The psychosocial impact of the COVID-19 pandemic on patients with monoclonal gammopathy of undermined significance, smouldering and active myeloma: findings from an international survey

Early in the coronavirus disease 2019 (COVID-19) pandemic, the UK National Health Service (NHS) identified patients with multiple myeloma (MM) as a ‘clinically extremely vulnerable’ population. In contrast, the clinical significance of COVID-19 to MM precursors, monoclonal gammopathy of undermined significance (MGUS) and smouldering MM (SMM) remains unknown.

Here for the first time, we summarise the impact of the COVID-19 pandemic on 274 MM spectrum individuals (66 MGUS, 33 SMM and 175 MM) who participated in the IMPaCCT (Investigating the impact of COVID-19 on caregivers and patients) study. The first wave of this online international longitudinal study took place between 24 April and 14 July 2020.

Participants answered open- and closed-ended questions to capture information on their demographics, COVID-19 status and the impact of COVID-19 on them and their care pathways. Quality of life (QoL) was assessed using the World Health Organisation Quality of Life (WHOQOL-BREF) and the EuroQol five Dimensions five Levels (EQ-5D-5L) instruments. The survey was pilot tested and then promoted online via social media, blogs and charity/patient advocacy groups. Descriptive statistics were applied to quantitative data. The WHOQOL-BREF and EQ-5D-5L questionnaires were analysed following published guidelines. Open-ended questions were analysed using qualitative content analysis and framework analysis by two independent reviewers (S.Q. and L.L.). Ethical approval was obtained from Queen’s University Belfast (MHLS 20_52).

The majority of respondents were female, aged >60 years, within 5 years of diagnosis and did not live alone (online Tables SI and SII). Most MGUS and MM respondents resided in the UK (60-6% and 78-9% respectively) whereas SMM respondents (54-5%) mostly resided in the USA. Although no participants reported a medically confirmed COVID-19 diagnosis, 15-2% suspected they had previously contracted the disease; commonly reported symptoms included fatigue (82-5%), cough (65-0%), fever (65-0%), headache (60-0%) and sore throat (57-5%).

While 69-3% of participants reported their QoL as being good or very good on the WHOQOL-BREF, participants scored lower (indicating less satisfaction) compared to pre-pandemic UK population norms, in the physical (P < 0.0001), psychological (P < 0.0001) and social (P < 0.0001) domains but scored higher in the environmental domain (relating to physical/home environment, physical safety, care access and quality, etc.; P = 0.001) (Table I).

All groups had lower scores (indicating more problems) across the EQ-5D-5L domains compared to pre-pandemic UK normative values, with MM respondents reporting more problems across all domains. Notably, high rates of anxiety/depression were reported by MGUS/SMM/MM participants (64-2%); however, only 7-2% considered this to be severe or extreme (Table I).

COVID-19-related anxiety and depression were frequently mentioned, and many people reported distress at being housebound. Older respondents and those with MM were more likely to report they were self-isolating (P < 0.001). While concerns about contracting COVID-19, experiencing severe symptoms and impact on the future were mentioned (“It feels as if my life is being wasted”), many concerns focussed on fears of disease progression (Concerned myeloma may have spread, a patient with MM, 1–3 years since diagnosis).

Significantly more MM than MGUS or SMM respondents reported altered healthcare appointments (69-7% vs. 40-3% and 40-6% respectively, P < 0.001). Changes to treatment appointments were reported, with 22 patients with MM reporting chemotherapy appointments were changed, delayed or cancelled. Many participants expressed concern about the impact of delayed or cancelled appointments (I worry appointments will be delayed meaning changes in condition aren’t picked up as soon as they could be, a patient with MGUS <1 year since diagnosis) (Table II). Fear about COVID-19 exposure, particularly at a hospital, was also noted (Reluctant to go to the hospital clinic at all, even for blood work and consultation, a patient with SMM >5 years since diagnosis). In contrast, patients with MGUS were more likely than other participants (P = 0.004) to report feeling their care had suffered or they had been abandoned (I feel neglected and that my illness isn’t of any importance, a patient with MGUS <1 year since diagnosis).

