

A Self Therapy Manual in English for Speech and Swallowing Difficulties in Persons with Parkinson's Diseases (PsWPD)

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Abstract

The advancements in the field of medical tourism in India have not yet found its roots in the remote society of the country. The motoric, cognitive, psychological, social and financial limitations of Persons with Parkinson's disease (PsWPD) and the requirement on the part of the family members to attend to regular long term management has given rise to the need for a self therapy manual for speech and swallowing difficulties of PsWPD. This self therapy manual is offered as a practical guide that includes general information about Parkinson's disease, answers to the most frequently asked questions by the PsWPD and their family members and also includes sections of most useful, practical, effective and easy to do muscle training exercises to improve the speech and swallowing problems in this population of clients. Also, information on augmentative and alternative communication methods and compensatory swallowing maneuvers are provided. The final section of this manual consists of a list of hospitals and specialized centers for medical and non medical management of Parkinson's disease and the contact numbers of these centers.

Key words: self therapy, manual, Parkinson's disease, speech and swallowing difficulties

Diagnosis of the progressive neurological condition of Parkinson's disease (PD) is always difficult for the client and the family to accept. After a phase of initial denial, when the client and family members ultimately come to terms with the diagnosis of the condition, there arise a number of questions, doubts, and worries in the members of the family and the Person with Parkinson disease (PWPd). The anxiousness to know what is the first best step to get rid of or cope with this disease is always on top of their thoughts.

Lack of awareness among the general public creates situations of social ridicule, non acceptance and many other factors which in turn subjects the PWPd as well as his/her family members to undue stress. Lack of a number of super specialty treatment centers specifically for the PsWPD in all cities of India is another big challenge, so much so that in rural areas, PD might get passed off as any other aging problem. Even for the PWPd whose diagnosis is made in multispecialty hospitals, the guidance received from medical professional stops at the level of rehabilitative measures in the first tier of the disease, which is about medical line of treatment. Not much is focused on rehabilitative services offered by Speech-Language Pathologist for swallowing and speech disorders, Physiotherapist and Occupational therapists for the physical issues, Dietician for management of the diet and other team members involved in the management of Persons with Parkinson's disease (PsWPD).

Sometimes, the medical professional themselves in many of the hospitals are not aware of the type of help a non medical professional such as speech-language pathologists, physiotherapists and dieticians can offer to PsWPD. Hence the PsWPD are in a blind spot and they do not seek management services from such professionals which in turn will have a bearing on the lifestyle and coping behaviors of the PWPd.

Compared to the western countries where many clinical facilities are available in almost all major hospitals for movement disorders such as PD, there are only a few centers offering specific treatments to PsWPD in India. These few clinics or hospitals are spread out in different states of the country and may not be accessible to all PsWPD and this means that the PWPd may not receive holistic management package to overcome his/her problems.

The medical treatment is the first step any family would take up for treatment of the PWPd. The doctor dealing with the client prescribes the needed dosage of medicines. Speech and swallowing difficulties may arise and become pronounced towards the middle and later stages of the disease. Most of the clients with PD do not get referred to speech-language pathologists due to lack of awareness on the part of the clients, their caregivers as well as medical professionals. A speech-language pathologist often deals with a PWPd when the disease has progressed and has significantly started affecting the speech and swallowing functions. At this stage of disease, the intervention strategies may not yield maximum benefits. A small percentage of them may be referred in the initial stages but the often discontinue the long term treatment due to the physical disabilities due to

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PD as well as its medications. Thus, PsWPD who receive long term treatments for speech, communication and swallowing functions under the direct supervision of a speech-language pathologist are very few. In order to counter these limitations a self therapy manual for PsWPD and their caregivers is proposed to help and guide them with respect to speech and swallowing functions that appear in the course of the disease.

