

Review Article

Multiple Myeloma in People of Working Age: A Systematic Review and Evidence Synthesis of Experiences of Paid and Unpaid Work

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Introduction. This review sought to synthesise the qualitative evidence pertaining to the experiences of myeloma patients and relatives of work, given the distinct symptom burden and illness trajectory. **Methods and Designs.** CINAHL, Medline, Web of Science, PsychINFO, SocIndex were searched on 22-Apr-2022. No limiters were used for language or date of publication. CASP was used for critical appraisal. An integrative synthesis was conducted to inductively construct analytic themes PROSPERO CRD42022323137. **Results.** 34 articles were included, published from 2004 to 2022. Nineteen were assessed as having low risk of bias, and four with moderate risk of bias. The following four themes were derived from analysis of the papers: (i) side effects, medicines, and stigma; (ii) relationships; (iii) creation and maintenance of identity; (iv) privilege and income. **Conclusion.** Myeloma impacts the engagement of patients and relatives in paid and unpaid work, yet very little is currently known on how the cancer impacts these important interdependent systems. Addressing workplace stigma, understanding the role of workplace relationships, the construction of self through work, interpreting data through a lens of life-course and, privilege offer helpful starting points.

1. Introduction

Myeloma (also known as multiple myeloma) is rare blood cancer that forms in the bone marrow. New treatment options such as high-dose therapy and autologous stem cell transplant significantly lengthen survival. However, myeloma remains incurable, and the disease becomes more aggressive and drug resistant over time, with shorter response intervals. The impact on people's lives can be considerable with treatments extending for years, with a high symptom burden such as pain, fatigue, and anxiety impacting quality of life [1–3].

Since the median age of diagnosis is 69 years [4], many patients are of working age. Combining illness, treatment, and work and life-cycle transitions present specific stressors. These impacts require better understanding to inform treatment decision making, employer supports, and the patient's engagement in meaningful activity.

The literature on employment and cancer is vast and growing, documenting a wide range of areas including the long and short term impacts [5–7], psychosocial factors [8, 9], return to work [7], and earnings [10–12]. Financial toxicity is a recognised risk for people living with cancer [12, 13], linked with reduced working hours (for patient and/or informal carer), and costs of treatments.

The impact of treatment side effects on work has been well-documented, and the subject of recent systematic reviews [14, 15]. Higher symptom burden is routinely associated with lower levels of engagement in employment, with fatigue being commonly cited as particularly problematic [16]. Other chronic symptoms and lack of workplace support are linked with poorer work engagement [17].

Many cancer survivors report negative work experiences, including deteriorating physical and mental health [18]. Recommendations have been made from qualitative studies for supporting people living with cancer in the workplace,

including gradual return to work, modifying performance expectations, supportive measures, and modifying the environment [19].

Stigma from cancer impairs employees' engagement in the workplace, leading to discrimination [20] and ultimately job losses [21] through contract termination, resignation, or demotion [22]. When work becomes problematic through symptom management or stigma, there are wider consequences for the individual's identity [23–25].

While such evidence is helpful in mapping the landscape of work and cancer, to date there has been limited focus on working age adults with myeloma to understand the impact on work and lives. Consequently, this research aims to synthesise the qualitative evidence pertaining to the work-related experiences of myeloma patients and relatives, given the distinct symptom burden and illness trajectory.

The review's research question was as follows: what are the experiences of working age people who have been treated for myeloma, and their family members?

2. Methods and Designs

Qualitative evidence synthesis is interpretative or aggregated [26], and the methodological interrogation of qualitative literature, via systematic review, can substantially add to the synthesis of evidence [27]. The approach intends to help develop new understanding and theories [28] and better comprehension of nuance in the phenomena of interest [29]. For this systematic review, an interpretative form of qualitative evidence synthesis, thematic synthesis [30], was chosen as the methodology.

2.1. Protocol and Registration. This qualitative evidence synthesis was conducted following the preferred reporting items for systematic reviews and meta-analyses (PRISMA) [31] reporting guidelines.

An *a priori* protocol was registered on the International Prospective Register of Systematic Reviews (PROSPERO CRD42022323137).

2.2. Study Eligibility Criteria. Table 1 outlines core study eligibility, focused on multiple myeloma including both patients and family members. Papers were included if qualitative data on myeloma could be separated from other cancers/conditions reported. Data were also included if authors included text such as “most participants said...” since the framing implies that even in a mixed sample there is a high likelihood that the claim applies to people with myeloma.

