



This is a repository copy of *What can patient narratives reveal to us about the experience of a diagnosis of myeloma? A qualitative scoping review.*

White Rose Research Online URL for this paper:
<https://eprints.whiterose.ac.uk/184190/>

Version: Published Version

Article:

Rubins, Z., Gibson, B.J. and Chantry, A. (2022) What can patient narratives reveal to us about the experience of a diagnosis of myeloma? A qualitative scoping review. *Journal of Patient Experience*, 9. ISSN 2374-3735

<https://doi.org/10.1177/23743735221079133>

Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial (CC BY-NC) licence. This licence allows you to remix, tweak, and build upon this work non-commercially, and any new works must also acknowledge the authors and be non-commercial. You don't have to license any derivative works on the same terms. More information and the full terms of the licence here:
<https://creativecommons.org/licenses/>


Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

What Can Patient Narratives Reveal to Us About the Experience of a Diagnosis of Myeloma? A Qualitative Scoping Review

Journal of Patient Experience
Volume 9: 1-11
© The Author(s) 2022
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/23743735221079133
journals.sagepub.com/home/jpx


Zoë Rubins¹ , Barry J Gibson, PhD, MMedSci, BSc (Hons), SFHEA², and Andrew Chantry, PhD, FRCPATH, MRCP, MBChB^{1,3}

Abstract

In recent years, there have been major advances in treatment options for myeloma and an improved prognosis as a result. There is a wealth of literature that explores the experience of specific treatments from a clinical perspective but there is comparatively little known about the reality of living with myeloma. This research aims to explore the experience of a myeloma diagnosis, to map out key patient experience literature, and examine common themes to support both medical practice and the planning of further research. Following a scoping review methodology, PubMed, StarPlus (the University of Sheffield online database), and Scopus were searched and 15 studies identified for analysis and qualitative synthesis. The literature indicated that myeloma was increasingly being experienced as a chronic condition rather than an acute diagnosis and that there are challenges meeting the needs of patients, understanding the overall symptom burden and the role of the family. The paper identifies emotional and psychological adjustment and coping as a potential area requiring further exploration in the context of a whole team approach to care.

Keywords

myeloma, narrative, scoping review

Introduction

Multiple myeloma is defined by Myeloma UK as “a blood cancer arising from plasma cells, accounting for 15 percent of hematological malignancies and 2 percent of all cancers.” Patients are mainly diagnosed over the age of 65 but overall, myeloma patients are a “very diverse population” (1). This means that the presentation and treatment pathway for each individual is highly variable. What each patient has in common however, is that myeloma is an incurable, relapsing-remitting disease process and the lived experience of it is complex. For example, patients can have periods of intense treatment, followed by potentially years without intervention (2). Treatment pathways are in a constant process of change, meaning that treatments continue to advance and the reality of survival has increased to over 50% at 5 years (2–4). Although each prognosis and treatment regime is individual, the experience of myeloma from a lived perspective can share some commonalities.

Due to improving prognosis, myeloma has been increasingly likened to a chronic disease process (5) and it is clear the experience of it has changed over time. What is still unclear however, is whether myeloma services have adapted and grown with this change. Through patient

narratives, this scoping review aims to reveal the reality of living with myeloma to help the medical team to appreciate the information available and how this can be applied to patients. Much of the literature focuses on the experience of specific treatment regimens, not allowing us to understand the journey as a whole and appreciate its associated emotions. When patients live in a constant state of uncertainty and “limbo” (6) a significant proportion of time must be spent coping and adjusting to this new fragile way of living. Yet by medicalizing the approach, the genuine needs of patients may be overlooked. Patients are best placed to inform how to shape practice and hearing their stories is, therefore, the first step in improving myeloma services. Refining the patient experience

¹ University of Sheffield Medical School, Sheffield, UK

² Academic Unit of Oral Health, Dentistry and Society, School of Clinical Dentistry, University of Sheffield, Sheffield, UK

³ Department of Oncology and Metabolism, Sheffield Hospitals NHS Foundation Trust, Sheffield, UK

Corresponding Author:

Zoë Rubins, University of Sheffield Medical School, Sheffield, UK.
Email: zzrubins1@sheffield.ac.uk



and access to services is central to the work of medical teams and must occur alongside tremendous therapeutic advances.