Most respondents accessing telemedicine services (78-3%) described their experience as positive or satisfactory, citing such advantages as increased convenience. Conversely, some
participants reported telemedicine to be less effective than face-to-face appointments, had difficulty understanding information relayed by telephone and were left feeling less reassured after their calls. Healthcare professionals and scientists were the most highly trusted sources of COVID-19 information (84.9% and 80.5% trusting most/all information

### Table I. WHOQOL-BREF and EQ-5D-5L findings.

| WHOQOL-BREF domain, mean (SD) | Normative values*\(^{8,9}\) | Total (N = 266*) | MGUS (N = 65) | SMM (N = 33) | MM (N = 168) | P (comparisons between MM subgroups) |
|-------------------------------|-----------------------------|-----------------|---------------|---------------|---------------|-------------------------------------|
| Physical health              |                             | 59.5 (20.3)     | 58.5 (22.5)   | 70.6 (19.5)   | 57.8 (19.1)   | 0.002                               |
| Psychological                |                             | 61.1 (18.5)     | 56.3 (20.2)   | 62.1 (20.6)   | 62.8 (17.1)   | 0.081                               |
| Social relationships         |                             | 61.5 (19.7)     | 57.8 (21.5)   | 63.6 (21.9)   | 62.5 (18.4)   | 0.153                               |
| Environment                  |                             | 68.2            | 71.5 (16)     | 65 (19.3)     | 75.2 (14.5)   | 0.002                               |

| EQ-5D-5L domain              |                             |                 |               |               |               |                                     |
| Mobility, n (%)              |                             | 18.4%           | 143 (53.8)    | 31 (47.7)     | 12 (36.4)     | 100 (59.5)                          | 0.027                               |
| No problems                  |                             | 123 (46.2)      | 34 (52.3)     | 21 (63.6)     | 68 (40.5)     | 0.066                               |
| Slight problems              |                             | 75 (28.2)       | 20 (30.8)     | 7 (21.2)      | 48 (28.6)     |                                     |
| Moderate problems            |                             | 44 (16.5)       | 6 (9.2)       | 5 (15.2)      | 33 (19.6)     |                                     |
| Severe problems              |                             | 24 (9.0)        | 5 (7.7)       | 0             | 19 (11.3)     |                                     |
| Unable                       |                             | 0               | 0             | 0             | 0             |                                     |

| Self-care, n (%)             |                             | 4.3%            | 61 (22.9)     | 13 (20.0)     | 4 (12.1)      | 44 (26.2)                           | 0.173                               |
| No problems                  |                             | 205 (77.1)      | 52 (80.0)     | 29 (87.9)     | 124 (73.8)    |                                     |
| Slight problems              |                             | 40 (15.0)       | 10 (15.4)     | 3 (9.1)       | 27 (16.1)     |                                     |
| Moderate problems            |                             | 20 (7.5)        | 3 (4.6)       | 1 (3.0)       | 16 (9.5)      |                                     |
| Severe problems              |                             | 1 (0.4)         | 0             | 0             | 1 (0.6)       |                                     |
| Unable                       |                             | 0               | 0             | 0             | 0             |                                     |

| Usual activities, n (%)      |                             | 16.3%           | 163 (61.5)    | 37 (57.8)     | 12 (36.4)     | 114 (67.9)                          | 0.002                               |
| No problems                  |                             | 102 (38.5)      | 27 (42.2)     | 21 (63.6)     | 54 (32.1)     |                                     |
| Slight problems              |                             | 88 (33.2)       | 22 (34.4)     | 8 (24.2)      | 58 (34.5)     |                                     |
| Moderate problems            |                             | 55 (20.8)       | 9 (14.1)      | 4 (12.1)      | 42 (25.0)     |                                     |
| Severe problems              |                             | 18 (6.8)        | 6 (9.4)       | 0             | 12 (7.1)      |                                     |
| Unable                       |                             | 2 (0.8)         | 0             | 0             | 2 (1.2)       |                                     |
| Missing values               |                             | 1               | 1             | 0             | 0             |                                     |