Papers were eligible for inclusion if data were collected from people under the age of retirement (this was operationalised as the national eligibility age for retirement, for the country where the study was conducted) or retirees talking about prior employment. Where age of sample spanned pre- and post-retirement, papers were included if data/quotes were reported with participant age, or where the mean age was under the country's retirement age. Consequently, some papers had older participants, but data were

extracted based on length of time since diagnosis and current age to interpret the meaning related to engagement in work and important activities.

Work was operationalised as referring to paid employment, voluntary work, and homemakers (including providing informal care to children or adults). Unpaid work was included, operationalised as tasks where someone would need to be paid to undertake the activity if they were unable to do it (such as dog walking).

No limits were used regarding date or language of publication.

2.3. Information Sources. Two reviewers (TS and LB), one experienced qualitative researcher and one clinical researcher with a background in systematic reviews, conducted a comprehensive search utilising the MEDLINE (via PubMed), CINAHL (via EBSCO), PsycINFO, SocIndex, and Web of Science databases from inception to 22-Apr-2022. This included a mixture of keywords and MeSH terms for multiple myeloma, work and qualitative research (Appendix).

2.4. Study Selection. Following removal of duplicate results, four reviewers (TS, LB, LF, and KG) independently screened titles and abstracts from the search utilising Rayyan Computing Research Institute (QCRI) Software [32]. Full texts of remaining articles were screened against eligibility criteria. Disagreements were resolved in consensus meetings between reviewers.

2.5. Data Collection and Synthesis. Initial data extraction included study and participant characteristics such as authors' name, publication year, country, language of paper, sample size, age, participant role (patient or family member), data collection method, and the data-analysis strategy used (Table 2). Qualitative evidence was regarded as textual data contained within the abstract, findings, or discussion sections of included studies [30]. We extracted data for analysis including authors' themes and interpretations alongside direct quotations from study participants [33] relating to paid and unpaid tasks indicated by participants to be important. All data extraction was conducted by three reviewers (TS, LB, and LF).

Extracted data were organised in Excel, which was also used to capture memos related to each source. Initial thematic coding was conducted using Excel and an online whiteboard.

Synthesis focused on the area outlined in the aims, to understand patient/family experiences of myeloma on work and other unpaid activities of importance to them.

Commencing with a process of familiarisation with the data, three reviewers (LF, TS, and LB) generated initial categories and codes. In an overlapping three-stage process, all three reviewers (LF, TS, and LB) coded findings inductively, line by line [30]. An initial descriptive label was applied based on content and meaning for each line coded. In many instances, team members applied several

TABLE 1: Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
22-04-22	People under the age of retirement at start of treatment and their families and/or significant others	People over the age of retirement at start of treatment and nonfamily/significant others
Sample	Treated for multiple myeloma (includes relapsed or refractory (any variation))	Not treated for multiple myeloma (any variation)
Phenomenon of interest	Any qualitative design, or mixed method design that includes, for example, interviews, focus groups, questionnaires, and surveys, which report qualitative data relating to the work-related experiences of people under the age of retirement, and/or their families, being treated for multiple myeloma	Mixed method designs where qualitative data are not reported separately and cannot be extracted or is unrelated to the work-related experiences of people under the age of retirement, and/or their families/significant others, being treated for multiple myeloma
Design	Explores work-related experiences, attitudes, and perspectives of working age people being treated for multiple myeloma, and/or their families/significant others, and how these have impacted their ability to engage in paid employment and/or unpaid activities of importance	Quantitative designs
Evaluation	Qualitative studies, and mixed method studies, where qualitative data are reported separately	Studies that do not explore work-related multiple myeloma experiences of people under the age of retirement, and/or their families
Research	Studies from inception to 2022	Quantitative studies or mixed methods studies where the qualitative data cannot be extracted
	Studies published in any country, in any language	N/A
Others	Primary peer-reviewed research, systematic reviews with third order analysis, and PhD theses	N/A
		Primary research that is not peer reviewed, secondary research including systematic reviews without third order analysis, conference abstracts, editorials, or any grey literature which is not a PhD thesis

TABLE 2: Detailed study characteristics.

