Idiopathic Multicentric Castleman disease (iMCD) is a subcategory of MCD, a rare lymphoproliferative disease characterized by enlargement of the lymph nodes and lymphatic system. As no curative therapies exist for iMCD, the primary focus of clinical management remains symptom control. Currently, no assessment of symptom burden exists within this population. Incorporating patient and caregiver perspectives on patients’ iMCD-symptom burden and impact on the caregivers’ daily life. Only the methodology and results for the patients are presented in this poster. More detailed results have been published elsewhere. 1

Methods

The iterative process followed is shown in Fig. 1. The initial literature review (April 2020) identified the MCD-SS, the CarerQol-7D and the SF-36 as existing relevant scales. Also identified were symptom themes and these, together with their impact on daily life of patients and caregivers were explored further and validated by clinical experts.

Fig. 1: Iterative derivation of iMCD survey

Results

A total of 27 unique symptoms were experienced by the 51 patients in the week prior to completing the survey. Five patients reported no symptoms. In patients reporting symptoms, tiredness was the most prevalent (78.4%), followed by weakness (41.2%), night sweats (39.2%) and numbness/tingling (37.3%).

Patients reported that their symptoms had a slight to moderate effect on their daily life (Fig. 2). The symptoms having the most severe impact on daily life included nausea/vomiting (60.0%), sluggishness (53.3%), weakness (physical) (52.4%), weight gain (50.0%) and stupor/feeling lethargic (50.0%) (Fig. 2). When looking closely at the aspects of daily life most affected by these symptoms, a moderate to very severe impact was reported on aspects of daily life that related to patient pain/discomfort (65.2%), ability to travel (65.2%), sexual function (56.5%), emotional and psychological wellbeing (52.2%), general wellbeing (52.2%), financial wellbeing (52.2%) and social life (50.0%) (Fig. 3).

Table 1: Characteristics of Patients and Caregivers participating in the iMCD survey

Conclusions

This international iMCD survey is, to our knowledge, the first large survey to systematically evaluate the spectrum of symptoms experienced by patients and the impact of symptom burden on everyday life from the patient perspective. It nonetheless had limitations that need to be considered. Firstly, identification of patients for this survey relied on respondents self-reporting their practitioner-confirmed diagnosis of iMCD as opposed to direct physician reporting or clinical documentation. Secondly, there were insufficient patient numbers to differentiate the impact by type of iMCD. Thirdly, though some treatment data were captured across every daily life activity (OR <1; Fig. 2).

Limitations

This international iMCD survey is, to our knowledge, the first large survey to systematically evaluate the spectrum of symptoms experienced by patients and the impact of symptom burden on everyday life from the patient perspective. It nonetheless had limitations that need to be considered. Firstly, identification of patients for this survey relied on respondents self-reporting their practitioner-confirmed diagnosis of iMCD as opposed to direct physician reporting or clinical documentation. Secondly, there were insufficient patient numbers to differentiate the impact by type of iMCD. Thirdly, though some treatment data were captured this was insufficient to determine the impact of this on symptoms and aspects of daily life. Lastly, COVID-19 restrictions may have impacted recruitment of patients.

Fig. 4: Forest plot of the odds ratios of impact on daily life by Multiplicity of symptoms

The multivariate regression model was adjusted by age, gender, and number of symptoms. Level of significance was set at p<0.05.