

SPECIAL ISSUE ARTICLE

Perspectives on returning to work of multiple myeloma patients: A qualitative interview study

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Abstract

Objective: Multiple myeloma (MM) is a rare and incurable disease. Because new treatments improved survival rates, return to work (RTW) became more relevant to MM patients of working age. Also, (health care) experts may be confronted with specific obstacles in guiding MM patients' RTW. Therefore, we aimed to qualitatively explore perspectives and experiences of MM patients and (health care) experts regarding RTW and participation at work.

Methods: Semi-structured interviews were conducted with patients ($N = 9$) and (health care) experts ($N = 15$). Interviews were transcribed verbatim and analysed using thematic analysis.

Results: Four themes resulted from the interviews with patients and (health care) experts: (1) severity of diagnosis and treatment impact RTW, (2) step-by-step reintegration facilitates RTW, (3) meaning of work differs between MM patients and experts and (4) lack of tailored counselling by experts.

Conclusion: Although MM patients' work ability may be limited due to the severity of diagnosis and side effects from treatment, most patients consider RTW important. Both patients and (health care) experts emphasise the benefits from early work ability assessment (in the hospital setting) and specialised RTW counselling, especially in those with physically demanding jobs.

KEYWORDS

cancer, haematological malignancy, multiple myeloma, rare cancer, return to work, work disability

1 | INTRODUCTION

Multiple myeloma (MM) is an incurable malignant plasma cell disease, with an annual incidence of 1200 patients in the Netherlands. About 35% of these haematological patients are younger than 65 years old at time of diagnosis [Integraal Kankercentrum Nederland (IKNL), 2019]. Since the introduction of novel therapies, the 5-year overall survival significantly increased from 29% in the period

1996–2002 to 52% in 2010–2016 (Dinmohamed, 2019). In MM patients up to 65 years old, the 5-year overall survival even improved from 38% in 1989–2000 to 64% in 2008–2016 (IKNL, 2019). In a recent trial in transplant-eligible MM patients, the 5-year survival improved up to 77% (Cavo et al., 2020), suggesting that survival rates will improve even further. Further, routine maintenance treatment has led to a higher possibility to control the disease at the cost of prolonged treatment with acceptable toxicity (McCarthy et al., 2017).

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This improvement in survival and disease control has created new perspectives for MM patients, making it more relevant to consider Quality of Life (QoL) related issues, such as social functioning and work ability.

Being able to work is an important determinant of QoL in cancer patients of working age (Duijts et al., 2017; Tamminga et al., 2019). Previous studies on return to work (RTW) showed that patients with haematological malignancies are less likely to RTW than other cancer patients, which could be explained by the intensity of treatment and severity of side effects, that are observed in almost all haematological malignancies (de Boer et al., 2008; Horsboel et al., 2013; Horsboel et al., 2015; Jackson et al., 2019; Short et al., 2005). Moreover, younger patients with MM generally receive combination chemotherapy followed by Autologous Stem Cell Transplantation (ASCT) over a period of 6 to 9 months, which may considerably limit their ability to work (Horsboel et al., 2013).

Exploration of work-related issues in MM patients is of importance because little is known about MM patients' perspectives regarding RTW and the barriers they experience regarding participation in a working environment (Kiasuwa Mbengi et al., 2016). Further, no information is available regarding the extent to which RTW issues are addressed, after diagnosis and during treatment of MM patients, by health care professionals (HCP). Moreover, experiences and knowledge about RTW of MM patients have not been explored among RTW experts, for example, occupational physicians (OPs), insurance physicians (IPs) and Human resources (HR)-consultants and representatives of patient organisations. This is important because both HCP and other experts may be confronted with specific obstacles in guiding MM patients in their RTW and participation at work process.

Therefore, the aim of this study was to explore perspectives and experiences of MM patients and (health care) experts regarding RTW and participation at work.

2 | METHODS

2.1 | Design and participant recruitment

In this study, a qualitative approach was used. MM patients were recruited from a single-site large community hospital in the Netherlands, that is, the Amphia Hospital in Breda in collaboration with the Erasmus University Medical Center Cancer Institute in Rotterdam. Haematologists from the department of haematology of this hospital identified potential eligible patients who were as follows: (1) diagnosed with MM between 2012 and 2019; (2) between 18 and 65 years old at time of diagnosis; (3) employed in, at least, a part-time job at time of diagnosis and (4) willing to sign a written consent to participate in this study. Variation in gender, age, time since diagnosis and type of employment contract before diagnosis was considered during the recruitment process.

Eligible patients received an invitational letter with information from their haematologist and an informed consent form. Patients who signed and returned the informed consent form to the researchers

were contacted to make an appointment for the interview. Due to the COVID-19 pandemic, interviews (approximately 30–45 min each) were conducted by telephone. Recruitment and inclusion of MM patients continued until data saturation was reached. Furthermore, HCP, RTW experts and representatives of patient organisations, collectively called 'experts' in this paper, were invited by e-mail or telephone to participate in an interview.

