



Patients' lived experience of myeloma

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Abstract

Aim To explore patients' lived experience of being diagnosed with myeloma.

Method A hermeneutic phenomenological approach was adopted for this study. Eleven patients with myeloma were interviewed for the study. Data analysis was guided by the reflective phases proposed by van Manen.

Results Participants described how they lived with what they described as 'unknown cancer', and talked of their feelings of loss. They described having an altered body image as a result of alopecia and fatigue. Fear of disease recurrence was expressed, as was the significance of the provision of support. Participants referred to feeling 'lucky' to being alive and that although the myeloma is incurable it was treatable.

Conclusion The study findings illustrate the importance and significance of providing support for patients with myeloma.

Keywords: Cancer, myeloma, phenomenology

MULTIPLE MYELOMA is a clonal malignancy of plasma cells (Harrousseau 2002), characterised by anaemia, renal dysfunction, lytic bone lesions and the presence of excess monoclonal immunoglobulin. It is the second most common haematological disorder after lymphoma (Devenney and Erikson 2004), which remains incurable (Chng *et al* 2005). It is a relapsing recurring disorder with specific treatment schedules depending on the drugs used previously in treatment, duration of response and potential side effects (Caers *et al* 2008). Although myeloma remains incurable, the development of treatment options has improved survival rates (Faiman 2007).

Nursing management of myeloma is challenging and nursing goals may vary and change over time, requiring ongoing assessment, evaluation and review (Sheridan 1996). The central role played by nurses in managing the care of patients with myeloma is reflected in the creation of a nurse leadership board by the International Myeloma Foundation. This initiative has resulted in the development of recommendations to manage side effects of *new treatments/ agents* for multiple myeloma (Bertolotti *et al* 2008).

Literature review

There have been a variety of empirical studies published relating to myeloma patients, including levels of pain intensity (Poulos *et al* 2001), the use of vertebroplasty in myeloma patients with osteolytic lesions of the cervical spine (Pflugmacher *et al* 2006) and measurement of patients' quality of life (Cocks *et al* 2007). More recently, Sherman *et al* (2009) reported on the psychosocial and quality of life difficulties experienced by myeloma patients treated with high-dose melphalan and autologous stem cell transplantation.

A number of qualitative studies exploring the experiences of patients with haematological malignancies have included those with myeloma (Bulsara *et al* 2004, McGrath 2004). However, the lived experience of patients with myeloma remains relatively unexplored. Only two other known qualitative studies have explored patients' experiences of living with myeloma. Dahan and Auerbach's (2006) grounded theory study explored the emotional effect of multiple myeloma among patients treated with peripheral blood stem cell transplant at a New York City cancer treatment centre. In addition, Vlossak and Fitch's (2008) qualitative study reported on in-depth telephone interviews with 20 patients receiving treatment for myeloma in a large regional cancer centre in Ontario, Canada.

Aim

The aim of this study was to explore patients' lived experience of having a diagnosis of myeloma

Method

A hermeneutic phenomenological approach, guided by the writings of van Manen (1997) was adopted for this study. Fifteen potential participants attending a regional specialist haematology oncology centre, who had been diagnosed with myeloma for more than six months (inclusion criteria) were invited by letter to be interviewed. Eleven participants, of which seven were males and four were females, agreed to be interviewed (**Table 1**). An interview guide was used to prompt questions around participants' lived experience of being diagnosed with myeloma.

Table 1 Study participants ($n=11$)

Age range	42-83 years of age (mean = 63)
Years since diagnosis	1.5-4 years (mean = 2 years)
Relapsed	$n=3$
Treatment included autologous stem cell transplantation	$n=5$
In employment	$n=2$
Location of interviews	Participant's home ($n=8$) Hospital clinic ($n=3$)
Interview length	60-90 minutes (mean=70 minutes)

Ethical approval for the study was granted from the local research ethics committee. The qualitative interview is unpredictable and it is not possible to forewarn study participants of how they will feel (Rosenblatt 1995). Therefore, additional emotional support following the interviews was provided by a clinical psychologist, if necessary. Furthermore, participants were contacted by telephone two weeks after their interview, to ensure no emotional distress had been incurred as a result of the interview and also to remind them that psychology services were available. All data were kept in a locked cupboard. Pseudonyms were used on the transcripts to protect participants' identities.