Author	Year	Location	Sample size	Mean age (range)	Patient/family or both
Coon	2004a	USA	21	52 (36–70)	Patient
Coon	2004b	USA	21	52 (38–70)	Patient
Johansson	2005	Sweden	12	56 (37–70)	Patient
Fine Dahan	2006	USA	6	57 (50–66)	Patient
Vlossak	2008	Canada	20	59 (44–88)	Patient
McGrath	2009	Australia	10 (8 with myeloma)	53.9 (23–72)	Patient
Potrata	2010	UK	15	58.2 (42–75)	Patient
Maher	2011	UK	8	Not specified (48–74)	Patient
Kelly	2011	Ireland	11	63 (42–83)	Patient
Molassiotis	2011	UK	20 (patients) 16 (family)	61.8 (not specified)	Both
Potrata	2011	UK	15	58.2 (42–75)	Patient
Craike	2013	Australia	24	62 (48–78)	Patient
Osborne	2014	UK	31	64 (median) (41–81)	Patient
Baz	2015	USA	20	60.4 (48–77)	Patient
Wagland	2015	Australia	5	48 (not specified)	Patient
Cormican	2016	Ireland	8 patients	Not specified (55–85)	Patient
Morris	2017	UK	7 (family)	55.6	Family
Asfaw	2018	USA	20	59 (29–71)	Patient
Cormican	2018	Ireland	15 (patients) 9 (family)	66 (51–80)	Both
Clifton	2018	Australia	18 (3 with myeloma)	51 (45–61)	Patient
Monterosso	2018	Australia	14	56.5 (age range: 36–74)	Patient
De Wet	2019	Australia	15	62 (51–74)	Patient
Parsons	2019	Canada	32	66 (51–83)	Patient
Quinoa-Salanova	2019	Spain	12	Mean not specified (40–>70)	Family
Cuffe	2020	Ireland	6	67.5 (63–73)	Patient
Jen	2020	Singapore	12 (patients) 12 (family)	Ages not specified	Both
Bennink	2021	Netherlands	9	54 (47–59)	Patient
Gries	2021	USA	30	69 (55–88)	Patient
He	2021	UK, France, Germany	30	60 (not specified)	Patient
Janssens	2021	Belgium, Finland, Romania, Spain	24	61 (46–73)	Patient
LeBlanc	2021	USA	15	64 (46–88)	Patient
Pritlove	2021	Canada	16 (patients) 8 (family)	Patient: 65 (57–70) Partner: 62 (41–68)	Both
Crawford	2022	USA, Canada, UK	39	60 (48–72)	Patient
Mccaughan	2022	UK	35 (patients) 10 (family)	Mean not specified (50–80)	Both

descriptive labels to capture multiple content and meaning within lines. Next, each label was defined, to explicitly illuminate the code meaning, with reiterations of the process until all data were coded and no new codes derived [34]. Last, to enhance the review's credibility, analytic memos, as reflective commentary, were written to record initial interpretations, and to identify emergent patterns and generated themes [35]. Although background literature did not have a formal role in informing analysis, the development of codes was done in cognisance of what would add to, rather than replicate, what was already available in the published literature. Categories and second order analytic themes were developed by three reviewers (LF, TS, and LB) and full agreement was reached on final descriptive and analytical themes of the study. Studies were compared and themes derived by identification of patterns across datasets by three reviewers (LF, TS, and LB). Codes were inductively identified, continually compared, and reorganised into both

descriptive and analytical themes [30]. In an iterative process, and following coding of the first study, remaining studies were coded into pre-existing codes, with new codes created as required. During a period of data familiarisation and immersion, and to confirm coding accuracy, line-by-line coding was performed multiple times. Coding continued until full agreement was reached on final descriptive and analytical themes of the study.

2.6. Risk of Bias. The critical appraisal skills programme (CASP) qualitative checklist was used to evaluate individual study quality for included articles at the full-text stage [36]. The checklist comprises 10 questions, nine of which require Yes/No answers and a final question addressing the value of the research. We used the first nine questions to rate articles as having low, medium, or high risk of bias (the tenth question on overall value of the paper was used

TABLE 3: Critical appraisal of included studies.