The study was not subject to the Dutch Medical Research Involving Human Subjects Act (WMO), and therefore, ethical approval was not required (Medical Research Ethics Committees United, Nieuwegein; registry number: W20.057).

2.2 | Data collection

Between April and June 2020, MM patients and experts were interviewed by the responsible researcher and a research assistant, using a semi-structured list with questions on the following topics: (1) MM-specific disease symptoms, treatment characteristics and their impact on RTW (e.g., severity of symptoms, intensity and duration of treatment, side effects and their impact on RTW; frequency and duration of sickness absence spells); (2) meaning and importance of work (e.g., financial necessity), and experience with RTW (e.g., timing of RTW, barriers regarding RTW) and (3) guidance and support from experts and their knowledge, experiences and expectations regarding the RTW process of MM patients.

The interviews with MM patients started with basic socio-demographic and disease-related questions regarding age, year of diagnosis, occupation at time of diagnosis and type of employment contract (e.g., self-employed or salaried job and full-time or part-time). The expert interviews opened with a question regarding experiences with this specific patient group and with the RTW and participation in work process of these patients. Furthermore, in both the patient and the expert interviews, similar topics were addressed, however, from different points of view. (The topic list is provided in Appendix A).

TABLE 1 Standard procedures for thematic analysis

Phase	Performed by	
Reading data	JJ-CB	Both researchers thoroughly read all interview data several times
Initial coding	JJ-CB	Both researchers coded six interviews independently and reached consensus on the codes to use. CB coded all other interviews
Defining themes	CB-SD	Based on the data and clustered codes, CB and SD decided on final themes
Reviewing themes	CB-SD-MK (team)	Themes were reviewed by the entire team
Discuss results	CB-SD-MK (team)	Results were discussed, leading to a first draft of the manuscript
Report	All authors	All authors were involved in writing the final manuscript

Interviews with patients and experts were performed in the same time period, so that new topics addressed by patients could be presented to experts and vice versa. All interviews were anonymously audio recorded and transcribed verbatim in Dutch.

2.3 | Data analysis

Standard procedures of thematic analysis, that is, a method consisting of six phases, were used (Table 1) (Braun, 2006). The transcripts were read in detail, and the first six interviews were separately coded by two researchers, using Atlas-ti 8 qualitative data analysis software (ATLAS.ti Scientific Software Development GmbH, 2019). The two researchers compared codes from the first six interviews and discussed them until consensus was reached. The remaining interviews were coded by the responsible researcher. After initial coding of the transcripts, identified topics were clustered by theme, which were reviewed and discussed by the research team. A selection of quotes was translated into English by a native English speaker.

3 | RESULTS

3.1 | Sample characteristics

In total, nine MM patients and 15 experts were interviewed. Six male and three female patients (mean age 54.2 SD 4.2) participated. All were diagnosed 1 to 5 years prior to the interview. At time of diagnosis, seven patients had an employment contract, and two patients were self-employed. Six patients worked full-time before diagnosis, and three patients worked part-time. At the time of the interview, three patients worked the same number of hours as stated in their contract, four patients had partly returned to work and two patients stopped working altogether. An overview of patient characteristics is presented in Table 2.

The interviewed experts ($N = 15$) consisted of HCP, that is, three haematologists, a specialised haematology nurse and a social worker specialised in cancer care, and RTW professionals, i.e., one HR-consultant from Amphia Hospital, a researcher in the field of cancer and work, two IPs and three OPs, two of which specialised in RTW of cancer patients. In addition, three representatives of patient organisations were interviewed (Table 3).

The following section will describe the results by theme: (1) severity of diagnosis and treatment impact RTW; (2) step-by-step reintegration facilitates RTW; (3) meaning of work differs between MM patients and experts; (4) lack of tailored counselling by experts. For each theme, a few illustrative quotes are added in the text. Quotes were selected based on being most representative and most illustrative for its theme. Additional quotes are provided in Appendix A.

1. Severity of diagnosis and treatment impact RTW

TABLE 2 Patient characteristics

Pat. nr	Gender	Age at diagnosis (in years)	Time since diagnosis (in years)	Type of work before diagnosis	Contract type before diagnosis	Current work status	Self-reported disease status at time of the interview
1	F	57	2	SHEQ manager	Part-time	Part-time; same hours	Relapsed disease; undergoing treatment
2	M	59	< 1	Computer programmer	Self-employed; full time	Self-employed; part-time	Recently received stem cell transplant
3	M	56	4	Service engineer	Full time	Part time	Undergoing treatment
4	M	59	3	Service engineer	Full time	Full time	Unknown
5	F	51	2	Accountant	Self-employed; full time	Self-employed; part-time	Relapsed disease; starting treatment
6	M	51	5	Project lead	Full time	Full time	Undergoing treatment
7	M	58	5	Mechanic	Full time	Disability pension	Receiving pain medication
8	F	50	3	Phlebotomist	Part-time	Disability grant	Unknown
9	M	47	3	Professor at university	Part-time	Part-time; less hours	Undergoing treatment

Note: Pat. Nr: patient number; Gender: F: Female, M: Male;

