Original Study

Changes in income and employment after diagnosis among patients with multiple myeloma in The Netherlands

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Abstract

This study investigated the changes in income in patients with multiple myeloma (MM) in The Netherlands. Both income from employment and employment decreased considerably between 1 year before and 4 years after diagnosis in MM patients, emphasizing the need for more awareness about the effect of being diagnosed with MM on income and employment.

Objective: Due to new treatment options, survival rates in multiple myeloma (MM) are improving. Consequently, maintaining work and income is becoming more important for patients and society. Therefore, we aimed to explore the change in income and employment in patients with MM. **Methods:** Data from the Netherlands Cancer Registry of MM patients diagnosed between 2012 and 2017 were merged with socioeconomic data from Statistics Netherlands. Descriptive statistics were used to analyse total income, income from employment, and accumulated income before and after diagnosis. **Results:** Income from employment decreased by 45% in MM patients, between 1 year before and 4 years after diagnosis Four years after diagnosis, 35% of the patients were still employed, with an accumulated 5-year productivity loss of €121 million. Higher income loss from employment and job loss was observed in female patients, patients with more extensive disease, or those not treated with autologous stem cell transplant. **Conclusion:** Loss of (income from) employment among patients with MM was high, causing financial burden on the patient and society. With improving survival in MM, more research and awareness are needed to better assess the importance of income and work for MM patients and society.

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Introduction

Multiple myeloma (MM) is a malignant plasma cell disease with an annual incidence of 1300 patients in the Netherlands, of whom 35% are younger than 66 years at the time of diagnosis.[1] The 5-years overall survival of patients with MM ≤65 years improved from 36% in 1989-1998 to 67% in 2009-2018.[2,3] Recent studies showed even further improvement in survival in MM patients of working age due to the introduction of new treatments (i.e., novel agents).[4-7] Despite this improvement in survival rates, MM is still incurable, and disease symptoms, intensity, and duration of treatment, as well as the severity of treatment side effects, limit the ability of MM patients to participate in the labour process. It is therefore expected that MM patients are less likely to return to work post-diagnosis and have higher rates of disability and disease-related retirement compared to other cancer patients.[8-13] Moreover, previous research showed that the inability to work, loss of employment or income, and financial insecurity may negatively affect Quality of Life (QoL) of MM patients and their caregivers.[13-16] Furthermore, it has been argued that the economic burden of productivity loss in MM, which is also higher compared to other malignancies, should be considered when assessing the total costs of MM.[17] This could eventually contribute to a more comprehensive evaluation of (cost-)effectiveness of MM treatments and the value of treatments for patients and society.

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However, research into the effects of diagnosis and treatment on total income in MM is limited[18,19] and frequently based on either relatively small samples of MM patients[7,8] or on patient-reported data.[10,12] Therefore, in this population-based study, we aimed to provide insight in income and employment of patients with MM of working age in the Netherlands, before and after diagnosis, from patients' and societal perspective.

Methods

Data Sources and Study Population

The Netherlands Cancer Registry (NCR)[20] was used to identify MM patients (International Classification Diseases for Oncology Morphology codes 9732/3)[21] with the following inclusion criteria: 1) being diagnosed with MM between 2012 and 2017 and 2) aged 18-65 years at time of diagnosis. The data from the NCR were matched with data from Statistics Netherlands (SN) from 2011 to 2021, providing a data set with clinical data at diagnosis and socioeconomic data on income from 1 year before to 4 years after diagnosis. Of the 2599 identified patients in the NCR, 43 patients could not be matched to the SN data, due to missing SN identification numbers, and were therefore excluded. Moreover, 32 patients with missing income data were excluded. In total 2524 MM patients were included in the analyses (Supplementary material Figure 1).

Variables and Measures

The following variables were retrieved from the NCR: 1) demographic characteristics: gender, age at diagnosis (categories: <55, 55-62, 63-65); 2) International Staging System (ISS), stages ISS-I and ISS-II (limited disease), and ISS-III (extensive disease) at diagnosis. ISS was unknown in approximately half of the patients due to the use of Salmon Durie staging before 2014 and therefore results by disease stage concern only half of the population; and 3) first-line treatment was categorised into patients receiving autologous stem cell transplant (ASCT), including induction chemotherapy, and MM patients treated with chemotherapy only (non-ASCT). The group of patients with no first-line treatment or other treatments consists of a diverse group of patients with either a wait-and-see treatment policy, patients who refuse treatment, or patients no longer eligible for any anti-MM treatment.

