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BACKGROUND

- Chronic refractory gout (CRG), also known as uncontrolled or refractory gout, is defined as a condition where the target serum urate level of <6 mg/dL is not adequately sustained.¹ Gout treatment includes the use of urate-lowering medications.² However, there are multiple challenges to gout management, including low treatment adherence, poor patient-physician communication, and disease and treatment misperceptions.³
- Patients with CRG experience recurrent uncontrolled gout flares that can lead to chronic arthritis and progressive tophaceous deposits, ultimately resulting in joint damage and chronic pain.1 The impact of CRG on physical functioning affects patients' mobility and health-related quality of life (HRQoL).4

"Even when you try to lay down in bed and just even putting a **Sheet** over the top of it, and just like it's – you'd think that the sheet was made of ead... you don't seem to get very much Sleep, a lot of tossing and turning."

OBJECTIVE

To understand the burden of CRG on patients' HRQoL.

METHODS

- A targeted review of literature was conducted in July 2021, using MEDLINE®, to identify studies published in the past 10 years describing signs, symptoms, and impacts of CRG. The results were used to develop a preliminary conceptual model of the impact of CRG on patients' HRQoL.
- Twenty US-based adult patients with CRG participated in concept elicitation interviews, which included open-ended questions around frequency, duration, and severity for each identified concept. Bothersome impacts were rated on a scale of 0–10.
- The conceptual model was refined on the basis of the interview results.

RESULTS

Literature review

 Of 135 abstracts yielded by the targeted literature review, 19 met the inclusion criteria* for key symptoms and impacts of gout.

Patient characteristics

• The mean age of participants interviewed (N=20) was 56 (range 35–77) years (**Table 1**). The majority self-identified as male (70%) and white (65%). More than half (60%) described their gout flares as severe (more than three flares in the past 6 months), while tophi severity was reported as severe (more than three tophi in the past 6 months) by 35% of participants.

