Rheumatology Advances in Practice, 2024, **8(3)**, rkae098
https://doi.org/10.1093/rap/rkae098
Advance access publication 14 August 2024
Letter to the Editor

British Society for Rheumatology
RHEUMATOLOGY ADVANCES IN PRACTICE
OXFORD

Letter to the Editor (Matters arising from published papers)

Comment on: Impaired health-related quality of life in idiopathic inflammatory myopathies: a cross-sectional analysis from the COVAD-2 e-survey: Reply

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Dear Editor, We thank Finsterer for the comments on our article [1], in which we investigated health-related quality of life (HRQoL) in patients with idiopathic inflammatory myopathies (IIMs) using Patient-Reported Outcome Measurement Information System (PROMIS) instrument data obtained from the second COVID-19 vaccination in autoimmune disease (COVAD-2) e-survey database [2].

In response to the first point, we concur that our study has several limitations inherent to e-surveys. Importantly, the diagnosis of autoimmune diseases including IIM subtypes and disease activity were patient reported and not verified objectively, although efforts were made to identify the group with correct classifications as part of an extensive data cleaning protocol. This was facilitated by eliminating responses wherein the diagnosis was not verified by a specialist (neurologist, dermatologist or rheumatologist), individuals with incomplete entries and those who chose multiple IIM subtypes. In fact, the demographics of IIM patients were consistent with previous epidemiological studies, with a mean age of 59 years and women accounting for 71.6% of patients. Current treatments reported by IIM patients also aligned with what we had expected; for instance, methotrexate (20.6%) and mycophenolate mofetil (17.0%) were the most commonly used immunomodulatory agents, followed by hydroxychloroquine (14.4%), intravenous or subcutaneous immunoglobulin (13.5%) and rituximab (9.9%). While we agree that there may not be absolute certainty that responses came from patients themselves, the COVAD-2 survey was designed specifically for IIMs and was shared extensively among myositis patient support groups, wherein most members either have IIMs themselves or are their caregivers [3]. These groups have policies to screen out individuals who may not have the condition. We excluded pregnant and breastfeeding women, as pregnancy and delivery significantly affect HRQoL [4]. Social media–driven research is a crucial frontier in the emerging landscape of digital health and assumes an even larger role in the context of rare disease research [5].

In terms of the second point of assessing physical and mental health using an electronic questionnaire, HRQoL is a domain of patient-reported outcome measures (PROMs) that evaluates the effect of a disease on the physical and mental health of individuals living with chronic diseases, including IIMs [6]. By definition, HRQoL must be evaluated by the patients themselves, and it is crucial to note that objective disease activity measures such as those proposed by the International Myositis Assessment and Clinical Studies Group fall short of assessing patients' lived experiences. PROMIS is a National Institutes of Health–funded initiative to develop and validate PROMs. PROMIS short forms are shown to have excellent feasibility and validity not only in daily clinical practice, but also in e-surveys [7]. A recent multicentre study in the USA, Myositis Patient Centered Tele-Research (My PACER), reported that the PROMIS physical function 20-item short form (PROMIS PF-20) demonstrated consistent psychometric properties, whether administered in-person or through smartphone- and web-based technology, highlighting the excellent feasibility of PROMIS short forms in telemedicine [8]. Given the study's self-reported nature, our results require validation through prospective cohort studies with physician and patient entries, which would be the focus of the next phase of the COVAD studies.

The third point is regarding data handling and the appropriateness of controls. From a statistical point of view, the large sample size and comparator group may potentially

Accepted: 12 August 2024
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adjust for inadvertent data entry errors. To address missing data, we conducted sensitivity analyses on variables with >10% missing values, excluding them from covariates, where results remained consistent. Finsterer [1] noted that many controls, defined as those without autoimmune diseases, had comorbidities and suggested excluding these controls from the analysis. Our large sample size allowed us to include all relevant comorbidities in the multivariable model, adjusting for their effects on HRQoL. Excluding controls with comorbidities would significantly reduce the sample size and remove older individuals, limiting the results' generalizability. Importantly, patients with IIMs were more likely to have comorbidities compared with other disease groups or controls. Furthermore, several comorbidities were identified as independent factors associated with impaired physical and mental health. We believe multivariable analysis was the best way to assess the modification effect of comorbidities on HRQoL.

