

Management of dystonia in Europe: a survey of the European network for the study of the dystonia syndromes

A. Valadas^{1,2,*}, M-F. Contarino^{3,4,*}, A. Albanese⁵, K. P. Bhatia⁶, C. Falup-Pecurariu⁷, L. Forsgren⁸, A. Friedman⁹, N. Giladi¹⁰, M. Hutchinson^{11,12}, V. S. Kostic¹³, J. K. Krauss¹⁴, A. Lokkegaard¹⁵, M. J. Marti¹⁶, I. Milanov¹⁷, Z. Pirtosek¹⁸, M. Relja¹⁹, M. Skorvanek^{20,21}, M. Stamelou^{22,23}, A. Stephens²⁴, G. Tamás²⁵, A. Taravari²⁶, C. Tzoulis^{27,28}, W. Vandenberghe²⁹, M. Vidailhet^{30,31}, J. J. Ferreira³² and M. A. Tijssen³³

¹Neurology Service, Hospital de São Bernardo, Centro Hospitalar de Setúbal, Setúbal; ²Clinical Research Unit, Institute of Molecular Medicine, Lisbon, Portugal; ³Department of Neurology, Academic Medical Center, Amsterdam; ⁴Department of Neurology, Haga Teaching Hospital, The Hague, The Netherlands; ⁵Istituto Clinico Humanitas and Università Cattolica del Sacro Cuore, Milan, Rozzano, Italy; ⁶Sobell Department of Motor Neuroscience and Movement Disorders, University College London (UCL) Institute of Neurology, London, UK; ⁷Department of Neurology, Faculty of Medicine, Transilvania University, Brasov, Romania; ⁸Department of Pharmacology and Clinical Neuroscience, Umea University, Umea, Sweden; ⁹Department of Neurology, Medical University of Warsaw, Warszawa, Poland; ¹⁰Neurological Institute, Tel Aviv Medical Center, Sackler School of Medicine, Sagol School of Neuroscience, Sieratzki Chair in Neurology, Tel Aviv University, Tel Aviv, Israel; ¹¹Department of Neurology, St Vincent's University Hospital, Dublin; ¹²School of Medicine and Medical Sciences, University College Dublin, Dublin, Ireland; ¹³Neurology Clinic CCS, School of Medicine, University of Belgrade, Belgrade, Serbia; ¹⁴Department of Neurosurgery, Hannover Medical School, Hannover, Germany; ¹⁵Department of Neurology, Copenhagen University Hospital Bispebjerg, Copenhagen, Denmark; ¹⁶Parkinson Disease and Movement Disorders Unit, Neurology Service, Institut d'Investigació Biomèdiques August Pi i Sunyer (IDIBAPS), Centro de Investigación Biomédica en Red sobre Enfermedades Neurodegenerativas (CIBERNED), Barcelona, Catalonia, Spain; ¹⁷University Hospital for Neurology and Psychiatry 'St Naum', Sofia, Bulgaria; ¹⁸Department of Neurology, University Medical Centre Ljubljana, Ljubljana, Slovenia; ¹⁹Referral Center for Movement Disorders, Department of Neurology, University Hospital Center Zagreb, University of Zagreb, School of Medicine, Zagreb, Croatia; ²⁰Department of Neurology, Safarik University, Kosice; ²¹Department of Neurology, University Hospital of L. Pasteur, Kosice, Slovak Republic; ²²Second Department of Neurology, Attiko Hospital, University of Athens, Athens, Greece; ²³Department of Neurology, Philipps Universität, Marburg, Germany; ²⁴Laboratory for Research in Rehabilitation, Riga Stradins University, Riga, Latvia; ²⁵Department of Neurology, Semmelweis University, Budapest, Hungary; ²⁶University Clinic of Neurology – Skopje, University 'St Cyril and Methodius', Skopje, Republic of Macedonia; ²⁷Department of Neurology, Haukeland University Hospital, Bergen; ²⁸Department of Clinical Medicine, University of Bergen, Bergen, Norway; ²⁹Department of Neurology, University Hospitals Leuven, Leuven, Belgium; ³⁰APHP, Department of Neurology, Salpêtrière Hospital, Paris; ³¹ICM (Brain and Spine Institute) UPMC/INSERM, UMR 1127, CNRS UMR7225, Pierre Marie Curie Paris-6 University, Paris, France; ³²Laboratory of Clinical Pharmacology and Therapeutics, Faculty of Medicine, University of Lisbon, Lisbon, Portugal; and ³³Department of Neurology, University Medical Centre Groningen, Groningen, The Netherlands