The approach to data analysis proposed by van Manen (1997) was used. van Manen (1997) suggested that carrying out phenomenological research involves a set of activities that are inseparable. The researcher is directed to focus on a phenomenon of interest, investigates the phenomenon as it is lived and reflects on the central theme that characterises it. The phenomenon is described through writing and rewriting; this acknowledges the researcher's role in the research process (Dowling 2007). Significant statements and phrases pertaining to living with a diagnosis of myeloma were identified and four main themes emerged (**Table 2**). Each transcript was then read again with the four main themes in mind and sub-themes were subsequently identified. In pursuit of trustworthiness (rigour in qualitative research), a haematology nurse with extensive haematology nursing experience validated the study findings through external peer review. This approach to trustworthiness in hermeneutic phenomenological studies can be adopted when member checking with study participants is difficult (Kahn 2000), as was the case in this study. Lincoln and Guba (1994) consider member checking the most important technique for establishing credibility of qualitative data. In this study it was impossible to return to all participants; one had died and others were not well enough to read through the twenty or more pages of the transcript.

Table 2 Study findings

Theme	Sub-theme
Lived body: a changed body	Alopecia Fatigue
Lived space: living in limbo	Living with an unknown cancer Stigma of cancer Loss Feeling 'lucky'
Lived time: time is precious	Fear of recurrence Limited time with healthcare professionals
Lived relations: significance of support	Family support Protecting others

Findings

Although each theme is discussed separately here, it is important to highlight that they can be differentiated, but are inter-related.

Lived body: a changed body

All participants commented on changes in their bodily functions and body appearance. For most, changes in appearance resulted in a negative view of self, while also acting as a constant reminder of their illness. Moreover, their concerns about how others viewed them and the realisation that they could no longer conceal their cancer had a major psychosocial effect.

Alopecia

None of the study participants were receiving treatment at the time of the interview, but hair loss featured extensively in participants' stories:

'When it came to my hair falling out...I had extremely long hair and an awful lot of it...I had a ponytail for about 25 or 30 years...that was the worst day of the whole lot...I was going somewhere and I just combed my hair and a bloody great chunk of it came out...and I said this is the worst of it and that sounds awfully naïve, but that was a horrible day...' (Richard)

'The only thing that was worrying me was about losing my hair...that was the big issue for me in the beginning, because I never cut my hair. I always had long hair.' (Chloe)

Fatigue

Fatigue was expressed by participants as the most debilitating symptom. Fatigue was present most of the time, but was much worse post treatment:

'I would get very tired in the evening time now...sometimes I go to bed at eight o'clock, which would be foreign to me...I never went to bed till two in the morning...' (Chloe)

'I get tired easily and I usually take a nap in the afternoon...also I wouldn't be able to do like heavy work...like cleaning windows, but I can't really...I get tired easily...and dancing...I could get out for one dance, but I feel tired. I look at my sister...she'd be on the dance floor all night...it's well for her...' (Alice)

'Well I have no speed in me anymore, I can't jump up...it would take me 15 minutes just to get my two legs out of the bed.' (Geraldine)

Lived space: living in limbo

Living with an unknown cancer

Living with an 'unknown' cancer was an important challenge faced by participants. The unfamiliar identity of myeloma was multidimensional encompassing lack of personal and public knowledge of the condition. Only one participant had heard of myeloma before diagnosis and three participants had not associated myeloma with cancer:

'I was told I had myeloma, now I never heard of myeloma...I did not think it was cancer and I did get a shock when I realised that it was cancer...' (Chloe)

'I didn't associate myeloma with cancer...I hadn't heard of myeloma...cancer was cancer and that was that.' (Liam)

Stigma of cancer

Two male participants talked about the stigma associated with cancer, referring to the 'whispers in public' and linked this to the fact that people did not talk about their myeloma because of its unknown nature and the mystery that surrounds it:

'People are not able to talk about it...it's this big monster you are carrying and it's nearly contagious and that people can't talk.' (Andrew)

Loss

A recurring sense of loss was common among participants, although the level and type of loss varied among individuals. Participants talked about their former self, experiencing loss of identity, loss of value and loss of friendship. For all, lifestyle changes occurred, accompanied with great sadness. Their ability to participate in life, as it was desired was no longer possible:

'I used to walk the road and danced quick steps and all those sort of things. But that is gone now...' (Dean)

'I don't go out anymore...I used to write, but I stopped writing when I got sick...I'd say it was a black part of my life.' (Liam)

'I wouldn't be the same party man as I used to too...it wouldn't matter to me if I never went out socially anywhere...' (Richard)

'...you get up to do something, but you wonder...what's the use? There's no future, there's absolutely no future...the past is gone...there is a whole lot of things I should have done...' (Patrick)

Feeling 'lucky'

Reference to feeling lucky was a recurring theme in the interviews. Many were reminded of others not so lucky and participants talked about being lucky to be alive and lucky there were treatment options for myeloma:

'We would often say, aren't we lucky that the treatment worked to a certain extent and that some people weren't so lucky.' (Patrick)

'Sure it can be treated...sure what more do you want...couldn't it have been an awful lot worse...if you have something that at least can be treated you know... Look at all the people that are out there that there is no treatment for ...you know thank your lucky stars...' (Geraldine)

Others spoke about luck comparing their life situation with others who had cancer:

'When you are older it's easier, but if I was a younger person, it probably would be different, it would be more difficult for a younger woman now to manage that way I would say...' (Chloe)

'When I go into oncology and see some of the other patients with lung cancer I feel lucky...' (Alice)

Lived time: time is precious

Fear of recurrence

Attending the review clinic and hearing of other myeloma patients' disease progression appeared to act as psychological triggers for uncertainty:

'That [fear of recurrence] worries me when the time is coming near for going back to the hospital; I would be wondering what it's doing. Is it coming back?' (Ciaran)

'Every morning I think about it alright...will I ever be alright...am I ever going to be okay...you wonder to yourself how long more left.' (Liam)

'I don't think about having myeloma...at all except once a month when I go for blood testswhen that goes well you are relieved....it's a relief when you don't hear anything bad...' (Alice)

'I suppose the thing that always sticks in my mind was he [doctor] said it was incurable, but treatable so I suppose that was the very thing of incurable I suppose it still haunts me.' (Andrew)

Several participants also spoke about their attempts to fight their illness and how it had helped them accept myeloma as part of their lives:

‘You can’t lie down and die. You have to live...’ (Alice)

‘I didn’t feel great, but as time went on like...I live with it- ya have to live with as long as you can...live as long as you can, die when you can’t help it...’ (Dean)

For some participants, their confrontation with death heightened their sense of the fragility of life; they had a second chance at life with the opportunity to re-evaluate:

‘... life to me is terrible precious...I love life...I love my home...I love my wife and the lads...life is so precious...’(Liam)

Limited time with healthcare professionals

A major concern for participants was the limited time spent with healthcare professionals. Participants perceived nurses and doctors were ‘too busy’ and as a result, they refrained from talking about important issues and questions remained unanswered:

‘...nurses don’t have the time to talk unless they were dressing a wound -- they do be coming and going...’ (Dean)

‘Well, I would love to have asked if I had enough time with the doctor...even the nurses...they are just so busy...but they haven’t got time and I think that’s a huge minus...’ (Richard)

Lived relations: significance of support

Participants considered support networks as central to their ability to cope:

‘The [family] are very important, they do everything for me...I’d be dead long ago only for that woman [wife]...’ (Liam)

‘My husband was brilliant...you really need someone at the time, from the start my husband was very good. I couldn’t have got through it without him...’ (Alice)

Participants spoke about the benefits of talking to other patients who had myeloma. This support usually began informally, in the waiting rooms of the clinic. However, for the majority of participants, the opportunity to talk to others with myeloma had not arisen. These participants welcomed any opportunity to converse about the condition, mainly because they did not talk to their family and friends about their disease:

'It would be good to be able to talk to other patients with myeloma.' (Ciaran)

'I haven't met anyone with myeloma....I would like to be able to talk to others with myeloma.' (Chloe)

'I don't read anything about it. Anything I know about it is from listening to people talk about it other people I have met ...you learn more from other people say in the ward or in the waiting room than you will anywhere else...I could pick up more from listening to people than in reading it myself, I could always do that ...' (Patrick)

All the study participants commented on how they welcomed the opportunity to talk about living with myeloma when interviewed for this study:

'It has [talking about myeloma] helped me immensely.' (Patrick)

'It's the first chance, I have really had to talk about it with someone who understands myeloma and it has really helped.' (Ciaran)

'It's endearing to have a conversation with somebody who actually understands what I am talking about.' (Geraldine)

Protecting others

All participants talked about their fears for their families, and focussed on their distress of leaving family behind after death:

'I was putting them [family] more so ahead of myself and trying to deal with that I suppose like anything in life there's probably a lot of pretending...we pretend an awful lot and you have to like, put on the good face at home like in front of the children.' (Andrew)

'I used to cry and lot...on my own. I wouldn't tell them bad news if I could help it. I wouldn't like to upset them.' (Liam)

'It's the other people that are left behind that I'd be thinking of...once you die I think that's it. It's harder on people left behind...I would like to see my daughter fixed up with a job and settled in life...and my wife...I have enough provided for my wife and daughter to live off when I am gone...' (Patrick)

All participants lived with a spouse or partner and all spoke of the strength and comfort they derived from family and extended social networks. Participants also mentioned they relied heavily on their relationships with others to overcome the obstacles associated with having myeloma, such as performing household tasks.

Limitations

The findings of this study only apply to the context and the point in time for the study participants (participants may feel differently later at disease relapses etc). With phenomenological interpretation, there is no clear end-point to interpretation, and interpretations are always open to re-interpretation. Furthermore, van Manen (1990) outlined that with hermeneutic phenomenological data analysis, the themes isolated should be revisited with the participants. However, this was not undertaken in this study because the condition of some of the study participants had deteriorated after being interviewed and it was decided that they may have not been well enough to read through the interpreted themes. Koch and Harrington (1998) also highlighted the problems associated with member checking with ill patients. The study population did not include any patients from minority backgrounds. However, minority groups are not prevalent in the geographical area where the study was undertaken.

Discussion

Myeloma treatment regimens take a toll on patients, almost all treatments have potentially serious side effects, significantly impacting on physical, emotional and psychological wellbeing. The 'changed body' reported by participants following myeloma treatment is also reported elsewhere (Dahan and Auerbach 2006). Alopecia affected participants' social world and withdrawal and concealment were common as previously reported (Rosman 2004, Lemieux *et al* 2008).

Participants reported fatigue, which concurs with the well-established belief that fatigue affects individuals emotionally, psychologically and socially (Ferrell *et al* 1996, Bower *et al* 2000, Fossa *et al* 2003). Wisløff and Hjorth (1997) reported that fatigue and reduced physical function, along with pain, are distressing problems for patients with myeloma. Dahan and Auerbach (2006) discussed myeloma patients' experience of 'absolute loss of energy' post transplant. Exercise is recommended as a strategy to combat fatigue among myeloma patients (Strong *et al* 2006, Coleman *et al* 2008). However, the pathophysiology of myeloma and the treatment regimens may affect the individual's ability to exercise (Jones *et al* 2004). A fine balance between intrinsic (e.g. *belief in exercise benefit, taking responsibility for own health, personal routines and goals*) and extrinsic factors (*having good support systems and prophylactic epoetin alfa*) will determine the individual's daily exercise routine, intrinsic fact (Coon and Coleman 2004).

Two study participants (both male) talked about the stigma of having myeloma. Participants' inability to hide their cancer because of hair loss and decreased bodily function were significant concerns. Furthermore, for these patients, the added mystery and unknown nature of this cancer added to the stigma. In a study by Vlossak and Fitch (2008) most patients had never heard of myeloma before diagnosis. Moreover, less than 3% of the UK population have heard of myeloma (Myeloma UK 2006). Myeloma UK (2006) reported that over one third of those interviewed wrongly thought myeloma was a skin cancer, emphasising the confusion surrounding myeloma and the need for greater public awareness. As a consequence of both personal and public lack of awareness, participants in the authors' study reported feelings of isolation and withdrew from social activities (captured in the sub-theme of loss). Furthermore, participants found that lack of public awareness prevented them from discussing their illness with others, further intensifying their isolation. A similar view is reported in a study by Power *et al* (2008), where women with ovarian cancer report claimed to feel as if they had a 'forgotten cancer' in view of the meagre attention it receives when compared to breast cancer.