TABLE 3 Expert characteristics

Expert nr.	Type of expertise	Organisation
1	Researcher cancer and work	University hospital
2	Oncology specific occupational physician	Self-employed
3	Patient support, haematology and work	Patient support organisation
4	Oncology specific occupational physician	University hospital
5	MM nurse specialist	General hospital
6	Haematologist	General hospital
7	Patient support, cancer and work	Patient support organisation
8	Haematologist	General hospital
9	Social worker specialised in cancer	General hospital
10	Insurance physician	Employee insurance agency
11	Advisor insurance physician	Employee insurance agency
12	Occupational physician	Occupational health organisation
13	HR advisor (expert on sickness leave)	General hospital
14	Haematologist	University hospital
15	MM patient	Patient support organisation

Abbreviations: HR, Human resources; MM, multiple myeloma.

Patients who are diagnosed with MM reported a variety of symptoms at time of diagnosis, ranging from hardly experiencing any complaints, that is, MM being discovered coincidentally during a routine medical check-up, to suffering from multiple symptoms, such as pain, fatigue and bone fractures.

At one time, I was doing some chores using my drill and broke my little finger. Two days later, I broke another bone and then I broke my collar bone out of the blue. Three days later I was admitted to hospital. (Male, 55 at diagnosis)

With regard to the subsequent treatment period, some patients reported to not have been able to work at all, whereas others tried to (partially) continue working regardless of their side effects, that is, fatigue, neuropathy and/or cognitive limitations, such as concentration and memory problems. Susceptibility to infections and adverse effects of medication were mentioned to impede work ability and to result in sickness absence spells as well.

The neuropathy in my feet limits me the most in my everyday life. I'm not able to walk for longer than five minutes and standing is limited to 10 minutes (Male, 56 at diagnosis).

Overall, patients were aware that MM is incurable and that relapses occur. These findings might explain that, in general, experts assume that MM patients and especially patients with relapsed disease are not able to RTW. However, four patients who relapsed relatively soon after ASCT were still working at the time of the interview, even though they expressed that the relapse was mentally difficult to accept.

2. Step-by-step reintegration facilitates RTW

A number of patients continued to work part-time or full-time after diagnosis, until ASCT. Others stopped working as soon as they received the diagnosis and were on sickness leave until they recovered from treatment. Time to RTW after ASCT was variable in the interviewed MM patients. Some patients resumed work within 1 or 2 weeks after discharge from the hospital, whereas in others, recovery took several months. The availability of alternative work and working flexible hours, mostly seen in patients with higher education, were mentioned by interviewees to facilitate RTW.

I am lucky that I can decide on my own working hours. I work the same number of hours as everyone else, I just start later in the day. (Female, 51 at diagnosis)

In contrast, side effects of treatment were indicated as inhibiting RTW, especially in those with physically demanding jobs. Also, as several MM patients expressed to be disproportionately mentally and physically fatigued, the option to work from home was indicated as preventing the additional burden of travelling, and providing the opportunity to lay down whenever needed. That is, many MM patients experience vertebral bone lesions and fractures, hindering them when having to sit longer periods of time.

Experts indicated to perceive differences between MM patients in a salaried job and those who are self-employed. Self-employed patients generally RTW earlier, because they often lack sick leave insurance. However, experts explained that it poses these patients more at the risk of crossing boundaries and drop-out later on in the trajectory. Interviewed experts also noted that, overall, employers prefer a step-by-step and sustainable RTW process.

I have noticed that people who are self-employed experience more stress. They're required to return to work sooner and as it turns out, this is often too soon, making them suffer from burn-out symptoms later on. (Expert)

3. Meaning of work differs between MM patients and experts

Although disease symptoms, side effects of treatment and the incurable character of MM are major barriers to RTW, all patients indicated that they highly value their ability to work. The two patients that were not able to RTW expressed that they still struggle with and grieve over the fact that they are not working. Patients explained that

they derive their identity from their work, that they feel meaningful to others when working, and that work provides them distraction as well as future prospects. Nevertheless, being able to undergo treatment was indicated by some of the interviewed patients as more important than the ability to work.

[Work is ...] Very important. Easily scores an 8 on a scale of 1 to 10. (Male, 56 at diagnosis)

Financial consequences of not being able to work, that is, due to job loss or receiving work disability benefits, were only mentioned by a few patients. However, financial reasons were not the most determining factor in their decision to RTW or not.

On the contrary, experts more often emphasised the financial importance of returning to work. Overall, they declared that the meaning of work and the value MM patients attach to their ability to work differs between patients, from intending to RTW as soon as possible to a desire to change directions in life due to their illness.

4. Lack of tailored counselling by experts

In general, patients expressed that they have not experienced much added value from their OP. They indicated that OPs appear to have insufficient knowledge of supporting cancer patients in their RTW in general, and MM patients in particular, that they use rigid schedules for reintegration and are precautious to support MM patients' RTW. Also, experts expressed that, although OPs lack expertise regarding MM, referral to OPs who are specialised in counselling cancer patients, hardly occurs. The interviewed OP acknowledged that counselling MM patients is rare and that specific skills regarding MM is lacking, but also that, in general, successful RTW mainly depends on employers' attitudes towards RTW of cancer patients.

