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REVIEW

Communication strategies to support decision-making by persons with aphasia: A scoping review

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Abstract

Background: An individual's ability to make autonomous decisions is fundamental to self-determination. The presence of neurological pathology, for example, aphasia, and its associated difficulties with language and/or cognition, may affect an individual's capacity to make decisions, or their ability to reveal their capacity to make decisions. Decision-making by persons with aphasia (PWA) can be enhanced when communication partners are trained and if communication supports are provided, for example, supports that reduce the linguistic and cognitive demands of the task, and/or that facilitate expression.

Aims: The main aim of this review is to identify the types of decisions for which persons with post-stroke aphasia receive support, the communication partners involved in supporting decision-making by PWA and the communication strategies implemented to support decision-making by PWA.

Methods & Procedures: A multifaceted search strategy was used. Specific keywords were used to search seven electronic databases. Hand-searches of two journals, as well as ancestral searches of the reference lists of selected articles was also performed. Through the application of predefined selection criteria, 16 journal articles, spanning from 1998 to 2021, were selected from the initial yield of 955 articles for inclusion in this review. Data pertaining to the aims of the study were extracted using a data-extraction form.

Outcomes & Results: This review shows that most of the research to date has focused on supporting persons with post-stroke aphasia in decisions pertaining to discharge planning or accommodation, and decisions pertaining to informed consent for participation in research. The communication partners cited most frequently as supporting decision-making by PWA are speech–language pathologists and family members. A range of communication strategies, most of which are components of Supported Conversation Techniques for Adults with Aphasia (SCA™), support decision-making by PWA. The most frequently listed strategies include augmenting information with different modalities, acknowledging the

competence of the PWA, thereby inviting initiation and collaboration by the PWA, and the allocation of sufficient time for the decision-making process.

Conclusions & Implications: This review presents research trends regarding the support of PWA in decision-making. Future research should focus on the effectiveness of the different strategies identified, and on the support of PWA in the making of a greater variety of complex decisions.

KEYWORDS
aphasia, decision-making, communication strategies, scoping review

WHAT THIS PAPER ADDS

What is already known on the subject

- PWA have the right to be given the opportunity to participate in personally relevant decision-making through all stages of life. Research has shown that decision-making can be enhanced with trained communication partners and if supports are provided that reduce the linguistic and cognitive demands of the task, and that support the expressive abilities of PWA.

What this study adds to existing knowledge

- This scoping review is the first to synthesize the findings of research regarding the types of decisions for which persons with post-stroke aphasia receive support, the communication partners supporting PWA in making these decisions and the communication strategies implemented to support decision-making by PWA.

What are the potential or actual clinical implications of this work?

- Clinicians working with PWA may be sensitized to the role they can play in supporting decision-making by PWA, the current state of the literature regarding types of decisions that may need to be supported, communication partners who can provide such support and communication strategies that may be helpful in this regard.

INTRODUCTION

The concepts of self-determination and well-being continue to receive increasing support in Western bioethics. Fundamental to self-determination is an individual's ability to make autonomous decisions in selecting, initiating, regulating and terminating engagement in activities aligned with his or her priorities (Haley et al., 2015). Decision-making is a complex, deliberative process (Gold & Shadlen, 2007) which is reliant on multiple cognitive and linguistic functions, including attention, working memory, inhibition and flexibility; auditory verbal comprehension; reading comprehension; the reasoning and weighing of different decision options and their likely consequences; and the expression of choice (e.g., Evans, 2008; Evans & Stanovich, 2013; Gold & Shadlen, 2007; McCormick et al., 2017). Adults are generally considered capable of making their own decisions and as such every adult deserves a starting presumption of decisional capacity, embodying the fundamental ethical principle of autonomy (Kapp, 2018). However, the presence of neurological pathology, and associated difficulties with language and/or cognition, may affect an individual's capacity to make decisions (Janssen et al., 2019; McCormick et al., 2017; Suleman & Kim, 2015), or their ability to reveal their capacity to make decisions (Kagan, 1998).

Aphasia, an acquired impairment of language comprehension, language production and the cognitive processes that underlie language (Murray & Chapey, 2001), poses challenges to the decision-making process. On the one

hand, the difficulties with language processing associated with aphasia may impact the comprehension of spoken or written information relevant to the decision that needs to be made (Braunack-Mayer & Hersh, 2001). On the other hand, the language production difficulties associated with aphasia are likely to impact the asking of questions and expression of choice related to the decision that needs to be made. As the neural substrates associated with language and some of those associated with rational decision-making share a common blood supply, persons with aphasia (PWA) are also likely to present with cognitive difficulties which further impact rational decision-making (Suleman & Kim, 2015). For example, PWA have been found to present with attention difficulties which, in turn, may impact the bringing of information relevant to the decision into consciousness for deliberate consideration (Evans, 2008). Furthermore, as comprehension and word retrieval might no longer be processed automatically in PWA, conscious language processing may take up resources within working memory which, in turn, results in difficulty manipulating information and running through hypothetical simulations (Evans, 2008). There is further a relationship between language and complex problem-solving (identifying different options, weighing the different options, selecting the best option and then developing a plan to implement the decision) (Suleman & Kim, 2015).

While aphasia may therefore affect decision-making in a number of ways, comprehension difficulties play a particularly prominent role. Most PWA regardless of severity, experience difficulties in the processing of spoken language, including reduced speech sound discrimination, difficulty associating meaning with spoken words, and short-term auditory memory difficulties. Reading comprehension is also often affected (Braunack-Mayer & Hersh, 2001). Unlike expressive difficulties, comprehension problems may remain covert. Kagan and Kimelman (1995), for example, in discussing informed consent in aphasia research, caution that while some PWA acknowledge that they do not understand, others either will not indicate lack of understanding, or do not realize when they have not understood.

As the degree of language and/or cognitive difficulty varies between PWA, the extent to which decision-making is affected also varies from person to person. Brady et al. (2012: 194) refer to a 'continuum of capacity'. At one end of the continuum are people with very mild aphasia, who can make their own decisions and are able to participate within the standard approaches to the provision of information without the need for adaptations. At the other end of the continuum are individuals who experience such severe language and cognitive impairment that proxy decision-makers are often called upon. Between these two extremes are those who have retained the capacity to make informed decisions, but who are unable to reveal their capacity owing to their language impairment (Brady et al., 2012).

Disability laws and acts are instruments that aim to put an end to discrimination against persons with disabilities and to remove barriers towards the full enjoyment of their rights and their inclusion in society. The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) (United Nations, 2006), as an international human rights instrument ratified by 164 countries, emphasizes the right to decision-making by persons with disabilities in general (Preamble). Furthermore, Article 12 highlights the role of appropriate support to enable persons with disabilities to exercise their legal capacity, and emphasizes that the rights, will and preferences of such persons need to be respected in all measures taken relating to the exercise of legal capacity. Since the adoption of the Convention, several countries have introduced recognition of support for decision-making into their legislation. While the scope and formality of the support regimes vary from country to country, they generally allow individuals to appoint one or more persons to assist them in obtaining and understanding information, evaluating possible alternatives and consequences of a decision, expressing and communicating a decision, and/or implementing a decision (United Nations, 2019).

