

Developing a Protocol for Measuring Participation of Persons with Aphasia

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Abstract

For persons with aphasia communication (activity & participation) and context (personal & environmental factors) are very important. Hence, the current investigation was aimed to develop a protocol for measuring participation in life situations in person with aphasia and administrator of this protocol on persons with aphasia and their caregivers. Development of a protocol for participation of person with aphasia was carried out in two stages. First the protocol was developed, which consisted of 4 domains i.e. understanding and expression, general tasks and demands, interpersonal interactions and relationships and facilitator and barriers. Further, it was administered on a total of twenty persons with aphasia and their family member/ caregiver. The results indicated that participation in terms of various contexts was greatest for persons with aphasia demonstrating mild communicative deficits and less associated problems. Across each domain, there was significant correlation among the responses of persons with aphasia and their caregivers. Duration of therapy played a significant role in enhancing participation of persons with aphasia across various contexts. Comprehension and expression ability was reported to be average among persons with aphasia. 40-50 % of the time persons with aphasia required help to understand and express the conversation. As result of stroke persons with aphasia lose almost 50-60% of the ability to carry out activities of daily living depending on the type of aphasia. At work place only 40% of the persons with aphasia could return. Majority of caregivers who supported persons with aphasia in various conditions were women. Thus, the results of the study do provide a conclusive base that as in persons with aphasia the activity and participation is affected in various situations which varies from the activities of daily living to the vocation. Hence, it is very imperative for speech-language pathologists to measure participation of persons with aphasia which in turn, will help in planning treatment.

Key words: protocol, participation of persons with Aphasia

Aphasia is characterized by a wide array of symptoms and characteristics which varies depending on the site of lesion, extent of lesion and associated problems. There have been numerous attempts to explain aphasia. However, no one definition has succeeded in explaining the exact nature, characteristics and consequences of this condition. Aphasia can influence one or more elements of communication such as speech, language or gesture. These deficits impact upon the expression and/or comprehension of language and cause remarkable alterations in day to day functioning of persons with aphasia. Aphasia can diminish participation of persons with aphasia across several real life contexts such as activities of daily living, at home, in social situations, in academics, and at work place.

The major emphasis in the literature is towards linguistic ability and associated aspects of persons with aphasia. However, in real life situations various other issues also play a vital role. For persons with aphasia and their family members participation across various situations is more important than knowing names of few lexical categories or repetition etc. (Le Dorze, Julian, Brassard, Durocher & Boivin, 1994; Le Dorze & Brassard, 1995). Following are few aspects which are noteworthy and needs to be kept in mind while working with persons with aphasia.

Accomplishment of several activities of daily living for instance bathing, eating, cleaning, shopping, travelling, watching TV, listening to

music, reading newspaper, writing letters, using computers, calculation, managing finance are more imperative for persons with aphasia. Meanwhile, most of these activities also involve some or the other aspect of communication. Aphasia also affects domestic life of persons with aphasia (Hilari, Smith, 1985; Wade, Hewer, David & Enderby, 1986; Wiggins, Byng & Smith, 2003).

Interpersonal interactions and social life include relationship with family members, relatives, friends, participating in various social events like festivals, religious activities, parties etc. Interpersonal interactions and relations are reported to be altered in persons with aphasia (Smith, 1985).

Work integration or returning to work place is a very essential issue in the life of persons with aphasia. Stroke hampers ability of an individual to return back to work (Le Dorze & Brassard, 1995; Salonen, 1995; Parr, 2001). There are more chances of change of job or reduction in timing etc. This can severely affect life of persons with aphasia. This reduces their confidence and can lead to depression.

The factors which help persons with aphasia to participate in various contexts act as a facilitator. Knowledge about them can help enhance communication of persons with aphasia apart from therapy. Another important issue is who provides support to persons with aphasia either family members or professionals or friends etc. Knowledge about barriers experienced by persons with aphasia is also necessary. If we know what are hurdles are faced by them, various steps can be taken to remove or reduce them to further enhance participation of persons with aphasia.

