A person-centred AAC intervention to support interpersonal interaction in persons with dementia: An exploratory study

by

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– *I can do all things through Christ who gives me strength* –

(Philippians 4:13)

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ABBREVIATIONS

AAC	:	Augmentative and Alternative Communication
AACOM-PwD	:	Augmentative and Alternative Communication Outcome Measure for Persons with Dementia
DAT	:	Dementia of the Alzheimer’s Type
EBP	:	Evidence-Based Practice
PCC	:	Person-Centred Care
PC-AAC	:	Person-Centred Augmentative and Alternative Communication
PPA	:	Primary Progressive Aphasia
PwD	:	Person with Dementia
PwPPA	:	Persons with Primary Progressive Aphasia
WHO	:	World Health Organization

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ABSTRACT

Background: The current mandate in dementia research is to develop interventions that are evidence-based and person-centred. However, person-centred augmentative and alternative communication interventions in dementia are limited. *Method*: A multimethod research design was conducted in three Phases. Phase one reviewed current research evidence to inform the development of a person-centred intervention. Phase two developed a person-centred augmentative and alternative communication intervention package with four components, (a) elements of person-centred care; (b) an electronic conversational support; (c) augmentative and alternative communication outcomes; and (d) an outcome measure. Phase three tested the feasibility of these four components by considering them in two ways (phase 3A and phase 3B). In 3A, Q-methodology was employed to obtain professionals' viewpoints. In 3B, a case study was used to test the feasibility of the researcher's implementation of an electronic conversational support with a participant with dementia and the scoring reliability of an outcome measure developed in this study. *Results*: Q-methodology results revealed professional views on (i) person-centred authorship, (ii) person-centred language style using supportive strategies (iii) adapted participatory methods with persons with dementia in their interventions. Case study results indicated that an electronic conversational support could be reliably implemented. Inter-rater reliability was not at an acceptable level for the multimodal domain of an outcome measure developed in this study. *Conclusion:* This study highlights the importance of using person-centred scaffolding strategies and exploring the potential of adapted participatory methods to develop and implement evidence-based, person-centred interventions in persons with dementia.

Keywords:
Augmentative and Alternative Communication, co-production, dementia, evidence-based practice, person-centred care, Q-methodology

CHAPTER 1: PROBLEM STATEMENT AND RATIONALE

1.1. Introduction

This chapter provides the problem statement and background to this study. The purpose of the study is stated, followed by explanations of the frequently used terminology and a list of abbreviations. The seven chapters of this thesis are subsequently outlined.

1.2. Problem statement and rationale

Interpersonal interaction is essential for human connection. It provides a context for developing a relationship with others by sharing stories, exchanging ideas and responding to humour (Person & Hanssen, 2015). Persons with dementia experience significant difficulty in maintaining interpersonal interaction with their conversational partners (Hall, Lund, Young, Okell, & Van Steenbrugge, 2018). They have challenges with the understanding of spoken language and retrieval of words in conversations (Hickey & Bourgeois, 2018). Confusion with word categories is often apparent, which affects the meaning of the messages that persons with dementia wish to express. For this reason, they have difficulty with initiating and contributing meaningfully to conversations (Samuelsson & Hydén, 2017).

As a major neurocognitive disorder, dementia brings about progressive and permanent changes in persons with dementia. With deterioration in verbal language, persons with dementia withdraw from interpersonal interaction, which increases social isolation and loneliness (Hickey & Bourgeois, 2018). Close relationships are fundamentally affected, and over time, the relational gap between persons with dementia and those around them widens (Webb, 2017). Conversational partners play a vital role in supporting the conversations of persons with dementia. However, conversational partners are unaware of how to use interaction strategies to support persons with dementia effectively (Alsawy, Mansell, MeEvoy & Tai, 2017). As a result, they have expressed a need for personalised interventions to enable them to facilitate meaningful interaction with persons with dementia (Wynn & Khayum, 2015).

Dementia-related communication difficulties have real-world implications for the 50 million people living with dementia. In fact, an exponential escalation of 131,5 million is probable by 2050 (World Health Organization [WHO], 2017). Moreover, the human population is said to be on the verge of reaching an extraordinary ageing milestone due to increased longevity. Accordingly, there is a notable acceleration in the number of persons older than 65 years, compared to the younger segment of the global populace (United Nations, 2019). This global mega-trend has concurrently increased the risk of developing dementia.

To address this extraordinary health phenomenon, the WHO (2017) has appealed for evidence-based interventions that improve the wellbeing of persons with dementia. Given this call, there is a need for interventions that can be substantiated by the best available scientific research and that require mandatory involvement with persons with dementia and the collaborative efforts of multiple stakeholders (WHO, 2017).

The availability of evidence-based interventions to support interpersonal interaction in persons with dementia is limited (Morris, Horne, McEvoy, & Williams, 2017; Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010). In particular, academic scholars have raised concerns that the majority of available communication interventions for persons with dementia are underpinned neither by theory nor a well-defined conceptual framework (Morris et al., 2017).

The current mandate for dementia research is to develop interventions that are evidence-based, and person-centred (Lanzi, Burshnic, & Bourgeois, 2017; Mahendra, 2019). Person-centred care is promoted as best practice in the context of working with persons with dementia (Brossard Saxell, Ingvert, & Lethin, 2019). In person-centred care, there is an emphasis not only on the preferences of persons with dementia but also in encouraging their involvement in decision-making regarding their choices. Although accepted as best practice for persons with dementia, there appears to be uncertainty about the definition of person-centred care and its implementation in clinical practice (Dewing & McCormack, 2017).

Person-centred care has recently been emphasised in the Augmentative and Alternative Communication (AAC) literature. McNaughton, Light, Beukelman, Klein, Nieder & Nazareth (2019) have recently highlighted the importance of person-centred planning. Person-centred planning in AAC underscores the centrality of the person who uses AAC in all phases of AAC assessment and intervention (McNaughton et al., 2019; Williams, Krezman, & McNaughton, 2008). Furthermore, AAC scholars have called for an agenda to expand person-centred research for adults with acquired communication disabilities (Fager, Fried-Oken, Jakobs, & Beukelman, 2019).

The evidence on person-centred care as it applies to AAC interventions in persons with dementia is still developing (Lanzi et al., 2017). There is research evidence related to the use of non-electronic aids (e.g., communication cards) to enable persons with dementia to express their preferences and choices (Bourgeois, Camp, Antenucci, & Fox, 2016). However, the evidence on how person-centred care is applied in the development of electronic conversational aids, namely general consumer-level mobile technologies with specific applications, *with* persons with dementia is scarce. This highlights the need to catalyse research evidence on person-centred electronic AAC interventions.

Alongside the escalating dementia prevalence and the associated real-world implications, is the critical need for AAC professionals to expand their understanding of person-centred AAC interventions. In sum, it is incumbent on AAC researchers to develop interventions that not only consider the best empirical research but also integrate clinical expertise with the perspectives of relevant stakeholders (Schlosser & Raghavendra, 2004). The novel contribution made by this study aims to respond to a pressing global need for innovative dementia research. This study should address the existing gaps in the available knowledge by providing evidence on a person-centred AAC intervention to support interpersonal interaction in a person with dementia.

1.3. Terminology

The following frequently used terminology are explained below:

- **Augmentative and Alternative Communication**

Augmentative and Alternative Communication (AAC) refers to the scientific field of research and clinical practice. AAC offers communication support through systems that are either unaided or aided (American Speech-Language-Hearing Association [ASHA], 2019). While unaided systems require no technology (e.g., gestures), aided systems comprise of non-electronic, paper-based solutions (e.g., memory books) or electronic, highly technologically dependent devices (e.g., computer technology) (Waller, 2019).

- **AAC intervention**

In this study, an AAC intervention refers to the implementation of evidence-based AAC scaffolding techniques and strategies (e.g., aided modelling) to support auditory comprehension of spoken messages, word finding, conversational initiation, topic maintenance, and turn taking in a person with dementia.

- **Communication supports**

Communication supports refer to any strategy, tool or technique used by a conversational partner to enable persons with neurodegenerative conditions to participate in activities. Communication supports can range from positive attitudes of conversational partners to policies that promote communication participation (Fried-Oken, Mooney, & Peters, 2015).

- **Electronic life story**

In this study, an electronic life story was a life story of a participant with dementia presented on an electronic AAC device. The electronic device consisted of an Apple iPad (4th generation) as the hardware platform using the GoTalk NOW application. The purpose of the electronic life story was to increase enjoyment when eliciting conversations about the participants' personalised stories.

- **Evidence-based practice**

In this study, evidence-based practice is defined as "the integration of the best and current research evidence with clinical/educational expertise and relevant stakeholder perspectives" (Schlosser & Raghavendra, 2004, p. 3).

- **Familiar conversational partner**

A familiar conversational partner, in this study, refers to an adult (spouse, child, family member, friend, or caregiver) who has background knowledge on the life history of a participant with dementia. The role of the familiar conversational partner is to assist the participant with dementia in selecting materials for the co-produced electronic life story conversational support (Kindell, Burrow, Wilkinson, & Keady, 2014).

- **Interpersonal interaction**

In this study, the term interpersonal interaction refers to the relational aspects of interactive communication. The focus of an interpersonal interaction is to establish or maintain a relationship with a person with dementia. There is emphasis to create a sense of social connection between a person with dementia and conversational partner, and to experience a level of shared enjoyment between the conversational partners (Davidson, Worrall, & Hickson, 2008).

- **Life story**

A life-story is a biographical approach that enables a person with dementia to communicate about their memorable past experiences and reminisce about their life history (McKeown, Clarke, & Repper, 2006). Life-story work can be presented in various formats, e.g., non-electronic books with photograph collages. In this study, the researcher developed the participant's life story from three main themes related to life events, family and friends, and values and beliefs (Skinner, Bonnet, Schlundt & Kalekar, 2019).

- **Person-centred care**

Person-centred care is a philosophical approach that emphasises that personhood is achieved in relation to and interaction with others (Kitwood, 1997). Person-centred interventions highlight the unique life history, values, preferences and needs of persons with dementia, which is realised in mutual collaboration and understanding with those with whom they interact with (Savundranayagam, 2012).

- **Person-centred AAC intervention for person with dementia**

This study developed a Person-Centred Augmentative and Alternative Communication (PC-AAC) intervention package to support interpersonal interaction in a person with moderate to severe dementia. The PC-AAC intervention for a person with dementia consists of four interlinked components. Component 1 refers to the elements of a person-centred care approach; Component 2 relates to an electronic life story conversational support; Component 3 relates to AAC outcomes for persons with dementia; and Component 4 developed an AAC outcome measure for persons with dementia. Each of the four components contain sub-components, underlying processes, materials and evidence-based strategies. In this study, the PC-AAC intervention for a person with dementia was developed, and the feasibility of the components were tested in two ways. Firstly, the views of professionals (based on their clinical and educational expertise) were obtained on all four components Secondly, Component 2: electronic life story conversational support was implemented in a real-life context with a person with dementia. The procedural reliability of implementation, as well as Components 3 and 4 were evaluated.

- **Person with dementia**

An individual diagnosed with dementia, specifically a person who experiences communication difficulties arising from a neuro-degenerative dementia (e.g., dementia of the Alzheimer’s type). Dementia is a major neurocognitive disorder in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) (American Psychiatric Association [APA], 2013). This study describes one person with moderate to severe dementia with probable dementia of the Alzheimer’s type.

1.4. Outline of chapters

This study report contains seven chapters.

- Chapter 1 provides the problem statement and background to this study. The frequently used terminology is defined, a list of abbreviations is provided, and an outline is given of the content of the different chapters.
- Chapter 2 offers an overview of literature related to the historical and theoretical underpinning of person-centred care, as well as current debates on the concept of

person-centred care. An evidence-based practice framework is presented as the conceptual framework for the current study. The chapter includes a research review of AAC interventions in persons with dementia. Specifically, the research review focused on electronic AAC strategies and techniques, AAC outcomes, AAC outcome measures and emerging trends as they relate to person-centred AAC interventions for persons with dementia. The chapter concludes with a summary of a secondary review on intelligent assistive technology devices for persons with dementia to supplement the information obtained in the research review. Both reviews of the literature were used to inform the development of a person-centred AAC intervention package for a person with dementia, described in Chapter 3.

- Chapter 3 describes the development of the person-centred AAC (PC-AAC) intervention package developed from the literature reviewed in Chapter 2. The PC-AAC intervention package is described in relation to its four main components, sub-components, underlying processes and developed materials. A co-production framework for developing an electronic life story conversational support (Component 2) with a person with dementia is subsequently depicted. An AAC outcome measure for persons with dementia (Component 4) that was developed in this study to measure turn taking within an interpersonal interaction is also presented.
- Chapter 4 outlines the research methodology employed in this study. The rationale for selecting the research design is provided, followed by the main aim and sub-aims and the three research phases. Phase 3 – a feasibility testing phase of the four components of the PC-AAC intervention package developed in Chapter 3– is reported on in two parts. Phase 3A describes Q-methodology and addresses the four steps involved in Q-methodology data collection procedures related to concourse development, selection of statements, ranking of statements by professionals, and factor analysis. Phase 3B presents a case study in which two components of the PC-AAC intervention package were implemented with a participant with moderate to severe dementia in a real-life setting. A description of the participant and setting, the participant selection criteria, in-person data collection procedures, recruitment materials, general procedures and ethical considerations is presented.
- Chapter 5 presents the results of the feasibility testing phase in two parts. In Phase 3A, AAC professional’s viewpoints are attained through in-person factor analysis using Q-methodology data. This is followed by Phase 3B, which reports on the procedural

integrity of implementing Component 2: electronic life story conversational support and the reliability of scoring the AAC outcome measure for PwD (Component 4). Qualitative data related to the self-reported enjoyment (Component 3) of the participant with dementia is presented. Collectively, these results represent the feasibility testing results of the four components of the PC-AAC intervention package developed in this study (in Chapter 3).

- Chapter 6 discusses and interprets the results of the study. In each section, the findings of this study are compared to previous research studies. Pertinent literature is also consulted to highlight important implications of this study.
- Chapter 7 presents a summary of the research that was conducted. This is followed by an evaluation of the study, highlights of the clinical implications, and recommendations for future research.

1.5. Summary

This chapter presented the problem statement and rationale for the study. The need for evidence-based, person-centred interventions for persons with dementia, underpinned by a theoretical or conceptual framework, was highlighted. The researcher emphasised the need to extend the knowledge base to improve interpersonal interaction using electronic AAC interventions within the field of AAC. The definitions of frequently used terminology were provided, and to conclude, the seven chapters comprised in this thesis were discussed briefly.

CHAPTER 2: LITERATURE REVIEW

2.1. Introduction

The chapter begins with a discussion of dementia and its impact on interpersonal interaction. This is followed by a discussion of the elements of a person-centred care approach and the current critical debates that surround this concept of care for persons with dementia. Next follows a discussion of evidence-based practice as applied in interventions within the field of dementia. The evidence-based practice conceptual framework as applied in this study is subsequently presented. The chapter concludes with an overview of the two reviews of literature related to current AAC interventions, strategies and techniques that are used to support communication in persons with dementia.

2.2. Interventions for persons with dementia

2.2.1. Defining dementia

Dementia is classified as a major neurocognitive disorder in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) (American Psychiatric Association [APA], 2013). Neurocognitive disorder was introduced as an alternative term to the word dementia, which may carry a stigma due to its Latin translation of being ‘out of one’s mind’. Despite the change in nomenclature, the term dementia is commonly used in research and clinical practice, and is still widely accepted (APA, 2013).

Dementia describes a cluster of irreversible and pervasive cognitive changes that occur in different parts of the brain. Notably, one or more cognitive domains – i.e., memory, language, executive function, learning and social cognition – may be progressively affected (APA, 2013). Dementia symptoms arise from various diseases affecting different parts of the brain. Accordingly, there are various dementia subtypes such as dementia of the Alzheimer’s type (DAT), vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (Klimova & Kuca, 2016). The most common dementia subtype, DAT, is caused by Alzheimer’s Disease that involves a progressive build-up of neuritic plaques and neurofibrillary tangles that degenerate different cortical areas (DeTure & Dickson, 2019).

Furthermore, vascular dementia, as the second most common dementia subtype, results from a progressive narrowing of cerebral blood vessels. Frontotemporal lobar atrophy manifests in semantic dementia (also referred to as fluent primary progressive aphasia).

Dementia subtypes can frequently co-exist and consequently present with a unique set of mixed symptoms (DeTure & Dickson, 2019; Hopper, Hickey & Bourgeois, 2018). Irrespective of the dementia subtype, persons with dementia (PwD) experience a significant decrease in cognitive functioning that gradually affects their independence in daily activities.

In defining dementia, is it essential to understand that the syndrome in itself is not an inevitable outcome of growing older. Although an advancement in age is a key risk factor for developing dementia, younger individuals are not exempt from developing dementia. This is indicated in prevalence statistics in which persons below 65 years of age account for 9% of young-onset dementia (WHO, 2020).

Although pharmacological intervention may assist in reducing behavioural symptoms and delaying the progression of cognitive deterioration, there is no available pharmacological intervention to cure dementia. This means that interventions that do not use medication but aim to enhance the psycho-social well-being and quality of life of persons with dementia are pivotal for enabling persons to live well with dementia symptoms.

2.2.2. Impact of dementia on interpersonal interaction

The innate human need for social connection is vital for one's quality of life. Social connection is a subjective feeling of relatedness to another individual that may be created through friendship and shared humour (Perion & Steiner, 2017; Sabat & Lee, 2012). A sense of social connection is facilitated and maintained through verbal and non-verbal communication as persons co-construct meaning with each other within an interpersonal interaction (Birt, Griffiths, Charlesworth, Higgs, Orrell, & Poland, 2020; Perion & Steiner, 2017). However, in persons with dementia interpersonal interactions are compromised. Whilst the expressive language of persons with dementia may appear grammatically and phonologically correct, difficulties with auditory comprehension of spoken language such as narratives and complex instructions are common (Mahendra, Hickey, & Bourgeois, 2018).

Interpersonal interaction is a collaborative process. As such, a person with dementia and a conversational partner contribute to an interpersonal interaction through a sequence of turns that facilitates shared meaning and common ground (Alant, 2017; Clark, 1996; Samuelsson & Hydén, 2017). Although the structural mechanism of turn taking within interpersonal interactions is generally preserved in persons with dementia, word-finding difficulties and longer processing time may result in difficulties with turn taking (Ekström, Lindholm, Majlesi, & Samuelsson, 2017).

Furthermore, word-finding and attentional difficulties affect their ability to sustain reciprocal responses (Bourgeois & Hickey, 2018). With a progression in communication challenges in both comprehension and expression of language, persons with dementia may withdraw from interpersonal interaction altogether. In this regard, Ward, Vass, Aggerwal, Garfield and Cybyk (2008) point out that persons with severe dementia may appear unresponsive and, in turn, their conversational partners may underestimate their need for interpersonal interaction.

The literature reveals that conversational partners may perceive that interpersonal interaction with persons with dementia, especially those with moderate to severe dementia, is futile (de Medeiros, Saunders, & Sabat, 2012; McEvoy & Plant, 2014). In fact, this perception is often shared by rehabilitation and medical professionals working with persons with dementia. Several authors raise concern over the notion of ‘therapeutic nihilism’ as a negative professional assumption that persons with dementia do not benefit from intervention (Giezendanner et al., 2019; Hopper, 2003; Mahendra, Scullion, & Hamerschlag, 2011; Mahendra, Fremont, & Dionne, 2013).

On the other hand, the perspectives of persons with dementia may differ from those of conversational partners and professionals. Despite the irreversible cognitive-communicative changes, persons with dementia preserve the need for interpersonal interaction and for maintaining social connection through companionships with those around them (Alant, 2017; Sabat & Lee, 2012; Savundranayagam, 2013). This is supported in qualitative evidence from a systematic review of 23 studies which indicated that persons with dementia believe that interpersonal interactions with supportive conversational partners are important to foster their wellbeing (Patterson, Clarke, Wolverson & Moniz-Cook, 2017). In parallel with these findings, Birt et al. (2020) synthesised 13 qualitative studies and indicated that social connection was an important priority for persons with dementia. Such connection is achieved through positive identity-supporting interpersonal interactions. According to Haapala, Carr and Biggs (2019), persons with dementia self-reported that their highest priorities were those of social inclusion and a sense of feeling connected in interpersonal interaction with others.

2.3. Person-centred care approach

2.3.1. Background of person-centred care

Person-centred care is advocated as best practice in care for persons with dementia. Person-centred care is a philosophy of care that emphasises the remaining strengths and abilities of a person with dementia rather than to focus on the trajectory of neurodegeneration (Kitwood, 1997). Person-centred care is founded on the humanistic theory of Carl Rogers (1958) who focused on client-centred therapy. The work of Rogers (1958) provided a person-centred care framework for the development of therapeutic relationships. The propositions of Rogers' person-centred care theoretical framework (1958) underscore the relationship that develops between a therapist and individual receiving therapy, based on a therapists' empathetic understanding, transparency, and perspective taking. Rogers (1958) further argued that it was the application of these principles that would enable a client to reach their full potential (Edgar, Wilson, & Moroney, 2020).

Kitwood (1997) built on the work of Rogers (1958) and introduced the concept of person-centred care for persons with dementia. Traditionally, interventions for persons with dementia were framed from a bio-medical lens, in which the trajectory of neurodegeneration was emphasised by loss of a sense of self, decline, and deficits (Kogan, Wilbur, Mosqueda, 2016; Sabat, 2019; Terkelsen, Petersen, & Kristensen, 2020). Kitwood (1997) in opposition to a bio-medical view, challenged this notion of dementia, and its associated assumption that neuro-cognitive decline was solely responsible for the loss of a sense of self in persons with dementia. Social psychological scholars assert that an interplay of neuro-cognitive and social psychological factors influences whether personhood is maintained (Kitwood, 1997; Sabat 2019; Sabat & Harre, 1992). In this regard, Kitwood and Bredin (1992) referred to the term 'malignant social psychology' in which negative conversational partner behaviours such as invalidation, patronisation, disempowerment and mockery not only lead to depersonalised interpersonal interactions but threatens the personhood of persons with dementia (Sabat, 2019).

From a socio-psychological theoretical perspective, Kitwood (1997) proposed that person-centred care was central to the idea of personhood and could be defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood, 1997, p. 7). While the concept of personhood is complex, Dewing (2008b) asserts that it could be seen as the unique attributes that make up an individual. Accordingly, person-centred care can be realised through supportive interpersonal interactions in which conversational partners place value on the uniqueness, preferences, choices, and autonomy of persons with dementia (Brooker, 2003; Kitwood, 1997; Fazio, Pace, Flinner, & Kallmyer, 2018).