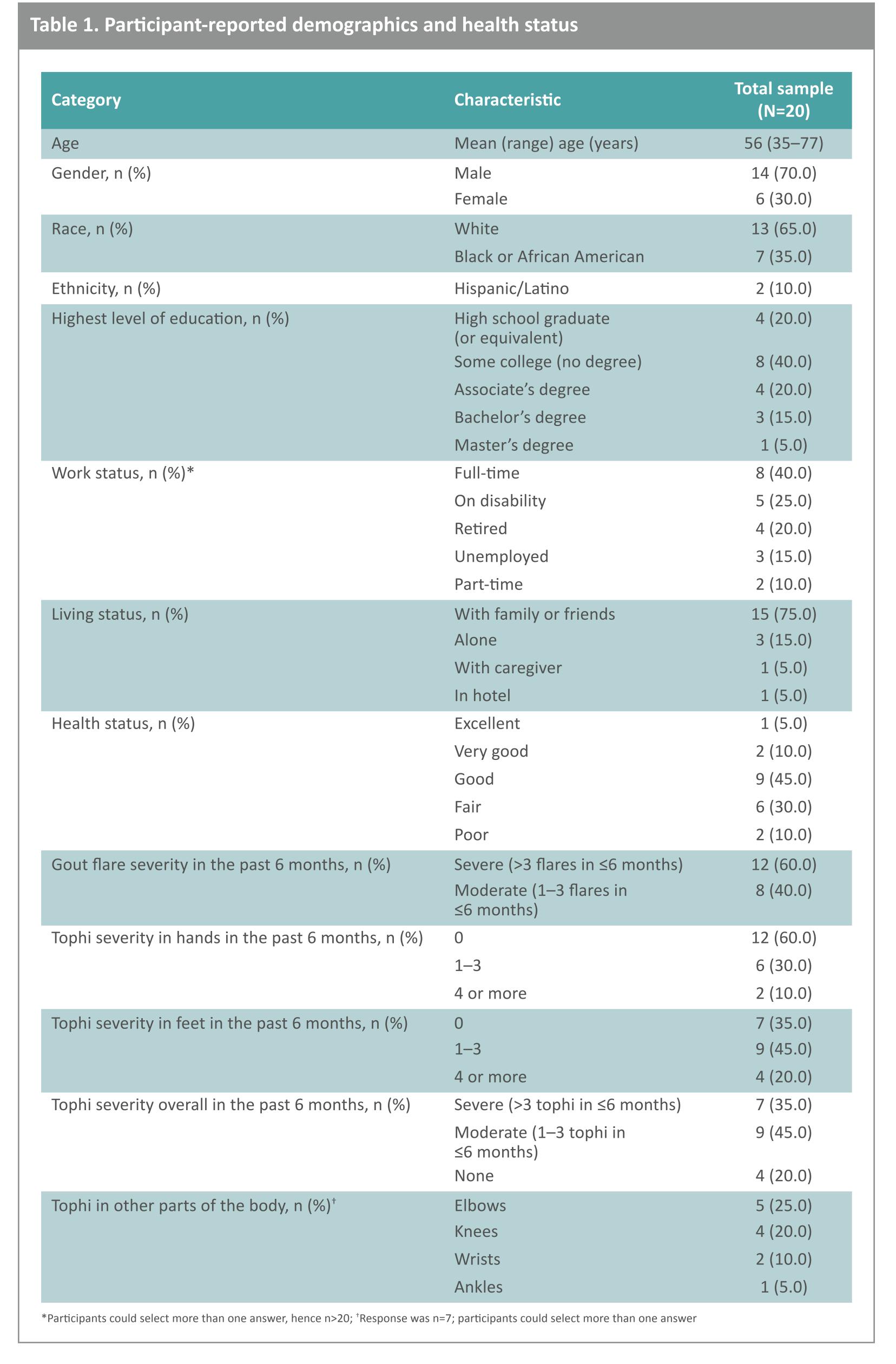
Signs and symptoms of CRG

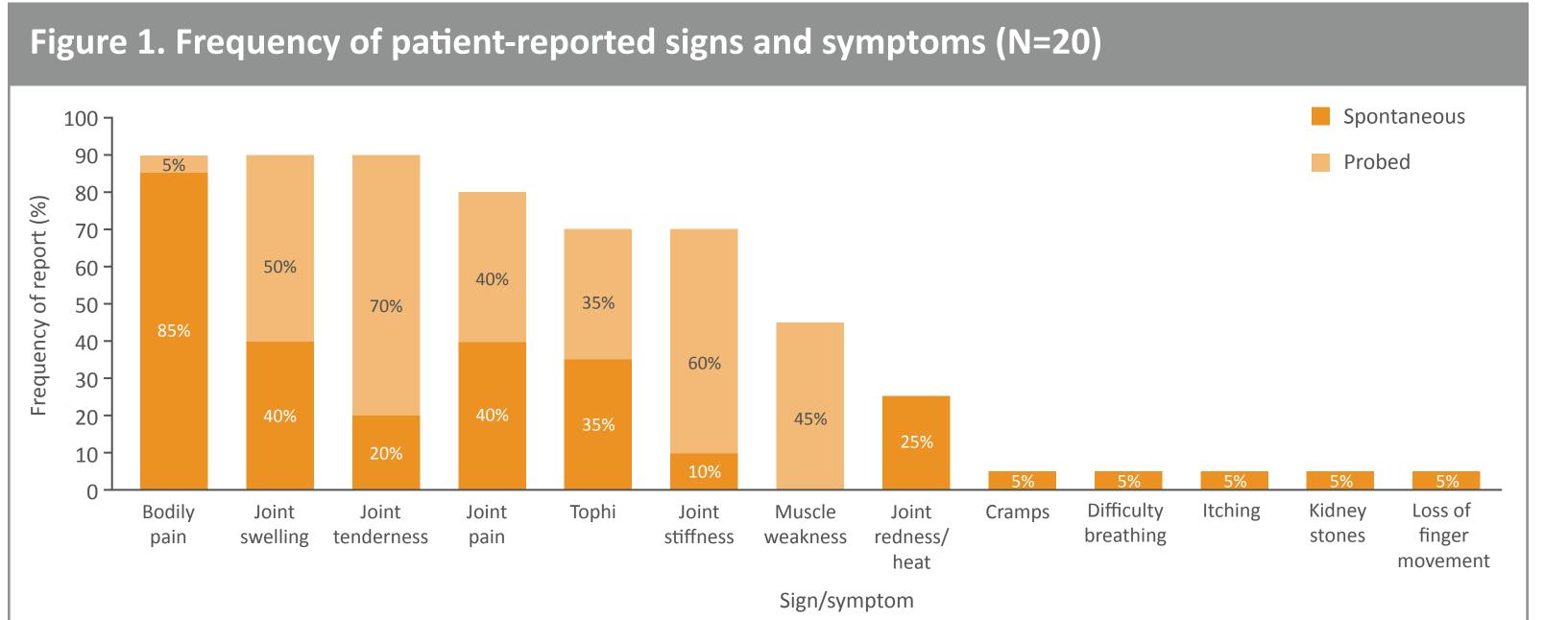
 The most frequently reported signs and symptoms were bodily pain, joint swelling, and joint tenderness, all reported by 90% of participants (Figure 1). Others were joint pain (80%), tophi (70%), and joint stiffness (70%). Joint pain was reported as the most bothersome symptom, with a mean rating of 9.1 (Figure 2).

