

The management of Parkinson's disease in the Middle East, North Africa and South Asia countries: the MDS task force for the Middle East survey

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1. Background

Middle East, North Africa and South Asia (MENASA) includes numerous developing countries with an estimated population of over 500 million. The prevalence of PD in the region is believed to be similar to the prevalence reported worldwide. The fields of PD and movement disorders are however underdeveloped and underserved in the region. The movement disorders society task force for the Middle East (MDS-Task Force for the Middle East) conducted a survey with an aim of characterizing the needs, the challenges and the limitations for providing care for people with Parkinson's disease in the region.

2. Survey Design, Administration, and Analysis

MDS-Task Force for the Middle East developed a survey for the specific purpose of this study. The survey was intended to elicit information about challenges and limitations in caring for individuals with PD in respondents' countries. Specifically, the survey consisted of 22 questions which focused on 1) the availability and affordability of medications and other therapies for PD in the surveyed countries, 2) availability of specialised centres and clinicians, and 3) opportunities for obtaining training and continuing education in the field of movement disorders (Table 1). Before its distribution, the survey was assessed for its face and content validity by task force members who were asked to comment on

whether questions 1) are easily understood, 2) are comprehensive, 3) match the aim of the project, 4) communicate clear and accurate content, and 5) contain any grammatical or spelling mistakes. Feedback was used to produce the final version of the survey.

The survey was distributed electronically via an online questionnaire, on September 9th 2016 to MDS members from the MENASA countries (Table 1 (n= 682)). Members were from Afghanistan, Bahrain, Iran, Iraq, India, Jordan, Kazakhstan, Kuwait, Lebanon, Pakistan, Palestine Territory, Saudi Arabia, UAE and Uzbekistan. All responses were anonymous. Three electronic reminders were sent to participants within 4 weeks of the initial deployment of the survey invitation. The survey was closed on September 30th 2016.

3. Survey Results

Fifty-three members from seven different countries responded to the survey (response rate 7.8%). All responders were physicians. Most respondents (76.7%) indicated that centres of excellence for PD do not exist in their countries nor do rehabilitation centres for PD (77.4% of respondents) (Table 2). Oral levodopa formulations, amantadine and donepezil were reported to be available and affordable in the vast majority of the countries (Table 3). Neurosurgical options or infusion therapies for treating advanced PD were lacking in most countries (90-94%). The scarce of the movement disorders' specialists, educational opportunities, research, as well as the high cost of treatment, the lack of general health infrastructure, resources and health insurance coverage were described as the main barriers to provide care for people with PD in the Middle East countries.

4. Conclusions

This is the first survey that sheds the light into the unmet needs in providing care for people with PD in the MENASA countries. The data suggests that there is a great need to increase the awareness of PD and provide educational opportunities within this field in the MENASA countries.

Table 1. Middle East, North Africa, and South Asia (MENASA) countries: demographics and PD epidemiology.

	Country population (in 2015; thousands) (1)	International Parkinson's Disease and Movement Disorders Society Membership, N (% of total members, 2017)	Number of MDS Task Force survey respondents N (%) (N=53)
Algeria	39 872	0.03	0
Egypt	93 778	0.84	0
Iran	81672	0.30	1
Iraq	36 116	0.13	2
Israel	8 065	0.39	0
Jordan	9 159	0.36	4
Kuwait	3 936	0.03	2
Lebanon	5 851	0.06	2
Libya	6 235	0	0
Morocco	34 803	0.19	0
Oman	4 200	0	0
Qatar	2 482	0	0
Saudi Arabia	31 557	0.21	6
State of Palestine	4 663	0.01	0
Sudan	38 648	0.03	0
Syrian Arab Republic	18 735	0	0
Tunisia	11 274	0.13	0
United Arab Emirates	9 154	0.12	3
Yemen	26 916	0	
Afghanistan	33 736	0.01	0
Bangladesh	161 201	0.67	4
Bhutan	787	0	
India	1 309 054	4.93	22
Maldives	418	0.01	0
Nepal	28 656	0.13	0
Pakistan	189 381	1.0	7
Sri Lanka	20 714	0.41	0

