Peer-to-peer Support: Digital Networking in Aphasia to Improve Quality of Life (PeerPAL) - Study Protocol for App Development and Evaluation

Christina Kurfess (christina.kurfess@oth-regensburg.de)
Ostbayerische Technische Hochschule Regensburg

Sabine Corsten
Katholische Hochschule Mainz

Marie Knieriemen
Katholische Hochschule Mainz

Daniel Kreiter
Ostbayerische Technische Hochschule Regensburg

Norina Lauer
Ostbayerische Technische Hochschule Regensburg

Study Protocol

Keywords: Aphasia, Quality of Life, Social Media, Digitisation, Peer-to-Peer Support

Posted Date: September 7th, 2021

DOI: https://doi.org/10.21203/rs.3.rs-844516/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License.
Read Full License
Abstract

**Background:** People with aphasia (PWA) often have a reduced quality of life. Nevertheless, there are currently only a few specific services that respond to this problem. Hence, there is a pressing need for action to improve participation and well-being of people with aphasia. An adapted social network could be a solution. Well-being could be increased by exchanging experiences with peers in a similar situation. Moreover, comprehensive digital coverage would also be possible in rural and underserved areas. This digital social network should be adapted to the specific needs of PWA. Therefore, a participatory, agile process with the involvement of the target group should be adopted.

**Aim:** The aim is to develop and evaluate a social media platform as a smartphone app to support the social integration of PWA and to improve their quality of life. In addition to the digital exchange, face-to-face meetings between PWA should be stimulated.

**Design:** The study will be conducted in a randomised pretest-posttest control group design with follow-up testing. The participants will be randomly assigned to the experimental intervention (36 participants) or the control intervention (36 participants). The primary outcome is quality of life, measured with the SAQOL-39. At all measurement times, psychological well-being is recorded with the help of two measuring instruments (GHQ-12 & DISCs). The secondary outcome is the recording of social contacts and activities as well as associated emotions, registered in a structured diary. In addition, communication skills (measured with the CPIB) and social support (recorded with the F-SozU) will be examined.

**Method:** During the first project phase, a user-centred, agile development process will be adopted to design the app. The target group will be involved in the app development in a participatory manner. A workshop is planned for the users of the app. In the second phase, the usability and user-friendliness of the app will first be evaluated in a feasibility study. Subsequently, in the main study, the app will then be tested by the target group for 4 months.

**Discussion:** The app developed in the research project is the first social network that is tailored to the needs and capabilities of PWA. It aims to enable better exchange between PWA to improve social participation and quality of life.

**Background**

Aphasia is an acquired language disorder due to brain damage. People with aphasia (PWA) show difficulties in producing or comprehending spoken or written language (Orchardson, 2012). Aphasia is a common consequence of stroke. It occurs in about 30% of all stroke patients (Pedersen et al., 1995). Up to 80% of aphasia are the result of a cerebral insult (Kolominsky-Rabas & Heuschmann, 2002). Every year around 270,000 people in Germany suffer a stroke. The prevalence of aphasia is around 100,000. It will continue to rise due to demographic change and increasing survival rates because of improved medical care (Rothwell et al., 2004).
PWA often have a reduced quality of life (Hilari et al., 2012). It is even known that aphasia reduces quality of life even more than cancer or Alzheimer's disease (Lam & Wodchis 2010; Manders et al., 2010). PWA experience considerable psychosocial changes along with a loss of autonomy and reduced social participation to the point of social withdrawal (Vickers, 2010; LeDorze et al., 2014; Musser et al., 2015; Jones, 2017; Konnerup, 2018). Along with social isolation (Lee et al., 2015), up to 62% of PWA show signs of depression twelve months after a stroke (Kauhanen et al., 2000). PWA take part in fewer social activities (Cruice et al., 2006; Vickers, 2010). As a result, they are also exposed to the risk of losing contact with friends and their wider social network (Fotiadou et al., 2014; Vickers, 2010; Northcott & Hilari, 2011, Ellis et al., 2019). Lack of involvement in the social context and the associated emotional burden lead to a considerable impairment of quality of life of PWA (Hilari et al., 2012; Lee et al., 2015; Santo Pietro et al., 2019). In addition, mobility is often reduced, which further restricts participation and quality of life (Lee et al., 2015).