We thank Finsterer [1] for initiating the discussion and concur that e-surveys have limitations despite the unique advantage of a large global sample of IIM patients that allowed the assessment of HRQoL in understudied subtypes like immune-mediated necrotizing myopathies and overlap myositis. This breadth is rarely achieved in academic cohorts. Our findings underscore the importance of patients' daily lived experiences and embody patient voices often overlooked in clinical practice.

Supplementary material

Supplementary material is available at *Rheumatology Advances in Practice* online.

Data availability

The datasets generated and/or analysed during the current study are not publicly available but are available from the corresponding author upon reasonable request.

Authors' contributions

A.Y., M.K., V.A. and L.G. were responsible for conceptualization. A.Y. and L.G. were responsible for the investigation. L.G., V.A. and A.Y. were responsible for the methodology. L.G. was responsible for the software. V.A. and L.G. were responsible for validation. R.A., V.A. and L.G. were responsible for visualization. A.Y., M.K. and L.G. wrote the original draft. All authors were responsible for data curation and reviewed and edited the manuscript.

Funding

No specific funding was received from any funding body in the public, commercial and not-for profit sectors for this article.

Disclosure statement: M.K. has received consulting fees, speaking fees and research grants from AbbVie, Argenx, Asahi Kasei, AstraZeneca, Astellas, Boehringer Ingelheim, Chugai, Corbus, Eisai, GSK, Horizon, Janssen, Kissei, MBL, Mitsubishi Tanabe, Mochida, Nippon Shinyaku, Ono Pharmaceuticals, Pfizer and Taisho. The remaining authors have declared no conflicts of interest.

Acknowledgments

The authors are grateful to all respondents for completing the questionnaire. The authors also thank the Myositis Association, Myositis India, Myositis UK, Myositis Support and Understanding, the Myositis Global Network, Deutsche Gesellschaft für Muskelkranke e. V. (DGM), Dutch and Swedish Myositis patient support groups, Cure JM, Cure IBM, Sjögren's India Foundation, Patients Engage, Scleroderma India, Lupus UK, Lupus Sweden, Emirates Arthritis Foundation, EULAR PARE, ArLAR research group, AAAA patient group, Myositis Association of Australia, APLAR myositis special interest group, Thai Rheumatism Association, PANLAR, AFLAR NRAS, Anti-Synthetase Syndrome support group and various other patient support groups and organizations for their contribution to the dissemination of this survey. Finally, the authors wish to thank all members of the COVAD study group for their invaluable role in the data collection. No part of this manuscript has been copied or published elsewhere either in whole or in part.

References

1. Finsterer J. Comment on: Impaired health-related quality of life in idiopathic inflammatory myopathies: a cross-sectional analysis from the COVAD-2 e-survey. Rheumatol Adv Pract 2024;rkae097. https://doi.org/10.1093/rap/rkae097.
2. Yoshida A, Li Y, Maroufy V *et al.* Impaired health-related quality of life in idiopathic inflammatory myopathies: a cross-sectional analysis from the COVAD-2 e-survey. Rheumatol Adv Pract 2024; 8:rkae028.
3. Fazal ZZ, Sen P, Joshi M *et al.* COVAD survey 2 long-term outcomes: unmet need and protocol. Rheumatol Int 2022;42:2151–8.
4. Andreoli L, Sen P, Lini D *et al.* COVID-19 vaccine safety during the antenatal period in women with idiopathic inflammatory myopathies. Rheumatology (Oxford) 2023;62:e175–9.
5. Kapoor KK, Tamilmani K, Rana NP *et al.* Advances in social media research: past, present and future. Inf Syst Front 2018;20:531–58.
6. DiRenzo D, Bingham CO 3rd, Mecoli CA. Patient-reported outcomes in adult idiopathic inflammatory myopathies. Curr Rheumatol Rep 2019;21:62.
7. Yoshida A, Kim M, Kuwana M *et al.* Impaired physical function in patients with idiopathic inflammatory myopathies: results from the multicentre COVAD patient-reported e-survey. Rheumatology (Oxford) 2023;62:1204–15.
8. Keret S, Silva RL, Chandra T *et al.* Patient reported outcome for physical function in idiopathic inflammatory myopathy. Rheumatology (Oxford) 2024;keae091.

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