



'It is a journey of discovery': living with myeloma

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Abstract

Purpose Although multiple myeloma (MM) is incurable, many people live with the disease for a number of years. Thus, understanding the effect of the disease and its therapies on the lives of those with MM is important. This qualitative study explores the impact of MM and its treatments on patients.

Methods People with newly diagnosed or relapsed MM were recruited from a tertiary institution. Participants were interviewed using a semi-structured approach. The questions were designed to obtain insight into how participants viewed their diagnosis, treatment, and symptoms and how these had impacted on their lives. Data were analysed using a phenomenological approach.

Results Fifteen people with MM with a mean age of 62 were recruited. Participants' mean time since diagnosis was 2.7 years and they had received a mean of 1.7 lines of therapy. The first major theme to emerge was lifestyle changes. Interviewees described MM as causing changes to all aspects of their lives, including substantial functional changes, as well as changes to employment, relationships, and their sense of self. The second major theme was 'adjust, adjust, adjust'. Alongside challenging life changes, participants described a range of practical, psychological, and relational approaches to adjusting to living with MM.

Conclusion This study highlights the importance of and the need for improved supportive care in patients with MM, ideally with a multidisciplinary approach. It also identifies the potential for further investigation of patient approaches to adjusting to MM and development of support strategies.

Keywords Multiple myeloma · Change · Ongoing symptoms · Adaptation

Introduction

In Australia, multiple myeloma (MM) accounts for 1% of new cancer diagnoses [1]. The risk of developing MM by the age of 85 is 1 in 114 [2].

MM is incurable. However, many people live with MM for years, as novel agents and autologous stem cell transplants have substantially extended life expectancy [3]. There is a need to understand the effect that the disease and therapy has on the lives of those living with MM. Research investigating the experiences and quality of life (QoL) of people living with MM is limited [4–6]. People with MM may have

a substantial symptom burden, including fatigue, fevers, constipation, neuropathy, nausea, sleep disturbance, anxiety, and cancer-related pain [4]. The symptom control needs of people with MM are similar to those with advanced solid organ cancer [7]. Therapy-related symptoms are also common [8]. Despite this, QoL measures are infrequently reported in published research of novel agents for MM [5].

Whilst a range of QoL tools have been useful in research, such tools are less well validated in the real-world setting, limiting their clinical utility. These tools assess the health status of patients by assessing the presence or severity of a problem; however, the broader psychosocial impact of illness upon people's life experiences, roles, and relationships is not assessed [9].

Qualitative research facilitates a detailed exploration of people's experiences of MM, through eliciting in-depth experiential and contextual data. This enables a broadened understanding of the impact of MM and its therapies on those living with MM [10]. Some studies found that MM treatment causes a substantial physical and psychological burden, disrupting social activities, impacting on relationships, and reducing independence [8, 11]. Qualitative research exploring the experiences of those living with MM is scarce [12], particularly in Australia.

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The aim of this study was to explore the experiences of patients with MM of their illness and treatment using qualitative research methodology.

Methods

This qualitative phenomenological study was undertaken in a single tertiary hospital in Western Australia. Ethics committee approval was obtained prior to commencement of the study.

Participant selection

People with MM presenting to the haematology unit at the study institution were identified through review of the departmental inpatient and outpatient lists. Potential participants had newly diagnosed or relapsed MM, were aged 18 years or older, could provide written informed consent and spoke adequate English to participate in an interview. People with cognitive impairment (as identified by a diagnosis of delirium or dementia), who were not well enough to participate in an interview or who had been treated for another malignancy were excluded. Participants were selected using purposive sampling, aiming to recruit people with varying demographic profiles and disease stages.

Semi-structured interviews

Participants were interviewed individually using a prepared interview guide (Table 1). The interviewer could deviate from the interview guide to explore responses in greater detail, in keeping with a semi-structured approach. The questions were designed to obtain insight into how participants viewed their diagnosis, treatment, and symptoms, and how these had impacted their lives. The interviews were conducted by a single investigator in private rooms on the ward or in clinic. They

Table 1 Interview transcript

1. Can you tell me about how you discovered that you had myeloma?
2. How has your diagnosis affected your day to day life?
3. Can you tell me about the treatment you have had for your myeloma?
4. How has the treatment affected your day to day life?
5. Have there been any particular symptoms or side effects that you have found troublesome?
6. Have there been things related to your diagnosis or treatment that have been easy or positive?
7. How has your diagnosis or treatment affected your family or friends?
8. Looking back, would you do anything related to your cancer treatment differently?
9. Is there anything you think healthcare professionals should know about what it is like to have a diagnosis of myeloma?
10. Have you been to a myeloma support group?

were audio recorded and transcribed verbatim. Interviews were continued until saturation of themes was reached.

