

The development of a tool to gather information regarding the activities and participation of persons with aphasia in Portugal

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1. Introduction

The most recent literature on working with people with aphasia (PWA) propose that Speech and Language Therapists (SLTs) consider in their intervention the effects of a client's communication and/or swallowing disorder on his/her everyday life [2].

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) [4] describe components that should be considered when working with someone who has a health disorder or disease. It considers Functioning (Body Function and Body Structure), Activities and Participation, and Contextual Factors. The Activities and Participation component of the ICF describes the complete range of human functioning from both an individual and a societal perspective. The individual perspective is expressed through the concept of Activity which is defined as "the execution of a task or action by an individual" [4], and the societal perspective is expressed through the concept of Participation, defined as "involvement in a life situation" [4]. However, both concepts are still represented in a single list and it is not clear yet which domains reflect Activities or Participation [2]. There are many discussions about this distinction in literature but a consensus is still not a reality.

There is a gap in the profession generally about collecting information on aphasic people's Activities and Participation domains. There is a lack of tools or questionnaires to do this adequately [3]. There is also a lack of research or evidence based practice concerning the activities and participation of PWA.

In Portugal, most SLTs working in the aphasia field work in a hospital setting in the acute phase and/or with PWA coming from their homes in an ambulatory system. When it is possible, their family members are involved in the therapeutic intervention. The Medical Model is still widely used, and people (medical professionals and the public alike) expect SLTs "to solve" the consequences of stroke. SLTs assessment and intervention practices are restricted to this setting, making it difficult to practically determine and intervene to address the reality of people's lives, that is, the psychosocial part of the biopsychosocial model presented in the ICF. They miss out on valuable opportunities to observe PWA interacting in their daily life and observe the impact that their local community contexts/environments have on their ability to participate socially. SLTs' assessment or information gathering/interviewing tools in Portugal are limited to translations of various impairment assessments which also constrain the whole intervention process described above.

The purpose of this paper is to present a tool, *The Activities/Participation Profile (TAPP)*, devised as part of a larger PhD project developed by the first author. There is a paucity of data on the real life functioning of PWA in Portugal. *TAPP* was developed to explore the usual activities of PWA and thus better understand the consequences of stroke and aphasia. Evaluating those persons with more limited communication skills is especially challenging because they cannot often participate in in-depth semi-

structured interviews. The preliminary data obtained during the project with PWA using *TAPP* will be presented.

2. Method

In theory, it is easy to understand the separate nature of the ICF Activities and Participation concepts. However, in reality, there is significant overlap and interdependence in the concepts. Thus, *TAPP* reflects the combined and integrated approach to viewing Activities and Participation.

SLTs can have an important role facilitating the whole communication processes needed to understand how a disorder impacts the quality of life and life satisfaction of those who they are working with. SLTs, especially those working in hospital setting, need to be able to “see” beyond the limitations of their defined work settings, and explore PWA’s Activity and Participation, and then consider those in intervention.

TAPP includes all domains of the ICF *Activities* and *Participation*, and not just the chapter entitled “Communication” because communication is essential to the other domains of the ICF such as “learning and applying knowledge,” “interpersonal interactions and relationships,” and “community, social, and civic life.” Thus, all domains are included so that SLT’s can determine how best to support the client in their daily life and help him/her to define the best goals to achieve in therapy.

The content of *TAPP* was derived from a range of sources: different assessment tools described in the literature; previously published research about the impact of aphasia on activities and participation; the professional opinions of 10 SLTs who participated in a focus group in the larger PhD research project; reflections based on 17 years of clinical practice as a SLT in the field of aphasia by the first author.

The participants in this research project were 14 PWA, recruited and assessed by the first author at the Hospitais da Universidade de Coimbra, Portugal. The inclusion criteria included the following: over 25 years of age; native speakers of European Portuguese; at least 3 months post onset following a stroke; living at home; aphasia diagnosis; demonstrated reliable yes/no response; no overt cognitive or depression disturbance; no hearing problems that were judged to interfere in the communication process.

Informed consent to participate was obtained from all participants. An aphasia-friendly informed consent sheet was used with the PWA.

The sample included eleven men and three women, with an average age of 65 years and ranging from 41 to 80 years. They were, on average, 29 months post-stroke (range 3-89 months) and had a mean education of 7 years (range 3-20 years). They had the following occupations before stroke: two drivers, one car mechanic, one farmer, one civil engineer, one librarian, two merchants, one army lieutenant colonel, one salesman, one potter, one house keeper, one hotel owner/manager and one businessman. Nine of the participants were retired, two lived from their own income, two had medical support and one was working part time. Eight of them had a physical impairment (right hemiparesis) as a consequence of stroke but were ambulant. In terms of aphasia classification types, seven had Anomic Aphasia, three had Motor Transcortical Aphasia, one had a Sensorial Transcortical Aphasia, one had Conduction Aphasia, one had Broca Aphasia, and one had Global Aphasia.

The first version of *TAPP* comprised 154 items. After being piloted with three people, *TAPP* was modified based on both their reactions to the tool and their suggestions. As

TAPP was considered too long and tiring, the main change was a reduction in items. This was achieved by eliminating some items and grouping similar ones.

Items such as “going to a wedding” were eliminated because of their low frequency of occurrence. Items such as “going to the hospital” were considered too general. Items such as “choosing what to do” or “staying in bed” were considered too ambiguous in formulation and too obvious as happening in daily life. Items such as “listening to a conversation” or “telling a secret” were considered “offensive”. Other items such as “going to a bar, disco, casino” were grouped.

