

Prevalence and diagnostic challenge of dystonia in Thailand: A service-based study in a tertiary university referral centre

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A B S T R A C T

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Although the subspecialty of movement disorders was established in neurology more than 20 years ago, it is relatively new in Thailand, and while most physicians are generally aware of Parkinson's disease, they often are not familiar with dystonia. As one of the common movement disorders seen in general practice, a number of family and population studies have suggested that as many as two-thirds of patients with dystonia may be underdiagnosed and it is likely that misdiagnosis occurs frequently. Moreover, there is little information on the prevalence of dystonia in Thailand.

The purpose of this study was to determine the prevalence and clinical profile of dystonia among Thai patients who came from the southern part of Bangkok, which is in the catchment area of Chulalongkorn University Hospital. In addition, the diagnostic accuracy of dystonia among referred patients was assessed. The medical records of 207 patients were reviewed and it was determined that a large proportion of them (71.9%) had focal dystonia with cervical dystonia being the most common form. Primary dystonia (68.1%) accounted for the majority of the cases. The prevalence of all forms of dystonia, primary dystonia and focal dystonia was 19.9, 13.6 and 14.3 per 100 000 persons, respectively.

The diagnostic accuracy of dystonia among referred patients was 85.5%. The most common misdiagnosis was cervical spondylosis, followed by myofascial pain syndrome. Most patients had an average disease duration of 4 years before dystonia was finally diagnosed. Most patients with focal dystonia responded well to botulinum toxin therapy, with 13.3% suffering only mild transient adverse events. In spite of the limitations of this study, this data will initiate a process of increasing both patient and professional awareness of dystonia in Thailand.

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Dystonia refers to a syndrome of sustained muscle contractions, frequently causing twisting and repetitive movements, or abnormal postures [1]. The disorder is heterogeneous and can be classified according to the age at onset, body distribution and aetiology as well as genetic factors. The prevalence estimates for primary dystonia range from two to 50 cases per million for early-onset dystonia and from 30 to 7320 cases per million for late-onset dystonia [2]. A literature review on the epidemiology of dystonia revealed that the prevalence of primary dystonia varies widely across studies. However, most reported data are derived from Ashkenazi

Jews and Caucasian populations in Western countries with limited information on Oriental populations from China and Japan [3–7]. Furthermore, there have been only a few studies on the prevalence and clinical features of dystonia in Southeast Asia. A 9-year review study of dystonia from a movement disorders clinic in Singapore suggested that the majority of patients (73%) had primary dystonia with cervical dystonia being the most common (47%) followed by writer's cramp (32%) [8]. Another study of botulinum toxin type A (BoNT-A) treatment for patients with various movement disorders at a university hospital in Thailand revealed that out of 900 patients who received BoNT-A injections, after excluding hemifacial spasm from the cohort, occupational cramp (10.22%) represented the most common type of focal dystonia in the clinic, followed by blepharospasm, Meige's syndrome and spasmodic torticollis [9]. However, more accurate measures of prevalence of dystonia from methodologically more robust service-based studies estimate a prevalence

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of 111 per million for early-onset dystonia in Ashkenazi Jews from the New York area, 600 per million for late-onset dystonia in northern England and 3000 per million for late-onset dystonia in the Italian population over the age of 50 [2].

As noted above, dystonia is a syndrome and a clinical diagnosis is essentially based on a core feature of 'sustained muscle contractions, frequently causing twisting and repetitive movements, or abnormal postures' with associated slow tonic posturing with faster movements, sometimes resembling a tremor [10–12]. Despite these distinctive features, family and population studies indicate that as many as two-thirds of people with dystonia may be undiagnosed in a given area and misdiagnosis is still frequent, partly due to a wide-ranging spectrum of dystonia symptomatology and a lack of awareness of the disorder among physicians [6,13–18]. Mild forms of dystonia can be difficult to distinguish from non-dystonic disorders or subtle motor deficits. For example, mild forms of blepharospasm can be confused with increased blinking. The term 'pseudodystonia' is used to encompass disorders that can mimic torsion dystonia, but are not generally considered to be a true dystonia [1]. Nevertheless, dystonia syndromes are among the most commonly observed movement disorders in clinical practice [19].

Although the subspecialty of movement disorders has been established in neurology for more than 20 years, it is relatively new in Thailand and there are only a few clinics dedicated to movement disorders in the country. The Chulalongkorn Comprehensive Movement Disorders Center (CUMDS) was recently established by the Thai Red Cross Society as the main tertiary care centre in Thailand specialising in the treatment and study of Parkinson's disease (PD), dystonia and various other movement disorders. Currently, the Center is staffed with two full-time, board-certified neurologists with fellowship training in movement disorders, two clinical fellows, three clinical and research nurses and two support personnel. A multidisciplinary approach is taken in the care of patients with movement disorders and there is strong collaboration between the Center and Neurosurgery (which has an active deep brain stimulation program), Psychiatry, Rehabilitation and the hospital laboratories. A recently

published census statement documented the need for developing additional specialised tertiary care centres for movement disorders in Thailand [20].