A possible solution could be to participate in daily activities with family, friends or self-help groups. Activities and relationships that are perceived as meaningful are decisive for quality of life and successful handling of aphasia (Brown et al., 2012). In particular, support from peers in a similar situation is seen as beneficial (Hilari et al., 2021; NHS Improvement - Stroke, 2011). Even basic emotional support from peers significantly reduces depressive symptoms (Mead et al., 2001). For stroke patients in the acute phase, individual peer support leads to emotional relief (Kessler et al., 2014). With support from other PWA, a target group-specific, antidepressant, preventive effect can be achieved (Baker et al., 2018).

Peer befriending consists of social and emotional support provided by people with experience of a (similar) condition in order to aid social or personal change (Solomon, 2004). The term “peer friendship” is widely used in mental health (Repper & Carter, 2011). One-to-one peer support (also called peer befriending) has the potential to improve psychological well-being in stroke and aphasia (Hilari et al., 2021). Mutual support and shared experiences increase the experience of self-efficacy (Solomon, 2004; Lanyon et al., 2018). However, the number of studies on peer support in the area of aphasia is still limited because most previous studies on peer-to-peer or peer-befriending support exclude PWA (Hackett et al., 2008). In the UK, a professionally guided, peer-befriending approach aiming at depression prevention was tested in a face-to-face tutor setting for PWA (Hilari et al., 2019). One participant in the acute phase was directly matched with one peer-befriender at least 1 year post-stroke. The study succeeded in establishing friendships between people with aphasia of the same age. There are indications that this procedure could prevent or reduce depression. Especially PWA post-stroke experiencing low levels of distress could benefit from the peer-befriending approach, particularly for mood in the longer term (Hilari et al., 2021).

With regard to self-help in aphasia intervention, the peer-to-peer approach has been increasingly considered in recent years (Tregea & Brown, 2013). Correspondingly, individual matching supervised peer-befriending approaches could also be used successfully in groups (e.g. Attard et al., 2015). PWA particularly benefit from exchange with peers in groups. However, these are often not managed by PWA themselves, but predominantly by speech-language pathologists or other health professionals (Lanyon et al., 2013). Therefore, PWA remain passive recipients of help (Code et al. 2003). Participation of PWA could be improved by giving them an organisational and moderation function within the group.
(Rotherham et al. 2015). This was the starting point of the research project “Support groups for people with aphasia – improving quality of life and competence” (shalk; Lauer & Corsten, 2018). The aim was to develop a training programme for peer leaders to enable them to run a group by themselves. Furthermore, quality of life of the group leaders and members was evaluated (Lauer & Corsten, 2018). The preliminary results show the effectiveness of the approach (Corsten et al., 2018).

However, structural restrictions make it difficult to participate in support groups (mobility, lack of speech therapy provision, especially in rural or underserved areas; Hilari et al., 2021; Lanyon et al., 2018). Such barriers to social participation could be remedied using digital solutions. Digital media can increase autonomous, social participation in the case of health impairments, as Moorhead et al. (2013) found in a review (regarding depression see Takahashi et al., 2009). In this way, contacts and friendships could even be made over distance. This could be helpful especially for people in socially problematic situations. Existing social media platforms such as Facebook are, however, too complex for PWA (Buhr et al., 2017). Moreover, adapted services so far relate primarily to exchanges via email (e.g. Mahmud & Martens, 2013, 2016; Thiel et al., 2017; Menger et al., 2020). Until now, digital media in aphasia rehabilitation have concentrated mostly on augmented communication in analogue situations and language-specific training as a videoconference (Brandenburg et al., 2013; Bilda, 2017; Asghar, 2021). Initial concepts use virtual environments in order to practice specific language skills (Egaji et al., 2019), but also social participation in groups e.g. EVA Park (Galliers et al., 2017; Marshall et al., 2020). Digital, autonomously usable peer-to-peer support for PWA to increase social participation has not yet been investigated.