Patients often speak highly of the care they receive and can even find the experience of myeloma to be life affirming. However, it is important to acknowledge that there are times that specific patients or patient groups feel less well supported—there is a need to harness and coordinate the expertise of the Multi-Disciplinary Team to provide a comprehensive and effective service. It is with this in mind that we sought to conduct a scoping review of the literature. Scoping reviews allow the mapping of existing literature (7) and can build context on the subject, creating a springboard for further research. This qualitative scoping review aims to explore what has been written on the experience of a myeloma diagnosis, to map out key patient experience literature, and to examine common themes to support both medical practice and the planning of further research. There has only been one previous study (8) to synthesize this type of information. Here, the focus was on providing “pragmatic results” for nursing staff. We seek to build on this important study by identifying new work that has been published since 2018 and at the same time identifying and emphasizing gaps in existing approaches. Our aim is to guide future research and consequently improve myeloma services.

Methods

This study has drawn on the framework outlined by Arksey and O’Malley (7), following 5 stages to identify qualitative papers that explore the experience of patients with myeloma. These stages can be seen in Figure 1 and the findings of these papers synthesized in the results (9). The literature search took place between December 2020 and March 2021.

Results

The data from the 15 studies selected was charted to complete the fifth stage of Arksey and O’Malley’s framework (full process seen in Appendix 1). The results were however synthesized and reported using a qualitative, interpretive approach (10). A mix of thematic analysis and narrative summary was utilized.

As expected from preliminary reading, the themes identified included symptom burden, alongside unmet needs, and support networks. The exploration of myeloma as a chronic condition was a more subtle theme that hadn’t been seen elsewhere in the literature focusing on the use of quality of life questionnaires. As the purpose of this scoping review is to highlight areas for further exploration by focusing on narrative studies only, an interesting discussion point subsequently emerged.

All studies were small-scale studies, with patients from a range of hospitals and trusts, worldwide—this includes Ireland, United Kingdom, Germany, France, Italy, Spain, Australia, United States, and Canada. Studies used an interview format (to provide the narrative feature as required by the inclusion criteria seen in Table 1) which ranged from semistructured to unstructured interviews as well as focus groups. The key themes that emerged in this review were that myeloma was increasingly being

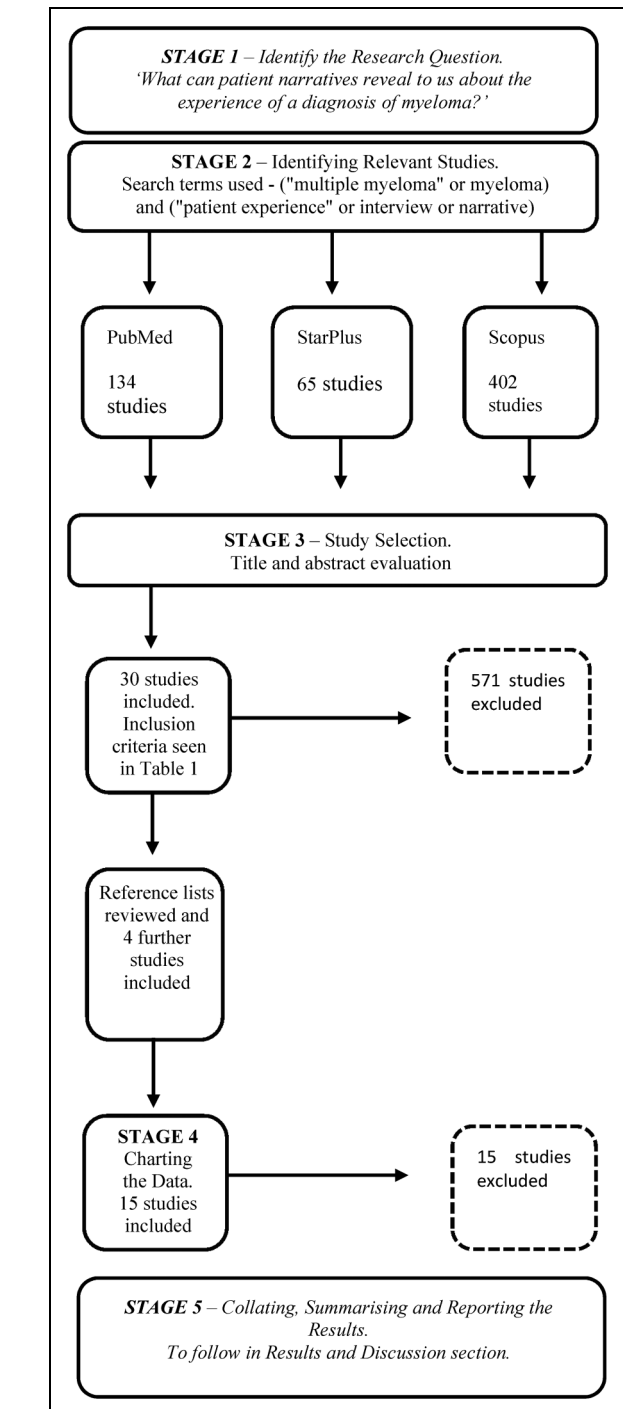


Figure 1. The process of searching the literature and identifying relevant studies.

experienced as a chronic condition, the challenge of meeting the needs of patients, the challenge of the symptom burden in the overall experience, and the role of the family.