Author/CASP	Year	1	2	3	4	5	6	7	8	9	Score
Coon	2004a	Low	Low	Low	Moderate	Low	Low	Moderate	Low	Low	11
Coon	2004b	Low	Low	Low	Moderate	Low	Low	Moderate	Low	Low	11
Johansson	2005	Low	Low	Low	Low	Low	Low	Low	Low	Low	9
Fine Dahan	2006	Low	Low	Low	Low	Low	Low	Low	Moderate	Low	10
Vlossak	2008	Low	Low	Low	Moderate	Moderate	Moderate	Moderate	Moderate	Low	14
McGrath	2009	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	11
Potrata	2010	Low	Low	Low	Low	Low	High	Low	Moderate	Low	12
Maher	2011	Low	Low	Low	Moderate	Moderate	High	Low	Moderate	Low	14
Kelly	2011	Low	Low	Low	Moderate	Moderate	Moderate	Low	Moderate	Low	13
Molassiotis	2011	Low	Low	Low	Moderate	Low	Moderate	Low	Moderate	Low	12
Potrata	2011	Low	Low	Low	Low	Low	Low	Low	Moderate	Low	10
Craike	2013	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	10
Osborne	2014	Low	Low	Low	Low	Low	Low	Low	Low	Low	9
Baz	2015	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	10
Wagland	2015	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	10
Cormican	2016	Low	Low	Low	Low	Low	Moderate	Low	Moderate	Low	11
Cormican	2018	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	10
Morris	2017	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	10
Asfaw	2018	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	10
Clifton	2018	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	10
Monterosso	2018	Low	Low	Low	Low	Low	Moderate	Low	Moderate	Low	11
De Wet	2019	Moderate	Low	Low	Moderate	Moderate	Moderate	Moderate	Moderate	Moderate	16
Parsons	2019	Low	Low	Low	Low	Low	Low	Low	Low	Low	9
Quinoa-Salanova	2019	Low	Low	Low	Low	Low	Low	Low	Low	Low	9
Cuffe	2020	Low	Low	Low	Low	Moderate	Moderate	Low	Moderate	Low	12
Jen	2020	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	10
Bennink	2021	Low	Low	Low	Moderate	Low	Moderate	Moderate	Low	Low	12
Gries	2021	Low	Low	Low	Low	Low	Moderate	Moderate	Low	Low	11
He	2021	Moderate	Low	Low	Low	Low	Low	Low	Low	Low	10
Janssens	2021	Low	Low	Low	Moderate	Low	Low	Low	Low	Low	10
LeBlanc	2021	Moderate	Low	Low	Moderate	Low	Low	Moderate	Moderate	Low	13
Pritlove	2021	Low	Low	Low	Moderate	Low	Moderate	Moderate	Low	Low	12
Crawford	2022	Moderate	Low	Moderate	Low	Low	Low	Moderate	Low	Low	12
Mccaughan	2022	Low	Low	Low	Moderate	Low	Moderate	Low	Moderate	Low	12

Risk of bias (score): low (1), medium (2), and high (3).

qualitatively). These were converted to ordinal scores (1 for low, 2 medium, and 3 high); consequently those with lowest scores were considered highest quality. To ensure rigour, all authors were involved in assessing risk of bias. Table 3 outlines the critical appraisal summary. The exclusion of methodologically weak studies is contested [37] and may weaken synthesis, notably, if studies use different methods or originate from other fields [38]. However, no studies were excluded due to bias, as none were judged to be fatally flawed; higher risk of bias in papers reflects inadequate reporting rather than necessarily methodological weakness. The decision not to exclude any study was also influenced by the limited availability of research on work-related experiences from the perspective of working age people, including their family members, who have been treated for myeloma.

3. Results

3.1. Study Selection and Characteristics. After duplicates were removed, 6873 records were screened for inclusion. Seventy-five underwent full-text review, and 34 were included in the final synthesis (see PRISMA diagram in Supplementary Materials (available here)). Despite setting no language limitations,

all publications were in English. Papers were published between 2004 and 2022, with 10 (29%) from 2020 to 2022 indicating an increased study of the phenomenon.

Study location included 39 countries; namely, the UK (9), the USA (8), Australia (6), Ireland (4), Canada (4), Sweden, Singapore, Netherlands, France, Germany, Belgium, Finland, and Romania (1). Some studies recruited in more than one country. Participant ages ranged from 23 to 88, with data extraction solely on patients/relatives of working age or reflecting on paid or unpaid work as impacted by myeloma. Study participant characteristics are described in Table 2.

One paper had an explicit focus on return to work [39], three focused on exercise [40–42], or development of a symptom questionnaire [43]. The remaining papers reported the impact of symptoms, medical treatments, and side effects on patients/relatives.

Four themes were inductively generated from the included papers.

3.1.1. Theme 1: Side Effects, Medicines, and Stigma at Work. Data within this theme included people's management of treatment side effects such as cognitive impairment, hair

loss, and mood changes. Some patients found that illness and treatment was “permanently and severely interfered with their everyday and professional lives” [44], with patients citing a ceiling to the amount of work they can manage while experiencing fatigue and other side effects [39, 45]. LeBlanc reports a third of their sample having to leave work due to the impact of side effects [46]. Loss of strength for physical jobs was important [41], as was fatigue for a range of jobs [45, 47] including driving to/from work [39, 43, 48].