Keywords:

dystonia, dystonia management, dystonia treatment, Europe, survey

Received 7 August 2015

Accepted 4 November 2015

European Journal of Neurology 2016, **23**: 772–779

doi:10.1111/ene.12940

Background and purpose: Dystonia is difficult to recognize due to its large phenomenological complexity. Thus, the use of experts in dystonia is essential for better recognition and management of dystonia syndromes (DS). Our aim was to document managing strategies, facilities and expertise available in various European countries in order to identify which measures should be implemented to improve the management of DS.

Methods: A survey was conducted, funded by the Cooperation in Science and Technology, via the management committee of the European network for the study of DS, which is formed from representatives of the 24 countries involved.

Results: Lack of specific training in dystonia by general neurologists, general practitioners as well as other allied health professionals was universal in all countries surveyed. Genetic testing for rare dystonia mutations is not readily available in a significant number of countries and neurophysiological studies are difficult to perform due to a lack of experts in this field of movement disorders. Tetrabenazine is only readily available for treatment of dystonia in half of the surveyed countries. Deep brain stimulation is available in three-quarters of the countries, but other surgical procedures are only available in one-quarter of countries.

Conclusions: Internationally, collaboration in training, advanced diagnosis, treatment and research of DS and, locally, in each country the creation of multidisciplinary teams for the management of dystonia patients could provide the basis for improving all aspects of dystonia management across Europe.

Correspondence: M. A. Tijssen, Department of Neurology AB 51, University Medical Center Groningen, PO Box 30.001, 9700 RB Groningen, The Netherlands (tel.: +31 50 3612400; fax: +31 50 3611707; e-mail: M.A.J.de.Koning-Tijssen@umcg.nl).

*These authors have contributed equally to the paper.

Introduction

Dystonia is a movement disorder characterized by sustained or intermittent muscle contractions causing abnormal, often repetitive, movements, postures or both. Dystonic movements are typically patterned, twisting and may be tremulous. Dystonia is often initiated or worsened by voluntary action and associated with overflow muscle activation [1]. Although an underdiagnosed condition, with an estimated prevalence rate in Europe of 15.2/100 000 for primary dystonia and 11.7/100 000 for focal forms, dystonia syndromes (DS) represent the third most common disorder found in tertiary movement disorder (MD) centers, which has led to a growing interest in this area [2]. However, not only are scientific initiatives fragmented across Europe, they are hampered by insufficient breadth and the lack of homogeneity in clinical care. The European network for the study of DS, sponsored by the European Cooperation in Science and Technology (COST) under the designation of COST Action BM1101, is a European initiative designed to overcome this gap, providing a bridge between countries with the aim of improving knowledge, standard of care, training of health professionals, and increasing public awareness about DS. In the present study, proposed by COST Dystonia Action, our aim was to document the management of DS in the different European countries that are part of this network, via an explorative survey.

Methodology

Study objectives

The main goal of this study was to document managing strategies, facilities and expertise available in the different countries that form the European network for the study of DS in order to identify which measures should be implemented to improve the management of DS.

