See discussions, stats, and author profiles for this publication at: https://www.researchgate.net/publication/282497827

Barriers and Facilitators in Physical Rehabilitation for Parkinson's Disease in the Arabian World

Article · June 2015

DOI: 10.1002/mdc3.12200

CITATIONS
READS

0
22

2 authors, including:

2 authors, including:

Hanan Khalil

Jordan University of Science and Technology

15 PUBLICATIONS

SEE PROFILE

All content following this page was uploaded by Hanan Khalil on 08 November 2016.

The user has requested enhancement of the downloaded file. All in-text references <u>underlined in blue</u> are added to the original document and are linked to publications on ResearchGate, letting you access and read them immediately.

CLINICAL PRACTICE

Movement Disorder

Barriers and Facilitators in Physical Rehabilitation for Parkinson's Disease in the Arabian World

Hanan Khalil, PhD,¹ Jawad A. Bajwa, MD^{2,3,*}

Parkinson's disease (PD) is a neurodegenerative disorder that, over time, leads to increased difficulties in various aspects of daily living and mobility, including walking, transfer, and balance.¹ The main form of treatment for PD is pharmacological (mainly dopamine replacement medications) and surgical; however, it should be noted that a number of problems have been identified with these forms of treatment. For example, phramacological treatment is often insufficient to improve nondopaminergic symptoms, such as lack of balance control, resulting falls, and freezing of gait, which all have become increasingly recognized as prevalent and as contributing factors to morbidity in the PD population.^{1,2} As a result, physical rehabilitation therapies have been introduced as an adjunct to medication use so as to enable patients with PD to maintain their maximum level of independence.³

The benefits of physical rehabilitation in PD is well documented.^{3–6} In a recent systematic review, brief exposure to various forms of physical rehabilitation in patients with PD produced significant positive effects on motor symptoms, including walking speed, balance, and freezing of gait.⁶ In addition, preclinical evidence in PD animal models have demononstrated that physical training may alter the course of the disease and directly alter the neurodegenerative process.⁷

In spite of the growing recognition that physical rehabilitation may provide health benefit for people with PD, it is being recognized that there are barriers to participation.^{8–10} The available evidence, however, is largely based on information obtained from the developed countries, where cultural, economic, and health care structure differs in significant ways from those in the developing countries. There is very limited reported literature from the developing world about life experiences, challenges, and the provision of rehabilitation services for patients with PD, especially from the Arabian world. Therefore, consensus views of specialists working routinely with PD in Arab countries are being reported here in an attempt to categorize the barriers to physical rehabilitation in patients with PD from the Arabian world.

The Arabian world consists of 22 countries, including Egypt, Algeria, Tunisia, Morocco, Libya, Somalia, Mauritania,

Djibouti, Sudan, Yemen, Oman, Qatar, Bahrain, Kuwait, Saudi Arabia, and United Arab Emirates, as well as Iraq, Syria, Lebanon, and Jordan, which share a lot of similarities in cultural and social aspects. All of these countries are developing countries in which this article is discussing the possible barriers for people with PD to get engaged in physical rehabilitation programs.

General Shared Barriers Among Developing Countries

As per other developing countries, people with PD in Arab countries may have limited access to resources. In the vast majority of Arab countries, rehabilitation centers for adults with disability are very few and extremely underdeveloped.¹¹ In particular, multiprofessional rehabilitation centers with specialized trained therapists for people with PD is almost lacking. Generally, rehabilitation centers in the vast majority of the developing countries are located in the main urban areas; this means that the rural population has to travel across distances for access to the available services. The lack of an appropriate public transport system adds to the complexity of the situation. Additionally, the financial burden of obtaining a rehabilitation treatment is a concern for those who are not under the government sector given that, usually, there is a lack of alternative payment coverage. Besides all of these general limitations, there are other barriers to participation in physical rehabilitation in PD that are specific to Arabian countries. Here, we categorize these barriers into cultural- and personal-related factors.