Patient insight into changes to their focus, attention and cognition meant they were often able to identify when they should withdraw from work [44]. Participants cited being unable to read or do “important tasks” due to the changes in cognitive function. Performance and presence at work was therefore moderated by symptom burden and treatment schedules [39–41, 45, 47, 49, 50]. Carers also experienced side effects of myeloma for example in exhaustion leading to poorer concentration which impacted work, and in taking time off to support the patient with their treatment side effects [51] and hospital appointments [52].

Stigma in the workplace was woven into accounts of adapting to illness, including “loss of power in the workplace” [53]. Internalising stigma and changes in ability led to

“Feelings of inadequacy in carrying out usual tasks whether or not it was within the home environment or at work were evident in most of the interviews. “I went from travelling around the world and managing 500 people to making lunches for my family. That was about the only useful thing I could do in the day”” (author analysis, and male patient, age 48, [54]).

Symptom burden was considerable, with papers reporting the ongoing and substantial impact this had on patients, where prior work tasks were rendered now impossible to achieve [39, 43–45, 47, 49, 50, 53–56].

Visible changes were not only useful signifiers of illness but also stigmatising [48]. Mood changes, triggered by steroids, were both isolating and spawned concern for people witnessing uncharacteristic behaviour [57, 58].

The world’s against you, so you just quit jobs, tell employers where to go, and how they should do it before you leave and things like that, and I’m not a nasty person by nature (no gender or age provided, patient, [57]).

Self-administration of medication enables participation in the workforce [59], with several studies noting that a regime which avoided hospital meant that attending work was more practical [39, 59, 60].

Proactive and reactive adaptations and accommodations to facilitate work were described in terms of disability assessment and flexible working [39, 43, 53, 61]. Planning ahead was considered important [61]. Some participants worked fewer hours after treatment started [39], or became self-employed to gain greater control and “cope with the demands” of work [53].

3.1.2. Theme 2: Relationships. Papers reported a number of categories relating to relationships including the dominance of isolation and loneliness as a by-product of absence from the workplace [49] and participation in volunteering and faith groups [62].

Managing workplace relationships was a conscious effort for some participants.

“Some days I was a bit sassy with them [work accounts]. And I’d forget where I’d put them and things like that. But I would try to leave it till I wasn’t on the drugs-the days when I wasn’t on the dexamethasone.” (no gender or age provided, patient [50]).

Conversely, data also showed that some relationships were enhanced. For example, focussing less on finances and more towards prioritising family [49]. Relational empathy was also visible, including myeloma patients being empathic toward clients experiencing other forms of cancer [63]. Colleagues could become part of the treatment system [59], and bonds were formed and deepened by sharing experiences [63].

The financial impact of cancer (loss of work and paying for treatment) meant that other relationships were launched into new territory, for example relying on the financial support of parents or moving back into the parental home [64].

For those whose work was unpaid housework and informal caregiving, the impact of illness and treatment extended to renegotiating roles, activities, and relationships. Some people with myeloma were unable to undertake their parenting responsibility anymore; participants reported guilt and frustration for not being able to care for family members [53]. Other routine relational interactions were framed as being suddenly noteworthy for the effort they required.

“Making the bed. That’s my job every morning. Going to the bathroom and preparing for the day. Having interaction with my daughter, who’s disabled.” (no gender or age provided, patient, [43]).

Partners may experience paradoxical guilt in that they want to help, but also maintain their independence [46] and thus, maintain relational equilibrium.

Family members’ use of work holiday entitlement had the potential to perturb caregiving responsibilities, adding to feelings of guilt if they prioritise time away or by themselves [65].

Absent from the data was reflection of colleagues being involved as sounding boards for treatment decision making. While this was noted as a role occupied by friends/family [48, 66] no such input was noted for colleagues. This may reflect participants framing their accounts as discussion with friends, when the individual is both friend and colleague.

3.1.3. Theme 3: The Creation and Maintenance of Self through Work. Work for many people is a core component to their

sense of self [54]; hence, potential or actual disruption to work was problematic. Work provided a sense of normalcy [43, 67] where other routines may be disrupted and provided respite from illness-saturated lives [68] and caregiving [51]. Work is positioned as a fundamental marker of identity, and indeed loss of ability to work is grieved [39].

“Patients explained that they derive their identity from their work, that they feel meaningful to others when working” (author analysis, [39]).

“Anything that could affect the brain or ability to concentrate (. . .) would really be a problem and would mean that I would have to give up my job which I really like and which forms a big part of my life” (no gender or age provided, patient, [69]).