Furthermore, person-centred interpersonal interactions entail both verbal and non-verbal communication supports that lead to outcomes that affirm the individuality of the person with dementia by recognising, validating and responding empathetically to their feelings (Alant, 2017; Lanzi et al., 2017; McEvoy & Plant, 2014). Conversely, Kitwood (1997) warned that personhood is undermined when these characteristics are not recognised and supported by individuals in the social environment of the person with dementia. In particular, the use of life stories as a person-centred intervention has shown to positively enhance the relational aspects of interpersonal interactions in persons with dementia (Astell, Savundranayagam, Kelson, Purves, & Phinney, 2018).

2.3.2. Life story work and person-centred care

Interventions focused on the life story of persons with dementia are fundamental to supporting person-centred care in clinical practice (Cooney & O'Shea, 2018; Doran, Noonan, & Doody, 2018). Research shows that person-centred care can be maintained through interpersonal interactions that are based on the personal life story, cultural background and experiences of the person with dementia (Cooney, & O'Shea, 2018; McKeown, Clarke, Ingelton, Ryan, & Repper, 2010; Villar, Serrat, & Bravo-Segal, 2019). Thus, reminiscence-based interactions in the personal life story of the person with dementia and the significance of their lived experiences come to the fore (Brooker & Latham, 2015; Dewing, 2008b). Life story work is a type of reminiscence-based approach that focuses on enabling a person with dementia to share their past history and maintain their personal identity in an attempt to preserve a social connection with those around them (Cooney & O'Shea, 2018; Gridley, Birks, & Parker, 2020; Kindell et al., 2014).

While the body of knowledge on life story work in dementia is still growing, evidence suggests the positive outcomes of using paper-based life story books to increase the well-being of persons with dementia by providing opportunities for reciprocity and by enhancing communication in care interactions (Gridley, Brooks, Birks, & Baxter, 2016; Grøndahl, Persenius, Bååth, & Helgesen, 2017; McKeown et al., 2010). According to Subramaniam and Woods (2016), electronic life story formats, using participatory design processes, increases enjoyment in persons with dementia, and the authors suggest that an electronic life story format may serve as a communication aid as dementia symptoms progress. Unfortunately, the evidence on electronic life story interventions for persons with dementia is underexplored (Astell et al., 2018; Critten & Kucirkova, 2019; Hashim, Rias, & Kamarauzaman, 2013). A recent systematic review of 14 studies highlighted that while there may be various formats of life stories, electronic life stories in particular are scarce (Elfrink, Zuidema, Kunz, & Westerhof, 2018). Moreover, Gridley et al. (2020) posit that there is scant evidence on life story work from the perspective of persons with dementia.

2.3.3. Critical debates on person-centred care

Despite being recommended as a philosophy of care for persons with dementia, person-centred care is highly debated (Dewing, 2019; Edgar et al., 2020). There appears to be ambiguity in its definition. Kogan et al. (2016) performed a systematic literature search of studies related to person-centred care in older adults from 1990 to 2014. The authors found 17 different definitions of person-centred care. Importantly, Kogan et al. (2016) affirmed that a consensus definition of person-centred care would not only improve classification of evidence-based person-centred interventions, but also the replication thereof in clinical practice. The literature further highlights a contention that the definition of person-centred care is not fully understood in current practice because it is condensed to a few basic attributes, such as being compassionate or just valuing patient preferences (Dewing & McCormack, 2017; Edgar et al., 2020; McCance, McCormack, & Dewing, 2011; McCormack, Dewing, & McCance, 2011). Further advancing this argument, Røsvik, Brooker, Mjroud and Kirkevold (2013) suggest that person-centred care is still a theoretical idea and remains elusive in clinical practice.

The need for an agreed-upon definition of person-centred care has been argued to have presented a range of person-centred care models with limited empirical support and value in practice (Dewing & McCormack, 2017; Pluut, 2016). Yet, at the same time, Gibson et al. (2019) affirm that various models of person-centred care could explicate the complexities of the concept and its application in various fields of clinical practice.

To operationalise the concept of person-centred care in clinical practice, researchers have developed different person-centred care frameworks. Advancing the work of Kitwood (1997), Brooker (2004) summarised four essential elements of person-centred care in her VIPS model of person-centred care. According to Brooker (2004), the VIPS model emphasises value for the person with dementia, individualised interventions, recognition of the perspective of the person with dementia and the importance of the social environment (Passalacqua & Harwood, 2012; Røsvik et al., 2013). In contrast to a focus on relational elements, McCormack and McCance (2017) developed the Person-Centred Practice

Framework in the field of nursing with five interrelated elements (e.g., macro context, person-centred processes, pre-requisites by professionals, the care environment) that lead to person-centred outcomes.

In the field of speech-language therapy, Hickey, Kinder, Khayum, Douglas and Bourgeois (2018) are of the opinion that speech-language therapists should be prepared to provide interventions that are person-centred. Yet, it cannot be assumed that speech-language therapists are prepared or are adequately skilled to provide person-centred interventions for persons with dementia. In a recent survey, Maltese speech-language therapists expressed a distinct need for training in person-centred care as well as processes of how to involve persons with dementia in decision-making (Saccasan & Scerri, 2020). In this regard, Douglas, Brush, and Bourgeois (2018) provided practical clinical guidance for the assessment and intervention of persons with dementia by recommending a person-centred approach underpinned by Montesorri For Aging and Dementia.

Although various person-centred frameworks have been developed to assist in the application of person-centred care, Swaffer (2019) asserts that person-centred care is still not translated into clinical practice because it remains merely an afterthought to a perceived best practice of working with persons with dementia. Such disagreement in the literature impacts not only the way in which person-centred care is applied and delivered through interventions, but also how research is practically conducted with persons with dementia (Edgar et al., 2020; Hennely & O’Shea, 2017; Hung & Chaudhury, 2011).

Furthermore, there are challenges associated with the practical implementation of person-centred care in clinical practice. Gibson et al. (2019) argue that the implementation of person-centred care in the design and delivery of interventions is challenging amid competing priorities of time constraints.

Several researchers have raised concern that persons with dementia are often not involved in, consulted with or informed of decisions related to the interventions they receive (Harding et al., 2019; Hubbard, Downs, & Tester, 2003; Lepore, Shuman, Weiner, & Gould, 2017). Accordingly, in negating the core elements of person-centred care, persons with dementia are being divested of their identity, independence and inclusion in matters that directly influence their lives (Bosco, Schneider, Coleston-Shields, & Orrell, 2019).

Involving persons with dementia as end users in the design and development of interventions is positioned as a re-thinking of traditional ways of working with persons with dementia (McLaughlin, 2020). Swaffer (2015) stresses that failure to include persons with dementia in intervention research may not only promote stigmatisation, but may also cast doubt on the validity of research findings. Therefore, the literature shows that dementia advocates are contending for a distinction between the perspectives of persons with dementia and those of health professionals and caregivers (Bartlett, 2014; Bartlett, Windemuth-Wolfson, Oliver, & Denning, 2017; Yeandle, Kröger, & Cass, 2012).

There is also an implicit expectation that researchers should involve persons with dementia in intervention research that concerns them, rather than to rely solely on family proxies (Keady, Hydén, Johnson, & Swarbrick, 2018). Innovation is needed to ensure that adapted methodologies be used that intentionally involve persons with dementia in intervention research (Hydén, Swarbrick, Johnson, & Keady, 2018). A growing body of research illuminates the importance of conducting research *with* persons with dementia instead of *for* them (Dewing, 2008a; Kindell, Keady, Sage & Wilkinson, 2017; Murphy & Oliver, 2013). In the same vein, Nedlund and Bartlett (2018), as well as Hydén and Antelius (2017) argue for the need to involve persons with dementia as collaborators in intervention research.

The literature shows evidence of various adapted participatory research methods such as ethnography (i.e., the scientific description of peoples and cultures with their customs and habits) (Antelius, Kiwi, & Standroos, 2018) and walking interviews (to generate rich data and knowledge about participants' connections to their environments) (Kullberg & Odzakovic, 2018). By using these participatory strategies, persons with dementia and other stakeholders are enabled to participate meaningfully in intervention research (Hydén et al., 2018). This emphasises important current research priorities not only about how intervention research is conducted, but also about whom it is conducted with.

Bosco et al. (2019) propose that person-centred care can be achieved through the active involvement of persons with dementia in the production of interventions. The involvement of these persons, together with assertions of their choices and autonomy, is in line with social and health care movements that encourage patient and public involvement (Alsawy, Tai, McEvoy, & Mansell, 2019; Terkelsen et al., 2020). Participatory research methodologies such as the co-production of interventions may be seen as an empowerment process that re-conceptualises persons with dementia to be active contributors to interventions that are developed for their use (McConnell et al., 2019; Realpe & Wallace, 2010). Co-production is one methodology recognised by the World Health Organization as a strategy aimed at achieving Integrated People-Centred Health Services (2015) in which researchers and relevant stakeholders work together to achieve person-centred outcomes (Kickbusch & Gleicher, 2012; WHO, 2015). Central to the idea of co-producing interventions is the notion that persons with dementia, their family and relevant stakeholders are experience-based experts who can contribute much knowledge and expertise to complement the knowledge and expertise of researchers (Boivin et al., 2018; Davies et al., 2019).

Despite the advantages of participatory methods such as co-production, persons with dementia are still perceived as passive recipients within person-centred care interventions (Bosco et al., 2019). The literature highlights that the preferences concerning a fully informed client is an important component of evidence-based practice (Dodd, 2007; Dollaghan, 2004). By not involving persons with dementia in the process of developing interventions through the use of participatory methods, hampers the advancement of the evidence-base (Hydén et al., 2018; Roulstone, 2015).

2.4. Evidence-based practice in dementia interventions

2.4.1. Evidence-based practice in health care

Evidence-based practice is endorsed as the recommended framework on which all healthcare professionals should base their clinical decision making (Dodd, 2007). Evidence-based medicine (EBM) was formally introduced to the field of clinical medicine as the "conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p. 71). EBM was expanded and widely adopted as evidence-based practice (EBP) in an attempt to enhance professional practices across various disciplines. Dollaghan (2007, p. 2) offered an expanded interpretation of evidence-based practice as an integration of (a) "best available external evidence from systematic research, (b) best available evidence *internal* to clinical practice, and (c) best available evidence concerning the preferences of a fully informed patient".

Recent literature shows a trend of heightened interest in evidence-based interventions for persons with dementia across various fields, namely nursing (Skela-Savič et al., 2020), occupational therapy (Smith & D'Amico, 2019), psychological care (Teri, Logson, McCurry, Pike, & McGough, 2020) and speech-language therapy (Ruggero, Croot, & Nickels, 2020). Since evidence-based practice is applied to various professional disciplines and can be defined differently by professionals (Rousseau & Guina, 2015), it is essential for the purposes of this study to understand evidence-based practice as applied in the field of Augmentative and Alternative Communication (AAC).

2.4.2. *Evidence-based practice in augmentative and alternative communication*

Augmentative and alternative communication (AAC) is a scientific field of evidence-based research and clinical practice that aims to maintain the quality of life, participation and engagement of persons with dementia by using a variety of compensatory strategies, techniques and devices (American Speech-Language-Hearing Association [ASHA], 2019).

The literature shows that AAC researchers have encouraged the use of evidence-based practice in AAC interventions to not only show accountability in intervention design, but also to promote the best intervention outcomes for all AAC users (Granlund & Olsson, 1999; Schlosser, 2006). In line with the framework of EBM (Sackett et al., 1996) and evidence-based practice suggested by Dollaghan (2007), Schlosser and Raghavendra (2004) emphasised the importance of evidence-based decision making in the field of AAC. The triadic integration of best and current research evidence with clinical expertise and the perspectives of relevant stakeholders are the three evidence-based practice cornerstones required in decision making for a specific direct stakeholder (Schlosser & Raghavendra, 2004). An evidence-based practice framework (Schlosser & Raghavendra, 2004) as applied in the current study is shown in Figure 2.1.

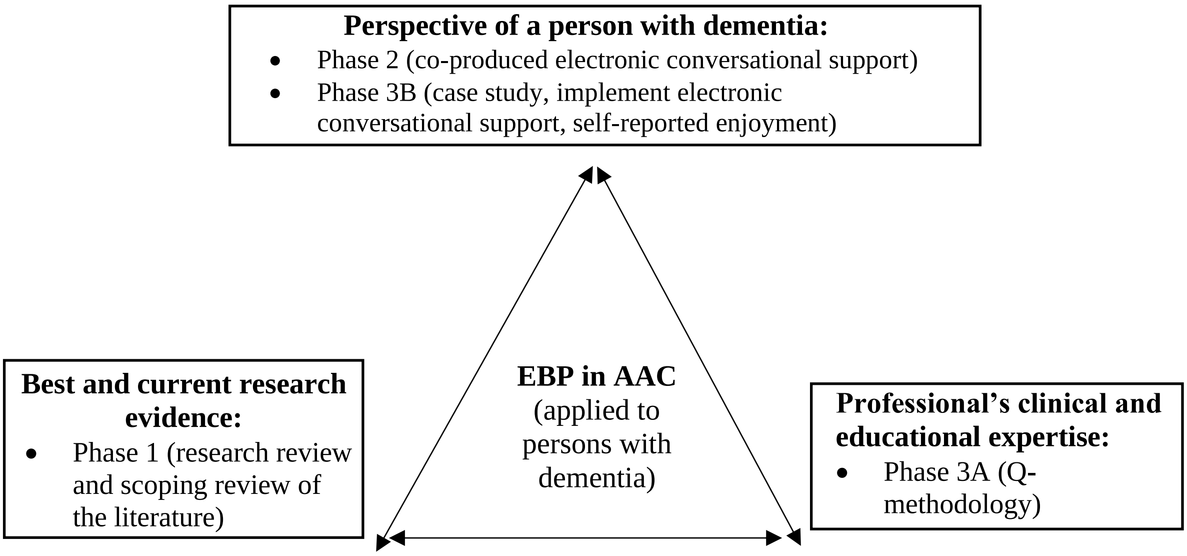


Figure 2.1: Evidence-based practice in AAC (Schlosser & Raghavendra, 2004)

Evidence-based practice has been regarded as a disciplined approach towards making clinical decisions that lead to the best desired outcomes for all persons with health conditions (Rousseau & Guina, 2016). Importantly, the integration of all three cornerstones is important in professional decision making for an individual person with dementia (Dollaghan, 2007; Schlosser & Sigafoos, 2009). The rationale for incorporating the perspectives of a person with dementia is not only in line with current discourses in the literature about including the voices of persons with dementia, but also ensures that the outcomes of AAC interventions are meaningful (Alant, 2017; Johnson, 2020). Involving stakeholders at various stages in the development of AAC systems is of vital importance (Waller, Balandin, O'Mara, & Judson, 2005). Since persons with dementia as direct stakeholders are affected by all decision making regarding their use of AAC systems, their opinions should be highly valued (Schlosser & Raghavendra, 2004). The clinical and educational experience of professionals are pivotal to validate different components of AAC interventions (Schlosser, 1999). AAC professionals are obligated to apply reliable and rigorous procedures in the implementation of their interventions (Gast & Ledford, 2018). The use of reliable measurement tools is a critical component of demonstrating the effect of AAC interventions in persons with dementia (Ledford, Dane, & Gast, 2018). For the advancement of evidence-based practice, research evidence demonstrating the real-life outcomes that AAC interventions have on interpersonal interaction in persons with dementia, is essential (Gast & Ledford, 2018; Smith & Murray, 2011; Spriggs, Lane & Gast, 2018).

Previous experimental research evidence that emerged from systematic reviews of literature constitutes an important cornerstone of evidence-based practice and shows the effect of AAC interventions (Roulstone, 2015; Schlosser & Raghavendra, 2004). However, Smith (2016) points out that not all AAC research focuses on the experimental effects of an intervention – it also focuses on the views and life experiences of persons who use AAC.

2.5. Phase 1 Research review: AAC interventions for persons with dementia

Synthesised summaries of research evidence are essential to assist AAC professionals in evidence-based decision making (Grant & Booth, 2009; Schlosser & Sigafoos, 2008). Whilst previous reviews offer insights into the benefit of AAC interventions for persons with dementia, AAC studies are scattered across various reviews and limited due to the focus of each enquiry. For example, Swan, Hopper, Wenke, Jackson, Till and Conway (2018) evaluated the evidence for speech-language interventions in persons with moderate to severe dementia and retrieved two AAC interventions that improved conversation. Morello et al. (2017) reviewed studies on language and communication interventions for persons with Alzheimer's disease and found two studies that used memory cards in conversation. It is clear that a more systematic approach is required to synthesise the current knowledge base of AAC interventions for persons with dementia.

2.5.1. Systematic search

May, Dada and Murray (2019) conducted a research review to identify and describe the current evidence-base pertaining to AAC interventions for persons with dementia. A research review method (Grant & Booth, 2009) was employed by May et al. (2019) as Phase 1 of the current study. The aim of the research review was to synthesise the AAC research related to AAC systems and strategies, AAC outcomes and AAC outcome measures for persons with dementia. A research review employs a systematic approach to the identification and synthesis of studies but, it does not include an appraisal of the literature as completed in a systematic review (Grant & Booth, 2009). The research review in Phase 1 of the current study used the following search terms:

> *"dementia" or Alzheimer* **"AND"** "augmentative and alternative communication" or "AAC" or augment* or "communication support" OR communication aid* OR "communication system*" OR "speech generating device*" OR "voice output communication aid*" OR gesture* OR sign* OR "graphic symbol" OR total communication OR Vocal* **"AND"** communicat* or "interaction" or conversat**

A multifaceted search strategy was adopted. The nine electronic databases that were searched for published studies and dissertations, were Cumulative Nursing and Allied Health Literature (CINAHL), PsycINFO, PsycARTICLES, Academic Search Complete, MEDLINE, Linguistics and Language Behaviour Abstracts (LLBA), ProQuest Dissertations and Theses Global, Scopus, and IEEE Xplore digital library. The database searches were restricted to temporal (1990-2018), linguistic (English) and source type (academic journals and dissertations) limiters. Furthermore, the journals of Augmentative and Alternative Communication and Communication Disorders were hand searched (1999-2018). Additional searches included an ancestral search of studies that met the inclusion criteria, and forward citations of included studies on Google Scholar.

The electronic studies were exported to Covidence, an online software application that facilitated the management of the review process (Veritas Health Innovation, n.d.).

Pre-defined study inclusion criteria were agreed upon by all three reviewers (i.e., authors of the review), and were based on the following four eligibility criteria:

i. Report on adult participants, 18 years and older, with a degenerative dementia, e.g., Alzheimer's dementia, vascular dementia, dementia with Lewy bodies, frontotemporal dementia (primary progressive aphasia (PPA)/semantic dementia). People with PPA (without dementia) prior to 2013 were also included (APA, 2013).

ii. Primary research on AAC strategies, techniques or technologies to support receptive or expressive language and memory for interaction purposes.

iii. Utilising a quantitative, qualitative or mixed-method design (including single case studies).

iv. Study published in an academic journal, or a master's thesis or doctoral dissertation.

Studies were excluded if they reported on persons with mild cognitive impairment and if data could be not isolated for persons with dementia.

Once the studies were exported to Covidence, the first two reviewers (i.e., authors) blind-reviewed each study at title and abstract level, and at full-text. The two reviewers applied the pre-defined eligibility criteria for each study, and a 'yes', 'no' or 'maybe' response was selected at title and abstract level in Covidence. A study was excluded, if both reviewers selected 'no', and were included at full-text if a reviewer selected 'yes', or 'maybe'. Furthermore, at full-text, each reviewer selected a reason from a list of drop-down options in Covidence to support the exclusion of a study.

The two reviewers followed a consensus-building process during screening disagreement. Subsequent to reading each study, detailed data was extracted independently by the first author. Fifty-two percent of the extracted data was independently checked by the remaining authors as per the following parameters: participants, research design, data collection method, setting, instructional format and administration of AAC technologies, description of AAC components, outcome measures, communication outcomes, reported AAC benefit, and key findings. As per the aim of the review, the included studies were further synthesised into four main categories: (i) AAC systems and strategies, (ii) AAC outcomes and (iii) AAC outcome measures for persons with dementia.

A flow chart of the study selection process is illustrated in Figure 2.2.

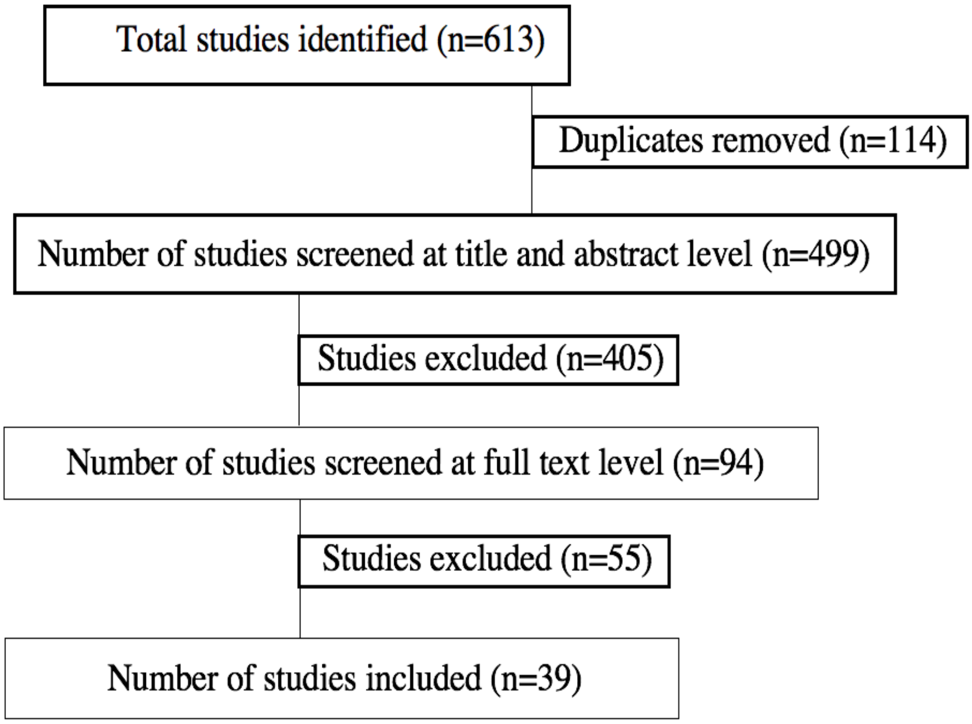


Figure 2.2: Flow diagram of the screening process in reviewing literature on AAC interventions for persons with dementia

As illustrated in Figure 2.2, altogether 613 studies were identified. At full text, the majority of the studies were excluded on account of the following: not having a communication or interaction outcome (n=22); not relating to AAC (n=9); incorrect publication type (n=8); unavailable online (n=5); did not focus on persons with dementia (n=4); incorrect study design (n=4); duplicated copy of study (n=2); foreign language (n=1). A corpus of 39 studies that met the inclusion criteria is summarised in Tables 2.1, 2.2, 2.3 and 2.4.