Also recognized in the UN CRPD (United Nations, 2006) are augmentative and alternative modes of communication (e.g., Article 2). Augmentative and alternative communication (AAC) is an area of clinical practice aimed at compensating for impairments in speech–language production and/or comprehension by using additional or alternative methods of communication. AAC refers to both the use of aided supports (e.g., the use of writing, photographs, communication books and speech-generating devices) and unaided supports (e.g., facial expression, body language and gestures) to facilitate communication (Dietz et al., 2020). In addition to the use of aided and unaided supports to facilitate the exchange of information by PWA; the use of simplified language, increased frequency of pauses, the writing of keywords, the provision of picture supports, the repetition of important points, the verification of understanding, and the use of both open- and closed-ended questions are further strategies that support communication by PWA (Kagan, 1998; Penn et al., 2009; Rowland & McDonald, 2009) and are incorporated in the communication method of Supported Conversation for Adults with Aphasia (SCA™) (Kagan, 1998). SCA is an approach based on the idea of conversational partnerships. Drawing on approaches that emphasize the role of context, functional communication, conversation analysis, communication partners and AAC, the focus of SCA is on providing PWA with opportunities

for genuine adult conversation in everyday life. Intrinsic to SCA is the idea that PWA have the right to communicative access. SCA provides the communication partners of PWA with methods and materials for achieving this goal (Kagan, 1998). Communication participation, participation in life, future planning and decision-making can be enhanced when communication partners are trained and supports are provided that reduce the linguistic or cognitive demands of the task (e.g., Berg et al., 2016; Dietz et al., 2020; Kagan, 1998; Kagan & Kimelman, 1995).

In discussing the provision of support to PWA during the decision-making process, a distinction needs to be drawn between supported decision-making, support with decision-making and shared decision-making. According to Browning et al. (2014), both supported decision-making and support with decision-making involve the offering of support to a person who is unable to independently navigate decision-making. However, supported decision-making results in greater legal capacity for the person as the shared capacity and interdependent nature of decision-making is legitimized while the will and preferences of the person remain central to the process (Browning et al., 2014). Support with decision-making, on the other hand, refers to the provision of assistance in the form of, for example, accessible information, improved communication or environmental modifications and should not be confused with the offering of advice with the actual decision being made (e.g., Kagan et al., 2020). 'Shared decision-making' is the term given to the evidence-based, collaborative approach in which a clinician and patient jointly participate in making a health decision, thereby providing a framework for clinicians to communicate with patients about healthcare choices (Hoffman et al., 2014). While acknowledging these different definitions, the current paper is not focused on a classification of decisional capacity in PWA but concerns the provision of communication supports to PWA (and their partners) across the spectrum of decisional capacity. Such communication supports may reveal and enhance a person's capacity to make independent decisions but may also be useful for persons whose capacity to make independent decisions is limited.

A number of studies have addressed decision-making supports for PWA. Carling-Rowland et al. (2014), for example, show how a communicatively accessible capacity evaluation process with training enhanced the confidence and skills of social workers in accurately judging the capacity of PWA to make decisions regarding admission to long-term care. Simmons-Mackie et al. (2007) illustrate how, through the implementation of the Communicate Access Improvement Project (CAIP) in different healthcare settings, increasing team members' knowledge and skill in providing communication supports improved communicative access to information and decision-making by PWA. However, a recent review examining and synthesizing the available evidence on shared decision-making approaches and interventions for PWA regarding healthcare decisions specifically, revealed a dearth of evidence informing use of shared decision-making for PWA (Charamis et al., 2022).

At present, no comprehensive summary exists of the communication strategies mentioned in the literature as useful in supporting decision-making in PWA. This paper aims to fill this gap. Specifically, we aimed to describe according to the literature (1) the types of decisions that PWA are supported in making (healthcare and other), (2) the partners who support PWA in making these decisions, and (3) the communication strategies implemented to support PWA with decision-making. The components of decision-making supported by the communication strategies identified will also be discussed.

METHODS AND PROCEDURES

The interpretative scoping literature review methodology based on the framework proposed by Arksey and O'Malley (2005), advanced by Levac et al. (2010) was adopted for this paper. Scoping reviews are a form of knowledge synthesis for the informing of practice and policy and for the directing of future research priorities (Arksey & O'Malley, 2005). While quantitative systematic reviews typically only summarize evidence from experimentally controlled studies, scoping reviews incorporate a range of study designs. In scoping reviews, information pertaining to the extent, range, and nature of research activity in a specific topic or field of evidence is systematically examined and synthesized (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Davis et al., 2009). In scoping reviews, the relevance, credibility and contribution of evidence is critiqued in an iterative, conceptual and interpretative approach, rather than according to rigidly determined methodological considerations (Arksey & O'Malley, 2005; Davis et al., 2009). Scoping reviews thus reflect a method of synthesizing knowledge on a topic, including clinically appraised, scientific research evidence and identifying knowledge gaps.

Search strategy

Search terms

Search terms relevant to the research question were selected with the input of a subject librarian. The search terms were piloted, refined and adapted in accordance with the subject terms or thesaurus of each database using keywords related to the population (*aphasi** OR *dysphasi**) and the construct (*decision** OR *informed consent*). The term *informed consent* is used to refer to

an individual's autonomous authorization of a medical intervention or of participation in research (Beauchamp & Childress, 2001). *Informed consent* was thus used as a term together with *decision** to ensure that the search would yield research pertaining to medical decision-making and decision-making about participation in research by PWA. In MEDLINE (Web of Science), MeSH (Medical Subject Headings) terms were used to exclude irrelevant diagnoses or topics. Although keywords related to the intervention (communication strategies) were piloted, these seemed to result in searches that were too narrow. For this reason, only search terms related to the population and the construct were included.

Data sources

Seven electronic databases (Academic Search Complete, CINAHL, Health Source: Nursing/Academic Edition, Linguistics Database, MEDLINE Web of Science, PsycARTICLES and PsycINFO) were searched in April and May 2022 for published studies related to decision-making by adults (18 years and older) with post-stroke aphasia. The database searchers were restricted to the date range of 1980–2022, and to studies published in English. The start date of 1980 was selected because it was from this time that ideas and practice in clinical aphasiology began to be influenced by approaches that started to move aphasia treatment from the therapy room into the real world (Kagan, 1998). Thus, although legislation pertaining to the rights of persons with disabilities such as aphasia had not yet been developed at that stage, it was reasoned that the intervention approaches that became popular during that time (aiming to reduce the psychosocial impact of aphasia, focusing on the effective exchange of information, social interaction and participation in life by PWA) (e.g., Davis & Wilcox, 1981; Kagan, 1998; Lyon, 1992), would promote the inclusion of PWA in the making of decisions and the expression of choice and preferences. In addition to database searches, two journals, namely *Aphasiology* and *The International Journal of Language and Communication Disorders*, were hand-searched for articles that appeared relevant to the review question. An ancestry search of included articles was also conducted.

Study selection

The electronic records sourced by means of the above search strategy were exported to Rayyan, a web-tool and mobile application designed to assist with the screening and selecting of studies for reviews (Ouzzani et al., 2016). The records sourced via the database search were exported separately from those sourced through the hand searching of the two journals.

For inclusion in this review, the research population was required to be adults (18 years and older) with post-stroke aphasia. Records reporting on PWA associated with degenerative conditions (e.g., primary progressive aphasia, dementia, Alzheimer's disease, fronto-temporal dementia), traumatic brain injury or malignancy were not selected for inclusion. The PWA were required to be the beneficiaries of the intervention described, even if the intervention was directed at communication partners.

Records were included if the intervention mentioned or described reflected communication strategies that support any or all aspects of the decision-making process. Records that described strategies to support general communication by PWA were not included, and neither were records that focus on assessment of decision-making capacity without reference to strategies that support decision-making by PWA. Records that focus on the perspectives of healthcare professionals regarding the decision-making abilities of PWA, or their role in assessing the decision-making capacity of PWA without listing or describing strategies to support decision-making by PWA were also excluded from this scoping review.

The decision types focused on in this review are complex decisions (e.g., legal, financial, medical and/or end-of-life decisions; and informed consent to medical intervention or participation in research), defined as those for which there is no obvious binary yes/no choice; for which there are multiple options; for which careful consideration and analytical thinking (as opposed to instinctive responses) are required; for which the main decision may need to be deconstructed into smaller decisions to be made; for which the consideration of external factors is required, for which it is not possible to predict all possible consequences, and for which the advice of others may be needed (Ekenberg et al., 2018; Nicholas, 2017). Records were not selected for inclusion in this review if the decisions discussed reflect day-to-day choices, such as what to have for lunch or what to wear. Records, with the exception of reviews, were not excluded based on their design.

