Productivity losses in people with Charcot-Marie-Tooth disease in the EU and US: interim results from an international digital real-world evidence study

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Background & Objectives

Charcot-Marie-Tooth disease (CMT) is a hereditary motor and sensory neuropathy that affects the peripheral nervous system, leading to distal muscle weakness, muscle atrophy and sensory loss.[1]

CMT is associated with substantial direct and indirect costs.[2]

Its impact on health care budgets and productivity losses has not been adequately studied in the published literature.

The objective of this analysis was to estimate productivity losses associated with CMT based on patient-reported real-world data from the EU and the US.

Methods

Adults with CMT were recruited to an ongoing two-year international study exploring the real-world burden of the disorder.

Data were collected via CMT&Me, a 'bring your own device' smartphone app, through which participants were asked questions about demographic and employment variables.

This interim analysis (data cut 30 May 2019, approximately seven months into the study) examined the impact of CMT on ability to work and study in participants from Germany, Italy, Spain, the UK and the US.

Results

Country of residence

Country of residence of the 635 respondents to this survey are presented in Table 1.

Table 1: Country of residence

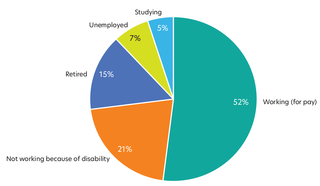
Country of residence (n,%)	Value
Germany (recruitment began January 2019)	59 (9)
Italy (recruitment began January 2019)	52 (8)
Spain (recruitment began April 2019)	105 (16)
UK (recruitment began November 2018)	211 (33)
US (recruitment began October 2018)	209 (33)

Employment status

Employment status for the overall study population is presented in Figure 1.

Of those who responded (n=635), just over half reported that they were currently working for pay. Just under a quarter reported not working because of disability.

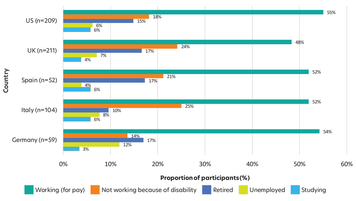
Figure 1: Employment status



Employment status by country is presented in Figure 2.

Employment status distribution was comparable across countries. The proportion of participants reporting that they were not working due to disability ranged from 14-25% across countries.

Figure 2: Employment status by country

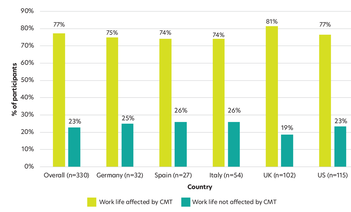


Impact of CMT on work life

The proportion of participants working for pay whose work life was affected by CMT is presented in Figure 3.

The majority reported that their work life was affected by CMT.

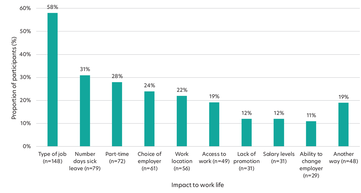
Figure 3: Proportion of participants whose work life was affected by CMT



The reported ways in which participant work life was affected by CMT are presented in Figure 4.

The most frequently reported ways in which work life was affected were type of job, number of days taken as sick leave, and working part-time.

Figure 4: Impact of CMT on work life



Note: participants were able to select multiple response options to this question

Table 2: Mean days of work missed in the past two weeks due to CMT

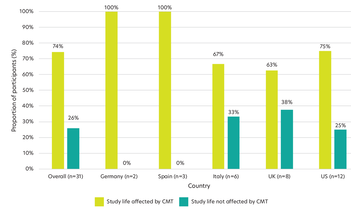
Country of residence (n,%)	Mean days of work missed	SD	Range
Germany (n=23)	2.04	4.02	0-14
Italy (n=39).	1.56	3.36	0-14
Spain (n=19)	0.42	0.82	0-3
UK (n=81	0.57	1.20	0-10
USA (n=87)	1.02	3.11	0-14
Overall (n=249)	1.08	2.81	0-14

Impact of CMT on study life

The proportion of participants who were studying whose study life was affected by CMT is presented in Figure 5.

The majority reported that their study life was affected by CMT.

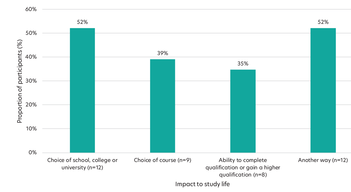
Figure 5: Proportion of participants whose study life was affected by CMT



The reported ways in which participant study life was affected by CMT are presented in Figure 6.

The most frequently reported ways in which study life was affected were choice of school, college, or university, and other ways (e.g., ability to stand in class, requiring extensions on assignments).

Figure 6: Impact of CMT on study life



Note: participants were able to select multiple response options to this question

Discussion

CMT has a significant impact on patients' work and study status.

Twenty-one percent of participants in the study were not working due to disability, while those who were working are affected by issues such as choice of job, number of days taken as sick leave, and having to work part-time due to CMT.

The majority of participants who were currently studying, meanwhile, reported that their study life was affected by CMT; which included choice of school/college/university and choice of courses.

The dataset is still immature to make extrapolations on an annual basis, but a mean one day of absence from work per fortnight could be translated to approximately 26 days per year; thus a significant number of work loss days. Such economic burden is in line with that of comparable neuromuscular conditions (e.g., amyotrophic lateral sclerosis and myasthenia gravis).[3]

Productivity losses due to CMT are comparable across EU countries and the US.

Further research is needed to explore the specific indirect costs associated with these productivity losses, and to better manage CMT's impact on patients' work/study lives.

Further exploration of this dataset could also investigate whether, in line with Johnson et al.'s 2014 findings from the Inherited Neuropathies Consortium Rare Diseases Clinical Research Network Contact Registry,[4] symptom severity in CMT patients is linked with employment status.

Conclusions

CMT is associated with substantial productivity losses, which are comparable across EU countries and the US.

Further research is needed to explore the specific indirect costs associated with these productivity losses, and to better manage CMT's impact on patients' work/study lives.

References

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