Interview analysis

The interview transcripts were analysed separately by two investigators using a phenomenological approach [12, 13]. Emerging ideas and concepts were compared through and between the interviews, and between investigators. Consensus was reached on themes and subthemes which emerged from the data. NVivo 11 software was used to store and organise concepts.

Results

Participant demographics

Fifteen people with MM, mean age of 62 years (51–74 years) consented to participate. The interviews took a mean of 26 min (12.5–60 min). Six people were interviewed during a hospital admission and nine in the outpatient setting. Their mean time since diagnosis was 2.7 years. Participants had received a mean of 1.7 lines of therapy (1–5). Participants' place of residence was a mean distance of 54 km from the hospital (4–251 km). Further participant characteristics are described in Table 2.

Lifestyle changes

The first major theme to emerge was a change in participants' lives, as one stated 'all my life has changed' (65 M). Interviewees described that MM had caused changes to all aspects of their lives. Symptoms, of the disease and treatment, had resulted in substantial functional changes. This had affected their employment, relationships, and sense of self. Subthemes included:

- Physical symptoms
- 'I can't do things like I used to'
- 'Affecting the family'
- Loss of sense of self.

Physical symptoms

The most prominent symptom was pain. For some, the pain was so severe that it was all-consuming, as one participant described 'the pain controls my day' (66 F).

'It hurts. It really hurts. Getting into bed hurts ... Getting out of bed hurts.' (50 M)

Table 2 Participant demographics

Demographic	Subgroup	Number of participants
Age	< 50	1
	50–59	4
	60–69	9
	≥ 70	1
Gender	Male (M)	11
	Female (F)	4
Country of birth	Australia	8
	Other*	7
Distance from hospital (km)	< 25	7
	25–49	4
	50–74	1
	75–99	1
	≥ 100	2
Years with MM	≤ 1	6
	2	3
	3	2
	4	3
	5	1
Lines of treatment	1	9
	2	4
	3	1
	4	0
	5	1
Prior ASCT [^]	Yes	11
	No	4
Work status	Working part-time	1
	Retired	5
	Not working	9

*Countries include Britain, South Africa, Zimbabwe, Italy, Macedonia, and New Zealand

[^]ASCT, autologous stem cell transplant

Fatigue was similarly common. Other symptoms included poor concentration and general weakness.

‘I don't have any energy... I have a carcass of a body with no strength in it all.’ (58 M)

Therapy-related symptoms also affected people's lives. Common acute side effects included nausea and diarrhoea. Most participants reported feeling ‘awful’ during therapy, with one person describing feeling ‘like death warmed up’ (74 M). Steroid-related side effects were common, with many people relating to falling off the cliff when they ceased the steroids.

‘On a Thursday I get a buzz with the steroids. I try to do the washing and tidy up but I try not to overdo it as I know I am going to crash. ... I couldn't get out of bed.’ (66 F)

Neuropathic symptoms including ‘numbness and tingles’ and ‘sharp pain’ were commonly persistent. People described being ‘scared’ of falling over, and kicking things due to the loss of sensation.

Many expressed concern at the tablet burden and the potential for side effects. Some admitted to omitting tablets. Analgesics were the most commonly missed medication despite substantial pain. Others described apprehension that they were ‘junkies’ and limited their use of analgesics due to concerns about ‘addiction’.

‘I didn't take pain killers today as I have taken 16 tablets today.... I thought what are these doing to my kidneys? So I didn't take any painkillers.’ (66 F)

‘I can't do things like I used to’

All participants described changes to their ability to perform their regular activities. Few were in any employment, most ceasing work after their diagnosis as they could not manage this due to symptoms and treatments. Those in employment had made changes to their work arrangements, such as reducing hours or changing to a less demanding role. This had significant financial implications.

‘I had to stop work. That was the hardest part.’ (49 M)
‘We sold everything.’ (63 F)

Many had to reduce or cease driving. Transport to the hospital for treatment and appointments thus became challenging. Many were reliant on others for transport, as their mobility or pain precluded using public transport. The cost of parking was a concern. One person reported catching public transport to avoid ‘paying these exorbitant parking fees’ (69 M).