The loss of a job and consequent renegotiation of identity are triggers for depression and impact family relationships and finances [46]. One carer expressed that she was not ready to give up her career, craving the “buzz” that comes with the environment [53] work was often viewed through a lens of time and the life course. Revisiting and changing priorities meant that the old work identity was substituted for a new one, such as newly becoming self-employed or becoming a stay-at-home parent [46, 53]. Serious illness destabilised some anticipated futures and disrupted people’s ability to plan for the future including retirement [66, 70]. Configuring a sense of self while unable to engage in usual activities resulted in people weighing up their priorities, with some wishing to privilege other activities, and some contrasting the myeloma-saturated life as an unwelcome element to integrate into their identity.

“I am a busy executive; I am not that old; I am used to doing a lot of things. And so, sort of being stuck at home was really almost more of an impact than anything” (48 year old male patient, [54]).

While working with myeloma is a struggle, caring for someone with myeloma also presents sequelae for individuals’ managing their identity [48]. Work and caring responsibilities and identities compete for informal carers [51] and may risk carers’ loss of self through burnout.

Some data were unclear as to whether working before/ during and after treatment was by choice or necessity [39]. Thus, it was unclear if work was always positioned as an essential identity component, distraction being deployed as a coping mechanism, or through financial need to maintain income or health insurance benefits.

3.1.4. Theme 4: Privilege and Income. The financial impact of myeloma was apparent in several papers [49, 52, 54–56, 64, 71]. Reliance on family was a by-product for some of the financial constraints imposed by myeloma [64], the impact of which was moderated by life-cycle stage. Younger patients, and those with young children [56], fared differently to those close to retirement as there were different decisions to take about continuing or ceasing work [62].

Your mind is concentrating on other things. . . is it life threatening. . . am I going to be able to work any more. . . have I got to retire. . . you’ve got the financial aspects. . . making sure your family is looked after. . . your brain is working on so many different levels (60–70 year old patient, gender not stated, [66]).

Those accessing treatment without copays, deductions, or employer insurance experienced fewer ramifications with their employment and income. Employers providing health insurance were able to exert power and influence over health, which can both reassure (financial peace of mind) and cause stress (being unable to change employer for loss of benefits) [58, 71]. Financial impact is also a concern for people reducing their hours or exiting paid employment [49] including relatives providing informal care [52].

Those in a more privileged and financially secure state were able to determine their priorities in the face of serious illness, including rethinking work as a source of income.

[It] is a second chance at my life. . . Life [has] got different things. It is not just about money (58 year old man, patient, [49]).

Those with less financial privilege were left to juggle generating income with significant symptom burden.

This sickness stop me from work ’cos it broken my back, my spine, and I’m not working right now. I have a mortgage to pay, I’ve a lot of bills to pay, and it’s just hand to mouth, you know, I haven’t got enough at this moment, you know. So life is much harder now than when I used to work (no gender or age provided, patient, [55]).

4. Discussion

This systematic review has synthesised 34 papers focused on work-related experiences of people living with myeloma as patients or family members. Analysis highlighted how people living with myeloma manage work in the context of considerable burden from side effects, medicines, and stigma. Papers on managing the side effects of myeloma treatment all reinforce the burden of such treatments. Loss of strength, pain (including neuropathy), hair loss, and cognitive impairment were all featured in the papers contained within this review, and support recommendations of other cancer survivors [19]. Management of pain may require specific attention, given other studies findings on this as being negatively associated with employment and health-related quality of life [72]. The use of oral medications rather than hospital-based infusions made for more flexible treatment protocols, which fitted better for patients balancing their life-cycle stage of being in employment with taking medicines. Of 34 papers included in this review, only one had an explicit dedicated focus on employment and return to work for people living with myeloma [39]. There is therefore a substantial evidence gap of the experiences of the working age population with this form of cancer.

The review findings have implications for physicians/insurance companies when determining treatment modalities. Consideration should be given to patients' attitudes/approach to work, type of work engaged in, and other activities considered important to them, to achieve better quality of life at work, based on patient's own needs. This would require patients, treating teams, and employers to work more closely. For example, offering more flexible approaches to treatment modalities or work routine, to reduce the impact on the patient.

Social stigma, from feeling inadequate in the workplace for people with myeloma, is a well-documented element of some cancer diagnoses [73]. The stigma which these papers point to indicates specific problems with the side effects of treatment around loss of strength, hair loss, and emotional sequelae of steroids. Insight into the importance of relationships at work indicates a key modifier of a comfortable return to work [74]. Yet, as indicated by the studies in this review, people with myeloma do not class themselves as returning to work, so much as continuing to work during and after treatment [75]. Understanding the relational elements of work engagement as an ongoing project may therefore be important to this cohort of cancer patients and informal carers.

