

The Parkinson's Disease and Movement Disorders Program at King Fahad Medical City

Fadi Y. AlSwaiti

Department of Communication Sciences and Disorders, University of North Carolina at Greensboro
Greensboro, NC

Robert Mayo

Department of Communication Sciences and Disorders, University of North Carolina at Greensboro
Greensboro, NC

Jawad A. Bajwa

Parkinson's, Movement Disorders and Neurorestoration Program, National Neuroscience Institute, King Fahad Medical City
Riyadh, Saudi Arabia

Financial Disclosure: Fadi Y. AlSwaiti is a doctoral student in the Communication Sciences and Disorders Program at the University of North Carolina at Greensboro. Robert Mayo is a professor at the University of North Carolina at Greensboro. Jawad A. Bajwa has no financial interests related to the content of this article.

Nonfinancial Disclosure: Fadi Y. AlSwaiti and Robert Mayo have no nonfinancial interests related to the content of this article. Jawad A. Bajwa is program director for Parkinson's, Movement Disorders and Neurorestoration Program at King Fahad Medical City.

Abstract

This paper chronicles the initiation and development of the Parkinson's disease and movement disorders program under the umbrella of the National Neuroscience Institute at King Fahad Medical City in Saudi Arabia. It discusses the methodology and philosophy behind achieving optimal care based on available resources, cultural considerations, and evidence-based practices. Currently, the program is the first in the country to provide comprehensive medical and rehabilitative services for patients suffering from Parkinson's disease and other movement disorders, setting high standards and establishing foundations for research and regional awareness.

Parkinson's disease (PD) is a progressive neurodegenerative disorder with symptoms ranging from movement difficulties such as Bradykinesia, tremor, and rigidity, to dementia, autonomic dysfunction, depression, and visual hallucination. This array of signs and symptoms makes the disease one of the most taxing and challenging conditions for patients, their families, caregivers, and those who provide medical services. According to the Parkinson's Disease Foundation (2014), Parkinson's annually affects approximately 60,000 Americans and currently, one million Americans are living with PD. Epidemiologic studies across the globe reveal PD prevalence and incidence rates are inconsistent from continent to continent. For example prevalence rate estimates from eight European countries ranged from 65.6 per 100,000 to 12,500 per 100,000 and annual incidence rates ranged from 5 per 100,000 to 346 per 100,000 (Campenhausen et al., 2005). Prevalence rates in Asian countries are slightly lower compared to Western countries while incidence rates in this region of the world are difficult to obtain due to the limited number of studies performed (Muangaisan, Hori, & Brayne, 2009).

The economic burden of PD is by no means insubstantial. It is estimated that the annual combined cost of PD in the United States is \$25 billion. Due to the detrimental affects the disease reflects upon patients, it has gained universal momentum resulting in more research aimed at increasing our knowledge of the disease and improving the care provided for patients with PD to have better and more productive lives. Furthermore, more funding is now allocated for medical and rehabilitation facilities to manage the disease.

Arab countries (members of the Arab League) have a population of 315 million residing in a vast geographical area ranging from North Africa to Western Asia. Prevalence rates of PD in Arab nations have reported to be from 27 to 43 per 100,000, and the incidence rate is 4.5 per 100,000 (Benamer, Silva, Siddiqui, & Grosset, 2008). Yet, in depth research on neurodegenerative disorders and PD specifically is by no means plentiful in Arab countries, and the Kingdom of Saudi Arabia (KSA) is no exception. Little is known about the prevalence of the disease in KSA except what is noted in a published survey conducted in 1993 by a team of researchers examining the residents of an eastern province in the kingdom to determine the prevalence of several neurological diseases. The researchers generalized their findings to the whole population of KSA after examining 23,227 individuals from the Thugbah district of KSA. They found that 0.27% of the population suffered from PD (al Rajeh et al., 1993). Similar to findings reported in the United States, the healthcare burden of PD in KSA is significant (Seddeq et al., 2014).