Myeloma as Chronic Condition

The theme of myeloma being experienced as a chronic disease process emerged in around half of the studies included in this

Table 1. Inclusion and Exclusion Criteria Used During the Search Process.

Inclusion criteria	Exclusion criteria
Reported original data	Reported in a language other than English
Focussed on patient experience of Myeloma	Published before 2000
Primary data from patient's own perspective	Primary focus on therapeutic regimes
Published between 2000-2021	Primary focus on Quality of Life
	Another haematological cancer was the predominant focus
	Primary data from carer's perspective

review (2,6,11–15). The therapeutic options for both transplant eligible and ineligible patients have advanced significantly. This means that for some patients instead of managing a short-term diagnosis, myeloma is instead experienced as a chronic condition, intruding into daily life, and demanding a high degree of self-management (13). It appeared, as a result, that the typical approach to managing myeloma in the clinic may be out of step with the lived experience of the condition.

Seven of the 15 articles focused on the experience of myeloma as a relapsing condition that inevitability induced fear and anxiety (2,5,12–16). Many of the patient narratives explained the heightened anxiety leading up to appointments, this would feed into a feeling of living in a state of prolonged uncertainty. One patient described it as living with a “darker force” and remarked that they were anxious about “running out of time,” and that it left them “afraid to look ahead” (2). This was not the only description of its kind. The inability to forward plan has a huge impact on both the individual and family (12), predictably leading to increased emotional and psychological stress. This is something that has been highlighted in an important previous qualitative synthesis (8).

Some patient narratives also outlined that although symptoms were expected to be the largest burden, the complex threat of recurrence and fragility in maintaining a normal lifestyle caused the most distress (4,11,12). One article described that living in an “ever-shifting perspective between illness and wellness consequently maintains a state of uncertainty” (11) and the impact of this cannot be underestimated. Approaching myeloma treatment with a different mindset, one that appreciates its chronic nature, has the potential to improve services and support to help patients adapt to living and coping with myeloma. With further research, we might be able to better understand the exact changes that could be made to benefit patients, making this an area worthy of further exploration.

Meeting the Needs of Patients

Accessing healthcare is a very personal experience (2) and this was well supported in the literature. Although one article described the utility of patient support groups (16), another mentioned the use of denial and not accessing information as a preferred coping mechanism (17,18). For one patient, this was undoubtedly the method of choice and they opted to not access information as otherwise, “you’d go out of your head” (17). Healthcare professionals cannot

be expected to immediately know the most appropriate strategy for each patient. However, by appreciating and improving emotional guidance for patients through the process, it may be possible to build more trust in the healthcare system (12,13). For example, without full understanding of how to access services and the limits on continuity of care (2,14,15) (which can increase trust and comfort in accessing healthcare), patients may not feel confident enough to reach out for extra support. This leaves them with unmet needs and a feeling of bewilderment at the healthcare system (17). Looking at integrating emotional guidance could be a simple first step to improving patients’ experiences.

The narratives of living with myeloma also reveal disparities in perceived and experienced needs. A common example of this is when doctors perceived a lack of time to provide information to patients (6,12,16) when realistically, patients in these studies indicated that their information needs were satisfied. Such needs are, after all, built into the management process. So while the previous qualitative “meta-aggregation” (8) has highlighted the importance of emotional well-being, new research since 2018 and the publication of this paper highlights the importance of emotional and psychological support (17) as a prominent sentiment in the literature. Many patient narratives expressed thoughts similar to one patient who felt they “didn’t want to burden the doctors” with their “emotional problems because that wasn’t their job...their job is to see to the physical problems” (17). Through experiencing an illness, many patients learn firsthand the practical matters related to their illness and with personal research (11) and a wealth of appointments, many do become the “expert patient” (15). However, learning to mentally cope and navigate healthcare is a hard process which can require specialist input and personal acceptance (17). In a handful of articles, this psychological support was organized and provided by a nurse-led team and when in place, was highly regarded (6,11). This review adds to the strong literature base, mainly centered on nursing (8), to suggest that perhaps the whole team who have regular interactions with patients, may be able to provide more sustained emotional support. Clearly, further work is needed to explore what this might mean.

