Person-centered intervention for people with dementia: an international expert panel

Identifying components of a person-centered augmentative and alternative communication intervention for people with dementia: Opinions of an international expert panel

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Abstract

Purpose: Despite general agreement on the importance of person-centered care in speech-language pathology, guidelines for developing person-centered interventions for those with dementia are limited. This study aimed to obtain expert opinion on the components of a person-centered augmentative and alternative communication (AAC) intervention for persons with dementia.

Method: A modified electronic Delphi technique was employed in a single round. A purposively sampled panel of experts was invited to provide their opinion on three open-ended questions related to (i) elements of person-centered care, (ii) communication supports, and (iii) interaction outcomes of a person-centered intervention. Thirty-one experts from nine countries participated on the panel. The majority were speech-language pathologists primarily involved in research. Qualitative written data were coded and analyzed using content analysis.

Results: Nine components were identified across the three open-ended questions: (a) the unique characteristics of the person with dementia, (b) working with a person with dementia, (c) preserving personhood, (d) a different view on person-centered care, (e) a range of communication supports, (f) supportive conversational partners, (g) designing communication supports, (h) interaction outcome measure, (i) meaningful interaction outcomes.

Conclusion: This study identified nine components that are useful to guide speech-language pathologists in crafting future person-centered AAC interventions for people with dementia.

Keywords: Person-centered care; person-centered intervention; dementia; speech-language pathology; augmentative and alternative communication, e-Delphi panel

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Person-centered care (PCC) is high on the research agenda in speech-language pathology. This aligns with international policy frameworks that appeal for advancing the evidence base on PCC in healthcare (World Health Organization, 2015). Across the spectrum of cognitive-communication disorders in speech-language pathology, a PCC approach has been particularly fore-fronted for people living with dementia (Gallée et al., 2023; Hickey et al., 2018; Lanzi et al., 2017). The neurodegenerative changes associated with dementia are devastating, permanently affecting communication on the level of making meaning in interpersonal interaction, participation, and independence in everyday life (Kindell et al., 2017; Nickbakht et al., 2023). To ensure that persons with dementia are validated and valued, despite the negative consequences of dementia, PCC is endorsed as the gold standard of care (Robertson & Fitzpatrick, 2022).

PCC attends to the person before the dementia diagnosis (Kitwood, 1997) by recognizing their strengths and abilities instead of a disease-focused perspective fixated on loss and deficits (Gibson et al., 2019). Built on the theoretical work of Carl Rogers (1958), PCC emphasizes partnerships that are developed between a client and clinician based on perspective taking and empathetic understanding. A central principle of PCC in dementia is personhood, which is upheld within relationships when persons with dementia are respected and valued by others (Kitwood, 1997). Supportive interpersonal interactions maintain personhood when conversational partners apply the elements of PCC, for example, respecting choices, valuing autonomy, and listening to the opinions of those with dementia (Kitson et al., 2012; Kitwood, 1997).

To enact the elements of PCC, conversational partners and persons with dementia require a range of communication supports (Fried-Oken et al., 2015). Speech-language pathologists (SLPs) play a vital role in developing interventions to support those with dementia (American

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Speech-Language-Hearing Association, n.d). In the last decades, there has been burgeoning literature on a wide range of evidence-based speech-language pathology interventions to support people with dementia at different stages of disease (Bourgeois et al., 2016; Hopper et al., 2013; Small & Cochrane, 2020; Swan et al., 2018). These include impairment-based interventions, for example, word retrieval interventions (Croot et al., 2019), script training (Schaffer et al., 2021), or spaced-retrieval (Benigas & Bourgeois, 2016) amongst others. Functional communication interventions include communication partner training (Folder et al., 2023), creative arts interventions (Jeppson et al., 2022) or compensatory strategies mediated through augmentative and alternative communication (AAC) (Ekström et al., 2017; Murray et al., 2022).

AAC intervention is one type of intervention that SLPs implement to support participation and engagement in life activities. AAC involves the use of evidence-based strategies and a variety of non-electronic aids (e.g., paper-based picture books), electronic devices (e.g., tablet computers with specific applications) or techniques (e.g., pointing to pictures while simultaneously using spoken language) as communication supports (Fried-Oken et al., 2015; Murray et al., 2022). Person-centered AAC interventions support people living with dementia to reminisce about their life stories (Subramaniam & Woods, 2016), participate in decision-making conversations (Chang & Bourgeois, 2020), and express preferences about their wellbeing (Murphy et al., 2010).

Despite widespread agreement on the importance of a PCC approach within speech-language pathology interventions (Forsgren et al., 2022; Hickey & Bourgeois, 2018; Lanzi et al., 2017; Mahomed-Asmail et al., 2023; Volkmer et al., 2023), the research evidence on PCC within AAC interventions for those with dementia is still emerging (Burshnic-Neal et al., 2022; May et al., 2019; Swan et al., 2018). As such, when researchers and clinicians develop person-centered

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AAC interventions, there are limited guidelines on what key elements of PCC should be considered and scant availability of validated instruments to measure person-centered interaction outcomes for people with dementia (Broomfield et al., 2019; Forsgren et al., 2022; May et al., 2019).

Research evidence poses further challenges. Firstly, there is debate about the definition of PCC which confuses its application in research concerning the development of person-centered interventions (Edgar et al., 2020; Mohr et al., 2021). Secondly, PCC is more than just a few basic features (e.g., being compassionate) (Dewing & McCormack, 2017); and various frameworks aim to capture its complexity. The Person-Centered Practice Framework (McCormack & McCance, 2017), for instance, describes the elements of PCC in the integrated domains of person-centered processes, prerequisites by professionals, the care environment, and person-centered outcomes. Although valuable to understanding PCC, this framework, amongst others, has been developed by professionals in other healthcare disciplines (e.g., nursing) and is not entirely applicable to speech-language pathology (Forsgren et al., 2022).

SLPs who work with people with dementia require a nuanced understanding of how the elements of PCC could be specifically applied within AAC-supported interactions. However, general PCC frameworks usually do not consider evidence-based communication supports for the cognitive-communicative challenges experienced by those with dementia, and therefore, may have limited application for SLPs (Allwood et al., 2017). In sum, when the available research evidence is underdeveloped, expert opinions from professionals with relevant research and clinical expertise, and client perspectives should be sought as aligned with evidence-based practice (Dollaghan, 2004).