Table 2: Survey components and responses

Survey Question	Possible Responses	Frequency and percentages of responses n (%)
Do you have a regular Parkinson's disease /movement disorders clinic in your city?	No	23 (34.4)
	Yes	30 (56.6)
Do you experience problems with any irregular supply of medicines not being available?	No	11 (33.3)
	Yes	22 (66.7)
Is your country tied to only using medicines on the WHO Essential Medicines List?	No	21 (65.6)
	Yes	11 (34.3)
Are there big differences in relation to cost, accessibility and availability between urban and rural areas?	No	13 (39.4)
	Yes	20 (66.6)
Are there big differences in relation to cost, accessibility and availability between different regions of your country?	No	13 (39.4)
	Yes	20 (60.6)
Is there any kind of private or public health insurance available to cover the costs of treatment of PD?	No	14 (41.2)
	Yes	20 (58.2)
Do many people with PD in your country visit a traditional healer?	No	16 (50.0)
	Yes	16 (50.0)
Do you have access to either neurosurgical interventions or infusion therapies for advanced Parkinson's disease in your country?	No	14 (43.8)
	Yes	18 (56.3)
Which procedures are available (if any)?	Pallidotomy	1 (5.0)
	Thalamotomy	0 (0)
	Deep brain stimulation (DBS)	18 (90.0)
	Subcutaneous Continuous Apomorphine infusion	0 (0)
	Levodopa Carbidopa Intestinal Gel Duodenal Infusion	1 (5.0)
Do any "center of clinical excellence" for PD exist in your country?	No	23 (76.7)
	Yes	7 (22.6)
Do any "rehabilitation center" exist in your country focused on Parkinson's disease?	No	24 (77.4)
	Yes	6 (22.6)
Do you currently use any telemedicine technology to provide clinical care to your patients from remote and underserved areas?	No	30 (96.8)
	Yes	1 (3.2)
Have you attended an annual MDS International Congress?	No	15 (48.4)
	Yes	16 (51.6)
Have you attended other MDS funded training /courses?	No	21 (67.7)
	Yes	10 (32.3)
Is there any scientific meeting regularly conducted in your country and region focused on Parkinson's disease and Movement Disorders?	No	17 (54.8)
	Yes	14 (45.2)

Table 3: Availability and affordability of medications in respondents' countries (based on survey responses)

Drug class	Medication	Available		Affordable to general public	
		No n(%)	Yes n (%)	No n (%)	Yes n (%)
Dopamine agonists (DA) – Ergot derivative	Levodopa with aromatic L-amino acid decarboxylase inhibitors	No: 3 (8.6%)	Yes: 32 (91.4%)	No: 3 (8.6%)	Yes: 32 (91.4%)
	Bromocriptine	No: 4 (11.4%)	Yes: 31 (88.6%)	No: 9 (26.5%)	Yes: 25 (73.5%)
	Carbergoline	No: 13 (38.2%)	Yes: 21 (61.8%)	No: 20 (57.1%)	Yes: 15 (42.9%)
	Pergolide	No: 26 (74.3%)	Yes: 9 (25.7%)	No: 23 (85.2%)	Yes: 7 (14.8%)
DA – Non-ergot derivative	Ropinirole	No: 7 (20%)	Yes: 28 (80%)	No: 15 (42.9%)	Yes: 20 (57.1%)
	Pramipexole	No: 7 (20%)	Yes: 28 (80%)	No: 13 (37.1%)	Yes: 22 (62.9%)
	Rotigotine Transdermal Patch	No: 22 (72.4%)	Yes: 13 (27.6%)	No: 21 (72.4%)	Yes: 8 (27.6%)
Catecholamine-O-Methyltransferase inhibitors (COMT inhibitors)	Entacapone	No: 13 (37.1%)	Yes: 22 (62.9%)	No: 18 (51.4%)	Yes: 17 (48.6%)
	Tolcapone	No: 31 (91.2%)	Yes: 3 (11.1%)	No: 24 (88.9%)	Yes: 3 (11.1%)
	Opicapone	No: 28 (87.5%)	Yes: 4 (12.5%)	No: 23 (88.5%)	Yes: 3 (11.5%)
Monoamine oxidase inhibitors type B (MAOIBs)	Selegiline	No: 7 (20%)	Yes: 28 (80%)	No: 9 (25.7%)	Yes: 26 (74.3%)
	Rasagiline	No: 16 (45.7%)	Yes: 9 (54.3%)	No: 20 (58.8%)	Yes: 14 (41.2%)
Anticholinergic drugs	<i>Trihexyphenidyl</i>	No: 4 (11.4%)	Yes: 31 (88.6%)	No: 3 (8.8%)	Yes: 31 (91.2%)
NMDA-antagonists	Amantadine	No: 2 (5.7%)	Yes: 33 (94.3%)	No: 10 (29.4%)	Yes: 24 (70.6%)
	Safinamide	No: 29 (90.6%)	Yes: 3 (9.4%)	No: 19 (67.9%)	Yes: 9 (32.1%)
	Memantine	No: 4 (11.4%)	Yes: 31 (88.6%)	No: 9 (25.7%)	Yes: 26 (74.3%)
Atypical antipsychotic drugs	Quetiapine	No: 4 (11.4%)	Yes: 31 (88.6%)	No: 8 (22.9%)	Yes: 27 (77.1%)
	Clozapine	No: 8 (22.9%)	Yes: 27 (77.1%)	No: 9 (27.3%)	Yes: 24 (72.7%)
Cholinesterase inhibitors	Donepezil	No: 3 (8.6%)	Yes: 32 (91.4%)	No: 7 (20%)	Yes: 28 (80%)
	Rivastigmine	No: 7 (20%)	Yes: 28 (80%)	No: 11 (33.3%)	Yes: 22 (66.7%)

1. United Nations Population Division 2017 [cited 2018 March 22, 2018, 2018]. Total population (both sexes combined) by region, subregion and country, annually for 1950-2100. Available from: <https://esa.un.org/unpd/wpp/>.