‘[I] used to take public transport ... But now I can't do anything.’ (66 F)

MM had also affected their ability to continue with recreational activities such as playing golf, darts, and soccer. The lack of predictability of when pain might recur created hesitancy when considering outings.

‘I cannot play golf anymore. I was a golf nut.’ (64 M)

For some, even more modest activities were a struggle. Many had to accept assistance with tasks such as shopping and housework. Some attributed this to pain, whilst others referred to lack of energy to complete or perform tasks.

‘Simple things like walking upstairs became a major problem. Five steps and then your legs just stop.’ (51 M)

'Affecting the family'

Whilst most described important support from family and friends, many expressed apprehension about being a burden to their loved ones. This potentially limited communication about their MM, their symptoms, and other concerns.

'A lot of stuff that I had feelings about, I just kept quiet. Because I didn't want to put a burden on anyone.' (67 M)

A couple of participants admitted that relationships had broken down entirely. These participants appeared to be socially isolated.

'It has affected the family. The wife has taken off with the kids. So I am on my own. She can't handle it.' (67 M)

Aside from close family and friends, most participants had lost contact with their wider social network. No longer being in employment resulted in the loss of work-place friends. Limited ability to participate in activities, a previous important foundation for friendships, was another reason identified. The MM itself had also caused barriers. As one participant described, their friends 'didn't know what to say' (65 M).

Loss of sense of self

The loss of sense of self included changes in appearance. One participant commented that she could no longer wear the same clothes due to the development of prominent veins on her chest. Another described the steroids as 'making you feel terrible and look terrible' (74 M). This affected their self-image.

'I came in to hospital feeling big and then 6 weeks later when I came out, I was ... all hunched over.' (50 M)

A loss of the ability to undertake physical tasks or work had resulted in a loss of identity as physically capable and productive. One participant reflected on no longer being able to do 'painting, decorating, everything' (58 M) around the house. For some, perceptions of their future self had changed.

'I always saw myself as one of those wrinkled old guys in his 80s still chasing cows around.' (64 M)

Concern regarding their uncertain future was commonly reported. Many struggled with the prognostic uncertainty associated with MM. This caused hesitation about whether to continue with therapy.

'You feel very unsure, all this suffering. If I come off this and then a year later, I am dead then you think 'well what is the ... point?' (67 M)

Adjust, adjust, adjust

The second major theme was 'adjust, adjust, adjust' (64 M). Alongside the challenging life changes, a range of approaches to coping with MM were reported. Subthemes encompassing these adjustment and adaptations included:

- Still doing something
- Just getting on with it
- A new way of looking at life
- They are always there.

These are summarised in Table 3.

Still doing something

Many participants described practical adaptations they had made. Some described slowing down to adjust to their physical limitations.

'It has mentally told me to slow down ...take a step back and don't go doing what you were doing.' (62 F)

Others described making changes to their lifestyles to adapt to physical limitations. One keen golfer set up a practice tee on his front veranda so that he could still enjoy golf.

'Each year, I have had to adjust the way I maintain my property to fit in with where my health is.' (64 M)

For many participants, remaining as active as possible, including continuing to work if feasible, appeared to be important.

'You can't stop working unless you are really sick. You have got to still do something. ... I would go nuts.' (51 M)

A number of participants reported finding new interests and activities, which provided distraction from pain and other symptoms. A focus on helping others was central to these new activities. They provided a sense of purpose and contribution.

'I keep myself occupied. Going around and helping other people in the yard. ... It takes my sickness off my mind.' (49 M)

'Just getting on with it' (66 F)

Many participants tried to maintain an optimistic attitude. Some achieved this by focussing on positive experiences or aspects of their situation. One person described being 'lucky' now, his pain had resolved following MM treatment.

