

INTRODUCTION

- There is a large body of literature on the use of questionnaires to describe the impact of aphasia on stroke survivors' quality of life (QOL).
- The findings demonstrate robust evidence for the severe effects of communication deficits on social integration and well-being for people with aphasia (PWA) post stroke.
- Traditionally, PWA are excluded as research partners, because of perceived barriers in communication. As a result, there is potentially a gap between the items chosen in the tools and the pragmatic needs of PWA.

AIM AND PURPOSE

The aim of this review is to determine the evidence showing the direct involvement of PWA in the creation of QOL and Aphasia Impact Related Questionnaires (AIR-Qs). The purpose is to explore the presence versus the absence of the contribution of PWA in the creation of QOL and AIR-Qs.

METHODOLOGY

- A scoping review was conducted by an expert librarian in health sciences and two independent reviewers based on the PRISMA-ScR protocol.
- Search strings were based on Mesh terms and keywords associated with the term 'stroke', 'people with aphasia', 'communication', 'well-being' and 'quality of life'.
- Five databases were used: Medline Complete, PubMed, PsychINFO, Scopus and Google Scholar.

RESULTS

- The PRISMA *four-stage flow diagram* detailing the review process of identification, screening, eligibility and inclusion of studies was used (see Figure 1).

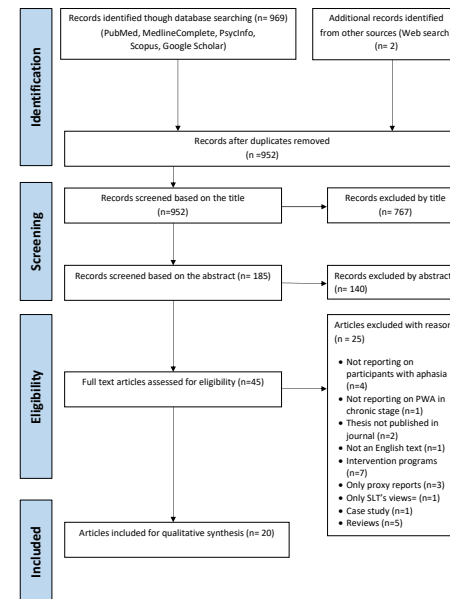
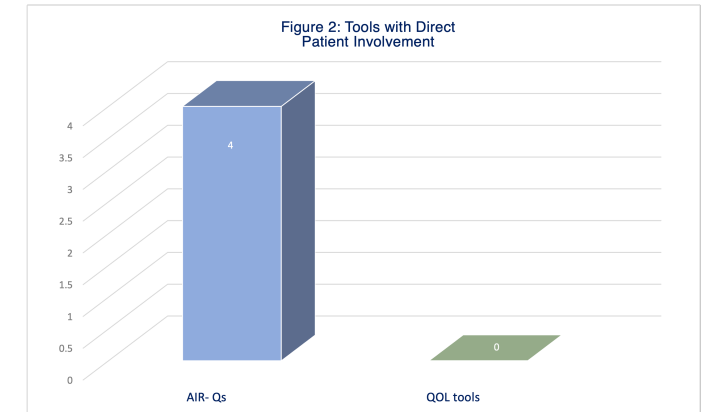


Figure 1: PRISMA Flow Diagram for the Scoping Review Process

- Out of 952 results, 20 studies met the eligibility criteria. Out of these, only 4 Aphasia Impact Related Questionnaires (AIR-Qs) studies (20%) were reporting the direct involvement of PWA. No QOL tools reported direct involvement of PWA (see Figure 2).
- Selected QOL studies reported that patient involvement has been mostly consultative in nature.



CONCLUSION

- There is a lack of a research framework which will promote consistency and transparency in reporting the involvement of PWA after Stroke in participatory studies.
- The absence of such framework limits the effectiveness to promote equitable best practice in stroke aphasia rehabilitation.

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