Healthcare in the Kingdom of Saudi Arabia

The Kingdom of Saudi Arabia is an emerging entity in the medical arena as far as the Arab World and the Middle East is concerned. Based on the Saudi Central Department of Statistics and Information (2014), the \$25 billion budget of the Saudi Ministry of Health represents a significant increase in recent years and surpassed the growth of healthcare expenditure of all the countries in the region combined by spending \$23 billion on healthcare. According to the World Health Organization (2014), Saudi Arabia's spending on healthcare is only exceeded by Turkey (\$50 billion) and Iran (\$37 billion), two countries with three times the population size. The major cities of the kingdom have seen an increased number of medical projects serving a growing population. The country has come far from being a tribal and rural based nation, to a modern, metropolitan country with rapidly growing healthcare systems in major cities.

One of the major projects that changed the landscape of Riyadh, the capital of Saudi Arabia, was the development of the King Fahad Medical City (KFMC) established in 2004 at a cost of more than \$600 million. KFMC serves a city with a population of close to six million. KFMC is located at the heart of the capital and has a total capacity of 1,095 beds which will increase in coming years, providing free medical care for more than 50,000 inpatients and over 600,000 outpatients annually. All patients are served in four hospitals within the KFMC campus, (a) the main hospital (b) the women's specialized hospital (c) children's hospital, and (d) rehabilitation hospital (King Fahad Medical City, 2014).

Laying Down the Foundations for a Healthcare Program

At the inception of KFMC, the administration realized the importance of providing medical and rehabilitation care for PD patients. The country had only one hospital providing dedicated outpatient care for patients with PD and movement disorders with waiting times reaching 9 to 12 months. The latter situation represented the motivation for the National Neuroscience Institute (NNI) at KFMC to start planning on initiating specialized services within the facility and utilizing many resources within KFMC. The NNI took responsibility for laying the basic foundations of an initiative that would see the utilization and organization of vast resources under KFMC in order to provide a program for patients with PD and Movement Disorders (MD). The idea was that all medical, nursing, social, neuropsychological, psychiatric, surgical, and rehabilitative services would be provided within the KFMC campus.

Appreciating the fact that the most important resource any medical facility must invest in is human resources, the NNI recruited a specialized movement disorders neurologist to lead the efforts of establishing a PD and MD program. Dr. Jawad A. Bajwa, a neurologist from the Cleveland Clinic in Ohio, was motivated by the prospect of starting a specialized set of services in a place that was in grave need of it. The plan was laid out officially to KFMC's administration based on three goals: (a) create an interdisciplinary approach towards clinical care for PD and MD program patients; (b) provide training and educational resources for the local community and for the region; and (c) engage in focused research leading to a better development of diagnostic and management processes for PD and MD program patients in the country and the region while adding to the global fund of knowledge so as to provide evidence-based care, and conduct research to enhance evidence-based care.

Interdisciplinary Approach

The team was inspired by Dr. Bajwa's previous colleague and patient, Dr. Terrance D. Capistrant. Capistrant, a former neurologist and a patient with PD, realized how physical activity aided immensely to his process of treatment and he repeatedly mentioned how he did not feel like his PD medication helped him much without his daily two mile walk in the morning. Indeed, there is a philosophical divide within the medical community of Saudi Arabia regarding how a cohesive team approach can apply inside the clinic. There are those physicians who solely advocate a linear and focal approach in providing medical care for patients, and there is the group who advocate for a broader, more interactive and comprehensive approach that merges several specialized services towards the same quality of life-improving goals that other physicians are drawn to. The former approach is still the most influential and most dominant in the Middle East because many physicians are yet to fully understand and appreciate what other allied medical disciplines can offer. Yet, one of the benefits of starting a new program is making sure that a dichotomy of medical and other service, especially rehabilitation services will be implemented. Creating an interdisciplinary perspective at KFMC from day one set the way for a comprehensive healthcare plan that utilizes the resources of rehabilitation services and complements and reinforces the medical care a PD patient can receive.