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This study formed part of a broader, multi-method doctoral research project of the first author, A. A. M. The original research goal was to determine the effect of a person-centered AAC intervention in persons with dementia by collecting data directly from them. However, due to the COVID-19 pandemic (i.e., the time in which the original study was planned to take place) and its impact on in-person data collection, the goal was amended. The amended, main research project aimed to develop a person-centered AAC intervention package for interpersonal interaction in persons with dementia and explore its feasibility. Intervention development guidelines (O'Cathain et al. 2019; Skivington et al., 2021) advise on involving various groups of people (e.g., professionals with specialist knowledge) to contribute towards generating ideas for intervention content. Expert opinion was acquired early in the development process to identify components of a future person-centered AAC intervention for those with dementia. Face-to-face expert panel discussions and interviews could not be considered, given the unprecedented circumstances of the COVID-19 pandemic, and flexible online research strategies were sought in the current study (Smith et al., 2020).

The current study

The specific aim of the current study was to obtain expert opinion on components of a person-centered AAC intervention for persons with dementia. Aligned to this aim, the following research questions were posed: *what elements of person-centered care, communication supports, and interaction outcomes would be important to include in a person-centered AAC intervention for interpersonal interaction in persons with dementia?* The main objective was to organize and summarize the data collected from an expert panel.

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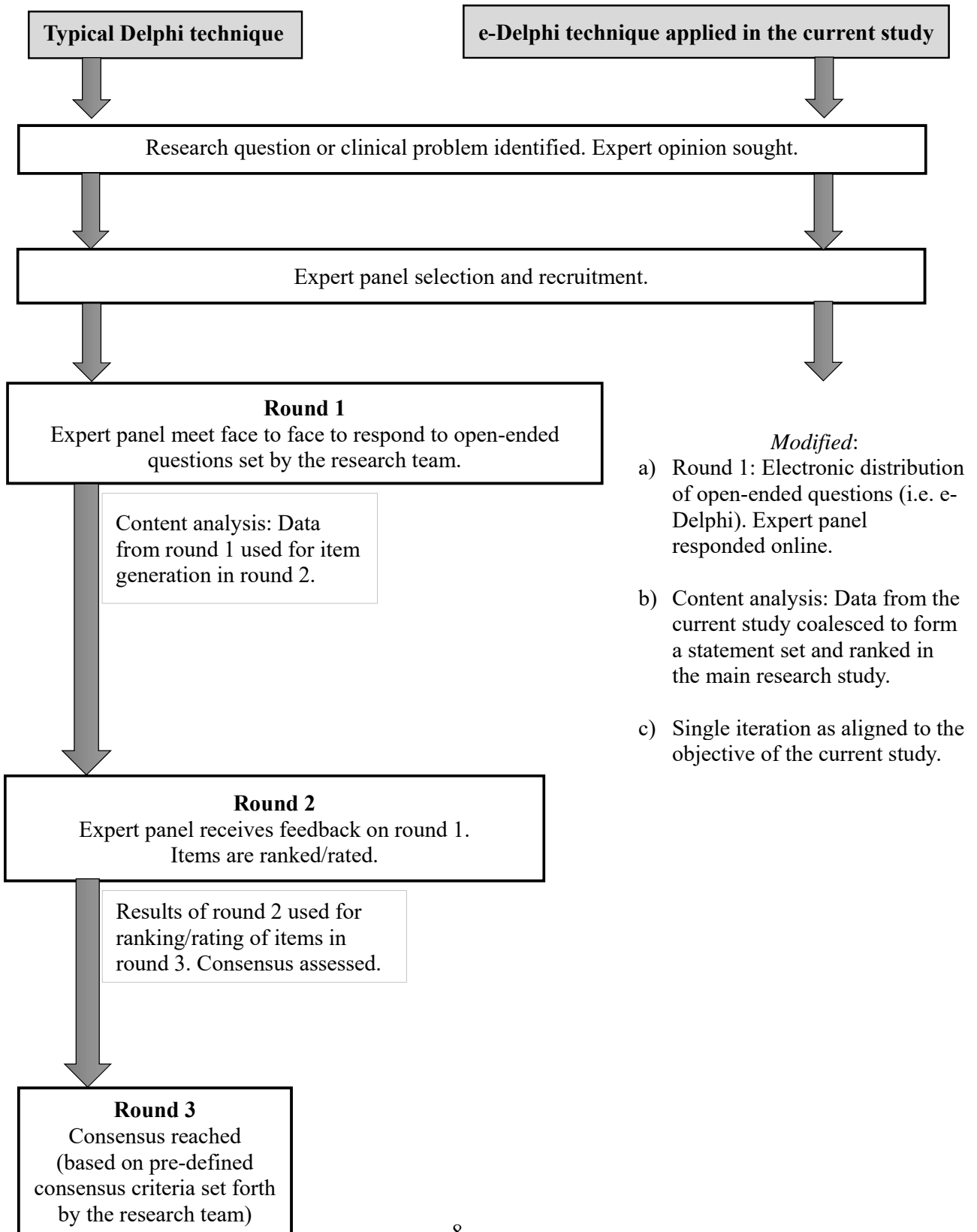
Method

Ethics approval was granted by the Research Ethics Committee of the University of Pretoria, South Africa (HUM0005/0719).

Research Design

The Delphi technique was used as a suitable method to acquire expert opinions on the research question (Hasson et al., 2000). Conventionally, the Delphi unfolds through a series of anonymized questionnaires undertaken over multiple rounds of iterative feedback (Donohoe et al., 2012). The first round usually poses open-ended questions to an expert panel which generates ideas to inform data for subsequent rounds until group consensus is reached (Hasson et al., 2000). Modifications to the Delphi technique, in terms of the format and number of rounds, is permissible and may be specific to a research project (Sossa et al.,2019). The e-Delphi, for example, is one adaptation of the original Delphi through its electronic, web-based format. Various applications of the e-Delphi have been noted in speech-language pathology research (Hardin et al., 2021; Santos et al., 2023; Tomlin et al., 2024; Wong et al., 2020). In the current study, a modified e-Delphi entailed a single round conducted via online data collection procedures (Donohoe et al., 2012). This study was conducted during the initial lockdown restrictions of the COVID-19 pandemic. Pragmatically, a modified e-Delphi panel offered the convenience of quick questionnaire distribution and accessibility to geographically dispersed experts during the COVID-19 pandemic. A single round was employed because reaching group consensus was not aligned with the objective of the current study. See Figure 2 in the Appendix for an illustration of the e-Delphi technique as applied to the current study.

