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Analysis of Free-Text Responses in an International Myeloproliferative Neoplasms Patient Survey to Assess Impact of the COVID-19 Pandemic on Clinical Care

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Background

The COVID-19 pandemic continues to challenge effective treatment delivery to hematologically-compromised patients, including those with myeloproliferative neoplasms (MPNs). MPNs are characterized by clonal proliferation of hematopoietic cell lines in bone marrow. As such, increasing reports of COVID-19 related thrombotic events highlight how MPN patients are at an increased risk in navigating potential complications during this pandemic. Mitigation strategies to lesson MPN patient exposure to COVID-19 are vital. Though, such efforts come at an inherent cost to effective healthcare delivery. Restriction of regular in-clinic treatments and reported shortages of MPN pharmacotherapies present these patients with diminishing continued care.

To understand how MPN patient care has been impacted by COVID-19, an internet-based questionnaire was deployed surveying a variety of disease and pandemic related items (reported elsewhere; Palmer J et al, ASH 2020 submitted). A single free-text response item instructed respondents to: "Please tell us anything else (bad or good) about how the COVID-19 outbreak has impacted your MPN care."

This qualitative analysis evaluated first-hand comments directly from patients in order to form a richer understanding of how those with MPNs have been managing disease-related care amidst this pandemic.

Methods
This COVID-19 survey was hosted via Mayo Clinic’s secured REDCap system for online surveys and posted on MPN organizational partner websites. Surveys were completely anonymous. The free-text responses describing impacts to MPN care were each independently reviewed by 2 individuals for overall sentiment (positive, negative, both, or neutral [no impact]) and categorized for themes. The 2 reviewers were assessed for agreement. Conflicting reviews were evaluated then adjudicated by an algorithm for cases meeting selected conditions or by lead author review for all remaining cases. Descriptive statistics are reported.

**Results**

Of the 1217 consenting adult patients participating in the overall COVID-19 study, 824 provided free-text responses. Of these, respondent MPN diagnoses included, essential thrombocythemia (n=324, 39%), polycythemia vera (n=251, 30%), myelofibrosis (n=153, 19%), and other/undisclosed (96, 12%); 69% (n=567) were female; median age was 63 (range 21-93); 38% (n=313) were from the US, 38% (n=313) UK, and 24% (n=198) other/unknown.

There was 89% (n=734) sentiment agreement between reviewers. Free-text responses about the impact of COVID-19 on MPN care were 49% (n=400) negative, 21% (n=177) positive, 8% (n=65) both positive and negative, and 22% (n=182) neutral/no impact. Table 1 shows a selection of MPN patient free-text responses reflecting common negative and positive sentiment themes.

**Negative impact (n=400):** The most common negative impact involved delays or cancellations of visits or perceived inaccessibility to regular providers (n=261, 65%). Primarily this sentiment was driven by lack of clinic availability and restrictions at treatment centers or by providers. However, some respondents reported delaying or canceling visits themselves due to fear of COVID-19 exposure. Perceived health consequences from this delay were also expressed. There were 129 (32%) respondents with concern regarding changes or access to medications, including explicit drug supply shortages. Some patients resorted to self-adjusting medications and reusing single-use supplies. General anxiety, stress, and isolation were also reported (n=98, 25%).

**Positive impact (n=177):** Availability of telemedicine comprised the majority of positive impacts of the pandemic (n=95, 54%), with many noting the reduced travel time to visits. Routine local testing coupled with follow-up telemedicine was favorable. Despite general positivity towards telemedicine, some reported preferences for in-person visits; commenting that telemedicine was impersonal, difficult to schedule or receive virtual communication, and expressed concern for lack of spleen examinations during virtual visits.

**Conclusion**
Positive and negative aspects were reported including MPN-specific issues. Healthcare systems should use such data to emerge from the COVID-19 pandemic and retain the positive impacts such as telemedicine, while developing education materials and other resources to address the reported negative impacts where possible.

| Table 1: Selection of MPN patient free-text responses reflecting common negative and positive sentiment themes |
|---------------------------------------------------------------|
| **Quote 1:** “My hemoglobin levels were sky high because I could not receive phlebotomy. They were the highest they’ve ever been. I felt short of breath, and unwell. I was nervous the symptoms were COVID and it was PV. I think my platelet levels increased due to stress. [...]” |
| **Quote 2:** “Cannot have spleen size checked. Prior to taking [MPN drug] it was enlarged and is usually checked every 3 months. Need venesection to bring ferritin level down and postponed till at least October” |
| **Quote 3:** “Because of work furloughs, I am unable to afford more medication. Our health insurance out of pocket max is $[...], and our income was suddenly and drastically reduced. I have been using previously drawn vials of [MPN drug] with clean syringes, even though they are supposed to be single use for the last 10 weeks” |
| **Quote 4:** “I was supposed to start [MPN drug] in late March, but because I have to travel 4 hours to the cancer center, between worries about having to stop along the way and about COVID at the hospital, treatment has been postponed indefinitely. I am also supposed to have bloodwork and a checkup every three months and I am still too worried about Covid-19 to make an appointment.” |
| **Quote 5:** “Unable to get [MPN drug A]. Supposed to switch to [MPN drug B].” |
| **Quote 6:** “I’ve had 6 TIAs. I wasn’t able to get my usual blood test to keep a tab on the thrombus which jump up and down by [it] and to see how sticky my blood was. When I didn’t feel good, I self-medicated by increasing my med on my own.” |
| **Quote 7:** “Too scared to go for a CBC” |
| **Quote 8:** “I was diagnosed by telephone just after Covid-19 outbreak and have been feeling isolated throughout. I am scared that I may fall through the cracks with my ongoing care and, although I have emailed my haematologist with questions on a couple of occasions, I have not heard back from him. [...]” |
| **Quote 9:** “Not able to visit hospital to speak face to face which gives you more confidence about what is going on. Phone calls and emails good but not the same. It’s an anxious time I think.” |
| **Quote 10:** “I was able to do a video call with my doctor instead of coming in. This was extremely helpful convenient to not have to go in to a doctor’s office during a pandemic. Not having to travel to the doctor is also very convenient!” |
| **Quote 11:** “I was able to have my bloods taken locally and the results sent to my clinical specialist. This meant I did not have to visit the hospital but was still able to have a telephone review with my clinical specialist. (Good impact as I did not need to visit hospital and possibly contract COVID)” |
| **Quote 12:** “I haven’t had a blood test for six months, so that feels a bit disconcerting. It has made me realize that I don’t know anyone else with an MPN, this hadn’t really hit home before. The phone call I got was from another team member, not my regular consultant, and I missed my face to face annual review, which I always find reassuring. I have emailed a couple of questions to the nurse at the hospital in the beginning. I was pleased they organized two webinar’s ([Hospital/Foundation]) I found these really useful at a time I was feeling isolated and more anxious than usual.” |

Redacted text is represented by italicized brackets: [...]
Mesa: CTI BioPharma: Research Funding; Promedior: Research Funding; Novartis: Consultancy; Sierra Oncology: Consultancy; Samus Therapeutics: Research Funding; Genentech: Research Funding; AbbVie: Research Funding; Incyte: Research Funding; LaJolla Pharmaceutical Company: Consultancy; Bristol Myers Squibb: Research Funding.

Author notes
* Asterisk with author names denotes non-ASH members.

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