Socioeconomic variables were retrieved from the SN databases and included: 1) income from employment: the sum of income from paid employment; 2) income from benefits: the sum of income from both unemployment and social security benefits, and disability benefits; 3) income from (retirement) pension; and 4) total income: the sum of income received from paid employment (labour) and benefits and pension (Supplementary Material Table 1, for the SN codes used).

Data Analyses

All analyses were performed using STATA statistical software[22] and Microsoft Excel to create (pivot) tables and graphs.[23] Descriptive statistics were used to analyse the data since this study focuses on a population of Dutch MM patients only and the primary aim of this study is to provide insight in the observed income and employment of patients with MM in the Netherlands, before and after diagnosis.

Data analyses were divided into analyses on patient level (A-C) and societal level.

A: Income from paid employment was obtained by calculating the proportional and absolute change in average annual income from paid employment per patient (i.e., 1620 MM patients employed 1 year before diagnosis and 1272 MM patients, regardless of whether they were still employed, 4 years after diagnosis); Additionally, analyses were performed to explore the effect of the number of excluded patients 4 years after diagnosis, due to (partially) missing SN data or death.

B: Employment status was analysed by calculating the difference in employed patients before diagnosis and 4 years after diagnosis.

C: Total income change was obtained by calculating the proportional and absolute change, in average annual total income (including income from paid employment as well as benefits and pension) per patient (i.e., 2524 MM patients in the year before diagnosis and 1896 MM patients 4 years after diagnosis);

Subgroup analyses were performed for gender, age, ISS stage, and type of first-line treatment to explore subgroups at risk of loss of income or employment. Since treatment and age are correlated, an additional subgroup analysis was performed showing change in income from employment by age group separately for ASCT and non-ASCT patients.

All analyses on patient level were performed between 1 year before and 4 years after diagnosis, referred further as 'before' and 'after' diagnosis.

At the societal level, the absolute change in the annual cumulative total income from paid employment was calculated by accumulating all income from paid employment in the year before diagnosis and comparing this to the accumulated income from paid employment 4 years after diagnosis, representing the annual loss of paid employment. Additionally, the loss of the accumulated income from paid employment between 1 year before and 4 years after diagnosis was calculated to show the 5-year loss of paid employment as a proxy for productivity loss. The change in accumulated income from benefits and pension was calculated similarly.

Results

Patient Characteristics

Table 1 shows the characteristics of 2524 patients with MM. The average age of patients at time of diagnosis was 57 years (median 59) and 60% (n = 1499) were male patients. The majority of the patients (n = 1438) received ASCT, 578 non-ASCT patients were treated with chemotherapy, 485 patients had no first-line treatment, and 23 patients received other treatments, e.g., radiotherapy. Patients with a known ISS were equally divided between groups. Within the group of employed patients (n = 1620), 1331 were categorized as being an employee before diagnosis, 49 patients were CEO/shareholder and 240 patients were self-employed. In total, 447 patients were unemployed and received social welfare (n = 229) or disability benefits (n = 218) before diagnosis (further called 'benefits'), 276 patients received (retirement) pension, and 181 patients received income categorized as other. Most patients (n = 1157) belonged to the mid-income group (Table 1).

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Table 1 Sample Characteristics

	N (%)
1 year before diagnosis	2524
4 years after diagnosis	1896
Demographics	
Gender (male)	1499 (59.4)
Age (median)	59
<55	743 (29.4)
55-62	1118 (44.3)
>62	663 (26.3)
Disease stage at diagnosis	
ISS-I	474 (18.8)
ISS-II	451 (17.9)
ISS-III	367 (14.5)
Unknown	1232 (48.8)
First line treatment	
ASCT	1438 (57.0)
non-ASCT	578 (22.9)
No treatment	485 19.2)
Other treatments	23 (0.9)
Employment, benefits and pension before diagnosis	
Employee	1331 (52.7)
CEO/shareholder	49 (1.9)
Self-employed	240 (9.5)
Unemployment/Social welfare	229 (9.1)
Disability benefits	218 (8.6)
Pension	276 (10.9)
Other[a]	181 (7.2)
Total income before diagnosis[b]	
< €20,000	829 (32.8)
€20,000-€50,000	1157 (45.8)
>€50,000	538 (21.3)

ISS, International Staging System; ISS-I/ISS-II, limited disease; ISS-III, extensive disease.
ASCT, autologous stem cell transplant; non-ASCT, non-transplant eligible multiple myeloma.
[a] Other: income as a family member or work with in-kind payment.
[b] Total income from work, benefits, or pension.