There is a pressing need to develop digital interventions to improve the psychosocial well-being of PWA (Hilari et al., 2019). Technical aids can improve access to and quality of communication among PWA (Dalemans et al., 2010). Yet it must be noted that aphasia is often associated with other neurological deficits such as hemiparesis or hemianopia (Fisher, 2009). Furthermore, as aphasia is more common among older adults, digital skills are often lacking (Menger et al., 2020). Possible secondary neurological diagnoses and the advanced age of the target group must be considered when designing the app. Nevertheless, Buhr et al. (2017) found in a feasibility study that an adapted social media tool used for the asynchronous exchange between PWA facilitated interaction among individuals with aphasia. The social network AphasiaWeb developed by Buhr et al. has a linguistically and visually simplified layout and multimodality input/output features. However, activities cannot be planned. The added value of a new social network over existing ones should be the mediation of “matching” PWA with regard to similar interests, but also same experiences for emotional and psychological support. In addition, it is necessary to support relationships by offering chat functions and a platform for appointments, activities and exchanges.

The project “Peer-to-peer support: digital networking in aphasia to improve quality of life (PeerPAL)” involves the development and evaluation of a social network in the form of a smartphone app. A participatory research approach is used by integrating the expertise of speech and language therapists on the one hand, but also the expertise of PWA on the other hand in the development process. Findings will be gained on digital learning for older adults under the condition of linguistic restriction. The guidance
and support the target group needs must be clarified. In detail, this includes the creation of a catalogue of requirements for the app in collaboration with PWA. In addition to implementing important functions such as the chat function or text input, it is becoming apparent that a matching function would help the target group to identify participants with similar interests. By testing the app as part of the participatory study, content-related and technical difficulties can be eliminated as far as possible. The aim is to gain knowledge of how digitisation can be used to promote a digital, but also analogue exchange between PWA.

The study contributes to digital exchange within a vulnerable population group and offers the potential to relieve both relatives of PWA and the health system. Since most PWA strengthen the bond with closest family members after stroke, they come into focus and constitute the most important contacts (Hilari & Northcott, 2006; Ellis et al., 2019). Exchange with other PWA can improve communication within the family, can reduce reliance of PWA on family members and can provide an opportunity for family members to have time on their own (Rotherham et al., 2016).

The overall goal of the PeerPAL project is to develop and evaluate an app to improve social exchange and quality of life in PWA. In addition, the app should help prevent depression. Exchange via a digital social network is also intended to prevent reduced psychological well-being and social withdrawal. The digital solution should help overcome physical distances. In addition to digital exchange, face-to-face meetings with peers and participation in social activities will be stimulated, which should result in further improvement of social inclusion. Closely related to the overarching goal is the implementation of the app to promote independence of PWA.

The first phase of the PeerPAL intervention program involves developing the app. Four PWA will be consulted within a user-centered, agile development process design. Thus, the concept will be developed and validated. In the second project phase, use of the app will be evaluated in a pretest-posttest control group design in form of a feasibility study. Additionally, in a third project phase, the app will be evaluated in the main study. A pretest-posttest design is used again, but this time with two subsequent follow-up surveys.

**HYPOTHESES**

**Primary hypothesis**

With smartphone-based peer-to-peer support, the subjective quality of life of PWA measured with the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39, Hilari et al., 2003) should significantly increase immediately after the intervention as compared to the baseline. This effect will remain stable over 3 and 6 months, respectively.

With smartphone-based peer-to-peer support, the psychological well-being of PWA in the intervention group should remain stable over the entire course of the study. Two tests are used to assess psychological well-being, the General Health Questionnaire (GHQ-12; Goldberg et al., 1988) and the
Depression Intensity Scale Circles (DISCs, Turner-Stokes et al., 2005). Psychological stability is constant in the intervention group immediately after the intervention as compared to the baseline.

**Secondary hypothesis**

Changes in quality of life, measured with the SAQOL-39, are greater in the experimental group than in the control group. Furthermore, participants of the intervention group will achieve a significant increase in their activities immediately after the intervention compared to the baseline. The activities are recorded in a structured activity diary (ATB; Bach et al., 2013). With the help of the Social Support Questionnaire (F-SozU, Fydrich et al., 2007), statements about support from the social environment are measured. Social support, especially through peers, will significantly increase immediately after the intervention compared to the baseline. The effects remain stable up to 6 months after the intervention.

Communication skills of the participants in the intervention group will significantly increase immediately after the intervention compared to the baseline. Communicative abilities are assessed using the Communicative Participation Item Bank (CPIB; Baylor et al., 2013). Again, the changes will be greater in the intervention group than in the control group. The effects remain stable up to 6 months after the intervention.

