

Experience Of Clinical Care Of Osteogenesis Imperfecta (OI) During The COVID-19 Pandemic



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BACKGROUND

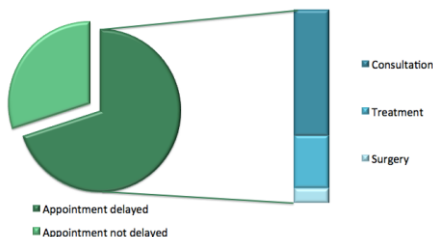
Research on the effects of the COVID-19 pandemic on people with rare diseases is limited. Few studies compare healthcare throughout the progression of the ongoing pandemic. Our aim was to assess the impact of lockdown on individuals with OI across two consecutive years of the pandemic, to understand what challenges were encountered, and to analyse the experience of remote consultation.

METHODS

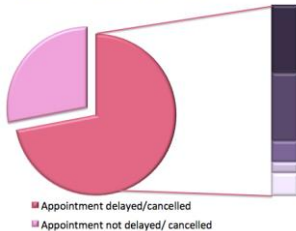
Two independent surveys were distributed in August 2020 and April 2021. The primary survey was distributed following the first lockdown, and the second survey built on the experiences reported from the initial survey.

RESULTS

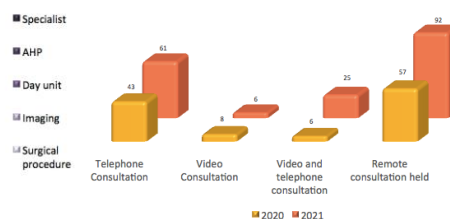
Delays in Treatment – 2020 Survey



Delays in Treatment – 2021 Survey



Type of consultation from 2020 to 2021



The primary survey in 2020 had 110 respondents, and the follow-up survey in 2021 had 124 respondents. The surveys explored four key themes.

Theme 1: Effect on therapy

The number of respondents having at least one appointment postponed increased from 69 respondents (63%) in the August 2020 survey to 89 (72%) in the follow-up survey. The type of appointment delayed is illustrated above. Of the 22 paediatric patients amongst this cohort, five (23%) had their transition to adult services impacted.

Theme 2: Alternatives to consultation

The number of survey participants having a remote consultation increased from 57 (52%) in the first survey to 92 of 124 (74%) in 2021. The type of remote consultation is shown above.

Theme 3: Effect on mental health

In the primary survey 63 of 91 (69%) expressed increasing anxiety due to lockdown, compared with 76 of 124 (61%) in the follow-up survey.

Theme 4: Perceived risks of COVID-19.

The majority of participants felt they would have a worse illness and require longer rehabilitation than someone without OI (81 of 117 respondents, and 77 of 120 respectively).

CONCLUSION

The pandemic has had widespread effects on both the care of people with OI as well as their mental health and will require further longer-term monitoring. The emergence of remote consultation as a direct consequence of COVID-19 may prove a viable long-lasting alternative to face-to-face appointments.