. The study was completed in an urban acute teaching hospital setting in the Republic of Ireland.

Ethical approval was granted by the research ethics committee of the academic institution and the hospital that was the site of the study.

The inclusion criteria were:

- Patients who had had a diagnosis of multiple myeloma for more than 1 year to highlight their lived experience and ensure they had all experienced a period of adjustment to their diagnosis
- They were aged over 18 years

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Table 1. Profile of group

| Age | Time from diagnosis/stage |
|---|-----------------------------------|
| Median | 67.5 years |
| Range | 63–73 years |
| Gender | |
| Female | 4 |
| Male | 2 |
| Relationship status | |
| Married | 3 |
| Single/divorced/widowed | 3 |
| Working status | |
| Retired | 5 |
| Employed | 1 |
| Length of diagnosis/stage of multiple myeloma | |
| Participant 1 | 2 years/in remission |
| Participant 2 | 4 years/relapsed multiple myeloma |
| Participant 3 | 4 years/relapsed multiple myeloma |
| Participant 4 | 6 years/relapsed multiple myeloma |
| Participant 5 | 5 years/in remission |
| Participant 6 | 6 years/relapsed multiple myeloma |

- They were English speakers
- Patients who were previously unknown to the researcher
The exclusion criteria were:
- Patients who had had a diagnosis of multiple myeloma for less than 1 year.

Purposive sampling was used (Streuber and Carpenter, 2011) because it was considered appropriate, given the specificity of the target group. The sample group, while small ($n=6$), was considered appropriate to permit the exploration and understanding of the phenomenon under study. It also became apparent that data saturation was reached, with all participants identifying similar issues. Unstructured interviews were used to obtain an accurate insight into the perspectives and experiences of each participant. Data were analysed using a descriptive framework devised by Colaizzi (1978). Representative quotes using pseudonyms were included to illustrate the main findings.

Results

A total of 6 haematology patients were included in the study. A summary profile of the group is presented in *Table 1* and this includes an overview of each participant’s length of diagnosis/stage of multiple myeloma.

Four themes emerged:

- Information and communication

- Treatment and symptom burden
- The importance of support from family/friends and professional help
- Psychosocial elements of survivorship.

Theme one: information and communication

None of the participants had had been aware of multiple myeloma before their diagnosis, and most felt confused when they were initially informed. This contributed to patients’ distress at diagnosis, feelings that were compounded by the relative intangibility of myeloma compared with solid tumours such as breast cancer.

‘I hadn’t heard of it. I suppose at the start I wasn’t even as aware as I am now of the seriousness in a way, the potential seriousness.’

Michael

‘Never in my whole lifetime did I ever hear of multiple myeloma.’

Anne

All participants described the lengthy process in getting a diagnosis (ie up to a year) and how such delays had contributed to their distress. Indeed, multiple myeloma is often diagnosed as a consequence of investigations for an unrelated health concern, as is highlighted in the quotes below. Other factors, such as health professionals’ lack of knowledge of multiple myeloma, patients’ comorbidities or the complexity of multiple myeloma itself, were also observed to play a role in such delays.

‘My doctor thought it was my heart as I was so breathless and tired, and sent me for loads of tests, but they couldn’t find what was wrong with me. I eventually broke a bone in my back and was diagnosed this way.’

Breda

‘It took a while to diagnose. I had back pain that wouldn’t go away, my doctor thought it was from sitting at the computer, then said it was osteoporosis. It got so bad I thought I was going to die in the middle of the night with the pain. They eventually did an X-ray and I got diagnosed with multiple myeloma.’

Mary

Another patient had felt unwell for months, but her rheumatoid arthritis was masking the fact that she had developed myeloma.

‘I was being treated for arthritis and had extreme tiredness for months and months. My bloods showed up that my organs were being damaged, and they kept asking me if I was drinking alcohol, although I don’t really drink. I think I had it for a long time before it was diagnosed.’

Nora

All participants highlighted the lack of time and lack of opportunities to talk with health professionals and the difficulties surrounding communication issues. One participant disclosed how access to information or someone to talk to was difficult at times. He suggested the need for health professionals to be trained in both communication skills and the specific disease specialty, because he did not always receive the helpful information he required about his health concerns.