Figure 2

Flow chart illustrating a typical Delphi technique and the modified e-Delphi panel in the current study

Typical Delphi technique	e-Delphi technique applied in the current study

Research question or clinical problem identified. Expert opinion sought.

Expert panel selection and recruitment.

Round 1
Expert panel meet face to face to respond to open-ended questions set by the research team.

Content analysis: Data from round 1 used for item generation in round 2.

Modified:

a) Round 1: Electronic distribution of open-ended questions (i.e. e-Delphi). Expert panel responded online.

b) Content analysis: Data from the current study coalesced to form a statement set and ranked in the main research study.

c) Single iteration as aligned to the objective of the current study.

Round 2
Expert panel receives feedback on round 1. Items are ranked/rated.

Results of round 2 used for ranking/rating of items in round 3. Consensus assessed.

Round 3
Consensus reached (based on pre-defined consensus criteria set forth by the research team)

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Expert Panel Recruitment

In this study, an expert was defined as a professional with the following characteristics (Arvella, 2016): (i) holding a doctoral degree (or is a doctoral candidate) in speech-language pathology, AAC or a related health science discipline (as AAC is an interdisciplinary field) and (ii) involved primarily in research. Panelists were recruited via purposive sampling based on the following panelist selection criteria: (a) meeting the definition of an expert in this study; and interest in either (b) dementia-related communication; adult cognitive-communicative disorders, interpersonal interaction (general), communication technology, or instrument development. Potential panelists were identified from the following sources: (i) the authors' professional networks, (ii) searching academic and research profiles on international university directories, and (iii) scanning publications in previous scoping reviews related to speech-language pathology, AAC and dementia. A list consisting of 63 potential panelists who met the selection criteria was compiled. As an extra measure to verify that potential panelists met the pre-requisite selection criteria, A. A. M undertook a review process. This entailed inspecting potential panelists' author details on their recent research publications and on their Open Researcher and Contributor Identity (ORCID) profile. Each potential panelist received a personalized invitation letter from the professional email account of the second and third authors (S. D and J. M). Personalized email contact facilitated email deliverability and mitigated the chances of an anonymous email being flagged as spam. Of the 63 invited panelists, 31 responded (49% response rate) and completed the questionnaire in full, and only their responses were included in this study.

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Materials

Online questionnaire

An online questionnaire was developed and administered through Qualtrics, a cloud-based research survey suite. Several iterations of questionnaire refinement occurred between all three authors, including technical checks to ensure compatibility on different web browsers and devices (mobile and desktop). Next, feedback was requested from a pilot tester (a SLP with a doctoral degree) on the questionnaire content and online administration. Feedback received included (i) inserting a glossary of terminology (i.e., communication support, interpersonal interaction) and (ii) simplifying the open-ended questions. The final questionnaire content comprised two sections; the first requested biographical information, and the second posed three open-ended questions to the panelists related to the research question of this study:

1. What elements of person-centered care are important to integrate into interventions designed to support interpersonal interaction with a person with dementia?

2. What communication supports are important for a conversational partner to facilitate interpersonal interaction with a person with dementia?

3. What interaction outcomes are important to include in an outcome measure for supporting interpersonal interaction in persons with dementia?

Panelists were allowed to explore the questions with as much detail as they preferred, which reduced the potentiality of introducing a response bias. An inbuilt saving feature enabled panelists to start and save the questionnaire without completing it in one sitting.

Procedures

Before data collection, panelists received a letter of invitation conveying the salience of the study, how their email addresses were acquired, ethical considerations, and the expectations

of their participation. The email included a short introductory paragraph concerning the attached invitation letter. Each letter included a personalized, embedded hyperlink to the online questionnaire on Qualtrics. Panelists provided informed consent electronically by clicking on the '*yes, I agree to participate*' option on the Qualtrics landing page, which confirmed their understanding of the written informed consent letter. Subsequently, they completed the two sections of the questionnaire as previously described. They had two weeks to complete the questionnaire, with an email reminder sent one week after the initial invitation. Panelists' final inclusion into the study was their submission of a completed questionnaire before the expiry date. Participation in the study was completely voluntary, and all biographical information was obtained for descriptive purposes only. Panelists were free to withdraw from the study without consequence. There were no incentives attached to their participation in this study.

Data analysis

All written responses to the open-ended questions were downloaded from Qualtrics and imported to ATLAS.ti, a qualitative software tool (for MAC, version 8.4). The dataset was de-identified for content analysis, which was the method applied to organize and summarize the qualitative data (Bengtsson, 2016). To do so, A. A. M read the data associated to each of the three open-end questions several times. Next, a unit of content (i.e., a word or phrase conveying an idea) was identified and labeled with a code. Coding analysis took place at a surface level (manifest content) by counting the frequency of codes in the data on ATLAS.ti (Bengtsson, 2016).

To facilitate transparency and coding reliability, a code list was formulated. A combined inductive-deductive approach (Elo & Kyngäs, 2008) to content analysis was employed. This involved assigning a literature-derived code (deductive) and dynamically generating new codes

from the data (inductive). Literature derived codes were pre-determined codes extracted from the literature (e.g., Dada et al., 2021; Lanzi et al., 2017; May et al., 2019; Swan et al., 2018).

Finally, codes with common characteristics were grouped into a code-category and linked into a main category (Elo & Kyngäs, 2008). As suggested by Elo et al. (2014), trustworthiness during coding organization in content analysis addresses coding credibility (i.e., coding analysis is believable) and conformability (i.e., coded data confirmed by others). The credibility of coding was assured as follows: Firstly, A. A. M independently coded the dataset several times. Then, an independent checker (a doctoral candidate), checked the entire dataset for accurate application of the coding and coding categories. Next, the complete dataset was re-coded twice to ensure all final coding was correctly applied, with the second and third authors (S.D and J.M) inspecting the final codes. Lastly, conformability was assessed by a second independent coder (a post-doctoral fellow in AAC), who coded 25% of randomly selected data associated to each of the three questions. Initial inter-coder agreement of 98% was calculated on Atlas.ti (percentage agreement). Coding discrepancy was addressed by re-examining the specific meaning unit in question and deliberation. Inter-coder agreement of 100% was reached. See Figure 1 in the Appendix for an overview of the coding analysis process.

