A New Program May Help People Build Self-Management Skills and Confidence After a Stroke

Stroke is the leading cause of long-term disability in the United States, according to the National Stroke Association. A stroke occurs when a blood vessel in the brain either bursts or becomes blocked. Stroke can be mild, moderate, or severe. Stroke can cause problems with movement, speech, or mental functions due to lasting brain damage. People who have had a stroke may face challenges with returning to work, independent living, or social activities after a stroke. In a recent NIDILRR-funded study, researchers tested a program designed to help people who have had a stroke to build self-management skills. They wanted to find out whether the program could increase the participants’ confidence in their ability to manage their health and moods, communicate with others, or participate in life activities such as working or doing household chores.

Researchers from the Rehabilitation Research and Training Center on Enhancing the Functional and Employment Outcomes of Individuals Who Experience a Stroke enrolled 185 people from St. Louis, MO and Chicago, IL in a study. The participants had experienced a mild or moderate stroke at least 3 months before the study, and had completed their rehabilitation care. Most of the participants had experienced their stroke within 5 years of the study, but many were 5 to 10 years into their recovery. All of the participants went through the 12-week experimental program. About half of the participants were randomly assigned to an experimental group where they participated in the program immediately. The other half who served as a control group did not participate in the program immediately but were put on a waitlist to participate in the program after a 12-week period.

The experimental program was called the Improving Participation After Stroke Self-Management (IPASS) program. It consisted of 12 weekly classes, with groups of 6-7 participants per class meeting with two trained instructors. The participants received training on the skills needed in the day-to-day management of treatment of chronic conditions as well as how to maintain and/or increase participation in life’s activities. The participants also attended educational sessions focusing on home, community, and work management after stroke. Contents of those education session included building skills for goal setting, action planning, and problem-solving related to community activity participation. For example, the participants learned strategies for organizing their homes, overcoming barriers in the community, and requesting reasonable accommodations on the job, among others.

All of the participants completed questionnaires at several points before and after the program. On the questionnaires, the participants were asked how confident they felt about their ability to manage challenges related to their stroke; how confident they felt
about their ability to participate in healthy behaviors, such as exercise; and their confidence in their ability to participate in home, work, and community activities. The participants in the experimental group completed the questionnaires before starting the program, after finishing the program, and again about 6-9 months after the program was over. The waitlisted participants completed the questionnaires at the start of the waiting period and again before beginning the program. They also completed the questionnaires immediately after completing the program and again at about 6-9 months after the program was over.

The researchers found that self-confidence scores of the experimental group went up in several areas between the beginning and end of the program, while scores for the waitlisted group went down while they waited for the program to begin. However, the waitlisted group showed the same improvements as the experimental group once they completed the program. Specifically, the researchers saw improvements in:

- Managing challenges: Participants felt more confident in their ability to manage moods, manage their condition in general, and ask for help when they needed it.
- Engaging in healthy behaviors: Participants felt more confident in their ability to exercise and to communicate with their doctors.
- Participating: Participants felt more confident about doing chores, staying organized, and managing home, community, and work activities.

When the researchers looked at the scores at 6 and 9 months after the program ended, they found that most of the scores stayed the same or fell only slightly when compared to the scores right after the participants finished the program. According to the authors, the increases in work-related confidence did not last as long as the others.

The authors noted that a self-management program may help people with stroke to build more confidence and skills in learning to manage their condition and resume participation in important activities, even if they experience mental impairments as a result of their stroke. In previous studies, self-management programs have shown promise for helping people to manage the symptoms of medical conditions. The results from this study build on these prior findings by suggesting that self-management programs can also help people adjust to long-term disabilities. Researchers may want to test how these kinds of self-management programs might help people with stroke to increase their engagement in personally meaningful activities, such as returning to work or getting out into the community.

To Learn More

For information about another self-management program which could be used following stroke, the University of Montana Research and Training Center on Disability in Rural Communities is currently developing a multi-media version of the highly successful Living Well with a Disability self-management program. The project is called Motivation for Self-Management Through Multi-Media Health Promotion: http://rtc.ruralinstitute.umt.edu/health-wellness/motivation-for-self-management/
The Living Well with a Disability program is also offered in an in-person format by many Centers for Independent Living across the US. Learn how to find a program in your area: [http://livingandworkingwell.ruralinstitute.umt.edu/find-a-consumer-workshop/](http://livingandworkingwell.ruralinstitute.umt.edu/find-a-consumer-workshop/)

The American Stroke Association offers Life After Stroke, a collection of guides and resources to help stroke survivors and their families recover after stroke and return to doing some of the things they love: [http://www.strokeassociation.org/STROKEORG/LifeAfterStroke/Life-After-Stroke_UCM_308546_SubHomePage.jsp](http://www.strokeassociation.org/STROKEORG/LifeAfterStroke/Life-After-Stroke_UCM_308546_SubHomePage.jsp)

The National Stroke Association also offers resources and publications for stroke recovery: [http://www.stroke.org/we-can-help/survivors/stroke-recovery](http://www.stroke.org/we-can-help/survivors/stroke-recovery)

To Learn More About this Study


Research In Focus is a publication of the National Rehabilitation Information Center (NARIC), a library and information center focusing on disability and rehabilitation research, with a special focus on the research funded by NIDILRR. NARIC provides information, referral, and document delivery on a wide range of disability and rehabilitation topics. To learn more about this study and the work of the greater NIDILRR grantee community, visit NARIC at [www.naric.com](http://www.naric.com) or call 800/346-2742 to speak to an information specialist.

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