



Shared Decision Making for Persons with Aphasia: A Scoping Review

Konstantina Charamis, Caitlin Parsons, Marie-Cécile Domecq,
Carol Leonard and Laura Boland

EasyChair preprints are intended for rapid dissemination of research results and are integrated with the rest of EasyChair.

August 26, 2021

Shared Decision Making for Persons with Aphasia: A Scoping Review

¹Konstantina Charamis, ¹Caitlin Parsons, ²Marie-Cécile Domecq,

^{1,3}Carol Leonard, ^{4,5}Laura Boland

¹School of Rehabilitation Sciences, University of Ottawa, Ottawa, ON, Canada

²Health Sciences Library, University of Ottawa, Ottawa, ON, Canada

³Heart and Stroke Foundation Canadian Partnership for Stroke Recovery

⁴Ottawa Hospital Research Institute, Ottawa, ON, Canada

⁵Western University, London, ON, Canada

Introduction: Persons with aphasia (PWA) often retain decision making (DM) capacity, but language impairments pose barriers to participation. This can lead to their marginalization from the DM process (Stein & Brady Wagner, 2006).

Shared Decision Making (SDM) is an evidence-based approach that promotes patient involvement in the DM process within healthcare. It encourages collaboration between the patient and the healthcare professionals and the exchange of information about healthcare options, their risks and benefits, and patient and family preferences and values (Makoul & Clayman, 2006).

SDM approaches could aid in overcoming the healthcare barriers faced by PWA; however little is known about SDM for PWA.

The purpose of this scoping review was to review and synthesize available evidence on SDM approaches and interventions for PWA.

Methods: We performed a scoping review following the six stages identified by Arksey and O'Malley (2005), enhanced by Levac et al. (2010): 1) identifying the research questions, 2) identifying relevant studies, 3) selecting the literature, 4) charting the data, 5) collating, summarizing, and reporting results, and 6) consulting with stakeholders and developing a knowledge translation plan. The following databases were searched: MEDLINE, EMBASE, PsycINFO, AMED, CINAHL, ComDisDome, LLBA and Scopus from 1982 to June 2020. We included peer reviewed and grey literature that reported on SDM approaches for PWA making a healthcare treatment or screening decision. We provided a narrative synthesis of the findings.

Two reviewers independently extracted data using a standardized and pre-piloted data extraction form. Inconsistencies in extracted data were resolved through consensus with a third rater. We extracted citation information (e.g., authors, year of publication, country of origin), study information (e.g., study aims, methodological approaches), SDM definitions, conceptual or theoretical underpinnings, aphasia subtypes, setting(s) of care, SDM interventions and associated communication interventions, SDM-relevant outcomes and measures, as well as important findings and gaps in the research.

Results: After deduplication, the search yielded 5492 citations. Of these, the full text was screened for 86 articles. Two studies met the inclusion criteria; one from Denmark (Isaksen, 2018), and one from the US (Brady Wagner, 2018) [Figure 1].

The decisions discussed were: whether to continue or terminate speech therapy (Isaksen, 2018); plans related to discharge (Brady Wagner, 2018). Neither study provided a clear definition of SDM or SDM interventions. The techniques and strategies used for supporting communication with PWA were: 1) Supported Conversation for Adults with Aphasia™; 2) Talking Mats; 3) other visual supports. No specific outcomes related to SDM for PWA were measured, nor was the effectiveness of SDM for PWA explored [Table 1].

Conclusions: There is a dearth of evidence informing the use of SDM with PWA. This population is at risk of being inappropriately excluded from decisions about their health due to their communication impairment. There is an ethical imperative to design, develop, and empirically evaluate SDM interventions tailored to PWA to ensure this population can make high quality and informed decisions that are consistent with their values and preferences.

References:

- Arksey, H. & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology: Theory and Practice*, 8(1), 19-32.
- Brady Wagner, L.C. (2018). Ethical framework of supporting medical decision making for persons with aphasia. *Perspectives of the ASHA Special Interest Groups*, 3(2), 80-87.
- Isaksen, J. (2018). Well, you are the one who decides: Attempting shared decision making at the end of aphasia therapy. *Topics in Language Disorders*, 38(2), 126-142.
- Levac, D. Colquhoun, H., & O'Brien, K.K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, 5(1), 1-9.
- Makoul, G. & Clayman, M.L. (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60(3), 301-312.
- Stein, J. & Brady Wagner, L.C. (2006). Is informed consent a "yes" or "no" response? Enhancing the shared decision-making process for persons with aphasia. *Topics in Stroke Rehabilitation*, 13(4), 42-46.

Acknowledgements:

Thank you to Ferne Mardlin-Smith, a PWA, whom we consulted for this review.

This project was partially funded by a Canadian Institutes of Health Research postdoctoral award to Dr. Laura Boland.