‘They are very efficient and pleasant, but there is poor communication at times. It’s hard to get help over the phone and my calls were not returned when I rang up to 4 times. Sometimes it’s difficult to get answers when I ask about exercise or relationship issues. Maybe people need to be trained in the communication process and the specialty as sometimes they just don’t know.’

Patrick

‘Nurses just don’t have the time to talk, everyone is very busy. They try to make time, but you can see you’re holding them up, it’s not their fault, they are so understaffed ... but would be nice if people had more time. I feel they are under pressure.’

Mary

One participant who was being treated in Asia revealed her helplessness at not being involved in any of her treatment decisions, despite attempting to communicate her wishes with the medical team.

‘When I was abroad getting treated I tried to communicate how I wanted to have an input into my treatment plan. They just nodded and carried on regardless with what they wanted to do and didn’t discuss it with me.’

Mary

This participant emphasised the importance of being cognisant of how information is relayed to patients. It was highlighted that when this is done carelessly it could cause patients needless emotional upset.

‘How information is given is vital. It’s easy to read into things and overanalyse what they have said, something is said carelessly and causes anxiety. I suppose that comes with experience. They need to take care how they divulge information and be alert to the sensitivity of the person as they could take stuff up wrong.’

Michael

‘It’s all very mechanical at times ... I suppose it has to be, to run efficiently ... they don’t really have time to talk about the other stuff.’

Michael

Box 1. What is involved in an autologous stem cell transplant

The procedure involves the removal of the patient’s own stem cells from their peripheral blood; these are then stored until needed (reinfusion usually takes place within 4–6 weeks of stem collection). Prior to reinfusion of the harvested cells the patient receives high-dose chemotherapy to kill any remaining cancer cells

An apheresis machine is used to separate the stem cells or lymphocytes from the other blood parts, which are drawn off and collected into a bag. The process uses one vein to draw blood into the machine, where the cells are separated out, and a second vein to return the rest of the blood to the patient

If veins cannot be used for some reason, the patient has a central catheter inserted, most often in the neck or groin. An anticoagulant drug is administered during the collection, which may cause tingling in the fingers, toes and lips. Some people will also have body chills

The procedure usually takes about 4 hours to complete

Theme two: treatment and symptom burden

Most participants received an autologous stem-cell transplant as part of their treatment for multiple myeloma (see *Box 1*). Participants who had undergone the procedure placed great emphasis on the way in which the ensuing severe side-effects impacted on their life. Fatigue, diarrhoea and vomiting were identified as the worst side-effects they experienced.

‘The transplant [procedure] was horrific, getting the stem cells off [removal of stem cells] was barbaric. It took hours and I couldn’t move while they were taking them off ... My life stood still ... It nearly killed me, nearly shoved me over the edge ... My insides were in bits—they say it affects you from your mouth to your bum, and it’s true ... I don’t think I’d do it again, think I’d be on a plane to Zurich ... However, it worked and I’m in remission now.’

Nora

‘The transplant was awful, I had horrific vomiting and diarrhoea and absolutely no energy. I had to get the nurses to help me shower and I felt awful for them. I had no life, was like a prisoner for 5 months.’

Anne

Triplet regimes containing an immunomodulatory drug (lenalidomide/thalidomide), a proteasome inhibitor (bortezomib) and high-dose steroids are known to give the best response in initial therapy (Dowling et al, 2016). Unfortunately, steroid toxicity, peripheral neuropathy and diarrhoea were all identified by participants as particularly burdensome side-effects of their treatments.

Steroids are an integral part of the treatment regimen for multiple myeloma.

'I'm anxious a bit to go on this medication. The thing is I've to go on steroids with it for a while, he said. I hate steroids. I can't sleep with them and I get very jittery.'

Anne

'My emotions broke down when I started the steroids, I had to see the psych oncology team because I just couldn't cope.'

Patrick

Peripheral neuropathy is the damage or degeneration of peripheral nerves involving sensory, motor or autonomic fibres (Morawska et al, 2015). Peripheral neuropathy is recognised as a common side-effect of treatment and can be a major source of concern for patients living with multiple myeloma. Two participants divulged that they still suffered from peripheral neuropathy despite not having been on any neurotoxic medication for a few years.

