Shared Decision Making for Persons with Aphasia: A Scoping Review

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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:


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.


Acknowledgements:

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Figure 1: PRISMA 2009 Flow Diagram

Records identified through database searching (n = 9558)

Additional records identified through other sources (n = 0)

Records after duplicates removed (n = 5492)

Records screened (n = 5492)

Records excluded (n = 5406)

Full-text articles assessed for eligibility (n = 86)

Full-text articles excluded, with reasons (n = 73)

Studies included in qualitative synthesis (n = 13)

Studies included in final synthesis (n = 2)

Full-text articles excluded, with reasons during data extraction (n = 11)
### Table 1: Information about included studies

<table>
<thead>
<tr>
<th>Study Characteristics</th>
<th>Article 1</th>
<th>Article 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Author</strong></td>
<td>Brady Wagner</td>
<td>Isaksen</td>
</tr>
<tr>
<td><strong>Year</strong></td>
<td>2018</td>
<td>2018</td>
</tr>
<tr>
<td><strong>Country</strong></td>
<td>USA</td>
<td>Denmark</td>
</tr>
<tr>
<td><strong>Objective</strong></td>
<td>“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.”</td>
<td>“Describe presence &amp; 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 &amp; times to increase SDM.”</td>
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<tr>
<td><strong>Design</strong></td>
<td>Case study/Clinical Vignette</td>
<td>Sequential mixed methods: phenomenology, ethnomethodology</td>
</tr>
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<td><strong>Main Findings</strong></td>
<td>Through supportive communication, SLPs and surrogates play a significant role in supporting PWA in the DM process.</td>
<td>SDM is desired and attempted, participants' views and roles can prevent SDM, SDM is not always necessary, aphasia can affect SDM.</td>
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