Table 2.1: Summary of studies on AAC interventions for persons with dementia (PwD): Unaided AAC Systems

Author(s), year, country	Design	Participant diagnosis, severity, age, conversational partner (CP)	AAC description	Study focus	AAC outcome measures	AAC outcomes
Ellis & Astell (2017) UK	Single-subject design	DAT, severe (n=5) 77-89 years CP: Researcher	Eye gaze, gestures, vocalisations, facial expressions	Non-verbal communication repertoires	Standardised 1) Direct observation of behaviour Non-standardised 2) Communicative behaviours coded and counted	Increased reciprocity when participants' communication behaviours were imitated by the researcher. Increased enjoyment and laughter in the interaction.
Hydén (2011) Sweden	Case study	DAT, severe (n=1) 85 years CP: Familiar CP (n=2)	Vocalisations, body movements, gaze direction	Non-verbal vocalisations in social interaction	Non-standardised 1) Frequency and types of non-verbal vocalisations identified	Participant attempted to initiate interaction using non-verbal cues and vocalisations.
Kindell et al. (2013) UK	Case study	Semantic dementia, mild (n=1) 71 years CP: Various (n=3)	Enactment using body posture, pointing, facial expressions	Everyday conversations	Non-standardised 1) Conversational patterns observed	Participant used enactment strategy to contribute to conversations. Reciprocal laughter within dyad.

Table 2.2: Summary of studies on AAC interventions for PwD: Electronic AAC systems (high technology)

Authors, year, country	Design	Participant diagnosis, severity, age, conversational partner (CP)	AAC description	Study focus	AAC outcome measure	AAC outcomes
Aitken (2015) New Zealand	Single-subject design	DAT, VD, mild to moderate (n=4) 61-88 years CP: Family member (n=4) and researcher	Digital memory book	Quality and quantity of conversations	Non-standardised 1) Conversational utterances and statements coded and counted 2) Family questionnaire	No improvement in on-topic statements and utterances. AAC facilitated easier conversation between the CPs and PwD.
Alm et al. (2004) UK	Quantitative group comparisons	Dementia*, moderate (n=9) 65-95 years CP: Caregiver/ care staff (n=9)	CIRCA	Interest and involvement of the PwD in interaction	Non-standardised 1) Evaluation questionnaires	Increased choice of conversational topics for the PwD. Enjoyment of interaction.
Astell et al. (2010) UK	Observational study (qualitative)	DAT, mixed severity (n=11) 65-95 years CP: Caregiver/ care staff (n=11)	CIRCA	Nature of dyadic interaction	Non-standardised 1) Checklist of interactional activity	PwD showed independence in choosing conversational topics. Increased laughter within the dyad.
Davis & Shenk (2015) USA	QUANT-qual	DAT, moderate (n=10) age unspecified CP: Researcher (n=8)	Multimedia videos	Engagement that promotes talking	Standardised 1) Observational Measure of Engagement Non-standardised 2) Language patterns identified from conversation analysis	More comments and smiles with personal videos. Greater diversity of language with generic videos.
Dynes (2018) Canada	Within-participants, prospective design	DAT, mild-moderate (n=7) 52-86 years CP: Family member (n=7)	Electronic conversational memory aid	Person-Centred Communication (PCC)	Non-standardised 1) Utterances coded as per adapted PCC coding chart	Interactions became more person-centred and enjoyable. CPs supported the preferences of PwD.
Ekström et al. (2017) Sweden	Case study	DAT, severity unspecified (n=1) 52 years	Digital communication book	Communication characteristics	Non-standardised 1) New conversational domain or conversation	Increased conversational length and time spent on talking about the device.

Authors, year, country	Design	Participant diagnosis, severity, age, conversational partner (CP)	AAC description	Study focus	AAC outcome measure	AAC outcomes
		CP: Family member (n=1)			initiation identified and counted 2) Conversational length recorded	AAC did not generate new topics within the interaction.
Fried-Oken et al. (2009) USA	Quantitative group comparisons	DAT, moderate (n=30) 50-94 years CP: Researcher	Digitised voice output	Conversational behaviours with digitised voice output	Non-standardised 1) Utterances counted and coded	Paucity of language, fewer elaborations, overall quantity of utterances reduced.
Fried-Oken et al. (2012) USA	Quantitative, group comparisons	DAT, moderate (n=30) pilot 1, CP: Researcher	Pilot 1: Digitised voice output	Conversational performance (with and without AAC aid, and voice output)	Non-standardised Conversations coded using a social communication framework	No improvement in quantity and type of utterances. Voice output reduced conversational performance.
Hamel et al. (2016) USA	Mixed-methods design	DAT, severity unspecified (n=18) Mean age 84 years CP: Familiar CP (n=14)	Mobile reminiscence aid	Feasibility and utility of a reminiscence aid in interaction	Non-standardised 1) Checklists 2) Themes from semi-structured interviews and direct observation	Device was a focal point to share experiences and enhance conversations. Increased enjoyment of interaction.
Mooney et al. (2018b) USA	Single-subject design	PPA, severity unspecified (n=6) 62-80 years CP: Familiar CP (n=6)	Mobile technology	Lexical retrieval skills during activity retell in conversation	Non-standardised 1) Number of target words recorded and counted 2) Direct user feedback	Improved lexical retrieval skills and conversational confidence (PwD). CPs scaffolded conversations.
Purves et al. (2015) Canada	Observational study (qualitative)	Dementia*, moderate (n=3) 81-90 years CP: care staff (n=1)	CIRCA	Regionally adapted programme for dyadic interaction	Non-standardised 1) Interactions transcribed	AAC used to initiate and maintain topics. Companionable silences.

Table 2.3: Summary of studies on AAC interventions for PwD: Non-electronic AAC systems

Authors, year, country	Design	Participant diagnosis, severity, age, conversational partner (CP)	AAC description	Study focus	AAC outcome measures	AAC outcomes
Andrews-Salvia et al. (2003) USA	Single-subject design	DAT, Dementia*, severe (n=4) 90-94 years CP: Researcher	Memory book	On-topic facts in severe dementia	Non-standardised 1) On-topic facts coded and counted.	Increased on-topic facts evident in all participants.
Bourgeois (1990) USA	Single-subject design	DAT, moderate (n=3) 59-66 years CP: Familiar CP (n=3)	Communication wallet	Quality of conversational content	Non-standardised 1) Utterances coded and counted 2) Satisfaction Rating Form	Improved factual statements and fewer ambiguous utterances. No changes in conversational behaviours noted by CPs.
Bourgeois (1993) USA	Single-subject design	DAT, moderate-severe (n=6) 74-88 years CP: Another PwD (n=6, i.e., 3 dyads)	Memory wallet/book	Conversational content and social skills of dyad	Non-standardised 1) Utterances and social behaviours (turn taking) coded and counted 2) Social validation rating scale	Some participants increased on-topic statements, elaborations and turn taking. CPs reduced ambiguous utterances.
Bourgeois & Mason (1996) USA	Single-subject design	DAT, mixed severity (n=4) 74-80 years CP: Volunteer staff (n=3)	Memory wallet	Conversational content (PwD), conversational behaviours (CP)	Non-standardised 1) Utterances coded and counted 2) Satisfaction rating	The PwD increased appropriate statements, decreased repetitive statements. Conversational behaviour of CP improved.
Bourgeois et al. (2016) USA	Within-subjects design	Dementia*, moderate-severe (n=37) 67-96 years CP: Nursing aide (n=33)	VoiceMyChoice™	Preference and choice making in interaction	Non-standardised 1) Preference Assessment Questionnaire (PAQ)	The PwD were able to communicate preferences. Nursing aides' understanding of the preferences of PwD improved.
Bourgeois et al. (2001) USA	Quantitative group comparisons	Dementia*, moderate (n=66) Mean 85 years CP: Nursing aide (n=66)	Memory book	Quality and quantity of naturalistic interaction	Non-standardised 1) Utterances and statements coded and counted 2) Duration of verbalisations, memory book use	Increased duration of speaking time, number of utterances, and conversational topics. CP reduced number of prompts.

Authors, year, country	Design	Participant diagnosis, severity, age, conversational partner (CP)	AAC description	Study focus	AAC outcome measures	AAC outcomes
Bourgeois et al. (2004) USA	Quantitative (Pretest – post-test)	Dementia*, moderate (n=125) 75-86 years CP: Nursing aide (n=126)	Memory book	Communication skills training programme	Non-standardised 1) Frequency of memory book use by nursing aides calculated	Low frequency of memory book use during care interactions.
Chang (2011) USA	Single-subject design	Dementia*, mixed severity (n=3) 82-88 years CP: Researcher	Memory book	Quality and quantity of conversations	Non-standardised 1) Utterances coded and counted	Increased on-topic statements of facts, decreased ambiguous, unintelligible, and perseverative utterances.
Chang (2015) USA	Within-subjects design	DAT, Dementia* mild-moderate (n=20) 76-97 years CP: Researcher	Decisional (visual) aid	Decisional capacity	Non-standardised 1) Adapted decisional capacity recording form 2) Quality of vignette statement form 3) Social validation rating scale	Participants increased understanding of treatment options. Improved clarity of statements.
Fried-Oken et al. (2012) USA	Quantitative, group comparisons (Pilot study)	DAT, moderate (n=11) pilot 2 50-94 years CP: Researcher	Pilot 2: Communication board (without voice output)	Topical vocabulary and references to AAC	Non-standardised 1) Utterances coded for topical vocabulary. 2) Number and percentage of target words, references to AAC device calculated.	AAC priming with spaced retrieval training increased references to device and the number of target words used.
Fried-Oken et al. (2015) USA	QUAL-quant	DAT, PPA, mild-moderate (n=109 Mean 75 years CP: Familiar CP (n=109), researcher	Communication board	Conversational topics selected by PwD	Non-standardised 1) Structured conversations with PwD. 2) Topics thematically coded	Selected conversational topics related to life experiences and personal narratives.
Gomès-Taibo et al. (2014) Spain	Single-subject design	DAT, mixed severity (n=3) 86-87 years CP: Researcher	Memory book	Quantity and quality of conversational content, and skills	Non-standardised 1) Utterances coded and counted	Increased self-identity statements, reduced ambiguous statements, improved conversations quality.

Authors, year, country	Design	Participant diagnosis, severity, age, conversational partner (CP)	AAC description	Study focus	AAC outcome measures	AAC outcomes
Hoerster et al. (2001) USA	Single-subject design	DAT, VD, severe (n=4) 83-90 years CP: Nursing aide (n=4)	Memory book	Conversational content (PwD), communication behaviours (CP)	Non-standardised 1) Utterances coded and counted 2) Social validation rating scale 3) Post-interview questions	The PwD increased their factual statements. Nursing aides' communicative behaviour improved post-training.
Johnson (2003) USA	Single-subject design	Dementia*, mild-moderate (n=5) 73-88 years CP: Nursing aide (n=1)	Sensory cues	Quality and quantity of conversations	Non-standardised 1) Utterances coded and counted 2) Social validation rating scale	No increase in the quantity or quality of conversations.
McPherson et al. (2001) USA	Single-subject design	DAT, VD, severe (n=5) 73-90 years CP: Caregiver/care staff (n=5)	Memory aids	Quality of conversations	Non-standardised 1) Topic-related and non-topic-related conversation coded and calculated	Some participants spent a higher percentage of time on topic-related utterances.
Murphy et al. (2010) UK	Quantitative group comparisons	Dementia*, mixed severity (n=31) 54-90 years CP: Researcher	Talking Mats™	Expression of views related to well-being	Non-standardised 1) Effectiveness framework of Functional Communication 2) Percentage of 'on-task' behaviour 3) Perseverations 4) Interview time	Increased on-task behaviours, involvement and conversational length. Perseverative behaviours decreased.
Murphy & Oliver (2013) UK	QUALI-quant	Dementia*, mixed severity (n=18) 60-86 years CP: Family member (n=18)	Talking Mats™	Discussions on managing activities of daily living	Non-standardised 1) Conversations thematically coded 2) Involvement Measure 3) Satisfaction questionnaire	The PwD increased their involvement in decision making. The dyad felt satisfied with the discussion.
Reitz & Dalemans (2016)	Cross-over design	DAT, mild-moderate (n-6) 84-90 years CP: Family member (n=6)	Talking Mats™ (Dutch version)	Shared decisions and language use	Standardised 1) The OPTION Scale	The PwD increased involvement in decision making.

Authors, year, country	Design	Participant diagnosis, severity, age, conversational partner (CP)	AAC description	Study focus	AAC outcome measures	AAC outcomes
Netherlands					Non-standardised 2) Utterances coded and counted	CP understood the PwD. No improvement in language use.
Ruiz (2015) Puerto Rico	Pretest – post-test	DAT, moderate (n=1), 75 years CP: Family member (n=1), researcher	Memory book	Quantity of conversational content	Non-standardised 1) Utterances and use of grammar coded and counted	The PwD increased on-topic responses. AAC did not improve the use of grammar.
Spilkin & Bethlehem (2003) South Africa	Case study	DAT, moderate to severe (n=1) 85 years CP: Family member (n=1)	Memory book	Quality of interaction structure	Non-standardised 1) Interaction structure coded (topic management, repair) 2) CP quality of interaction rating scale	The CP scaffolded the interaction. The PwD improved topic maintenance, decreased topic perseveration.

Table 2.4: Summary of studies on AAC interventions for PwD: Combined AAC systems (unaided, non-electronic and electronic)

Authors, year, country	Design	Participant diagnosis, severity, age, conversational partner (CP)	AAC description	Study focus	AAC outcome measures	AAC outcomes
Broughton et al. (2011) Australia	Pretest – post-test	Caregiver/care staff (n=52)	Unaided + non-electronic AAC	Memory and communication strategies	Non-standardised 1) Knowledge of support strategies test 2) Post-training survey	Staff's knowledge of communication strategies improved. Staff self-reported greater respect and empathy for the PwD.
Cress & King (1999) USA	Case study	PPA, severity unspecified (n=2) 59-60 years CP: Family member (n=4)	Unaided + non-electronic AAC	Cued comprehension and augmented expression	Non-standardised 1) Comprehension of symbols tallied by CP	Cued comprehension ineffective with unfamiliar listeners. Familiar CPs increased success in cueing new topics.
Mooney et al. (2018a) USA	Pretest – post-test	PPA, severity unspecified (n=5) 63-73 years CP: Familiar CP (n=6)	Unaided, non-electronic + electronic AAC	Multimodal communicative interactions	Non-standardised 1) Modes of Communication Survey	Dyads learned to match AAC strategy to their communication needs.
Trahan et al. (2014) USA	Single-subject design	Dementia, vascular dementia, mild-moderate (n=3) 85-87 years CP: Researcher	Unaided + non-electronic AAC	Picture-based communication responses, skill maintenance	Non-standardised 1) Frequency of independent card exchanges and vocal responses	Participants learned to exchange a picture card for a highly preferred activity.
Wong et al. (2009) USA	Case study	Semantic dementia, mild (n=1) 61 years CP: Family member (n=1)	Unaided + non-electronic AAC	Communicative effectiveness	Non-standardised 1) Modified communication framework 2) Codified ideas	Participants showed improvement in expressing opinions. The CP scaffolded interactions with verbal and nonverbal support.

As reflected in Tables 2.1, 2.2, 2.3 and 2.4, studies included had been published in the past 28 years, between 1990 and 2018. The majority (n=20) were conducted in the USA, seven in the UK, three in Canada, two in Sweden and one each in Australia, New Zealand, Spain, the Netherlands, Puerto Rico and South Africa. Of the 39 studies included, 33 were published as journal articles, four master's theses and two doctoral dissertations. The majority of the studies (n=23) sampled participants with DAT, dementia of an unspecified subtype (n=13) and vascular dementia (n=4). Persons with frontotemporal dementia, i.e., PPA or semantic dementia, were researched in only five studies, while some samples included persons with two dementia subtypes (DAT and vascular dementia). Persons with Lewy body dementia were not encountered in any of the studies. The information obtained from the 39 studies are summarised in the next section to highlight trends and gaps related to AAC strategies and techniques, AAC outcomes and AAC outcome measurement.

2.5.2. AAC strategies and techniques

AAC intervention research for persons with dementia began in 1990 (Bourgeois, 1990; Bourgeois, 1993; Bourgeois & Mason, 1996). In a series of intervention studies using single-subject experimental designs, early research for persons with dementia documented the benefit of using non-electronic AAC systems (e.g., memory books, communication passports and communication wallets) with generic or personalised photographs, and autobiographical sentences (Andrews-Salvia, Roy, & Cameron, 2003; Bourgeois, 1990, Bourgeois 1993, Bourgeois & Mason 1996, Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001).

From an interactional perspective, seminal AAC research focused on supporting conversational topics, and improving the quantity and quality of utterances in persons with mild to moderate dementia. For instance, researchers demonstrated the use of paper-based memory wallets in increasing turn taking, on-topic statements, topic elaborations and reducing off-topic statements in persons with dementia (Andrews-Salvia et al., 2003; Bourgeois, 1990; Bourgeois, 1993; Bourgeois & Mason, 1996; Cress & King, 1999).

Cress and King (1999) used two case studies as a research method to emphasise the benefit of multimodal AAC strategies. For example, augmented input and the use of facial expressions and gestures within natural communicative contexts were used to support persons with primary progressive aphasia (semantic dementia) (Cress & King, 1999). With a growing evidence-base, research began to demonstrate the benefit of non-electronic AAC systems for persons with severe dementia. In a pilot study with a single participant, researchers highlighted that a person with severe dementia increased the proportion of time spent on on-topic utterances when supported with a simple, paper-based memory aid (McPherson, Furniss, Sdogati, Cesaroni, Tataglini, & Lindesey, 2001). In a related study, Hoester, Hickey and Bourgeois (2001) demonstrated that the equity of conversational turn taking increased between a person with milder dementia and a conversational partner when using a memory aid, however this effect was not evident in persons with more advanced dementia.

Interest in electronic AAC systems using technologically dependent devices has grown steadily in view of a global research agenda for innovative social and health technologies to support persons with dementia (Baxter, Enderby, Evans, & Judge, 2012; Bourgeois, Fried-Oken, & Rowland, 2010; WHO, 2017). The reviewed literature shows that research into electronic AAC systems for persons with dementia began in 2004 and has increased slowly, albeit incrementally since 2010.

With the advent of technology and mobile computing, researchers from the USA (Davis & Shenk, 2015; Hamel, Sims, Klassen, Havey, & Gaugler, 2016; Fried-Oken et al., 2009; Fried-Oken et al., 2012; Mooney, Bedrick, Noethe, Spaulding, & Fried-Oken, 2018b), Canada (Crete-Nishihata et al., 2012; Dynes, 2018; Purves, Phinney, Hulko, Puurveen, & Astell, 2015), Sweden (Ekström, Ferm, & Samuelsson, 2017), New Zealand (Aitken, 2015) and the United Kingdom (Alm et al., 2004; Astell et al., 2010) have offered preliminary evidence on the use of electronic AAC system options to support interpersonal interactions in persons with dementia. Given that approximately 60% of persons with dementia live in non-Westernised low- and middle-income countries (WHO, 2018), the complete lack of research on electronic AAC systems for persons with dementia living in these countries is alarming.

Electronic AAC systems with computer-based memory aids and mobile technologies appear to contribute to enriched interpersonal interaction for persons with dementia (Alm et al., 2004). Research has demonstrated multimedia communication tools support conversation and relationships in persons with Alzheimer's disease (Astell et al., 2010). Despite noting possible pitfalls of electronic AAC support in their study, Ekström et al. (2017) found that a personalised AAC application had the potential to encourage interpersonal interaction with a person with dementia.

There appears to be an interest in exploring AAC technology with natural language processing abilities as noted in a study by Mooney et al. (2018b). These authors used a specific AAC research application, CoChat, by employing features of natural language processing (NLP), just-in-time principles and social media. Multimedia digital life history interventions consisting of past memories and wearable computing technology (SenseCam) (Crete-Nishihata et al., 2012) are beginning to be explored by researchers (Davis & Shenk, 2015). Empirical data shows that reminiscence-based activities with multimedia content are not only enjoyable activities for persons with dementia but also enhance interpersonal interactions between conversational partners (Alm et al., 2004; Astell et al., 2010; Hamel et al., 2016; Purves et al., 2015). The development of electronic life stories can also be useful to enhance person-centred care with the addition of recorded voice and digital photographs (Astell et al., 2018).

However, in the reviewed studies, the use of voice output was found to have a negative effect on interpersonal interaction in persons with dementia. This was evident in two pilot studies on digitised voice output that had been embedded in customised communication boards and in which a label was spoken out each time a person with DAT touched a picture (Fried-Oken et al., 2009; Fried-Oken et al., 2012).

AAC interventions for persons with dementia suggest an interest in person-centred care. Non-electronic aids enable persons with dementia to express their opinions in conversations about their wellbeing by using the Talking Mats™ communication framework (i.e., line drawings on a visual scale) (Murphy, Gray, Van Achterberg, Wyke, & Cox, 2010; Murphy & Oliver, 2013; Reitz & Dalemans, 2016). Likewise, AAC interventions with non-electronic communication cards (i.e., VoiceMyChoice™) (Bourgeois, Camp, Antenucci, & Fox, 2016) and decisional aids (Chang, 2015) assist persons with dementia to voice their preferences and choices in decision-making conversations.

Whilst the implementation effect of AAC interventions is important, the process of developing interventions with persons with dementia as co-producers is also essential (Swarbrick, 2015). Crete-Nishihata et al. (2012) supported a person with dementia in authoring his own life story intervention with an electronic aid. The positive person-centred outcomes of this study included affirmation of self-identity, independence in sharing stories and enjoyment in aided-conversations (Crete-Nishihata et al., 2012). The direct inclusion of persons with dementia in selecting conversational topics and authoring their own life stories represents a shift towards a person-centred approach within AAC-supported interactions.

Person-centred communication is used by a conversational partner through statements that recognise and affirm the identity of a person with dementia (Alsawy et al., 2019; Savundranayagam, Basque, & Johnson, 2020; Savundranayagam & Moore-Nielsen, 2015; Savundranayagam, Sibalija, & Scotchmer, 2016). Emphasis is thus placed on validating the feelings of a person with dementia (Williams et al., 2017). Alant (2017) refers to empathetic listening in which a conversational partner listens and responds with the intent to understand the person with dementia at a feeling level. In so doing, a conversational partner focuses on building a sense of connection within the interpersonal interaction in collaboration with a person with dementia (Kindell et al., 2017).