Barriers in the Arabian World to Physical Rehabilitation in PD

Cultural

At the cultural level, conservative social norms may negatively influence the provision of rehabilitation services provided for women with PD. Traditionally, women in some Arabic

¹Department of Rehabilitations Sciences, Faculty of Applied Medical Sciences, Jordan University of Science and Technology, Irbid, Jordan; ²King Saud Bin AbdulAziz University for Health Sciences, Riyadh, Saudi Arabia; ³Parkinson's, Movement Disorders and Neurorestoration, Department of Neurology, National Neuroscience Institute, King Fahad Medical City, Riyadh, Saudi Arabia

*Correspondence to: Dr. Jawad A. Bajwa, Parkinson's, Movement Disorders and Neurorestoration program, Department of Neurology, National Neuroscience Institute, King Fahad Medical City, Riyadh, Saudi Arabia; E-mail: drbajwa@gmail.com

Keywords: Parkinson's disease, physical rehabilitation, Arabian World.

Relevant disclosures and conflicts of interest are listed at the end of this article.

Published online xx Xxxxx 2015 in Wiley InterScience (www.interscience.wiley.com). DOI:10.1002/mdc3.12200

© 2015 International Parkinson and Movement Disorder Society

Received 6 January 2015; revised 25 April 2015; accepted 27 April 2015.

countries are usually accompanied by a male family member (e.g., husband or father) when going outdoors. This, in turn, may reduce opportunities for participation in a rehabilitation program that requires frequent trips to a clinical facility. As yet, the custom around the physical contact between men and women in Arabic Islamic countries has its consideration in terms of the access that these women can get out of community rehabilitation services. Community work in Arab countries is restricted to male therapists¹¹; this limits therapy for women if available to their homes.

An additional concern that would act as a barrier for people with PD from being engaged in rehabilitation is the large extended family structure that exists in most Arabian countries; therefore, older individuals in general are usually dependent on their family members for making decisions and obtaining services.

Personal

A number of personal factors need to be considered. For example, lack of education, which is resembled by the high literacy rate, particularly among older people who are at risk for PD in Arabian countries, is a concern.¹² The literature suggests that there is a strong relationship between level of education, understanding the relevance of treatment, and, consequently, the adherence rate to medication and therapies.¹³ In Arabian countries, lack of education in this cohort may be even more complicated by unavailability of any informational resources, such as a website, society, or a support group in Arabic language. The limited information regarding the potential benefits of physical rehabilitation in managing PD was perceived as a main barrier for not seeking physical rehabilitation therapies by PD patients in Jordan.¹⁴

Other potential personal barriers may include lack of interest in exercise and lack of motivation. Lack of motivation is a common perceived barrier for engagement in a rehabilitation therapy or an exercise program in older adults as well as in people with PD.¹⁰ This may be a particular concern for people with PD in Arabic countries, partly owing to the gap in knowledge about the potential role of physical rehabilitation therapies in managing PD symptoms and, additionally, owing to lack of past "habit" of exercise and being active. In Arabic countries, several barriers can affect the general population as a whole to stay active¹⁵; these barriers may even affect people with PD at a larger scale. The sedentary lifestyle in some Arabic countries is largely culturally rooted; the evolution of wealth in the last century in these countries had a dramatic effect on traditional lifestyle, including eating habits, sleep structure, and, consequently, physical activity. The lack of role models in peers, family, or society would act as a main factor for the lack of interest in being physically active.

Recommendations

At all levels, various interventions can be linked to barriers to promote participation in physical rehabilitation in the region. As for cultural reasons, women with PD may be less favorable than men in getting access to community-based rehabilitation opportunities; hence, there is an urgent need to change cultural attitudes. One possible solution is to increase the number of female therapists who work with PD and make it possible for them to work in the community. Annotative approaches need also to be considered. In particular, the use of technology to support people with PD to engage in unsupervised rehabilitation programs at home merits serious considerations. For example, the idea of using an exercise DVD as well as telemedicine approach, which has been previously used successfully in other neurological diseases,^{16–18} could also be beneficial to support people with PD to engage in a rehabilitation therapy at their homes.