Study participants

Twenty-four countries are part of the European network for the study of DS (COST Action BM1101) and participated in this study. These include 20 out of the 28 countries which are part of the European Union (EU) (Germany, UK, Bulgaria, Croatia, France, Hungary, Italy, Latvia, Netherlands, Poland, Slovakia, Slovenia, Spain, Sweden, Denmark, Ireland, Portugal, Greece, Romania and Belgium) plus Israel, Republic of Macedonia, Norway and Serbia. The eight EU countries not participating in this action were Austria, Cyprus, Czech Republic, Estonia, Finland, Lithuania, Luxembourg and Malta (Fig. 1) [3]. The management committee of this network is made up of two representatives from each country. These individuals were invited to the network not only because of their expertise in DS but also for the prominent role they play in the local management of dystonia. For this study, the survey was submitted to one of the two COST management committee repre-

Figure 1 Europe map. Surveyed countries are marked with an asterisk; Israel is inserted at the bottom right of the figure. Adapted from the website Europa.eu.



sentatives for each country. The respondents were instructed to fill in the questionnaire by themselves.

Survey

A questionnaire was developed and sent, by email, to the participants, including instructions on how to fill in the form, using an email address exclusively created for this purpose (Data S1). The questionnaire was composed of 13 questions divided into three parts: part I, participant's characterization (i.e. name, qualifications, email address, country, main area of interest in dystonia); part II, country characterization (i.e. availability of training in MDs and specifically training in DS for physicians, nurses and therapists, accessibility of patients with dystonia to dystonia experts and tertiary centers, availability of ancillary tests and treatment options); part III, an open question on urgent measures to be implemented in their countries to better manage patients with dystonia. In part II, to rate the availability/accessibility to experts, ancillary tests and treatment options a three-item scale was used: easily accessible; satisfactory/accessible with some difficulty; difficult/not available (Data S1).

Statistical analysis

A descriptive analysis was performed with IBM SPSS Statistics for Windows, Version 19.0. (IBM Corp., Armonk, NY, USA).

Results

All countries replied ($n = 24$).

Respondents' characterization

All respondents have expertise in neurology and the German physician has neurosurgical training. The clinical characteristics of DS are one of the major interests of all respondents.

Clinical care

Expertise and patients' accessibility. All countries except the Republic of Macedonia have MD experts who are also experts in dystonia, according to the judgment of the responders (Table 1). Regarding patients' accessibility to dystonia experts, 12 countries considered it satisfactory, six difficult (Bulgaria, Republic of Macedonia, Latvia, Poland, Serbia, Greece) and six easy (Germany, Netherlands, Norway, Slovenia, Ireland, Belgium). The main reason given hindering accessibility was the small number of experts in dystonia, who are present mainly in univer-

sity centers. Dystonia tertiary centers exist in 21 countries, but only in seven are the patients evaluated in these centers at least once during the course of disease (Table 1).

Training. All the countries have teaching courses and symposia for residents and general neurologists (GNs) to facilitate training in MDs. Ten countries have programs for internship in MD centers for neurology residents, and 12 have teaching courses for general practitioners (GPs). Specific training in DS with teaching courses or symposia for residents and GNs occurs in 21 countries and for GPs in six (Table 1). Specific training in MDs is available for nurses, physiotherapists and speech therapists in 10, 12 and seven countries respectively. In six countries a specific training in dystonia exists for nurses, in 11 for physiotherapists and in four for speech therapists (Table 1).

Ancillary tests. Genetic testing (i.e. DYT1 and DYT6) of patients with dystonia is easily accessible in 12 countries, accessible with difficulty in nine and not available in three (Republic of Macedonia, Bulgaria, Romania). The main difficulties highlighted relate to the unavailability of tests for less frequent mutations (i.e. other than DYT1 and DYT6) and economic reasons. Electrophysiological testing (i.e. polymyography, transcranial magnetic stimulation, coherence tests) is easily accessible in 11 countries, accessible with difficulty in 11 and not available in two (Croatia and Israel). The main reported difficulty related to the absence of expertise in MDs by neurophysiologists.