In line with this view, Dynes (2018) specifically trained family members to use person-centred communication to validate the feelings of persons with dementia and to negotiate with them during interactions with an electronic aid. As an outcome of the intentional focus on person-centred communication, family members perceived interpersonal interactions to be more meaningful. Similarly, albeit from a different perspective, Broughton et al. (2011) found that nurses' empathy and validation of personhood improved AAC-supported care interactions. Purves et al. (2015) also adapted computer-based multimedia to be culturally, linguistically or socially relevant to persons with dementia who are from Chinese, Hispanic or multicultural backgrounds.

Interpersonal interaction can be supported by using the unique set of non-verbal communicative behaviours of persons with severe DAT and semantic dementia. These included imitated communication behaviours termed 'adaptive interaction' (e.g., eye gaze) (Ellis & Astell, 2017); non-verbal vocalisations and non-verbal cues (e.g., eye rubbing) (Hydèn, 2011); and 'enactment' as a compensatory strategy that includes direct reported speech with body posture, pointing and facial expressions (Kindell, Sage, Keady & Wilkinson, 2013).

Finally, persons with dementia may benefit from multimodal AAC interventions (Fried-Oken et al., 2015). The benefit of multimodal AAC strategies was evident in the reviewed studies that focused on the use of unaided AAC and non-electronic aids (Broughton et al., 2011; Cress & King, 1999; Trahan, Donaldson, McNabney, & Kahng, 2014; Wong, Anand, Chapman, Rackley, & Zientz, 2009). Furthermore, the literature indicates that the combined use of various non-electronic aids (PPA wallet cards), and high-technology (mobile technology) as well as AAC strategies (augmented input through keywords and/or written choice) support conversations in persons with PPA (Mooney, Beale & Fried-Oken, 2018a).

2.5.3. AAC outcomes for persons with dementia

Companionship and connection with others are unmet needs for persons with dementia (Hancock, Woods, Challis, & Orrell, 2006; van der Roest et al., 2009). Within the reviewed studies, outcomes that enhanced companionship within a dyad were expressed as laughter, smiles, enjoyment of interaction (Alm et al., 2004; Astell et al., 2010; Hamel et al., 2016; Purves et al., 2015; Wong et al., 2009), feelings of social closeness, increased engagement (e.g., eye contact) (Davis & Shenk, 2015) or an expressed desire to interact with others (e.g., imitation of communication behaviours) (Ellis & Astell, 2017; Hydén, 2011; Kindell et al., 2013).

The self-reported outcomes from the perspective of persons with dementia provides important evidence on the effectiveness of AAC interventions (Broomfield, Haarop, Judge, Jones, & Sage, 2019; Cohen & Hula, 2020). Within the reviewed AAC interventions, these were noted in the self-reported increase in confidence of PwPPA when interacting with others (Mooney et al., 2018a; Mooney et al., 2018b), and in the affirmation of self-identity in a person with dementia (Gomèz-Taibo, Amado, Dominguez, Iglesias, & Real, 2014).

The majority of outcomes of AAC interventions focused on language-based outcomes related to the quantity and quality of conversational content (e.g., increased on-topic statements, and decreased ambiguous, unintelligible and repetitive utterances) (Andrews-Salvia et al., 2003; Chang, 2011; Gomèz-Taibo et al., 2014; McPherson et al., 2001; Ruiz, 2015). The quantities of utterances, topic initiations and elaborations were reduced when a digital memory book (Aitken, 2015) or communication board programmed with an embedded voice output (Fried-Oken et al., 2009) was used in conversations with persons with mild to moderate DAT. Conversely, PwPPA increased their lexical retrieval skills when using mobile technology (Mooney et al., 2018b) and persons with DAT increased their conversational time when interacting with a digital communication or memory book (Dynes, 2018; Ekström et al., 2017). While most of the conversational time focused on the usage of the digital communication book or its content, there was no evidence that the electronic aid supported the initiation of new conversational topics (Ekström et al., 2017).

Within the context of training conversational partners, outcomes related to balanced turn taking, increased duration of speaking time, and improved facilitative behaviours such as acknowledgments by communication partners have been noted (Bourgeois, 1990; Bourgeois & Mason, 1996). However, these outcomes were not consistently observed as functional communication changes based on judgements of individuals unfamiliar to the intervention (Bourgeois, 1990; Bourgeois, 1993; Bourgeois & Mason, 1996; Chang, 2015; Hoerster et al., 2001; Johnson, 2003).

In a pilot study reported by Fried-Oken et al. (2012), persons with DAT underwent a training procedure prior to interacting with a communication board, and as a result, increased references to the aid and a greater use of targeted vocabulary were evident.

AAC outcomes have focused on interactive coaching and modelling of communication strategies or use of AAC techniques with conversational partners. Communication outcomes included improved caregiver topic elaborations (which in turn improved topic maintenance and decreased perseverations by the person with dementia) (Spilken & Bethlehem, 2003) and conversational partners' improved use of cued comprehension strategies for PwPPA (Cress & King, 1999, Mooney et al., 2018a).

2.5.4. AAC outcome measures for persons with dementia

Smith and Murray (2011) emphasise that, in line with EBP, AAC professionals should have outcome measures to demonstrate the effectiveness of AAC interventions. Developing and validating outcome measurement tools have been noted in AAC for persons with aphasia (Brock, Koul, Corwin, & Schlosser, 2019) and persons with mild neurocognitive disorders (Lanzi, Bourgeois, & Dedrick, 2020).

Within the reviewed studies, researchers developed non-standardised outcome measures for their specific intervention studies. These included a Preference Assessment Questionnaire (PAQ) (Bourgeois et al., 2016); evaluation questionnaires; interaction checklists; and questions for family interviews (Alm et al., 2004; Astell et al., 2010; Crete-Nishihata et al., 2012; Hamel et al., 2016). An Involvement Measure (Murphy & Oliver, 2013) and a decisional capacity questionnaire (Chang, 2015) were developed by adapting questions from other tools to measure the decision-making skills of persons with dementia in interactions.

As part of training programmes, non-standardised tests and pre-post training surveys or questionnaires were used to measure nurses' knowledge of memory and communication support strategies (Broughton et al., 2011), as well as the use of multimodal communication strategies by PwPPA and their communication partners (Mooney et al., 2018a).

Three standardised outcome measures that were developed included the following three instruments: *Observational Measure of Engagement* (Cohen-Mansfield et al., 2009) to measure engagement that promoted talking in a persons with dementia (Davis & Shenk, 2015); *Direct Observation of Behaviour* (Bowie & Mountain, 1993) to measure nonverbal communicative behaviours of persons with dementia (Ellis & Astell, 2017); and the *OPTION Scale* (Elway, 2003) to measure shared decision-making skills in persons with dementia and their communication partners when using a communication aid (Reitz & Dalemans, 2016).

The majority of AAC intervention studies for persons with dementia relied on standardised, quantitative instruments to measure conversational content (e.g., ambiguous utterances, on-topic statements, repetitions, target vocabulary) that had been coded according to pre-determined criteria and counted (Aitken, 2015; Andrews-Salvia et al., 2003; Bourgeois et al., 2001; Chang, 2011; Dynes, 2018; Fried-Oken et al., 2009; Fried-Oken et al., 2012; Gomèz-Taibo et al., 2014; McPherson et al., 2001, Mooney et al., 2018b; Reitz & Dalemans, 2016; Ruiz, 2015). The specific aspects of conversational content that were measured depended on the communication focus of each study.

Granlund and Blackstone (1999) proposed five necessary domains of an AAC outcome measure, of which one was a measure of satisfaction. Within the reviewed studies, there was limited evidence that the satisfaction of a person with dementia was measured as an outcome. Some researchers used standardised, quantitative measurements, but included a subjective social validation procedure or satisfaction rating scale by means of which persons unfamiliar with the intervention detected functional changes in the targeted communicative behaviours (Bourgeois, 1990; Bourgeois, 1993; Bourgeois & Mason, 1996; Chang, 2015; Hoerster et al., 2001; Johnson, 2003). While these were standardised measures within specific studies, their clinical utility was limited to the scope of the respective studies.

Although the majority of aforementioned studies employed quantitative measures, conversational analysis as a qualitative research method provided salient details of AAC supported interactions. For instance, Spilken and Bethlehem (2003) used conversational analysis to analyse turn taking, repair strategies, and interaction structure (e.g., topic maintenance) to improve a conversational partners' use of a memory aid with a person with dementia. Hydén (2011) utilised conversational analysis to identify the frequency and types of verbal and non-verbal vocalisations in persons with severe dementia. By analysing the transcriptions of verbal utterances and vocalisations, Hydén (2011) raised the importance of responding to the vocalisations of persons with severe dementia as meaningful interactional attempts. Kindell et al. (2013) examined the interactional strengths of a person with semantic dementia by transcribing and analysing naturally occurring interactional data. Accordingly, the authors identified nuanced detail of the use of enactment as an adaptive interaction strategy in a person with semantic dementia. Likewise, through analysis of interaction, researchers examined the 'communication initiatives' (i.e., introducing a new topic without a partner prompt or topic initiation after a lapse of silence) and conversational length of a person with dementia who used an electronic device in an interaction with a conversational partner (Ekström et al., 2017).

Lastly, modified or adapted functional communication frameworks were used to code interactions according to utterance types, communication functions or conversational behaviours (e.g., engagement during interviews) (Fried-Oken et al., 2012; Murphy et al., 2010; Wong et al., 2009).

The use of outcome measures with established reliability or validity data appears to be more favourable in clinical practice compared to tools that require subjective judgements (Zaga, Cigognini, Vogel, & Berney, 2020). Evidence from the reviewed literature reveals that there are currently no available psychometrically validated AAC outcome measures to measure interpersonal interaction in persons with dementia.

2.6. Secondary review: Scoping review

A scoping review was conducted in an independent study by Dada, Hyman, May and Murray (2020). A summary of the findings is described in this study as it supplements the information on electronic AAC systems (described in Par 2.5.2). The scoping review followed scoping review methodology (Arksey & O'Malley, 2005) to map the currently available research on intelligent artificial assistive technology devices (IATDs).

The aims of the scoping review were as follows: Firstly, to provide an overview of the literature on IATDs. Secondly, to report on the benefits and limitations of IATDs, and thirdly, to identify trends and gaps in the literature. The scoping review applied a multifaceted search strategy; and used databases and search terms similar to those employed by May et al. (2019). However, Dada et al. (2020) included additional terms specifically related to "assistive technology", "assistive device", and "intelligent". Following screening procedures, the included studies (n=105) were described according to (a) the types of IATDS, (b) the cognitive and communicative domains targeted and (c) their commercial availability.

The results showed that the majority of research on IATDs, currently remain at the conceptual stage of prototype development (n = 41). Importantly, persons with dementia were not involved in the development of technologies designed for their use. The majority of reviewed studies using artificial intelligence entail companion robots (n=63) to support memory and attention difficulties in persons with dementia (Takayanagi, Kirita, & Shibata, 2014). Studies (n=33) on social robots, to a lesser extent, could interpret and respond to the utterances and facial expressions of persons with dementia to reinforce turn taking (Hendrix, Feng, van Otterdijk, & Barakova, 2019; Moyle et al., 2017, 2015).

Most research using IATDs focus on the memory and attention difficulties in persons with dementia. AAC scholars have advised that innovative technology with artificial intelligence can benefit individuals who use AAC (Light et al., 2019). The results of this scoping review highlight that intelligent assistive technology devices have the potential to respond to a broad range of communication needs and capabilities of persons with dementia. Therefore, the need for AAC interventions to consider the role of intelligent assistive technology in persons with dementia is pertinent.

2.7. Current Study

From the reviewed AAC literature in the previous sections (Par 2.5, and 2.6), it is evident that important research findings have developed the evidence-base for persons with dementia. It is clear that research has shown the evolving nature of AAC interventions from seminal studies using non-electronic aids, to the current potential of artificial intelligence to support communication in persons with dementia. However, in light of the contemporary discourses related to person-centred care, it appears that person-centred AAC research for persons with dementia is limited.

Although persons with dementia have been involved in different aspects of designing their AAC interventions (e.g., selecting materials or topics of conversation), this has been performed in a limited way. AAC researchers have not fully explored the range of adapted participatory methods that could be employed to include persons with dementia in developing their own AAC interventions. Given the rise in the prevalence of dementia, there is potential for professionals to consider innovative methods to develop AAC interventions with persons with dementia. However, there are limited guidelines for AAC professionals on how to apply such adapted participatory methods in research.

Due to the critical debates related to person-centred care in the literature, there is a need to understand the views of professionals toward this evolving concept and its operationalisation in AAC research and practice. Furthermore, there is a paucity of research guidance in the literature on what elements of person-centred care could be included in AAC interventions for persons with dementia. More specifically, how AAC strategies could be integrated within a person-centred care approach to support interpersonal interaction in persons with dementia, is currently underexplored.

While quantitative experimental designs were necessary to demonstrate the effect of interventions in persons with dementia, the use of multiple methods or mixed-method research designs are underexplored in the literature. In this regard, studies that utilise a multiple method research design have the potential to enhance the robustness of AAC findings for persons with dementia.

Lastly, multimodal AAC outcome measures with established or preliminary psychometric properties to measure interpersonal interaction in persons with dementia was not located in the reviewed literature. Based on the aforementioned limitations highlighted in the reviewed AAC literature, the current study aimed to develop and test the feasibility of a person-centred AAC intervention for a person with dementia. The intervention was developed by employing adapted participatory methods and was underpinned by a person-centred care approach comprising four components extrapolated from the literature. The feasibility of implementing the intervention was tested by obtaining the views of professionals on its four components. Additionally, the person-centred AAC intervention was implemented with a person with dementia and an outcome measure developed in the study was assessed for scoring reliability.

2.8. Summary

This chapter discussed the available literature as it pertains to person-centred care in supporting interpersonal interaction in persons with dementia. Although emphasised in the AAC literature, person-centred care and its operationalisation in developing electronic AAC interventions with persons with dementia are only emerging. Given the impetus of participatory research, the current literature points to important gaps that are potentially unexplored and that should be taken into consideration in developing person-centred, evidence-based interventions for persons with dementia. The reviewed research evidence outlined in this chapter informed the development of a person-centred AAC intervention described in the next chapter.

CHAPTER 3: DEVELOPMENT OF A PC-AAC INTERVENTION FOR PWD

3.1. Introduction

This chapter provides an outline of a PC-AAC intervention for PwD developed in this study. First, an overview is presented of the four components that comprise the PC-AAC intervention for PwD. Next, each component is described individually in relation to its sub-components, underlying processes, and materials. The first and second components are described as an electronic life story conversational support co-produced with a person with moderate to severe dementia. Linked to the two preceding components, the third and fourth components relate to AAC outcomes and an AAC outcome measure for PwD, after which the chapter is concluded.

3.2. Phase 2: Development of a PC-AAC intervention for PwD (Overview)

The PC-AAC intervention for PwD consisted of four interlinked components. As depicted in Figure 3.1, these four interlinked components integrated concepts and processes related to a person-centred care approach; electronic life story conversational support; AAC outcomes for PwD; and an AAC outcome measure for PwD.

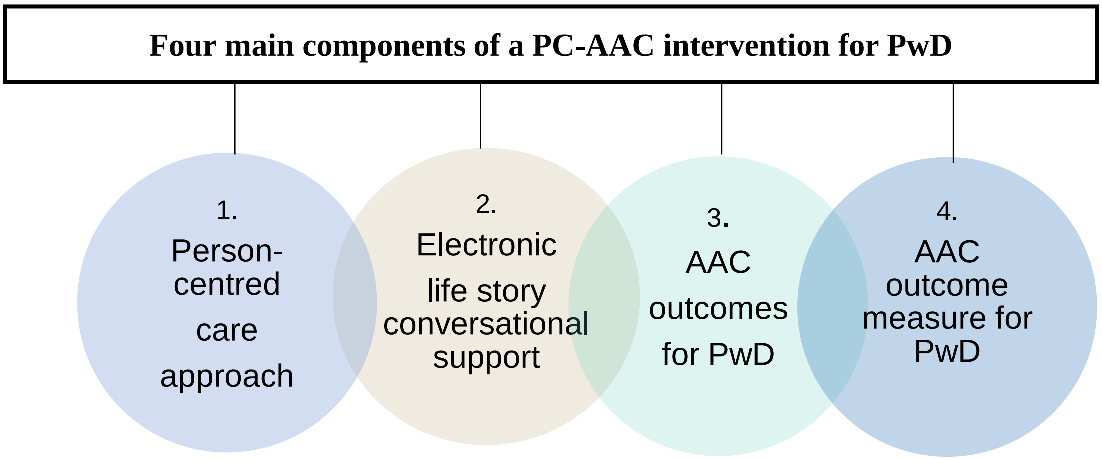


Figure 3.1: Overview of a PC-AAC intervention for PwD developed in this study

The four components were identified as existing gaps or unexplored areas within the existing body of AAC research for persons with dementia (see Par. 2.5 and Par. 2.6). Each component was guided by six key AAC principles for research and intervention recommended by Blackstone, Williams and Wilkins (2007) and was tailored for a specific participant in Phase 3B of the main study, i.e., a person with moderate to severe dementia (see Par. 4.10.3.1). In adherence to the ethical protocol of this study (see Par. 4.4), a pseudonym – Mrs Anna Brown – was used to refer to the participant to protect her anonymity. Aligned with the principle of the co-production of research, the participant was involved in different roles as listener, co-thinker, decision maker and indirect advisor. These roles were adapted from an Involvement Matrix by Smits, Meeteren, Klem, Alsem and Ketelaar (2020) and a definition of the different roles and AAC principles (Blackstone et al., 2007) as embedded in each of the four components is summarised in Table 3.1.

Table 3.1: Involvement role and AAC principles embedded in the PC-AAC intervention for PwD

Component	Involvement (role) (Smits et al., 2020)	AAC principles (Blackstone et al., 2007)
Component 1 PCC participatory processes	*Listener*: The person with dementia listens and is present at meeting with family.	- *Principle 1*: Adapted methodologies enable a person with dementia and stakeholders to participate in AAC intervention research.
Component 2 Electronic life story conversational support	*Co-thinker:* The person with dementia is asked for their opinion on their life story, and their choice of AAC symbols. *Decision maker*: The person with dementia is involved in decision making related to the customisation of electronic life story conversational support.	- *Principle 2:* Theoretical constructs and the selection of interpersonal interaction strategies are based on empirical evidence. - *Principle 3:* AAC device features are selected in accordance with the strengths and capabilities of a person with dementia. - *Principle 4:* on the role of conversational partners in scaffolding an interpersonal interaction with a person with dementia is emphasised.
Component 3 AAC outcomes	*Indirect advisor*: Self-reported meaningful outcomes from qualitative studies are reviewed. *Co-thinker:* The person with dementia is asked for their opinion and feedback on the AAC outcomes (enjoyment).	- *Principle 5*: Conversational supports offer a person with dementia opportunities to participate in interpersonal interaction and to maintain social connection with their conversational partners.
Component 4 AAC outcome measure		- *Principle 6:* Meaningful AAC outcomes are measured from the perspective of a person with dementia.

All four components, including the roles played by the participant and AAC principles were subsequently incorporated into an organising framework to enable the researcher to operationalise all four components in clinical practice in a systematic and principled manner. The organising framework is illustrated in Figure 3.2.

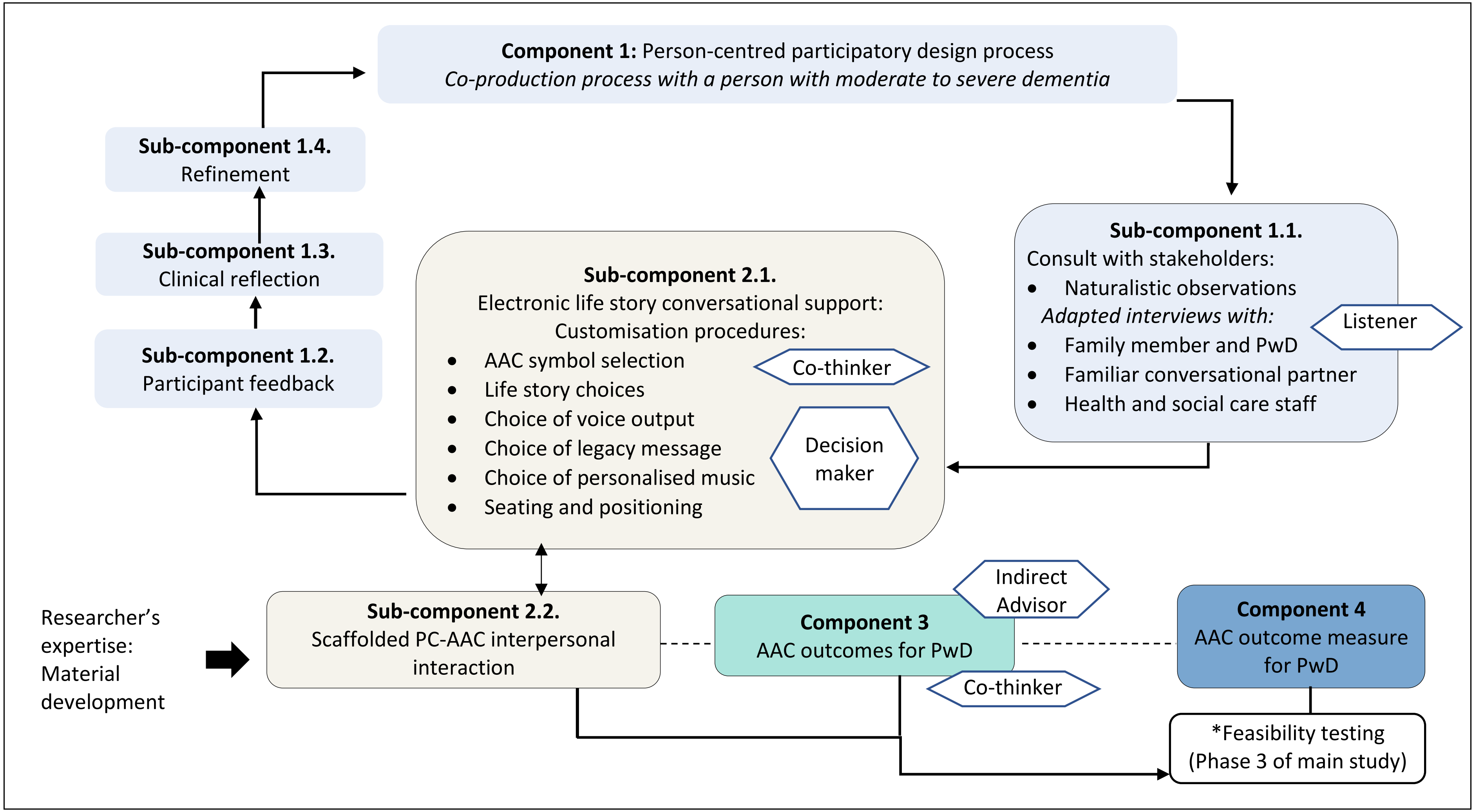


Figure 3.2: Organising framework of the PC-AAC intervention for PwD

3.3. Component 1: Person-centred co-production process

As shown in Figure 3.2, Component 1 was an iterative co-production process that consisted of four sub-components: consultation with multiple stakeholders; participant feedback; clinical reflection; and refinement of the electronic life story conversational support. Before observations were made and the person-centred co-production process began, ethics approval was obtained from the Research Ethics Committee at the Faculty of Humanities, University of Pretoria (Appendix G1). The participant and all stakeholders were made aware that their participation in the research study was voluntary (McMillan & Schumacher, 2014). Should they have wished to withdraw from the study at any time, they were permitted to do so without penalty. The researcher ensured that the participant with dementia did not undergo any form of harm or undue distress and was treated with respect throughout the research study.