This study was designed to evaluate the number, clinical profiles and prior diagnoses of patients with dystonia seen at outpatient clinics for movement disorders at Chulalongkorn University Hospital in Bangkok, Thailand, over a 5-year period.

1. Methods

1.1. Area of investigation

Patients participating in this study resided in the southern part of Bangkok (area 2) (Fig. 1). The area is determined by the Bangkok Metropolitan Administration as it is the catchment area of Chulalongkorn University Hospital. The population of the area was 1 039 595 on 1 December 2008 [21]. The area is divided into 11 districts of which Pathumwan is both the largest and the location of Chulalongkorn University Hospital. The CUMDS is affiliated to the Chulalongkorn University Hospital and the Thai Red Cross Society, and is the only tertiary care movement disorders referral centre in this area. Good communication networks have been developed by the Center with all the physicians, neurologists and psychiatrists in the area.

1.2. Patients

We identified all patients with dystonia seen from October 2005 to October 2010 at the movement disorders clinics of the CUMDS. A standard data collection form was used to document the frequency of different types of dystonia, demographic data (age and sex), patient characteristics (age at onset of dystonia, age at presentation and duration of illness before the final diagnosis of dystonia), prior diagnosis, disease characteristics (initial symptoms and their distribution), aetiologies, diagnostic evaluations and treatment regimens. Adverse events related to BoNT treatment were specifically recorded. A movement disorder specialist (RB) established the dystonia database and services as well as a botulinum toxin clinic at CUMDS in 2005.

Patients for the study were identified from this database and the medical records of these patients were reviewed to obtain demographic and clinical characteristics of each patient. Descriptive statistical analyses were performed where appropriate. Data were analysed using Statistical Package for the Social Sciences (SPSS) version 15.0 (Chicago, IL, USA). Continuous data are expressed as means (standard deviation, SD) and ranges. Comparisons of distributed continuous variables were performed using the Student's *t*-test. For categorical data, significance testing for differences between proportions was calculated using the χ^2 test. For calculations of prevalence, the denominator was the total population of area 2 of Bangkok, which is the catchment

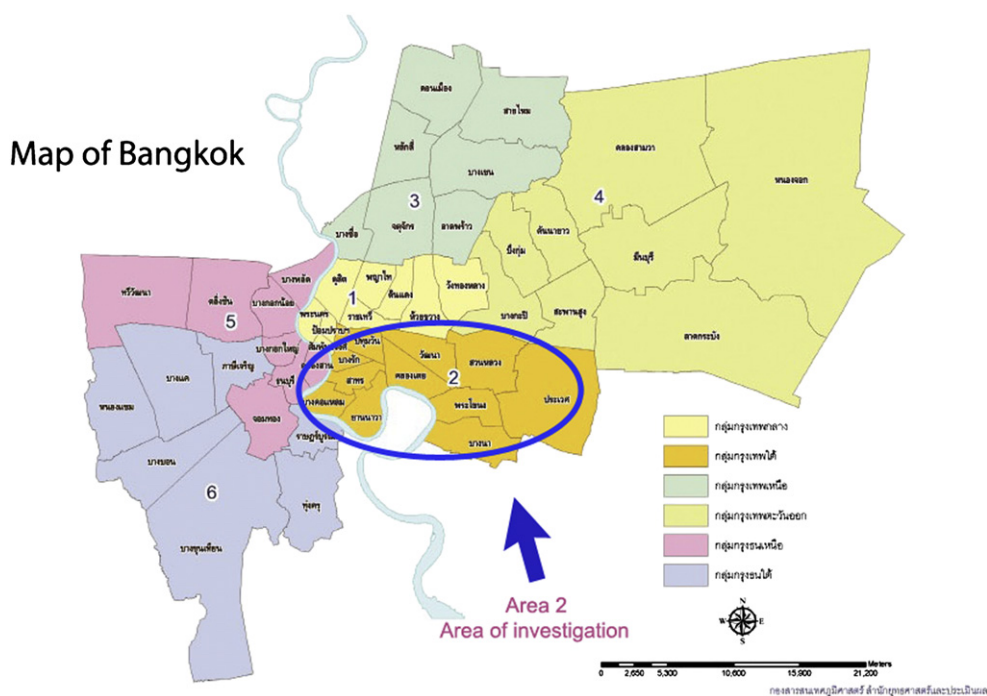


Fig. 1. Map of Bangkok: Different areas of Bangkok as determined by the Bangkok Metropolitan Administration. Area 2 (Southern part of Bangkok) is the catchment area of Chulalongkorn University Hospital.

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