PCR233

SOCIOECONOMIC IMPACT OF MUSCULAR DYSTROPHIES ON PATIENTS AND THEIR CAREGIVERS IN THE CZECH REPUBLIC

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OBJECTIVES

Muscular dystrophies (MD) are a family of genetic muscle diseases manifesting with progressive weakness and loss of muscle mass. The disease poses a considerable burden not only on patients but also on their caregivers. In the Czech Republic, muscular dystrophies affect approximately 350 patients prevalently (approximately 10 new diagnoses per year). This study evaluates the socioeconomic impact of MD, primarily from the perspective of caregivers, and assesses the accessibility of health and social care services for patients with MD in the Czech Republic.

METHODS

A cross-sectional questionnaire-based study was conducted among Czech patients with MD and their caregivers between December 2022 and February 2023. The questionnaire consisted of six sections:

1) patients' demographic and clinical characteristics
2) caregivers' demographics
3) disease-related activities
4) out-of-pocket costs
5) use of social care resources
6) use of medical devices.

In total, 80 responses were obtained from patients with MD and their caregivers, representing 23% of the MD population in the Czech Republic which can be viewed as representative.

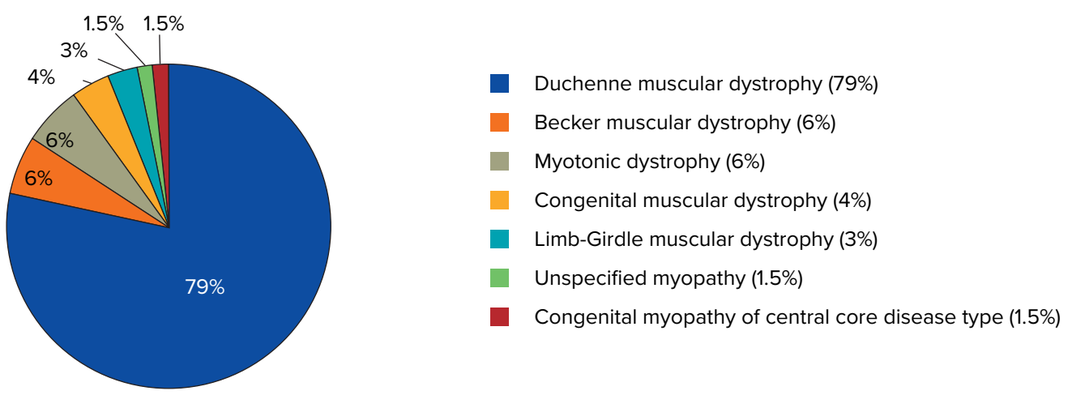
Table 1. Demographic characteristics of caregivers and patients and basic data on the disease

Age of respondent/caregiver (mean)	43.0 years
Patient age (mean)	13.4 years
Age at disease diagnosis (mean)	3.6 years
Number of specialists seen, excluding practitioners (mean)	4.3
Time spent per month in healthcare facilities (mean)	11 hours
Patients with DMD who have taken or are taking corticosteroids (%)	84%

RESULTS

The respondents' demographics are shown in **Table 1**. The questionnaire was answered by 68 women, and the average age of the respondents was 43 years. Almost 80% of the respondents were caring for patients with Duchenne muscular dystrophy (**Figure 1**). The mean age of all patients was 13.4 years, and the diagnosis was made at an average age of 3.6 years. The disease is diagnosed more than a year earlier in the Czech healthcare system than abroad, confirming the system's excellent patient capture capability.[1]

Figure 1. Proportion of each type of disease among the respondents

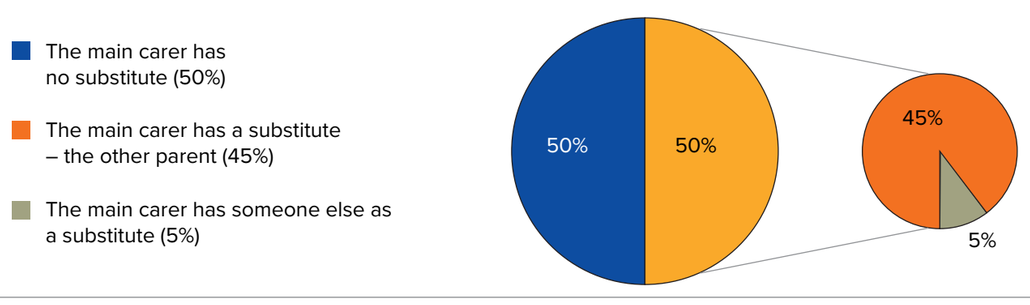


On average, caregivers spend 11 hours per month accompanying the patient in healthcare facilities, traveling 96 km to the neuromuscular centre. One quarter of carers have experienced involving their child in a clinical trial. On average, a caregiver with a patient visits more than four health professionals besides a general practitioner. Corticosteroids have been used by 84% of Duchenne muscular dystrophy patients surveyed, which is almost ten percentage points higher than the international average.[2] In total, 64% of patients take nutritional supplements, which corresponds to the upper limit of the average compared to foreign data.[3] Also, 91% of respondents exercise regularly with the patient at home.