The synthesis indicates that workplace relationships are impacted, in both positive and destructive ways. For example, through growth of empathy and closeness and conversely through struggles with managing changed roles and expectations. Our analysis shows that loss of income due to an inability to work impacted people differently based on life-stage and axes of privilege, such as access to quality healthcare beyond employment benefits. While relationships with managers have been cited as important in enabling people with cancer to return to work [76], little has been explored regarding peer and managers' impact on managing treatment and making treatment decisions. Yet, such the presence or deficit of such support will impact the whole system including patients, partners, colleagues, and the business' customers.

The included studies highlighted how work was closely tied with people's identities, and can provide respite from illness-saturated lives, though for those unable to continue working due to symptom burden there was tension in losing self in the loss of work. Work is a recognised component of many people's identity [77], including those receiving palliative care [78]. Cancer diagnosis and treatment can be experienced as biographical disruption [79] and trigger the renegotiation of identity [80]. The threat or actual loss of work as a component of identity may be particularly marked for people in early or middle adulthood, reconciling a change in a defining characteristic of self, alongside the disability that symptoms and side effects beckon. Social class and occupation may be a predictor of exiting the workplace after cancer, with white collar breast cancer survivors less likely to be in employment than manual workers [81]. Improved access to psychological support may assist patients and family members to adjust to shifts in their identity as a consequence of myeloma and its treatment. This may be particularly pertinent where there are familial cancers and

susceptibility [82]. Therapeutic supports which are attentive to social context, including class, could be particularly effective in helping patients and families navigate and process their shifting identities while recognising the social systems in which people live, work, and experience cancer [83].

Our analysis of the included papers highlighted the importance of considering privilege in understanding the relationship between work and myeloma. Cancer's impact on employment has a growing literature including financial toxicity, from insurance copays, travel to treatment centres and reducing work hours. Early retirement also poses financial dilemmas for families [84], and ceasing employment is a common outcome of cancer treatment [85] across age ranges. Awareness of clinicians about the impact of financial toxicity has been recognised [86] and referral to services which can assist with grants or advice is important alongside systemic interventions which address the cost of medicines [87]. It is critical that the relationship between employment, treatment adherence, and social determinants of health [88] are integrated into holistic discussions with patients and families.

While literature on paid employment forms a critical component of understanding and responding to cancer's impact on people's lives, there is little literature pertaining to unpaid labour such as childcare and domestic chores. Through our analysis of the included papers, we suggest that lack of such data means that the evidence base has an unwittingly neoliberal and gendered gaze on a specific subsection of the population living with myeloma and other cancers. The need to understand people's privilege, income and life-course stage means that a fuller and systemic [89], understanding of myeloma's impact on unpaid work is needed. Indeed, in the small number of papers which recruited carers only 4/6 included data pertaining to carers' work. This dearth of informal carer experiences and outcomes reflects a bias in the literature which is also deserving of attention in future studies.

4.1. Limitations. Included studies replicated recognised sampling biases such as only interviewing in one language (e.g., English in Australia, [57]), recruitment through hospitals [43], or patient recruitment firms [60] and excluding those with high symptom burden [43, 57]. Future studies should aim for broader samples, report participant ages with data extracts, and take an explicit focus on work as a core component to people's experience of the illness.

All studies except one in Romania [69] were conducted in global minority, high-income, countries likely to significantly vary from other localities with less developed healthcare systems and available treatment options. Therefore, the possibility for cultural bias and/or omissions in interpretation means that findings may not be directly transferable to different settings and samples.

Although a comprehensive and specific search was conducted, it did exclude primary research that was not peer reviewed, secondary research, including systematic reviews without third order analysis, conference abstracts, editorials, and grey literature which was not a PhD thesis. Given the

lack of primary research which specifically explores the work experiences of working age adults diagnosed with multiple myeloma, the inclusion of such literature may have provided extra insight, including such evidence not commercially published which is not subject to publication bias [90].

5. Conclusion

This is the first systematic review of paid and unpaid work for people living with myeloma. While employment and cancer has attracted a growing number of studies, this specific patient and family subgroup has not been foregrounded. The high morbidity and mortality from this cancer means that it is important to build a more comprehensive body of research, which could deepen our understanding of the working experiences of adults, under the age of retirement, and diagnosed with myeloma. Important contributions include understanding more about how colleagues impact treatment decision making, given their role in the work milieu and understanding of how side effects may play out for those continuing to work. This would include activities to plan for management of symptoms while not undermining the person's professional role. Second, greater understanding is needed regarding engagement in unpaid labour (such as caregiving) of people living with myeloma. Third, the review has indicated the impact on the wider family system, yet there remain considerable deficits in understanding how actions, such as combining households with parents/adult children to manage the financial sequelae of myeloma on income, are planned and experienced in the short and long term. Fourth, there is much more to learn regarding how identity can be shaped by employers, colleagues, and customers; while myeloma remains a rare disease there is great capacity for employees to share knowledge and understanding of this cancer impacting their own identity as well as colleagues' insights into illness. Addressing workplace stigma, understanding the role of workplace relationships, the construction of self through work, and interpreting data through a lens of life-course and privilege offer helpful starting points.

