445P

Utilization and costs of healthcare services and labour market affiliation of persons with adult-onset myotonic dystrophy type 1 (DM1) – a Danish register-based study (Study II)

Charlotte Handberg[1,2], Jan Håkon Rudolfsen[3], Henning Andersen[4], John Vissing[5], Charlotte Dahl Rossau[6], Pia Dreyer[6], Jens Olsen[3], Simone D Bengtsson[3], Heidi Aagaard[1], Ulla Werlauff[1]

1 National Rehabilitation Center for Neuromuscular Diseases, Aarhus, Denmark
2 Department of Public Health, Faculty of Health, Aarhus University, Aarhus Denmark
3 EY, Copenhagen Denmark
4 Department of Clinical Medicine - The Department of Neurology, Aarhus University Hospital, Aarhus, Denmark
5 Copenhagen Neuromuscular Center, Copenhagen University Hospital, Copenhagen, Denmark
6 Department of Anaesthesiology and Intensive Care, Aarhus University Hospital, Aarhus, Denmark

Charlotte Handberg
Senior researcher,
associate professor,
RN. PhD
chha@rcfm.dk
www.rcfm.dk

The National Rehabilitation Center for Neuromuscular Diseases

Aim

To apply national health registers to provide updated knowledge on cost and use of healthcare services and labour market affiliation of persons with adult-onset myotonic dystrophy type 1 (DM1) in Denmark.

Background

Adult-onset DM1 is characterised by a diagnostic delay due to milder physical symptoms than the infantile and juvenile forms.

The presence and progression of cognitive symptoms and comorbidities in DM1 have negative biopsychosocial consequences which may impact quality of life, education, and labour market affiliation.

Because of the diagnostic delay and milder symptoms, persons with adult DM1 may receive less attention in the healthcare system with lower adherence to vital hospital follow-ups, increasing the risk of adverse events or early death due to, especially, acute pulmonary and cardiac complications. While there are no targeted treatment for DM1, the condition is associated with a range of comorbidities resulting in a need for frequent care.

Methods and materials

Patients with DM1 were identified using the Danish National Patient Register (NPR) from which data of healthcare utilisation were also obtained. NPR contains information on all somatic and psychiatric hospitalisations, outpatient contacts and primary care services, including diagnoses and procedures, emergency, planned contacts, and all tariffs and costs associated with a specific treatment. Data on utilisation of home care services were retrieved from the data-base on municipality services from Statistics Denmark. The costs associated with use of primary care were obtained from the Danish National Health Service Register, costs associated with consumption of prescription medicine were obtained from the Danish National Prescription Registry, and data on annual income, labour market affiliation, public transfer payments, unemployment benefit, sickness benefit, disability pension payments, and study grants were obtained from the Income register and DREAM data-base. Each person with DM1 was matched with ten reference persons without DM1 from the general Danish population.

Conclusion

Compared to their controls, the use of health services calculated as inpatient and outpatient contacts and hours of home care were higher for persons with DM1 (especially males). Moreover, persons with DM1 had a lower educational level, higher risk of early disability pension, unemployment, long-term sick leave, and a lower income (mostly males). This calls for attention from healthcare professionals to address practical issues related to management and care, and to help the patients navigate in the health care system.

Results

Table 1: Summary statistics at baseline

	Persons with DM1, N= 949	Controls, N=9,427
Age	**43 (32,54)**	**43 (32,54)**
Sex		
Men	473 (50%)	4,702 (50%)
Women	476 (50%)	4,705 (50%)
Region		
The Capital Region	311 (33%)	3,088 (33%)
Central Denmark Region	216 (23%)	2,152 (23%)
Region of Southern Denmark	161 (17%)	1,617 (17%)
North Denmark Region	141 (15%)	1,391 (15%)
Region Zealand	120 (13%)	1,179 (13%)
Education		
Primary education	377 (40%)	2,017 (21%)
Higher primary education	359 (38%)	3,797 (40%)
Bachelor	136 (14%)	2,250 (24%)
Master or higher	55 (5.8%)	1,093 (24%)
Unknown	22 (2.3%)	270 (2.9%)