Treatment availability. Almost all respondents considered that the most commonly used oral medications (including anticholinergics, antiepileptics, benzodiazepine, levodopa and neuroleptic drugs such as clozapine) are easily accessible in their countries, with the exception of tetrabenazine (essentially only used in tardive dystonia) which is easily accessible in only 12 countries, accessible with some difficulty in eight and not available in four (Table 2) [4]. The reported reasons for the difficulty of access to drugs are patients having to support the high costs of tetrabenazine with subsequent difficulty for reimbursement by healthcare systems and availability only for selected indications (i.e. Huntington's disease). In addition, botulinum toxin is easily available in 18 countries and available with some difficulty in the remaining six (Table 2).

With regard to surgical procedures, deep brain stimulation (DBS) is easily accessible in 13 countries, difficult in five and not available in six (Bulgaria, Republic of Macedonia, Latvia, Serbia, Ireland and Romania). Conversely, stereotactic lesion procedures are not available in 13 countries, accessible with difficulty in four and easily accessible in only six (Belgium, Hungary, Israel, Netherlands, Sweden, UK)

Table 1 Expertise in movement disorders and dystonia per country

	BE	BG	DE	DK	EL	ES	FR	HR	HU	IE	IL	IT	LV	MK	NL	NO	PL	PT	RO	RS	SE	SI	SK	UK
Movement disorders																								
Society	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Experts	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Stages for residents in neurology	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Teaching courses for residents/GNs	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Teaching courses for GPs	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Specific training for nurses	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Specific training for speech therapists	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Specific training for physiotherapists	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Clinical trials	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Dystonia																								
Networking group	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Experts	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Tertiary centers	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Teaching courses for residents/GNs	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Teaching courses for GPs	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Specific training for nurses	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Specific training for speech therapists	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Specific training for physiotherapists	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Clinical trials	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
National patients association	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+

BE, Belgium; BG, Bulgaria; DE, Germany; DK, Denmark; EL, Greece; ES, Spain; FR, France; HR, Croatia; HU, Hungary; IE, Ireland; IL, Israel; IT, Italy; LV, Latvia; MK, Republic of Macedonia; NL, Netherlands; NO, Norway; PL, Poland; PT, Portugal; RO, Romania; RS, Serbia; SE, Sweden; SI, Slovenia; SK, Slovakia; UK, United Kingdom.

GPs, general practitioners; GNs, general neurologists; +, yes; -, no.

Table 2 Dystonia treatment availability by country

	BE	BG	DE	DK	EL	ES	FR	HR	HU	IE	IL	IT	LV	MK	NL	NO	PL	PT	RO	RS	SE	SI	SK	UK
Anticholinergic drugs	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+/-	+	+	+	+/-	+	+	+	+
Antiepileptic drugs	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+/-	+	+	+	+
Benzodiazepines	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+/-	+	+	+	+
Levodopa	+	+	+	+	+	+	+	+	+	+	+	+	+/-	+	+	+	+	+	+	+	+	+	+	+
Antidopaminergic drugs (i.e. risperidone, clozapine etc.)	+	+	+	+	+	+	+	+	+	+	+	+	+/-	+	+	+	+	+	+	+	+	+	+	+
Dopaminergic blockers (i.e. tetraabenazine)	+	-	+/-	+	+	+	+	+	-	+	+	+	+/-	+	+	+/-	+/-	+	+	-	+/-	+	-	+/-
Botulinum toxin	+	+/-	+	+	+	+	+	+	+/-	+	+	+	+	+	+	+	+/-	+/-	+/-	+/-	+	+	+	+
Myectomy	Nkn	-	+/-	+/-	+/-	+/-	+/-	-	-	-	-	+/-	-	-	+/-	+	-	-	+/-	+/-	-	+	-	+/-
Selective peripheral denervation (Bertrand's surgery)	Nkn	-	+/-	-	+/-	+/-	+/-	-	-	-	-	-	-	-	+/-	-	-	-	+/-	+/-	+/-	+	-	+/-
Deep brain stimulation	+	-	+	+	+/-	+/-	+	+	+	-	+	+/-	-	-	+	+	+/-	+	-	-	+	+	+	+
Stereotactic lesions (pallidotomy)	+	-	+/-	-	+/-	Nkn	-	-	+	-	+	-	-	-	+	-	+/-	-	+/-	-	+	-	-	+
Physical therapy and rehabilitation	+	+	+	+	+/-	+/-	+/-	+	+/-	+	+	+/-	+/-	+/-	+	+	+/-	+/-	+	+/-	+/-	+	+	+/-

