



Having the courage to be competent: persons and families living with aphasia

Robert C. Marshall*

*Division of Communication Disorders, University of Kentucky, 1030 South Broadway, Suite 5,
Lexington, KY 50504-2605, USA*

Received 23 October 2001; received in revised form 18 December 2001; accepted 18 December 2001

Abstract

This paper provides examples and illustrations of how aphasic people can and do demonstrate their competence in managing their lives despite chronic aphasia. It discusses a number of ways in which aphasic persons and their families can learn to live fully despite the intrusion of aphasia.

Educational objectives: After reading this paper, participants should (1) have a more fully developed appreciation of what it means to live courageously with aphasia, (2) recognize the importance of developing a lifespan perspective following the onset of aphasia, and (3) better understand competence in aphasia. © 2002 Elsevier Science Inc. All rights reserved.

Keywords: Long-term perspective; Problem solving in aphasia; Competence; Courage

1. Introduction

In June 2000, I was privileged to deliver a keynote address at the second National Conference of the American National Aphasia Association (Marshall, 2000). This event brought professionals from many disciplines together (e.g., speech–language pathology, medicine, psychology, art, music, rehabilitation), but more importantly it allowed aphasic people and their families to have face-to-face dialogue and to share and exchange information about coping with a devastating disorder. By definition, aphasia is a language problem caused by brain injury, usually from a stroke. To greater or lesser degrees, it affects the individual's ability

*Tel.: +1-859-257-7923; fax: +1-859-257-1017.

to speak, read, write, comprehend, and gesture. Unlike many diseases (e.g., cancer) people don't die from aphasia. They live with the frustration of the disorder, usually for many years.

The World Health Organization (2001) has recently provided an update of their conceptual framework that has aided our understanding of the long-term consequences of aphasia. The present WHO's International Classification of Functioning, Disability and Health not only highlights the impairment (language deficit) of aphasia, but also the limitations on activities (inability to talk to friends), and the resultant limitations on one's ability to participate in society that are consequences of the disorder of aphasia. This model is described in detail in the chapter in this volume by Worrall et al. (2002).

Lyon (1998) has described life after a stroke for aphasic persons and their families as a journey with multiple stops and detours along the way. The "guides" for these journeys are those individuals who devote their lives and careers to improving the quality of life of persons with aphasia and their families. This issue of the *Journal of Communication Disorders* (JCD) recognizes the accomplishments and the contributions of an exemplary guide in the person of Dr. Martha Taylor Sarno. For nearly half a century, Dr. Sarno has been a role model for those seeking to aid individuals affected by aphasia.

Although this issue of JCD is dedicated to Dr. Sarno, this paper is not about Martha or aphasia clinicians per se. Clinicians do *support* and *guide* persons with aphasia and their families (Marshall, 1997; Van Harskamp & Visch-Brink, 1991). They also help individuals and their families to learn to compensate for and adjust to the permanent residuals of the disorder. These are vital services, but ultimately the quality of life for those impacted by aphasia will require having "the courage to be competent." In this paper I (1) salute and congratulate those aphasic individuals and their families who have attained this goal, and (2) challenge those who have not reached this point to consider developing "the courage to be competent" as rehabilitation's true goal.

Two things need to happen before aphasic individuals and members of their support systems can develop the courage to be competent. One, a long-term perspective on aphasia and its consequences needs to be adopted. Two, hope needs to be balanced with purposeful action with regard to communication and other daily activities.

2. The long-term perspective

Rehabilitation has been defined as "the restoration of form and function" (Dorland, 1965). Certainly this might occur when a National Football League running back suffers a knee injury. Re-constructive surgery, intensive physical therapy, and drugs might get Pete Pigskin ready for Sunday's game. Human brains, however, are more complicated than knees. Although rehabilitation improves the stroke victim's speech, language, cognitive, and physical functions,

متن کامل مقاله

دریافت فوری ←

ISIArticles

مرجع مقالات تخصصی ایران

- ✓ امکان دانلود نسخه تمام متن مقالات انگلیسی
- ✓ امکان دانلود نسخه ترجمه شده مقالات
- ✓ پذیرش سفارش ترجمه تخصصی
- ✓ امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
- ✓ امکان دانلود رایگان ۲ صفحه اول هر مقاله
- ✓ امکان پرداخت اینترنتی با کلیه کارت های عضو شتاب
- ✓ دانلود فوری مقاله پس از پرداخت آنلاین
- ✓ پشتیبانی کامل خرید با بهره مندی از سیستم هوشمند رهگیری سفارشات