Figure 1: Mean number of inpatient contacts, outpatient contacts and hours of home care services per year for each group

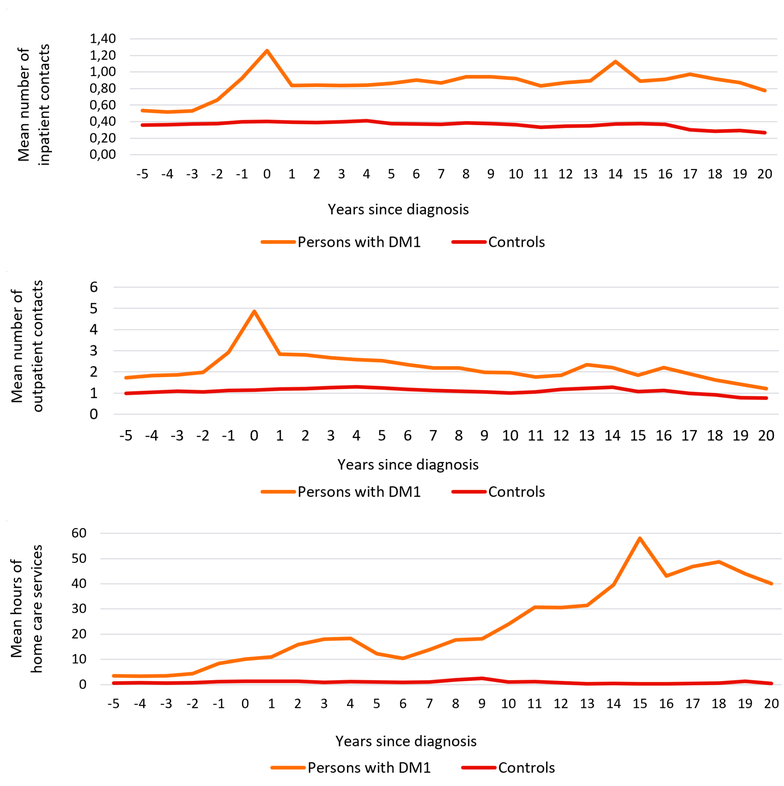

Figure 1
For both inpatient and outpatient hospital contacts, the difference was highest in the year following diagnosis, where persons with DM1 had 3.13 times more inpatient contacts (1.3 vs. 0.4) and 4.3 times more outpatient contacts (4.9 vs. 1.1) on average compared to their controls. In the 20 years following diagnosis, each person with DM1 had, on average, 11.6 additional inpatient contacts (19.1 vs. 7.5) and 24.2 additional outpatient contacts (47.3 vs. 23.1) compared to their controls.

Furthermore, persons with DM1 received significantly more hours of home care services from time of diagnosis and throughout the study period. On average, each person with DM1 received 29.1 times as many hours of home care services (582.5 vs. 20) as their controls during this period.

In the 20 years following diagnosis, the attributable costs generated by each person with DM1 summed to EUR 62,800 for inpatient care and EUR 19,200 for outpatient care. In the 20 years following diagnosis, the total mean healthcare costs attributable to each person with DM1 was EUR 117,000.