As recommended by Arksey and O'Malley (2005) and Levac et al. (2010), two reviewers, namely the first author and a research assistant (a speech–language therapist with 6 years of clinical experience), screened all the records for in- and exclusion, applying the inclusion and exclusion criteria to the citations on title and abstract level. The remaining two authors each screened 10 of the records. Each record was thus screened by at least two reviewers. Inter-rater agreement for inclusion on title and abstract level pre-consensus was 97%. Disagreements between reviewers were discussed and consensus was reached on which records to include on full text level. Reasons for exclusions

were noted. Those records that were selected for inclusion on full-text level were then screened by the first author and a research assistant for in- and exclusion. Interrater agreement for inclusion on full-text level pre-consensus was 92%. Again, any disagreements between the reviewers were discussed and consensus was reached on which records to include in the review. In cases where agreement between the first author and research assistant could not be reached, one of the remaining two authors was consulted.

Data extraction

A data extraction sheet was developed on Microsoft Excel 2016 and data were extracted pertaining to: (1) general descriptive data for each article (e.g., authors, date of publication, country, aims, research design, data collection procedures and results), (2) the types of decisions supported, (3) the research participants/communication partners of the PWA supporting those decisions, and (4) the communication strategies reported.

The first author extracted data from all included articles. The second author checked the data extraction and proposed changes where needed. Consensus between the first and second authors regarding the data extracted was 95%. Differences were discussed until full consensus was reached.

RESULTS

The number of records screened, assessed for eligibility and included in this review is indicated in Figure 1. The database searches yielded a total of 955 articles. Of these 955 articles, 266 were identified as duplicate articles. Of the 689 remaining articles, 647 were excluded at title and abstract level. A total of 42 articles from the database search was screened at full text level. A total of 27 of the 42 articles were excluded from the review on account of not referring to communication strategies found to support decision-making by PWA. Three of these 27 articles excluded also reported on the wrong population. One of the 42 articles was excluded as the decisions supported did not meet the criteria for complex decisions. The remaining 14 articles met the criteria for inclusion in this scoping review.

A total of 81 hand-searched articles was identified, of which one was a duplicate article. Of the remaining 80 articles, 62 were excluded at title and abstract level. A total of 18 hand-searched articles was screened at full text level. Of these, four were excluded on account of being duplicates of articles sourced from the database search. Of the remaining 14 articles, 12 were excluded on account of not referring to strategies to support decision-making by PWA. The remaining two articles met the criteria for inclusion in this review. The 16 articles selected for inclusion in this scoping review are summarized in Table 1.

General characteristics

The articles selected for inclusion in this review are all journal articles and span from 1998 to 2021. More than half (10) of these articles were published between 2010 and 2021, and, of these, three were published between 2020 and 2021. Five of the 16 articles were written by researchers from Canada. Three of the articles were written by researchers from both the UK and Australia. Two articles were written by researchers form the USA and Europe, respectively, and one by researchers from South Africa.

A total of 10 of the 16 articles are theoretical in nature and discuss the impact of aphasia on decision-making (e.g., Suleman & Kim, 2015; Zuscak et al., 2016); the impact of aphasia on the informed consent process (e.g., Braunack-Mayer & Hersh, 2001); the extent to which PWA have been excluded from participation in stroke research; and the need for accessible informed consent procedures for PWA (e.g., Brady et al., 2012). Suggestions for improving the informed consent procedure for PWA are made (e.g., Kagan & Kimelman, 1995; Palmer & Patterson, 2011), and means to deal with the challenges related to decision-making by PWA, including the value of a multidisciplinary team approach to supporting decision-making by PWA, are discussed (e.g., Kagan et al., 2020; Maxwell et al., 2021; Stein & Brady Wagner, 2006; Zuscak et al., 2016).

The remaining six articles are empirical in nature. Of these six, three have qualitative designs, one has a quantitative design and two have mixed methods designs. One of the three qualitative studies gives a description of how a PWA was supported in making a will (Ferguson et al., 2003). In another of the qualitative studies, the process of obtaining informed consent by an SLP from three PWA to participate in a drug trial is described (Penn et al., 2009), and in the third qualitative article, the communication skills of social workers to allow PWA to participate in decision-making in healthcare are evaluated (Rowland & McDonald, 2009).

The quantitative study compares the performance of PWA on linguistic and non-linguistic decision-making tasks (Kim et al., 2020). The two mixed methods design studies examine the decision-making process between PWA and their SLPs regarding therapy goals (Isaksen, 2018) and the effectiveness of a tool in establishing capacity to give informed consent (Jayes & Palmer, 2014), respectively.