Income From Employment

Analyzing changes in income from employment showed an average decrease in income from paid employment of 45%, from €41,952 (SD 36,364, n = 1620) before to €22,914 after diagnosis (SD 33,792, n = 1272; Figure 1A). Of the 1272 patients post-diagnosis (regardless of whether or not they were still employed), 757 patients had an income loss of >50% and 50 patients had an increase in income of >50% (Supplementary Material Table 2).

The decrease in average income from paid employment was higher in female patients compared to male, (60% and 40%, respectively). Patients older than 62 years experienced a higher loss of income from paid employment (88%) compared to patients younger than 62 years. Patients with extensive disease showed a loss of income of 53% compared to 41% in patients with limited disease. Patients who received an ASCT experienced an income loss of 46% compared to a 52% income loss from paid employment in non-ASCT patients (Table 2). For patients that did not receive. ASCT, income loss was most pronounced in the younger age groups (Supplementary Material Table 3).

In patients who were excluded due to missing income data or death within 4 years post-diagnosis (n = 1068), the average baseline income from employment before diagnosis was 24% lower (€37,660) compared to the average baseline income (€49,407) of patients still employed and included in the analysis after diagnosis (n = 565).

Employment After Diagnosis

Of the 1620 patients initially employed before diagnosis, 565 (35%) were still employed 4 years after diagnosis. More men than women were still employed post-diagnosis (38% vs. 29%, respectively). With increasing age, employment post-diagnosis decreased (52%, 29%, and 8% for <55 years, 55-62 years and 62-65 years, respectively). Of patients with limited disease stage, 41% were still employed after diagnosis, while 26% of the patients with extensive disease were still employed after diagnosis. Regarding type of first-line treatment, 37% of the patients with ASCT, and 17% of the patients without ASCT were employed after diagnosis (Table 3). For patients that did not receive ASCT, there was an inversely correlation with age (Supplementary Material Table 3).

Total Income From Work, Benefits, and Pension

Analyses of the average total income from employment, benefits, and pension among the 2524 MM patients showed, on average, no income loss after diagnosis (Figure 1B; Supplementary Table 4). After diagnosis, the total average income among 1896 patients increased by 2%, of whom 180 patients (9%) experienced an income loss of more than 50% and 269 patients (14%) an income increase of more than 50% (Supplementary Material Table 5).

Accumulated Income From Employment, Benefits and Pension

The accumulated income from paid work was €69 million for all patients with MM before diagnosis. This income decreased to €30 million. 4 years after diagnosis, i.e., an annual decrease of income from employment of almost €40 million. The cumulative 5-year loss of income from employment between 1 year before and 4 years after diagnosis was €121 million. Income from benefits and pension increased annually by €7 million and €12 million 4 years post-diagnosis, i.e., a cumulative 5-year increase of €68 million between 1 year before to 4 years post-diagnosis (Figure 1C).

Discussion

Main Findings and Interpretation of Findings

In this study, changes in income and employment in patients with MM before and after diagnosis were explored. Average income per patient from paid employment decreased by 45% and only one-third of the patients were still employed 4 years after diagnosis. This is in line with previous studies that reported a 30%-39% return to work in MM patients and also a 30-39% return to work after ASCT.[8,24,9,10] However, only 17% of the non-ASCT patients were still employed 4 years after diagnosis compared to 37% of ASCT patients. While ASCT treatment may be more intensive in the first year after diagnosis, 4 years after diagnosis the non-ASCT group