BE, Belgium; BG, Bulgaria; DE, Germany; DK, Denmark; EL, Greece; ES, Spain; FR, France; HR, Croatia; HU, Hungary; IE, Ireland; IL, Israel; IT, Italy; LV, Latvia; MK, Republic of Macedonia; NL, Netherlands; NO, Norway; PL, Poland; PT, Portugal; RO, Romania; RS, Serbia; SE, Sweden; SI, Slovenia; SK, Slovakia; UK, United Kingdom.
+, easily accessible; +/-, accessible with some difficulty; -, not available; Nkn, not known.

and myectomy and selective peripheral denervation are even less available being only easily accessible in two and one countries respectively (Table 2). In only half of the countries surveyed was physical therapy and rehabilitation easily accessible (Table 2).

Research. Clinical trials in MDs, including studies sponsored by the pharmaceutical industry, are run in all but two countries (Republic of Macedonia and Ireland) and in 19 countries clinical trials for dystonia are running (Table 1). In 21 countries at least one type of research into dystonia is carried out: nine basic research, 21 clinical, 16 genetics, 13 neurophysiology, 12 imaging and four brain bank. In Bulgaria, Latvia and Republic of Macedonia no dystonia research is performed, whilst in Denmark, France, Italy and the Netherlands all kinds of research studies are undertaken.

Scientific societies and patients' associations. A local MD society exists in all but five countries (Israel, Serbia, Latvia, Republic of Macedonia, Romania); a dystonia networking group (e.g. lists of experts in dystonia and botulinum toxin centers) exists in 13 countries and 16 have a dystonia patients' association (Table 1).

Priorities regarding management of DS

Overall, the main concerns of respondents were in relation to physicians' education, genetic testing and treatment options. For physicians' education, the priorities were related to improving GNs' and GPs' knowledge by promoting training courses in dystonia. In relation to genetic testing, priorities related to reimbursement and increased availability and, in treatment, the priority was to increase research for more effective treatments, including specific physical rehabilitation programs for dystonia. Other points related to improving accessibility of botulinum toxin and DBS for patients with DS.

Discussion

To our knowledge, this is the first study exploring the management of DS across Europe. Information was collected from clinicians with expertise in the field of dystonia, representing a large proportion, including some of the most populous, of the EU countries. Management of patients with dystonia is a challenge. As reported in previous studies, patients' health-related quality of life goes far beyond symptomatic treatment [5,6], and, due to the lack of diagnostic tests and the significant variability in the ability of physicians to diagnose dystonia, the guidelines issued by the European Federation of Neurological Societies