Symptom Burden and Overall Experience

In all this literature, the physical experience of symptoms tends not to be the focus of distress, but rather, the symptoms

themselves tend to trigger more complex emotions, that perpetuate the difficulties of experiencing illness. Peripheral neuropathy, fatigue, and hair loss were all mentioned as problematic because these symptoms had the power to change patients' sense of who they are (5,6,11,18,19). This was articulated by one patient, who described, "I am not liking what I am seeing. I don't like being the way I am right now because it doesn't look like me. It doesn't feel like me. It's not what I am really." By bringing patient narratives to the fore it is clear that visual symptoms and inability to function in work and in the home (2,5,18) are the symptoms that make it impossible to hide from the label and feeling of being "ill" (17). Narrative studies have been favored in this scoping review in contrast to more widely seen "quality of life" questionnaires which seek to quantify symptom burden because narratives can explore in more depth the social and psychological dimensions of patient experience. These aspects of the experience can be masked when a predominantly clinical approach to analysis is adopted making narrative interviews important for identifying gaps in the knowledge base.

When focusing on diagnosis, most patients tell a story and focus much more on key phrases, emotions, and lifestyle changes (20) rather than the actual physical, medical issue at the time. This redirects the focus of research to look at the whole experience rather than only the biomedical approach (12). Myeloma tends to have a chaotic and delayed pathway to diagnosis (21), so when the diagnosis is given, there is no alteration in physical symptoms. Instead, it is a lifestyle and an inner feeling that changes almost instantly. One patient compared his feelings at the time of diagnosis to when he had spun off an icy road in his car. Although he escaped the accident unscathed, he was left with a "numb feeling." He likened this feeling to how he felt when listening to his diagnosis and rather than experiencing an emotional response, he "digested the information without a reaction" (20). This transition period is clearly complex, with some patients not realizing they truly were ill until the chemotherapy drugs were already "pumping" into them (20). Coping with this appears to be neglected in interactions with doctors, with a demand for a holistic focus prevalent in the literature.

The Role of Family

Family was the final prominent feature of the research findings in the literature. In most cases, families were purely positive, providing a strong support network. For others, the complex emotional and physical experience led to people pushing away friends and family in an attempt to protect, to feel "normal," or to prevent becoming a burden to their family (18). Indeed many expressed feelings similar to this patient who stated, "a lot of stuff that I had feelings about, I just kept quiet." Support from family was largely seen in the diagnostic process and family often encouraged patients to stop normalizing symptoms, seek help and not delay the

process any further (21,22). Although family dynamics (5) are individual to each patient, they form a central part of the qualitative research and clearly, the patient experience.

Discussion

For medical professionals, patient narratives provide a unique opportunity to understand the other side of their clinical practice. By removing the pressures and societal norms that may prevent patients from being genuine in their interactions with doctors and providing a space for patients to be candid, we can more effectively explore the needs of our patients. By bringing patient narratives of myeloma to the fore, this review reveals the subtle factors that contribute to the experience of myeloma. The rich evidence provided can help the whole team including doctors appreciate the emotional impact of the disease process on patients and the importance of managing this. Much of the previously published literature has focused on nurse-led emotional support. In conducting this research, we can appreciate that support from doctors and other members of the team may also form an important aspect of clinical care. This would lead to all members of the MDT working together, to support patients. If this were the case then there may well be potential to make real change. It may also be the case that specific interventions either derived from clinical psychology or other evidence-based approaches could be integrated into care pathways.

The literature suggests that clinic appointments are a complex experience for patients in which they feel, for unclear reasons, that they are only able to focus on clinical matters (11). As a result, patients may find it inappropriate to bring up matters associated with emotional support and instead, be left coping independently with the psychological impacts of illness. Without emotional needs fitting into a test result or the time-pressured environment of clinics, it can seem difficult to approach the subject. Addressing the psychological needs of patients—a clearly central part of the experience—is therefore something that needs to be carefully considered. When talking about symptom burden in interviews, patients tended to lead on to how this had impacted them emotionally. By undertaking further narrative interviews, we may be able to better understand why these barriers arise and work to improve the integration of emotional support into the patient journey.

The key themes established in this qualitative scoping review can provide useful synthesized evidence on the experience of myeloma, both to guide research into better meeting the needs of our patients (23) and also to provide useful information to those practicing medicine. Previous research has described how myeloma treatment (and therefore the experience and prognosis) is undergoing change, which is only set to continue. Yet in most of this literature, it seemed that most patients were still being approached as if they had an acute, life-threatening diagnosis, leaving little time for adjusting in everyday life. Myeloma patients are experiencing both

acute and chronic diagnoses and it seems it is time to explore how to appropriately address both dimensions of this condition.

