Aphasia Camps as a Transformative Experience.

COMMENTARY
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Every 9 minutes someone suffers a stroke in Canada (1). It is the third leading cause of death and the leading cause of adult disability (2). In Canada there are estimated to be more than 400,000 people living with the effects of stroke, and this number is set to almost double over the next twenty-five years (3). Rehabilitation from stroke is progressive and aims to aid each individual to reach his or her “optimal, physical, cognitive, emotional, social and functional activity level” (4). The Canadian Stroke Best Practice Recommendations lists return to driving, return to vocation, sexual and leisure activity as the key areas to cover in Resumption of Life Roles and Activities following Stroke (4,5).

Aphasia impacts approximately 35% of stroke survivors (2). There are an estimated 100,000 people in Canada living with aphasia today (6). Aphasia is a communication impairment that can disrupt a person’s ability to read, write, express or understand language (2). In addition to physical and language barriers, people living with aphasia can face “social isolation, loss of autonomy, and stigmatization.” (2). In recent years, emphasis has shifted from traditionally focused clinical speech therapy to targeting other consequences of aphasia such as social isolation, a reduced sense of well-being, and diminished participation in favored activities (7).

Since 2008, Stroke Recovery Canada® (a program of March of Dimes Canada), in partnership with various academic institutions and community organizations, have held aphasia camps in Ontario. An Aphasia Camp is a three day weekend retreat that originated to support stroke survivors and their families to better live with aphasia - through participation in physical, social and educational activities in an environment that is “aphasia-friendly” (8). Aphasia Camp follows the philosophy of the internationally recognized Life Participation Approach to Aphasia, which emphasizes living life well despite a profound communication disability (9). Aphasia camps aim to combat loneliness, encourage inclusivity and build awareness of aphasia in the broader community.

Aphasia camps address the need for leisure activity post-stroke as indicated by The Canadian Stroke Best Practice Recommendations (5). The most frequent gaps in stroke recovery have been in leisure and social activity (5). Currently there is a dearth of literature examining recreational and social models and how they impact people living with aphasia. Historically, this
has been as a result of their communication disorder (2, 11). Looking forward, researchers should continue to apply existing adaptive communication tools to enable them to qualitatively examine what the lived experiences are for people with aphasia.

Currently, a joint University of Toronto and March of Dimes Canada study is examining what the experience of attending an Aphasia Camp brings to the quality of life of an individual living with aphasia. This study has been approved by the University of Toronto, Dalla Lana School of Public Health, Research Ethics Board*. This qualitative study is based on 11 semi-structured interviews involving individuals who have attended one or more aphasia camps. It includes 4 caregivers and 7 people with mild to moderate aphasia. The interviews were conducted in a communicatively accessible environment with the assistance of a speech and language pathologist. The content for the interview guide was inspired by the Quality of Life conceptual model of Being, Belonging and Becoming produced by the University of Toronto’s Centre for Health Promotion (10).

Preliminary results describe camp as “an emotional and physical boost” while creating an environment of “camaraderie” and inclusivity. In the words of a caregiver who attended camp twice with her partner; “for him [Aphasia Camp] has been a sort of a godsend, the comfort when you realize that there are other people like you and you have to make a new normal, you don’t fit in to the normal society anymore […].”

The results not only show a sense of belonging but a renewed sense of purpose post-stroke. Individuals interviewed that have attended aphasia camps have gone on to become actively involved in their communities – some of them directly crediting their attendance at an Aphasia Camp for allowing this transformation and transition to occur. Rehabilitation is not merely physical and cognitive recovery. Social and emotional functionality, as revealed in our preliminary results, are essential to rehabilitation. Recovery is an ever-evolving process that fundamentally has at its core the need to re-empower, re-engage and re-ignite the individual who has experienced a life set back.

*Authors Note: The University of Toronto, Research Ethics Board Protocol Number # 25561.

References