I tried to convince him [the OP] of the fact that I was capable of still doing quite a lot, but he was trying to hold me back instead of being encouraging. (Male, 47 at diagnosis)

Patients who were referred to an IP for work disability assessment indicated that having had structured reintegration guidance, closely involving both the employer and the employee, facilitated their disability assessment process. Patients stated that IPs, as OPs, often have no specific knowledge of MM. Experts expressed that IPs are often rigid and offer insufficient support, due to strict regulations and legislation, but also because of high work load. The interviewed IPs confirmed this lack of MM knowledge due to low incidence rates. However, they stated to be able to provide a proper work disability assessment based on the functional (in)abilities, reported by the patient. They acknowledged that it is not always possible to provide tailor-made solutions for each patient.

The insurance physician easily becomes stuck due to all the regulations and associated forms. When dealing with

cancer it is often necessary to offer a tailored approach. In my opinion, the insurance physician does not have enough expertise regarding this illness. (Expert)

Further, patients indicated that work-related issues hardly receive any attention from HCPs in the hospital. Interestingly, they also do not expect their HCPs to address this topic in an extensive way. However, experts expressed that the HCPs should at least address the importance of RTW early in the treatment process, in a hospital setting, to prevent adverse work-outcomes later on.

This was hardly or not at all discussed by the hospital. To be honest, I did not expect the doctor to address it at that moment. (Male, 47 at diagnosis)

4 | DISCUSSION

4.1 | Main findings

The aim of this study was to explore perspectives and experiences of MM patients and experts regarding RTW and participation at work. By bringing together these perspectives, a broad range of experiences, opinions and ideas on RTW in MM patients have been highlighted. Overarching themes retrieved from the interviews were that (1) severity of diagnosis and treatment impact RTW, (2) step-by-step reintegration facilitates RTW, (3) meaning of work differs between MM patients and experts and (4) tailored counselling is lacking in experts.

4.2 | Interpretation of findings

In this study, we found that, although survival rates have improved, the impact of being diagnosed with MM, and the subsequent extensive treatment, impact the ability to RTW. This is in line with previous research by Horsboel et al. who reported that MM had the lowest RTW percentage (32%) compared with all patients with haematological malignancies (65%) (Horsboel et al., 2013). The impact of the diagnosis, disease symptoms and especially functional limitations due to the disease and its treatment are widely acknowledged to affect RTW negatively in cancer survivors. (Moskowitz et al., 2014) However, awareness is needed that new, more effective therapies may improve work ability, even in patients with incurable diseases, such as MM. Therefore, options to RTW should be discussed and explored by experts with this specific patient group, even though their patient journey might be considered as extremely challenging.

As already indicated by many previous studies, we confirmed in our study in MM patients, that successful and sustainable RTW depends, among others, on work-related characteristics, such as type of job, employer's attitude towards RTW, the ability to work from home in flexible hours or in alternative employment. Moreover, we found in our study that RTW is most successful if it is a step-by-step

process, tailored to the needs of the patients. This is in line with previous research by Persoon et al., who reported that not having physically demanding work, being able to do less demanding tasks, being able to work from home, and gradually RTW in flexible hours, facilitate RTW in patients with haematological malignancies, who underwent stem cell transplantation (Persoon et al., 2019). Although a step-by-step reintegration may be the most optimal approach for all cancer patients, it is considered especially helpful in MM patients, as they suffer from severe disease symptoms and/or need ongoing treatment with considerable side effects, which increases the risk of long-term absenteeism and work disability.

Further, it has been shown in previous studies that the possibility to make arrangements at work is frequently associated with a higher level of education in employees. For example, Hartung et al. reported that haematological cancer patients with higher education RTW sooner than patients with a lower level of education (Hartung et al., 2018). More specifically, lower educated MM patients with physically demanding jobs, for whom no alternative or adapted work arrangements are possible, may suffer from high levels of fatigue. On top of that, they may experience bone disease, neuropathy and cognitive limitations, placing them at risk for work disability. Timely identification of this specific patient group, within the overall group of MM patients, and tailored counselling by RTW experts are therefore highly needed.

With regard to the meaning of work, all patients in our study, including those with relapsed illness and those who did not work at all, emphasised the importance of the ability to work. Similar to other studies, interviewed patients explained that work provides structure and distraction in daily living, it makes them meaningful to others and enhances their feeling of having a future, which all positively impact QoL. This is in line with research by Duijts et al. who reported that patients who are able to continue working, report better health and QoL than those who are not able to work (Duijts et al., 2017). Related to the importance of RTW for QoL, experts in our study mentioned the financial importance of RTW and the burden patients might experience in case of job loss. Correspondingly, Horsboel et al. reported that MM patients are at high risk for reduced work capacity and dependency on disability benefits (Horsboel et al., 2014). Therefore, it is necessary that experts and MM patients discuss the importance of work on QoL and on financial stability, and consider both in the reintegration trajectory.