Figure 2: Mean number of weeks with long-term sick leave and unemployment per year and annual income for each group

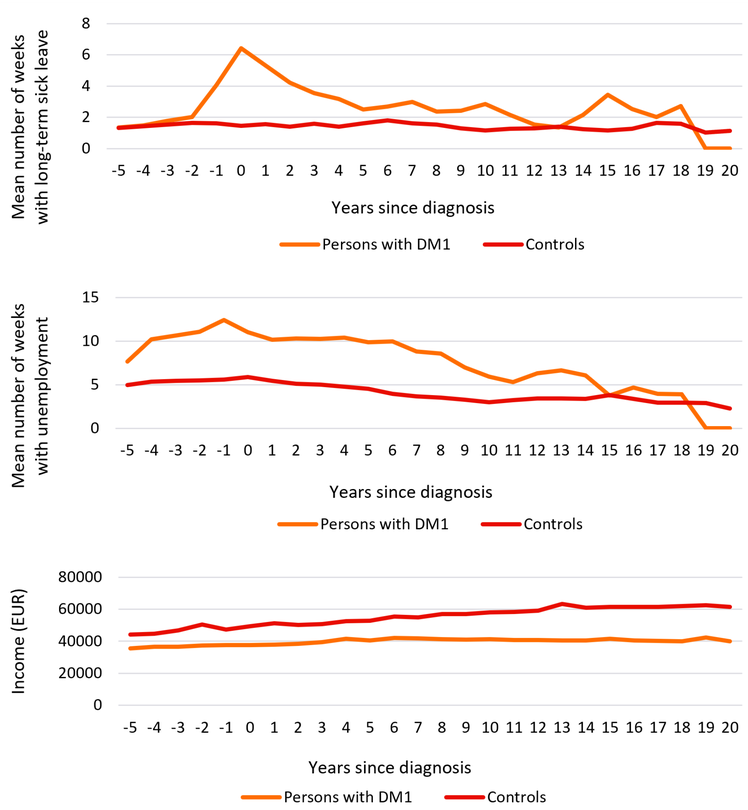

Figure 2
From one year before diagnosis until four years after, persons with DM1 had significantly more weeks of long-term sick leave than their controls. The difference was greatest in the year of diagnosis, where a person with DM1 had an average of 5 more weeks of long-term sick leave.

With regards to unemployment, we found that persons with DM1 had significantly more weeks of unemployment each year compared to their controls from 5 years before diagnosis until 10 years after. The difference was greatest the year before diagnosis, where each person with DM1 had an average of 6.9 more weeks with unemployment.

The reduced labour market affiliation among persons with DM1 was also reflected in their annual income. Throughout the study period, there was a statistically significant difference in mean income among persons with DM1 and their controls.

Figure 3: Kaplan-Meier plot of disability pension

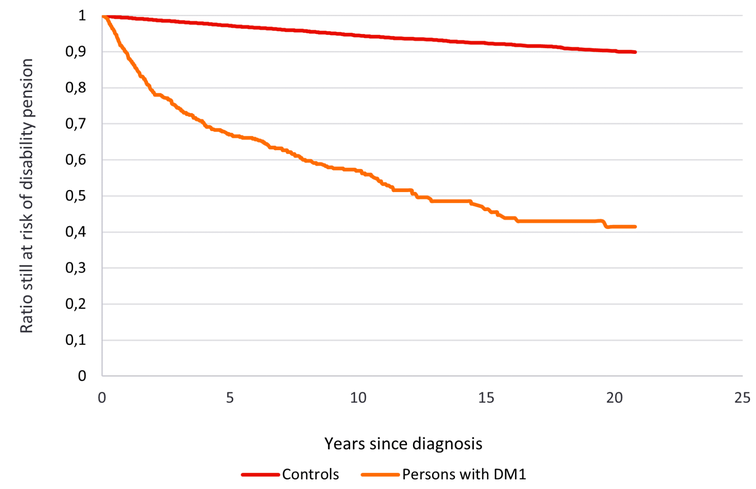

Figure 3
The rate of disability pension was higher among persons with DM1 compared to their matched controls. The cox regression estimated that a person with DM1 had a 11.6 times higher hazard of disability pension compared to their controls (95% CI: 9.92-13.6, p < 0.001).

Conflict of interest: The authors declare no potential conflict of interest.

Funding: There is no funding to report.