Generally, for cultural and Islamic aspects, family plays an important role in people's life in Arabic countries. A caregiver will usually be a family member; this has to be taken into account in designing a rehabilitation program. The concept of a family-caregiver–supervised program, which has been previously shown to be safe and effective in people with dementia,¹⁹ could also be used in the PD population. Using this approach, a family member will be taught strategies to identify and provide activities that are appropriate for the individual's current level of functioning and implement environmental modifications that support activities of daily living (ADL) function.

Personal

At the individual level, knowledgeable support seems to be an unmet need. The value of the patient's knowledge of managing their condition is evident in the literature.²⁰ Because there is a paucity of readable information in the Arabic language for people with PD, advice and education provided by the patient's physician and other health care professionals who are responsible about PD patients' routine care is essential. This is an important aspect considering that, in Arabic countries, the physician's recommendations are usually valuable and trusted. At National Neuroscience Institute (King Fahad Medical City, Riyadh, Saudi Arabia), various patient-related educational materials have been written and translated into Arabic to meet this significant need.

Overall, we should be realistic about what education could achieve considering the number and the levels of barriers identified here. Indeed, it is important that the patient's education is situated within the broader social, cultural, and environmental context of the patient's lives. Within this realm, counseling or other approaches, such as motivational interviewing,²¹ in which barriers at an individual level are identified and addressed, is warranted.

To address the motivational aspects, a client-centered approach is recommended in which a rehabilitation therapy program has to be tailor made in order to be successful.²⁰ This requires a continuous feedback loop, identifying obstacles and adjusting the program accordingly. An important element of this approach is that the training is directed toward the patient's goals. Within this context, culturally important dependent

ADLs, such as eating using hands, prayers, sitting on floor, wearing a scarf for women, and others, are all important to be screened and targeted within the rehabilitation program.

Conclusion

In conclusion, barriers for participation in physical rehabilitation in Arab countries may be different from those reported in other countries. Thus, culturally sensitive, suitable rehabilitation programs in which barriers are identified and addressed could be feasible and beneficial for overall quality of life in patients with PD. Given that this is an area that almost lacks research in the region, cohort studies are encouraged to be undertaken to expand our understanding regarding barriers for participation in physical rehabilitation from patients' perspectives. Universities and rehabilitation centers in the region are encouraged to take active role in establishing research tracks in PD. International cooperation in sharing models of good practice, education, and research initiative²² as yet considering the cultural and environmental specifications of the region is highly recommended. Achieving this will not only be reflected on a better quality of care provided for people with PD in the region, but also potentially on reducing the economical burden on the health care system in these countries.

Author Roles

(1) Research Project: A. Conception, B. Organization, C. Execution; (2) Statistical Analysis: A. Design, B. Execution, C. Review and Critique; (3) Manuscript Preparation: A. Writing of the First Draft, B. Review and Critique.

H.K.: 1A, 3A, 3B J.A.B.: 1A, 3B

Disclosures

Funding Sources and Conflicts of Interest: The authors report no sources of funding and no conflicts of interest.

Financial Disclosures for previous 12 months: Dr. Khalil received research support from Jordan University of Science and Technology as well as from the Support to Research Technological Development and Innovation in Jordan (SRTD-II) funding scheme. Dr. Bajwa received research support from King Fahad Medical City.