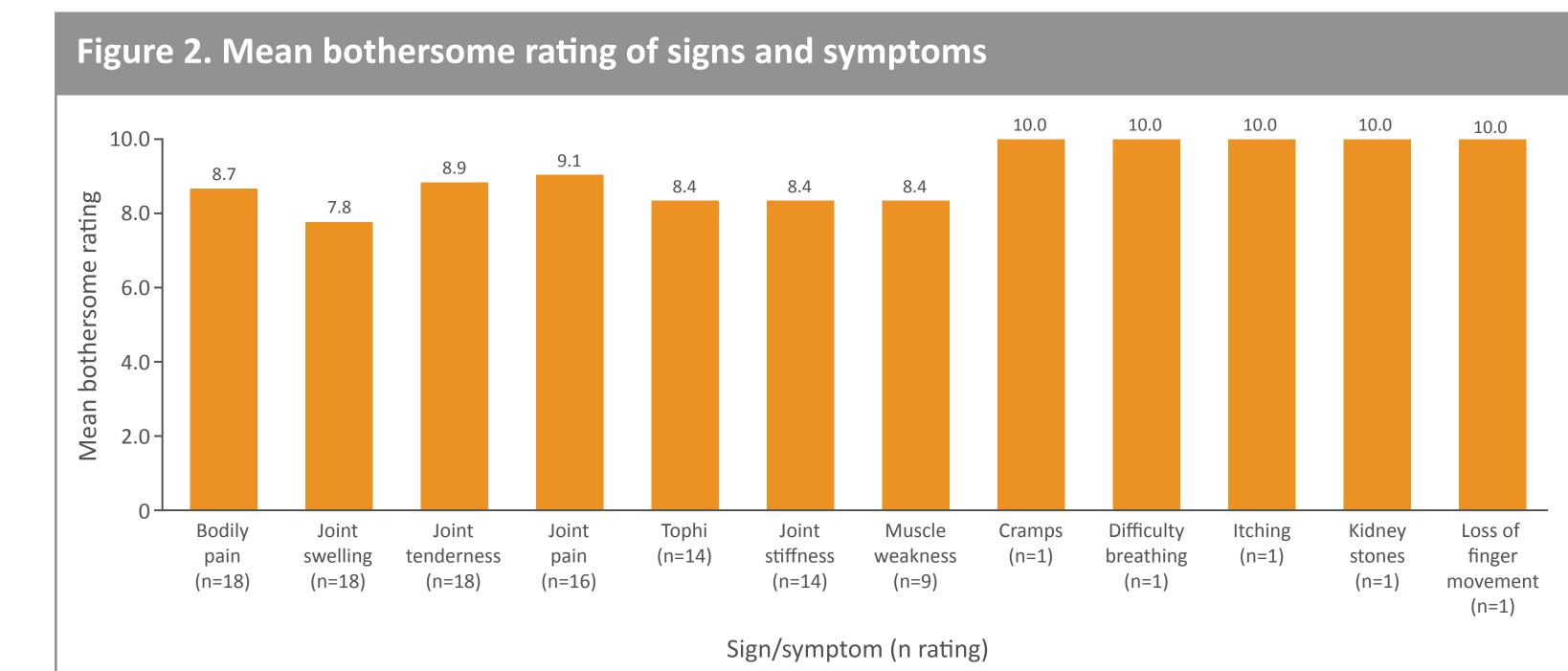
"[It's like] someone your joint when you're taking a Step."