Care pathways exist to guide treatment and therefore shape the patient journey. These care pathways are unique to each malignancy, in each area making them a useful tool for comparison and evaluation. For example, in Sheffield and Oxford (UK), care pathways are built on chemotherapy guidelines (24,25). As a result, patient contact is based on these cycles. This research suggests that patients should have access to both medical and psychological support at the beginning and end of each cycle. It would be an interesting next step to explore the efficacy and degree of patient-centered care involved in various care pathways. It is evident from this review that without advocacy from family or others throughout the care pathway, many patients may well not be receiving enough emotional support.

Current approaches to care find it easy to provide symptomatic support, but still have far to go when it comes to the topic of mental health and emotional support. The feeling of discomfort and intrusion when broaching this subject can be felt by the doctor and indeed reciprocated by the patient. It would be a generalization to expect all patients to want to receive emotional support from healthcare professionals. However, by shying away from this topic routinely, we appear to be depriving support to groups of patients. Much of the literature has described apprehension building as appointments approach, with the experience of appointments developing into an emotional climax. This can prevent patients from interacting naturally during the appointment and therefore not benefitting as much as possible from the interaction. Exploring ways this could be addressed is not only what patients deserve but could also have a significant positive impact on outcomes and cost. Without research into this aspect of care we will not really know how far this might be true.

Conclusion

Overall, it appears that appointments center around results, treatment regimes, physical symptoms, and management. In a society where we are looking to change the narrative and speak openly about mental health and illness, it seems only fitting to challenge our approaches to patients with myeloma. Coping with a chronic disease process is significantly different from an acute illness, with both having the power to instantly change the lives of those who experience them. In a public healthcare system, it is impossible to approach every single patient in a personalized way, but alongside the advances in treatment, we are capable of scrutinizing care pathways and trialing new methods, structures, or approaches to advance the patient experience and optimize services. This scoping review has allowed the general context of the experience of myeloma to be more comprehensively understood. The main themes identified in this process do corroborate with what was expected. However, the literature

has directed the focus of future research more toward emotional coping and adjustment than initially expected.

Limitations and Next Steps

This qualitative scoping review has only been able to map out the literature and therefore no changes or interventions have been suggested. To do so, further narrative interviews will need to be conducted, as well as comparison to other services internationally alongside more research into outcomes, cost efficiency, and other factors. The data reported in this paper is taken from around 100 participants, from different healthcare systems worldwide. Future research on more patients, from different demographic groups, is needed. The literature reported here was synthesized qualitatively rather than being critically appraised for its methodology and reliability. This is a potential area of improvement but one that was chosen as the findings of the study could be more eloquently presented in this way. This scoping review purposely excluded the literature that focused on carers and their needs, in an attempt to focus on the reality of the patient experience. However, the complex experience of chronic illness along with all the accompanied uncertainty appears in the literature to be sometimes better articulated by those around the patient and may form part of future research.


Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Zoë Rubins  <https://orcid.org/0000-0002-0926-1181>

References

1. Larocca A, Bonello F, Gaidano G, D'Agostino M, Offidani M, Cascavilla N, et al. Dose/schedule-adjusted Rd-R vs continuous Rd for elderly, intermediate-fit, newly diagnosed multiple myeloma patients. *Blood*. 2021;137(22):3027-36. doi:10.1182/blood.2020009507
2. Cuffe CH, Quirke MB, McCabe C. Patients' experiences of living with multiple myeloma. *Br J Nurs*. 2020;29(2):103-10. doi:10.12968/bjon.2020.29.2.103
3. Rajkumar SV, Kumar S. Multiple myeloma current treatment algorithms. *Blood Cancer J*. 2020;10(9):94. doi:10.1038/s41408-020-00359-2
4. John S, Broggio J. Office for National Statistics—Cancer survival in England—adults diagnosed, 2019.
5. Vlossak D, Fitch MI. Multiple myeloma: the patient's perspective. *Can Oncol Nurs J*. 2008;18(3):141-5. doi:10.5737/1181912x183141145