'The peripheral neuropathy is bad to my feet. I got a really bad reaction to the Velcade (bortezomib). My bowel stopped working, couldn't eat solid food for a few months.'

Mary

Diarrhoea is one of the most common and inadequately managed symptoms that patients with myeloma experience due to novel therapies. The following participant describes how it affects her daily life.

'I have to think of the nearby facilities before I go out. You know, the diarrhoea from the medications can catch you out sometimes, it just comes on so quick.'

Breda

While most participants did not experience any symptoms of pain at the time of the interview, two participants indicated that their lives were restricted due to back pain from lytic lesions.

'I can't mind my grandchildren now due to my back. I can't lift or carry them.'

Breda

Often patients require hospitalisation due to septic episodes and, understandably, most participants revealed their fears of acquiring infections, as well as the measures they take to avoid developing them.

'I was in hospital five times last year with lung infections, I was very vulnerable at that time. I'm more aware of hygiene because I'm afraid of infections, anyone that comes into the house now must wash their hands.'

Anne

Theme three: importance of support from family/ friends and professional help

Most participants considered family and friends to be the most significant source of support. However, the impact of the individuals' illness on family and friends was a concern and the importance of support for caregivers was also emphasised.

'My family are a great support, they come with me to appointments all the time. The family network is hugely important. Although my wife worries a lot, and I feel it's so important that she gets support too, I rarely talk to friends about it.'

Michael

Conversely, not all participants received social support from family and a minority described how discussing their illness with family members contributed to the negative feelings they experienced during that time.

'I don't really like to bother anyone, I'm a very private person. I don't go into details with my family or friends. My daughter is living with me and she's an alcoholic, so I can't really talk to her as she has her own problems.'

Anne

There were also mixed views concerning professional support. One participant noted the value of counselling and the positive impact it had on stress levels. Other participants appeared wary of counselling and felt that family support was sufficient. In particular, some participants preferred to seek out other interests to distract them, rather than focus on their illness.

'I don't really want to talk or go back over everything. It emphasises the fact you're sick, when you're trying to live a normal life and put it to the back of your mind. I prefer to go to my choir with my sister and be in something not for cancer survivors.'

Mary

Another participant articulated that, when they did engage with health professionals, sometimes this care was provided in an automatic and emotionless manner. He suggested that providing care while socially interacting with the person helped one to unwind when feeling stressed and to build an amiable rapport with the health professional.

'The caring aspect is so important, sometimes it can be mechanical which is necessary, but just saying how are you when taking your blood pressure ... or you look well makes a difference. This social interaction and rapport makes you feel comfortable. Don't underestimate the human aspect of being looked after or focus solely on the medical side of things like bloods.'

Michael

Indeed, other participants in this study identified that provision of holistic, empathetic care was as important to them as looking after their physical needs and disease management.

‘The whole being is important. You know, it affects the whole person, treatment should include the physical and psychological, like why go through treatment to get a remission if the quality of life then isn’t addressed. Some nurses were great, they talked to me not just the disease.’

Patrick

Theme four: psychosocial elements of survivorship

All interviewees described the turmoil they face as they live with the uncertainty of multiple myeloma. Although patients are surviving longer with the condition, inevitably each relapse raises further concerns as patients progress along their multiple myeloma journey. Some participants described it as ‘a darker force’ or a ‘black dog’ in the background, always present in their consciousness. This fear led to feelings of anxiety and panic attacks in certain cases.

‘I’ve been having these panic attacks lately, wondering how much time I’ve got left.’

Anne

‘There’s this darker force there now. I’m anxious that I’m running out of time, or that the combination of drugs won’t work anymore. I’m afraid to look ahead.’

Michael

‘I’m not really fearful of it (the future), although I know the myeloma is sneaky. I’m wary of bad news, it’s a black dog there in the background.’

Nora

Multiple myeloma is a disease characterised by multiple remissions and relapses. Therefore, it is understandable that participants experienced feelings of distress, and some described their life like being on an emotional rollercoaster.