putting a knife through

*Abstract that specifically discussed refractory gout or gout in general terms, or article that discussed symptom presentation and/or general impacts and HRQoL





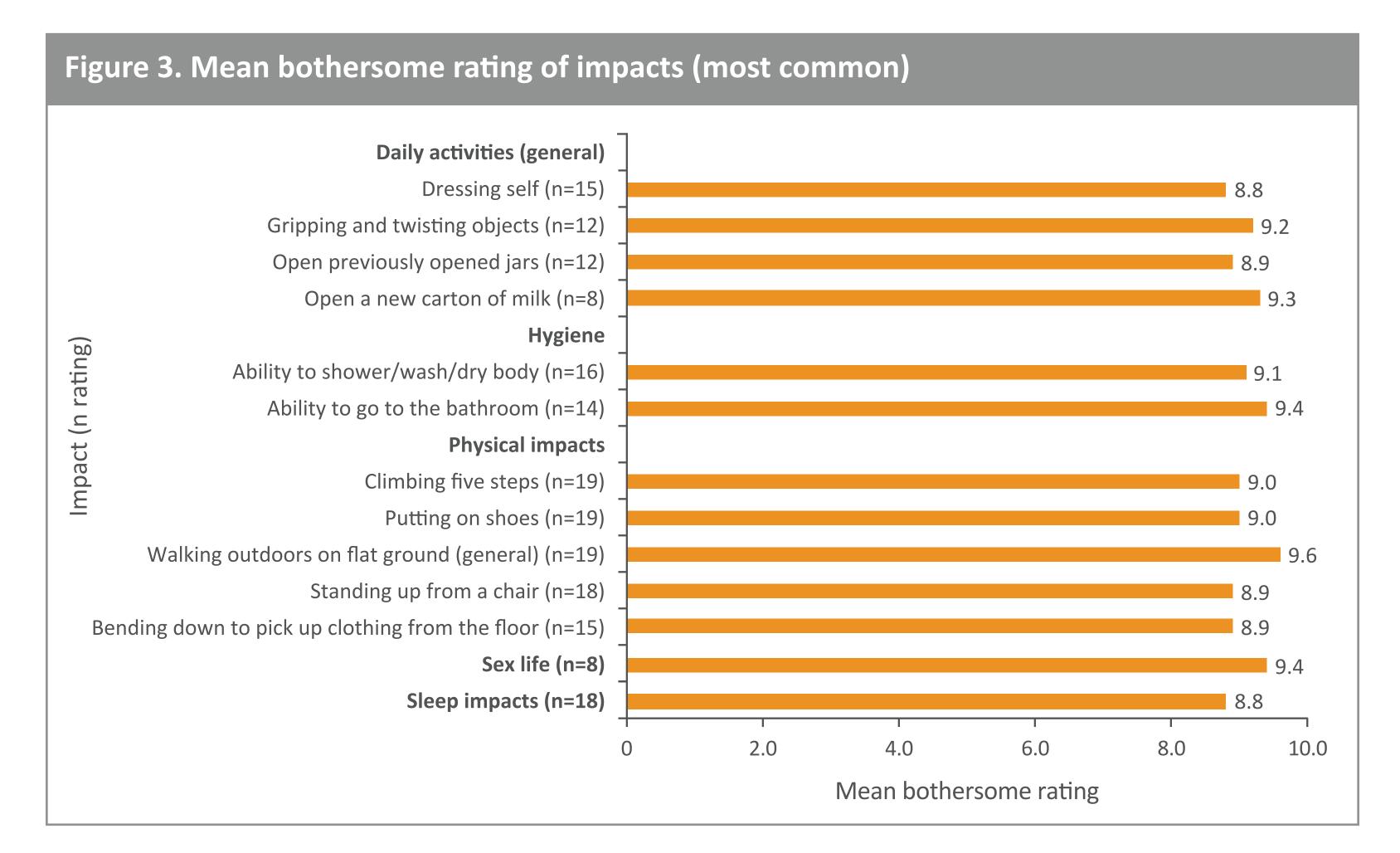


Impacts of CRG

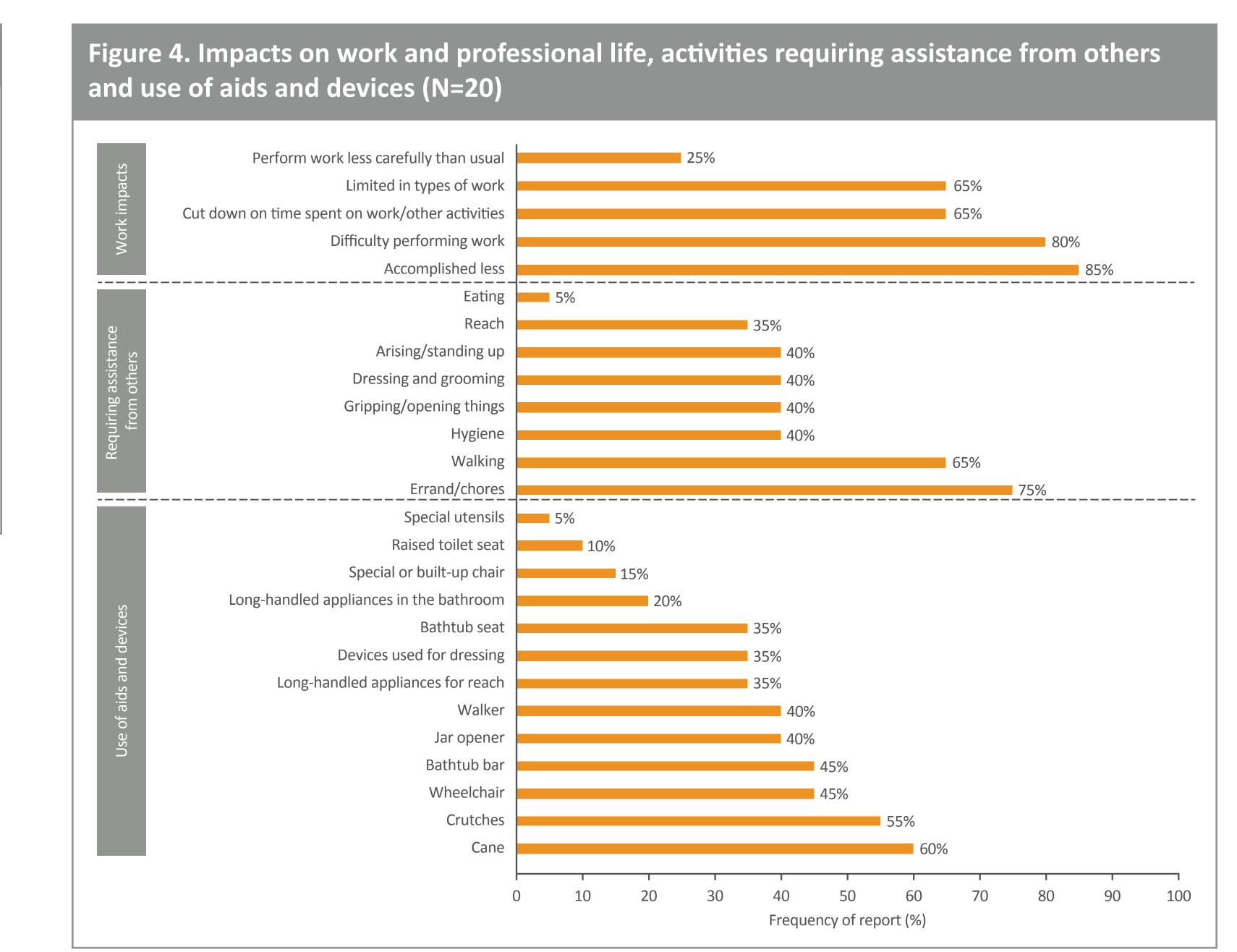
- All participants reported difficulty climbing a flight of stairs or several flights of stairs as an impact of CRG. The other most frequently reported impacts were difficulty completing chores (95%), difficulty running errands and shopping (95%), climbing five steps (95%), putting on shoes (95%), and walking outdoors on flat ground (95%).
- Emotional impacts such as feeling depressed or anxious were reported by nearly all participants (95%).