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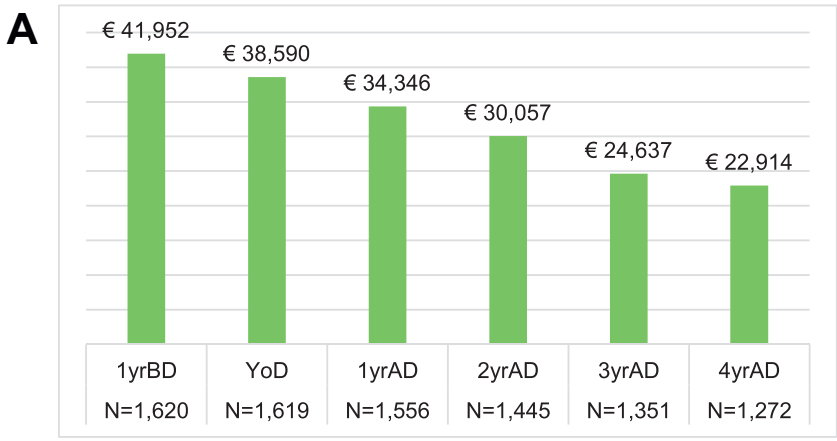
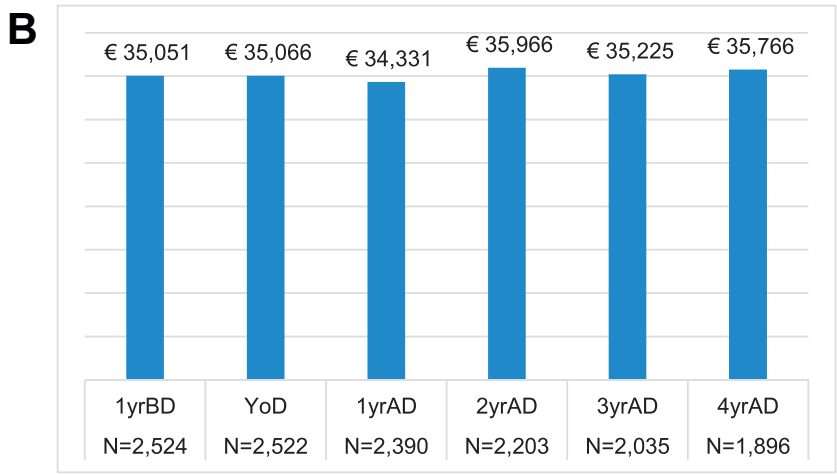
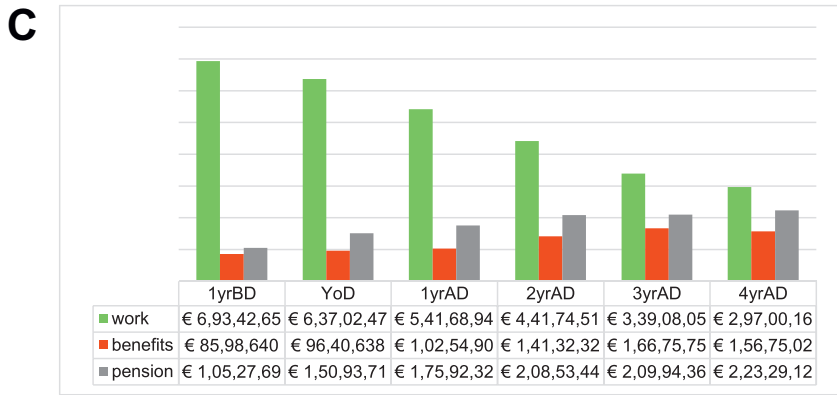
Figure 1 (A-C) Change in mean and accumulative income in MM. (A) Mean annual income/patient from employment. (B) Mean total annual income from employment, social benefits, or pension. (C) Total accumulated income from employment, benefits, and pension. *AD, after Diagnosis; BD, Before Diagnosis; N, Number of patients in the analysis each year; YoD, Year of Diagnosis; Yr, year.*







	1yrBD	YoD	1yrAD	2yrAD	3yrAD	4yrAD
work	€ 6,93,42,65	€ 6,37,02,47	€ 5,41,68,94	€ 4,41,74,51	€ 3,39,08,05	€ 2,97,00,16
benefits	€ 85,98,640	€ 96,40,638	€ 1,02,54,90	€ 1,41,32,32	€ 1,66,75,75	€ 1,56,75,02
pension	€ 1,05,27,69	€ 1,50,93,71	€ 1,75,92,32	€ 2,08,53,44	€ 2,09,94,36	€ 2,23,29,12

experienced higher loss of employment and higher loss of income from employment, especially in the younger age groups. This could be explained by the fact that ASCT is the preferred treatment for patients who are fit enough to receive this treatment, hence, the younger patients who did not receive ASCT are most likely not fit.