**Methods**

**Design**

The project consists of three phases. The first phase will last for 12 months and will include development of the app and training for the participants. During the second phase, a feasibility study will take place. Four PWA will use the app over 2 months after a 3-hour training session. During the first month, participants will be closely supervised. In the second month, only technical support will be provided. Finally, the third phase will involve a randomised pretest-posttest study with a control group and two follow-up surveys. A single-blind, mixed-method, parallel group design will be used. The study will consist of two phases. During the first 2 months, participants will receive close supervision. During the second 2 months, only technical support will be provided. A total of 72 PWA will be included in the main study. Figure 1 shows the study design.

The app will be open sourced after the project, so participants in the control group who are interested in the app will have the opportunity to use it afterwards. The Template for Intervention Description and Replication (TIDieR) guide (Hoffmann et al., 2014) was used for description of the study interventions. The development of the study design is oriented towards international recommendations. The Recommendations for Interventional Trials Standard Protocol Items: Recommendations for Interventional Trials [SPIR-IT] 2013 statement (Chan et al., 2013) was used for this purpose.

**Participants: inclusion and exclusion criteria**
Inclusion criteria for participants in the feasibility study and the pretest-posttest control group study are as follows:

- Persons with chronic aphasia (6 months postonset): determined by the Aachen Aphasia Test (AAT; Huber et al., 1983). At this early stage, an intensive language-specific therapy is predominant and coping processes are the main focus.

- Low levels of emotional distress: This is to ensure that participants do not require more complex psychological interventions. As the present intervention is preventive, participants should show only first signs of depression, operationalised with a score ≤ 8 on the Geriatric Depression Scale (GDS, Sheikh & Yesavage, 1986). For values between 5 and 8, psychological support is recommended. This will be discussed with the participants in a personal meeting.

- Participants should have a smartphone with internet access.

- Vision (with aids) should be sufficient for smartphone use.

No criteria for linguistic abilities are formulated (see Buhr et al., 2017). Thus, the participants should represent a broad spectrum. Persons who do not meet the above inclusion criteria will be excluded from the study.

**Two-stage consent process**

The control group will be blinded to the intervention. The Ethics Committee has approved this approach, but it requires an adjustment in the information process for participants. After randomisation, PWAs will be informed of the project content depending on their group assignment to avoid debriefing. The PWA will be informed in advance that there will be two groups and that the use of the smartphone in everyday life will be investigated. For the intervention group, a detailed briefing will take place immediately after group allocation. For the control group, a debriefing is planned after the intervention is completed. This is to prevent bias effects on the data.

**Randomisation**

Participants will be randomised within three days of the baseline assessments being completed. Each participant will be randomised to the intervention or control group using a computer and assigned a unique patient identification number (PIN). Assignment to the intervention or control group will be based on blinding of the control group before basic education of the intervention group.

**Blinding**

The primary and secondary outcomes will be evaluated independently of the study assessors performing the pre- and post-intervention assessments. The evaluation will be performed by other staff members who are experienced in administration and evaluation. Thus, the Outcome-Scorer and assessors will be different employees, but both are integrated in the project. However, rules will be established in advance to ensure the Outcome-Scorers and assessors do not discuss the investigations. The scorers will only
receive an anonymous copy of the test sheets to be evaluated. They will be blinded to group allocation (experimental, control) and testing session (baseline, posttest or follow-up). Unblinding of outcome scorers will not lead to the termination of a participant’s participation in the study. In the case of unblinding, an attempt will be made to replace the outcome scorers and re-administration will take place.

App development and feasibility study

The app will be developed for use on mobile devices (iOS and Android). The development process is structured in an agile and user-centred manner, such that PWA will be involved in the whole development process. As a first step, a design sprint workshop has already taken place. During the workshop, PWA were asked to share their ideas and requirements for the app. As a result, a first prototype was developed and built as a click dummy. In six focus group meetings with four PWA, an agile process is currently being adopted to further develop and finalise the prototype. At this point, agile means alternating between discussions in the focus group and revision of the app. After a final review, four participants will test the app over 2 months under the conditions of the main study. The support provided is based on the main study.