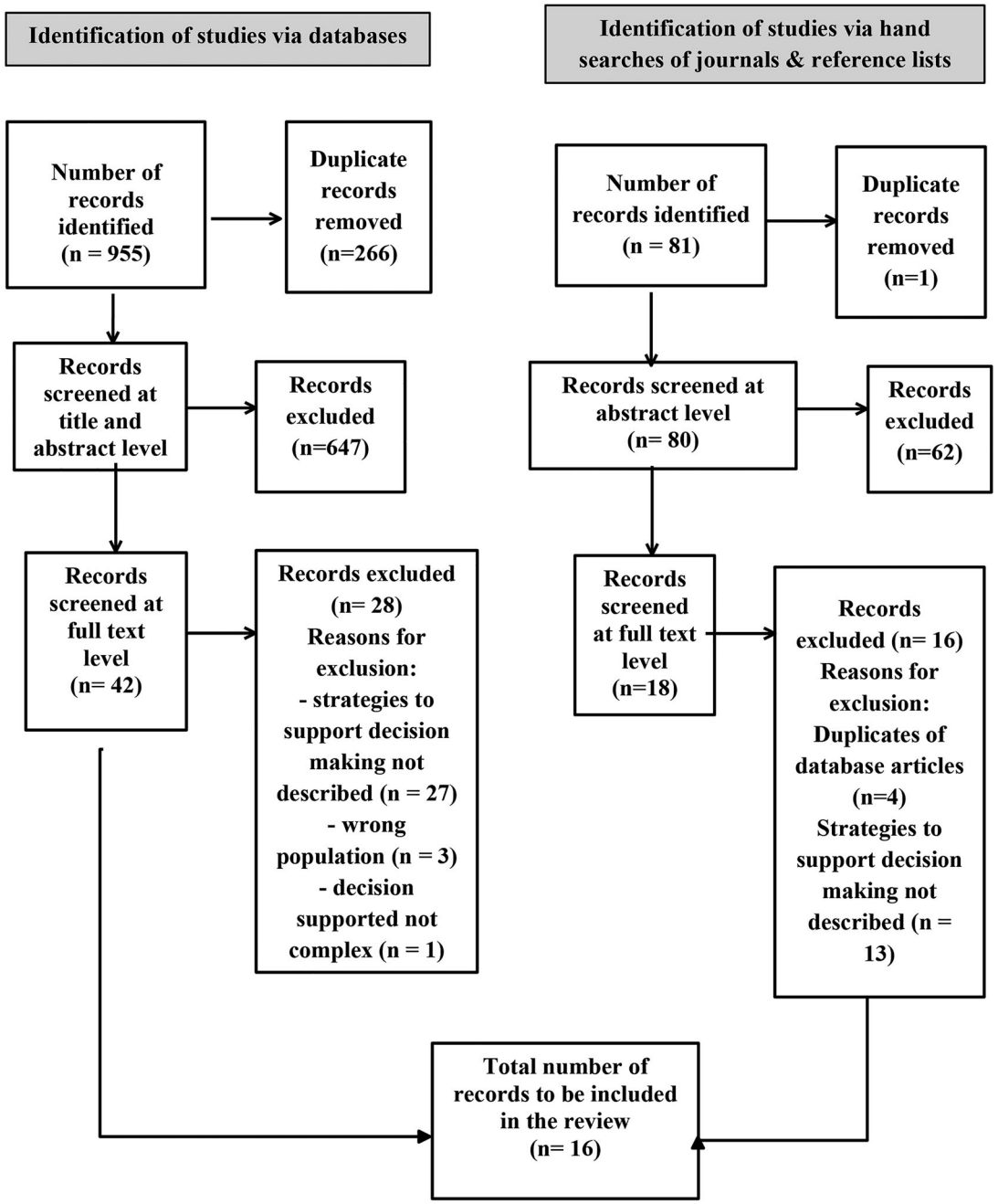

FIGURE 1 PRISMA flow diagram of the study selection process

Decision types

The decisions mentioned or discussed in the articles, or for which a description is given of how PWA were supported in making them, are presented in Table 1. The decision types most frequently referred to are decisions pertaining to discharge planning or living arrangements (referred to in seven articles) and informed consent for participation in research (referred to in seven articles). Reference is also made to informed consent for medical treatment, legal decisions, financial decisions, and decisions pertaining to therapy goals and leisure activities. Of the 16 articles, nine provide a description of the process followed and of the communication strategies used in supporting PWA in making the specific decisions referred to. In the remaining seven articles, the decision types are either mentioned or discussed, without a direct application of the communication support strategies to the specific decision referred to. Of the nine articles in which a description of how PWA were supported in decision-making is given, three provide a description of how PWA were supported in participating in discharge planning (Brady Wagner, 2018;

TABLE 1 Articles selected for inclusion in the review

Article number, authors (date), country	Title	Aim	Article type	Decisions mentioned, discussed, supported	Research participants/communication partners of PWA
1. Brady et al. (2012) UK	People with aphasia: capacity to consent, research participation and intervention inequalities	Highlights the extent to which PWA have been excluded from full participation in stroke research. Emphasizes the need for accessible research information and consent processes	Theoretical	Discussed: informed consent for participation in research	
2. Brady Wagner (2018) USA	Ethical framework of supporting medical decision-making for persons with aphasia	Provides tools and examples to assist providers in dealing with ethical challenges related to decision-making for PWA	Theoretical (with reference to case vignette)	Mentioned: dysphagia management, exercise, nutrition Discussed: informed consent for medical treatment Supported: discharge planning	PWA, SLP, physician, 3 family members and 3 friends
3. Braunack-Mayer and Hersh (2001) Australia	An ethical voice in the silence of aphasia: Judging understanding and consent in people with aphasia	Discusses the impact of aphasia on the informed consent process. Gives suggestions to provide an improved model of practice for clinicians who inform and seek consent from PWA	Theoretical	Discussed: informed consent for participation in research	
4. Ferguson et al. (2003) Australia	Case study: Testamentary capacity and aphasia: A descriptive case report with implications for clinical practice	Suggests guidelines for clinical practice based on information considered relevant for court in determining testamentary capacity	Empirical: qualitative (descriptive case study)	Supported: making a will	PWA (deceased); solicitor, family members, general practitioner, nurse
5. Isaksen (2018) Denmark	'Well, you are the one who decides': Attempting shared decision making at the end of aphasia therapy	Provides insight into decision-making processes towards the end of aphasia therapy	Empirical: sequential mixed methods	Supported: decisions regarding therapy goals	12 SLPs and 28 PWA and their significant others (parents or adult children)
6. Jayes and Palmer (2014) UK	Initial evaluation of the Consent Support Tool (CST): A structured procedure to facilitate the inclusion and engagement of people with aphasia in the informed consent process	Evaluates the CST: a procedure developed to identify the best way to present information to PWA to ensure comprehension of information before giving consent	Empirical: case series Mixed methods	Supported: informed consent for participation in research	CST was administered to 13 PWA

(Continues)

TABLE 1 (Continued)

Article number, authors (date), country	Title	Aim	Article type	Decisions mentioned, discussed, supported	Research participants/communication partners of PWA
7. Kagan and Kimelman (1995) Canada	Informed consent in aphasia: Myth or reality?	Discusses questions arising from preliminary experience with an adapted informed consent form, and the associated process of obtaining informed consent	Theoretical (and describes brief survey of the PWA's opinions on consent procedures)	Discussed: informed consent for participation in research	50 PWAs participated in the survey
8. Kagan et al. (2020) Canada	Assumptions about decision making capacity and aphasia: Ethical implications and impact	Explores the issue of aphasia and decision-making	Theoretical (with reference to case vignettes)	Supported: discharge planning Supported: decisions pertaining to financial management of business	PWA, hospital staff, and SLP, PWA; his wife, rehabilitation physician, psychiatrist and SLP
9. Kim et al. (2020) Canada	Decision making by people with aphasia: a comparison of linguistic and non-linguistic measures	Investigates performance of PWA on linguistic and non-linguistic decision-making. Explores the relationship between decision-making and cognitive test performance	Empirical: quantitative quasi-experimental design	Mentioned: healthcare, place of residence and finances	16 PWA and 16 matched controls
10. Maxwell et al. (2021) Ireland	Using a multidisciplinary approach to reveal decision-making capacity within acute care for an individual with aphasia	Demonstrates a multidisciplinary team approach to supporting the health and social care decision-making of PWA	Theoretical: case report	Supported: discharge planning	PWA, her husband and family members, SLP, occupational therapist and nurses
11. Palmer and Paterson (2011) UK	One size does not fit all: obtaining informed consent from people with aphasia	Describes a procedure that is being piloted to differentiate methods of making information accessible according to aphasia severity	Theoretical	Mentioned: power of attorney, medical treatment, discharge planning Discussed: informed consent for participation in research	
12. Penn et al. (2009) South Africa	Informed consent and aphasia: Evidence of pitfalls in the process	Identifies potential facilitators and barriers to the process of informed consent	Empirical: qualitative (systematic observation, video analysis)	Supported: informed consent for participation in research	SLP and 3 PWA

(Continues)

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TABLE 1 (Continued)

Article number, authors (date), country	Title	Aim	Article type	Decisions mentioned, discussed, supported	Research participants/communication partners of PWA
13. Rowland and McDonald (2009) Canada	Evaluating social work communication skills to allow people with aphasia to be part of the decision-making process in healthcare	Examines how social workers are trained to interact with PWA	Empirical: qualitative (grounded theory analysis of focus group data; observations of social workers with PWA)	Mentioned: treatment decisions, discharge planning, plan of care (e.g., dressing, home activities)	Reference made to 1 PWA and to the communication skills of an unspecified number of social workers
14. Stein and Brady Wagner (2006) USA	Is informed consent a Yes/No response? Enhancing the shared decision-making process for persons with aphasia	Focuses on the challenge of obtaining informed consent in aphasia and proposes a solution to this problem	Theoretical (with reference to case vignettes)	Supported: informed consent for medical treatment	PWA, his wife, physician, neurologist, SLP and vascular surgeon
15. Suleman and Kim (2015 Canada	Decision-making, cognition and aphasia: developing a foundation for future discussion and inquiry	Discusses cognitive processes associated with decision-making, the dual-process theory of decision-making, and how these cognitive processes may be impaired in PWA	Theoretical	Mentioned: discharge planning, all conscious decisions	
16. Zuscak et al. (2016) Australia	A collaborative approach to supporting communication in assessment of decision-making capacity	Explores clinical implications of acquired communication disorders in decisional capacity	Theoretical	Mentioned: financial decisions, discharge destination/accommodation decisions and service provision decisions (e.g., community supports in the home), informed consent for participation in research	

Kagan et al., 2020; Maxwell et al., 2021) and two (Jayes & Palmer, 2014; Penn et al., 2009) provide a description of how PWA were supported in providing informed consent to participate in research. The support provided to a PWA in the making of a will (Ferguson et al., 2010), in decisions regarding termination of speech–language therapy (Isaksen, 2018), in decisions pertaining to the running of a business (Kagan et al., 2020), and in informed consent for medical treatment (Stein & Brady Wagner, 2006) is described in each of the remaining four articles, repectively.