The personal information of the participant with dementia as well as all information obtained from the familiar communication partner, family member and other stakeholders were kept strictly confidential following the University of Pretoria's ethical research policy on data management. The participant's personalised life story content on the AAC device was used only for the purpose of the study by the researcher. After the completion of data collection, the participant with dementia and her family member were given a printed version of the digital life story as a memento. Full details of the ethics approval and informed consent procedures are further elaborated on in Par. 4.4 and Par 4.10.1 respectively.

The section below presents the procedures related to the consultation with multiple stakeholders and clinical reflection. Sub-components related to participant feedback, customisation and refinement of the electronic life story conversational support (Component 2.1), although interlinked with Component 1, are described in Par. 3.4.1.

3.3.1. Consultation with multiple stakeholders

3.3.3.1. Observations in everyday contexts

Naturalistic observations were performed to obtain an understanding of the interpersonal interaction of the participant in daily activities with different conversational partners at the care home. Observations were performed by means of unobtrusive and 'participant' observations. During unobtrusive observations, the researcher observed the participant from afar (Atelius et al., 2018). The participants' preferences for interpersonal interaction at specific times of the day, and the level of support provided by various conversational partners were captured on an observation form (Appendix A) developed by the researcher. ‘Participant’ observations were performed not only to obtain observational information, but also to establish rapport with the participant prior to the co-production process (Atelius et al., 2018). To do so, the researcher participated in the daily routine of the participant. This entailed joining the weekly music group, arts and crafts activities, and sitting in the dining area during mealtimes with the participant. Subsequent to the ‘participant’ observations, the researcher recorded information on the observation form (Appendix A) related to the participants’ preferences, her frequently used phrases, and the activities she particularly enjoyed. Overall, observations took place at a minimum of three times per week over a period of two weeks.

3.3.3.2. Adapted stakeholder interviews

The researcher interviewed multiple stakeholders to gain different perspectives on the life story, preferences and interests of the participant. The four stakeholder groups consisted of the participant’s closest family member, her familiar conversational partner, nursing staff, her occupational therapist, and her music therapist. The researcher was sensitive to the time constraints and work priorities of each stakeholder, and therefore the setup of the interviews was adapted. The walking interview was employed as a participatory research method as an alternative to a structured interview for persons with dementia (Kullberg & Odzakovic, 2018). This method was also adapted to involve nursing staff without imposing the need for a traditional sit-down interview. All information obtained from the adapted stakeholder interviews was documented on an observation form (see Appendix A). A summary of the materials, procedures and outcomes of the adapted interviews appears in Table 3.2.

Table 3.2: **Summary of adapted interviews with multiple stakeholders**

Stakeholder	Data collection	Materials	Procedure	Outcome
Family member Participant Familiar conversational partner	Face-to-face informal discussion in a social setting	Participants' family photographs; personal information forms (Appendix B)	A personal information form was emailed to the family member in advance. Via email, a meeting time was arranged in a relaxed social setting (coffee shop) at the research site. This was attended by the family member who granted consent, the participant herself and her familiar conversational partner.	The family member completed and returned the personal information sheet and brought along the participant's family photographs. Additional supplemental life story information (e.g., scrapbooks and family biographies written in the participants own words) was supplied. The family member provided an in-depth background of the family's religious beliefs and Jewish traditions. The participant listened and contributed to the discussion in a reminiscing way.
Participant	Walking interview	Observation form (Appendix A)	The familiar conversational partner wheeled the participant in her wheelchair through the garden of the care home. Natural conversations arose with the researcher.	One walking interview took place and unfolded as a naturally occurring conversation. The researcher followed up on conversations that the participant directed about trees and flowers, and her family stories. The familiar conversational partner contributed to these conversations.
Nursing staff	Walking interview	Observation form (Appendix A)	Nursing staff were informally asked questions while 'walking and talking'.	Nursing staff provided information on the participant's personal fashion style, and personal grooming choices.
Occupational therapist	Informal interview	Observation form (Appendix A)	The occupational therapist was informally interviewed at the research site.	The occupational therapist provided information about the participant's favourite topics and personal preferences (e.g., food, traditions).
Music therapist	Informal interview	Observation form (Appendix A)	The music therapist was informally interviewed following a music group session.	The music therapist provided information on music that the participant enjoyed and suggested music to be included in the life story conversational support.

3.3.3.3. *Clinical reflection*

Subsequent to each observation, the researcher engaged in intentional reflection by writing in a reflective journal to reflect on the lessons learned about the participant (May, Dada, & Murray, 2020). This provided a channel for the researcher to evaluate some of her own assumptions held in relation to cultural differences and the strength of persons with dementia in general (Mahendra et al., 2013).

3.4. Component 2: Electronic life story conversational support

The electronic life story conversational support consisted of three sub-components, namely customisation of the electronic conversational support, PC-AAC scaffolding strategies, and procedural implementation. The sub-components and materials are reflected in Table 3.3.

Table 3.3: **Component 2: Sub-components and materials developed**

Component 2	Sub-components	Materials developed
Electronic life story conversational support	Sub-component 2.1: Customisation procedures	*Life story content* • Two personalised life stories *Customised electronic AAC system choices:* • AAC symbol selection • Voice output • Legacy message • Personalised music • Seating and positioning *AAC device and familiarisation:* • iPad • GoTalk Now application
	Sub-component 2.2: Scaffolded PC-AAC interpersonal interaction	*PC-AAC scaffolding strategies*: • Aided modelling • Prosodic emphasis • Attentional cues • Expectant delays • Person-centred communication *PC-AAC interpersonal interaction script*
	Sub-component 2.3: Procedural implementation	• Procedural checklists

3.4.1. Customisation of the electronic conversational support

3.4.1.1. *Life story content*

Life story work supports person-centred care as it aims to value the unique identity and personal life history of persons with dementia (McKeown et al., 2010). The researcher collated all information that emerged from the stakeholder interviews (see Par. 3.3.1), including all the photographs supplied by the family member (see Table 3.2). The photographs were then collaboratively selected by the participant and her familiar conversational partner. With each photograph selected, the familiar conversational partner assisted by facilitating a reminiscing conversation with the participant. This provided the researcher with an opportunity to record supplemental information for the life story. This process took place during two separate sessions lasting approximately 25 minutes each.

Next, the researcher wrote two life stories by integrating seven to ten facts related to the photographs and information extracted from family scrapbooks or family biographies. The researcher put together two draft life stories, based on preferred topics stated by the family member and the information gathered in consultation with multiple stakeholders (see Par. 3.3.1).

The life story was structured with a life story title, based on each life story topic. An integrative review of 13 studies on life story work in older persons by Doran et al. (2018) revealed that there is no prescribed approach to developing a life story. Based on the information collated from stakeholders in Par. 3.3.1, the researcher arranged the participant's information into a framework of three main life story themes related to the milestones and highlights of the participant's life (Skinner et al., 2019). The researcher developed the participant's life story from three main themes related to life events, family and friends, and values and beliefs (Skinner et al., 2019) (Appendix C).

From these life story themes; two life stories were written. Each life story consisted of six to ten short and simple sentences. These sentences highlighted happy moments, milestones or memorable events in the participant's life and were associated with a highly salient context-relevant photograph. A vignette of one life story is presented in Appendix D, and screenshots of the life story on the electronic aid are found in Appendix E. Generic pictures from Google Images that have personal relevance to the participant were also used to supplement the life story where family pictures were unavailable.

3.4.1.2. Customised electronic AAC system choices

The participant played the role of decision maker in selecting the AAC symbols (photographs selected in Par. 3.4.1.1) that she preferred to be included in her life story. To facilitate conversations related to the customisation of the electronic life story conversational support, the researcher supported the conversations using AAC strategies (e.g., pictures cards, aided modelling and pointing). The researcher offered the participant choices supported by pictures related to her preference for colour or black-and-white photographs, the use of voice output in the form of a legacy message and music, and if voice output was preferred, then the type of legacy messages and type of music. Legacy messages are personalised words or phrases that are considered to be a trademark of an individual recorded in their own unique voice (Costello, 2016).

The participant independently participated in decision making with regard to her electronic life story conversational support by using a combination of pointing and verbal utterances. She indicated her preferences and chose colour photographs, preferred voice output using her own messages/phrases, and she selected classical music. Due to difficulties in executive functioning, the participant experienced difficulty in spontaneously recording her own legacy message. Therefore, the researcher audio-recorded naturally occurring conversations with the participant using the audio-recording function on an Apple iPhone 6. This enabled audio extraction of specific words and phrases to be utilised later as voice output on the participant’s AAC device.

3.4.1.3. AAC device and familiarisation

The AAC device consisted of an Apple iPad (4th generation) as the hardware platform using the GoTalk NOW application (app). GoTalk NOW is an AAC app for persons with communication difficulties that can be customised with sound, internet images, personal photographs and video clips (Attainment Company Inc., 2020). The GoTalk NOW app was selected for its accessibility and affordability for research with persons with dementia in the South African context. The Apple iPad was selected as the family member reported to have previously used the device for playing memory games and scrolling through digital family photographs with the participant.

A universal, adjustable table computer stand was used to support the AAC device to increase the participant’s comfort and ease of viewing the AAC intervention content (see Figure 3.3). The participant’s selected photographs were scanned using a colour scanning device and then they were uploaded electronically to the AAC device. The researcher included a familiarisation procedure of the AAC device when the PC-AAC scaffolding strategies were applied (see Par. 3.4.2.2. and Table 3.5). The familiarisation entailed the researcher demonstrating three navigational points on the AAC device: light, single touch with pad of finger on the AAC device; press the Home button, and press the GoTalk NOW app icon.

Figure 3.3: AAC device (iPad) supported by a universal stand

Customisation of the electronic life story conversational support overlapped with Component 1 as stated in Figure 3.2. The process was iterative and dependent on the participant's feedback. Following a first draft of the life story (see Par. 3.4.1.1) on the AAC device, the researcher trialled the electronic life story conversational support with the participant. This created an opportunity for the researcher to make refinements based on the participant's feedback and preferences. Although music was played through the in-built speakers of the AAC device, a portable Bluetooth speaker was also connected to the AAC device to increase the audibility of voice output. The volume was adjusted to suit the participant's hearing comfort. The participant expressed a preference to remain seated in her wheelchair seat, instead of a regular seat. This was noted for subsequent sessions to increase her comfort during the use of the electronic life story conversational support.

Previous studies showed that visual scenes resulted in an increased number of conversational turns for persons with aphasia (Brock, Koul, Corwin & Schlosser, 2017). Therefore, a visual scene in this study included a static but highly contextual, personal photograph or a personally relevant generic photograph to discuss the characters within the life story context. In certain instances, the visual scene was embedded with music or voice output (in the form of pre-recorded voice messages) (see Par. 3.4.1.2).

3.4.2. Scaffolded PC-AAC interpersonal interaction

3.4.2.1. Identification of PC-AAC scaffolding strategies

A life story interpersonal interaction was scaffolded by the researcher with application of PC-AAC scaffolding strategies. Theoretically, this was underpinned by Bruner's (1978) scaffolding theory which asserts the role of graded support by an adult to assist a child (novice) to solve a problem on their own (Bakhurst & Shanker, 2001). Similarly, within the context of an electronic life story support with the participant, the role of the conversational partner (researcher) was to scaffold the interpersonal interaction using person-centred AAC strategies (i.e., PC-AAC scaffolding strategies).

The literature demonstrates the positive impact of aided modelling (as an augmented input strategy) to enhance the ability of a person using AAC to understand verbal messages (Dada, Stockley, Wallace, & Koul, 2019; Dada, Flores, Bastable, & Schlosser, 2020; Dietz, Knollman-Porter, Toth, & Brown, 2014; Wallace, Dietz, Hux, & Weissling, 2012; Wallace, Knollman-Porter, Brown, & Hux, 2014). In this study, aided modelling was applied as an input strategy to read the life story content to the participant verbally and simultaneously point to AAC symbols (photographs) or written text on the AAC device. In this way aided modelling was used to increase the auditory comprehension of the spoken life story (see Section 3.4.1.1). Furthermore, person-centred communication related to validation, recognition, validation, and empathy were integrated with the AAC scaffolding strategies (Alant, Samuelson, & Ogle, 2015; Alsawy et al., 2019; McEvoy & Plant, 2014; Savundranayagam, et al., 2016; Savundranayagam & Moore-Nielsen, 2015; Williams et al., 2017).

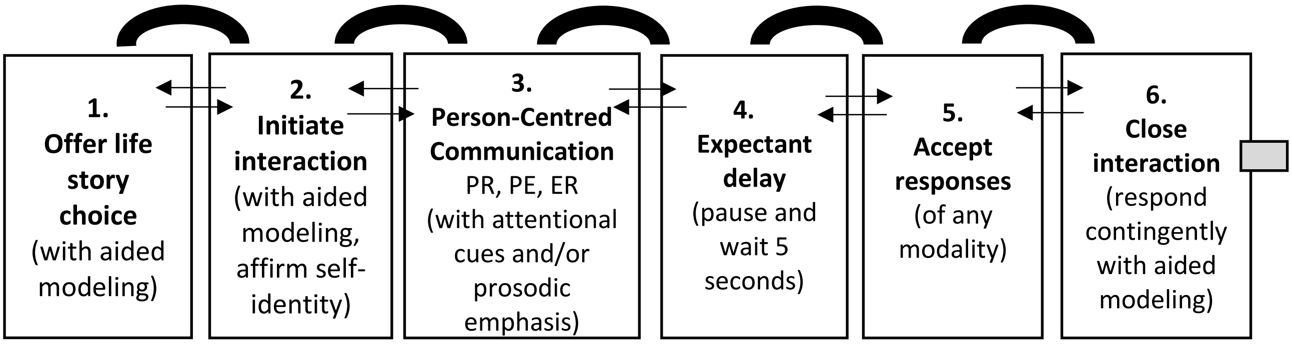
Table 3.4 presents a summary of studies that the researcher consulted, the authors involved, and key aspects of supporting interpersonal interaction with AAC strategies and person-centred communication.

Table 3.4: Evidence-based PC-AAC scaffolding strategies

Evidence-based scaffolding strategies	Authors	Description of evidence source	Population	Main techniques, strategies extracted
Aided AAC modelling (augmented input techniques)	Dada et al. (2019); Dada et al. (2020); Dietz et al. (2014); Wallace et al. (2012); Wallace et al. (2014)	Intervention studies	Persons with aphasia	Auditory comprehension supported by supplementary spoken language and pointing to AAC symbols. The conversational partner highlights information with multiple modalities (written text, gestures) during interpersonal interaction.
Multimodal cues Attentional cues Prosodic emphasis	Diehl & Wallace (2018); Rebstock & Wallace (2020); Wallace et al. (2012)	Individual intervention studies	Adult neuro-cognitive communication disorders	Prosodic emphasis to supplement spoken language and assist in comprehension. Attentional cues to gain attention
Expectant delay	O'Neill, Light & Pope (2018)	Meta-analysis (28 studies)		Aided input combined with expectant delay (giving the person with dementia time to respond).
	Kent-Walsh, Murza, Malani, & Binger (2015)	Meta-analysis (17 studies)		
	Pennington, Goldbart, & Marshall (2004)	Systematic review (four studies)		Interactional partners' responsiveness.
Person-centred, and empathetic communication	Alant, Samuelson, & Ogle (2015); Alsawy et al. (2019); McEvoy & Plant, 2014; Savundranayagam et al. (2016); Savundranayagam & Moore-Nielsen (2015); Williams et al. (2017)	Individual intervention studies	Persons with dementia	Relates to statements: Empathetic responsivity: Responds at a feeling level. Personal recognition: Communicates a well-known trait of the person with dementia. Personal elaboration: Elaborates a personal aspect of the person with dementia.

3.4.2.2. Turn taking with the implementation of PC-AAC scaffolding

To facilitate turn taking, the evidence-based PC-AAC interaction strategies (see Table 3.4) – aided modelling; expectant delay; attentional cues; prosodic emphasis; person-centred communication (personal recognition, personal elaborations, validation, empathetic listening) – were applied in six steps. The purpose of these steps was to provide PC-AAC scaffolding to support the participant to also take a turn. The participant's turn taking responses could be verbal (V), gestural (G), aided (A) or multimodal (MM) (e.g., a combination of verbal utterance and a gesture, such as a head nod 'yes' in agreement). The purpose of using PC-AAC scaffolding was to support the participant to use multimodal interaction to increase her turn taking ability and to interact in the electronic life story (described in Par. 3.4.2.1). The six steps are explained in detail in Figure 3.4.



Turn taking opportunity: From initiation to closure of interaction

<u>Key</u>

⌒	Indicates the sequence of PC-AAC strategies implemented by the researcher.
⇄	Indicates turn taking within a turn taking opportunity that should be scored on the companion AAC outcome measure for PwD
□	Indicates 5 seconds after the closure by the researcher, but the participant responds.
ER	Empathetic response*:* Validates the participant at a feeling level or provides affirmation.
PE	Personalised elaboration: Communicates an expansion or elaboration of a personal aspect of the life story sentence.
PR	Personal recognition: Communicates a recognised/well-known key trait, personalised action performed by the participant or family member in the AAC symbol (photographs).
Attentional cue	A cue to direct the attention of the participant (e.g., using the participant's name or the word "so, in this picture"…).
Prosodic emphasis	Raised intonation of spoken utterance to draw emphasis to meaning of a word.

Figure 3.4: Schematic representation of the turn taking opportunities within the life story interpersonal interaction

Table 3.5 contains a description of each of the six steps and an example of an interpersonal interaction script in order to illustrate the application of the life story interpersonal interaction with the participant.

Table 3.5: **Application of the PC-AAC scaffolding strategies and conversational partner script**

INTERVENTION STEP 1-6 (begin after familiarisation with the AAC device)	**Application of PC-AAC scaffolding (with an example of the researcher's script)** (only applied in the intervention phase)	**OUTPUT** (participant's possible responses)			
		V	**G**	**A**	**MM**
1. Offer life story choice	**Aided modelling:** Point to life story topics on AAC device while offering each life story choice.				
2. Initiate interaction	**Aided modelling:** Point to AAC symbols while reading life story sentence. Researcher reads life story sentence: (e.g., "*I am Anna Brown. I was an actress and model when I was younger.*"	x	x	x	x
3. Person-centred communication (use participant's name+ Personal Recognition [PR] comment/question [PE], [ER]	**Attentional cue** +**Aided modelling:** Attentional cue (name/"so"..) + point to AAC symbols (photograph) while verbalising PCC comment or question. Contextual support of people, object, location. **Prosodic emphasis** +**Aided modelling:** To supplement spoken speech Researcher says: "*Mrs Brown in this picture you* (prosodic emphasis) *are on the front cover of a magazine." "That must have been a special moment?"*	x	x	x	x
4. Expectant delay. Wait 5 seconds. If no response after 5 seconds: *(a)* Researcher repeats the script once with aided modelling. Wait 5 seconds. *(b)* If no response after (a), researcher makes a choice, confirms with participant. *(c)* If inappropriate response, researcher responds contingently, re-focuses participant back to topic, then performs (a) and or (b) accordingly.					
5. Multimodal responses		x	x	x	x
6. Close interaction	**Respond** contingently to the participant's responses with **aided modelling** while pointing to AAC symbols. **Prosodic emphasis:** To supplement spoken speech. Researcher says: e.g. *"Yes, Mrs Brown, being on the front cover of a magazine must have been a special moment…"*	x	x	x	x

Before the researcher applied the PC-AAC scaffolding strategies, the participant was familiarised with the AAC device (see Par. 3.4.1.3). As was subsequently shown in Table 3.5, the researcher adhered to a semi-structured conversational partner script and applied the PC-AAC conversational partner strategies. Collectively, these procedures were undertaken in six intervention sessions with the participant.

3.4.2.2.1. Offer life story choice

Aligned with a person-centred approach, the participant was offered two choices of life story topics (see Par. 3.4.1.1). The researcher used aided modelling to point to the labels of two life story topics, while simultaneously naming each topic verbally. The researcher throughout maintained eye contact with the participant and waited for 5 seconds for a response.

3.4.2.2.2. Initiate interaction

The interaction began by the researcher initiating the life story with an attentional cue (e.g., using the participant's name), followed by a person-centred comment or question with an attentional cue (e.g., "in this picture"). She then waited for a response and concluded by a modelling prompt of the participant's responses. Next, the researcher used aided modelling to either prompt the participant to provide a response or support them in elaborating, in order to create further turn taking opportunities.

3.4.2.2.3. Person-centred communication

The use of person-centred communication in the form of comments or questions was applied as a personal recognition, personal elaboration or empathetic response.

3.4.2.2.4. Expectant delay

The researcher paused and waited to allow the participant time to respond. If the participant did not make a topic choice, the researcher repeated the AAC intervention.

3.4.2.2.5. Accept any responses

Since the outcomes were intended to create enjoyment and satisfaction with the interpersonal interaction (rather than to focus on the quality of the language), off-topic responses were not corrected. Hence, off-topic responses were counted as a turn and coded accordingly.

3.4.2.2.6. Close interaction

Aided AAC modelling was used at the closure of the interaction to contingently respond to the participant. The researcher paused for five seconds after the closure of one turn taking opportunity and before beginning the next, so as to allow the participant to respond. Any turn taking responses by the participant within this five-second interval were scored (see Section 3.6.1.1 and Table 3.9).

3.4.3. Procedural checklists

Two procedural checklists were developed to implement the electronic life story conversational support in a real-life context.

3.4.3.1. Procedures checklist: Baseline phase

A general procedures checklist (Appendix W) with a score sheet was developed to rate the procedures applied in a baseline phase during which the researcher did not apply the

PC-AAC scaffolding strategies with the participant. Further details of this checklist are found in Par. 4.11.3.

3.4.3.2. Procedures checklist: Intervention phase

A general procedures checklist (Appendix X) was developed to rate the procedures for applying the PC-AAC scaffolding strategies as outlined in Par. 3.4.2.2. This checklist ensured that the researcher provided a familiarisation procedure (see Par. 3.4.1.3) of the AAC device prior to the application of six PC AAC scaffolding strategies. Further description of this checklist is presented in Par. 4.11.3.