6. Kelly M, Dowling M. Patients' lived experience of myeloma. *Nurs Stand*. 2011;25(28):38-44. doi:10.7748/ns2011.03.25.28.38.c8397
7. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci*. 2010;20(5):69. doi:10.1186/1748-5908-5-69
8. Hauksdóttir B, Klinke ME, Gunnarsdóttir S, Björnsdóttir K. Patients' experiences with multiple myeloma: a meta-aggregation of qualitative studies. *Oncol Nurs Forum*. 2017;44(2):E64-E81. doi:10.1188/17.Onf.E64-e81
9. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19-32. doi:10.1080/1364557032000119616
10. Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Policy*. 2005;10(1):45-53. doi:10.1258/1355819052801804
11. Monterosso L, Taylor K, Platt V, Lobb E, Musiello T, Bulsara C, et al. Living with multiple myeloma: a focus group study of unmet needs and preferences for survivorship care. *J Patient Exp*. 2018;5(1):6-15. doi:10.1177/2374373517715011
12. Maher K, De Vries K. An exploration of the lived experiences of individuals with relapsed multiple myeloma. *Eur J Cancer Care*. 2011;20(2):267-75. doi:10.1111/j.1365-2354.2010.01234.x
13. Stephens M, McKenzie H, Jordens CFC. The work of living with a rare cancer: multiple myeloma. *J Adv Nurs*. 2014;70(12):2800-9. doi:10.1111/jan.12430
14. Cormican O, Dowling M. Living with relapsed myeloma: symptoms and self-care strategies. *J Clin Nurs*. 2018;27(7-8):1713-21. doi:10.1111/jocn.14232
15. Cormican O, Dowling M. Managing relapsed myeloma: the views of patients, nurses and doctors. *Eur J Oncol Nurs*. 2016;23:51-8. doi:10.1016/j.ejon.2016.04.003
16. Hulin C, Hansen T, Heron L, Pughe R, Streetly M, Plate A, et al. Living with the burden of relapse in multiple myeloma from the patient and physician perspective. *Leuk Res*. 2017;59:75-84. doi:10.1016/j.leukres.2017.05.019
17. Molassiotis A, Wilson B, Blair S, Howe T, Cavet J. Living with multiple myeloma: experiences of patients and their informal caregivers. *Support Care Cancer*. 2011;19(1):101-11. doi:10.1007/s00520-009-0793-1
18. de Wet R, Lane H, Tandon A, Auguston B, Joske D. 'It is a journey of discovery': living with myeloma. *Support Care Cancer*. 2019;27(7):2435-42. doi:10.1007/s00520-018-4502-9
19. Potrata B, Cavet J, Blair S, Howe T, Molassiotis A. Understanding distress and distressing experiences in patients living with multiple myeloma: an exploratory study. *Psychooncology*. 2011;20(2):127-34. doi:10.1002/pon.1715
20. Schaepe KS. Bad news and first impressions: patient and family caregiver accounts of learning the cancer diagnosis. *Soc Sci Med*. 2011;73(6):912-21. doi:10.1016/j.socscimed.2011.06.038
21. Howell DA, Hart RI, Smith AG, et al. Myeloma: patient accounts of their pathways to diagnosis. *PLoS One*. 2018;13(4):e0194788. doi:10.1371/journal.pone.0194788
22. Howell D, Hart R, Smith A, et al. 'Unpacking' pathways to lymphoma and myeloma diagnosis: do experiences align with the model of pathways to treatment? Findings from a UK qualitative study with patients and relatives. *BMJ Open*. 2020;10(2):e034244-e034244. doi:10.1136/bmjopen-2019-034244
23. Polit DF, Beck CT. Generalization in quantitative and qualitative research: myths and strategies. *Int J Nurs Stud*. 2010;47(11):1451-8. doi:10.1016/j.ijnurstu.2010.06.004
24. Snowden J, Chantry A, Ezaydi Y. Clinical guidelines for plasma cell malignancies, <http://www.yhscn.nhs.uk/media/PDFs/cancer/Haem%20docs/SYR%20Network%20Guidelines%20for%20Myeloma.pdf> (2017, accessed February 11, 2022).
25. Ramasamy K. TVSCN Myeloma NSSG Algorithm, <http://nssg.oxford-haematology.org.uk/myeloma/op-policy-and-guidelines/MM-29-myeloma-algorithm.pdf> (2020, accessed February 11, 2022).