Figure 1

Overview of coding analysis

| Step 1:
A.A.M read the entire dataset several times. Initial coding performed. |
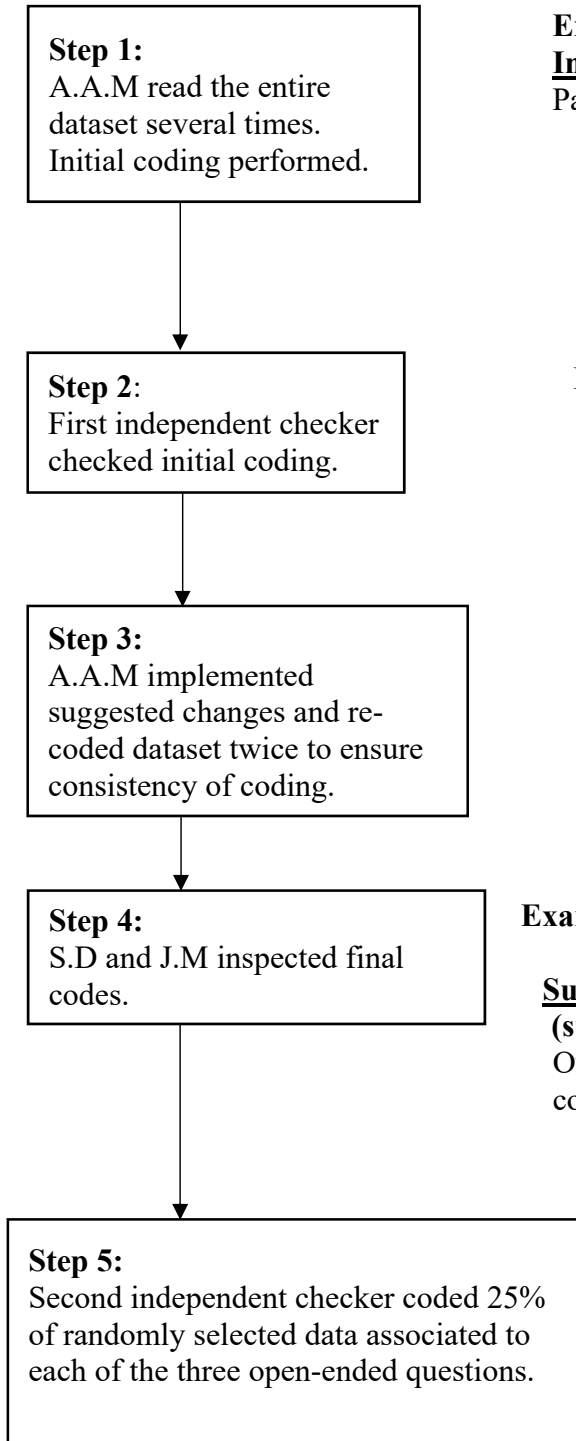
Example of initial coding

Initial code	**Code examples**
Participation-based outcomes	▪ *engagement* ▪ *increase the participation* ▪ *engage in an interaction* ▪ *partners are engaged* ▪ *participation of all involved*

| Step 2:
First independent checker checked initial coding. |

Example of suggested changes
- Separate the initial code into two separate codes (i.e., engagement and participation).
- Categorize the two new codes into one sub-category, 'outcome constructs'.
- Resolved by discussion between A.A.M. and independent checker and revisiting code book on Atlas ti.

| Step 3:
A.A.M implemented suggested changes and re-coded dataset twice to ensure consistency of coding. |

| Step 4:
S.D and J.M inspected final codes. |

Example of final coding

Component 9: Meaningful outcomes

Sub-component (sub-category)	Code	Examples of codes
Outcome constructs	Engagement outcomes	▪ *engage in an interaction* ▪ *engagement* ▪ *partners are engaged*
	Participation outcomes	▪ *increase the participation* ▪ *participation of all involved*

| Step 5:
Second independent checker coded 25% of randomly selected data associated to each of the three open-ended questions. |

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Results

Description of panelists

Table 1 displays the panelists' demographics. A total of 31 (N=31) panelists from nine countries participated in this study. The majority of the panelists were from the United Kingdom ($n = 14$, 45%). The rest of the panelists were from the United States ($n = 5$, 16%), Sweden ($n = 4$, 13%), Ireland ($n = 2$, 6%), Australia ($n = 2$, 6%) as well as Brazil ($n = 1$, 3%), Finland ($n = 1$, 3%), Germany ($n = 1$, 3%), and South Africa ($n = 1$, 3%). More than half ($n = 17$, 55%) of the panelists were professionals in speech-language pathology. Other professional disciplines represented were psychology ($n = 8$, 26%), linguistics ($n = 5$, 16%), and nursing ($n = 1$, 3%).

Most of the panelists ($n = 16$, 52%) were involved in research only, whilst others were involved in research and clinical work ($n = 7$, 23%), research and teaching ($n = 6$, 19%), or research and leadership ($n = 2$, 6%). Their scope of research interest ranged from interpersonal interaction generally ($n = 10$, 32%), AAC technology ($n = 9$, 29%) or dementia-related communication ($n = 6$, 19%) specifically. Most panelists specialized in AAC ($n = 11$, 35%) in general, AAC and dementia ($n = 5$, 16%) or dementia studies ($n = 5$, 16%). Approximately a third of the panelists ($n = 10$, 32%) indicated their specialization in other areas (e.g., communication disability and ageing, palliative care). Of those who participated on the expert panel, 74% ($n = 23$) were female with the vast majority ($n = 21$, 68%) having had work experience of 16 to 20 years or more.