Next, in our study, it was shown that RTW experts, that is, OPs and IPs, lack sufficient knowledge to provide tailored guidance. In line with this, recent research by Shim et al., on OPs' perspectives on RTW of cancer patients in Korea, showed that most OPs had little experience in guiding cancer patients, their involvement in RTW started too late, and their collaboration with employers was often considered to be poor. (Shim et al., 2019). With regard to the role of IPs, in a study by van Muijen et al., it was indicated that IPs' perspectives on RTW of cancer patients predominantly is on the assessment of medical factors and less on personal factors (van Muijen et al., 2015). Consequently, MM patients' work ability might mainly be determined by IPs on the incurability of MM and the severity of its treatment, instead of careful consideration of both medical factors

and MM patient's expectations towards RTW. In line with this, in our study, experts acknowledged that MM patients may benefit from timelier and specialised RTW counselling and that adequate communication between experts may increase successful RTW. This has also been confirmed by Zegers et al. who reported that, in the hospital setting, work-related issues are only discussed with only about one-third of the cancer patients, whereas the need to be informed about work-related consequences of diagnosis and treatment is much higher (Zegers et al., 2021). In MM patients, this is of particular importance as these patients are confronted with a rare disease with intensive treatment and continuous introduction of new therapies, making expert guidance especially needed.

4.3 | Strengths and limitations

The strength of this study is that, to our knowledge, it is the first that addressed both the complexity and the importance of RTW for patients suffering from MM, a rare and incurable disease. However, several limitations should be reported as well. First, the study concerns a single site study with a small number of MM patients, most of whom were able to RTW. This means that we had limited insights into the experiences of patients that did not RTW. Therefore, results might not be generalisable to the whole MM patient group and should therefore be interpreted with caution. In addition, patients were preselected, on the basis of whether their health allowed them to be interviewed, and they were informed on the interview topic, which may have caused selection bias. That is, patients who experienced successful RTW may have been more likely to accept the invitation. Further, due to the COVID pandemic, all participants were interviewed by telephone, which may have caused loss of non-verbal and in-depth information. Finally, the expert group consisted of professionals with a range of areas of expertise, and although this provided insight into different opinions about RTW, data saturation for each specific group of experts may not have been reached. However, in our opinion, all topics have been fully addressed. We also believe it is a strength of our study that this approach provided us with a broad insight into ideas and opinions on RTW in MM patients. Although, it could be considered a limitation of this study that we did not specifically focus on differences between patients and specific groups of experts.

4.4 | Implications for research and practice

With the increasing survival rates in MM patients and introduction of new treatments, this study contributes to awareness of the increasing importance of RTW. However, the fast pace of developments in MM treatments, and its positive effects on survival and side effects, requires ongoing research into its significance on RTW. Additional in-depth qualitative research on specific groups of experts, as well as population-based research regarding work-related outcomes in MM patients, may contribute to broader insight into RTW in MM patients.

With regard to daily practice, especially in MM patients, it is important to consider to address work-related issues with patients early and more structurally within the hospital setting. In addition, OPs should start counselling soon after diagnosis and should follow-up with both patients and employers during treatment. Also, timely referral to specialised RTW counselling could induce a more tailored and step-by-step RTW. A training programme on developments in work-related issues in cancer care, especially in rare or incurable cancers, might improve both the level of knowledge and collaboration between experts.

5 | CONCLUSION

Although both patients and experts emphasise the importance of RTW, MM symptoms and its treatment effects may considerably limit RTW in these patients. Step-by-step and flexible reintegration may facilitate their RTW. However, MM patients, especially those with lower education, physical limitations and in physically demanding jobs, may benefit from earlier and more tailored assessment and counselling from specialised RTW experts.

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CONFLICT OF INTEREST

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AUTHOR CONTRIBUTIONS

CB, MK and PS presented the idea. CB and MK designed the study and recruited the patients. CB supervised the interview and transcription process. CB and SD performed the analysis and drafted the manuscript. CB, MK, HS and SD critically revised the manuscript and approved the final version.