Appendix I

	Primary author	Year	Title	Participants	Method	Key findings
(14)	Cormican and Dowling	2018	Living with relapsed myeloma: Symptoms and self-care strategies	Ireland 15 participants	Focus groups that were audio-taped, transcribed, and thematically analyzed.	<ul style="list-style-type: none"> – Main themes—symptom burden of peripheral neuropathy, fatigue, steroid-induced effects. Self-care (risky behaviors), feeling vulnerable, and needing continuity – Managing a relapsing condition is a difficult process, patients would benefit from continuity in being supported through the range of issues (outlined above), as this helps with patient education and empowerment – a more structured approach could help with this and prevent patients presenting with very severe relapses
(15)	Cormican and Dowling	2016	Managing relapsed myeloma: The views of patients, nurses, and doctors	Ireland 8 relapsed myeloma patients	Focus groups and individual interviews with thematic analysis	<p>Main themes—“shared decision making with the expert patient” and “unpredictable disease journey”</p> <p>relapsed patients tend to be more informed and makes the experience easier—this relies on personal background reading however</p> <p>talk about palliation earlier</p> <p>Need for comfort and support—but often not accessed as prefer to keep to themselves</p> <p>Trust results in better outcomes but takes time to build</p> <p>Referrals to palliative care aren’t timely</p> <p>Good example interview questions</p>
(2)	Cuffe et al	2020	Patients’ experience of living with multiple myeloma	Ireland 6 people with at least a years long diagnosis	Unstructured interviews	<p>Delayed diagnosis and difficulty in communicating with health professionals enough were prevalent. Disparities with different cancers could be attributed to a lack of widespread knowledge</p> <p>Severe side effects, especially peripheral neuropathy has a large symptom burden</p> <p>Support from doctor or family is a personal preference</p> <p>Relapses induce fear and anxiety, therefore a holistic approach needed</p>
(16)	Hulin et al	2017	Living with the burden of relapse in multiple myeloma from the patient and physician perspective	United Kingdom, France, Germany, Italy, and Spain 50 patients	Semistructured interviews that we analyzed with Verbal Rating Scales + graphical, hand drawn depiction of emotions over time	<p>First relapse seemed to be the most devastating and biggest burden on the family → large negative emotional impact</p> <p>Barriers to communication with doctor link to workload.</p> <p>May not have the time tools or training to address this</p> <p>Suggest self-tracking and patient advocacy groups</p>

(continued)

Appendix I (continued)

	Primary author	Year	Title	Participants	Method	Key findings
(11)	Monterosso et al	2018	Living with Multiple Myeloma: A Focus Group Study of Unmet Needs and Preferences for Survivorship Care	Australia 18 participants for 2 structured focus groups	Focus groups structured around themes from the literature and analyzed using codes and themes	Information mainly found on the internet Results in advance to gain the most from appointments? Side effects were often not prepared for well enough and found peripheral neuropathy, fatigue, and hair loss most impactful Pressure to have a positive outlook Chronicity Nurse-led care was suggested as something to improve the link and dynamic relationship needed
(22)	Howell et al	2020	“Unpacking” pathways to lymphoma and myeloma diagnosis: Do experiences align with the Model of Pathways to Treatment? Findings from a UK qualitative study with patients and relative	55 patients interviewed	Semistructured interviews which made up the qualitative part of a mixed methods analysis	Pathway to diagnosis was similar to the MPT but was more chaotic Hyperawareness of symptoms Self-help and alternative therapies were used commonly for side effects. Symptoms often attributed to self-limiting issues Often symptoms were put off, attributed to different things and it was friends/family that made the first seeking of help First presentation often didn’t lead to diagnosis—potentially as symptoms are vague and commonly seen In representation, patients had to be more forceful and needed family to advocate to get tests etc. Lots of patients blamed themselves for the delayed diagnosis Chaotic pathways lead clearly to increased anxiety. Family input was substantial at all parts
(21)	Howell et al	2018	Myeloma: Patient accounts of their pathways to diagnosis.	20 patients United Kingdom	In depth, individual interviews that had a list of topics to explore but overall could be led by the patient	Pathway to diagnosis was never linear. There was a large range of reported symptoms, namely back pain. These all tended to be gradual and subtle Normalization and adaptation to symptoms were common → often felt it was only family who made them seek help. Often felt it was their fault the diagnosis was delayed. Others felt GPs didn’t have a full understanding of myeloma Mixed opinions of continuity of GP Overall the nature of myeloma and plausibility of initial diagnosis is the issue—might make people feel regretful and silly

(continued)

Appendix I (continued)