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Expert panelists' opinions

Overall, content analysis generated 74 codes which were grouped into 26 code categories (sub-components) and linked to nine main categories (components). These nine components were identified across the three open-ended questions:

- Component 1: The unique characteristics of the person with dementia

- Component 2: Working with a person with dementia

- Component 3: Preserving personhood

- Component 4: A different view on PCC

- Component 5: A range of communication supports

- Component 6: Supportive conversational partners

- Component 7: Designing communication supports

- Component 8: Interaction outcome measure

- Component 9*:* Meaningful interaction outcomes

Components 1–4 are summarized in Table 2 and relates to panelists' responses to the question on elements of PCC. Components 5–7 are presented in Table 3 and aligns to the question on communication supports for persons with dementia. Components 8–9 are shown in Table 4 and aligns to the question on interaction outcomes of interpersonal interaction in persons with dementia. Each of the nine components is described in the next section with a frequency count of its embedded sub-components and associated codes. The frequency count reveals the number of times a particular idea or concept was raised by the experts and is not indicative of its level of importance (Sandelowski et al., 2009). Details of frequency counts and concept areas are provided in Tables 2–4. In the following section, each component is presented in boldface, sub-components are italicized, and exemplar quotes are provided within quotation marks.

Table 1

Demographic description of expert panelists (*N* = 31).

Characteristic	*n*	%
Country		
Australia	2	6%
Brazil	1	3%
Finland	1	3%
Germany	1	3%
Ireland	2	6%
South Africa	1	3%
Sweden	4	13%
United Kingdom	14	45%
United States	5	16%
Professional discipline		
Speech-language pathology	17	55%
Psychology	8	26%
Nursing	1	3%
Other (linguistics)	5	16%
Years of experience		
0–5 years	1	3%
6–10 years	4	13%
11–15 years	5	16%
16–20 years>	21	68%
Gender		
Female	23	74%
Male	7	23%
Prefer not to say	1	3%
Specialization		
AAC (general)	11	35%
AAC and dementia	5	16%
Dementia studies	5	16%
Other (communication disability in ageing, palliative care)	10	32%
Focus of work		
Research	16	52%
Research and clinical work	7	23%
Research and teaching	6	19%
Other (research and leadership)	2	6%
Area of interest		
Adult cognitive-communicative disorders (general)	4	13%
Dementia-related communication (specific)	6	19%
Interpersonal interaction (general)	10	32%
Instrument development	2	6%
Other (AAC technology)	9	29%

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Component 1: The unique characteristics of the person with dementia

In this component (see Table 2) panelists emphasized two sub-components related to *personalization* and the *dementia diagnosis*. *Personalization* was associated with the preferences of the person with dementia and tailored support around their remaining strengths. Representative comments included, "Person-centered care means that the person is asked about their preferences", and "Gaining an in-depth understanding of the person is really important to ensure that the intervention is tailored to suit them." Panelists also highlighted the significance of life stories and personal biography. For example, one panelist commented on the importance of, "Life history and understanding how the person with dementia approaches certain issues in their life previously."

Personalization in PCC for those with dementia also involved "…understanding the persons own communication goals" (e.g., for interpersonal interaction). Furthermore, panelists emphasized that the unique characteristics of the person with dementia must be understood relative to their *dementia diagnosis* and the neuro-cognitive changes experienced by the person with dementia. For example, one panelist indicated that this entailed gaining, "Knowledge of the individual, their likes and dislikes–what makes them unique and recognizing that the person may change over time".

Table 2

Elements of Person-Centered Care (PCC) for persons with dementia.

Component, sub-component and codes	Frequency count
Component 1: The unique characteristics of the person with dementia	
Personalization	68
Preferences	26
Tailored support	16
Personal biography	14
Strengths	9
Personal goals	3
Dementia diagnosis	24
Neuro-cognitive changes	24
Component 2: Working with a person with dementia	
Partnerships	24
Family and caregivers	20
Building relationships	4
Supporting independence	21
Involvement	9
Decision-making	7
Self-determination	5
Component 3: Preserving personhood	
Personhood principle	12
Respect and dignity	8
Not being patronized*	4
Component 4: A different view on PCC	
Critical debates	1
PCC does not work*	1

Note. This table summarizes content analysis of panelists' responses to the question: "What elements of person-centered care are important to integrate into interventions designed to support interpersonal interactions with a person with dementia?". The component is displayed in bold face followed by the sub-component and associated codes; * = code emerged from the data.

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Component 2: Working with a person with dementia

As presented in Table 2, the panelists advised on two ways of working with a person with dementia. First, they placed emphasis on forging *partnerships* with family and caregivers. For example, one panelist recommended that, "Prior to developing any communication support, work closely with the person with dementia and their family". Focusing on building relationships with a person with dementia, others advised on "establishing rapport" and "building trust by becoming familiar with the person with dementia". Second, some panelists believed that working with a person with dementia necessitates *supporting independence* through their involvement. This was echoed by a panelist who stated that people with dementia "…should be involved". Other panelists emphasized the importance of decision-making by making sure to "…follow up decisions with the person" and valuing the self-determination of those with dementia.

Component 3: Preserving personhood

Within this component, the *personhood principle* (see Table 2) was highlighted. According to the panelists, personhood is demonstrated by a display of respect and dignity towards the person with dementia. One panelist suggested, "Central to working with any individual is valuing their personhood...basic respect should underpin any interaction or intervention". Additionally, others suggested that preserving personhood involved an "avoidance of patronization".

Component 4: A different view on PCC

There was one panelist with a different view on PCC (see Table 2) who remarked, "I am not a fan of person-centred care–it does not work and have rarely seen it in action." This remark did not reflect the importance to integrate PCC into interventions to support interpersonal interactions with a person with dementia.

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Component 5: A range of communication supports

As shown in Table 3, the panelists recommended a range of communication supports for interaction with a person with dementia. *Non-electronic supports* were frequently suggested, "Consider visual schedules to assist with talking about future events", as well as "communication books", and the use of "Tangible objects/objects of reference where appropriate for the topic of conversation." There were also comments related to, "The use of meaningful gestures or hand pointing" as *unaided supports*.

Some panelists focused on the conversational partners' use of *language-based supports*. For example, one panelist advised, "Ask more closed-ended questions", and another stated, "No open-ended questions!". Other panelists focused their opinions on the simplicity of sentences and the use of familiar words, for example, "Use structurally simple sentences" and "Use words that are familiar to the person with dementia."

Memory supports for recognition and recall were also recommended, as one panelist stated, "Use calendars as memory aids for recall of past events." Furthermore, the usefulness of *electronic supports* for those with dementia through technology and applications was considered. One panelist commented that, "High technology with voice generator might be useful". Still, others recommended *combined supports*, as noted in a comment, "Use multimodal communication, consider the use of all modes of communication."

