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The impact of SARS-CoV-2 (COVID-19) on the treatment and care of patients with myeloma and AL amyloidosis

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Introduction / aims

As the SARS-CoV-2 (COVID-19) pandemic unfolded in 2020, Myeloma Patients Europe (MPE) became aware that the healthcare, treatment, and lives of myeloma and AL amyloidosis patients and their families were impacted by new health policies and national restrictions related to COVID-19. Findings from a small UK study also suggested that myeloma patients were more likely to die from COVID-19 than members of the general population (Cook et al, 2020) and MPE as a patient organisation wanted to know more to plan support for European patient advocates, patients and caregivers. Focus groups were conducted to learn more about the impact of COVID-19 on the lives of patients and their caregivers, with a focus on diagnosis and treatment. Data was transcribed, analysed, and presented to our members, with findings summarised here.

Our aim was to discover how the COVID-19 pandemic, as well as the health policies and restrictions imposed, affected the healthcare and lives of people with myeloma and AL amyloidosis and their caregivers.

Methods

Researchers at MPE conducted four online focus groups in Europe examining the views and experiences of patients with myeloma and AL amyloidosis and their caregivers. 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 two to three 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 five were in remission. Sixty percent of participants were male.

Three focus groups were held in English and one was held in Spanish. Participants answered questions both from their personal experiences during the COVID-19 pandemic and insights gained through the patient organisations of which they are members. Recordings of the focus groups were transcribed and thematic analysis was used to generate themes from the data.

Findings

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. 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.

Extracts from primary themes

Barriers to treatment in hospital

"I was effected by the pandemic because I was scheduled for an autologous transplant in mid-March 2020, which was put on hold. I finally had the autologous transplant. It was at the end of August, when the COVID-19 figures were better." Patient 6

"Due to travel restrictions, of course patients had problems getting to the hospital...patients from smaller towns...had issues to get to the hospital and to stay somewhere. Because the hospital hotels were closed and the other hotels were often suspended as well. So, this was an issue." Patient 1

Delays in treatment

"The transplant, in some cases the procedure was delayed for safety reasons of course, because it's such a severe procedure....[a treatment delay is] psychological, it's a massive burden. Because patients don't know what to expect." Patient 1

"I was supposed to have a bone marrow biopsy... around April last year. So, we rescheduled it for around August." Patient 4

In contrast, most patients taking oral medicines (tablets) reported that their treatment continued as normal.

"I am on Revlimid and this is oral, so this has not been affected" Patient 4

"My treatment currently... I am taking it only at home, you know...I don't need to get to the hospital, only to see my doctor every few months. So, there was no real impact on my day-by-day medicine that I am taking." Patient 5

Telemedicine

Patients reported mixed feelings about the use of telemedicine for their myeloma treatment during the pandemic.

"I only left the house for my blood tests. The rest was dealt with over the telephone. I have realised that going to the doctor in person is not as necessary as I thought." Patient 2

"I am not a fan of telemedicine. You just can't get into the routine you need. I want to be able to look my consultant into the eyes. Let's have an open discussion on that. Being on the other side of a phone, sometimes you forget some things you want to talk about." Patient 4

"And now everything is now telemedicine. Now you have a phone call with a doctor. It's much more difficult to issue a certain referral and for the person to go to a hospital or to go to a place where they can get tested." Patient 1

Clinical trials

Four patients in our focus groups said they had taken part in a clinical trial during the COVID-19 pandemic. One clinical trial was paused, while others continued without delay. One patient was preparing to receive experimental chimeric antigen receptor T cell (CAR-T) therapy for myeloma when the pandemic began. Her CAR-T therapy was delayed, which she believes led to the progression of her disease.

"In March I started the bridging treatment to undergo CAR-T. But the pandemic arrived, and everything stopped. That treatment was ruled out and I switched to a maintenance treatment. And that's when the disease really progressed. I didn't have any blood tests for a month, and in that time, everything went through the roof." Patient 8