Since establishing KFMC, the Rehabilitation Hospital was quickly recognized as one of the country's most advanced rehabilitation centers. It is internationally recognized and certified (receiving accreditation from the Commission on Accreditation of Rehabilitation Facilities in 2010). With an inpatient capacity of 140 beds, an opportunity was foreseen in providing comprehensive services that will offer a spectrum of rehabilitative services. These services were manifested in speech therapy, occupational therapy, and physical therapy. A series of meetings and brainstorming sessions were carried through with the Rehabilitation Hospital administration over the course of eight months, the main aim of which was to design a collaborative protocol to facilitate rehabilitative services specially focused on improving the quality of life of PD patients and to ease the burden of care for their caregivers.

Cultural Considerations in Establishing the Program

Working in one the most conservative societies in the Middle East is a challenge all by itself. Saudi Arabia is a Muslim society with deep tribal roots that cherishes tradition and vigorously maintains inherited religious and old social values. The cultural challenges vary in its affects, and in many cases, have a dichotomous blend of negative and positive influence. For example, the great respect and high regard for physicians is a very noticeable cultural belief especially within the senior population where medical professionals occupy a well-defined stature in society. A physician may find it beneficial to sense that unrelenting compliance to his/her instructions making the whole treatment process a bit easier to implement especially with patients who have leadership positions in their families, tribes, and/or rural communities. Yet, there is a hidden drawback to this type of thinking. In several cases, many patients used to shy away from

expressing their physical or emotional concerns and personal worries that surrounded their disabilities due to their deep belief that they are supposed to provide unrelenting cooperation without disturbing the physician's efforts and it sometimes takes the shape of unjustified intimidation based on the fact that they are meeting with a physician in a big city hospital. This is particularly true with patients who are referred from rural and tribal provinces where they rarely meet with a rehabilitation specialist, or specialized physicians and surgeons.

Team members discovered that providing more time to establish a rapport with the patients was the best way to overcome these unseen barriers between a patient and his/her physician or therapist. The long-term relationship that patients with MD have with their medical and rehabilitative service providers guaranteed that trust could be established in the long run, paving the way to a transparent reciprocation of information that can be maintained at all times.

Another cultural attribute to Middle Eastern societies in general and Saudi society in particular is the great level of respect and care senior populations are accorded within their families and within their communities. Indeed, the more years one has the greater the respect he or she garners from all members of the community, especially from direct family members. It is considered a grave dishonor for a family of sisters and brothers to send their father or mother to a nursing home; this is due to powerful religious commandments in a region where religion is the major source of influence when it comes to values and beliefs. This is evident by the lack of nursing homes for senior citizens in Saudi communities. Many families will prefer to provide nursing care to the older members of the family within the comfort of their homes. While this can prove to be a beneficial cultural trait, when it comes to facilitating medical and rehabilitative care, it does have its challenges. Many families will go further in providing care to the extent that it will affect the daily life independence that the rehabilitation team encourages patients with MD and especially PD to achieve. Many patient family meetings were called solely for that purpose, to urge family members to allow their older members to start taking care of themselves. Many families expressed that they did not see the goal of easing the burden of care upon them to be a valid one; they wanted to show gratitude and care to those who stood by them while they were young, not knowing that by doing so too much, they are actually doing the opposite of what they intend to do. The level of education that was required by all hospital staff to deal with this issue was great. Speech-language pathologists (SLPs), physical therapists (PT), occupational therapists (OT), the psychologist, the social worker, the health educator, and many other professionals made a coordinated effort to educate patients and their families about the importance of being independent in performing the activities of daily living as well as making an effort to maintain their ability to produce intelligible verbal communication. Each inpatient will have at least two family meetings with planned emphasis on the benefit of achieving independence, while outpatients and their families were provided with documented educational information emphasizing the role of the family to facilitate patient independence in performing regular tasks.