‘You’re on a drug and it works, and then you relapse and go into remission and then relapse again. The emotional roller-coaster is so hard... Was told before Christmas I only had a few months to live. Mentally, I was ready to die and then the numbers went down again on the drug I’m on now ... so I’ve had to readjust my thinking. So hard to get my head around it, my funeral was arranged and everything. It’s so different to other cancers as there’s not as many remissions/relapses. That’s what so hard to adjust to.’

Mary

Nevertheless, despite the adverse effects of living with multiple myeloma, overall patients reported remaining positive and optimistic in their outlook on life. Incorporating the management of multiple myeloma into their lives and not focusing on their illness assisted these participants to cope. Many described how they integrate their multiple myeloma treatment into their lives with minimal disruption. Participants also described using coping techniques, such as focusing on other factors in their lives, which served as a distraction from their multiple myeloma.

‘I’ve good interests outside of the myeloma. My work keeps me distracted, and I remain optimistic.’

Michael

‘I feel happy now. We really take life for granted. My mother always said take one day at a time and put your feet on the floor, put your hands up like that, ‘Oh God, thank you for this day’. So I’m just keeping as much of a calmness about me as I can. Each day I try to keep busy. I’m going for counselling and I’m going to start knitting too. You can have a great day and you can have a bad day. But I really don’t let it get into my head.’

Anne

Discussion

The aim of this study was to describe the experiences of patients living with multiple myeloma. The findings highlight the importance of patients having access to information about their diagnosis, as well as how effective (and ineffective) communication by health professionals affects their experience as a patient. Concerns regarding communication also occur in other cancer patient groups and the findings of this study are consistent with that of Drury et al (2020), who reported similar unmet information needs in their study of colorectal cancer survivors. The challenges faced by individuals was apparent and both symptoms of the disease itself as well as the side-effects of treatment had a significant impact on patients’ lives. The nature of this burden was very individual, highlighting the importance of patient-centred care.

All participants in this study reported that, prior to their diagnosis, they had been unaware of this type of cancer, a finding that reflects that of a similar study by Stephens et al (2014). While the sample was not representative of the population, it does suggest that the disease is relatively unheard of compared with more common malignancies. Indeed, as observed in the current study, previous studies have identified that people often feel isolated due to the relatively unknown nature of myeloma (Kelly and Dowling, 2011; Wagland et al, 2015). Information provision is a crucial aspect of good supportive cancer care (Husson et al, 2013). Clear, accurate and reliable sources of information influence patient decision-making, adherence with treatment and self-management, and can reduce anxiety among cancer patients (Snowden et al, 2017).

Addressing the public profile of multiple myeloma and increasing information among health professionals is another important action to raise awareness of this condition (Multiple Myeloma Ireland, 2017). Indeed, participants also commented on the prolonged duration required for diagnosis and, as the Republic of Ireland's *National Cancer Strategy 2017–2016* (Department of Health (DoH), 2017), maintains, raising public awareness of specific symptoms is a critical step towards earlier diagnosis. A prolonged delay before diagnosis is associated with a significant impact on the clinical course of multiple myeloma, highlighting the importance of awareness building (Kariyawan et al, 2007).

As observed in this study, skilled communication was considered by all interviewees to be a key aspect of effective cancer care. Many emphasised how their interactions and conversations with staff influenced their feelings of effective care and support by health professionals. It was clear that some individuals considered that the communication skills of medical staff were not adequate. Trivial actions or omissions by the healthcare team can have life-changing consequences for patients and their families (Coon et al, 2007). Indeed, Cormican and Dowling (2016) found that health professionals themselves were concerned about their ability to provide adequate time for discussions with patients in busy hospital environments. Health professionals require astute interpersonal communication skills to understand patient information needs and ensure their meaningful participation in treatment decisions (Koutsopoulou et al, 2010; Cartwright et al, 2014; Holz and Ruhl, 2016).

Patients with multiple myeloma experience the highest level of symptoms and the lowest quality of life compared with patients with other haematological cancers (Snowden et al, 2017). The most frequent and distressing symptoms while undergoing stem-cell transplant were reported to be fatigue, diarrhoea, vomiting and decreased appetite. Not one participant mentioned concerns about alopecia (which occurs with patients undergoing transplant). El-Jawahri et al (2016) confirmed that a decline in quality of life and an increase in the likelihood of patients experiencing depression during hospitalisation for stem-cell transplant can lead to post-traumatic stress disorder symptoms 6 months post transplant. Several studies have acknowledged the negative effects of the disease on body image in other cancer groups (Tripaldi, 2019; Drury et al, 2017; Loughery and Woodgate, 2019). In this study, none of the participants discussed the negative impact that multiple myeloma had on their own body image. Perhaps this was due to other symptoms being perceived as being far worse than alopecia.