Caregivers pay an average of €109[4] per month for transport for the medical examination; however, 79% of respondents do not ask their health insurance company for reimbursement of travel costs. Up to 71% of caregivers regularly pay for nutritional supplements, on average €84[4] per month.

Of the 55 patients who attend school, 84% have a teaching assistant who is in 93% of cases provided by the school. Of the nine carers who said that their child did not have a teaching assistant, five said it was because the child did not need one then. Two respondents said that the child had to change schools because of wheelchair accessibility. Of the respondents, 29% answered that the school made special accommodations because of the patient.

Figure 2. Proportions of carers by substitute carer option



Forty respondents (50%) said they did not have any substitute caregiver. Of those who had, 33 (45%) responded that the substitute is the other parent (**Figure 2**). A quarter of respondents use social services, most often having experience of personal assistance at residential events of Parent Project association, and twelve carers have experience of personal assistance at home (**Figure 3,4,5**). Of the carers, 21% are unemployed (**Figure 6**), of whom 89% report caring for the disabled patient as the reason for unemployment. The unemployment rate is therefore significantly higher than that in the general population, which was below 3%. In total, 94% of carers responded that their educational attainment was not affected by a neuromuscular disease in the family.

On average, children were granted care allowances at six years of age due to their diagnosis, and respondents applied on average more than twice for it, 79% of respondents had already undergone a reassessment of their level of dependency. Fifty-one (64%) respondents had made an appeal in relation to their illness (i.e., some social benefits were not granted by the system), almost half of which were appeals against the disallowance of disability ID card, 37% of respondents were appealing against not being granted a care allowance (**Figure 7**). The most common benefit received outside care allowance is mobility allowance, with 81% of respondents. In total 33 respondents receive a regular monthly allowance from a foundation in connection with their illness, on average €284 per month.

