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## P-130

### The impact of COVID-19 on the treatment regimens of myeloma and AL amyloidosis patients

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**Background:** As the COVID-19 pandemic unfolded in 2020, Myeloma Patients Europe (MPE) recognized that the pandemic was impacting the healthcare and lives of people with myeloma and AL amyloidosis, and their caregivers. Findings from a small UK study suggested that myeloma patients were more likely to die from COVID-19 than members of the general population who contracted the virus [Cook et al, 2020]. Focus groups were conducted to learn more about the impact of COVID-19 on the lives of patients and their families, with a focus on its impact on diagnosis and treatment.

**Method:** MPE researchers conducted four online focus groups in Europe examining the views and experiences of myeloma and AL amyloidosis patients and caregivers during the COVID-19 pandemic. Fifteen patients and two caregivers took part. Thirteen patients had myeloma and two had AL amyloidosis. Participants were from Spain (n = 6), the UK (n = 2), Belgium (n = 2), Germany (n = 2), the Netherlands (n = 1), Iceland (n = 1), Israel (n = 1), Poland (n = 1), and Romania (n = 1). Eleven patients had been diagnosed within the last few years, while four were living with myeloma for a decade or longer. Ten patients were receiving active treatment for myeloma or AL amyloidosis during the pandemic, while others were in remission. **Results:** Sixty percent of study participants reported that the COVID-19 pandemic negatively affected their treatment. Three patients said that medicines given in hospital (by infusion or injection) were delayed due to COVID-19 restrictions. Sometimes, the frequency of these treatments was reduced. In contrast, most patients taking oral medicines (tablets) reported that their treatment continued as normal. Seven participants said their or another patient's invasive procedure (such as a bone marrow biopsy or stem cell transplant) had been delayed. These procedures took place after approximately 1–6 months later than originally scheduled, once HCPs and patients felt it was safe to do so. One patient reported an improvement in her treatment due to the pandemic restrictions. Her 4- to 5-hour long infusions of daratumumab in hospital had been switched to subcutaneous injections with fewer side-effects.

**Conclusions:** Findings suggest that COVID-19 had an impact on patients with myeloma and AL Amyloidosis and their treatments. Some aspects of this may be positive, with preference data showing that patients have a preference for oral administrations (Fifer et al, 2020) and as such, switching patients to at home treatment regimens may have both avoided treatment delays and also been in line with patient preferences for treatment administration. MPE suggest that the administration of treatments should be examined regularly. COVID-19 upended existing treatments and other healthcare services, but patients and their healthcare providers should be reviewing options on an ongoing basis to ensure both high quality of care and changes in patient preferences over time.

## P-131

### Use of the European Organisation for research and treatment of cancer quality of life Multiple Myeloma questionnaire (EORTC QLQ-MY20): a review of the literature 25 years after development

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**Background:** The EORTC QLQ-MY20 is a widely used myeloma-specific patient-reported outcome measure originally developed in 1999. It consists of 20 items covering Disease Symptoms (DS), Side Effects (SE), Future Perspectives (FP) and Body Image (BI). Novel treatments and multiple lines of therapy mean the treatment for myeloma patients and life expectancy has changed dramatically and there is a need to ensure the measurement of health-related quality of life remains current for these patients. The original validation study was almost exclusively in newly diagnosed patients reflecting the nature of clinical trials at the time. This review was conducted as part of an EORTC funded grant to update the QLQ-MY20, with the aim of summarising the published literature from the QLQ-MY20 to date including any further validation results for the QLQ-MY20. **Methods:** Literature search was conducted using the Ovid SP platform (Medline, EMBASE and PsycINFO) from 1996 (first release of the questionnaire). Abstracts were included if they were reporting: a clinical study using the QLQ-MY20 or validation studies. Information about the study design was extracted alongside whether the population were newly diagnosed or relapsed, and the supplementary instruments used alongside the QLQ-MY20. For randomised control trials, information on the type of analysis and results were also extracted. For validation studies data on the instrument structure and data distribution, reliability, validity and ability to detect change/interpretation of change scores was extracted. **Results:** 656 abstracts were screened to 74 included papers (65 clinical studies, of which 21 were interventional clinical trials, and 9 validation studies). Supplementary instruments used alongside QLQ-C30 and MY20 included BPI-SF (Brief pain inventory short form), EQ-5D-5L (generic preference-based measure), FACT-GOG-Ntx (neurotoxicity) and the EORTC QLQ-CIPN20 (chemotherapy induced peripheral neuropathy). In contrast with the original validation study, 34 out of 43 clinical studies included either exclusively relapsed patients (n=24) or a mix of newly diagnosed and relapsed (n=9). DS and SE were the most commonly reported results from the QLQ-MY20. Further validation studies supported the factor structure, reliability and validity, with the only potential issue being observed ceiling effects for the BI subscale. **Conclusions:** The shift in HRQOL measurement to patients experiencing multiple lines of treatment and novel treatments, highlights the need for updating the conceptual model for the QLQ-MY20. Interviews are currently underway internationally with 90 patients and 20 healthcare professionals to identify the issues relevant to myeloma patients today. The current questionnaire has been shown to be