Participants also emphasised the unpleasant side-effects of steroids in this study, a finding reflected in the literature (McGrath and Holewa, 2010; Baz et al, 2015; Sloom et al, 2015). Steroid toxicity, diarrhoea and peripheral neuropathy were all identified by participants as particularly burdensome side-effects from their treatments. Peripheral neuropathy is also recognised as a common treatment side-effect and was a major source of concern for patients in this study. Unfortunately, there are no proven treatments for peripheral neuropathy, and dose modification and assessment are the only way to prevent severe chemotherapy-induced peripheral neuropathy. Binner et al (2011) conducted an exploratory study of oncology nurses' knowledge of

chemotherapy-induced peripheral neuropathy: this study highlighted that there were knowledge deficits among nurses in assessing peripheral neuropathy. Detecting early symptoms may prevent patient injury and minimise progression of peripheral neuropathy through early intervention (Dowling et al, 2016).

There were mixed views regarding the importance of support by the social network of an individual, as well as professional services. This, again, highlights the importance of considering patients' individual needs. Nevertheless, it was clear that the acute and recurrent nature of this disease led to long-term emotional struggles for individuals, as was also observed by Hulin et al (2017). Similarly, Monterosso et al (2018) revealed in their study how participants thought their emotions fluctuated with disease status. Many patients had undergone a relapse and discussed their fears of recurrence. In some cases, it was felt the recurrence was as devastating as the initial diagnosis. Considering the challenges of the illness and its treatment discussed above, the provision of long-term support is needed for all patients living with multiple myeloma (Molassiotis et al, 2011a). In the current study, families and friends were reported as being the most significant sources of support. This is similar to the findings of Maher and DeVries (2011), who highlighted the importance of family support to enable adjustment to diagnosis and coping with the disease. One interviewee described how they requested support for their relatives rather than themselves, and this altruism has been reported elsewhere (Lamers et al, 2013). This is comparable with other cancer groups, as highlighted by Lopez et al (2019) who discussed the importance of how patients with gynaecological cancer require support for their families also. Molassiotis et al (2011b) suggested that health professionals also need to be cognisant of the stress and worry that caregivers endure while caring for patients with myeloma.

Conversely, some participants did not want to discuss their illness with friends or colleagues. Some participants in Potrata et al's (2011) study expressed the view that their friends and neighbours might cause considerable distress through constant inquires about their health, especially given the chronic nature of the disease. This highlights the importance of an individualised, patient-centred approach to social support. Patients with limited social support are at a greater risk of developing psychological disorders compared with those whose psychosocial needs are addressed (El-Jawahri et al, 2016).

One participant who had limited family support found it helpful to attend a support group. However, the other participants in this study appeared wary and did not want to attend support groups, a finding also observed elsewhere (Molassiotis et al, 2011a). However, Lamers et al (2013) identified how the diagnosis of multiple myeloma is associated with an emotional crisis that exceeds individual coping skills, and their study revealed that half of patients desired some form of psychosocial interventions. It is likely that the availability of an individualised support service could provide appropriate psychosocial support for patients. However, as Ireland's *National Cancer Strategy* (DoH, 2017) highlights, many patients are not even aware of the cancer support centres that exist in the community and there are no organised referral systems in place between hospitals and support centres.

Complex medical therapies and advancing practice have improved survivorship for patients who have multiple myeloma. However, Kelly and Dowling's (2011) study had similar findings to those in this study, in that patients expressed fear of recurrence of the disease, worried about the results of their blood tests, and were preoccupied about how and when their end would come. Maher and DeVries (2011) suggested that uncertainty becomes a way of life for patients with multiple myeloma and fear of relapse is ever present. This was a similar finding as that in studies involving colorectal and gynaecological patients who also live with the fear of relapse (Drury et al 2017; Lopez et al, 2019).