Communication partners involved in the decision-making process

The communication partners involved in the decision-making process of the PWA are indicated in Table 1 and range from healthcare professionals (including SLPs, social workers, psychiatrists, rehabilitation practitioners, general practitioners, occupational therapists and nurses) to family members (including spouses and adult children), friends, and, in one case, a solicitor. In six of the 16 articles, family members were cited as the communication partners of the PWA and in six of the articles, SLPs were the research participants or communication partners of PWA. Reference to a psychiatrist, to nurses and to social workers are each made in one of the articles. Two of the 16 articles each refer to the involvement of friends of the PWA in the decision-making process. In the majority of the articles, the communication partners provided a supporting role to the decision-making process. However, communication partners also took on the role of advocate in, for example assisting PWA in making decisions regarding living arrangements and financial decisions (Kagan et al., 2020) and in making decisions pertaining to medical intervention (Stein & Brady Wagner, 2006).

Communication strategies that support decision-making by PWA

The communication strategies referred to in the articles that support decision-making by PWA are presented in Table 2. The strategies are grouped according to the components of the decision-making process that they are reported to support. The first group of strategies represents general strategies to be implemented throughout the decision-making process. The following two groups of communication strategies are those that may be implemented by communication partners when presenting verbal and written information pertaining to the decision to PWA. The fourth group of communication strategies represents those that the communication partner may implement to verify that the PWA has comprehended the information presented. It is important to note that the focus here is not on the assessment of capacity, which entails a more rigorous process (e.g., Ferguson et al., 2003; Jayes & Palmer, 2014), but on the real-time processes to detect a breakdown in comprehension that may then be addressed by employing strategies to better support comprehension. This is followed by a group of strategies that support the weighing of options and reasoning about consequences by the PWA. The final two groups of strategies are those that communication partners may implement to facilitate the expression of choice by the PWA, and to verify understanding of the information conveyed by the PWA. Although specific reference to SCA (Kagan, 1998) is made in only nine of the 16 articles, it is recognized that most of the strategies listed in Table 2 (including acknowledging the competence of the PWA, the presentation of information in more than one modality, verification of understanding, use of simplified language, repetition, increased frequency of pauses, and the use of both open- and closed-ended questions) are applications of SCA.

General strategies that support the decision-making process

The strategies described under this heading are those that support the decision-making process as a whole. Strategies to promote the deontic rights, thereby inviting initiation by and collaboration with the PWA in the decision-making process, are referred to in 11 of the 16 articles. These strategies include acknowledging the competence and strengths of the PWA (Kagan et al., 2020), and respecting the experiences and opinions of the PWA and their significant other (Isaksen, 2018). According to Isaksen (2018) clinicians need to be flexible, as well as transparent about which decisions the PWA can influence to generate a genuine negotiation. The importance of establishing a relationship of trust with the PWA is mentioned by Brady Wagner (2018). Sensitivity, as well as active and empathic listening (e.g., Braunack-Mayer & Hersh, 2001; Rowland & McDonald, 2009; Zuscak et al., 2016) are additional strategies that invite collaboration by the PWA.

The strategy of setting aside sufficient time for the decision-making process is referred to in eight of the 16 articles. Time should be set aside to prepare materials (Zuscak et al., 2016) to manage the PWA's fatigue (Ferguson et al., 2003), for the repetition, rephrasing and explaining of information and the processing of information by the PWA (e.g., Braunack-Mayer & Hersh, 2001), for all parties to express themselves (e.g., Rowland & McDonald, 2009) and for the PWA to take information

TABLE 2 Strategies that support decision-making by PWA

	Included articles[a]																
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**Total**
General strategies to support decision-making by PWA																	
Acknowledge PWA's competence, thereby promoting collaboration and initiation by the PWA		×	×	×	×	×	×	×				×	×	×		×	11
Allow sufficient time for the decision-making process			×	×	×			×				×	×		×	×	8
Control environmental stimuli (minimize background noise and distractions); allow face-to-face interaction		×	×	×				×							×	×	6
Use alerting signals to gain and focus attention of PWA			×					×				×			×	×	5
Include the significant other of the PWA in the decision-making process		×		×								×			×	×	5
Ensure PWA can hear (e.g., insert hearing aids)								×					×				2
Ensure PWA can see (e.g., apply visual acuity aids)								×									1
Strategies to convey verbal information to the PWA regarding the decision to be made																	
Convey information in more than one modality		×	×	×	×		×	×	×	×	×	×	×	×	×	×	14
Use simple language (syntax and semantics)			×					×	×			×	×	×	×	×	8
Repeat information			×	×				×				×		×		×	6
Pause (between important pieces of information)			×		×			×				×		×		×	6
Rephrase information			×				×	×					×				4
Chunk important information								×						×		×	3
Summarize information						×						×	×				3
Only present relevant information												×			×		2
Provide explanations											×	×					2
Maintain natural prosody													×			×	2
Do not omit relevant information			×														1
Present information in a hierarchy or according to the stages of decision-making		×															1
Provide examples												×					1
Emphasize important words												×					1
Strategies to convey written information to the PWA regarding the decision to be made																	
Use simple language	×		×			×		×			×	×					6
Use a large font size	×		×			×	×	×			×						6
Augment writing with pictures and symbols			×			×	×	×			×						5
Highlight keywords			×				×	×			×						4
Increase space between text	×							×			×						3
Repeat information						×		×			×						3

(Continues)

TABLE 2 (Continued)

	Included articles[a]																
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**Total**
Limit amount of text						×		×									2
Separate information with bullet points						×					×						2
Use advance organizers to alert PWA to information that will be presented/staged information						×		×									2
Adapt informed consent documents to match different levels of severity of aphasia						×					×						2
Provide written summaries								×			×						2
Present one main idea per sentence											×						1
Strategies to verify that the PWA has understood the information regarding the decision to be made																	
Ask yes/no questions		×		×		×	×				×	×		×			7
Take note of body language of PWA				×					×			×	×	×			5
Engage in successive/frequent questioning			×	×			×					×					4
Invite PWA to ask questions						×		×				×		×			4
Have PWA participate in picture sorting tasks						×					×						2
Have PWA choose between forced alternatives						×					×						2
Ask PWA to paraphrase what has been conveyed						×					×						2
Use response solicitations (e.g., 'Ok?')												×					1
Verify understanding in two different ways													×				1
Have PWA participate in picture sequencing tasks											×						1
Provide verbal corrected feedback								×									1
Strategies to support the PWA in weighing information and reasoning about options																	
Informed consent: clearly distinguish between treatment and research			×				×					×					3
Invite the asking of questions by the PWA						×						×					2
Make use of decision support charting								×								×	2
Present only relevant information												×			×		2
Provide verbal and written summaries								×									1
Use keywording								×									1
Provide diagrams								×									1
Assist with notetaking								×									1

(Continues)

TABLE 2 (Continued)