	Primary author	Year	Title	Participants	Method	Key findings
(17)	Molassiotis et al	2011	Living with multiple myeloma: experiences of patients and their informal caregivers	Purposeful selection of those who had filled out a survey on supportive care needs. 20 were selected Manchester	Cross-sectional design using semistructured interviews. Analyzed on the principles of grounded theory. Used qualitative and quantitative methods	Difficult to cope with the sudden label of being “ill” Big impact on daily life due to fatigue and back pain. Large impact on work Coping mechanisms include overreading, ignoring the issue, keeping active, concealing so as not to burden others Unmet needs didn’t surround information but more access to support services and adapting to life with myeloma
(19)	Potrata et al	2010	Understanding distress and distressing experiences in patients living with multiple myeloma: an exploratory study	Manchester 15 patients	Semistructured interviews with a retrospective view and cross-sectional using qualitative methods. Some ethnic minorities were purposefully selected.	Distress from symptoms tended to touch on briefly or attribute to other causes Body changes such as shrinking and hair loss had a big impact—visually obvious Family and friends constant inquiry into health can be distressing although were also spoken of very positively Not knowing whether some information was true was distressing for the “expert patient” Stem cell transplant was seen as very traumatic—seen as temporary destruction of the self which can cause considerable anxiety Overall it’s not the symptoms that cause distress but the complex threat and change of lifestyle they cause
(18)	de Wet et al	2019	“It is a journey of discovery”: living with myeloma. Supportive Care in Cancer	15 participants England	Qualitative phenomenological study—semistructured interviews that continued to the point of saturation	- Lifestyle changes mainly due to fatigue and physical symptoms—unable to function normally - Affected the family and caused a lot of relationships to break down or lose friends - Loss of sense due to physical capability, appearance, etc - Lots of different approaches to adjusting. Do you just get on with it or do you make changes? - A new outlook on life mainly centered around family - Very little mention of needing support from healthcare professional—some found this depressing - Tablet burden - Suggests more screening tools to check physiological and psychological coping mechanism
(6)	Kelly and Dowling	2011	Patients’ lived experience of myeloma.	11 participants Ireland	Hermeneutic phenomenological approach Hour long interviews with a guide of questions	Lived body—inability to hide once hair had fallen out and fatigue Living in limbo as not much is known about myeloma and not commonly heard of—stigmatizing and isolation loss of sense of self but some felt lucky due to advances and treatability

(continued)

Appendix I (continued)

	Primary author	Year	Title	Participants	Method	Key findings
						<p>Fear of recurrence. Nurses would be vital here for psychological support</p> <p>Limited time with healthcare professional</p> <p>Family and talking to others with myeloma was spoken about widely. All welcomed participating in the study because of this</p> <p>Similar to other cancers by the unknown nature adds to distress and potentially feel more time needed for questions</p>
(12)	Maier and De Vries	2011	An exploration of the lived experiences of individuals with relapsed multiple myeloma	8 participants London	Hermeneutic phenomenology was used after conducting open-ended, unstructured interviews	<p>Feeling of uncertainty was overarching and present in all parts of life</p> <p>Intuitive knowledge about their body which kept them constantly on high alert</p> <p>Maintenance of normality and adjustment was constant and fluid—links to the Shifting Perspectives model of Chronic illness (Paterson 2011)</p> <p>Spirituality was something positive to come out of it along with hope</p> <p>Often wary of wasting doctor's time and having to put a lot of trust in healthcare professional</p>
(20)	Schaepe	2011	Bad news and first impressions: Patient and family caregiver accounts of learning the cancer diagnosis	United States 28 participants	<p>Semistructured guided interviews took place at 4 intervals</p> <p>Used grounded theory to analyze</p>	<p>The diagnostic process was made into a narrative by patients and focussed much more on the multiple interactions with healthcare than the diagnosis itself</p> <p>Many only deeply understood the diagnosis after a period of time had passed</p> <p>Acute or subacute onset makes a big difference to the experience</p> <p>The ability to cope with news is strongly linked to the execution of disclosure</p>
(13)	Stephens et al	2014	The work of living with rare cancer: multiple myeloma	Australia 21 patients with progressive or relapsed myeloma	In depth interviews carried out 3 times in a 12-18 month period	<p>Creates work through calculating risk (to well-being, injury, infection and to carers well-being) and also emotionally (changed a lot around appointment times when anxiety and sadness was often reinforced)</p> <p>The fact that people are living longer changes the approach</p> <p>Chronic illness is well known to intrude into everyday life and demands a lot of self-management</p>

(continued)

Appendix I (continued)

	Primary author	Year	Title	Participants	Method	Key findings
						Constantly working to manage the risk while decreasing the impact on their own and their carers well being
(5)	Vlossak and Fitch	2008	Multiple myeloma: the patient's perspective	20 patients Canada	In depth, open-ended interviews focusing on demographics, personal experience in treatment and diagnosis, and impact Transcripts were thematically analyzed and then categorized	All found the diagnosis shocking and felt their lives changed almost instantly Treatment options depended a lot on age and responsibility in family Dramatically changes the family dynamic—often changes self-image Fatigue was very prominent for all and one of the other strongest feelings was that of a loss of independence Uncertainty and obsession around recurrence Almost all were satisfied with the medical care they received but it was their emotional and psychological needs that required and due to that lack of cure, sometimes this is difficult to address in the more mainstream ways as hope is related to healthy prolonged life rather than cure