During the development phase, adjustments will be made to the app if necessary. Specifically, after each of the six focus group meetings, changes to the app prototype are expected and will be integrated. During the feasibility study and main study, only bug fixes will be integrated. If further changes are considered necessary in the feasibility study, adjustments will be made between, but not during, project phases.

App content

The app will be designed to have a clear and more simplified appearance (Buhr et al., 2017). The following functions will be integrated into the app:

- Chat function: Users will be able to communicate with each other via written language, images and emojis. Both individual and group chats are planned.
- Telephone function: There will be a telephone function with and without an additional video option.
- Feed function: There will be a feed function where PWA can post on a public page about interesting events and activities or if they need or offer help for example when visiting a doctor
- Participant matching: Participants will be able to search and find contacts by entering optional matching parameters in order to network with others.
- Activity invitations: It will be possible to plan and share activities with other users. Digital networking will also stimulate exchange in the real world.

For example, if participants would like to go on a hike with other users, they could set a location and time for the hike and send it to selected contacts or post it on the feed. Invited users would then have the option of accepting or declining the invitation. The app would send them two appointment reminders. To prevent forgetting the appointment, users would be asked a few days before the meeting, and a few hours before the meeting, whether they still want to attend the event. They could confirm this with one click.
Workshop concept

The workshop is scheduled for three hours and is based on an action-oriented approach (Pihlanto, 1994). In small groups of four participants, technical and media skills as well as knowledge of multimodal communication will be taught. In training exercises, participants should practice using the app independently. Following the feasibility study, the contents of the workshop will be revised and optimised before the participants of the pretest-posttest control group study receive training.

Intervention

36 participants in the intervention group will use the app independently in their daily lives over a period of 4 months. During the first 2 months, one visit to each of the participants will take place to support them in posting content and handling issues. In addition, participants will receive weekly individual feedback on their usage behaviour. The type of feedback will depend on the preferred communication modality. This should increase the participants’ motivation to use the app (Zapata et al., 2018). To encourage independent use of the app and self-directed learning, participants will be asked to take at least two actions in the app each week during the first phase, e.g. by messaging in a chat, planning activities or accepting an activity invitation. In the second phase of the intervention, users will receive weekly feedback and support in case of technical issues. After the intervention is completed, participants should continue to use the app. Technical assistance is provided as required up to the second follow-up.

The 36 participants in the control group will receive usual care, comprising all health care, social care and voluntary services available in their area. They are also free to use apps (except the PeerPAL app) on their smartphone to share or meet with others.

Measures

Primary outcomes

The primary outcome will be quality of life of PWA, to assess the impact of the measure on quality of life and psychological well-being. This will be determined using the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39, Hilari et al., 2003). The time required for the test is manageable, suitable for the target group and internationally compatible. The test shows good values in internal consistency, test-retest reliability and construct validity (Hilari et al., 2003). The General Health Questionnaire 12 (GHQ-12; Goldberg et al., 1988) will also be carried out. This is a mental health assessment. The procedure replicates that of Hilari et al. (2019). The number of participants unable to finish the GHQ-12 will be examined. In addition, the use of the Depression Intensity Scale Circles (DISCs, Turner-Stokes et al., 2005) is planned. The GHQ-12 will be used as the primary outcome. The DISCs will be used as a supplement. If 10 % of the subjects cannot finish the GHQ-12, the DISCs will be scored as a primary outcome; otherwise, the DISCs will be used as a secondary outcome. The DISCs was recently translated into German by the study group and will be used for the first time in Germany, so it is useful to re-examine its usability. All tests will be applied in the feasibility and the main study.
Secondary outcomes

As a secondary outcome, a structured activity diary for listing social contacts or activities and emotions felt during these activities will be used, which was developed by members of the research group and successfully tested with PWA (Bach et al., 2013). It can be evaluated quantitatively and qualitatively. The quantitative evaluation enables a comparison of the multiplicity of different activities. The qualitative evaluation makes it possible to learn more about the type of activity and the associated emotion. The activity diary will only be used in the main study. The Social Support Questionnaire (F-SozU, Fydrich et al., 2007) examines perceived support from the social environment. Communication abilities are assessed using the Communicative Participation Item Bank (CPIB; Baylor et al., 2013), a self-assessment test. This procedure was also translated from English into German by the research group in a scientific translation. All tests will be carried out at all test times, t0, t1, t2, and t3. The F-SoZu and the CPIB will be used in both the feasibility study and the main study.