Female patients, older patients (>62) and patients with more extensive disease were showed higher loss of income and employment compared to the other subgroups. This is in line with a previous study by Horsboel et al., who found that female patients and older patients were more likely to become dependent on disabil-

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Table 2 Differences in Mean Annual Income From Employment

Variables	Mean Income From Employment/Patient		
	1 Year Before Diagnosis (N)	4 Years After Diagnosis (N)	% Difference[a]
Total	€41,952 (1620)	€22,914 (1272)	−45%
Gender			
M	€50,848 (1039)	€30,330 (800)	−40%
F	€26,042 (581)	€1360 (472)	−60%
Age group			
<55 years	€43,735 (600)	€32,899 (500)	−25%
55-62 years	€41,776 (783)	€19,899 (596)	−52%
>62 years	€38,016 (237)	€ 4739 (176)	−88%
Disease stage			
ISS-I/ISS-II	€43,670 (622)	€25,773 (533)	−41%
ISS-III	€44,522 (230)	€20,807 (156)	−53%
Unknown	€3979 (768)	€20,860 (583)	−48%
First line treatment			
ASCT	€44,634 (997)	€24,070 (841)	−46%
NTE-MM	€36,899 (316)	€17,861 (160)	−52%
No treatment	€38,491 (297)	€22,666 (264)	−41%

ASCT, autologous stem cell transplant; F, Female; ISS, International staging system; ISS-I/ISS-II, limited disease; ISS-III, extensive disease; M, Male; N, Number; non-ASCT, no ASCT treatment.
[a] Proportional difference in income from employment before and after diagnosis.

ity benefits.[11] Notably, patients no longer employed after diagnosis had lower incomes before diagnosis compared to the patients still employed after diagnosis, which could be an indication for blue-collar labor, working in part-time or flexible contracts and, hence, an association with lower income and higher risk of loss of employment.[16]

On average, MM patients experienced no loss of total income, indicating that loss of income from paid work is compensated by benefits or pension. This is supported by research by Horsboel et al., who reported that among patients with hematological malignancies, patients with MM had the highest relative risk of becoming dependent on disability benefits.[11] The Dutch social security system seems to offer a financial safety net to MM patients. The advantage of a safety net is that it reduces financial stress for patients. However, more research is needed to identify whether this safety net aligns with patients preferences and to ensure that there are no inverse incentives arising from this safety net, e.g., whether it may deprive MM patients of the opportunity to remain in paid employment.

The 5-year loss of income from paid employment of €121 million provided a rough indication of the impact of productivity loss in MM patients on society. In several previous studies, high productivity losses among cancer patients were found. However, comparing these results to the current study is difficult due to differences in patient populations, type of cancer, number of included patients and differences in used research methods.[10,25,26] For example, Ortega-Ortega et al. showed high productivity losses in patients with haematological diseases. Their study also reported on the higher productivity losses due to the increased legal retirement age throughout Western Europe, which was introduced to alleviate the economic burden of our ageing population.[25] In the Netherlands, the legal retirement age increased from 65 in 2016 to 67 years in 2023, adding 2 labour-productive years to society. Since cancer is mostly seen in older patients, the effect of increased retirement age on productivity losses caused by cancer needs more attention.

Strengths and Limitations

Studies on loss of income among patients with MM are limited, although there is a growing interest in the financial and economic burden of MM. Therefore, it could be considered a strength that, in this study, the developments in income and employment status before and after being diagnosed with MM were described. However, the generalizability of our results requires adjusting for differences in country-specific legislation and social security systems. Furthermore, a more extensive study design (i.e. including a control group) is recommended to establish causality.