Another cultural challenge was the lack of awareness of the roles of rehabilitation professions. Professionals such as SLPs and OTs have only been recently integrated into the healthcare system and their undeniable contributions in the health sector in Saudi communities are yet to be understood. Annual activities to spread awareness of PD and other movement disorders were conducted with the participation of all rehabilitation staff to spread awareness of the vital roles of these professions and how they can help patients to live better personal and social lives. Media coverage of these public awareness-promoting activities have proved to be important to establish a level of ubiquity regarding these professions in the Saudi communities.

The program has come a long way since its first clinic, with the help of the capable and socially well-connected rehabilitation staff, many cultural challenges were managed by improving the level of awareness in the community and providing the educational resources necessary for patients and their families to utilize all the services they can receive from KFMC and translate it to a better way of living.

Providing Training and Educational Resources

A rehabilitation committee of three senior staff members (Mr. Hazem Qannam, OTR, Ms. Sana Madi, PT, and Mr. Fadi AlSwaiti, SLP) was briefly merged into the PD and MD team to insure the proper training of rehabilitation staff and provide a full spectrum of rehabilitative services. The need to train qualified staff was important. A budget was provided to train rehabilitation staff on the Lee Silverman Voice Therapy (LSVT) LOUD program for SLPs and LSVT BIG for physical and OTs. LSVT as a treatment protocol had proven its efficacy as evidence-based therapy for patients with PD. Five members of LSVT Global including the three founding members, Dr. Lorraine Ramig, Dr. David McFarland, and Dr. Cynthia Fox were contracted to train 65 clinicians on both LSVT LOUD and LSVT BIG at KFMC in December 2012. After ensuring that a certified, well-trained rehabilitation staff was ready to provide services for patients with PD, referral to rehabilitation hospital, and bed allocation was established.

One of the major challenges that emerged when planning for the delivery of services was that ambulatory services were not well established in Saudi Arabia. This required an emphasis on providing a more focused and diverse inpatient rehabilitative care, which was crucial considering the lack of hospitals providing tertiary care in the country resulting in a vast geographical reach KFMC has in a country that is one-third the size of Europe. Building the PD and MD program around outpatient care was not considered practical at the moment and would lead to long waiting lists. Eventually, two beds were allocated in the neuroscience ward as well as three beds in the Rehabilitation hospital. This also required extensive coordination to reduce time from referral to service provision and more team assignments.

Prior to the establishment of the PD and MD program, no specialized services were provided for patients with PD in KFMC, no specialized movement disorders neurologists (MDN) were recruited, no specified tests were conducted, no specialized imaging was performed, not many available prescriptions, and the administrative infrastructure was nonexistent. The team commenced their initial work by designing clinical pathways, and engaged in multi- and interdisciplinary team meetings to coordinate medical, surgical, nursing, social, neuropsychological, psychiatric, specialized equipment, pharmaceutical, and logistic sourcing. In April 2, 2012, the Movement Disorder Program(s) (MDP's) outpatient clinic saw its first patient. The team since then managed to establish a database of patients requiring services, and provided administrative guidelines and fund allocation requests.

A second MDN has joined the program and a clinical coordinator has been assigned to meet growing needs of the PD and MDP program. One MD clinic is open while a second clinic is soon to be open for patients each week. Two beds are allocated in the neuroscience ward at the main hospital and three beds for patients with PD and MD in rehabilitation hospital. Two Botulinum injection clinics are offering their services for patients with MD. Most needed and up-to-date medications are now available in KFMC's central pharmacy. Carbidopa-Levodopa Intestinal Gel Pump therapy along with Apomorphine Pump therapy is now available for advanced PD. DaTscan, a special type of dopamine transporter imaging single-photon emission computerized tomography (SPECT) scan, is now available for diagnostic testing and more than 20 patients with PD and MD were scheduled for deep brain stimulation surgery in 2015. Patient and family support groups are conducted on a quarterly basis, and plans for advocating for PD patients and increasing the local community's awareness towards the disease were implemented by celebrating "Parkinson's Disease Day" in the shape of an awareness day that saw representatives from all departments within KFMC participating in the event.