Qualitative Outcomes

Immediately after the workshop and after the feasibility study, semi-structured interviews will be conducted to evaluate the process and results. Additionally, semi-structured interviews regarding the social network and living situation will be conducted with ten randomly selected participants of the intervention group directly after the intervention (t1) and during the follow-up evaluation (t2 and t3).

Power calculation

The sample size for the primary outcome was set based on the group intervention. The statistical power was calculated with G*Power. With 36 participants each in the intervention and control group, a mean effect size of 0.6 in the primary outcome is sufficient to confirm differences (with n = 30 a mean effect size of 0.65). The t-test for differences between two independent means was used. The input parameters were one-tailed calculation with an alpha error of 0.05 and a power of 0.8 given the exploratory character of the study.

Statistical methods: data analysis

The feasibility study will examine the handling of the app and user behaviour of the participants. A very small sample will be used for this purpose. No quantitative statistical evaluation is planned. The data of this study phase will be analysed descriptively and qualitatively.

In the main study, inferential statistics of intra-individual changes and inter-individual differences as well as group differences will be evaluated after testing for normal distribution either with nonparametric or parametric procedures with the IBM SPSS 25.0 statistics program. The study data, which refer to the effectiveness of the intervention, will be evaluated as a pre-post analysis with an observation period of four months. The metric variables will be analysed according to the distribution characteristics by means of a t-test for connected samples or Wilcoxon test. In addition, regression analyses and the Kruskal–Wallis test will be used. The number of factors will depend on the extent to which the recorded group
In this study, the first adapted smartphone-based social network for PWA will be developed. The aim is to increase quality of life of PWA and prevent depression. Improved scores in the SAQOL-39 (Hilari, 2003) are expected, which correspond with an increase in quality of life. The scores in the GHQ-12 (Goldberg et al., 1988) and DISCs (Turner-Stokes et al., 2005) are expected to be stable. This would mean no manifest depression develops. By this, the preventive character of the intervention could be shown. The adapted digital network is expected to prevent psychological pathologies in aphasia and psychotherapeutic interventions. This assumption is supported by the well-documented relationship between social participation, health and mortality risk (Holt-Lundstad & Smith, 2012).

Fidelity

To ensure adherence to the protocol and comparability of the implementation, the feedback provided to participants by project staff will be recorded in detail (number of posts, number of messages sent, time spent online). This is developed and defined in advance according to international guidelines. Workshop fidelity is monitored by video recordings and evaluated with a checklist. The template is a checklist that was developed and evaluated in a previous project, “Biography work in long-term residential aged care with tablet support to improve the quality of life and communication” (BaSeTaLK; Corsten & Lauer, 2020).

Data management

A data management plan has been created via DMPonline. For secure data exchange between the network universities, Synology Cloud Station Drive will be used, which enables data storage on a server of the OTH Regensburg. Project staff at each university will enter anonymised participant data directly into Synology Cloud Station Drive. Once data collection has commenced, the study’s chief investigators will monitor data for completeness and accuracy. They will also continuously monitor the progress of the study, adverse safety events and data accuracy. No formal criteria exist for discontinuing the trial early.

Discussion

In this study, the first adapted smartphone-based social network for PWA will be developed. The aim is to increase quality of life of PWA and prevent depression. Improved scores in the SAQOL-39 (Hilari, 2003) are expected, which correspond with an increase in quality of life. The scores in the GHQ-12 (Goldberg et al., 1988) and DISCs (Turner-Stokes et al., 2005) are expected to be stable. This would mean no manifest depression develops. By this, the preventive character of the intervention could be shown. The adapted digital network is expected to prevent psychological pathologies in aphasia and psychotherapeutic interventions. This assumption is supported by the well-documented relationship between social participation, health and mortality risk (Holt-Lundstad & Smith, 2012).