The resources for treatment of PD clients are often available in the form of text books for clinicians. A practical guide or manual for this purpose has never been attempted by speech-language pathologists in India. While textbooks about Parkinson's disease, its assessment, diagnosis and management (Biziere & Kurth, 1997; Duvoisin & Sage, 2001; Christensen, 2005; Tuite & Fernandez, 2009) reaches many clinicians very few reaches the client and family of PsWPD (Weiner & Schullman, 2001; Foltynie, Lewis & Barker, 2003; Schwarz, 2006). A self help guide for patients with PD was developed by Jahanshahi and Marsden in 2000 to bridge the gap between patient-professional communications. But the information provided in this self help guide is now outdated as the science has improved over the decade. There is none that is adapted to the Indian scenario and none focusing on speech and swallowing functions in PsWPD. Hence this self therapy manual is written for the benefit of clients with PD in India.

The aim was to prepare a self therapy manual in English that specifically deals with the behavioral management of speech and swallowing difficulties in PsWPD and the family members along with a section of Frequently Asked Questions (FAQs) about the disease and treatment. This manual consists of three parts:

Part I includes section on FAQs for PWPd and their family members.

Part II includes material for therapeutic management of speech and swallowing problems in PsWPD. In this section, exercises and strategies are suggested to cope and improve speech, communication and swallowing abilities in a PWPd.

Part III includes a list of centers and professionals who deal specifically with the management of Parkinson's disease in India.

Method

A self therapy manual in English was prepared for persons with PD in India, which can easily be comprehended and used to improve their speech,

communication and swallowing functions at all stages of the disease. The manuscript of this manual was prepared and verified for its sensitivity in six stages.

Stage 1: Preparation for the manual: Information from the literature on different aspects of Parkinson's disease (PD) was collected and compiled. Taking this as the baseline, the contents of the manual was written, instructions and supportive material such as photographs, list to resources etc. was collated to develop the manual in English.

Stage 2: Development of the structure of the manual: The manual mainly consists of three parts.

Part I: Frequently asked questions: This part consists of three sections.

Section 1: Frequently asked questions about PD: This section consists of a set of frequently asked questions about the Parkinson's disease. It provides information on Parkinson's disease, especially speech and swallowing difficulties, the factors that affect these, the changes that might be expected with the progression of disease, the treatment options available to PsWPD in a very simple and easy to understand language.

Section 2: Frequently asked questions by PsWPD: This section consists of "frequently asked questions" by the PsWPD.

Section 3: Frequently asked questions by the family members or caregivers of PsWPD: This section was developed by keeping in mind, the family of a PWPd. The questions that may arise in the minds of every family member of a PWPd, their concerns was compiled and answers were provided.

Part II: Management of speech and swallowing disorders in PsWPD: This section was developed by collecting the best information on the speech and swallowing treatment options for PsWPD. It further consists of two sections.

Section A: Management of speech and communication problems in PsWPD: An introduction to normal aspects of speech and swallowing functions was included as the first section, in order to help a PWPd to understand the rationale behind every exercise that is recommended for improving speech and swallowing systems. This section is further subdivided into 5 subsections.

Section A.1: Questionnaire for speech and communication difficulties in PsWPD: This section consists of a questionnaire on speech production mechanism and communication systems. This questionnaire was developed by including the most common problems a PWPd encounters in his/her activities of daily living. The questionnaire included bipolar questions (Yes or No questions). The PWPd can read and answer the questions by himself/herself and

also consult family members to answer the questions. From the answers to the questionnaire a three point rating scale of severity was developed with equal intervals, on which a PWP can rate his/her difficulties in different speech production systems as mild, moderate or severe.

Section A.2: Management of speech and communication difficulties in PsWPD: This section includes exercises suggested for strengthening the four speech subsystems that are eventually affected in PsWPD: Respiration, Phonation, Articulation and Prosody. Exercises for each of these subsystems were given as separate subsections under the headings:

- A.2.1. Exercises to improve breathing abilities in PsWPD.
- A.2.2. Exercises to improve quality of voice in PsWPD.
- A.2.3. Exercises to improve production of speech sound in PsWPD.
- A.2.4. Exercises to improve prosody/ tune of speech in PsWPD.

Exercises for improving resonatory system were not included in the manual because the literature on hypokinetic dysarthria reported that difficulties with this system are not common in PD. The suggested sequence in which these exercises need to be practiced is based on the recommendation by Dworkin (1991). The exercises recommended for improving functions of these speech subsystems are those recommended in literature and the most effective exercises are adapted to the Indian home scenario. Care was taken to recommend the use of common materials that are found in every home in India for these exercises.