3.5. Component 3: AAC outcomes for persons with dementia

3.5.1. AAC outcomes with the electronic life story conversational support

The interpersonal interaction of the participant with the electronic life story conversational support (Component 2 in Par. 3.4) has a relational focus. The goal is to maintain relationships or to create a sense of social connection between a person with dementia and their conversational partner with the use of the electronic life story conversational support. The outcomes are intended to be on two levels (intra-personal and interpersonal). On an intra-personal level, the intended outcome is enjoyment, and satisfaction with interaction that unfolds when the electronic life story conversational support is used with a conversational partner. As such, these are best rated from the direct perspective of the person with dementia. On an interpersonal level, the outcomes are an increase in turn taking and they are measured using the AAC outcome measure developed in this study (see Par. 3.6).

3.6. Component 4: AAC outcome measure for persons with dementia

The Augmentative and Alternative Communication Outcome Measure for Persons with Dementia (AACOM-PwD) was developed in this study as a companion outcome measure to the electronic life story conversational support described in Par. 3.4.

Table 3.6: **Component 4: Sub-components and materials developed**

Component 4	Sub-components	Outputs developed in the study
AAC outcome measures	AAC Outcome Measure for Persons with Dementia (AACOM-PwD)	AACOM-PwD - Four turn taking domains - 11 turn taking sub-domains - Turn taking coding scheme - Turn taking score sheets

Since an AAC outcome measure for persons with dementia does not exist, the researcher reviewed five outcome measures with established psychometric properties from the field of nursing (Williams, Newman, & Hammar, 2018; Jones, Sung, & Moyle, 2018), speech-language therapy (Brady et al., 2018) and psychogeriatrics (Mabire, Gay, Vrignaud, Garitte, & Vernooji-Dassen, 2016). Table 3.7 provides an outline of the existing outcome measures, the authors and the main interpersonal domains of each measure that was inspected.

Table 3.7: **Existing outcome measures that informed the development of the AACOM-PwD**

Outcome measure	Authors, year, field	Main domains of each measure
Verbal and Non-verbal Interaction Scale	Williams, C., Newman, D., Hammar, L.M. (2018) *Nursing*	• Social (nonverbal) • Unsocial (non-verbal) • Social (verbal) • Unsocial (verbal)
Communication Complexity Scale	Brady, N.C., Fleming, K, Romine, R., Holbrook, A., Muller, K., & Kasari, C. (2018) *Speech-Language Pathology*	(Expressive) Communication levels • Pre-intentional communication (e.g., oriented to an object with non-words vocalisation or gestures) • Intentional-non-symbolic (intentional gestures, e.g., pointing with eye gaze) • Intentional-symbolic (e.g., spoken words or use of AAC symbol selection, signs)
Social Observation Behaviours Resident Index (social interaction between people with dementia)	Mabire, Gay, Vrignaud, Garitte, & Vernooji-Dassen (2016) *Psychogeriatrics*	• Facial expressions (e.g., eyebrow raise) • Verbal interaction (e.g., requests, answers) • Quasi-linguistic interactions (e.g., pointing) • Interactive behaviours (body orientation towards speaker)
Engagement of a Person with Dementia Scale (EPWDS)	Jones, Sung, & Moyle (2018) *Nursing*	• Verbal sub-scale (initiates, participates or maintains verbal conversation or sounds in response to activity) • Visual subscale (maintains eye contact with activity) • Behaviour subscale (responds to an activity/person by approaching, touching)

3.6.1. The AACOM-PwD description

Following the review of existing outcome measures in Table 3.7, the AACOM-PwD was developed to measure turn taking. Jones, Sung & Moyle (2018) developed the Engagement of a Person with Dementia Scale (EPWDS) which has established psychometric properties. The researcher considered measuring engagement by using the EPWDS (Jones et al., 2018) as a complementary outcome measure to the AACOM-PwD. However, in the context of exploratory probing into the AACOM-PwD with a single case study participant, the researcher decided that the AACOM-PwD would be piloted first as an outcome measure to measure concrete turn taking domains.

In this study, turn taking was operationalised as the exchanges that occur between the dyad and that are independent of the form used by the conversational partners (Granlund & Wilder, 2006; Wilder, 2008). The AACOM-PwD was developed as an observation-based measure to observe the turn taking of a person with dementia with a conversational partner (the researcher) during a ten-minute video-recorded interpersonal interaction. The turn taking domains are measured as the participant's responses during the use of the electronic life story conversational support before (i.e., baseline) and after (see Par. 3.4.1.2 and Figure 3.4) the application of the PC-AAC scaffolded strategies.

The AACOM-PwD categorises turn taking into four domains: verbal turns (V), gestural turns (G), aided turns (A) and multimodal turns (MM). The turn taking process is set within the boundary of a mutual focus of attention (i.e., electronic life story conversational support on the AAC device). Each domain is divided further into eleven sub-domains to specify the type (form) of turn taking within the respective domain. The domains and sub-domains are summarised in Table 3.8, and the full operational definitions of the AACOM-PwD domains are found in Appendix F2.

3.6.1.1. AACOM-PwD coding scheme and scoring

Aligned to each life story topic (see Par. 3.4.1.1*)*, there are a minimum of six turn taking opportunities. Turn taking is scored according to the six PC-AAC scaffolding steps to support the participant in taking turns (see Par. 3.4.2.2). Turn taking is coded using a turn taking coding scheme (see Table 3.8), and a full score sheet is found in Appendix F1.

Table 3.8: **AACOM-PwD scoring on scoring sheet (example)**

	Turn taking Domains											
Interaction 1	**Verbal (V)**		**Gestural (G)**			**Aided (A)**		**Multimodal (MM)**				**Turns**
	Turn taking Sub-domains											
	a	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	**c**	**d**	
Offer Choice	✓											
PCC+wait		✓										
Model choice	✓								✓			
Subtotal	2	1							1			4
Subtotal	3							1				

Turn taking Domains: (V) Verbal turns: turn taking with vocalisations or verbal utterances, (G) Gestural turns: turn taking with body movements, head nods or facial expressions, (A) Aided turns: turn taking with or without the use of the AAC device, (MM) Multimodal turns: a combination of two or more of the aforementioned turns.
Turn taking sub-domains: Va (Vocalisations), Vb (Verbalisation), Ga (Body movement), Gb (Head nod), Gc (Facial expressions), Aa (aided turn with assistance), Ab (aided turn without assistance), MMa (Verbal + Gestural), MMb (Verbal + Aided), MMc (Gestural + Aided), MMd (Verbal + Aided + Gestural)

As shown in Table 3.8, a score is assigned in each interpersonal interaction opportunity for the turn taking domain (e.g., verbal) and the sub-domain, i.e., specific modality of verbal turn taking (e.g., a verbal turn using a vocalisation). Scoring is linked to the operational definitions in Appendix F2. The domain and sub-domain turns are tallied within each turn taking opportunity. At the end of the entire 10-minute video recording, turn taking is scored on three levels: the total number of turns taken by the participant, and the type of turn taking at a domain level and sub-domain level.

3.7. Summary

Chapter 3 described the PC-AAC intervention package for PwD as it was developed with a person with moderate to severe dementia in this study. The intervention comprised four main components, and each component was described individually in relation to its sub-components, underlying processes, developed materials and evidence-based strategies. The first and second components described the roles the participant played in co-producing her electronic life story conversational support. Next followed a description of the AAC outcomes and of the development of an AAC outcome measure to measure turn taking with the electronic life story conversational support (second component). The chapter concluded with an outline for scoring the AAC outcome measure for PwD. The feasibility of testing and implementing various components of the PC-AAC intervention package for PwD will be described in the next chapter.

CHAPTER 4: METHODOLOGY

4.1. Introduction

This chapter discusses the research methodology used in this study. First, the main aim and sub-aims are presented. This is followed by a description of the research design, the rationale for this study, and an overview of the three research phases. Next, research Phase 3 is detailed in two parts: Phase 3A describes the four steps involved in Q-methodology related to online data collection methods, the recruitment of professional participants, and data analysis procedures. Phase 3B presents a case study with a description of the participant and setting, participant selection criteria, in-person data collection procedures, recruitment materials and data analysis procedures.

4.2. Research aims

4.2.1. Main aim

The main aim of this study was to explore the development and feasibility testing of a person-centred AAC intervention package to support interpersonal interaction in persons with dementia. Hereafter, this is referred to as a PC-AAC intervention for PwD.

4.2.2. Sub-aims

In order to fully explore the main research aim, four sub-aims were delineated:

i. To review the current literature in a systematic manner to identify AAC interventions in persons with dementia. A research review was conducted by May et al. (2019) and described in Par. 2.5.1. A supplementary scoping review was performed by Dada et al. (2020) and is described in Par. 2.6.

ii. To develop a PC-AAC intervention for PwD based on the findings in (i). The development process is described in Chapter 3.

iii. To identify and describe the patterns of expert professionals’ viewpoints on four components of the PC-AAC intervention for PwD developed in (ii).

iv. To implement the PC-AAC intervention for PwD developed in (ii) in a real-life context with a participant with dementia in order to:

    a) Assess the procedural reliability of implementing an electronic life story conversational support (i.e., Component 2) with a participant with moderate to severe dementia.

b) Assess the intra-rater and inter-rater reliability of scoring an AAC outcome measure for PwD (i.e., Component 4) of the PC-AAC intervention for PwD developed in (ii). This assessment can be found in Par. 4.13 and Par. 5.4.
c) Determine the self-reported enjoyment (Component 3) of a participant with moderate to severe dementia when using a co-produced electronic life story conversation support.

4.3. Multimethod research design

This study used a multimethod research design (Hunter & Brewer, 2006). According to Pearce (2015), a multimethod research design is a hybrid method as it entails a combination of different types of research methods, data collection strategies and data analysis procedures that are employed within a single research study (Hunter & Brewer, 2015). A multimethod research design adopts a pragmatic philosophical approach (Hesse-Biber, 2015) that centres around the research aim. Pragmatism orients itself to solving practical solutions in the real world, and pragmatic epistemology infers that knowledge is based on experience, actions and beliefs (Kaushik & Walsh, 2019). Furthermore, a pragmatic philosophical approach utilises multiple methods in order to meet the specific research purpose (Kaushik & Walsh, 2019). The rationale for selecting a multimethod research design for the current study was as follows:

The initial research aim of this study was to determine the effect of an electronic PC-AAC intervention for interpersonal interaction in persons with dementia by means of collecting data directly from them. However, after a single day, data collection for the original study was abruptly halted in March 2020 due to the COVID-19 pandemic. The subsequent lockdown measures in South Africa directly impacted the original research method in two ways:

i. The intended participant sample had to be changed. Elderly persons aged 60 years and older, including persons with dementia living in frail care and in care homes for the elderly, were classified as a high-risk group for contracting COVID-19 due to the higher prevalence of underlying or co-occurring health conditions in this age group (Department of Health, Republic of South Africa, 2020).
ii. The geographical location of data collection was also affected. The Western Cape, the province in which data collection had been planned, was the first province to record the highest COVID-19 infection rates per capita in South Africa (Western Cape

Government, 2020). Consequently, in-person data collection with persons with dementia at the original research sites was suspended indefinitely.

Given the unprecedented circumstances brought about by the COVID-19 pandemic and its direct impact on the original research study, flexible and innovative online research strategies had to be sought (Smith, Ostinelli, & Cipriani, 2020; Nicol, Piccirillo, Mulsant, & Lenze, 2020). Hence, the research aim was amended to be exploratory by employing a multimethod research design. Overall, the multimethod research design adopted in this study included three methods: a research review methodology and a scoping review (Grant & Booth, 2009); Q-methodology (Brown, 1980); and a case study with a single participant with dementia (Yin, 2011). Each research method yielded its own dataset and required its own data analysis procedures. However, there was an overall level of complementarity, as each method informed the main aim of the study (Morse, 2003).

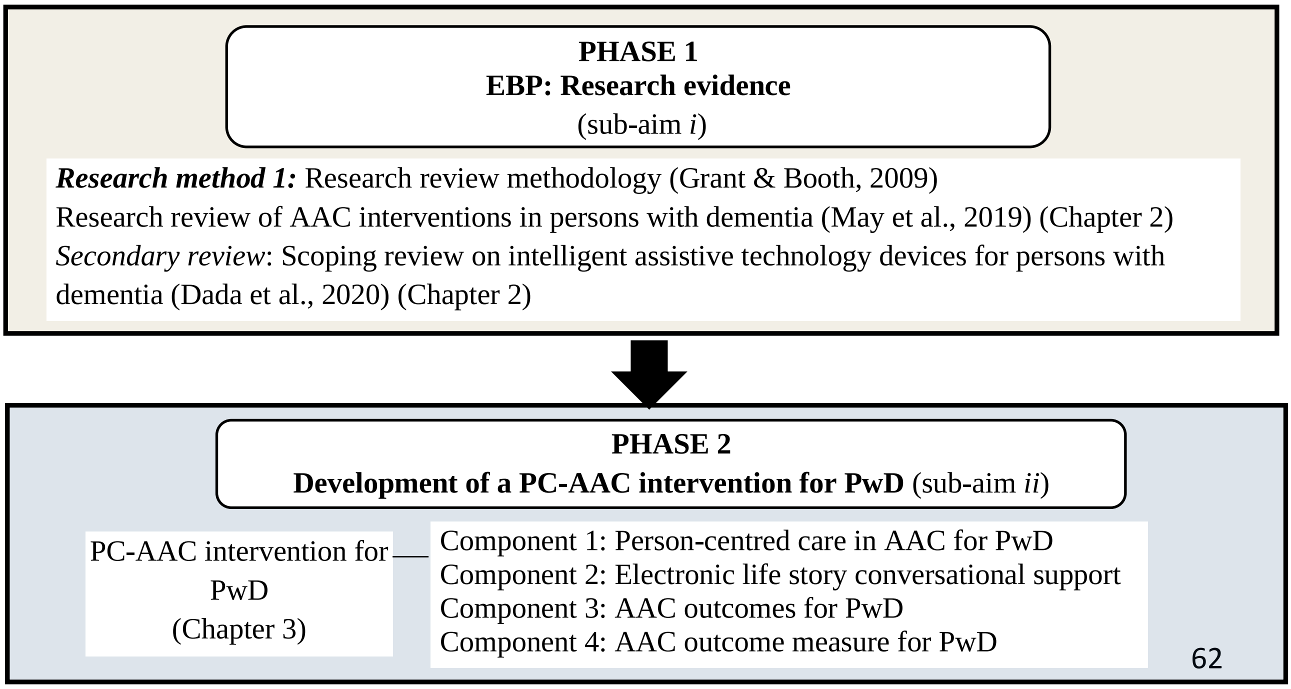
4.3.1 Research phases

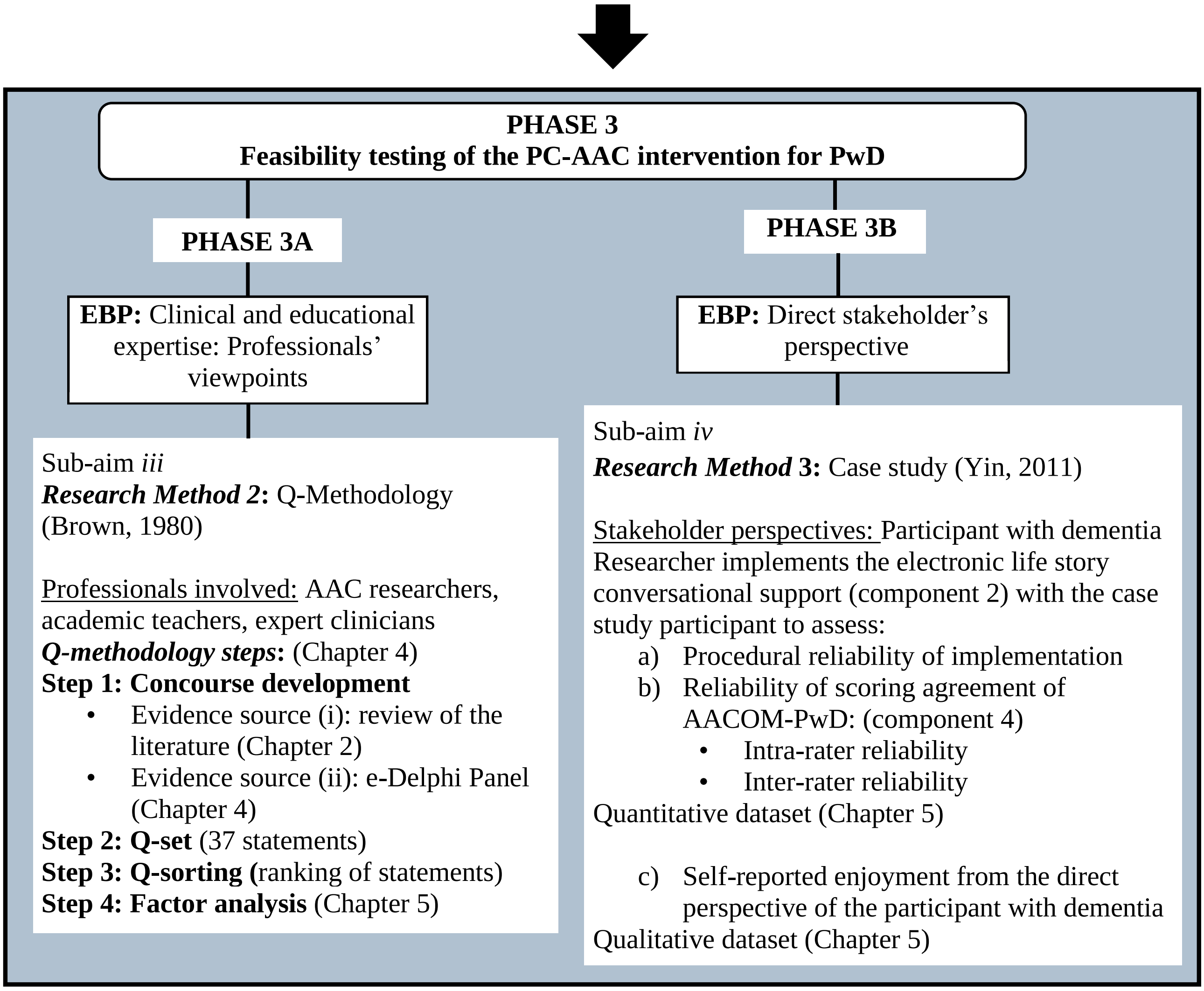
This study comprised of three research phases (see Figure 4.1) mapped onto the three cornerstones of evidence-based practice (Schlosser & Raghavendra, 2004):

i. *Phase 1* relates to the current research evidence on AAC for persons with dementia.

ii. *Phase 3A* relates the viewpoints of professionals on the four components of the PC-AAC intervention for PwD based on their clinical and educational expertise, and

iii. *Phase 3B* relates to the direct stakeholder perspectives of a person with dementia in using the electronic life story conversational support (component 2) with the researcher. The direct stakeholder perspective is interlinked with Phase 2 (stakeholder involvement in the development of Component 2).





PHASE 3
Feasibility testing of the PC-AAC intervention for PwD

PHASE 3A

EBP: Clinical and educational expertise: Professionals' viewpoints

Sub-aim *iii*
Research Method 2**:** Q-Methodology (Brown, 1980)

Professionals involved: AAC researchers, academic teachers, expert clinicians
Q-methodology steps**:** (Chapter 4)
Step 1: Concourse development
- Evidence source (i): review of the literature (Chapter 2)
- Evidence source (ii): e-Delphi Panel (Chapter 4)

Step 2: Q-set (37 statements)
Step 3: Q-sorting (ranking of statements)
Step 4: Factor analysis (Chapter 5)

PHASE 3B

EBP: Direct stakeholder's perspective

Sub-aim *iv*
Research Method **3:** Case study (Yin, 2011)

Stakeholder perspectives: Participant with dementia
Researcher implements the electronic life story conversational support (component 2) with the case study participant to assess:
a) Procedural reliability of implementation
b) Reliability of scoring agreement of AACOM-PwD: (component 4)
    - Intra-rater reliability
    - Inter-rater reliability

Quantitative dataset (Chapter 5)

c) Self-reported enjoyment from the direct perspective of the participant with dementia

Qualitative dataset (Chapter 5)

Figure 4.1: Three research phases of this study

Figure 4.1 illustrates the three research phases in this study. In Phase 1, a research review methodology (Grant & Booth, 2009) was used to undertake a review of AAC interventions in a systematic manner. This was the primary review for the current study conducted by May et al. (2019). The methodological process of conducting the research review, together with a summary of the results, are presented in Chapter 2. A secondary review by Dada et al. (2020) was performed as an independent scoping review. However, it was integrated into the current study as it contributed supplementary literature on electronic AAC systems for persons with dementia.

In Phase 2 (see Par. 3.2), a 4-component PC-AAC intervention for PwD was developed for this study. The PC-AAC intervention for PwD comprised of various sub-components, underlying processes and materials related to person-centred care in AAC for persons with dementia, electronic life story conversational supports, AAC outcomes for persons with dementia, and the development of the AACOM-PwD (an outcome measure for person with dementia). Following the development of the PC-AAC intervention package for PwD, Phase 3 (feasibility testing) was conducted in two parts.

In Phase 3A, feasibility testing focused on obtaining the viewpoints of expert professionals on the four components and underlying sub-components of the PC-AAC intervention package for PwD. Q-methodology (Brown, 1980) was employed as a research method to be executed in four steps to examine professionals' viewpoints in a systematic manner. Step 1 involved developing a concourse from various sources of information to identify current discourse related to the research topic. In this study, evidence sources included two reviews of the literature (conducted in Phase 1). Additionally, an international e-Delphi panel of expert professionals provided their opinion on three broad areas of the PC-AAC intervention for PwD. Themes generated via content analysis were combined with literature-derived information to build a set of statements (Step 2). These statements were then ranked by a second group of professionals in Step 3 through an online Q-sorting process. Following Step 3, Q-data was analysed quantitatively using factor analysis (Step 4).

In Phase 3B, a case study was employed (Yin, 2011). Two components of the PC-AAC intervention for PwD were implemented with a person with moderate to severe dementia in a real-life setting. The threefold purpose of Phase 3B was to assess the procedural reliability of implementing the electronic life story conversational support, assess inter-rater and intra-rater reliability of scoring the AACOM-PwD and determine the participants' self-reported enjoyment in using the conversational support with the researcher.

4.4. Ethical considerations for the overall study

This study received ethical approval from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria (see Appendices G1 and G2). All participants who took part in both Phases 3A and 3B were assured of their confidentiality and anonymity. Their biographical information was obtained for descriptive purposes only and was not disclosed to any person outside of this study. Participants were ensured that, should their responses be included in the thesis for the interpretation of the study results, a generic non-identifiable coding system would ensure that all responses would be anonymised.