Figure 1: PRISMA 2009 Flow Diagram

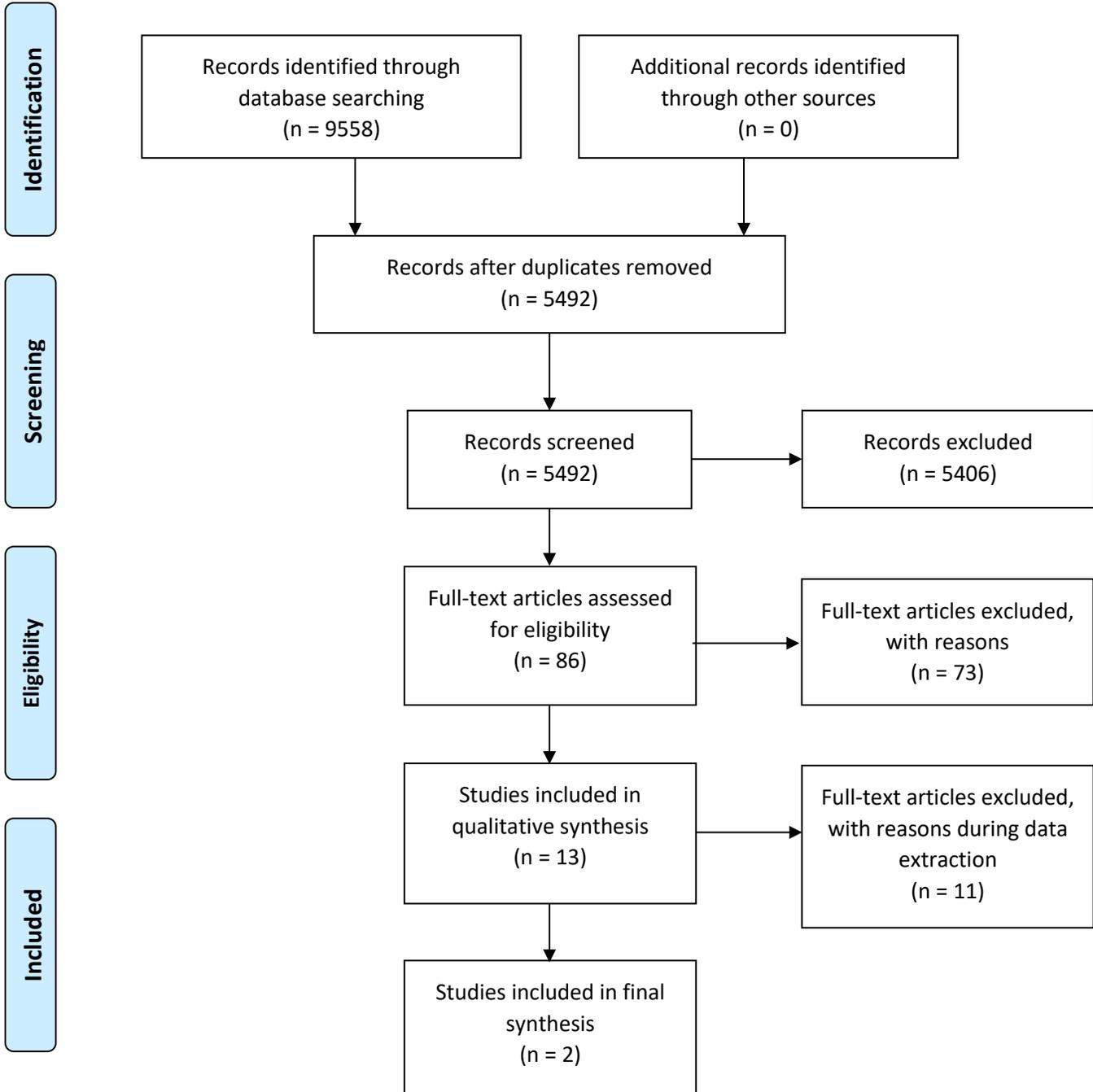


Table 1: Information about included studies

Study Characteristics		
	Article 1	Article 2
Author	Brady Wagner	Isaksen
Year	2018	2018
Country	USA	Denmark
Objective	“Uses a case discussion and review of the relevant literature to provide tools and examples to assist providers in dealing with ethical challenges related to DM for persons with aphasia.”	“Describe presence & process of Decision making (DM) as part of the clinical discourse between SLPs and PWA. Describe SLPs views on involvement of PWA in DM. Analyze discourse patterns between SLPs and PWA. Explore possible ways & times to increase SDM.”
Design	Case study/Clinical Vignette	Sequential mixed methods: phenomenology, ethnomethodology
Main Findings	Through supportive communication, SLPs and surrogates play a significant role in supporting PWA in the DM process.	SDM is desired and attempted, participants' views and roles can prevent SDM, SDM is not always necessary, aphasia can affect SDM.