Such work would create an opportunity for evidence-based policy development (for example in human resource policy on managing treatment side effects) and practice change, and ongoing review to define best practices and improve the working experiences and wellbeing of this demographic. Greater insight into the impact on identities and relationships would also offer considerable advantage to the wider system impacted by myeloma including families and colleagues.

Appendix

(myeloma OR "multiple myeloma" OR "bone marrow neoplasms" OR "plasma cell myeloma" OR "plasma leukaemia" OR "plasma leukemia" OR PCL OR myelomatosis OR "kahler disease" OR "smouldering multiple myeloma" OR "smoldering multiple myeloma" OR "asymptomatic multiple myeloma" OR

"solitary plasmacytoma" OR "solitary plasmacytoma of bone" OR "isolated plasmacytoma" OR "localized plasmacytoma" OR "extramedullary plasmacytoma" OR "immunoglobulin d myeloma" OR "igd myeloma" OR "immunoglobulin e myeloma" OR "ige myeloma" OR "immunoglobulin a myeloma" OR "iga myeloma" OR "immunoglobulin m myeloma" OR "igm myeloma" OR "monoclonal gammopathy of undetermined significance" OR "monoclonal gammopathy of unknown significance" OR mgus OR "nonsecretory myeloma" OR "nonsecretory myeloma" OR "oligosecretory myeloma" OR "light chain myeloma" OR "bence jones myeloma" OR "osteosclerotic myeloma" OR "osteosclerotic plasma cell myeloma" OR "osteosclerotic multiple myeloma" OR "stage 1 myeloma" OR "stage-I myeloma" OR "stage-one myeloma" OR "stage-2 myeloma" OR "stage-II myeloma" OR "stage-two myeloma" OR "stage-3 myeloma" OR "stage-III myeloma" OR "blood cancer" OR "blood disease" OR "refractory myeloma" OR "intractable myeloma" OR "incurable myeloma" OR "terminal myeloma" OR "relaps*myeloma" OR "recur*myeloma" OR "reoccur*myeloma" OR "regress*myeloma") AND ("life experience" OR "lived experience" OR "experience" OR "attitudes" OR "views" OR "feelings" OR "thoughts" OR "beliefs" OR "meaning" OR "opinion" OR "perception" OR "perceive" OR "perspective" OR "needs" OR "priorit*" OR "choice" OR "discrete choice" OR "life change*" OR "famil*" OR "partner" OR "spouse" OR "relatives" OR "significant other*" OR "infor mal carer" OR "carer" OR "child*" OR "preference" OR "concern" OR "health" OR "wellbeing" OR "well-being" OR "issue" OR "matter" OR "decision-making" OR "decisions" OR "important*" OR "impact" OR "effect" OR "problems" OR "challenges" OR "barriers" OR "difficulties" OR "disadvantages" OR "advantages" OR "benefits" OR "affect*" OR "influence" OR "work*" OR "employ*" OR "hobby" OR "hobbies" OR "interest*" OR "job*" OR "career" OR "occupation" OR "work-life balance" OR "work-life balance" OR "quality of life") AND ("Qualitative studies" OR "qualitative" OR "ethnographic research" OR "ethnograph*" OR "phenomenological research" OR "phenomenology" OR "phenomenol*" OR "grounded theory" OR "hermeneutic*" OR "observational methods" OR "observation*" OR "focus groups" OR "interview*" OR "mixed method*" OR "mixed-method*" OR "multimethod studies" OR "multimethod*" OR "multimethod*" OR "questionnaire*" OR "survey*")

Data Availability

The data used to support the findings of this study are available from the corresponding author upon request.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' Contributions

Liz Forbat, Tim Sedgley, and Laura Bellussi conceptualised the study, created the methodology, and reviewed and edited the paper; Tim Sedgley and Laura Bellussi searched the literature; Liz Forbat, Tim Sedgley, and Laura Bellussi performed data analysis and interpretation; Liz Forbat prepared the writing of original draft; Liz Forbat acquired the funding.

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Supplementary Materials

PRISMA flowchart of search and inclusion/exclusion of materials. (*Supplementary Materials*)

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