A limitation of this study is that gross annual income may consist of income not related to employment (i.e., income from financial assets, or other benefits, e.g., child support). In this study, we focused on income from employment, benefits and pension and extending the analysis to gross annual income should be subject to further research. Further, this study did not address out-of-pocket costs and increased expenses due to being diagnosed with MM, although some research suggested that these costs are sometimes considerable, even in patients with sufficient health insurance.[27,28] Also, a decline in savings and assets, and an increase in debt, mortgage and insurance costs were reported.[29,30] Therefore, income losses and financial impact may have been underestimated in our study.

Furthermore, patients over 62 years were included in this study, most of whom were eligible for retirement pension within the 4 years of follow-up. This may have affected the loss of income and employment not or only partly attributed to MM. Also, the number

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Table 3 Difference in number of patients employed before and after diagnosis

Variables	Number of patients employed		
	1 year before diagnosis	4 years after diagnosis	% employed after diagnosis*
Total	1,620	565	35%
Gender			
M	1,039	395	38%
F	581	170	29%
Age group			
<55 years	600	314	52%
55-62 years	783	231	30%
>62 years	237	20	8%
Disease stage			
ISS I-II	632	257	41%
ISS-III	292	114	26%
Unknown	768	248	32%
First line treatment			
ASCT	997	364	37%
non-ASCT	316	54	17%
No treatment	297	145	49%

* Percentage of the number of patients initially employed before diagnosis, who are still employed after diagnosis
N: number; M: Male; F: Female; ISS: International staging system; ISS-I/ISS-II = limited disease; ISS-III= extensive disease; ASCT: Autologous Stem Cell Transplant, non-ASCT: no ASCT treatment.

of patients excluded from the analysis 4 years after diagnosis by either loss of employment or death was high and their income from employment was lower at baseline compared to the patients still employed after diagnosis. This may have led to an underestimation of the change in income from employment.

Implications for Future Research and Practice

Although this study contributes to the limited knowledge regarding the impact of MM on income and employment, more research is needed addressing patient and job characteristics, e.g., educational level, type of job, and contract to identify specific subgroups at risk for financial toxicity.

In this study, productivity losses were based on cumulative income losses from paid employment. However, previous studies showed a wide variety of both qualitative and quantitative research methods and analysis approaches to measure productivity losses.[31, 32] Therefore, with increasing survival, more research is needed, using more advanced statistical methods to measure income effects in MM patients over time or between groups.

Furthermore, the importance of research assessing the impact of employment on quality of life requires more attention beyond guaranteeing financial stability. Finally, more awareness of the importance of income and work in MM is needed among healthcare professionals in clinical practice, occupational, and insurance physicians, and in society in general. Especially with increasing survival and the increasing retirement age, preventing loss of income and employment in MM becomes increasingly important.

Conclusion

MM patients in the Netherlands on average suffer high loss of income from paid employment and two-thirds of the MM patients lost their income from employment. Income loss and a decrease in employment were more frequently observed among female and older patients, patients with more extensive disease and patients not receiving ASCT. The high productivity loss and the increasing income from benefits and pensions contribute to the already exponentially increasing costs of MM care on society. With improving survival in MM, more research and awareness are needed to gain a comprehensive understanding of the importance of income and employment on MM patients and society.

Clinical Practice Points

- Survival rates in Multiple Myeloma (MM), improved significantly over the past decades, making quality of life considerations increasingly important.
- Both financial stability and ability to work contribute to quality of life.
- Population-based research into change in income and employment is still scarce but is becoming increasingly important as more MM patients may want or need to return to work.
- Analyses showed that loss of income from employment and employment in MM in the Netherlands are significant.
- Female patients, patients with higher age and disease stage, and patients who did not receive an autologous stem cell transplant showed higher loss of income from employment and higher loss of employment.
- The effect of MM on income and employment needs more research and attention in clinical practice and from occupational and insurance physicians, both in the interest of the individual patient and society as a whole.

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CRediT authorship contribution statement

Christine Bennink: Writing – review & editing, Writing – original draft, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Mirian Brink:** Writing – review & editing, Data curation, Conceptualization. **Hans Scheurer:** Writing – review & editing, Conceptualization. **Pieter Sonneveld:** Writing – review & editing, Supervision, Conceptualization. **Hedwig M. Blommestein:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Data curation, Conceptualization.

Ethical Approval

NA.

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Supplementary materials

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