Finally, some panelists offered ideas on the use of *AAC strategies and techniques.* For example, one stated, "Use cues and prompts to support conversation", whilst others mentioned, "augmented input" and "visual scenes".

Table 3

Communication supports for persons with dementia.

Component, sub-component and codes	Frequency count
Component 5: A range of communication supports	
Non-electronic supports	42
Visual aids	23
Objects	11
Paper-based books	8
Unaided supports	20
Gestures	11
Proxemics	5
Touch	3
Prosodic	1
Language-based support	20
Closed-ended questions	7
Simple sentences	6
Familiar words	4
Short phrases	3
Memory supports	10
Recognition and recall	10
Combined supports	7
Multimodal communication	7
AAC strategies and techniques	5
Cues and prompts	3
Augmented input	1
Visual scenes	1
Electronic supports	4
Technology and applications	4
Component 6: Supportive conversational partners	
Enabling conversational partner characteristics	34
Adaptable	8
Repair strategies	7
Follow the lead of the Person	4
Being patient	4
Being trained	4
Consistency*	3
Being present	2
Listening skills	2

Component, sub-component and codes	Frequency count
Empathetic communication	29
Making-meaning	9
Attentiveness	9
Attunement	8
Empathy	3
Component 7: Designing communication supports	
Communicative context	33
Communicative purpose*	18
Environmental adaptations	15
Meaningful content	14
Materials and music	14
Complexity of communication supports	7
Reduced cognitive effort	7

Note. This table summarizes the content analysis of panelists' responses to the question:

"What communication supports are important for a conversational partner to facilitate

interpersonal interaction with a person with dementia?" The component is displayed in bold

face followed by the sub-component and associated codes; * = code emerged from the data.

Component 6: Supportive Communication Partners

Within this component (see Table 3), the panelists underscored the significance of supportive conversational partners through their opinions on two sub-components–*enabling conversational partner characteristics* and *empathetic communication*. They mentioned that conversational partners should be adaptable by being "…ready to adapt the supports to suit how the person with dementia is at any given time". Some panelists suggested specific repair strategies such as "repeating and rephrasing", whilst others focused on conversational partners who are patient. For example, one panelist suggested that, "The conversation partner is not in a hurry but should have patience".

Furthermore, panelists highlighted that conversational partners should "Follow the lead of the person with dementia". Emphasizing the importance of trained conversational partners, one panelist opined, "I think the most important support for a person with dementia is a having a partner who is trained". Other characteristics of conversational partners included consistency, for example, "The communication partner must be consistent in their responses". Similarly, other panelists provided their opinions on being present and displaying listening skills, as reflected in one comment, "The listener needs to genuinely show that they are listening".

Panelists also shared ideas on *empathetic communication* which were associated with making–meaning and attentiveness. For example, one panelist advised on "…making sense of the interaction", and another stated, "Attention– you need to focus on the individual". Within this sub-component, there were ideas related to attunement, as one expert commented, "The partner must be attuned to the person's communication". Other panelists emphasized that conversational partners should show empathy within an interaction with a person with dementia, noted in a comment, "Empathy –putting himself in other´s shoes".

Component 7: Designing communication supports

The panelists provided considerations for designing communication supports for people with dementia by highlighting three sub-components (see Table 3): The *communication context* received a predominant focus as panelists believed that communication supports for those with dementia are designed for a specific communicative purpose. For example, as one panelist stated, "Focus on sharing jokes and humour." Others shared ideas on environmental adaptations, for example, "Optimise on the communication environment by ensuring a reduction of distractions, the environment should support communication".

Additionally, some panelists were of the opinion that communication supports should be designed with *meaningful content* using specific materials, such as "newspapers" and activities such as "music and singing". The *complexity of communication supports* was also considered by the panelists, which focused on ensuring reduced cognitive effort by the person with dementia. For example, one expert stated that, "The goal is to reduce cognitive effort, so the support is modified to reduce the abstraction level and the complexity of the AAC " for the person with dementia.

Component 8: Interaction outcome measure

As shown in Table 4, in this component, the most frequently occurring expert opinions related to interaction *outcome measure domains*. These domains included turn-taking, such as "…length of turn-taking", or "… number of conversational turns." Language domains were also suggested, for example, "Measure expressive language, and word finding", and "Measure comprehension." Regarding behaviour and emotion domains, there were recommendations to, "Capture behavioural measures, mood and level of frustration of the person with dementia and partner" and include "measures of pleasure/comfort".

Table 4

Interaction outcomes of interpersonal interaction in persons with dementia.

Component, sub-component and codes	Frequency count
Component 8: Interaction outcome measure	
Outcome measure domains	61
Turn-taking	21
Language	18
Behavior and emotion	11
Communication partner responses*	5
Body language	3
Gestures	2
Vocalizations	1
Analysis of interaction	27
Pace and timing	15
Video-recorded analysis	4
Pauses	3
Topic maintenance	3
Topic initiations	2
Analysis of communication supports	15
Communication supports in context *	15
Types of outcome measures	4
Performance-based measures*	2
Patient-reported measures*	1
Combined measures*	1
Component 9: Meaningful interaction outcomes	
Outcome constructs	32
Engagement outcomes	14
Participation outcomes	13
Quality of life and wellbeing	5
Intrapersonal outcomes	20
Satisfaction	10
Interaction success	5
Control of interaction *	3
Confidence	2
Interpersonal outcomes	11
Social closeness	10
Enjoyment	1
Identified outcomes	7
Self and conversational partner identified	5
Conversational partner identified	2

Note. This table summarizes the content analysis of panelists' responses to the question: "What interaction outcomes are important to include in an outcome measure for supporting interpersonal interaction in persons with dementia?". The component is displayed in bold face followed by the sub-component and associated codes; * = code emerged from the data.

Panelists also focused on measuring communication partner responses. For example, one panelist believed it was important to "Measure partner responsiveness", whilst another advised on measuring "…aspects of body language between conversation partners in the interaction." Domains related to the use of gestures and vocalizations within interaction were also considered by the panelists, for example, "Include the gestures used within the interaction", and the "Use of vocalizations." Additionally, panelists provided insights on the *analysis of interaction* from the perspective of pace and timing of interaction. For example, one expert considered, "Can the person speak and respond in their own time?" and another recommended analyzing the "…pauses within the interaction".