The second version, used in the data collection, comprised 110 items. Each activity was explored in terms of whether carried out before stroke, how often (daily, weekly, fortnightly, monthly, rarely or never), still carried out after stroke or not and why, would like to do it again. At the end, the PWA were questioned about the actual global degree of satisfaction with the developed activities.

TAPP was designed to be completed by the PWA with the SLT assistance. Each of the items was explored individually. It was read aloud by the first author and PWA could point to their answer in the paper sheet which described a range of frequency options, as well as a 1 to 5 point scale organised for that purpose. Repetition and simultaneous reading was used whenever necessary as well as a slow rate of speech to facilitate comprehension. Depending on the severity of aphasia, the *TAPP* took 30-40 minutes to be administered.

3. Results

Before stroke, 108 activities in a total of 110 were referred as being carried out sometime at least by one of the 14 PWA. The only activities not referred at all were “to participate in political activities” and “going to physiotherapy or other treatments”. Of these 108 activities, 5 were referred by all the 14 PWA. These were: “reading the newspaper”; “watching television”; “answering and talking on the telephone”; “signing the name”; “talking to family”. Seventy six (76) of these 108 activities were carried out daily, 72 on a weekly basis, 45 twice a month, 45 monthly, and 83 rarely carried out.

After stroke, 87 activities out of the 108 carried out before stroke were referred as *not being carried out* anymore by any of the 14 PWA. The main motives pointed for leaving these activities were: the stroke in general (23); language and other related disorders such as aphasia, writing and reading, vision and memory (88); motor disorders (48); emotional reactions such as unwillingness, disinterest, discouragement, fear, feeling greater difficulty, irritability, lack of patience and tiredness (41); usual family reactions, as the replacement of functions and roles and overprotection by the spouse and/or children (14); unemployment and/or early retirement with consequent changes in economic status (20); adaptation of functions and activities to the new situation (5); changing health-related habits and other related activities (7); lack of time (3); sexual disorders (3).

Thirty two (32) of the 108 activities carried out were referred by at least one of the 14 PWA as being modified in terms of frequency. According to the Wilcoxon test, there were statistical significant differences ($p < 0.05$) in the frequency of 14 of the 108 realised activities before and after stroke.

Sixteen new activities were reported as being initiated after stroke by some of the 14 PWA, including: household activities and family dynamics (4); activities related to health (6); activities involving reading and writing skills (3); religious activities (1); other leisure activities (2). The main motives presented were: more spare time; the need to

work on language and memory skills; a greater concern for health after stroke; the need to accompany the spouse.

Despite these significant changes in life activities and participation, 5 PWA reported being maximally satisfied (reported “5” on 1-5 scale of satisfaction); 4 PWA reported “4”, 4 PWA reported “3”; only 1 PWA reported “1”.

4. Conclusions

The consequences of stroke are enormous and diverse. *TAPP* was useful in determining the previous and current activities and participation of Portuguese PWA, and appears to clearly illustrate activities and participation post-stroke. It is suggested that *TAPP* can be used in daily therapy helping SLTs to collect and discuss with the PWA which are the most important activities that are not being done at the moment and explore why this is so. Determining which activities the person would like to do again, can assist SLTs in collaboration with the PWA to define goals for intervention. These activities should then be explored in terms of where the activity is occurring, with whom, with what purpose, what kind of facilitators would be needed, and what to do about the explored *barriers* [1]. In the future, *TAPP* should be complemented with coloured drawings to illustrate each of the items as well as items being organised in semantic categories, so it can be used with people with more severe aphasia. Normative studies as well as other studies involving different populations should be done.

5. Bibliography

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Abstract (296/300)

THE DEVELOPMENT OF A TOOL TO GATHER INFORMATION REGARDING THE ACTIVITIES AND PARTICIPATION OF PERSONS WITH APHASIA IN PORTUGAL

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Introduction and aims of the study: The most recent directives on working with people with aphasia (PWA) propose that Speech and Language Therapists (SLTs) consider in their intervention the effects of a client's disorder on his/her everyday life. In Portugal, most SLTs working in the aphasia field work in a hospital setting, making it difficult to address these directives. The Activities/Participation Profile (TAPP), devised as part of a larger PhD project will be presented. TAPP allowed, in the absence of Portuguese studies about the subject, to better understand the usual activities 14 PWA developed in their lives before and after stroke.

Methods: The content of TAPP was derived from a range of sources. Fourteen PWA were involved. Each activity was explored in terms of whether carried out before stroke, how often, still carried out after stroke or not and why, would like to do it again.

Results: Before stroke, 108 activities in a total of 110 were referred as being carried out sometime at least by one of the 14 PWA. After stroke, 87 activities out of these 108 were referred as *not being carried out* anymore by any of the 14 PWA. Thirty two of the 108 activities carried out were referred by at least one PWA as being modified in terms of frequency. Sixteen new activities were referred as being initiated after stroke.

Conclusions: TAPP was useful in determining the activities and participation of Portuguese PWA, and appears to clearly illustrate activities and participation post-stroke.

Short Summary (60/60 words)

The most recent directives on working with people with aphasia (PWA) propose that Speech and Language Therapists consider in their intervention the effects of a client's disorder on his/her everyday life. The purpose of this paper is to present a tool, The Activities/Participation Profile, which allows clinicians to understand the consequences of stroke and aphasia in the life of PWA.

Learner Outcomes

Participants will be able to discuss the Activities/Participation Profile (TAPP) and define the activities and participation profile of Portuguese PWA.

Duration of Parts

Introduction: 2 minutes
Methodology: 3 minutes
Results: 7 minutes
Conclusions: 3 minutes

Matos, M. (46/50 words)

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Cruice, Madeline (50/50 words)

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Gomes, Ana Allen (50/50 words)

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