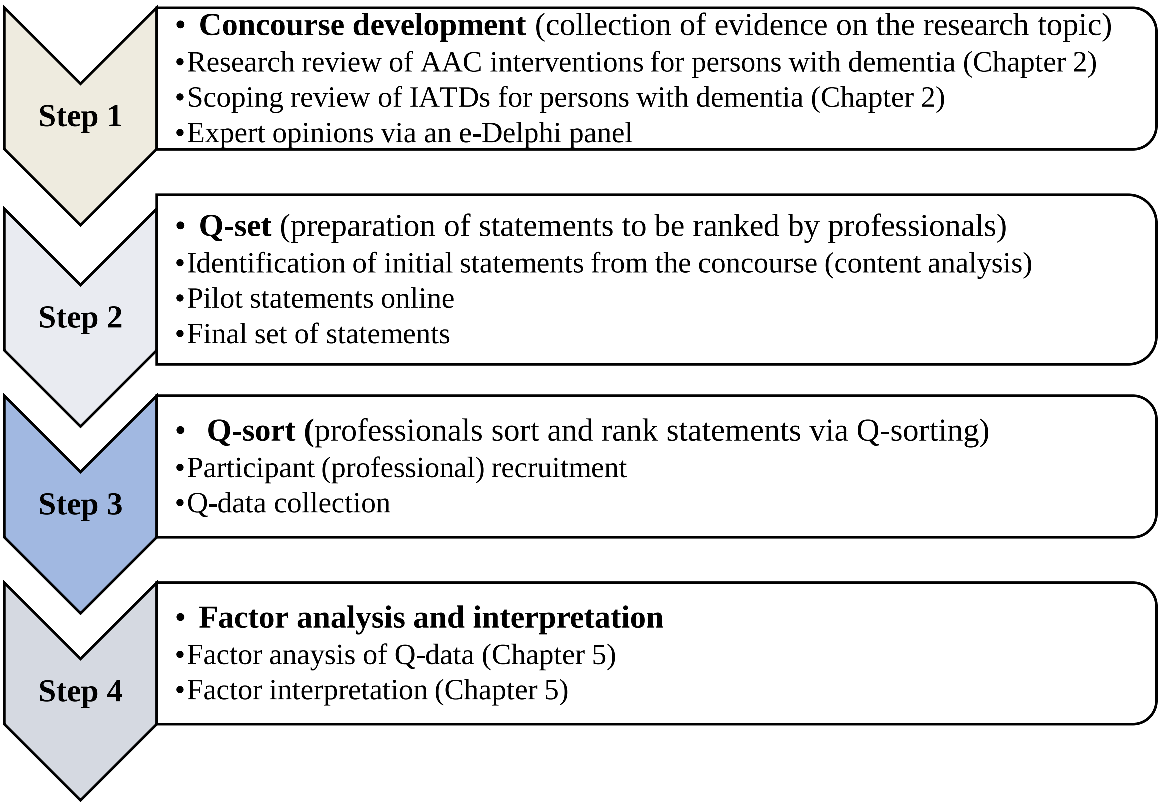
Participation in this study was completely voluntary, and all participants were free to withdraw from the study at any time without providing a reason. Participants were informed that all the study data was to be stored on a password-protected computer and would be accessible only to the student researcher and supervisors of this study. They were also informed that once the research study had been completed, all data would be stored at the Centre for AAC, Faculty of Humanities, for a period of 15 years, in accordance with policy at the University of Pretoria. There were no tangible or financial incentives attached to their voluntary participation in this study.

4.5. Phase 3A: Q-methodology

The aim of Phase 3A was to explore the viewpoints of professionals with relevant clinical and educational experience on the components of the PC-AAC intervention for PwD developed in this study (Chapter 3). To address the aim of Phase 3A, a Delphi method was considered as a possible strategy to obtain professionals' views. According to Hasson, Keeney and McKenna (2000), the purpose of a Delphi method is to perform multiple rounds of iterative feedback from professionals to obtain consensus on a research topic. Since the purpose of Phase 3A was to explore and describe professionals' viewpoints, rather than to obtain consensus of professional opinion, Q-methodology was selected as an appropriate research method.

Q-methodology is an integrated approach that is used to understand human subjectivity (Brown, 1980). Based on an individual's subjectivity, viewpoints can be extracted to highlight aspects that may be relevant or important to an individual at a specific point in time (Watts, & Stenner, 2012). In this study, understanding the viewpoints of AAC professionals on components of the PC-AAC intervention for PwD contributes an understanding of what may currently be important for or contentious in AAC research and practice with persons with dementia.

Q-methodology is unique as it obtains professionals viewpoints qualitatively, but employs quantitative research techniques to systematically evaluate qualitative data (Brown, 1980; Yang, 2016; Zabala & Pascual, 2016). Q-methodology has the advantage that it enables a more nuanced and detailed understanding of patterns of professionals' viewpoints, which is uncommon in conventional survey methods (Yang, 2016). Furthermore, in comparison to traditional survey designs, small sample sizes do not affect the research findings in Q-methodology studies. This is due to the methodology being well-suited for exploratory research, which renders generalisability irrelevant to Q-methodology studies (Brown, 1980; Yang, 2016). Q-methodology is conducted as a sequential multistep process (McKeown & Thomas, 2013), and in this study, four sequential steps were involved. These were concourse development, developing a set of statements called a Q-set, ranking the set of statements though a process called Q-sort, and factor analysis and interpretation of Q-data. The details of the four steps are depicted in Figure 4.2.



Step 1

- **Concourse development** (collection of evidence on the research topic)
- Research review of AAC interventions for persons with dementia (Chapter 2)
- Scoping review of IATDs for persons with dementia (Chapter 2)
- Expert opinions via an e-Delphi panel

Step 2

- **Q-set** (preparation of statements to be ranked by professionals)
- Identification of initial statements from the concourse (content analysis)
- Pilot statements online
- Final set of statements

Step 3

- **Q-sort (**professionals sort and rank statements via Q-sorting)
- Participant (professional) recruitment
- Q-data collection

Step 4

- **Factor analysis and interpretation**
- Factor anaysis of Q-data (Chapter 5)
- Factor interpretation (Chapter 5)

Figure 4.2: Orientation to Q-methodology employed in this study

Next, an overview is given of the Q-methodology steps as shown in Figure 4.2, based on the methodological procedures applied within each step.

4.5.1 Step 1: Concourse development

In Q-methodology, the concourse is the foundation of broader scientific evidence and the range of current discourses related to the research topic, extracted from various evidence sources (McKeown & Thomas, 2013). In this study, three main sources of evidence added to the comprehensiveness and richness of the concourse. Firstly, the researcher conducted a review of AAC interventions for persons with dementia in a systematic manner undertaken in Phase 1 of the main study (Par.2.5.1). This information was supplemented by a second scoping review on intelligent assistive technology devices for persons with dementia. In Q-methodology, data from in-person focus groups and professional interviews is typically used in developing the concourse (Newman & Ramlo, 2013). However, given the imposed COVID-19 social distancing regulations of 2020, in-person focus groups were not possible.

Therefore, the third evidence source was obtained from a geographically dispersed panel of international professionals who provided their expert opinion on three broad, open-ended questions related to the research topic (i.e., a single- round international e-Delphi panel). Collectively, all three evidence sources formed the basis of statements developed in Step 2. The next section describes the e-Delphi panel participants, and general procedures followed by the e-Delphi panel.

4.5.1.1. Step 1.1: Professional participants

To participate in the e-Delphi panel, professionals were selected based on three selection criteria.

i. In alignment with the research aim, participants had to be professionals from the disciplines of AAC, speech-language therapy or a related health science discipline by virtue of their scholarly work in the AAC and dementia-related communication literature.

ii. In this study, an expert was defined as a professional who met two pre-requisites. The professionals had to hold a degree in the aforementioned professional disciplines, and they had to be involved in AAC and/or dementia-related research, clinical work or teaching in their respective professional disciplines. As a measure to verify professionals' educational qualifications, the researcher undertook a three-pronged review process. This process entailed the review of the author details of potential professional participants as these appeared in their recent research publications, as well as checking their Open Researcher and Contributor Identity (ORCID) profiles and their online clinical profiles (where applicable).

iii. Professionals were also selected based on their area of research interest within the scope of adult cognitive-communicative disorders, interpersonal interaction research in general or dementia-related communication in particular, person-centred care in dementia studies, communication technology, or instrument development. This resulted in a diversity of professional perspectives (Avella, 2016). Professionals' final inclusion in this study depended on their voluntary consent to take part in the e-Delphi panel and their submission of a completed questionnaire before the expiry date of the e-Delphi panel round.

4.5.1.2. Step 1.2: Recruitment of professionals

A non-probability, purposive sampling strategy was employed to recruit professionals for the e-Delphi panel. The aforementioned selection criteria were applied, which resulted in a list of 63 potential professionals who were invited to participate.

The potential e-Delphi panel of professionals were recruited by obtaining their email addresses from their publicly available online professional profiles. An invitation letter (described in Par. 4.5.1.4) was personally addressed and emailed to each potential professional participant. This was sent from the email accounts of the two supervisors of this study. Temporal and work-related factors were the reason for making initial email contact in this manner. This was because recruitment procedures overlapped with the mid-year summer vacation of potential professional participants in the northern hemisphere, and the increased academic and clinical demands of potential participants had to be considered owing to the COVID-19 pandemic (Sahu, 2020). As such, the chances of potential participants flagging the researcher's email as unsolicited or spam were much higher than usual under these circumstances. In total, 37 professionals were volunteered to participate in the e-Delphi panel and are described next.

4.5.1.3. Step 1.3: Description of professionals

Professionals contributed to two datasets in Step 1 and Step 3 of the Q-methodology process. As shown in Figure 4.2, professional opinions were obtained in Step 1 (i.e., concourse development, source 2, e-Delphi panel) and professionals performed the Q-sort in Step 4. The latter group of professionals are referred to as the P-set (McKeown & Thomas, 2013). For ease of reference, in describing the professionals, both sets of professionals are presented in Table 4.1.

Table 4.1: Description of professionals

		e-Delphi panel (N= 31)	P-set (N=33)
Gender	Female	23	29
	Male	7	4
	Prefer not to say	1	n/a
Years of experience	0-5 years	1	1
	6-10 years	4	7
	11-15 years	5	1
	16-20 years>	21	24
Region	Australia	2	1
	Brazil	1	1
	Canada	0	1
	Finland	1	0
	Germany	1	1
	Ireland	2	1
	South Africa	1	13
	Sweden	4	3
	United Kingdom	14	10
	United States	5	3
Profession	Speech-language therapy	17	25
	Psychology	8	3
	Nursing	1	0
	Other (communication technology, human rights, education)	5	5
Area of specialisation	AAC	11	19
	AAC and dementia	5	0
	Dementia studies	5	6
	Communication technology	*	2
	AAC, dementia and technology	0	1
	Other	11	5
Focus of work	Research	16	5
	Clinical work	0	6
	Research and clinical work	7	1
	Research and teaching	6	10
	Research, clinical work and teaching	0	10
	Other	2	1
Area of interest	Instrument development	2	2
	Adult cognitive-communicative disorders (general)	4	**
	Dementia-related communication (specific)	6	2
	Interpersonal interaction (general)	10	12
	Person-centred care	0	9
	Other (AAC technology)	9	1
****Patient population served**	Adults with acquired communicative disorders		16
	Children with disabilities		5
	Adults with acquired communicative disorders and children with disabilities		12

**This category was only specified for Step 4 (Q-sort)

In total, 31 professionals participated in the e-Delphi panel (response rate of 49%) and 33 performed the online Q-sort (response rate of 54%). Overall, the vast majority of these professionals were speech-language therapists (n= 17 and n=25 respectively) who specialised in the field of AAC (n=11; n=19). Professionals on the e-Delphi panel were primarily involved in research (n=16), followed by research and clinical work (n=7), and research and teaching (n=6). Professionals in the P-set were equally involved in research and teaching (n=10), and in a combination of research, clinical work and teaching (n=10). The main interests of the majority of professionals were interpersonal interaction (n=10 and n=12 respectively). Participants were geographically dispersed across ten countries, with the majority from the United Kingdom (n=14 in the e-Delphi panel) and South Africa (n=13 in the P-set). The professionals, mainly female, were overall well experienced, with work experience of between 16 and 20 years or more. Professionals' expertise focused on interaction with adults with acquired communicative disorders (n=16) or a combination of both adults and children with communication disabilities (n=12), while five participants focused primarily on interaction with children with disabilities only (n=5).

4.5.1.4. Step 1.4: Concourse development procedures

An invitation and informed consent letter was sent to each potential professional participant to inform them of the reason for conducting an e-Delphi panel, the purpose of the study, how their email addresses had been obtained, and what was expected of their participation as an e-Delphi panellist (see Appendix H).

The e-Delphi panel questionnaire (Appendix I) comprised two sections, namely the biographical information of professionals, and three open-ended questions related to the research topic:

i. AAC strategies and communication supports for PwD
ii. Person-centred care within AAC-supported interactions
iii. Outcomes to include in an AAC interpersonal interaction outcome measure for PwD

Open-ended questions ensured that professionals' responses were not prompted nor led by the researcher, and thus prevented response bias (Sinha, Smyth, & Williamson, 2011). Unlimited free text gave professionals the liberty to provide as much input as they preferred. Participants were asked a final question on whether they would consider continuing with the study in the Q-sort by ticking yes, maybe or no. The online questionnaire was developed on and administered via Qualtrics (www.qualtrics.com) as a dedicated online survey software program.

4.5.1.5. Step 1.5: Concourse development data analysis

e-Delphi panel data was downloaded from Qualtrics.com and analysed with qualitative data analysis software, ATLAS. ti^{TM} for MAC, version 8.4. The purpose of analysing the e-Delphi panel data was to contribute to the development of a set of statements to be ranked in the Q-sort (Step 3). Data was analysed using a combined inductive-deductive approach to content analysis (Fereday & Muir-Cochrane, 2006). Data was analysed for content that was observable and measureable to obtain a frequency count of instances in which codes occurred (Graneheim & Lundman, 2004). Codes were assigned deductively by assigning a pre-determined code extracted from the literature (i.e., literature-derived). Data that could not be assigned to a literature-derived code were created as a new code in an inductive manner (Fereday & Muir-Cochrane, 2006).

Coding of data took place in four waves. Firstly, the researcher coded the dataset independently several times. Next, an independent checker, a PhD student, checked the entire dataset for accurate application of the coding rules and appropriateness of coding categories and broad themes. Disagreements were discussed and agreement was reached on the final set of codes, categories and themes. Thirdly, the researcher re-coded the complete dataset twice to ensure all final coding was correctly applied. Finally, trustworthiness of the data coding was assessed by a second independent coder, a post-doctoral fellow in AAC, who coded a randomly selected portion of the dataset to assess inter-rater reliability of coding. Coding disagreements were discussed by re-examining the meaning unit in question and deliberating until consensus was reached.

The final themes used for the generation of the concourse are shown in Appendix J.

4.6. **Step 2: Q-set (Statements)**

The Q-set consists of statements derived from the concourse and ranked by each professional. Based on the themes developed in Step 1.5 (Par. 4.5.1.5), an initial set of 50 statements was generated by the researcher. Through an iterative process and in consultation with the supervisors of the study, the researcher reduced the statements to 37 preliminary statements which were piloted by two pilot testers as outlined in the section below.

4.6.1. Step 2.1. Piloting testing of the online Q-set

The preliminary 37 statements (Appendix K1) were ranked online on QMethod Software (Lutfallah & Buchanan, 2019), a computer-based Q-methodology application purchased by the researcher via a subscription package. The two pilot testers assessed the representativeness of the statements against the concourse and assessed the feasibility of ranking the statement on QMethod Software (Lutfallah & Buchanan, 2019). Both pilot testers were speech-language therapists: one was an AAC doctoral student with extensive experience of adult-acquired cognitive-communicative disorders, and the second was an AAC Master's student whose research is based on assistive technology and persons with dementia.

Cognitive interviews, considered to be best practice in testing survey content prior to its use, were used as a technique to improve the validity of the online Q-sort (Behr, Meitinger, Braun, & Kaczmierk, 2017; Howlett, McKinstry, & Lannin, 2017). The purpose of a cognitive interview is to understand the cognitive processes used by, in this instance, the pilot testers. Specifically, it explored the testers' (i) comprehension of the Q-sort questions, (ii) retrieval of information from memory, (iii) how they made their decisions and (iv) how they selected their final survey responses (Howlett et al., 2017). The cognitive interviews were conducted retrospectively. In other words, immediately after the pilot testers had completed their online Q-sorts, the researcher telephoned each pilot tester individually. Following guidelines by Howlett et al. (2017), the researcher used a combination of pre-planned and spontaneous verbal probes to ask the pilot testers questions. These questions related to the comprehension of each written question, how pilot testers arrived at answers, the clarity of statements, and the technical challenges experienced with the online platform. The researcher captured the pilot testers' responses on a table in Microsoft Word$^{©}$ 2016. Both sets of responses were integrated and utilised to inform revisions to the final Q-set. The findings of the cognitive interviews and adaptations that were made are summarised in Table 4.2. A final Q-set of 37 statements is evident in (Appendix K2).

Table 4.2: Piloting of the online Q-sort: Aim, procedures, findings and adjustments

Aim	*Procedures*	*Findings*	*Adjustments*
To determine whether biographical information was adequate.	The pilot testers were emailed a link to the online Q-sort.	Biographical information: • One question has two embedded sub-questions, namely population and area of interest.	• What is your area of interest within research, teaching or clinical work? • Which population does your research, teaching or clinical work focus on?
To assess the comprehensiveness of instructions.		• Reiterate the time required to complete the Q-sort Remind participants of the following: • The grid is forced-choice distribution. Provide an explain of what this means. • Clarify: one statement in one cell.	Instructions adjusted as follows: • “Rank the statements (from the pre-sorted piles) accordingly to a forced-choice distribution grid that contains 37 cells. This means each statement is placed individually into one cell on the grid (i.e., one cell=one statement).”
Statements: • To assess the representativeness of the statements against the concourse. • To identify the clarity of wording of statements.		• Two redundant statements were found. • There were too few statements on non-electronic and unaided AAC strategies. • Specific dementia severity was not stated. • Statements have high clinical utility. Clinicians should be invited as part of the Q-sorting. • Too few negative statements had been included. Pilot testers suggested to change some positive statements to negative ones, as there were too few statements to disagree with.	• Redundant statements were removed. • Dementia severity was inserted in specific statements. • Potential clinicians were recruited and added to the invitation list for the Q-sort in Step 3. • Ten positive statements were changed to negative statements.
To test the feasibility of online administration related to technicalities/ concerns/ participant code login, etc.	The two pilot testers conducted the Q-sorting on various devices (laptop, smart phone, desktop computer).	• None	• None

4.7. **Step 3: Q-sort (ranking of statements)**

In Q-methodology, the Q-sort refers to the process in which participants rank a set of statements according to a forced-choice distribution grid while considering all other statements. In this study, the Q-sort was facilitated electronically through QMethod Software (Lutfallah & Buchanan, 2019) and the results of the Q-sort data provided the main data Phase 3A of this study. Q-methodology does not enforce a priori meaning to the statements that are ranked (Watts & Stenner, 2005), which encourages participants to rate the significance of statements based on their unique perspectives.

4.7.1. Step 3.1: Q-sorting – general procedures

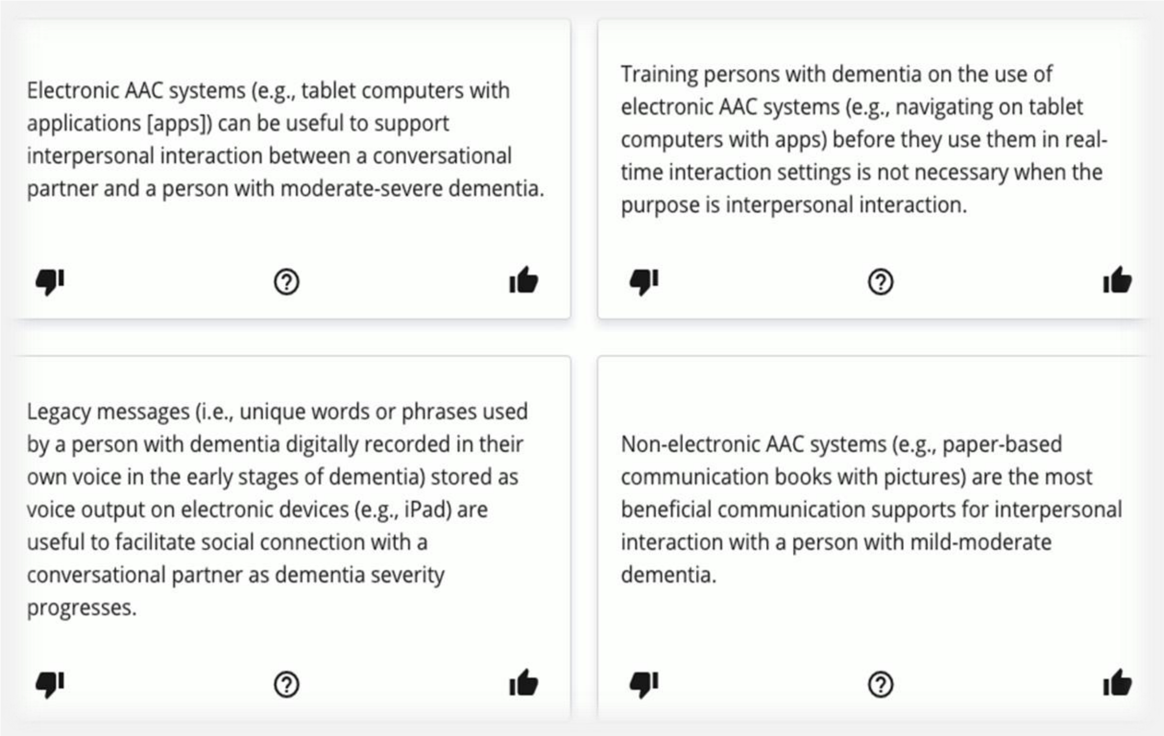
Given the low response rate from the e-Delphi panel (Par. 4.5.1.3), and based on recommendations from the pilot testers of the Q-sort (see Table 4.2), professionals who had not been invited to the e-Delphi panel were invited to participate in the online Q-sort. The same participant selection criteria as had been applied to the e-Delphi panel (Par. 4.5.1.1) were applied to professionals invited as the P-set. Potential professionals in the P-set were sent a letter of invitation (Appendix L) to state the purpose of the study, what was expected of them in the Q-sorting process and to inform them that their participation was voluntary. In total, 61 professionals were invited to participate as the P-set. The description of the P-set appears in Table 4.1.

For the online Q-sort administration, each professional was emailed a link to the online Q-sort as well as a unique participant login code. Upon clicking and entering the landing page on QMethod Software (Lutfallah & Buchanan, 2019), participants completed a biographical questionnaire, followed by detailed two-step Q-sorting instructions (Appendix M).

