

Description of the project

Peer-led aphasia support groups – improving participation and Quality of Life

- Joint research project of the Catholic University of Applied Sciences Mainz and the University of Applied Sciences Fresenius, Idstein.
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In Germany about 270.000 people annually suffer a stroke. Aphasia, a neurologically based language disorder, affects about one third of acute stroke patients, with 15% still having aphasia 18 months later. Besides the grave impact on communication people with aphasia and their relatives suffer particularly from the psychosocial consequences. There is a great impact on Quality of Life. About 70-80% are unable to return to work. Decreased QoL is accompanied by typical burdens: social isolation and diminished autonomy, depressed mood up to depression, with an average prevalence after stroke of 29%. Even up to 62% of the patients with aphasia fulfill the criteria of depression 12 months after stroke. Furthermore, relatives develop e similar emotional and physical problems.

Support groups might be helpful. However, they are typically led by a professional leader, which involves the risk of forcing people with aphasia into the role of passive recipients of care. Besides, there are barriers which deter people with aphasia from joining a support group. Furthermore, an independent systematic offer for the relatives doesn't exist in Germany yet.

In our interdisciplinary study we aim at initiating peer-led support groups to improve the sense of empowerment and shared ownership for the leading persons and the members. We develop a training for peer leaders to enable them to run a group by themselves. The training is based on a pre-study which aimed at learning more about the actual situation of support groups and on the literature. The planned three-days training combines elements of empowerment didactics. It includes impulse talks as well as exercises of group moderation and finding relevant topics, e.g. biographical aspects. We expect an improvement of Quality of Life of the peer-leaders as well as of the group members. As a quantitative measure we will use the Aachen Life Quality Inventory (ALQI). For qualitative analysis we plan to use videography and interviews to learn more about the interaction in the groups.

In a first attempt with ten participants with a chronic but different type of aphasia an early version of the training procedure was considered positive. Most participants experienced post-training an increase in self-confidence as measured by a specially designed questionnaire. Participants learned more about discussion rules and addressing relevant group issues. Regarding all contents, the participants wanted further information.

A support period which should follow the training to sustain the initiated peer-led groups will be constructed. Additionally, a support offer for the relatives will be developed.

An increase of knowledge regarding the support of people with a chronic disease will be achieved by this work. New ways of dealing with the demographic change might be detected. With further proven effectiveness the role of the speech therapist in providing support to peer leaders has to be redefined.