

Quality of life in leaders and members of peer-led aphasia support groups - preliminary results of a systematic approach

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Background & Aims

People with aphasia (PWA) often experience reduced quality of life (QoL) with diminished autonomy and challenges in maintaining strong social relationships (Hilari & Northcott, 2016). Support groups can stimulate communication, social inclusion, adjustment to the situation and growth in purpose in life, but they are typically managed by professionals or family members. This risks forcing PWA into the role of passive care recipients. In contrast, peer-led support groups can provide a sense of worth and meaningful participation for PWA (Rotherham et al., 2015). Thus, we initiated peer-led support groups to improve self-efficacy and shared ownership within the group leaders and members (Attard et al., 2015).

The aims of the project 'Support groups for people with aphasia – improving quality of life and competence (shalk)' are:

- the development of a training for peer leaders to enable them to run a group by themselves
- the evaluation of QoL of the group leaders and members



Method

Intervention

- 3-days training for group leaders (biography work, moderation skills, framework conditions)
- an introductory phase with supervision, an experimental phase in which the groups worked almost independently, and a fully autonomous phase (each with 6 sessions)

Evaluation

- the pictorial version of the Aachen Life Quality Inventory (ALQI, Engell et al., 2003)

Training content

Topic 1: definition of self-help

- aims & benefits
- group leaders & challenges

Topic 2: relevant topics & moderation

- introduction to biography work
- function & responsibilities of moderator
- questioning technique

Topic 3: framework conditions

- rules
- time structure of a meeting

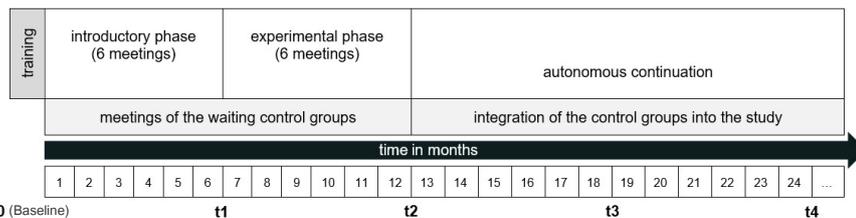


Figure 1 Research design

Results

Table 1 Group characteristics (n = 17)

characteristics	participants
Mean age(SD), range, years	62.0 (7.49), 52-76
Male sex, n (%)	12 (70.6)
Time since stroke at inclusion mean (SD), range, months	114.37 (106.82), 10-444
Degree of impairment (speech production)*, n (%)	
– mild	6 (35.3)
– moderate	3 (17.6)
– severe	8 (47.1)

*Classification based on the clinical judgment

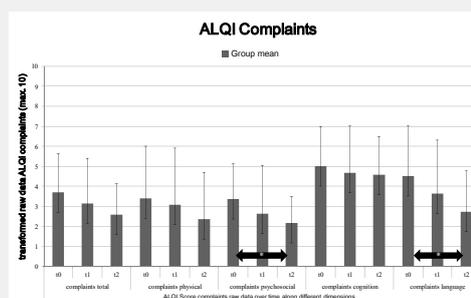
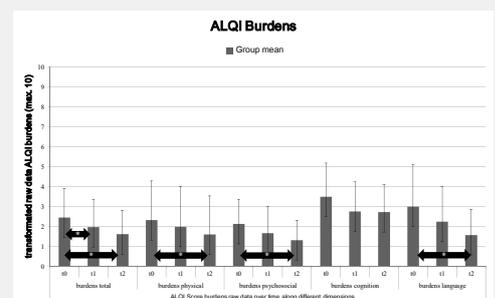


Figure 2 & 3 ALQI Complaints and Burdens ($p < .02$, Wilcoxon signed-ranks test, two-tailed, Bonferroni-Holm adjusted)

significant decrease: in Complaints (Cohen's d)

- psycho-social (t0 vs. t2, d.773)
- language (t0 vs. t2, d.786)



significant decrease: in Burdens (Cohen's d)

- overall score (t0 vs. t1, d.336; t0 vs. t2, d.623)
- physical (t0 vs. t2, d.368)
- psycho-social (t0 vs. t2, d.738)
- language (t0 vs. t2, d.812)

Discussion

Our attempt to improve QoL in PWA by means of peer-led support groups proved to be successful. There is a continuous improvement in QoL over the introductory phase and the experimental phase, especially in the subjective burdens score. This could be due to an increase in the sense of autonomy (Rotherham et al., 2015) and the biographical orientation of group meetings. Obviously, the improvement starts during the introductory phase. However, it may take more time to implement the approach independently, which is why the following improvements are weaker. The data after another 6 months are still missing. With demonstrated effectiveness of the intervention, SLTs could be trained to initiate new peer-led groups or to transfer professionally-led groups into peer-led groups.

Literature

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