Table 3 Overview of emergent themes and subthemes from the experiences of people living with MM

Lifestyle changes		Adjust, adjust, adjust	
Physical symptoms	Substantial symptom burden related to MM and treatment was common, in particular pain.	Still doing something	Participants made practical adaptations to cope with MM, including finding new interests and activities.
I can't do things like I used to	Changes in their ability to participate in activities including working, driving, recreational activities, and activities of daily living.	Just getting on with it	Participants actively maintained a positive attitude, whilst others chose not to focus on negative aspects of their situation.
Affecting the family	Strains on relationships, with loss of some relationships. Social networks frequently narrowed, often related to ceasing employment or no longer being able to undertake recreational activities.	A new way of looking at life	Shift in focus and changing priorities, due to facing an uncertain future.
Loss of sense of self	Changes in appearance and physical abilities were related to a loss of sense of identity. An uncertain future resulted in a loss of sense of future self.	They are always there	Family and friends provided important practical and psychological support. Formal support groups were of limited benefit.

'Be positive and enjoy what you have got. If it is a day, enjoy the day....' (67 M)

Others achieved this by not dwelling on negative aspects of their situation. They chose to focus on other aspects of their life.

'[I] try not to let it affect my life...I just get on with it'. (66 F)
'I try not to think about it until the pain reminds me. ... I am not in denial, but I just don't dwell on it.' (66 F)

A new way of looking at life

Facing an uncertain future resulted in a shift of focus, with some participants changing their priorities in life. One participant described that MM had 'concentrated my bucket list' (67 M). Another described shifting his focus away from finances, instead prioritising health and family.

'[It] is a second chance at my life. ... Life [has] got different things. It is not just about money.' (58 M)
'I made big adjustments – a whole new way of looking at life.' (64 M)

Some participants appeared to have reached a degree of acceptance of the terminal nature of MM and their impending dying, speaking openly about this.

'We all know that our life is finite.' (67 M)
'I am not ready to go. I accept that it is inevitable. I would be pleased if it wasn't next Friday.' (64 M)

'They are always there' (49 M)

Support from family and friends appeared important to coping with MM. Substantial practical support was described,

including providing help around the house, delivering shopping and meals.

'Friends, they have all chipped in. Always offering to help.' (49 M)

Family and friends also provided important psychological support. Following his diagnosis, one participant stated 'we sat at the kitchen table talking and crying until 3am' (64 M).

'You know that there are people around you, that they are going to support you in the darkest hour.' (67 M)

Family was a motivation to live in a positive manner. One participant described wanting to 'be strong' for his sons.

'I always try to keep going forward in life too. Cos if I break down they [sons] will break down. So they have to see me going forwards in life.' (49 M)

There was little mention of healthcare professionals providing support. One participant found benefit in the available myeloma support groups; others found that they were counter-productive and 'depressing'. One participant stated 'I don't feel the need to have the support of all these people [support group]. We are all dying, so what!' (67 M).

Discussion

This study demonstrates that MM substantially altered the lives of those with MM in many ways, even though medical therapies were controlling their disease. Participants were diverse, with a wide range of disease stages and backgrounds. Despite this diversity, 'all my life has changed' emerged as a common experience.

Pain and fatigue were troubling and common amongst study participants, as were therapy-related acute and longer-term side effects. This is in concordance with other studies that also identify pain, fatigue, and therapy-related symptoms as common [8, 12, 14, 15]. Through its qualitative approach, this study additionally enables appreciation of the substantial effects of these symptoms on everyday life. Mortensen and Salomo also highlight the effects of disease and therapy-related symptoms, particularly peripheral neuropathy, on cognitive and physical function in their qualitative study of MM [12].

Participants described a significant psychological burden due to MM, particularly related to uncertainty regarding their future, given the relapsing and remitting nature of MM. Mols et al. identified that whilst physical symptoms are prominent, up to a third of patients experience anxiety and worry regarding their disease and future, in an assessment of health-related QoL in 156 MM patients [15]. Molassiotis et al. demonstrated a high rate of anxiety and depressive symptoms amongst patients with MM and their partner, in a cross-sectional survey [16]. Thus, psychological symptoms are also a common and often neglected unmet supportive care need.

Interestingly, a number of participants reported omitting prescribed analgesics, despite experiencing pain. Sloot et al. have demonstrated that analgesic side effects are common in people with symptomatic MM [11]. In this study, analgesics were omitted due to concerns about the potential for addiction and tablet burden, rather than side effects. These concerns resulted in untreated pain impeding QoL, which could potentially have been reduced with patient education about analgesic use.

A need for improved symptom management for people with MM is clearly identified by this study and the work of others. The high symptom burden identified suggests that healthcare professionals may be focussed on disease treatment, with limited consideration of symptom management. Barriers to improved symptom management might include limited consultation time, lack of education and expertise in symptom management, or lack of recognition of symptom burden.