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Even though above described elements are more relevant to life of persons with aphasia, very few attempts have been made to assess these aspects. In spite of the abundance of available measures, existing appraisal of aphasia may be inadequate. To focus socially relevant and important treatment, a clinician must also evaluate the impact of residual deficits on a person's participation in life situations. Available functional communication measures, for example: Communicative Abilities in Daily Living (CADL Holland, 1980), Functional Communication Profile-(FCP Sarno, 1969), American Speech Language hearing Association Functional Assessment of Communication Skills for Adults(ASHA FACS, Frattali, Thompson, Holland, Wohl & Ferketic, 1995) may or may not measure aspects of actual life participation (Simmons-Mackei, Threats & Kagan, 2005).

Further research is required to fill the empty space in the literature regarding participation. Such research should be guided by a clear conceptual framework and well-defined concepts. These could possibly be derived from existing frameworks like:

The International Classification of Functioning, Disability and Health-ICF (World Health Organization, 2001): This framework conceptualizes health and the consequences of disease (World Health Organization, 2001). It is a valuable tool in research into disability, in all its dimensions that is impairments at the body and body part level, person level activity limitations, and societal level restrictions of participation. It is a biopsychosocial model.

Disability Creation Process model-DCP (Fougeyrollas, St-Michel, Bergeron, Cloutier & Cote, 1999): DCP is a theoretical model. It explains and focuses specifically on the social construction of disability and impact on participation or "life habits" (Noreau, Fougeyrollas & Vincent, 2002). It comprises of four components, which are: risk factors (cause), personal factors (organic system and capabilities), environmental factors and life habits. There is dynamic interaction among factors of this model.

Living with Aphasia: Framework for Outcome Measurement-AFROM (Kagan, Simmons-Mackie, Rowland, Huijbregts, Shumway, McEwen, Threats, & Sharp, 2008) ICF classification is very broad while A-FROM tries to simplify it by considering the elements which are more relevant for aphasia. It includes following domains: Aphasia severity (correlate of ICF body function/impairment), participation/life habits, personal factors including identity and emotions and environment.

In Indian context very less work has been done in this area. A study by Jeslma (2009) showed that only six studies have been published related to ICF from developing countries, with Germany and the USA responsible for almost 50% of the total. Thus, there is a need, to strengthen the existing research and to study from Indian per se.

Communication (functioning, activity, participation) and context (personal and environmental factors) are equally important, as well as interdependent, for the person with aphasia. There is a necessity to develop measures that appraise ability of persons with aphasia to participate in desired life situation (Ross & Wertz, 2003). Very few measures exist for the purpose of appraising ability of person with aphasia to become or remain involved in desired life situations.

The study was planned to develop a protocol for measuring participation in life situation in person with aphasia and to administer this assessment protocol on person with aphasia and on their family member/ caretaker and thereby gain an understanding towards ability of persons with aphasia to participate in life situations.

Method

The main aim of the current investigation was to develop a protocol for measuring participation in real life situation in person with aphasia and to administer this on person with aphasia and on their family member/ caretaker. Development of the protocol was done in two stages.

Stage 1: Development of the protocol

Protocol for measuring activity and participation was developed based on the principles of ICF-WHO, DCP and AFROM. Protocol consisted of following four sections:

- A. Understanding and Expression: This section has questions regarding their comprehension and expression of verbal, nonverbal and figurative language.
- B. General Tasks and Demands: It comprised of questions related to ability of persons with aphasia to perform different daily activities.
- C. Interpersonal Interactions and Relationships (participation in society): This included their performance at their work place, academic, social situations, and home.
- D. Facilitator and Barriers: It incorporated questions concerning the factors which acts as a facilitator and barriers to participate in various contexts.