Figure 3. Use of social services among respondents

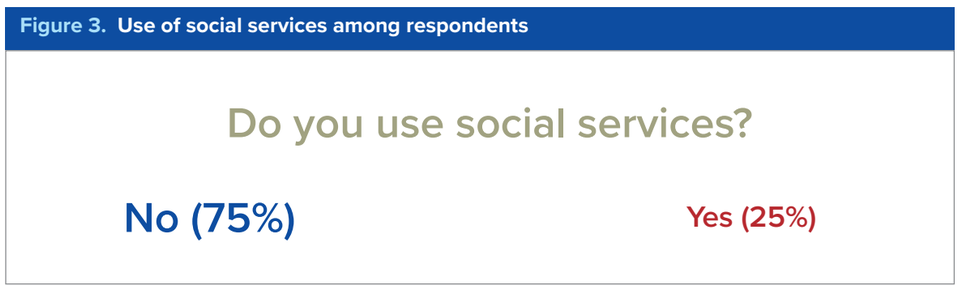


Figure 4. Reasons for not using social services

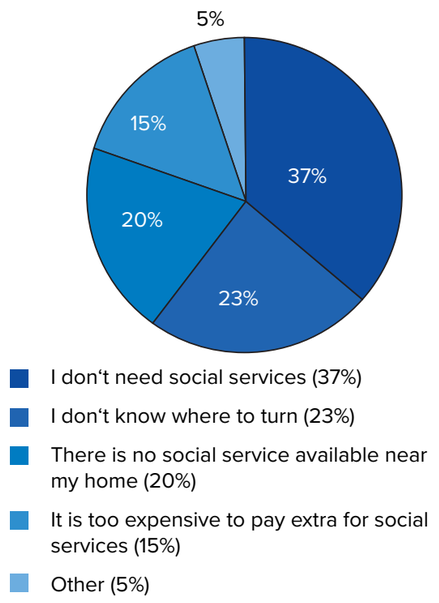


Figure 5. Specific social services used

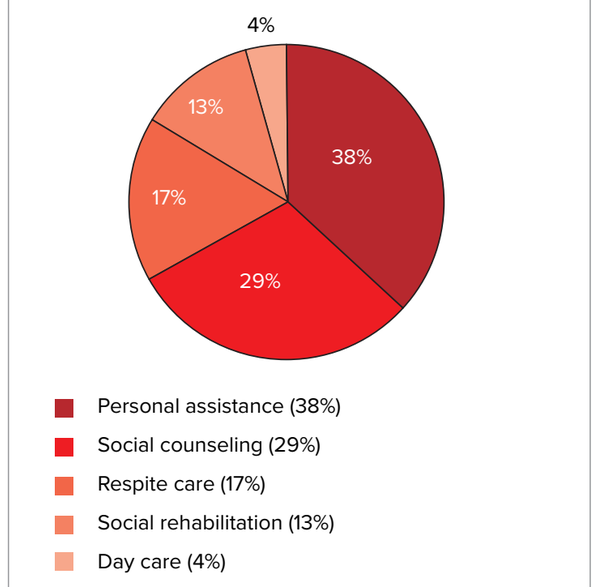


Figure 6. Work status of respondents

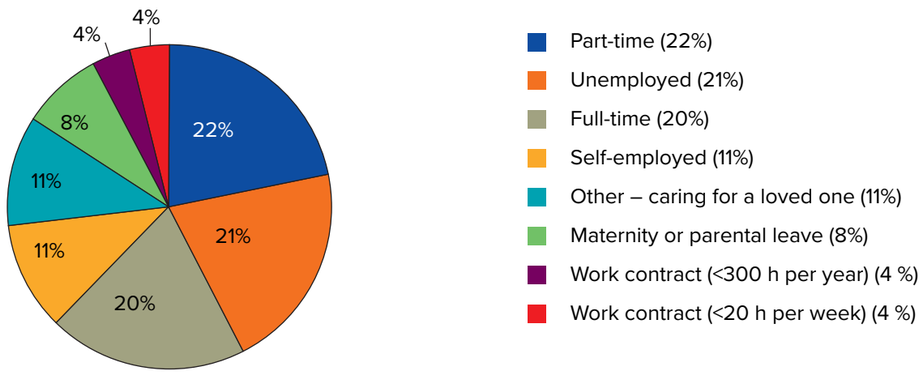
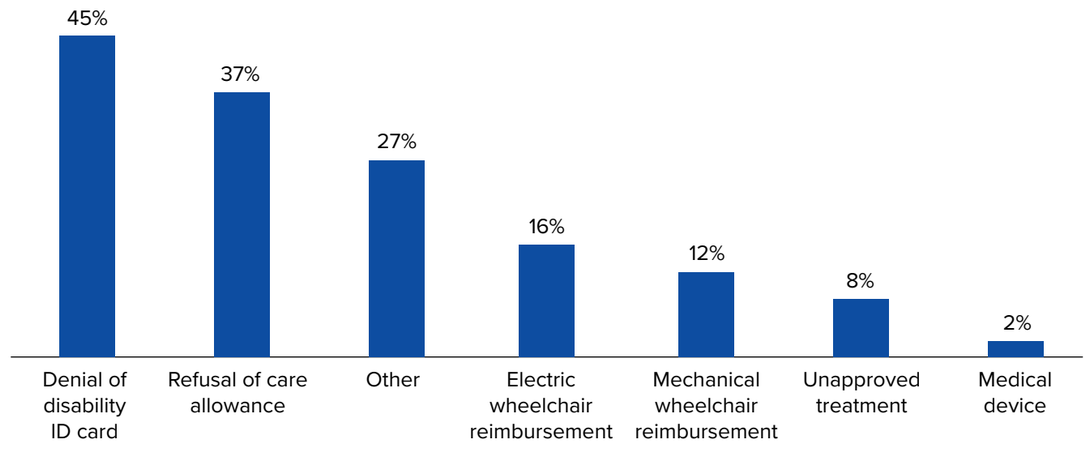


Figure 7. Reasons for and numbers of appeals filed (percentage of respondents who filed an appeal in a given case; considered from respondents who had ever appealed in the past n=51, one respondent could have filed multiple different appeals)



CONCLUSION

The study highlights the significant socioeconomic burden faced by patients with MD and their caregivers and underscores the critical importance of ensuring the availability of adequate health and social care services. Inarguably, families burdened with neuromuscular disease face many administrative difficulties within the health and social systems. Importantly, caring for patients significantly affects carers' ability to work and increases the likelihood of unemployment (>7 times) and thus overall labor market participation.

References

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