Peer-to-peer contact and peer-befriending will be supported in a low-threshold way. The target group will be involved in the development of the app. The social network will be open sourced after the end of the project. Thus, the app could be used beyond the end of the project and a continuous, flexible adaptation with low operating costs could take place. In addition, training courses for speech and language therapists, neuropsychologists and social pedagogues are planned in order to make PWA aware of the app and, if necessary, provide assistance during initial use. Professionals could benefit as PWA will gain
more autonomy and rely less on the support of professionals. Through autonomous networking, the shortage of specialists in the health professions, especially in rural regions (Walter & Altgeld, 2000; Keck & Doarn, 2014; WHO, 2016; Roche & Nicholas, 2019), is countered.

Due to the expected positive effects on quality of life and well-being, care of PWA could be optimised. The Covid 19 pandemic has had a major negative impact on the social well-being of all people, especially PWA (Pisano, Giachero, Rugiero, Calati & Marangolo, 2020). The pandemic reinforces the urgency to develop new solutions both for therapy and for PWA, even without therapeutic intervention, to train communication skills (Pisano et al. 2020). Digital solutions for communication exchange are therefore also relevant in the future, both to compensate for the negative consequences of the pandemic and to positively enrich the everyday lives of those affected. Consequently, depression and secondary diseases can be prevented, which would lead to cost savings for the healthcare system. A transfer of the app to other groups, e.g. with neurogenic speech disorders, dysarthria in Parkinson's disease or multiple sclerosis, could be evaluated in following projects. In this way, further benefits can be generated. In addition, the project could be evaluated with a larger sample within the framework of a randomised controlled trial (RCT).

**Trial status**

The project started in December 2020 and the first focus group meeting took place in March 2021. A total of six focus group meetings are planned until August 2021. The project is officially registered and can be viewed on the public website of the German Register of Clinical Trials and in the World Health Organization's search portal (http://apps.who.int/trialsearch/). Cooperation agreements have been signed with the following practice partners: “Aphasie Landesverband” (Aphasia National Association) in Bavaria, the “Aphasiker-Zentrum” (Aphasia Center) in Lower Franconia, the AsklepiosKlinik Schauing, the “Berufsfachschule für Logopädie” (Vocational school for speech therapy) in Regensburg, the “Logopädische Praxis Brigitte Brauer” (speech therapy practice Brigitte Brauer) in Mainz, the “Logopädische Praxis Bruni Zeuner” (speech therapy practice Bruni Zeuner) in Idstein and the “Praxis für Logopädie und Neurolinguistik” (practice for speech therapy and neurolinguistics) in Regensburg.

**Declarations**

**Ethics approval**

Ethical approval was received from the Ethics Committee of the German Society of Nursing Science (reference: 20-032).

**Consent for publication**

Not applicable.
Availability of data and materials

The data sets used and analysed in the current study are available from the corresponding author upon reasonable request. No data of the intervention phases are available yet. Information on this can only be provided once the corresponding data collection has been completed.

Competing interests

None.

Funding

This project is funded by the Federal Ministry of Education and Research (BMBF). No additional funding was obtained.

Authors Contributions

CK elaborated and researched content on the background and hypotheses. MK compiled content on the method and wrote the discussion. Significant contributions have been made to the paper as a whole by NL and SC who are both responsible for the research conception and design, and who contributed to literature search, screening and editing the paper. DK is responsible for the programming and design of the app. All authors read and approved the final manuscript.

Acknowledgements

The trial sponsor is the Federal Ministry of Education and Research (grant from 2020-2023, 13FH077SA8, 13FH077SB8).

References


61. Rotherham A, Howe T, Tillard G. We just thought that this was Christmas": perceived benefits of participating in aphasia, stroke, and other groups. Aphasiology. 2015;29(8):1–18. doi:10.1080/02687038.2015.1016887.


**Figures**

<table>
<thead>
<tr>
<th>Workshop</th>
<th>Close supervision</th>
<th>Technical support only</th>
</tr>
</thead>
<tbody>
<tr>
<td>t0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IG (n=36) Workshop</td>
<td>Close supervision</td>
<td>Technical support only</td>
</tr>
<tr>
<td>CG (n=36) No intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>t0 Baseline</td>
<td></td>
<td>t1 After 4 months</td>
</tr>
<tr>
<td>t2 After another 3 months</td>
<td></td>
<td>t3 After another 3 months</td>
</tr>
</tbody>
</table>

*IG = intervention group; CG = control group*

**Figure 1**

Feasibility study, Main study with control group