One major milestone was organization of the First Middle East Camp for Parkinson's, Movement Disorders and Neuromodulation through International Parkinson's and Movement Disorders Society on April 12-13, 2014 which was a tremendous success with over 150 medical providers in attendance from the region yielding way to the 2nd Middle East camp scheduled for

November 19-21, 2015 in Dubai, United Arab Emirates. The success of this major regional education activity clearly indicates the significant unmet need in the field of PD and MDs.

Research and Future Plans

Since April 2, 2012 till the time of writing this paper, 253 patients were provided with services through the PD and MD program and 87 of them were seen for inpatient and outpatient rehabilitative services. As seen in Figure 1, PD comprises more than 50% of the numbers of movement disorders served by the PD and MD programs, while Figures 2 and 3 depict age groups of program patients and gender distribution, respectively. Eight seven PD patients were referred for LSVT LOUD and LSVT BIG therapy protocols (Figure 4), and under the partial supervision of the paper's first author, 11 of 31 referred patients have successfully concluded LSVT LOUD therapy.

Figure 1. Types and Numbers of Movement Disorders Served by the PD MD Program.

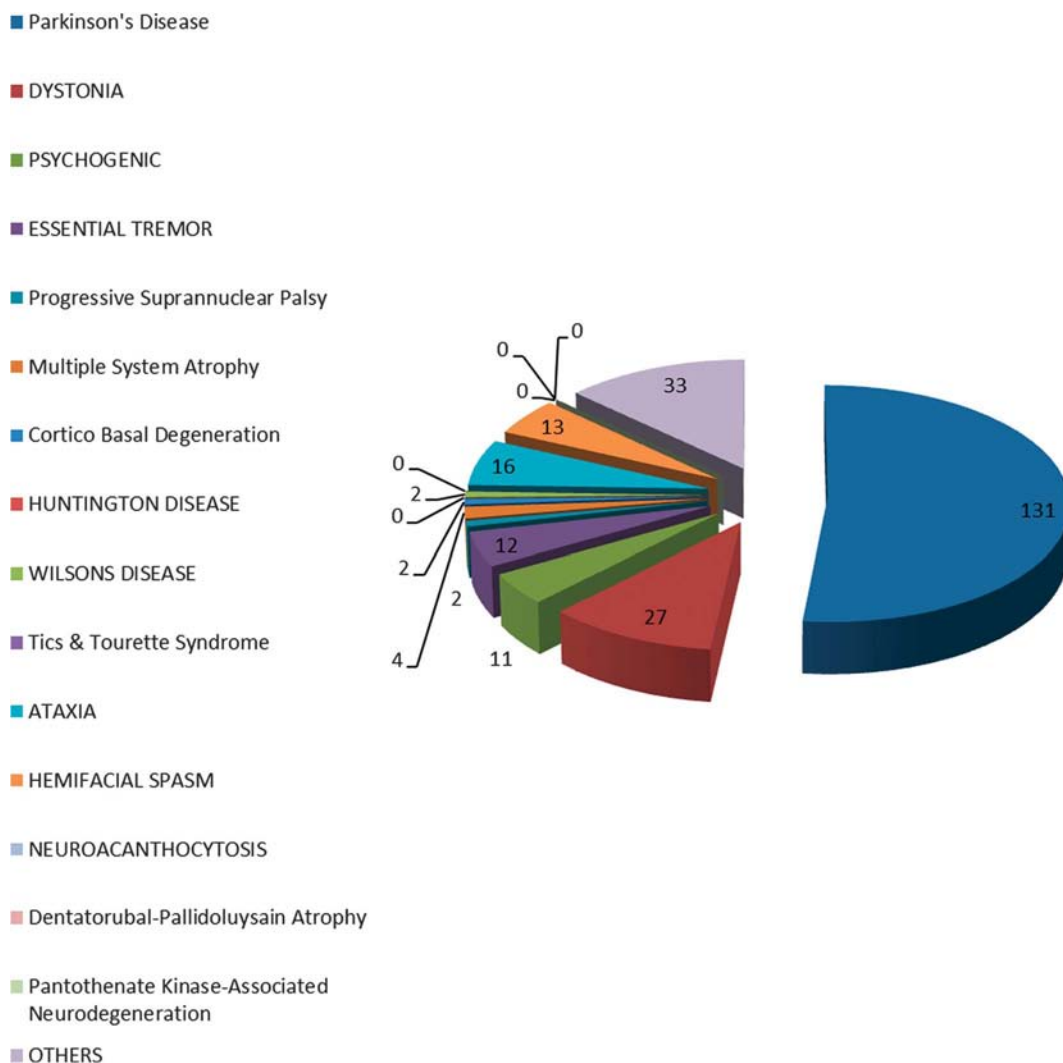


Figure 2. PD Patients Age Groups and Numbers Served by the MDP.

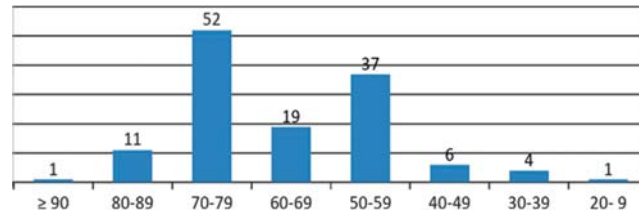


Figure 3. Gender Distribution of Patients Served by the MDP (1 - Male, 2 - Female).

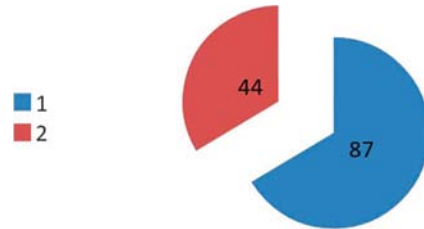
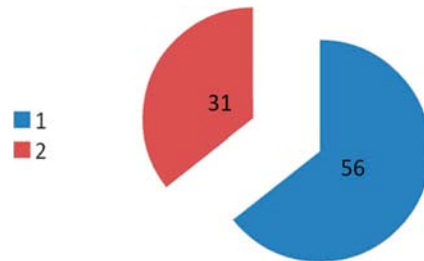


Figure 4. LSVT Referrals by the MDP (1 - LSVT LOUD, 2 - LSVT BIG).