| Pain/discomfort, n (%)       |                             | 33.0%           | 214 (80.8)    | 50 (78.1)     | 26 (78.8)     | 138 (82.1)                          | 0.750                               |
| No problems                  |                             | 51 (19.3)       | 14 (21.9)     | 7 (21.2)      | 30 (17.9)     |                                     |
| Slight problems              |                             | 108 (40.8)      | 22 (34.4)     | 17 (51.5)     | 69 (41.1)     |                                     |
| Moderate problems            |                             | 82 (30.9)       | 21 (32.8)     | 9 (27.3)      | 52 (31.0)     |                                     |
| Severe problems              |                             | 24 (9.1)        | 7 (10.9)      | 0             | 17 (10.1)     |                                     |
| Extreme problems             |                             | 0               | 0             | 0             | 0             |                                     |
| Missing values               |                             | 1               | 1             | 0             | 0             |                                     |

| Anxiety/depression, n (%)    |                             | 21.0%           | 170 (64.2)    | 49 (76.6)     | 20 (60.6)     | 101 (60.1)                          | 0.059                               |
| No problems                  |                             | 95 (35.9)       | 15 (23.4)     | 13 (39.4)     | 67 (39.9)     |                                     |
| Slight problems              |                             | 103 (38.9)      | 26 (40.6)     | 8 (24.2)      | 69 (41.1)     |                                     |
| Moderate problems            |                             | 48 (18.1)       | 15 (23.4)     | 10 (30.3)     | 23 (13.7)     |                                     |
| Severe problems              |                             | 15 (5.7)        | 6 (9.4)       | 2 (6.1)       | 7 (4.2)       |                                     |
| Extreme problems             |                             | 4 (1.5)         | 2 (3.1)       | 0             | 2 (1.2)       |                                     |
| Missing values               |                             | 1               | 1             | 0             | 0             |                                     |

| Visual assessment score, mean (SD) | 77.3 | 66.2 (19.1) | 64.9 (19.6) | 69.3 (20.6) | 66 (18.7) | 0.4378 |

MGUS, monoclonal gammopathy of undetermined significance; MM, multiple myeloma; SD, standard deviation; SMM, smouldering multiple myeloma.

*Includes only those who responded to WHOQOL-BREF or EQ-5D-5L questionnaires.
Table II. Supporting quotes from qualitative analysis of COVID-19 impact on myeloma-spectrum respondents.

Psychological impacts

- I’ve followed all the rules but it has made me anxious – MGUS, female, >5 years since diagnosis
- It’s increased my already high level of anxiety – MGUS, female, 4–5 years since diagnosis
- Worried if I get sick I would be considered high risk and end up in ICU – MGUS, female, >5 years since diagnosis
- Feel more frightened now of having cancer now that there is the added threat of coronavirus – MM, female, 1–3 years since diagnosis
- Depressed, which isn’t good when you have cancer – MM, male, 1–3 years since diagnosis
- Sensation of having been abandoned – SMM, female, >5 years since diagnosis
- I’m a prisoner in my own home – MM, male, unknown time since diagnosis
- It feels as if my life is being wasted – MM, female, over 5 years since diagnosis

Social/financial impacts

- I desperately miss cuddles with my young grandchildren and my own children – MM, female, 1–3 years since diagnosis
- Miss socialising with friends and family. The magnitude of these sacrifices is increasing – MM, male, >5 years since diagnosis
- My son (aged 7) is at home 24/7. I have very little time to myself – MM, female, 1–3 years since diagnosis
- Not able to go out dancing or to restaurants. These are what keep me sane – MM, female, 4–5 years since diagnosis
- I have lost business due to the virus – SMM, female, >5 years since diagnosis
- Nearly all of my scheduled work has been postponed indefinitely or cancelled – SMM, female, >5 years since diagnosis