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DATA AVAILABILITY STATEMENT

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

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REFERENCES

- ATLAS.ti Scientific Software Development GmbH. (2019).
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Cavo, M., Gay, F., Beksac, M., Pantani, L., Petrucci, M. T., Dimopoulos, M. A., Dozza, L., van der Holt, B., Zweegman, S., Oliva, S., van der Velden, V., Zamagni, E., Palumbo, G. A., Patriarca, F., Montefusco, V., Galli, M., Maisnar, V., Gamberi, B., Hansson, M., ... Sonneveld, P. (2020). Autologous haematopoietic stem-cell transplantation versus bortezomib-melphalan-prednisone, with or without bortezomib-lenalidomide-dexamethasone consolidation therapy, and lenalidomide maintenance for newly diagnosed multiple myeloma (EMN02/HO95): A multicentre, randomised, open-label, phase 3 study. *Lancet Haematology*, 7(6), e456–e468. [https://doi.org/10.1016/s2352-3026\(20\)30099-5](https://doi.org/10.1016/s2352-3026(20)30099-5)
- de Boer, A. G., Verbeek, J. H., Spelten, E. R., Uitterhoeve, A. L., Ansink, A. C., de Reijke, T. M., Kammeijer, M., Sprangers, M. A., & van Dijk, F. J. (2008). Work ability and return-to-work in cancer patients. *British Journal of Cancer*, 98(8), 1342–1347. <https://doi.org/10.1038/sj.bjc.6604302>
- Dinmohamed, A. (2019). Belangrijke cijfers over hematologische kankersoorten. 11.
- Duijts, S. F., Kieffer, J. M., van Muijen, P., & van der Beek, A. J. (2017). Sustained employability and health-related quality of life in cancer survivors up to four years after diagnosis. *Acta Oncologica*, 56(2), 174–182. <https://doi.org/10.1080/0284186x.2016.1266083>
- Hartung, T. J., Sautier, L. P., Scherwath, A., Sturm, K., Kröger, N., Koch, U., & Mehnert, A. (2018). Return to work in patients with hematological cancers 1 year after treatment: A prospective longitudinal study. *Oncology Research and Treatment*, 41(11), 697–701. <https://doi.org/10.1159/000491589>
- Horsboel, T. A., Nielsen, C. V., Andersen, N. T., Nielsen, B., & de Thurah, A. (2014). Risk of disability pension for patients diagnosed with haematological malignancies: A register-based cohort study. *Acta Oncologica*, 53(6), 724–734. <https://doi.org/10.3109/0284186x.2013.875625>
- Horsboel, T. A., Nielsen, C. V., Nielsen, B., Andersen, N. T., & De Thurah, A. (2015). Wage-subsidised employment as a result of permanently reduced work capacity in a nationwide cohort of patients diagnosed with haematological malignancies. *Acta Oncologica*, 54(5), 743–749. <https://doi.org/10.3109/0284186x.2014.999871>
- Horsboel, T. A., Nielsen, C. V., Nielsen, B., Jensen, C., Andersen, N. T., & de Thurah, A. (2013). Type of hematological malignancy is crucial for the return to work prognosis: A register-based cohort study. *Journal of Cancer Survivorship*, 7(4), 614–623. <https://doi.org/10.1007/s11764-013-0300-z>
- Integraal Kankercentrum Nederland (IKNL). (2019). Het multipel myeloom in Nederland, 2014–2016.
- Jackson, G., Galinsky, J., Alderson, D. E. C., D'Souza, V. K., Buchanan, V., Dhanasiri, S., & Walker, S. (2019). Productivity losses in patients with newly diagnosed multiple myeloma following stem cell transplantation and the impact of maintenance therapy. *European Journal of Haematology*, 103(4), 393–401. <https://doi.org/10.1111/ejh.13298>
- Kiasuwa Mbengi, R., Otter, R., Mortelmans, K., Arbyn, M., Van Oyen, H., Bouland, C., & de Brouwer, C. (2016). Barriers and opportunities for return-to-work of cancer survivors: Time for action—Rapid review and expert consultation. *Systematic Reviews*, 5, 35. <https://doi.org/10.1186/s13643-016-0210-z>
- McCarthy, P. L., Holstein, S. A., Petrucci, M. T., Richardson, P. G., Hulin, C., Tosi, P., Bringham, S., Musto, P., Anderson, K. C., Caillot, D., Gay, F., Moreau, P., Marit, G., Jung, S. H., Yu, Z., Winograd, B., Knight, R. D., Palumbo, A., & Attal, M. (2017). Lenalidomide maintenance after autologous stem-cell transplantation in newly diagnosed multiple myeloma:

- A meta-analysis. *Journal of Clinical Oncology*, 35(29), 3279–3289. <https://doi.org/10.1200/jco.2017.72.6679>
- Moskowitz, M. C., Todd, B. L., Chen, R., & Feuerstein, M. (2014). Function and friction at work: A multidimensional analysis of work outcomes in cancer survivors. *Journal of Cancer Survivorship*, 8(2), 173–182. <https://doi.org/10.1007/s11764-013-0340-4>
- Persoon, S., Buffart, L. M., Chinapaw, M. J. M., Nollet, F., Frings-Dresen, M. H., Koning, S., Kersten, M. J., & Tamminga, S. J. (2019). Return to work experiences of patients treated with stem cell transplantation for a hematologic malignancy. *Support Care Cancer*, 27(8), 2987–2997. <https://doi.org/10.1007/s00520-018-4596-0>
- Shim, H. Y., Lee, C. W., Yu, E. S., Park, B. Y., & Yang, E. J. (2019). Cancer survivors and returning to work perspectives from occupational health physicians in Korea. *Journal of Korean Medical Science*, 34(11), e98. <https://doi.org/10.3346/jkms.2019.34.e98>
- Short, P. F., Vasey, J. J., & Tunceli, K. (2005). Employment pathways in a large cohort of adult cancer survivors. *Cancer*, 103(6), 1292–1301. <https://doi.org/10.1002/cncr.20912>
- Tamminga, S. J., Verbeek, J. H. A. M., Bos, M. M. E. M., Fons, G., Kitzen, J. J. E. M., Plaisier, P. W., Frings-Dresen, M. H. W., & de Boer, A. G. E. M. (2019). Two-year follow-up of a multi-centre randomized controlled trial to study effectiveness of a hospital-based work support intervention for cancer patients. *Journal of Occupational Rehabilitation*, 29(4), 701–710. <https://doi.org/10.1007/s10926-019-09831-8>
- van Muijen, P., Duijts, S. F. A., Kornet-van, D. A., van der Beek, A. J., & Anema, J. R. (2015). Work disability assessment of cancer survivors: Insurance physicians' perspectives. *Occupational Medicine (London)*, 65(7), 558–563. <https://doi.org/10.1093/occmed/kqv098>
- Zegers, A. D., Coenen, P., van Belzen, M., Engelen, V., Richel, C., Dona, D. J. S., van der Beek, A., & Duijts, S. F. A. (2021). Cancer survivors' experiences with conversations about work-related issues in the hospital setting. *Psycho-Oncology*, 30, 27–34. <https://doi.org/10.1002/pon.5529>

