BSR 2021 Abstract Submission

Topic: Paediatric and adolescent rheumatology? COVID-19 service provision (including audit)? COVID-19 science?

Self-reported disease activity was the main determinant of the perceived impact of COVID-19 pandemic on adolescent and young patients with Juvenile Dermatomyositis (JDM) and Juvenile Onset Systemic Lupus Erythematosus (JSLE)

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Introduction

The impact of the COVID-19 pandemic on adolescent and young patients with chronic diseases is likely to be multi-factorial, and influenced by various aspects, such as age, sex, education, ethnicity, as well as disease control or personal coping strategies. In adolescents and young adults, disruption to their education and social life, uncertainty related to professional prospects and long-term disease outcomes are all associated with significant personal concerns.

Objectives

The aim of this survey was to assess the main determinants of COVID-19 associated concern in adolescent and young adults with JSLE and JDM as well as their well-being and resilience.

Methods

Questionnaires comprising X questions related to patient and disease characteristics, wellbeing, resilience and concern about the COVID-19 pandemic were disseminated through hospital contacts and patient charity social media platforms. Participation was voluntary and implied consent. The preliminary results of this ongoing survey have been analysed using descriptive statistics and linear regression.

Results

The main patient and disease characteristics, self-reported well-being, resilience and perceived concern about the COVID-19 pandemic are presented in comparison in male vs. female patients.

	Female	Male	p-value
Number	38	9	
Current age mean (IQR)	22.21 (18.25- 25.75)	18.89 (14.00-26.00)	

Age at diagnosis years mean (IQR)	13.01 (9.00-15.00)	9.333 (7.00-11.00)	
Disease duration Mean (IQR)	9.197 (4.000-13.000)	9.556 (2.000-13.000)	
Ethnicity; White Non-white	 25 (65.8%) 13 (34.2%)	 7 (77.8%) 2 (22.2%)	0.4841
Location; England (%) Other (%)	 35 (92.1%) 3 (7.9%)	 9 (100%) 0 (0%)	0.2578091
Well-being (VAS -2 to +2) **mean (IQR)**	-0.6765 (-2.0000 – 0.0000)	-0.4286 (-1.0000 – 0.0000)	0.5667
Resilience (VAS 1-7) **mean (IQR)**	4.906 (4.000 - 6.000)	5.0 (4.5 - 5.5)	0.8718
Self-reported disease activity (VAS 1-100) **mean (IQR)**	35.32 (15.00-53.00)	18.67 (3.00-25.00)	0.06429
Self-reported COVID concern (VAS 1-100) **mean (IQR)**	62.92 (50.00-80.00)	32.33 (15.00-40.00)	0.01052
Still in education No Yes Not recorded	 16 (42.1%) 18 (47.4%) 4 (10.5%)	 3 (33.3%) 4 (44.4%) 2 (22.2%)	
Currently working No Yes Not recorded	 24 (63.2%) 10 (26.3%) 4 (10.5%)	 5 (55.6%) 2 (22.2%) 2 (22.2%)	

Linear regression showed that the strongest determinant of COVID concern was self-reported disease activity ($p<0.0003$). The self-reported disease activity was associated with the COVID-19 concern level in both female ($P= 0.003$) and male patients ($p=0.004$). The COVID concern was not affected by any other factors such as disease duration, employment, education, well-being or resilience.

Conclusion

The preliminary analysis of our survey showed that patient-reported COVID-19 concern during the pandemic was strongly determined by the self-reported disease activity irrespective of patients' sex, despite significantly increased concern in the female compared to male patients. We propose that further strategies for better patient support during the pandemic should focus on their optimal disease control as well as take into consideration the sex-biased patient concerns.