In order to ensure effective symptom management and improve patients' quality of life, it is important to regularly assess the individual's mood and anxiety through holistic needs assessments and refer to support resources or psychological care, if needed (Molassiotis, 2011b; Boland et al, 2014; Snowden et al, 2017). The participants in this study identified that being provided with holistic care was as important to them as having their physical needs looked after. Patients expected information to be supplied in a holistic manner, and advice about various aspects of their illness, including psychosocial support, to be provided (Brandenburg et al, 2017). Patients frequently report that health professionals appear more interested in the disease than the person (Molassiotis et al, 2011a). Clinical guidelines for managing multiple myeloma suggest that routine holistic needs assessment should be considered at the commencement and conclusion of each treatment to identify individual patient needs and concerns (Snowden et al, 2017). Nurses are in a prime position to provide emotional support to patients by conveying trust, confidence, hope and emotional warmth. Caring in cancer nursing focuses on the individual person and not just the disease (Karlou et al, 2015).

Limitations

The views of the group involved in this study provide important insights into the experiences of living with multiple myeloma. The authors acknowledge that the small sample size limits the generalisability of these findings and so only highlight the experiences of a small cohort. The authors also acknowledge that using an unstructured interview approach, by a single interviewer, introduces the risk of interviewer bias. However, the involvement of a single experienced interviewer ensures that a similar standard and consistent approach is taken throughout the interviewing process. Furthermore, the use of unstructured interviews was considered an important component of the methodology. This approach encouraged the interviewee to guide the interview and focus on the aspects of living with myeloma that they considered important. The challenges faced by this group highlight the importance of this type of research. The limitations of this study are acknowledged and future studies looking at the experiences of people living with multiple myeloma across a range of contexts would support the development of appropriate and needs-based services.

Conclusion

The literature suggests that greater understanding of the disease can lead to improved diagnosis, treatment and support for

KEY POINTS

- The importance of a holistic approach to care was emphasised in this study, focusing on individual needs rather than solely on disease management
- Empathic and compassionate information provision was considered important but was not always experienced. Appropriate time with the patient, as well as active listening by healthcare staff, were considered key factors in the delivery of effective care
- The emotional rollercoaster of remissions and relapses takes its toll on patients. Early assessment of distress and identification of a patient's support network was considered important in managing these challenges
- Public and professional awareness of multiple myeloma was considered a contributing factor to delayed diagnosis. More public awareness campaigns are needed to increase people's understanding of lesser known cancers

individuals with a diagnosis of multiple myeloma. The lack of public and professional awareness of the disease highlighted by the participants in this study suggests therefore that more awareness building would be useful to ensure improvements in services in the local setting of the study.

This paper also highlights the physical and emotional rollercoaster resulting from the remission and relapse cycle of myeloma, and the toll that this takes on patients. The importance of early assessment of distress and identifying patients' support networks was highlighted in this study. The complex symptoms of multiple myeloma also need to be assessed regularly to manage the unpredictable nature of the disease.

Patients need to be treated in a holistic manner, focusing on their individual needs rather than solely on disease management. The side-effects of treatment need to be monitored on an ongoing basis to prevent further deterioration in patients' quality of life. In line with the Republic of Ireland's *National Cancer Strategy 2017–2016* (DoH, 2017), the expansion of the roles of clinical nurse specialist (CNS) and advanced nurse practitioner (ANP) in areas such as nurse-led clinics for new patient assessment, oral chemotherapy, follow-up support and survivorship are positive steps towards such necessary specialist and holistic care. This is important for improving cancer services because evidence suggests that the presence of CNS and ANP roles results in patients having better access to individualised and high-quality care (Maier et al, 2017; Barber and Mullen, 2017; Laurant et al, 2018). **BJN**

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CPD reflective questions

- There is a lack of awareness about myeloma among health professionals and the public. How could you help increase awareness about the condition and keep patients better informed throughout their treatment?
- Patients stressed the importance of holistic, empathetic care. Consider how we, as nurses, provide more patient-centred care to patients and improve our rapport/interactions with patients
- Multiple myeloma is characterised by multiple relapses and remissions. Consider how support for patients could be improved to help them cope with the uncertainty this brings into their lives?

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