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APPENDIX A: TOPIC LIST

General information

Patients

- Profession and type of contract at time of diagnosis
- Age at diagnosis
- Age at time of interview

Experts

- Profession

- Experience with RTW of multiple myeloma patients

Situation at diagnosis

- Symptoms at diagnosis
- Treatment-plan after diagnosis
- Treatment effects
- Work situation during treatment

Current situation (patients)/Ongoing disease and treatment (experts)

- Disease symptoms (influencing RTW)
- Treatment symptoms (influencing RTW)
- Work situation

Meaning of work

- Important?
- Why yes/no

Return to work

- Moment (for experts: best moment of RTW and moment of RTW)
- Build-up (for experts best build-up-scheme and experienced schemes)
- Absenteeism due to disease or treatment

Guidance and support

- Role, importance and expertise medical team
- Role, importance and expertise employer and colleagues
- Role, importance and expertise occupational physician
- Role, importance and expertise insurance physician
- Communication, coordination between professionals

Barriers and facilitators

- Medical
- Work and contract characteristics
- Guidance
- Other

Wrap-up

- Ideal situation
- Is there anything to add to the interview that was not asked yet

Additional quotes

Patient; E = Expert.

Topic	Quote	P/E
Symptoms at diagnosis	<i>I do not have any symptoms. I still do not know what I am supposed to feel. I have no complaints whatsoever</i>	P
Work during initial treatment	<i>I was home from work right up to my stem cell transplantation. I wasn't able to work, I just did not have the energy.</i>	P
	<i>I even ended up doing some work on the day of my stem cell transplantation in Rotterdam.</i>	P
	<i>I went to work as usual right after I was given the diagnosis, just like every other day. I just went ahead and did my job.</i>	P
Moment of RTW	<i>I was in hospital for 2.5 weeks and at home for one week. I was back at work working half days the following week.</i>	P
	<i>I started working gradually after a period of 14 months.</i>	P
	<i>Most patients do not have work on their minds while they are in the diagnostic phase.</i>	E
Side effects effecting RTW	<i>Just falling asleep on the spot. Not being able to do anything. It can hit you at anytime, anywhere.</i>	P
	<i>I had great difficulty learning new things. I constantly needed mnemonics and reminders to remember stuff</i>	P
	<i>Dexamethasone has an enormous impact on your energy levels, concentration and sleep pattern. It disrupts your life considerably. It does not only affect you professionally but also emotionally, how you respond in some situations.</i>	E
Effect treatment on presence at work	<i>I plan my treatment on Mondays and try to schedule my hospital appointments on Fridays because I'm also on an immunoglobulin IV since a year. But I am at the hospital even more because I'm also receiving APD treatment.</i>	P
	<i>I need to go to hospital for an IV an entire day each week. So that's one day lost already.</i>	P
Relapsed disease	<i>Nine months after my stem cell transplant, the disease was back and I needed treatment again. I found that very disappointing (male, 56 at diagnosis)</i>	P
Meaning of work	<i>I just do not feel like myself when I do not work. It makes me feel off balance.</i>	P
	<i>Yes, it certainly makes me feel good to have some sense of importance.</i>	P
	<i>My work is not as important as my treatment.</i>	P
	<i>Work is of such an essential importance. It represents financial independence; it offers people a form of structure.</i>	E
	<i>We know that cancer patients, more so than other groups of patients, are highly motivated to get back to work. For a number of people however, the significance of work changes.</i>	E
RTW facilitators	<i>I was lucky that they made use of my knowledge.</i>	P
	<i>I was able to work online so I worked part-time from my own home.</i>	P
	<i>The line of work you end up in and the level of autonomy you are granted can partly depend on your level of education.</i>	E
	<i>I have noticed that people who are self-employed experience more stress. They're required to return to work sooner and as it turns out, this is often too soon, making them suffer from burn-out symptoms later on.</i>	E
Self-employed	<i>I hear people say that they carry on working to their ability during their treatment but it should be noted that most of them run their own business. For them it's a different level of necessity.</i>	E
Burden of travelling for work	<i>I was on the road for 2 hours just to get some work done. For me that was tough because I did not feel very confident in traffic.</i>	P
	<i>It was just a thirty-minute drive but it was awful. In all honesty, I was a danger on the road driving home after a day's work.</i>	P
	<i>It is like opening a bottle of wine, it is impossible to drive after that. So many drugs have some sort of effect on your brain and that does not help when in charge of a vehicle.</i>	E
Finding the right balance	<i>I just wanted to carry on and achieve my usual goals ... it was at that time that I lost it. I still have trouble accepting that ... then I just fall onto the sofa, too tired to even move.</i>	P
	<i>This is accepted much easier than someone who constantly pushes himself too hard and consequently has to call in sick.</i>	E
	<i>It is because they push themselves so hard that after two years, they still end up at home suffering from the delayed effects and fatigue.</i>	E
Rehabilitation	<i>I followed a twelve-week rehabilitation programme at Revant during the summer. That also proved to be beneficial. I made strong physical progress but it was also beneficial to my mental state.</i>	P
	<i>I'd much rather go for a bike ride. I'll be cycling no less than 80 km next Friday...</i>	P