	Included articles[a]																
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**Total**
Provide PWA with a range of hypothetical simulations and factors to consider															×		1
Give visual depictions of possible solutions and the benefits or risks associated with each															×		
Explicitly state the implications of information to reduce the cognitive load for inferencing																×	1
Strategies to support expression by the PWA regarding the decision made (this is a subheading)																	
Provide a range of choices in pictures and writing for PWA to point to			×		×			×			×		×			×	6
Encourage use of all modalities by PWA (gestures, writing, pointing, drawing)				×				×			×		×	×			5
Observe the body language of the PWA		×			×									×		×	4
Provide visual representations of degrees of emotion			×		×								×				3
Give fixed choices for PWA to point to in response to open-ended questions													×	×		×	3
Ask PWA to slow down if their speech is difficult to understand											×			×			2
Ask open-ended questions					×												1
Ask PWA directly for their decision or opinion					×												1
Apply question/answer format to informed consent documents											×						1
Strategies to verify that the information conveyed by the PWA regarding the decision to be made has been understood																	
Repeat what was understood and ask PWA to confirm				×									×			×	3
Expand on what the PWA has conveyed		×											×			×	3
Summarize what was communicated and understood (verbally and in writing)		×						×								×	3
Make assumptions/multiple guesses and ask PWA to confirm				×									×				2
Paraphrase what PWA has said					×								×				2
Ask PWA for clarification/initiate repair when PWA has not been understood								×									1
Reflect on what the PWA has conveyed		×															1

Note: [a]Numbering as per Table 1.

home to consult their significant others should they so wish (e.g., Penn et al., 2009; Zuscak et al., 2016). Ferguson et al. (2003) found that taking time to become familiar with the PWA, their favoured mode of communication, and the topic to be discussed supported the decision-making process. The importance of continually sharing information with the PWA and the ongoing negotiation of the decision with the PWA is referred to in three of the articles (e.g., Penn et al., 2009).

The strategy of controlling environmental stimuli is referred to in six of the 16 articles and includes selecting a quiet, private setting in which distractions are kept to a minimum (e.g., Brady Wagner, 2018). In five of the 16 articles, reference is made to the use of alerting signals to gain, focus and maintain the attention of the PWA. These alerting signals include the touch of the arm of the PWA, a change of gaze, the presentation of a phrase prior to important information and clear indication of topic changes (e.g., Kagan et al., 2020; Penn et al., 2009; Suleman & Kim, 2015; Zuscak et al., 2016). The value of including the significant other of the PWA in the decision-making process is referred to in five of the 16 articles (e.g., Brady Wagner, 2018; Penn et al., 2009; Stein & Brady Wagner, 2006). Other general strategies to support the decision-making process include ensuring that the PWA can see and hear their communication partner by inserting hearing aids and applying visual acuity aids (Kagan et al., 2020).

Strategies to convey verbal information to the PWA regarding the decision to be made

The communication strategy listed most frequently (in 14 of the 16 articles) to apply when conveying verbal information to the PWA is that of presenting information in more than one modality, including gestures, written keywords, pictures, maps, calendars, scales and photos (e.g., Braunack-Mayer & Hersh, 2001; Maxwell et al., 2021; Rowland & McDonald, 2009; Zuscak et al., 2016). The second most frequently cited strategy to implement when conveying verbal information to the PWA is that of using syntactically and semantically simple language (referred to in eight of the 16 articles). Zuscak et al. (2016) recommend the use of direct, active sentence types rather than passive or complex sentence types; and the breaking up of lengthy sentences into shorter sentences. The avoidance of jargon is recommended by Penn et al. (2009).

The communication strategies of repeating information and pausing, particularly in-between important units of information, are referred to in six of the 16 articles. Zuscak et al. (2016) recommend that information be repeated in different ways and Penn et al. (2009) recommend that important information be stressed regularly. Strategies to support the conveying of verbal information to PWA referred to less frequently include the rephrasing of information, the chunking of important units of information, the provision of concrete examples and explanations, and the placement of emphasis on important words. Braunack-Mayer and Hersh (2001) and Kagan et al. (2020) recommend that information be presented in a hierarchy or according to the stages of decision-making, and Penn et al. (2009) and Zuscak et al. (2016) recommend that only information relevant to the decision to be made be presented to the PWA.

Strategies to convey written information to the PWA regarding the decision to be made

The two most frequently listed strategies to apply when providing written information to the PWA (each referred to in six of the 16 articles), are the use of simple written language and increased font size. Regarding the use of simplified language, Palmer and Patterson (2011) recommend the use of active rather than passive sentence forms, and the avoidance of jargon or acronyms. The strategy of augmenting writing with pictures and symbols is referred to in five of the 16 articles and the use of highlighted keywords in four of the 16 articles. Use of repetition to support reading comprehension by the PWA is referred to in four of the 16 articles. Braunack-Mayer and Hersh (2001) recommend discussing the informed consent form with the PWA before interviewing them, while Jayes and Palmer (2014) and Palmer and Patterson (2011) recommend that the PWA be afforded the opportunity to refer back to information sheets during the informed consent procedure. Similarly, Kagan et al. (2020) recommend the provision of multiple learning trials during the informed consent process. Less frequently listed strategies to apply when providing written information to the PWA include limiting the amount of text per page (Jayes & Palmer, 2014; Kagan et al., 2020), separating information with bullet points (Jayes & Palmer, 2014; Palmer & Patterson, 2011), using advance organizers to alert the PWA to information that will be presented (Jayes & Palmer, 2014; Kagan et al., 2020), and presenting one idea per sentence (Palmer & Patterson, 2011). The recommendation for the adaptation of informed consent documentation to different levels of severity of aphasia is made by Jayes and Palmer (2014) and Palmer and Patterson (2011). The Consent Support Tool (CST) is a tool that has been found to accurately establish the level of support required by the PWA during the informed consent process (Jayes & Palmer, 2014).

Strategies to verify that the PWA has understood the information presented

The most frequently listed strategy to verify whether the PWA has comprehended the information presented (referred to in seven of the 16 articles) is the asking of closed ended yes/no questions. This is followed by the strategy of taking note of the body language of the PWA (referred to in five articles). Ferguson et al. (2003), for example, note that frustration by the PWA may signal a lack of understanding. The frequent verification of the PWA's understanding, at the time that information is presented is referred to in four of the 16 articles, as is the strategy of directly inviting PWA to ask questions and to seek clarification. Jayes and Palmer (2014) and Palmer and Patterson (2011) recommend that PWA's understanding be verified through picture sorting tasks, having the PWA choose between forced alternatives, and requesting the PWA to explain, in their own words, what has been conveyed to them. Less frequently cited strategies to verify understanding by the PWA include presenting a series of questions in pictured and simple written format, the use of response solicitations (e.g., 'Ok?'), and picture sequencing tasks (Palmer & Patterson, 2011; Penn et al., 2009; Rowland & McDonald, 2009).

Strategies to support PWA in weighing information and reasoning about options

In dealing with the matter of informed consent, Braunack-Mayer and Hersh (2001), Kagan and Kimelman (1995) and Penn et al. (2009) emphasize the need to clearly specify whether the consent requested is for participation in treatment or research. Penn et al. (2009) found the use of mitigative language helpful in avoiding false hope and therapeutic misconception by the PWA when deciding to participate in research. Inviting the asking of questions by PWA or engaging in iterative question and answer exchanges with the PWA, making use of decision support charting (in which information is visually depicted in accordance with the steps of decision-making), and the presentation of only relevant information, are each referred to in two of the 16 articles as strategies to support the reasoning component of the decision-making process. Suleman and Kim (2015) recommend providing the PWA with a range of hypothetical simulations, as well as visual depictions of possible solutions and the benefits or risks associated with each. Additional strategies to support the weighing of information and reasoning about choices and consequences by the PWA, include providing written summaries, using keywording, providing diagrams and assisting with notetaking (Kagan et al., 2020), as well as explicitly stating the implications of choices to reduce the cognitive load required for inferencing (Zuscak et al., 2016).