Some panelists suggested video-recordings of interaction, which were reflected in comments such as, "Have recordings, ideally video recordings of interaction", and "…video-recordings of interaction between conversational partners." Other panelists considered the analysis of interaction structure, in terms of topic maintenance and topic initiations. Their comments included, "analysis of staying on topic", and "…perhaps analyzing proportions of initiation." Regarding the *analysis of communication supports* in context of an interaction, some panelists stated, "Evaluate which communication strategies worked", and "Measure the extent of communication supports used in the interaction".

Specific *types of outcome measures* were suggested by the panelists. These were conveyed in comments such as, "Use performance-based measures", or "Consider patient-reported measures". In contrast, one panelist who had an opinion on combined measures stated, "I think that we need to use a hybrid outcome approach that combines both patient-reported outcome measures and performance-based measures".

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Component 9*:* Meaningful interaction outcomes

In this component (see Table 4), the panelists recognized that meaningful interaction outcomes were mostly associated with specific *outcome constructs*. Specifically, engagement outcomes for the person with dementia were suggested, for example, "Outcomes on the level of engagement with their social circle". Other panelists considered, "Communicative engagement of both partners in the interaction." Additionally, participation outcomes were reflected in panelists' remarks such as, "Measure whether the person can participate fully in communication activities", and "It is essential to maximally support participation of the person with dementia in important life activities." Outcomes related to quality of life and wellbeing were also highlighted by some panelists. For example, one panelist considered, "General quality of life measures, and individual well-being or lack of it".

Furthermore, according to the panelists, *intrapersonal outcomes* were those in which the person with dementia experiences satisfaction and interaction success. Comments made by the panelists included, "Most important is their satisfaction with the interaction.", and "…their perceptions of interaction success". Focusing on the person with dementia, some panelists commented on the control of interaction and confidence in interacting. One panelist mentioned, "Being able to control communication situations", and another stated, "The level of confidence in being able to interact".

Still, other panelists highlighted *interpersonal outcomes* such as social closeness and enjoyment experienced between the person with dementia and their conversational partners during an interaction. These ideas were conveyed in panelists' comments such as, "It is important to look at social closeness in the communication situation", and "…enjoyment of the interaction"

Lastly, panelists shared opinions on desired *identified outcomes* of interpersonal interaction in persons with dementia and their conversational partners. For example, a panelist suggested that "This is individually defined from the patient with dementia and a caregiver", and another added, "Ask the person with dementia and their partners!" In contrast, other panelists focused on outcomes identified by conversational partners, as one advised, "Interview the communication partner to identify what may be useful for the interaction."

Discussion

This study aimed to obtain expert opinion on components of a person-centered AAC intervention for persons with dementia. Data was collected from an e-Delphi panel aligned to three research questions related to the elements of PCC, communication supports, and interaction outcomes of interpersonal interaction in persons with dementia. Based on expert opinion acquired in this study nine components, with various embedded sub-components, were identified: (a) the unique characteristics of the person with dementia, (b) working with a person with dementia, (c), preserving personhood, (d) a different view on PCC, (e) a range of communication supports, (f) supportive conversational partners, (g) designing communication supports, (h) interaction outcome measure, (i) meaningful interaction outcomes.

Although the results were obtained in accordance with the three questions posed (i.e., elements of PCC, communication supports, and interaction outcomes), all nine components identified by the expert panelists are interconnected within a person-centered AAC intervention. This infers that the application of PCC elements influences the choice of communication supports, the selection of interaction outcomes and measurement of those outcomes. Key findings related to the panelists' views on the elements of PCC, communication supports, and

interaction outcomes of a person-centered AAC intervention for those with dementia are further discussed.

Elements of PCC in person-centered AAC interventions

According to the panelists, person-centered AAC interventions should focus on the unique characteristics of the person with dementia; by designing communication supports tailored to their individualized needs. The knowledge gained from expert panelists in this study, informs SLPs to apply a personalized approach by understanding the preferences, choices, personal biography, personal goals, and strengths of the person with dementia. Findings from our study correspond with an expert consensus study by Volkmer et al. (2023) which collectively illuminates the importance of knowing the *person*, beyond merely knowing their name– but in a deeper, more personalized way which is fundamental to person-centered AAC interventions (Doran et al., 2018; Mohr et al., 2021). A personalized approach also calls for understanding the impact of communication difficulties on the people around the person with dementia (Hickey & Bourgeois, 2018; Nickbakht et al., 2023). As reflected in the results of our study, this relies on developing partnerships with family members, caregivers, and conversational partners. These individuals play a vital role in maintaining interaction with persons with dementia, and their involvement becomes necessary when designing communication supports (Murray et al., 2022).

Recognizing the necessity of the environment in which interaction occurs, the panelists highlighted the need for compensatory environmental adaptations to enhance interpersonal interactions with those with dementia. This finding resonates with previous research recommending that caregivers should be trained to make necessary environmental modifications to support person-centered interactions with people with dementia (Vasse et al., 2010; Volkmer et al., 2023). It is important to note that interactions may be impacted in a positive or negative

manner depending on the specific setting in which they occur (Allwood et al., 2017). For instance, interactions between paid caregivers and people with dementia in nursing facilities tend to be patronizing, task-focused and less person-centered (Vasse et al., 2010). Acquiring panelists' opinions on how interpersonal interaction in persons with dementia differ in specific settings (e.g., home setting, hospital setting or nursing facility) would have been interesting. However, none of the panelists in the current study commented on this issue.

According to findings in this study, personalized communication supports with meaningful content (e.g., paper-based life stories) and AAC strategies may operationalize PCC elements. This is in line with previous studies which have emphasized that conversational partners who scaffold interactions with AAC and use person-centered conversational partner strategies could positively affirm the identity of those with dementia throughout the progression of communication decline (Doran et al., 2018; Gomèz-Taibo et al., 2014; Subramaniam & Woods, 2016).

It is interesting that although most opinions were positive towards the concept of PCC, there was one opinion that PCC does not work. This finding may seem surprising given the importance of PCC in speech-language pathology (Forsgren et al., 2022). However, it is also anticipated, considering the critical debates in the literature surrounding the operationalization and implementation of PCC (Edgar et al., 2020; Mohr et al., 2021). Although this finding represents only one opinion; it is indeed important, as opinions of PCC can be influenced by contextual factors, cultural perspectives, and personal experiences (Mahomed-Asmail et al., 2023). Therefore, this finding warrants further investigation into factors that shape SLP's views on PCC across different contexts.