Health/care impacts

- Need assurance that condition is stable – MGUS, female, >5 years since diagnosis
- Concerned myeloma may have spread – MM, female, 1–3 years since diagnosis
- Essential treatment will be cancelled, delayed or not available to me – MM, male, 4–5 years since diagnosis
- We are older, retired and more susceptible to germs – SMM, female, <1 year since diagnosis
- I feel neglected and that my illness isn’t of any importance – MGUS, female, <1 year since diagnosis
- I worry appointments will be delayed meaning changes in condition aren’t picked up as soon as they could be – MGUS, female, <1 year since diagnosis
- Reluctant to go to the hospital clinic at all, even for blood work and consultation – SMM, female, >5 years since diagnosis

Telemedicine experience

- Nearly as good as in person – MGUS, male, 1–3 years since diagnosis
- I don’t have to wait in the waiting room for three hours – MM, female, over 5 years since diagnosis
- It is not always as easy to take in information in a phone call – MM, female, 1–3 years since diagnosis
- Not as reassuring as a face to face appointment – MM, female, 4–5 years since diagnosis

What further information/services/support would be useful for you at this time?

- Being able to attend my appointments – MGUS, female, 4–5 years since diagnosis
- Specific advice around multiple myeloma and COVID-19 – MM, male, 4–5 years since diagnosis
- It would be useful to know how people with Smouldering Multiple Myeloma are doing with COVID-19 diagnosis. Are they doing the same, worse or better than the normal population? – SMM, female, >5 years since diagnosis
- I don’t know if I should be shielding with MGUS – MGUS, female, 4–5 years since diagnosis
- Knowing if/when shielding will end or be modified – MM, male, 4–5 years since diagnosis
- I would like normal service, help and support for cancer patients. We have been forgotten during this crisis and there should have been plans in place to continue help and support – MM, male, 1–3 years since diagnosis

Quotes which are underlined are those which appear in the text, with demographic descriptions of the respondent provided.
pandemic, recommended social distancing and self-isolation, plus reduced availability of support and care services. Supporting this, Myeloma UK, the leading UK MM charity, reported unprecedented demand for their MM Infoline and ‘Ask The Nurse’ service in March 2020, with service users particularly interested in COVID-19-specific issues including risk of infection, lifestyle, emotional issues and end-of-life support.

The present study benefits from a mixed-methods design and inclusion of both patients with MGUS and SMM, providing novel insight into the impact of the COVID-19 pandemic across the MM spectrum. Planned follow-up surveys will lead to identifying long-term impacts of the COVID-19 pandemic and additional support needs for this population. However, online recruitment and questions asking for self-reported disease status may reduce the generalisability of the findings to the wider MGUS/SMM/MM population.

Participant concerns over undetected disease progression and lack of timely healthcare appointments/treatments are also linked to the desire for unambiguous information about any heightened COVID-19 risk. As services resume, healthcare and other service providers should also be aware of patients’ fears about accessing care in hospitals during the pandemic and plan to address the psychosocial needs of patients across the MM spectrum.

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Competing interests

The authors have no competing interests.

Author contributions

Lesley A. Anderson and Charlene M. McShane designed the initial concept for the study with input from the wider IMPaCCT team based at Queen’s University Belfast and University of Aberdeen. Stephen J. Quinn, Charlene M. McShane and Lynne Lohfeld analysed the data. Stephen J. Quinn wrote the first draft of the paper. Stephen J. Quinn, Charlene M. McShane, Lesley A. Anderson and Lynne Lohfeld had access to the data and reviewed/revised the paper.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Table SII. Demographic characteristics of MGUS, SMM and MM participants.

Table SIII. COVID-19 symptoms, concerns and preventative measures across myeloma-spectrum groups.

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