Section A, B, and C also had questions regarding whether they require help, their ability is same as before stroke and their satisfaction level. Each section had questions which were supposed to be rated on a five point rating scale. Following rating

scale was used: 1- Able to do less than 25% of the time, 2- Able to do 25-50% of the time, 3- Able to do 50-75% of the time, 4- Able to do 75-90% of the time and 5- Able to do more than 90 % of the time

These questions were given to ten judges. Speech- Language pathologists (SLPs) served as the judges. They were asked to rate the questions on a Feedback questionnaire for aphasia management manual (Field testing of Manual for Adult Non-fluent Aphasia therapy manual- *MANAT-K*, Goswami, Shanbal, Samasthitha & Navitha, 2010). Few parameters from the feedback questionnaire were removed as they were not relevant such as size of the picture, color and appearance, arrangement iconicity, trainability. Judges were also asked to give suggestions regarding the rating scale used and any other changes in the protocol.

Further, pictures were incorporated to capture all the concepts and to make it easier to understand for persons with aphasia. A professional artist made all the pictures. Further, these pictures were subjected to their ambiguity and familiarity validation by five judges. Judges were experienced SLPs. They were asked to rate pictures on their familiarity and ambiguity. Items with 90% agreement were included in the assessment tool. Based on suggestions of judges modifications were made.

Stage 2: Administration of this protocol on persons with aphasia and their family members

Participants: A total of 20 persons with aphasia along with their caregivers (20) participated in the study. Persons with aphasia were identified through hospitals, neurological clinics and/ or speech and hearing centers. They were diagnosed using Western Aphasia battery (WAB, Kertesz, 1982) by experienced speech language pathologist. The age range of persons with aphasia was from 28 to 80 years. Among the aphasia group various types of aphasia were represented (six global aphasia, four Broca's aphasia, two transcortical motor aphasia, one Wernicke aphasia, one transcortical sensory, three anomic aphasia, two subcortical aphasia, and one progressive non fluent aphasia).

Participants were selected by adhering to the appropriate ethical procedures. Participants and caregivers were explained the aim and procedures of the study, and an informal verbal and/ or written consent were obtained. Participants were randomly selected based on the inclusionary criteria.

Inclusion Criteria for person with aphasia:

Persons with aphasia following stroke or other left hemisphere damage were included. Those with no known history of pre-morbid neurological illness, psychiatric disorders and/or cognitive decline, and no

other significant sensory and/or cognitive deficits that could interfere with the individual's performance in the investigation were also selected.

Procedure: The protocol was administered on persons with aphasia and their family members. They were instructed to rate it as per their ability to perform different tasks on a rating scale ranging from 1 to 5. The responses included were either pointing or verbal responses. Their responses were recorded on a scoring sheet. Testing time varied from 20-30 minutes. Further these responses were subjected to analysis using SPSS software (version 16.0).

Results and Discussion

The results of the current investigation are being presented and discussed under the following sections:

A. Understanding and expression: This domain evaluated the comprehension and expression (verbal, nonverbal and figurative language) in persons with aphasia. Furthermore, it assessed whether they require help, performance as compared to previous and the satisfaction level.

The results showed the following trends. Comprehension was reported to be good among almost all types of aphasia by persons with aphasia and their caregivers. The reason behind this can be as it was self rated so there were more chances of bias and other reason could be that caregivers tend to overestimate the ability of person with aphasia as they were more interested in participation ability of person with aphasia rather than their linguistic capacity. Expression ability was reported to be average among persons with aphasia. 40-50% of the time persons with aphasia required help to understand and express the conversation. These results indicate that aphasia can have a profound impact on ability of person with aphasia to participate in conversations.

Comprehension and expression was greatest for persons with aphasia demonstrating mild communicative deficits and less associated problems. The results are being strengthened by the findings reported by Peuser and Schriefers (1980). Various other investigators have also reported similar findings (Milberg & Blumstein, 1981; Semenza & Goodglass, 1985; Goswami, 2004). Hence, results of current investigation are in accordance with the literature. The findings indicated that linguistic ability, language recovery, pre morbid linguistic ability, associated problem, duration of therapy attended, age of onset of problem were the few factors contributing to change in their ability to comprehend and express with respect to before stroke. These factors can affect ability of person with aphasia to comprehend and express to a large extent.