recommends an expert evaluation for the diagnosis of DS [7,8]. However, our results bring to light that, although dystonia expertise exists in almost all European countries surveyed, only about a third of countries consider the access to dystonia experts easy. As a consequence, a relatively large number of dystonic patients are potentially precluded from an appropriate diagnosis. The small number of experts per country, who are mainly located in tertiary or university hospitals and are therefore not always readily accessible for all patients, is blamed for this problem. In most European healthcare systems, GPs and GNs are an important source of referral of patients to experts. Thus, the education and training of these physicians in dystonia is of the utmost importance. Data from our study showed that, although teaching courses on MDs exist for GNs, specific dystonia training is less available, and this is particularly true for GPs. This tendency seems not to be related to economic resources or classification in specific healthcare indices. For example, in the *Euro Health Consumer Index 2014* [9], an index supported by patients' opinions of the general healthcare system, the most well classified countries are the Netherlands, Switzerland, Norway, Finland, Denmark, Belgium, Iceland, Luxembourg and Germany, and, according to another health system score by the World Health Organization (WHO) [10], France, Italy, Spain are in the top three, but despite this the training of physicians is a common problem in all countries surveyed. Another issue highlighted by WHO is the benefit of trained nurses in the management of patients with chronic diseases, and more than half of the surveyed countries did not have trained nurses to deal with dystonia patients. The *Euro Health Consumer Index 2014* [9] also highlights the importance of active participation of patients and patients' associations in the discussion of the management of the diseases but according to our data only about two-thirds of the surveyed countries have an organized dystonia patients' association. Although the diagnosis of dystonia is mainly clinical, neurophysiological evaluations are sometimes useful [8]. Our study has shown that neurophysiological evaluations are difficult to access mainly due to lack of expertise in MDs by neurophysiologists. Alongside financial issues, half the countries also reported difficulties in genetic diagnosis of DS mainly related to infrequent mutations, supporting the case for a centralized European laboratory for the study of more rare disorders. Overall, oral treatments are easily available in most countries, with the exception of tetrabenazine which is available with difficulty or not available in about half of the respondents' countries. Taking into account the indices of health mentioned above it seems that both top and

bottom countries have similar difficulties in the availability of this type of treatment suggesting that economic factors are not the only reason for the lack of availability of tetrabenazine in dystonia [9,10]. Perhaps the low interest of pharmaceutical companies in rarer disorders may partly explain this difficulty. Botulinum neurotoxin is easily available in about three-quarters of countries surveyed. Those who indicated reduced availability related this to financial issues, mainly reimbursement of patients [9,10]. Regarding more invasive surgical treatments, the availability of DBS for dystonia is variable. In accordance with the 2000 WHO health system classification and *Euro Health Consumer Index 2014* it seems that DBS is most readily available in the most well classified countries. However, in almost all countries, selective peripheral denervation, myectomy and stereotactic lesion, although less expensive than DBS, are not available. This may reflect concerns with the efficacy and safety of these procedures compared to DBS, as reported by some treatment guidelines like National Institute for Health and Care Excellence [11], but may also reflect the lack of expertise in such highly specialized procedures. Dystonia specific physical and speech therapy is available in only half of countries, which may reflect national differences in education plans, e.g. in Denmark it is not possible for physiotherapists to specialize in MDs. Research in dystonia is running fully only in four countries, where almost all areas of investigation are performed. Nevertheless, in the majority of surveyed countries there is at least one area of investigation performed, mainly clinical and genetics studies. This fragmentation of data from different countries can probably explain the small amount of collaborative studies across European countries. Interestingly, respondents' opinions regarding urgent measures for the management of dystonia in their countries were in line with the main difficulties reported by most countries: training, genetic testing and availability of treatment options. Although a large proportion of countries of the EU were included in this study, it is limited because not all European countries were represented and this might bias the estimate of needs. In addition, the results were based on a single subject response per country; however, all respondents are well-known physicians involved in the treatment of dystonia and likely to be well informed on the national situation concerning dystonia management.

Based on our findings the following priorities are identified for the improvement of DS management across Europe:

- 1 Training: enhance the training of physicians and allied health professionals (i.e. nurses, physiotherapists,

speech therapists, occupational therapists) in dystonia, by reinforcing the number of teaching courses and training schools at all levels in each country. Implement exchange programs for (young) physicians and allied health professionals to share expertise of specialized centers. Stimulate the training of neurologists and neurosurgeons in advanced treatment options (surgery, botulinum toxin). Expand the concept of specialized dystonia nurses, with personalized training actions.