References

1. Sethi KD. Clinical aspects of Parkinson disease. Curr Opin Neurol 2002;15:457-460.

- Strecker K, Schwarz J. Parkinson's disease: emerging pharmacotherapy. <u>Expert Opin Emerg Drugs</u> 2008;13:573–591.
- Kwakkel G, De Goede CJT, Van Wegen EEH. Impact of physical therapy for Parkinson's disease: a critical review of the literature. *Parkinsonism Relat Disord* 2007;13:S478–S487.
- Fox C, Ebersbach G, Ramig L, Sapir S. LSVT LOUD and LSVT BIG: behavioral treatment programs for speech and body movement in Parkinson disease. *Parkinsons Dis* 2012;2012:391946.
- 5. Tomlinson CL, Patel S, Meek C, et al. Physiotherapy versus placebo or no intervention in Parkinson's disease. *Cochrane Database Syst Rev* 2012;8:CD002817.
- Tomlinson CL, Patel S, Meek C, et al. Physiotherapy intervention in Parkinson's disease: systematic review and meta-analysis. *BMJ* 2012;345: e5004.
- Tillerson J, Caudle W, Reveron M, Miller G. Exercise induces behavioral recovery and attenuates neurochemical deficits in rodent models of Parkinson's disease. *Neuroscience* 2003;119:899–911.
- Ellis T, Boudreau JK, DeAngelis TR, et al. Barriers to exercise in people with Parkinson disease. *Phys Ther* 2013;93:628–636.
- Ellis T, Cavanaugh JT, Earhart GM, et al. Factors associated with exercise behavior in people with Parkinson disease. *Phys Ther* 2011;91: 1838–1848.
- 10. Quinn L, Busse M, Khalil H, Richardson S, Rosser A, Morris H. Client and therapist views on exercise programmes for early-mid stage Parkinson's disease and Huntington's disease. *Disabil Rehabil* 2010;32:917–928.
- 11. Oraibi S, Dawson V, Balloch S, Moore A. Rehabilitation services for persons affected by stroke in Jordan. *Disabil CBR Incl Dev* 2011;22:73-84.
- 12. Hammoud HR. Illiteracy in the Arab world. Adult Educ Dev 2006; 66:83.
- 13. Kickbusch IS. Health literacy: addressing the health and education divide. *Health Promot Int* 2001;16:289–297.
- Khalil H, Nazzal M, Al-Sheyab N. Exploring practices and perceptions toward exercise among PD patients in Jordan. *Mov Disord* 2014;29 S1:426.
- 15. Benjamin K, Donnelly TT. Barriers and facilitators influencing the physical activity of Arabic adults: a literature review. Avicenna 2013;8:10.5339.
- Khalil H, Quinn L, van Deursen R, et al. What effect does a structured home-based exercise programme have on people with Huntington's disease? A randomized, controlled pilot study. *Clin Rehabil* 2013;27:646– 658. DOI: 10.1177/0269215512473762.
- Ionita C, Sharma J, Janicke D, et al. Acute ischemic stroke and thrombolysis location: comparing telemedicine and stroke center treatment outcomes. *Hosp Pract* 1995;2009:33–39.
- Golomb MR, McDonald BC, Warden SJ, et al. In-home virtual reality videogame telerehabilitation in adolescents with hemiplegic cerebral palsy. *Arch Phys Med Rehabil* 2010;91:1–8.e1.
- Steinberg M, Leoutsakos JMS, Podewils LJ, Lyketsos C. Evaluation of a home-based exercise program in the treatment of Alzheimer's disease: the maximizing independence in dementia (MIND) study. Int J Geriatr Psychiatry 2009;24:680–685.
- 20. Elsworth C, Dawes H, Sackley C, et al. A study of perceived facilitators to physical activity in neurological conditions. *Int J Ther Rehabil* 2009;16:17.
- 21. Ang DC, Kaleth AS, Bigatti S, et al. Research to encourage exercise for fibromyalgia (REEF): use of motivational interviewing, outcomes from a randomized controlled trial. *Clin J Pain* 2013;29:296.
- 22. Barnes MP. Standards in neurological rehabilitation, June 1997. Eur J Neurol 1997;4:325–331.