Chapter 13
Assessment of Significant Other’s Burden and Their Communication Strategies to Enhance the Treatment Outcome in Aphasia

Pinki Singh
All India Institute of Medical Sciences-Bhopal, India
Apoorva Pauranik
MGM Medical College and Hospital, India

ABSTRACT

Post-stroke management of person with aphasia (PWA) needs the crucial involvement of significant others (SOs) or caregivers of PWA. The manners in which SOs perceive the burden and execute their supportive communication strategies (SCS) are highly variable and are influenced by many factors like their motivation, emotional attachment, constraints of time and economy, self-confidence, and the clinical and individualistic attributes of the PWA herself or himself. There are variations regarding motivation, supportive communication strategies (SCS), significance and burden of communication to PWA by SO. These variations lead to a prognosis of a PWA, which needs to be evaluated for a better understanding of the diversity of burden and SCS before incorporating tailor-made treatment planning. These aspects have a significant bearing on the prognosis of aphasia, hence must be evaluated prior to treatment planning.

INTRODUCTION

Aphasia is an acquired language disorder resulting from an injury to the brain, such as from a stroke or traumatic brain injury (TBI). Symptoms of aphasia include difficulty in finding words, using sentences, and communicating with others. All the treatment approaches related to aphasia focused on improvement of communication skills of the person with aphasia (PWA). In order to achieve this goal, significant others (SOs) of PWA follow and execute all the recommended communication facilitating activities in their natural settings.

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In the literature, terms “carer” or “caregiver” are used more often to refer the individuals who are involved with the PWA and considered as equivalent to the term “family”. In many studies, a narrower term i.e. Partner (spouse or cohabitant) of the PWA is also being used frequently. The use of the appropriate term is significant to understand the extent and intensity of its implied meaning. “Carer” or “caregiver” could be perceived to imply a nursing role that may not be present, and “family” might be taken as the too narrow term (Blom Johnsson, 2012). When a person suffers from a stroke and aphasia, life not only changes for him or her, but also for their significant others (Le Dorze and Brassard, 1995; Michallet, Tétreault, and Le Dorze, 2003). To acknowledge the significant involvement of family members, friends and other persons who are important to the PWA, they are termed as “Significant Others (SOs)” in this chapter. Post-stroke responsibilities of SOs towards PWA, their home and family increases suddenly. They need to plan their everyday life i.e. social and personal more carefully than before (Kitzmüller, Asplund, and Häggström, 2012). They also have to act as “interpreters” at social events as well as at formal encounters e.g. doctor visits (Michallet et al., 2003).

Irrespective of the aphasia treatment approaches i.e. functional, environmental, language-oriented, the involvement of significant others (SOs) of a PWA during therapy and rehabilitation are robust and crucial. In many severe cases with aphasia, it is found that family member tends to focus on only verbal output in initial years. Later, when they fail to get success in achieving a verbal output, then most of them ignore other modes of communication i.e. written, drawing and other innovative modes. SOs act as an active receiver of the message (assumed to be sent by PWA) i.e. SOs perceives and understand the need of a PWA without any evident or specific indication given to them. They try to understand the need of PWA based primarily on environmental context or regular routine/time scheduled activity. Due to these communication gaps, incidences of frequent misunderstanding and feeling of the burden of SOs to interpret communication intention of PWA are quite evident.

Post-stroke physical and communicative deficits lead to the reduction in communication opportunities, communicative effectiveness, interactional competence, language, and communication-related activities. It generates frequent irritation and frustration to both i.e. PWA and SOs and gives rise to many interpersonal problems and communication burden on each other.

**REVIEW OF THE LITERATURE**

Conversations between two people who do not have communication impairment often follow a basic structure, to begin with a greeting, an act of introduction of the main topic, conversational turn-taking where each partner exchange message as needed and then a closing of a topic (Sacks, Schegloff, and Jefferson, 1974; Stokoe, 2013). When one partner experiences communication impairment such as aphasia, this exchange becomes difficult, yet the behaviors by both the PWA and their SO can influence the course of the conversation.

Several authors have discussed various conversational facilitators, defined as behaviors that move the conversation forward. Other authors discuss barriers or behaviors that tend to impede information exchange (Bauer and Kulke, 2004; Perkins, 2014; Simmons-Mackie and Kagan, 1999; Stokoe, 2013). When SOs encounters a breakdown in communication, they often attempt to engage in repairing strategy. Repairing strategy such as starting the conversation again, repeating questions in a simplified manner or otherwise repeating the use of facilitating behaviors in order to repair the miscommunication.
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