(Continues)

Topic	Quote	P/E
Employer's attitude towards RTW	<i>I received a lot of support from my employers right after I was diagnosed. They visited often and showed a lot of interest in my situation. I now do sedentary work and I can last for quite a while. As a result, I hardly ever have to call in sick.</i>	P
	<i>I have a fantastic employer who tells me to do what I can and if I'm not up to it, I'm told to go home. He has offered me every opportunity to carry on working.</i>	P
	<i>Having an employer who is not invested in getting you back to work is one of the most hindering factors you can be faced with.</i>	E
Counselling by OPs	<i>Well, there was hardly any contact with the health and safety service. I was under the impression that they had no idea of what MM was. I would have liked the health and safety service to have shown some more interest.</i>	P
	<i>I was allowed to come and work for a whole 1.5 hours on a Monday. That's how they make a plan for you. I thought to myself, that man has lost the plot.</i>	P
Specialised OP	<i>I have heard of second opinions being suggested but I have no experience with referrals to a specialised cancer OP.</i>	E
	<i>That is why a specialised OP is so interesting in this case, they look into factors that are overlooked by regular company physicians as they are fundamentally generalists.</i>	E
	<i>An additional problem is that they do not have a finance structure in place yet. Health insurance companies could benefit, or at least absenteeism insurance companies, as it would result in less absenteeism.</i>	E
Counselling by IPs	<i>At a certain point, the insurance physician determined me to be medically disabled for 65%, this because I wanted to carry on working. My employer is content with the situation and I could not be happier.</i>	P
	<i>Then you find yourself negotiating whether or not you can become a postman, very odd discussions to have.</i>	E
	<i>A few years ago, there was talk of perhaps training specialised insurance physicians, ... yes, that would be great but then you would also need to create some sort of consultation strategy with the oncologists.</i>	E
HCPs addressing RTW	<i>We aren't saying that an oncologist should also be a labour expert but it would not hurt if they were aware of the fact that it is extremely important to patients</i>	E
	<i>It's emphasised that patients should start exercising as soon as physically possible. The hospital should also focus on return to work as a treatment goal during their treatment programme.</i>	E
	<i>If the patient is a pianist, I can tweak the treatment so that he or she may experience less neuropathic symptoms. This is surely an element which belongs in the hospital.</i>	E
Patient's role in RTW	<i>I myself joined in when setting up the RTW-plan. So many hours in the first week and gradually increasing the number of hours. I was able to determine the details myself, which allowed me to follow my ideal route.</i>	P
	<i>An important predictor in RTW is the patient's personal situation, it is highly dependable on the patient's state of mind, their set of competences, level of conviction and coping skills.</i>	E
	<i>It can be a big ask for patients to stand up for their own interests at a time when they are feeling as sick as can be and need to arrange all sorts of matters, they might not have the expertise for.</i>	E
Communication between experts	<i>You have to figure out everything by yourself, all that is related to the employee insurance agency, your employer and the company physician.</i>	P
	<i>Still, physicians do not react (well) to all the letters they receive. This is mostly due to simply not having the time or just rather dealing with the issue in a telephone call. Besides this, the physician forwards the letters to the GP who in turn notifies the company physician but usually is not able to answer his or her questions properly.</i>	E
	<i>I do, however, think that in case of a rare and specific disease such as myeloma, it is essential to be able to ask your haematologist to write a letter to inform your OP so that he or she understands the context and any possible consequences. This matter is just too rare and specialised for a regular company physician to deal with.</i>	E
	<i>It would be like having occupational physicians working beside us during our outpatient care and that we would assess together. If you would ask me what the ideal scenario would be, this is it.</i>	E