The last subsection of section A.2 (section A.2.5.) consists of information about Augmentative and Alternative forms of Communication (AAC) to improve communication in PsWPD.

Section B: Management of swallowing difficulties in PsWPD: This section consists of two major sections.

Section B.1. Questionnaire on swallowing difficulties in PsWPD: This section included a questionnaire that facilitates rating of the swallowing difficulties of PsWPD in different phases of swallowing. Each phase of swallowing is addressed separately. The questions include bipolar questions (Yes or No questions), in a simple language so that it could be well understood and easily answered by the PWP him/her self and if needed with the help of the family members or care givers. At the end of each section of the questionnaire, a three point rating scale of equal interval is provided to rate the severity of difficulty the PWP faces in that particular phase of swallowing. Based on this, the exercises were recommended in the further sections.

Section B.2. Management of swallowing difficulties in PsWPD: This section consists of the basic exercises to improve swallowing. This section is further subdivided into the following subsections.

- B.2.1. Exercises to improve the strength of muscles of mouth (Oral preparatory and Oral phase of swallow).
- B.2.2. Exercises to improve the movement of food from pharynx to food pipe (pharyngeal phase of swallow).
- B.2.3. Postures that help in improving swallowing ability in PsWPD.
- B.2.4. Diet modifications for different stages of PD.

The exercises included in all these sections are based on literature survey. The most effective techniques are provided with adaptations to the Indian context. The modifications in diet are also recommended based on a review of literature on dysphagia diet and nutrition status specifically for PsWPD.

Part III: Addresses and contacts of hospitals and professionals who deal with PsWPD in India: This section aimed at providing further guidance and support that might be required to the client and family. It included information about centers of services for medical, speech and swallowing function, information on self help groups or associations that function for the social, personal and financial welfare of PsWPD. The details about these were collected by running a wide search on the internet about medical tourism in India.

Stage 3: Check for content validity: The manual was given to three Speech- language pathologists who were experienced in rehabilitation of individuals with Parkinson's disease for their feedback on the contents of the manual. The feedback was collected in the form of a three point rating scale on various sections of the manual. The rating scale provided was as follows:

- 1- The contents are not very valid.
- 2- Some contents are valid but some are not.
- 3- All contents are valid.

Stage 4: Modification of the content based on the feedback obtained in Stage 3: The suggestions obtained from the judges of stage 3 were incorporated and the modified manual was subjected to further procedures.

Stage 5: Sensitivity of the manual as a resource material for PsWPD: Three individuals suffering from Parkinson's disease were provided with the manual for their use. Their suggestions and feedback was obtained on a three point rating scale. The rating scale provided was as follows:

- 1- Difficult to comprehend the content of all sections
- 2- Easy to comprehend few sections only.
- 3- Easy to comprehend all the sections.

Stage 6: Modification of the content based on the feedback from the client and family members and finalization: After incorporating all the changes that were suggested by the PsWPD and their family members or caregivers who may use this manual, the manual was finalized for its content and structure.

Conclusions

This self therapy manual was proposed to help PsWPD to cope with their speech and swallowing difficulties during the course of the disease. This manual was prepared based on the best knowledge of literature, clinical evidences and reports. The sections of this manual were rated to be well understood by three PsWPD and approved for its contents by experienced speech-language pathologists. Thus, this manual is expected to be useful for PsWPD.

Limitations of this manual

The manual is in English and thus may be useful only for literate PD clients and their families. Although it is well attempted to offer as a comprehensive manual for self therapy, it may not satisfy the needs of all PD clients because it is known that PD clients exhibit a wide heterogeneity in their characteristics. Hence in some clients, the manual may only serve as a rudimentary guide.

Recommendations

The manual needs to be clinically validated for its usefulness and suitable modifications incorporated based on the feedback obtained from the target groups such as PD clients, their caregivers and others in the society. Translation of the information in this guide to other native Indian languages will help in reaching out to more families who need such help. Also, this manual can be digitalized to help families access the information almost instantaneously.

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