A feeling of loss was common among the study participants. Feelings of isolation among myeloma patients post-transplant are also reported by Dahan and Auerbach (2006). Moreover, myeloma patients also report loss of independence (Vlossak and Fitch 2008).

Fear of recurrence remained with participants throughout their disease trajectory. Fear of recurrence is also a concern for those post-transplant for haematological malignancies (Cohen and Ley 2000, Saleh and Brockopp 2001), and myeloma patients in other studies (Dahan and Auerbach 2006, Vlossak and Fitch 2008). An 'obsession of how and when the end will come' and a dreading of the results of blood tests have also been expressed by patients with myeloma (Vlossak and Fitch 2008).

Addressing psychological aspects of fear, anxiety and uncertainty, which accompany a diagnosis of cancer is essential. As myeloma patients require close follow up the opportunity arises to perform regular assessment of symptoms and psychological adjustment (Poulos et al. 2001). Nurses play a vital role in ensuring that patients receive the optimal psychological support necessary to promote well-being and overall QOL (Tariman and Estrella, 2005). Of paramount importance also is the need to draw on other health professionals to provide additional support e.g. psychology services.

The study participants talked about the lack of time spent with healthcare professionals. They were all attending a specialised regional centre with access to specialist oncology nurses and therefore this finding is significant. However, organisational issues may have been a contributing factor. For instance, patients with myeloma elsewhere have expressed a reluctance to discuss their feelings with healthcare professionals because they appear too busy to talk and there are too many other patients waiting to be seen in the clinic (Vlossak and Fitch 2008). Patients have reported that one of the most positive and helpful aspects of care included time and willingness from healthcare professionals to listen (Frost *et al* 1999). However, patients may be hesitant or uncomfortable about asking questions or requesting additional information about their condition for fear of taking up too much time, appearing uninformed or feeling that they are being a bother (Parker *et al* 2005).

All participants lived with a spouse or partner and all spoke of the strength and comfort they derived from family and extended social networks. Social support features consistently in the literature on psychosocial adjustment to cancer (Tan 2007, Sammarco and Konecny 2008, Sjölander and Bertero 2008). Participants mentioned they relied heavily on their relationships with others to overcome the obstacles associated with myeloma, such as carrying out household tasks. Similar findings have been reported elsewhere (Dahan and Auerbach 2006, Vlossak and Fitch 2008). However, participants simultaneously expressed the need to protect their loved ones from their true fears and concerns (Vlossak and Fitch 2008)

Participants' comments on feeling 'lucky' may reflect an effort to cope. Similar sentiments from colorectal cancer patients are reported by Houldin and Lewis (2006). The positive outlook expressed was interpreted as an attempt to maintain control. Optimism has been found to be a feature of the cancer experience (Jarrett and Payne 2000), and is associated with better mental health outcomes during treatment (Cohen *et al* 2001). Moreover, maintaining positive illusions about illnesses, such as cancer, may enhance coping (Taylor *et al* 2000).

Although bone pain can cause pronounced distress in patients with myeloma (Wisløff and Hjorth 1997), participants in this study focussed on pain experienced pre-diagnosis. All the study participants were receiving monthly biphosphonate therapy and this may have contributed to pain not being an issue for them. Similarly, patients

with myeloma, interviewed by Vlossak and Fitch (2008), seemed satisfied with physical care and identified their primary needs to be emotional and psychosocial.

[A HEAD] Conclusion

This study highlights the physical, emotional and psychosocial changes experienced by patients with myeloma. While the findings reflect similar experiences of patients with other cancers, the 'unknown' nature of myeloma contributes to the distinctive nature of patients' experiences of living with this form of cancer.

Participants' expressions of having limited time with healthcare professionals are significant. It is important that healthcare professionals provide patients with opportunities to talk about their fears, concerns and experiences. In addition, nurses should seek the advice and intervention of a psycho-oncology service where necessary. Other support networks may include the International Myeloma Foundation, Myeloma UK and The Multiple Myeloma Research Foundation in the United States.

Implications for practice

- Myeloma remains an incurable cancer.
- Patients live in fear of relapse and death.
- Nurses must address patients emotional and psychosocial needs and recognise the significance for support.
- Healthcare professionals need to provide time to listen to myeloma patients' stories.
- Through listening and knowing myeloma patients, nurses can identify resources and help people in accessing them.

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