"I get down on myself because I Can't do what I normally do, [I] get depressed because I Can't do it, and it makes me hard to be around"

- Participants found walking outdoors on flat ground to be the most bothersome impact of gout (mean rating 9.6; Figure 3). Impacts on sex life and ability to go to the bathroom were both rated as highly bothersome (mean rating 9.4).
- Many participants reported impacts on work and professional life; accomplishing less (85%) and difficulty performing work (80%) were reported most frequently (Figure 4). The activity for which most participants reported requiring help from others was performing errands or chores (75%). Canes (60%) and crutches (55%) were the most frequently used aids or devices.



"There were days that I was Unable to WOrk because I just – I couldn't walk [...] – I was a direct care assistant in a nursing facility, so yeah, it affected my ability to work."



Conceptual model

• Based on the results of the interviews, an additional six signs/symptoms (muscle weakness, itching, cramps, difficulty breathing, kidney stones, and loss of finger movement) were added to the conceptual model. Six impacts were also added (bathing/hygiene, arising, eating/feeding activities, difficulty driving, being teased or made fun of, and feeling embarrassment; Supplementary Figure).

CONCLUSIONS

• The targeted literature review and qualitative interviews demonstrated that symptoms and impacts of CRG have a considerable burden on the HRQoL and emotional wellbeing of patients, whose ability to work and carry out everyday tasks can be restricted by pain and reduced mobility

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Acknowledgments

Medical writing and editorial support, funded by Swedish Orphan Biovitrum AB, was provided by Helen Bristow, BSc, Bioscript Group, Macclesfield, UK.

Funding

The study was funded by Swedish Orphan Biovitrum AB.

MP declares consultancy for Sobi, Horizon, Fortress Biotech, and research funding from Horizon and Hikma. VS declares consultancy for AbbVie, Amgen, Aria, AstraZeneca, Bayer, Bioventis, Blackrock, BMS, Boehringer Ingelheim, Celltrion, Chemocentryx, Equillium, Gilead, Genentech/Roche, Glenmark, GSK, Horizon, Inmedix, Janssen, Kiniksa, Kypha, Lilly, Merck, MiMedx, Novartis, Pfizer, Priovant, Regeneron, Rheos, R-Pharma, Samsung, Sandoz, Sanofi, Scipher, Setpoint, Sorrento, Spherix, and Tonix. AO, NK, CY, DB, and HS have nothing to disclose.