Therefore, these factors should be kept in mind while considering the participation of a person with aphasia.

There was significant correlation noticed among the responses of persons with aphasia and their caregivers. The results are in accordance with the view of Davis and Mehan (1988), where they have reported better results in understanding as reported by the caregivers compared to the scores shown by the rehabilitation workers. Indeed, many researchers advocate that families should be included in aphasia therapy and that they should also be given counseling and support (Wahrborg & Borenstein, 1989; Denman, 1998; Le Dorze, Croteau, Brassard & Michallet, 1999; Chapey, Duchan, Elman, Garcia, Kagan & Lyon, 2001; Pound, Parr & Duchan, 2001). Hence, findings of current investigation are in harmony with above mentioned studies.

Duration of therapy played a significant role in enhancing participation of persons with aphasia across various contexts. Various studies have reported that if therapy duration was more than it was found to be more effective (Hagen, 1973; Mazzoni, Vista, Geri, Avila, Bianchi & Moretti, 1995).

B. General Tasks and Demands: This domain assessed questions concerning ability of person with aphasia to perform a variety of daily activities. Like previous section it also assessed whether they require help, performance as compared to previous and their satisfaction.

As a result of stroke persons with aphasia lose almost 50-60% of the ability to carry out activities of daily living depending on the type of aphasia. Reduced linguistic, sensory and motor ability following stroke can be the reason behind reduction in performance across tasks. Various researchers have reported that aphasia can have a profound impact on person with aphasia everyday activities and communication (Bullinger, Anderson, Cella & Aaronson, 1993).

Almost half of the time persons with aphasia required help to execute activities of daily living. Ability of person with aphasia to fully participate in activities of daily living and their satisfaction level could be affected by interaction of many factors together such as severity of deficits, associated problems, support from family and professionals etc. Language deficits and other associated problems (paralysis, sensory deficits) can be the major reason which hampers their ability to participate in various daily life contexts. Due to which support from others is important factor while performing everyday life activities (Bullinger, Anderson, Cella & Aaronson, 1993; Worrall & Hickson, 2003; Hilari & Northcott, 2006).

Almost similar responses were obtained for persons with aphasia and their caregivers with respect to their performance to carry out everyday activities, need for help, performance as compared to previous and their satisfaction. These findings indicate a greater understanding of caregivers towards the ability of persons with aphasia to execute various general task and demands (Lubinski, Duchan & Weitzner-Lin, 1980; Ferguson, 1992, 1994; Milroy & Perkins, 1992; Goodwin, 1995; Laasko, 1997, 2002; Laasko & Klippi, 1999; Lindsay & Wilkinson, 1999; Oelschlaeger, 1999; Oelschlaeger & Damico, 2002; Perkins, 2002). Thus, results are being supported by above mentioned studies.

Results also revealed that along with caregivers' assistance, speech and language therapy helps persons with aphasia to fully participate and perform daily activities almost similar to before stroke. This depicts role of therapy in recovery from the aphasia and can lead to better participation in social context (Hagen, 1973; Marshal, Pound, White-Thomson & Pring, 1990; Davis & Pring, 1991; Byng, 1993; Mazzoni, et al., 1995; Nickels & Best, 1996). Thus, therapy is very important factor while dealing with persons with aphasia which enhances their activity and participation in various social domains.

C. Interpersonal Interactions and Relationships (participation in society): This domain assessed their performance at their work place, academics, social situations, and home. Like previous domain it also assesses whether they need help, performance in contrast to previous and their satisfaction in various situations.

