

Family education seminars and social functioning of adults with chronic aphasia

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Abstract

Aphasia affects functional activities and participation in social roles years after onset. Some group and individual programs have reported success in improving social activities and perceived wellness. These programs typically last several weeks or months. A short, 2-day seminar style program designed for adults with chronic aphasia and their families is described in this report. Six-month follow-up data from participant pairs demonstrates a significant improvement in functional activity level, improved knowledge of aphasia, and improved family relationships. Nonparticipant pairs did not demonstrate any changes over the same period. These findings replicate and extend those of a previous study on the same 2-day seminar [Top. Stroke Rehabil. 2 (1995) 53.]. The results of this study demonstrate the important outcomes of even a very brief program designed to address the long-term psychosocial needs of adults living with aphasia and their families. Educational objectives: As a result of this activity, the participant will be able to: (1) describe a brief family education seminar for adults with chronic aphasia; (2) discuss outcomes in family adjustment, community reintegration, and activities of daily living associated with participation in a family education seminar; and (3) evaluate areas of programming and outcomes that should be addressed in future research. © 2001 Elsevier Science Inc. All rights reserved.

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1. Introduction

The long-term psychosocial consequences of chronic aphasia are well known (Sarno, 1993). Depression, social isolation, significant decreases in productivity and activities, and changes in family roles and functions are some of the documented effects of chronic aphasia (Astrom, Adolfsson, & Asplund, 1993; Gainotti, 1997; Spencer, Tompkins, Shulz, & Rau, 1995; Wahrborg, 1991; Williams, 1996). Living with aphasia requires a reconceptualization of the self, of the family, of the nature of friendships, and of the activities that one engages in throughout the day (Brumfitt, 1993; Holland & Beeson, 1993).

The psychosocial consequences of living with a disability are being formally recognized on many levels, including the *ICIDH-2: International Classification of Functioning and Disability* (ICIDH-2, 1999). In this descriptive framework, impairments of cognition and communication may result in activity limitations, such as difficulty communicating basic needs and ideas. Participation restrictions may also result, which include participating in typical social roles, such as household finance management or gainful employment.

As researchers, social policy makers, and insurers pay more attention to the long-term consequences of living with a communication disorder, clinicians are developing programs that focus on activity limitations and participation restrictions due to aphasia. For example, the Communication Partners program, in which volunteers are trained to interact effectively and to engage in pleasurable activities with adults with aphasia is associated with improvements in perceptions of well-being (Lyon et al., 1997). Group approaches are also associated with positive activity- and participation-level outcomes and are associated with improved wellness, functional abilities, and self-esteem (Brumfitt & Sheeran, 1997; Elman & Bernstein-Ellis, 1999; Hoen, Thelander, & Worsley, 1997; Hubert & DeGiovani, 1993).

While the long term needs of adults with chronic aphasia have not been widely addressed, several approaches have provided potential solutions, including training of communication partners, supported conversation groups and caregiver training in a community center format, and group therapy. These interventions have ranged from 10 weeks to 6 months in duration. Is it possible that a very brief course of education and social support can also have an influence on participation in life?

In a previous study, Hinckley, Packard, and Bardach (1995) reported 6-month outcomes for just this kind of brief family education program. The program provided information and resources to adults with aphasia and their families, while offering opportunities for social support and exchange in a 2-day conference format. Six-month outcomes of this program showed that participants reported important improvements in knowledge of aphasia and resources, independence at home, and communication with partner and children. A majority of the participants successfully located community resources that were important to them by 6 months after program attendance. There was also a significant

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