Strategies to support the expression of choice by the PWA

The strategy most frequently referred to in supporting the expression of choice by the PWA (appearing in six of the 16 articles), is the provision of a range of choices in pictures and writing for the PWA to point to. The strategy of encouraging use of all modalities by the PWA to convey information is referred to in five of the 16 articles. In four of the 16 articles, the recommendation is made for the body language of the PWA to be observed. Isaksen (2018), for example, found that a downward gaze and pausing by the PWA signalled disagreement or disappointment. Zuscak et al. (2016) note that the body language of the PWA may signal whether their verbal yes/no response is what they intended.

The communication strategies of presenting the PWA with open-ended questions with fixed choices to point to and the provision of visual depictions of degree of emotion (e.g., scales or smiley faces) each appear in three of the 16 articles as strategies to support the expression of choice by the PWA. The strategy of directly asking the PWA for their opinion or decision is referred to in the article by Isaksen (2018), while Palmer and Patterson (2011) recommend applying a question/answer format to informed consent documents.

Strategies to verify that the information conveyed by the PWA has been correctly understood

One of the most frequently listed strategies to verify that the information or choice conveyed by the PWA has been correctly understood (appearing in three of the 16 articles) includes that of repeating what the PWA has conveyed and then asking the PWA, for example, by means of yes/no questions, to confirm whether this is correct. Ferguson et al. (2003) and Rowland and McDonald (2009) note that it may be necessary to make assumptions or multiple guesses regarding the information conveyed and then to ask the PWA to confirm the accuracy thereof. The strategies of expanding on what the PWA has said, and of summarizing the information conveyed also each appear in three of the 16 articles. Kagan et al. (2020) recommend that these summaries be presented verbally and in writing. Additional strategies listed to support the verification of understanding of information conveyed by the PWA include paraphrasing what the PWA has

conveyed, reflecting on what they have conveyed, and requesting clarification or initiating repair when the information conveyed has not been understood (e.g., Rowland & McDonald, 2009).

DISCUSSION

The purpose of this scoping review was to identify, according to the literature, the types of decisions PWA are supported in making, their decision-making partners, and the communication strategies that support decision-making by PWA.

There appears to be a growing interest in the field of decision-making by PWA as more than half of the articles included in this review were published between 2010 and 2021, and almost a quarter were published between 2020 and 2021. Furthermore, although five of the articles were published in Canada, articles published by researchers from the USA, the UK, Europe and Australia over the past 10 years were also included in this review, suggesting a growing interest in the field of decision-making by PWA in different parts of the world. Fifteen of the 16 articles were published in high income countries. As only articles published in English were selected for this review and owing to the prevalence of English in publications from high income countries, publications from other parts of the world may have been missed. A further explanation for why most articles included in this review were published in high-income countries may be the limited expenditure in areas of education and scientific research in low-income countries (Helmy et al., 2016); and the challenges posed by resource limitations and low educational levels to obtaining truly informed consent from patients in low-income countries (Harris, 2011), regardless of whether or not they have aphasia. Additionally, while several countries have introduced recognition of supported decision-making regimes into their legislation since the adoption of the UN CRPD (United Nations, 2019), legislation pertaining to the rights of PWA and others with disabilities to receive such support may not exist in all countries, providing a further possible explanation for why research on this topic was limited to specific countries. Also, to be considered is the fact that autonomy is not a universal value, but rather applies to a particular culture or group of cultures at a particular time (Harris, 2011). Penn et al. (2009) note, in discussing challenges to the informed consent process, that demographic variables, including culture, gender, level of education and literacy, influence the process. Similarly, Brady Wagner (2018), note that supporting the medical decisions of PWA involves revealing their unique values, which, in turn, are influenced by culture, religious belief, and life experience.

The majority of the articles included in this review are theoretical in nature. Thus, despite the apparent growing awareness of the need to include PWA in research and life decisions, the inclusion of this population in empirical studies on these topics remains limited. Penn et al. (2009) note that the informed consent process is widely discrepant, and, because of the range of symptoms and severity of aphasia, it is not possible to have a standard informed consent protocol. The implementation of a tool such as the Consent Support Tool (CST), which identifies the best way to present information to PWA (Jayes & Palmer, 2014; Palmer & Patterson, 2011), is likely to facilitate the consent and inclusion of PWA in empirical research. The time and cost implications associated with adapting research material and informed consent documentation for PWA may be a further reason for the limited inclusion of this population in empirical research. Also, to be considered is the abstract nature of the construct of decision-making, which makes it a difficult construct to measure in empirical research.

The decision categories most frequently referred to are those pertaining to discharge planning or living arrangements, and informed consent to participate in research. Decisions pertaining to the discharge destinations of PWA following their release from a medical facility are likely to be encountered frequently by healthcare professionals; possibly explaining why this decision category has received greater attention in the field of decision-making by PWA than other life decisions have. The exclusion of individuals capable of making discharge decisions has serious implications, resulting in the potential violation of the worth and dignity of the individual (Rowland & McDonald, 2009). To this end, the Communication Aid to Capacity Evaluation (CACE), a communicatively accessible capacity evaluation tool with communication training supports, was developed by Carling-Rowland et al. (2014) to allow healthcare professionals to more fairly evaluate the capacity of people living with aphasia to consent to be admitted to long term care.

Previous assumptions that PWA lack capacity to provide informed consent to participate in research, has resulted in the exclusion of PWA from stroke research. This, in turn has led to a lack of clinical validity of research findings, impacting the care of this population (Brady et al., 2012; Jayes & Palmer, 2014). Increased awareness of the need for inclusion of PWA in stroke research, and of their vulnerability during the process of recruitment for participation in research (Jayes & Palmer, 2014), has given rise to research into tailoring the informed consent process to meet the diverse, individual needs of PWA. The CST is the product of this research and provides a means of establishing the best way in which to present information to the PWA during the informed consent procedure (Jayes & Palmer, 2014).

The focus of research on the inclusion of PWA in discharge decisions and on means to support PWA in providing informed consent to participate in research is encouraging. However, of concern is the lack of research into supporting PWA's decision-making in other important life areas.

The people referred to most frequently as communication partners of PWA during the decision-making process appear to be family members. SLPs are cited most frequently as the healthcare professionals involved in the decision-making process with PWA. Decisions pertaining to discharge destination of PWA from hospital are likely to involve family members to whom the PWA may or may not be discharged. For those PWA who are able to return home, family members are likely to be their everyday communication partners, as illustrated by the scenario presented by Kagan et al. (2020) in which a PWA indicated to his wife that he suspected the people who were acting as his attorneys of poor performance; and by Ferguson et al. (2003), in which the judge gave priority to accounts of the everyday communication of the PWA (provided by family members) in revealing testamentary capacity. Of significance is the finding that these family members did not serve as proxy decision-makers but rather supplemented the communication between the PWA and, for example, healthcare workers.

The finding that SLPs are the most frequently cited healthcare professionals involved in decision-making by PWA is also not surprising. SLPs are uniquely qualified to identify and manage the impairments associated with aphasia and have a moral obligation to provide communication supports to reveal communicative competence and capacity to make specific decisions (Brady Wagner, 2018; Kagan et al., 2020). Kagan et al. (2020) clearly differentiate between supported decision-making (describing decision-making that is shared among carefully selected individuals and the PWA), and the provision of communication support during decision-making; the latter of which falls within the realm of the SLP.

A range of communication strategies was identified in this review that may compensate for the language and cognitive difficulties experienced by PWA during the various stages of the decision-making process. Although SCA is specifically referred to in only nine of the 16 articles, the individual strategies listed are considered elements of this approach. SCA is based on the idea of conversation partnerships, addressing language and understanding in an interactive conversational context. SCA focuses on acknowledging and revealing the competence of the PWA (Kagan, 1998; Kagan et al., 2020).

PWA may abdicate their role as decision-makers if they orient to their communication partners as primary decision-maker (Isaksen, 2018). Acknowledging the competence of PWA as people who 'know more than they can say' (Kagan et al., 2020: 226), balances the roles of PWA and their communication partners; promoting initiation and collaboration by the PWA. According to Kagan (1998), acknowledgement of competence may be implicit (e.g., using appropriate tone of voice), or explicit (e.g., verbally acknowledging that the PWA knows what he/she wants to say). Both implicit and explicit strategies to acknowledge competence were identified in this review.