- 2 Improve the accessibility of patients to dystonia experts by creating national and European clinical networks for clinicians, patients and researchers. Improve care in all countries by the implementation and/or promotion of easily accessible national specialized centers with a reasonable number of experts. Create a group of European dystonia centers specialized in rarer disorders where patients from all parts of Europe could be evaluated. Implement telemedicine and virtual collegial consultations between the treating physicians and European experts.
- 3 Implement international collaboration in research projects to enhance the quality and results of the research data, e.g. by making use of European dystonia network platforms [12].
- 4 Improve the availability of genetic testing in each country for more frequent disorders/mutations. Introduce implementation, certification and maintenance of quality standards for new and existing laboratories.
- 5 Optimize the treatment resources of the different countries. Create mechanisms to expedite the reimbursement of treatment with botulinum toxin in each country. Facilitate cross-border referral systems so that small countries can refer patients to adjacent countries where DBS expertise already exists. Quality controls, reporting of results, including the number of surgeries performed and adverse events, should be encouraged amongst centers.

These priorities should be brought forward to national and international medical and patients associations in all European countries in order to raise awareness and encourage action by MD clinicians and researchers and by public health authorities in each country.

It can be concluded that, internationally, collaboration in training, advanced diagnosis, treatment and research of DS and, locally, in each country the creation of multidisciplinary teams for the management of dystonia patients could represent the basis for improving all aspects of dystonia management across Europe.

Acknowledgement

This study was partially funded by the European Cooperation in Science and Technology (COST) Action BM1101.

Disclosure of conflicts of interest

Dr Contarino serves on advisory boards of Medtronic, Boston Scientific. She is a co-inventor on a patent application relevant to DBS and has received speaking fees from Abbvie, Medtronic, Boston Scientific, ECMT. Dr Albanese reports speakers' honoraria from Ipsen, Medtronic, Merz, UCB Pharma and Zambon Pharma. Dr Bhatia received funding for travel from GlaxoSmithKline, Orion Corporation, Ipsen and Merz Pharmaceuticals LLC; serves on the editorial boards of *Movement Disorders* and *Therapeutic Advances in Neurological Disorders*; receives royalties from the publication of *Oxford Specialist Handbook of Parkinson's Disease and Other Movement Disorders* (Oxford University Press, 2008); received speaker honoraria from GlaxoSmithKline, Ipsen, Merz Pharmaceuticals LLC and Sun Pharmaceutical Industries Ltd; personal compensation for scientific advisory board for GSK and Boehringer Ingelheim; received research support from Ipsen and from the Halley Stewart Trust through Dystonia Society UK, and the Welcome Trust MRC strategic neurodegenerative disease initiative award (reference number WT089698), a grant from the Dystonia Coalition and a grant from Parkinson's UK (reference number G-1009); co-applicant PD UK grant K-1303, 'Single-centre open label exploratory phase two pilot study of exogenous oral melatonin for the treatment of nocturia in Parkinson's disease'. Dr Falup-Pecurariu reports personal fees and non-financial support from UCB Pharma, non-financial support from Lundbeck, personal fees from MDS, non-financial support from Ipsen, personal fees from Bristol-Myers-Squibb, personal fees from Pfizer, personal fees from STADA and personal fees from KRKA. Dr Giladi serves as consultant to Teva-Lundbeck, IntecPharma, Neuroderm, Armon Neuromedical Ltd and Pharma Two B; received payment for lectures at Teva-Lundbeck, Novartis and UCB and receives research support from the Michael J Fox Foundation, the National Parkinson Foundation, the European Union 7th Framework Programme and the Israel Science Foundation. Dr Hutchinson served on a medical advisory board for the CONFIRM study (BG00012) for Biogen Idec, serves on the editorial board of the *Multiple Sclerosis Journal*, has received speakers' honoraria from Merk-Serono, Novartis,