This clinical effort was followed by an emerging emphasis to conduct translational and clinical research as there is very little known about PD and MDs in persons of Arab ancestry. More recently, eight abstract papers were presented in the annual International Parkinson's and Movement Disorders Society congress held in Stockholm, Sweden from June 8-12, 2014, as well as plans to publish over 20 research abstracts and over 10 papers in the year 2015. In addition to several institutional review board approved research projects, two major grants are being planned for 2015 based on preliminary data collected from the initial research work. There is already an existing grant funded in the inaugural year of the program. In little over two years' time, major features were achieved and major obstacles were overcome to provide all the services required by the PD and MD population without the need to seek additional services beyond KFMC.

Conclusion

As the need for geriatric care increases in KSA and in the Middle Eastern region as a whole, more work is needed to insure proper services are provided for Movement Disorders patients in general and Parkinson's disease patients in particular. The best approach is to start actively with the best service provision trends and invest in human and community resources to promote competency and awareness. This is the ideal time to adopt and establish a well-organized information system and database for a better understanding of the needs of targeted population. Sometimes starting from almost nothing has its merits, as these merits can be realized by making sure well

devised tertiary services protocols be planned and implemented while setting an eye towards future advocacy and research.

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History:

Received April 28, 2015

Revised June 03, 2015

Accepted June 06, 2015

doi:10.1044/gics5.1.33