The strategy of involving significant others to support the PWA in the decision-making process is referred to by several authors in this review. Despite techniques to facilitate communication, the complexity of many medical decisions necessitates a verbal component to allow for questions to be asked, which PWA are likely to find challenging. Stein and Brady Wagner (2006), in discussing informed consent, propose a model of facilitated consent, in which the significant other asks questions about alternative options and provides context on issues of greatest personal importance to the PWA. By supplementing the direct communication between the PWA and the healthcare provider, the autonomy of the PWA (who remains the one who provides the actual consent) can be enhanced. There is a growing awareness of the relational dimension of autonomy in healthcare, in which the social reality of the individual in making decisions is acknowledged (Gómez-Vírseda et al., 2019). The interests of the significant other may be integral in promoting agency in cases where individuals give more weight to the preferences of their significant others than their own clinical interests (Ho, 2008). Similarly, significant others may find themselves assuming the role of proxy decision-makers if there is an assumption by the communication partner or PWA that the PWA cannot or should not take on the role of decision-maker. Those involved with decision-making by PWA need to be aware of these dynamics and their impact on autonomy during decision-making.

In addition to acknowledging the competence of the PWA, SCA focuses on revealing the competence of the PWA using techniques to aid comprehension and expression, and to verify understanding of what has been communicated (Kagan, 1998). As decision-making requires multiple linguistic and cognitive skills, strategies to support decision-making by PWA are required to not only compensate for language difficulties, but also reduce cognitive load (Kim et al., 2020). SCA techniques compensate for limited working memory capacity, attention related deficits and impaired inhibition, all of which may impact decision-making by PWA (Suleman & Kim, 2015). Several strategies identified in this review support more than one function, and more than one component of the decision-making process.

PWA have difficulties with sustained attention, selective attention and attention switching (Suleman & Kim, 2015). The strategies of selecting a quiet environment in which to hold discussions, using alerting signals, highlighting written keywords, placing verbal emphasis on keywords, chunking information, using pauses to separate important units of information, and the application of use of hearing and visual aids (e.g., Braunack-Mayer & Hersh, 2001; Kagan et al., 2020) support both language comprehension and the cognitive function of attention. The presentation of information in more than one modality not only reduces the linguistic demands of the task, thereby supporting comprehension; but also engages attention, and reduces the amount of information to be stored in the working memory (e.g., Kagan & Kimelman, 1995; Suleman & Kim, 2015). The communication strategy of presenting information using direct, syntactically and semantically simple language not only supports auditory verbal comprehension, but also cognition by reducing the need for inference (Kagan et al., 2020).

Difficulties with the inhibition of irrelevant information from entering the working memory workspace may be experienced by PWA (Suleman & Kim, 2015). The strategy of excluding irrelevant detail and information from discussions with PWA (Penn et al., 2009; Suleman & Kim, 2015) reduces the cognitive load for inhibition. Brady Wagner (2018), however, cautions that, while information presented to the PWA should be simplified, a balance must be maintained between simplifying information sufficiently and omitting important information based on assumptions regarding the information requirements of the PWA.

PWA may have smaller storage capacity and difficulties manipulating information in working memory. As a result, PWA may struggle to run through hypothetical simulations within their working memory (Suleman & Kim, 2015). In supporting the reasoning aspect of decision-making, Suleman and Kim (2015) therefore recommend providing the PWA with a range of hypothetical simulations and factors to consider, as well as giving visual depictions of possible solutions, and the potential benefits and risks associated with each. Braunack-Mayer and Hersh (2001) and Isaksen (2018) also refer to the strategy of providing the PWA with a comprehensive range of choices and options although, again, only relevant information and viable options, should be included in decision-making discussions (Carling-Rowland et al., 2014; Penn et al., 2009). Kagan et al. (2020)'s recommendation for engaging in iterative question and answer exchanges, and the use of tag questions (e.g., 'right?' or 'What do you think?') support reasoning while also inviting collaboration by the PWA. The use of mitigative language to avoid false hope, and clearly distinguishing between research and treatment (e.g., Penn et al., 2009) are strategies that not only support comprehension by the PWA but support the weighing of options by the PWA during the informed consent process.

The implementation of strategies to support decision-making by PWA poses several challenges to the communication partners of PWA. The need to set aside sufficient time is referred to in several articles and includes time for preparation of aphasia-friendly material, for conveying information to the PWA in an aphasia-friendly format, for the PWA to process the information presented, to allow for expression by the PWA, and for PWA to consult others before making a decision (e.g., Braunack-Mayer & Hersh, 2001; Kagan et al., 2020; Penn et al., 2009; Rowland & McDonald, 2009). A further challenge to supporting decision-making by PWA is the range of symptoms and degrees of severity of aphasia. As a result, a standard protocol or set of materials to support decision-making by PWA is not possible, necessitating person-specific adaptations to materials (Penn et al., 2009).

In conclusion, Kagan et al. (2020) recommend that each situation requiring decision-making by the PWA be evaluated based on the degree of complexity and the degree of risk associated with the decisions that are to be made. Thus, despite the range of strategies identified that support decision-making by PWA, the process remains complex and challenging.

Future directions

Areas for future research are highlighted by this review. Most articles included in this review were published in high-income countries. As autonomy is not a universal value, and as demographic variables, including culture, gender, level of education and literacy, may impact autonomy and decision-making, research on supporting PWA in decision-making in developing countries is needed. The focus of research on supporting PWA in decisions pertaining to informed consent and discharge planning has positive implications regarding quality of life and the development of management approaches for PWA. However, to enhance participation of PWA in all aspects of life, there is a need for research that focuses on supporting PWA in other complex life decisions, including legal, financial, medical and/or end-of-life decisions. Most of the studies included in this review are theoretical in nature. There is a need for empirical research in the field of decision-making by PWA. Penn et al. (2009), for example, found that aphasia-friendly materials did not always have a facilitating effect on the informed consent process; finding the strategies of periodic review, pausing, and verification of comprehension more effective. Empirical research into the effectiveness of the different strategies identified is thus needed.

LIMITATIONS

Only records published in English were included in this review. This may have resulted in the exclusion of other relevant non-English publications. Only two search terms were used for the construct of decision-making, namely *decision** and *informed consent*. While the term *decision** seems rather wide and would have covered articles that mentioned supported decision-making, shared decision-making or support with decision-making, it is possible that terms specific to countries and legislative regions may have been missed. This review aimed to identify the types of decisions that PWA are being supported in making, their communication partners, and the strategies used to support them in the decision-making process. A thematic analysis, which may have led to a deeper understanding of the information extracted, was not performed. Furthermore, in this review the focus was on the communication strategies used to support complex decision-making by PWA. By limiting the search to complex decisions, communication strategies to support other types of decisions, which remain applicable to the supporting of complex decisions, may have beenmissed.

CONCLUSIONS

The presence of communication difficulty does not negate decisional capacity (Braunack-Mayer & Hersh, 2001; Zuscak et al., 2016). SLPs have a moral obligation to explore how best to use alternative methods to promote language competence and expression so that PWA can reveal their decision-making ability (Braunack-Mayer & Hersh, 2001; Kagan et al., 2020). This review presents an overview of research (since 1980) into communication strategies that support decision-making by PWA, the decision types most frequently supported, and the communication partners most frequently involved in supporting these decisions. Through adopting a systematic approach to searching the literature and synthesizing the available information, research trends and gaps are identified.

CONFLICT OF INTEREST STATEMENT

The authors report no conflict of interest. The authors alone are responsible for the content and writing of the paper.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable as no new data were created or analysed in this study.

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