Biogen Idec and Bayer-Schering and receives research support from Dystonia Ireland, the Health Research Board of Ireland and the Foundation for Dystonia Research. Dr Kostic serves on the advisory board of Abbvie, has received honoraria for lectures from Novartis, Boehringer Ingelheim, Roche, Lundbeck, Glaxo; grant support from the Ministry of Education and Science, Republic of Serbia (project ON175090) and received research grants from Novartis, Boehringer Ingelheim, Lundbeck, Glaxo, Swiss Pharm, El Pharma. Dr Krauss is a consultant to Medtronic and to Boston Sci. He received honoraria from St Jude and from Abbvie. Dr Marti has received speaking fees from Ipsen, Merz, Allergan and UCB and research grants from Ministry of Health and Social Services, Marato TV3, Centro Investigacion Biomedica en Red and Michael J Fox Foundation for Parkinson's Research. Dr Skorvanek received research funding from the Slovak Research and Development Agency and from the Slovak Scientific Grant Agency. He also received speakers' honoraria from Abbvie, Actavis, Lundbeck, Medtronic and UCB. Dr Tamás reports personal fees and non-financial support from Medtronic Inc., and non-financial support from St Jude Medical Inc. Dr Vidailhet received research support from INSERM (ANR), APHP (PHRC) and patients' association (APTPEs, France Parkinson, AMADYS) and travel grants from the Movement Disorders Society (speaker), advisory board for Merz and Medtronic. Dr Ferreira serves as consultant to GlaxoSmithKline, Novartis, Teva, Lundbeck, Biogen, Ipsen, Merz, Merck-Serono, Bial, Solvay and Abbott and received speakers' honoraria from Biogen and Bial. He also received grants from GlaxoSmithKline, Grunenthal, MSD, Teva, Allergan, Novartis and Fundação MSD (Portugal). Dr Tijssen is funded by STW Technology Society – NeuroSIPE, Netherlands Organization for Scientific Research – NWO Medium, Fonds Nuts-Ohra, Prinses Beatrix Fonds, Gossweiler Foundation, Phelps Stichting, Stichting Wetenschapsfonds Dystonie Vereniging and educational grants from Ipsen,

Allergan, Merz, Actelion and Medtronic. The remaining authors have nothing to disclose.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Data S1. Management of dystonia syndromes around Europe.

References

1. Albanese A, Bhatia K, Bressman SB, *et al.* Phenomenology and classification of dystonia: a consensus update. *Mov Disord* 2013; **7**: 863–873.
2. Epidemiological Study of Dystonia in Europe (ESDE) Collaborative Group. A prevalence study of primary dystonia in eight European countries. *J Neurol* 2000; **247**: 787–792.
3. European Union 2015. http://europa.eu/about-eu/countries/index_en.htm (accessed 01/08/2015).
4. Thenganatt MA, Jankovic J. Treatment of dystonia. *Neurotherapeutics* 2014; **11**: 139–152.
5. Carr AJ, Gibson B, Robinson PG. Measuring quality of life: is quality of life determined by expectations or experience? *BMJ* 2001; **322**: 1240–1243.
6. Comella C, Bhatia K. An international survey of patients with cervical dystonia. *J Neurol* 2015; **262**: 837–848.
7. Albanese A, Asmus F, Bhatia KP, *et al.* EFNS guidelines on diagnosis and treatment of primary dystonias. *Eur J Neurol* 2011; **18**: 5–18.
8. Logroscino G, Livrea P, Anaclerio D, *et al.* Agreement among neurologists on the clinical diagnosis of dystonia at different body sites. *J Neurol Neurosurg Psychiatry* 2003; **74**: 348–350.
9. Euro Health Consumer Index 2014. <http://www.health-powerhouse.com/index.php?Itemid=55> (accessed 02/08/2015).
10. World Health Organization 2000. <http://www.who.int/whr/2000/en/> (accessed 02/08/2015).
11. NICE interventional procedure guidance [IPG80]. Selective peripheral denervation for cervical dystonia. <https://www.nice.org.uk/guidance/ipg80> (accessed 02/08/2015).
12. European Cooperation in Science and Technology (E-COST) 2011. http://www.cost.eu/COST_Actions/bmbs/Actions/BM1101 (accessed 01/08/2015).