One approach to improving symptom management may be incorporation of symptom screening tools into clinical practice, to assist identification of troubling symptoms and prompt focus on their management. A validated myeloma-specific symptom inventory consisting of 26 questions has been developed [17]. This tool is concise and potentially useful in the treatment setting and future clinical trials. Zabora et al. have proposed a myeloma-specific model of psychosocial care [18], with critical points for screening for psychological distress identified, including at diagnosis, first treatment and relapse, and recommended interventions to reduce psychosocial distress. MM commonly occurs in older people. A myeloma-specific geriatric assessment has been demonstrated to be predictive of survival and risk of toxicity, and may aid decisions about the most appropriate therapy [19]. The use of such a tool during initial assessment could reduce therapy-related side effects.

Another approach is incorporation of palliative care services, focussing on symptom management, alongside haematology care. Given the complexity of decisions, patients and haematologists are required to make regarding MM therapy, it is easy to appreciate that symptoms may not be adequately addressed. Early palliative care in patients with newly diagnosed metastatic non-small cell lung cancer has been demonstrated to improve QoL, reduce depressive symptoms, reduce aggressive end of life care, and even improve survival [20]. A similar approach in MM warrants investigation. Greater collaboration with allied health professionals could assist in addressing some of the practical and social challenges associated with MM. Physiotherapists and occupational therapists can provide practical strategies and equipment to aid activities of daily living. Social workers can assist with accessing community-based services and financial and transport assistance. At our study institution, allied health and psychooncology services are available; our study highlights the need to improve access to these services.

Many participants described remarkable adjustment to living with MM, despite experiencing challenging life changes and burdensome symptoms. Strategies which appeared helpful included practical approaches, such as maintaining interests and activities, manageable within physical limitations. Psychological strategies described to be of help included adopting an optimistic attitude, whilst avoiding dwelling on negative aspects of their disease.

These adjustments to coping with MM suggest resilience, a capacity to cope with adversity. Resilience has been associated with optimism, acceptance of illness, and positive cognitive appraisal in the physically ill [21]. Resilience has been shown to be protective against emotional distress amongst cancer patients [22]. Interventions to promote resilience amongst breast cancer patients and survivors are promising [23].

Support from family and friends appeared important to adjusting to MM. Social support has been demonstrated to be predictive of resilience [21]. Unfortunately, MM was occasionally associated with relationship breakdown amongst study participants. This is perhaps not surprising, in view of the high rate of reported anxiety and depressive symptoms amongst partners of people with MM [16]. This highlights the importance of providing psychological support to family members, as well as those with MM.

Interestingly, few participants found formal support groups helpful. For some, they focussed attention on negative aspects of MM, which those actively trying to be optimistic might wish to avoid. Attention needs to be paid to the activities of formal support groups if they are to meet the needs of more people living with MM. A broadened scope of such organisations could be envisaged, for example, promoting meaningful social interaction through assisting people to remain in part-time employment, participate in volunteering, or engage in recreational activities.

Limitations to this study may have affected the outcomes of this research. The researcher conducting the interviews was a physician. Some participants may have felt inhibited in disclosing views which might appear critical of their healthcare. The interviews took place in a hospital setting, aiming to minimise interruption to the participants; however, some interviewees may have felt inhibited in discussing aspects of their healthcare in the hospital setting.

The majority of participants in this study were of Anglo-Australian ethnicity; the results may not be transferrable to other cultural groups. Views and approaches to serious illness and treatment decisions have been shown to vary across cultural backgrounds [24, 25], therefore the views and experiences of people from other ethnic backgrounds is an important avenue for further exploration.

This study highlights the importance of and the need for improved supportive care in patients with MM. We have the potential to substantially improve patients' QoL through extending our focus beyond disease treatment, to symptom management and provision of functional, practical, and psychosocial support. Models of care integrating multidisciplinary teams, including palliative care, from early in the disease course would facilitate a shift away from a purely medical focus to place appropriate importance on these broader needs.

Despite experiencing high symptom burden and major life changes, many study participants appeared to have adjusted remarkably to living with MM. Future exploration into the strategies and approaches used by those coping well would enable development of support strategies to optimise coping and QoL for those living with MM.

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Compliance with ethical standards

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Dr Rosslyn de Wet has full control of the primary data which is available for review.

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