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Communication supports for persons with dementia

A range of communication supports; specifically non-electronic communication supports (visual aids, paper-based books, objects), were frequently suggested to maximize communication participation in persons with dementia. This finding may be attributed to the well-established research evidence on non-electronic communication supports for persons with dementia (Bourgeois et al., 2016; Chang & Bourgeois, 2020; Fried-Oken et al., 2015; Lanzi et al., 2017; May et al., 2019; Murphy et al., 2010). As proposed by the panelists in this study, it may be useful to further explore the potential of developing electronic communication supports. This finding supports the emerging body of work on customized electronic devices to increase enjoyment within interpersonal interaction with persons with dementia (Ekström et al., 2017; Samuelsson & Ekström, 2019). Central to the development of electronic communication supports is the direct involvement of people with dementia as well as their families and caregivers alongside SLPs and other interdisciplinary professionals (Dada et al., 2021; Murray et al., 2022).

Interaction outcomes for persons with dementia

Further knowledge gained from the expert panelists revealed the essentiality of determining what interaction outcomes people with dementia value most. Rather than exclusively focusing on outcomes on an impairment level; findings of our study highlighted the significance of participation and engagement outcomes for those with dementia. This finding resonates with the literature reporting that participation in everyday interactions have real-life outcomes for people who use communication supports (Fried-Oken et al., 2015; Hickey & Bourgeois, 2018; Hickey et al., 2018; Nickbakht et al., 2023).

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A notable finding of this study is the expert opinion on domains to be measured in an outcome measure for persons with dementia who use AAC. For instance, domains such as multimodal turn-taking may capitalize on the communication strengths that a person with dementia still possesses despite a decline in expressive language. Thus, developing strength-based, person-centered outcome measurement tools for those with dementia appears to be a worthwhile consideration for future research (Lanzi et al., 2017; Kogan et al., 2016). Of added significance in this study, was expert opinion on the importance of identifying meaningful interaction outcomes by involving persons with dementia in making their own decisions about those outcomes (e.g., satisfaction) through patient-report outcome measures. Given the lack of validated outcome measures for person-centered interventions in dementia generally (Kogan et al., 2016), and no existing patient-reported outcome measure for adults who use AAC specifically (Broomfield et al., 2019), our findings suggest the potential for developing an AAC outcome measure for people with dementia in this respect.

Implications for Research and Clinical Practice

This study is unique because, to the best of our knowledge, it is the first to gather opinions from an international expert panel to identify components of a person-centered AAC intervention for people with dementia. A major strength of this study is its alignment with evidence-based practice in obtaining experts' opinions on the research question. When integrated with current research evidence on PCC from scoping reviews (Forsgren et al., 2022), experts' opinions, such as those reflected in this study, contribute towards an enhanced understanding of PCC in speech-language pathology for persons with dementia. By using a modified e-Delphi technique, the opinions gathered were those of SLPs with extensive experience on the research topic and specializing in AAC. A modified e-Delphi technique allowed for the data to be

collected conveniently from a geographical dispersed expert panel, reducing the possibility of negative group dynamics from influencing data collection, as is commonly noted in other group survey methods (Donohoe et al., 2012). The inclusion of doctoral holders or doctoral candidates ensured that the opinions acquired were those of highly qualified experts. Overall, this contributed to the validity of the results (Hasson et al., 2000).

It is worth noting that most of the experts who participated in this study were from the UK, which has a more socialized healthcare system through the National Health Service (NHS). The structures and processes of healthcare and how they interact with other services (e.g., social care services) are different across the globe. These differences may impact on access to dementia support, specifically AAC systems and services, and the ongoing care required by people with dementia (NHS, 2016).

Given the current interest in PCC, the results of this study serve as a small, albeit essential step, towards advancing further dialogue around person-centered interventions in speech-language pathology. Additionally, the intervention components identified in this study could serve as a starting point to guide researchers and clinicians in crafting future person-centered interventions for people with dementia.

Limitations and Future Directions

This study has the following limitations: First, the selection criteria focused on research expertise, and the results primarily represent those of researchers. The inclusion of clinical practitioners on the expert panel would have complemented the current findings through their practice-based expertise. In acknowledgement of this limitation, the researchers included the views of non-doctoral, practicing SLPs in subsequent research linked to the current study (May et al., 2024). Second, due to recruitment restrictions for elderly people living in frail care and

care homes during the COVID-19 pandemic, those with dementia were not included in the expert panel which restricts the diversity of opinions acquired. Individuals with dementia are experts based on their lived experience of dementia-related communication challenges and their perspectives are unique to those of SLPs with research and clinical expertise (Nickbakht et al., 2023). Therefore, future research on PCC in speech-language pathology should include people with dementia and their family members on expert panels. Importantly, SLPs should consider the value of inclusive and participatory research methods with evidence-based AAC tools (Murray et al., 2022) to support the involvement of people with dementia in research.

Third, the purposive sampling strategy and the increased work demands of panelists during the COVID-19 pandemic may have contributed to the 49% response rate. Taken together, this may have limited the breadth of opinions gathered and the results are, therefore, not exhaustive. Finally, this study is part of a broader research study, and offers only surface-level descriptions of the data. Furthermore, there is no hierarchy of importance to the results obtained. The information obtained from the current study was coalesced into a statement set and ranked by a different sample of professionals as reported in May et al. (2024). Thus, the current study should be neither interpreted independently nor conclusions made solely from the current data but rather complemented with the details reported by May et al. (2024).

Conclusion

This study provides expert opinions forming nine components of a person-centered AAC intervention to support interpersonal interaction in persons with dementia. The nine intervention components identified in this study suggest the importance of a personalized approach by developing partnerships with persons with dementia and their family, applying person-centered conversational partner scaffolding strategies, understanding the communication context, focusing

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on participation and engagement outcomes, and measuring communication strengths. These findings may offer SLPs guidance for the development of future person-centered AAC interventions for those with dementia.

Acknowledgments

Data Availability

The dataset analyzed in the current study is not publicly available due to privacy concerns.

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