At work place only 40% of the persons with aphasia could return. However, they could not regain full employment stage same as before stroke. Ability of persons with aphasia to perform well at work place is affected to a large extent following factors like working requirements and support from other employee, linguistic and motor ability. These findings are also supported by various other researchers i.e. return to work is often characterized by reduced hours, return to another job, or return to the same job with modifications (Carriero, Faglia & Vignolo, 1987; Black-Schaffer & Osberg, 1990; Sarno, 1992; Hinckley, 2002; Parr, 2001). Often there was no return at all (Le Dorze & Brassard, 1995; Garcia, Barrette & Chantal, 2000; Parr, 2001; Hinckley, 2002; Hilari, Wiggins, Byng & Smith, 2003). Persons with aphasia are less satisfied with their performance at work place. This could be attributed to their reduced ability to perform the task assigned to them at work place, reduction in working hour or change of job/vocation due to occurrence of stroke. Here, also severity of aphasia played a significant role to predict the performance of persons with aphasia in vocation/ employment.

Ability of persons with aphasia to participate in social situations and communication at home was reduced by 50% after the onset of the stroke. There are reports of change in interaction of persons with aphasia with friends and relatives. However, many factors tend to influence participation ability of persons with aphasia such as communicative ability, support from family and professionals. Communication difficulty may result in social isolation, challenges with interpersonal relationships, mental and emotional changes, and corresponding lack of independence (Cruice, Worrall, Hickson & Murison, 2003; Ross & Wertz, 2003; Worrall & Holland, 2003). This can further restrict participation of persons with aphasia social contexts.

Persons with severe communication deficits were less satisfied with their communication at various contexts. These findings could be attributed to their inability to communicate in various situations as reported by Cruice, Worrall, Hickson and Murison (2003); Hilari and Byng (2009).

There was significant correlation among the responses of persons with aphasia and their caregivers. However, only for one question i.e. whether performance at work place is same as before stroke (C2), there was less correlation. This indicates that caregivers need to understand persons with aphasia in various aspects of employment. Therapy had a positive effect on ability of persons with aphasia to participate in society. Research by various other authors reported the similar findings (Hinckley & Packard, 2001; Hinckley, 2002).

D. Facilitators and Barriers

This included questions which inform us about the factors which acts as a facilitator and barriers for persons with aphasia to participate in various daily situation. It also included questions which inform us about who help persons with aphasia to participate in various daily situations such as at home, in social situations, at work place, in academics etc.

Majority of caregivers who supported persons with aphasia in various conditions were women. These findings receive support from studies conducted by Hodson, Wood and Langton, (1996) and Swati (2008), who reported majority of women and spouse are caregivers of persons with aphasia.

Almost 60% of the factors helped persons with aphasia to participate in various contexts. However, for person with aphasia having severe communication deficits, fewer factors facilitated their participation in turn leading to participation restriction. Speech and language therapy enhanced their participation to some extent, however the trend obtained was not much conclusive.

40% of the problems are faced by persons with aphasia. This can hamper their participation in daily situations. A study conducted by Davidson, Worrall and Hickson (2003) also reported that persons with aphasia generally engage in communicative activities less frequently than others. Thus results of the present study obtain support from above mentioned studies. Therapy tends to show a positive impact on their participation ability. However, the trend obtained is not much conclusive.

Conclusions

Hence, to conclude this protocol can be administered on persons with aphasia to measure their activity and participation in real life situation. Poor scores i.e. rating of 1 or 2 signifies restricted participation of person with aphasia, on the other hand score of 4 or 5 signifies good participation in various questions. Domains of this protocol are more relevant for persons with aphasia. The areas of participation where participation is restricted can be taken as intervention goals. This can also help in planning the intervention goals which are more relevant for persons with aphasia. This protocol can be used in assessment to determine severity of participation restriction. It can aid in research regarding the effectiveness of intervention. As it is aphasia friendly version it provides a format for communicating with person with aphasia about goals and expected outcomes. Person with aphasia can have an opportunity to determine and choose what outcomes are relevant from his/ her perspective.

It can also be helpful in deciding which factors are facilitating participation in persons with aphasia and which factors create barriers which hinder participation in persons with aphasia. Knowledge regarding facilitators and barriers can in turn help to enhance participation of persons with aphasia. This can also help in generating a barrier free environment for person with aphasia. Application need not be limited to the assessment of person with aphasia. With slight adaptation this protocol would be appropriate for measuring participation restrictions associated with other communication disabilities.

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