Medication administration

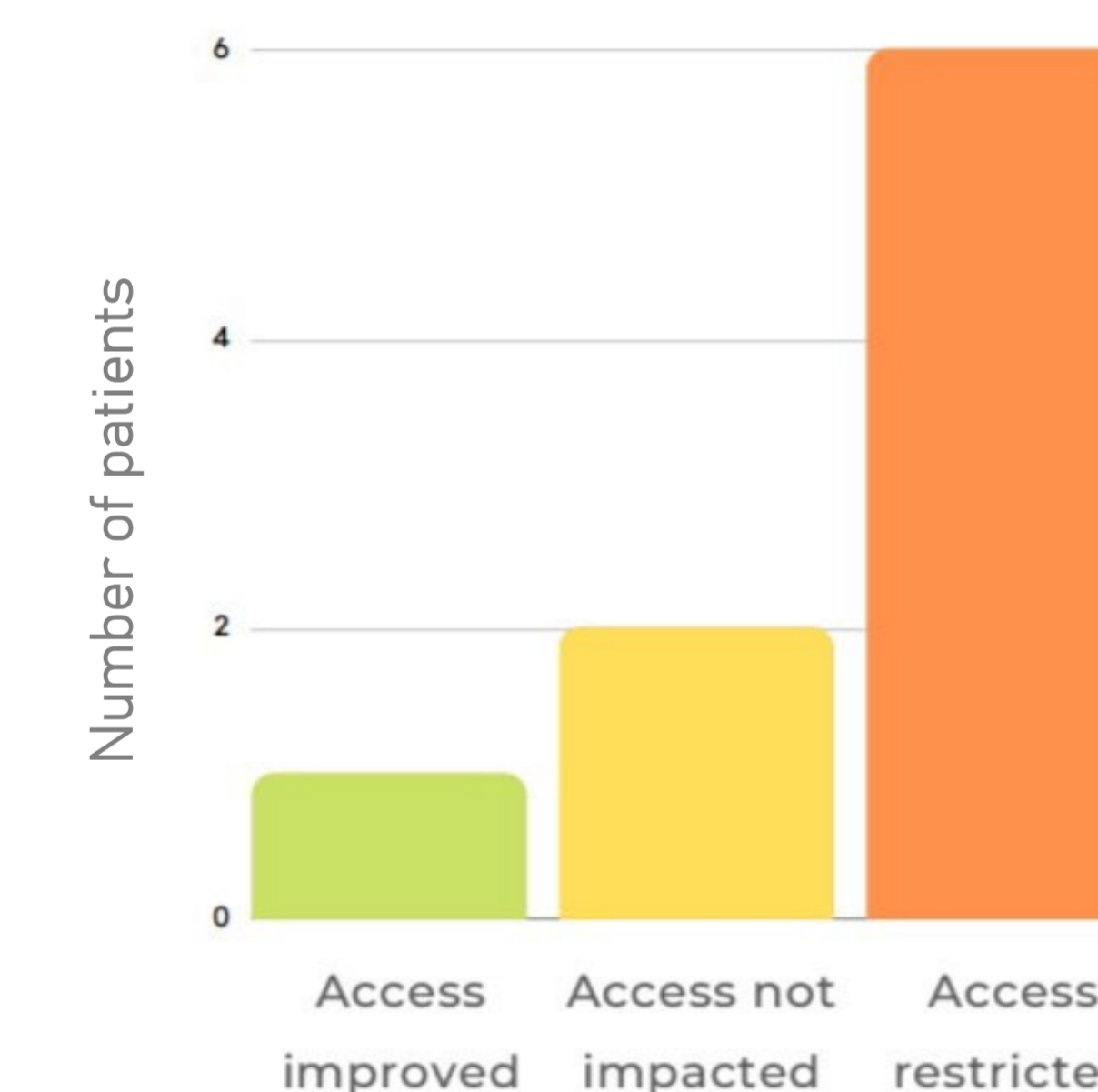
One patient reported an improvement in her treatment due to the pandemic restrictions, specifically regarding a change from an infusion to subcutaneous injections.

"I think [the] pandemic has benefited me in the treatment of my disease, in the sense that, before COVID-19, I was given daratumumab intravenously for four to five hours, and now in just five minutes I get a subcutaneous injection in my stomach. In addition, the subcutaneous formulation of daratumumab has almost no side effects." Patient 9

Findings

Findings from our qualitative work suggest that COVID-19 had an impact on patients with myeloma and AL Amyloidosis and their treatments. Some aspects of this may be positive, mirroring recent myeloma preference study data suggesting 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. Other impacts, including barriers to hospital access, changes and delays in treatment, psychological burdens, and limitations of telemedicine were negative.

EFFECT OF THE COVID-19 PANDEMIC AND RESTRICTIONS ON ACCESS TO WIDER HEALTHCARE SERVICES



Conclusion

Findings suggest that the administration of treatments should be reviewed regularly. COVID-19 impacted existing treatments and other health care services, but myeloma and AL amyloidosis patients and their healthcare providers should be reviewing options on an ongoing basis to ensure both high quality of care and flexibility according to changes in patient preferences over time. MPE also suggests close monitoring of patients who experienced treatment delays as well as research into the impacts of these delays on quality of life, outcomes, and overall survival.