Professionals were able to start the Q-sort and continue at a later time if preferred. They had two weeks in which to complete the Q-sort, with a weekly reminder. During this time, there was an unexpected automatic upgrade to the software, and some professionals experienced technical difficulties in accessing their online Q-sort. Therefore, Q-sort data collection was extended for a further two weeks (i.e., four weeks in total).

4.7.2. Step 3.2: Q-sorting

The researcher electronically uploaded all 37 statements from the Q-set to the QMethod Software (Lutfallah & Buchanan, 2019). A 37-cell forced-choice distribution grid was automatically generated using QMethod Software (Lutfallah & Buchanan, 2019). The online Q-sort was undertaken in two steps in which professionals subjectively sorted and ranked the 37 statements. The first step entailed pre-sorting, where professionals divided the 37 statements into three piles and clicked on three icons to indicate their initial agreement, disagreement or neutrality toward each statement. An example of the pre-sort is shown in Figure 4.3.



Electronic AAC systems (e.g., tablet computers with applications [apps]) can be useful to support interpersonal interaction between a conversational partner and a person with moderate-severe dementia.

Training persons with dementia on the use of electronic AAC systems (e.g., navigating on tablet computers with apps) before they use them in real-time interaction settings is not necessary when the purpose is interpersonal interaction.

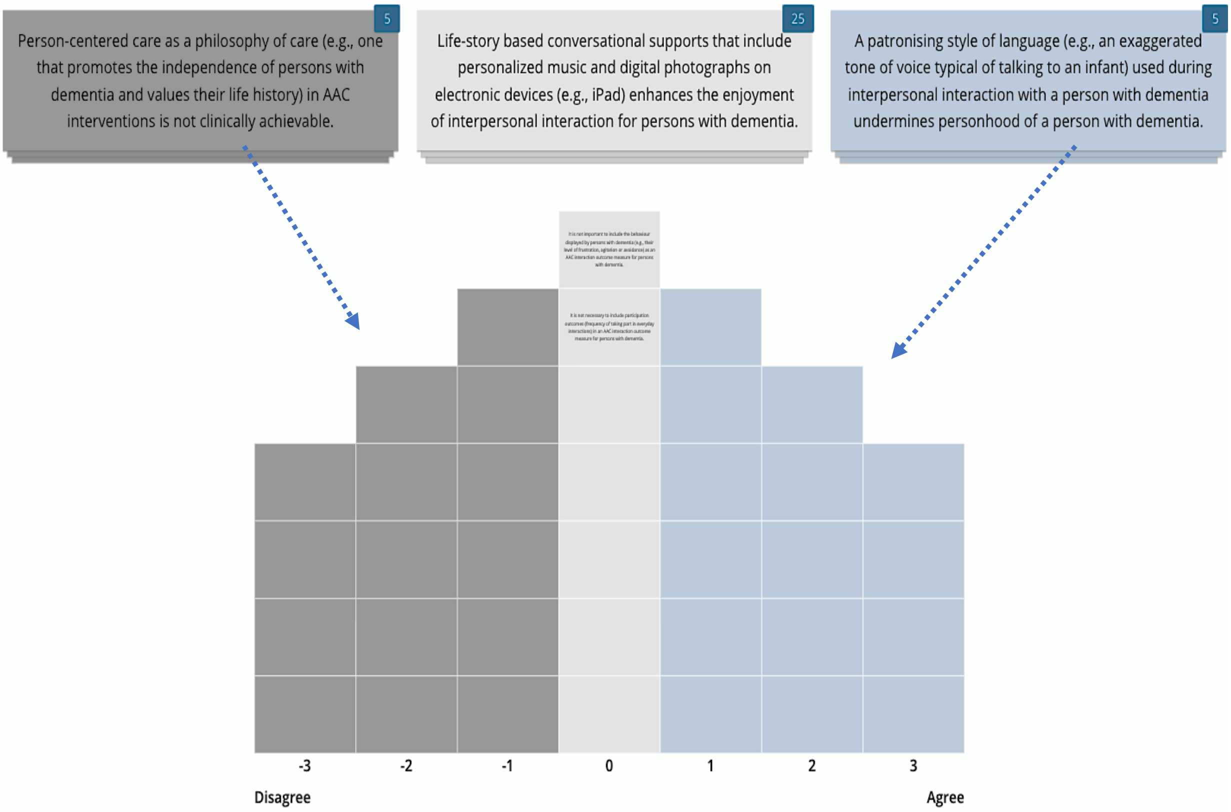
Legacy messages (i.e., unique words or phrases used by a person with dementia digitally recorded in their own voice in the early stages of dementia) stored as voice output on electronic devices (e.g., iPad) are useful to facilitate social connection with a conversational partner as dementia severity progresses.

Non-electronic AAC systems (e.g., paper-based communication books with pictures) are the most beneficial communication supports for interpersonal interaction with a person with mild-moderate dementia.

👍 (agree), 👎(disagree), ? (neutral)

Figure 4.3: Q-sort (pre-sorting statements) on QMethod Software

The second step was the final sorting, in which the pre-sorted statements were arranged according to a forced-choice distribution grid, based on a condition of instruction. This meant that professionals had to rank the statements based on how strongly they agreed with each statement. As shown in Figure 4.4., statements could be dragged from the top panel of pre-sorted piles into the extreme right-hand side of the distribution grid to be ranked as strongly agree (+3). The converse was inferred to statements on the extreme left-hand side, ranked as strongly disagree (-3). Those statements with no definitive agreement were dragged and dropped in the middle of the distribution grid as a 0 (neutral) view. This final sorting step aimed to capture each professional's unique views of the statements and, based on the premise of subjectivity, there were no right or wrong answers.


Person-centered care as a philosophy of care (e.g., one that promotes the independence of persons with dementia and values their life history) in AAC interventions is not clinically achievable.

Life-story based conversational supports that include personalized music and digital photographs on electronic devices (e.g., iPad) enhances the enjoyment of interpersonal interaction for persons with dementia.

A patronising style of language (e.g., an exaggerated tone of voice typical of talking to an infant) used during interpersonal interaction with a person with dementia undermines personhood of a person with dementia.

It is not important to include the behaviour displayed by persons with dementia (e.g., their level of frustration, agitation or avoidance) as an AAC interaction outcome measure for persons with dementia.

It is not necessary to include participation outcomes (frequency of taking part in everyday interaction) in an AAC interaction outcome measure for persons with dementia.

Figure 4.4: Q-sort (final sorting of statements) on QMethod Software

The online Q-sort on QMethod Software (Lutfallah & Buchanan, 2019) required from professionals to drag the pre-sorted statements and drop them into a cell on the forced-choice distribution grid. This meant that only one statement was permitted in one cell. Consequently, professionals were free to swop and re-rank the statements based on their unique subjectivities as many times as they wished before making a submission. This could be time consuming and perhaps cognitively complex for professionals, which are common limitations of Q-methodology. All completed Q-sort data was automatically captured on QMethod Software (Lutfallah & Buchanan, 2019) and at the end of data collection, factor analysis was performed as is detailed in the next section.

4.8. Factor analysis

In Phase 3A, factor analysis of Q-sort data was facilitated on QMethod Software (Lutfallah & Buchanan, 2019), which enabled the automatic process of Q-data input, correlation of factors, factor rotation, and the process of factor extraction. In this study, a factor was defined as a group of professionals whose completed Q-sorts shared a similar point of view on the components of the PC-AAC package for PwD developed in this study.

Person-by-person factor analysis was employed as a data reduction method (Watts & Stenner, 2012) to sort data into factors. Factor analysis was based on Q-sort data and a synopsis of how the final Q-sorts were determined is presented in Table 4.3.

Table 4.3: Synopsis of Q-sort data

Q-sorts	**Number (N=61)**	**Percentage**
Sent to professionals	61	100%
Not initiated	18	29%
Initiated but not completed	10	10%
Completed and submitted for factor analysis	33	54%
• Average time to complete Q-sort 29 minutes 26 seconds		

As shown in Table 4.3, 61 potential professionals were invited to participate in the online Q-sort. They had to subjectively arrange 37 statements (see Par. 4.7.2) according to an agreement scale ranging from strongly agree (+3) to strongly disagree (-3). The statements related to various components of a PC-AAC intervention for PwD (see Chapter 3, Par. 3.2). Eighteen of the professionals (29%) did not initiate their online Q-sort, while 10 (16%) initiated the Q-sort, but did not complete the sorting process. A total of 33 professionals (54%) took an average time of 29 minutes 26 seconds to complete and submit their Q-sort. The Q-sort data of these 33 professionals was analysed using factor analysis.

Factors were extracted and analysed by utilising the in-built statistical tools on QMethod Software (Lutfallah & Buchanan, 2019). The analysis of factors in Q-methodology refers to the application of statistical techniques to determine the patterns of viewpoints and to explain the maximum variances in professionals' Q-sort data (Watts & Stenner, 2005). Factor rotations were performed to maximise the explained variance between Q-sorts. QMethod Software (Lutfallah & Buchanan, 2019) offered various options as factor rotation techniques. However, in line with the purpose of this study, Varimax rotation was selected to statistically explain the maximum range of variances shared by the professionals. This eliminated human error and contributed to the reliability and ease of visual inspection of factor analysis results.

Following factor rotation, factor loadings were automatically generated from QMethod Software (Lutfallah & Buchanan, 2019) and examined for their significance. In this study,

$p<0.5$ was used to determine the significance of a factor loading and was calculated as 0.42, based on the recommended equation by McKweon (2013):

$$2.58\, x \frac{1}{\sqrt{N}} \quad \text{where N represents the number of Q-sorts in the study.}$$

Therefore, in this study, the significance level of factor loadings was $2.58\, x \frac{1}{\sqrt{37}} = 0.42$.

4.9. Phase 3B: Case study

The aim of Phase 3B was to assess the feasibility of implementing the electronic life story co-produced with a person with dementia (see Par. 3.3 and 3.4). The threefold purpose of Phase 3B (aligned to sub-aim i*v* of the main study) was as follows:

i. Assess the procedural reliability of implementing the electronic life story conversational support in a real-life context with a person with moderate to severe dementia and the researcher as the conversational partner.
ii. Determine the self-reported enjoyment of a participant with dementia in using the electronic life story conversational support with the researcher (see Par. 3.5.1).
iii. Assess the reliability of scoring the outcome measure, i.e., AACOM-PwD (see Par. 3.6.1).

In order to meet the aims of Phase 3B, a case study design was employed. Yin (2011) describes a case study as an empirical enquiry that investigates a single case or multiple cases within a real-life context, using multiple data sources and data analysis methods. Based on Yin's (2011) perspective, a single case study was found to be an appropriate method to achieve the threefold purpose of Phase 3B.

Furthermore, a case study allowed for a detailed description of the process of co-producing a life story conversational support for a specific person with dementia. This process was explained in Par. 3.3. In the section that follows, the selection criteria, recruitment and description of the case study participant are outlined, and ethical considerations for data collection procedures are detailed.

4.10. Phase 3B: Participants

The recruitment of participants and the sampling method used, the criteria for selectin participants, details of the participants, as well as the recruitment site are described next.

4.10.1. Recruitment of participants and sampling

A non-probability, purposeful sampling method was used to recruit participants for the case study in Phase 3B. This sampling technique is time efficient, economical and assures that the data obtained is representative of the case population under investigation (McMillan & Schumacher, 2014).

Dementia-specific organisations were sought to retrieve a database list of dementia care homes (i.e., old age homes, adult day-care facilities and frail care facilities that cater for persons with dementia) in the Western Cape. This geographical location was convenient for and accessible to the researcher.

Six organisations were telephoned, but only one expressed any interest in the study. The Head Nurse of an organisation for the aged was sent an email to request permission (Appendix N) to recruit participants from their organisation. Permission was granted to recruit participants from five of their satellite dementia care homes within the Cape Town Metropole. Following written permission from the organisation for the aged (Appendix N), the nursing manager at each of the five care homes provided the details of potential participants' next of kin or legal guardian within their memory care unit. Furthermore, a recruitment flyer was placed in the common lounge area of each dementia care home, for distribution to visiting family members. Nursing staff assisted in reading an adapted recruitment flyer (Appendix O) to potential participants (i.e., persons with dementia).

The researcher sent an email with an attached letter of information (Appendix P) to the legal guardians of 12 potential participants. One legal guardian expressed interest in the study. A three-step informed consent process was employed to obtain the participation of a person with dementia in the current research (Murphy, Gray, & Cox, 2007).

i. Firstly, the purpose of the research study was explained in an email to the potential participant's legal guardian which contained a letter of information (Appendix P). The legal guardian granted informed consent by signing and returning the informed consent reply form (Appendix P). The legal guardian identified a potential familiar conversational partner to participate in the study and provided the details of an identified individual for the researcher to contact personally. The researcher made telephonic contact with the familiar conversational partner before a letter of information (Appendix Q) and a biographical questionnaire (Appendix U2) were delivered by hand. The familiar conversational partner agreed to take part in the study by signing the informed consent form (Appendix Q).

ii. Secondly, the researcher met the potential participant personally at the dementia care home to explain the purpose of the study by reading an adapted letter of information (Appendix R) to request informed consent. The researcher supported the informed consent process by using AAC strategies such as simplified keywords and pointed to pictures on the letter while reading each sentence (Appendix R). AAC strategies were employed to aid the potential participants' understanding of the recruitment process. Informed consent was provided by one person with dementia who verbally expressed a 'yes' in response to three informed consent statements which the researcher recorded on an informed consent reply form (Appendix R). The participants' informed consent was validated under the observation of a nurse at the dementia care home to ensure that the participant provided voluntary informed consent. An observer-to-informed-consent form was accordingly signed by the nurse (Appendix S).

iii. Thirdly, the researcher abided by a process of ongoing consent to re-establish the participants' willingness to participate in the study at every instance of interaction with the researcher (Dewing, 2008a; Slaughter, Cole, Jennings, & Reimer, 2007). An ongoing informed consent form (Appendix T) making use of picture symbols was used to support the participant in providing ongoing informed consent. If the participant showed signs of transient fatigue or refusal to participate on any particular day during the recruitment and subsequent interactions, the recommendations by Slaughter et al. (2007) were followed:

   - The researcher ensured that the participant was made to feel comfortable by addressing the immediate signs of distress and thereafter requesting their permission to proceed.
   - If consent was declined, the study was suspended for that day.
   - Dissent to participate in the study was confirmed if the participant was approached on a different day and participation was refused.
   - Accordingly, the participant's involvement in the research study would be terminated.

One participant who was eventually recruited – along with her familiar conversational partner – to participate in the case study was selected based on the participant selection criteria outlined below.

4.10.2. Participant selection criteria

Table 4.4 outlines the selection criteria of the participant who was recruited for the case study in Phase 3B.

Table 4.4: Selection criteria for person with dementia as case study participant

Criteria	Justification	Measure
Older adults (60 years+)	Age is a chief risk factor for developing dementia (American Psychiatric Association [APA], 2013).	Biographical questionnaire Par. 4.11.2.1, Appendix U
Degenerative dementia of mild, moderate or advanced severity without co-morbid conditions	A medically documented or probable diagnosis of Alzheimer's Disease (AD). Alzheimer's dementia is the most common degenerative dementia subtype (APA, 2013). Participants with the same dementia subtype will ensure homogeneity in behavioural and communication characteristics.	i) Biographical questionnaire Par. 4.11.2.1, Appendix U (ii) Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) to describe the clinical stage/severity of dementia Par. 4.11.2.2.
Dementia-related communication difficulties	Specific language and communication difficulties are apparent in persons with mild and moderate dementia.	Dementia Communication Difficulties Scale (Murphy & Gray, 2007) Par. 4.11.2.4.
English as first language	The co-produced electronic life story conversation will be conducted in English.	Biographical questionnaire Par. 4.11.2.1, Appendix U
Functional hand mobility	Participants need to navigate the AAC device.	Manual Ability Classification System (MACS) (Eliasson et al., 2006) Par. 4.11.2.3.
Functional vision	Participants must be able to see the picture symbols on the AAC device.	(i) Biographical questionnaire Par. 4.11.2.1, Appendix U (ii) Participants will be requested to wear their prescription reading glasses if applicable.

The familiar conversational partner was recruited for the purpose of assisting the participant to select photographs for Component 1 of the PC-AAC intervention package (see Par. 3.4.1.1). The selection criteria for this partner are shown in Table 4.5.

Table 4.5: Selection criteria for familiar conversational partner

Criteria	Justification	Measure
Adult, who is familiar with the participant with dementia	An adult (spouse, adult child, family member, friend, professional carer) who has background knowledge of the participant's life history to assist the participant in selecting materials for the co-produced electronic life story conversational support (Kindell et al., 2014).	Biographical questionnaire Par. 4.11.2.1, Appendix V
Proficiency in English	All procedures relating to the co-production of the electronic life story conversational support will be performed in in English.	Biographical questionnaire Par. 4.11.2.1, Appendix V

4.10.3. Participant description

4.10.3.1. Participant with dementia

The participant with dementia was a 77-year-old female, with probable Alzheimer's Disease. She had been a highly skilled speech and drama specialist who studied music, film and theatre professionally at an international institution. The participant was recently widowed as her husband had died soon before she moved into the dementia care home. She shared a close bond with her only daughter, who was also her legal guardian. There were no reported concerns about her hearing. The participant had recently visited an optometrist for a new pair of prescription spectacles. Medically, the participant was on chronic diabetic medication for Type 1 Diabetes. She obtained a total score of 7/30 on the MoCA (Nasreddine et al., 2005), which described her as a case of moderate to severe dementia (Chang et al., 2012). She scored 19/39 on the Dementia Communication Difficulties Scale (DCDS) (Murphy & Gray, 2007) which rates her communication difficulties in the upper range of moderate stage dementia.

The participant experienced difficulty with understanding information presented to her verbally, struggled to maintain a conversational topic and always substituted content words with empty words (e.g., thing). The participant's ability to handle objects in daily activities was categorised as Level II on the MACS (Eliasson et al., 2006). She was left-handed and was observed to have a slight weakness of her wrist due to possible age-related osteoarthritis. This appeared to reduce the speed and accuracy of her hand movements and she was observed to require assistance in independently performing certain actions that required a firm hand grip. She was able to walk independently but preferred to be pushed in a wheelchair inside the care home due to fatigue induced from walking a distance.

4.10.3.2. Familiar conversational partner

The familiar conversational partner had a longstanding relationship with the participant and her family. She had worked at the family's residence for five years. Since the participant moved into the dementia care home, the familiar conversational partner was employed privately by the participant's family. She spent eight hours a day with the participant at the dementia care home for six days a week. The familiar conversational partner was also responsible for attending to the participant's personal care needs (e.g., driving her to doctor's appointments). The familiar conversational partner was a highly proficient second language English speaker.

4.10.4. Description of recruitment site

The case study was undertaken at a dementia care home which is part of a multilocation organisation that specialises in care residences for the elderly. This care home, which had a designated memory care unit in which persons with dementia were residents, was geographically located in an urban area in the Cape Town metropole. The majority of the population residing in this area are typically professionals and are classified as high-income households.

Within the dementia care home, all residents had their own private rooms. All research procedures involving the participant were undertaken in her private room. There was a common area in which all residents' meals were served meals and where they participated in joint activities such as music therapy and art and crafts. The dementia care home was a large, multistorey building with a garden, and a coffee shop in which residents often met their visitors if preferred.

4.11. Materials

The material related to the permission and informed consent letters, screening materials and data collection are described below.

4.11.1. Materials used for permission and informed consent

4.11.1.1. Recruitment flyer

The recruitment flyer was used to invite potential legal guardians and potential participants (Appendix O). The recruitment flyers contained an invitation for potential participants, together with the contact details of the researcher.

4.11.1.2. Permission letter to the dementia care home

The permission letter (Appendix N) was addressed to the manager of the dementia care home and contained information on the purpose of the study, a request to distribute recruitment flyers at the dementia care home, and permission to use the premises as a research site to recruit participants. The permission letter detailed how data was to be collected from participants and how it would be securely stored. It also confirmed that details of the dementia care home would remain confidential. A signed permission reply slip (Appendix N) was requested from the dementia care home to indicate their granting or refusal of permission to conduct the study at the site.

4.11.1.3. Letter of information and informed consent: Legal guardian or next of kin

This letter contained the purpose of the study and requested the legal guardian’s consent to approach the potential participant to invite their participation in the study. The letter also requested consent to utilise the participants’ personal photographs in the electronic life story conversational support, to identify a familiar conversational partner to assist the potential participant in selecting photographs, and consent to have all interactions between the researcher and participant video-recorded. The letter stated that all information would be kept confidential and be stored electronically in password-protected files at the Centre for AAC at the University of Pretoria for 15 years. Additionally, the letter assured participants’ voluntary participation and confirmed the protection of their identity. The legal guardian acknowledged understanding of the contents of the letter, and indicated their informed consent on a reply slip (Appendix P).

4.11.1.4. Letter of information and informed consent: Familiar conversational partner

The letter to the participants’ familiar conversational partner (Appendix Q) stated how they were identified as a potential participant in the study, the purpose of the study and the role they would play, should they take part in the study. Details of their voluntary participation and withdrawal from the study at any point were also stated in the letter. A signed reply slip indicating their informed consent to take part in the study was essential for their participation in the study (Appendix Q).

4.11.1.5. Letter of information and informed consent: Participant

Since the letter of information was adapted for the participant, it contained simple language. The information was presented in written text with picture symbols to support the participant in understanding the purpose of the study, how data was to be collected and stored, and that all interactions with the researcher were to be video-recorded (Appendix R). The adapted letter stated that participation in the study was voluntary, the participant could withdraw from the study without giving a reason and all personal information would remain confidential and be stored securely at the centre for AAC for 15 years. The adapted reply slip consisted of written text and pictures (Appendix R).

4.11.1.6. Observer to informed consent

This form included a tick box in which an observer had to tick a yes or no response related to whether they felt the participant provided voluntary consent without being coerced into taking part in the study, and understood what was expected of them in the study (Appendix S). The form included a section in which the observer could include additional written comments.

4.11.1.7. Ongoing informed consent form

For ease of administration of the ongoing informed consent procedures, the form was adapted into a booklet (Appendix T) that included picture symbols and options for the participant to provide verbal, or gestural responses by pointing to symbols to indicate ‘yes’ or ‘no’. The ongoing informed consent form contained questions that reminded the participant of the purpose of the study, that they could take a break if they felt tired and that they could stop at any time. It also asked whether they were still happy to continue with the research.

4.11.2. Materials used for screening procedures

4.11.2.1. Biographical questionnaires

The participant’s biographical questionnaire contained information describing the participant’s personal details, such as age, date of birth, gender, sensory functioning, highest educational qualification, previous occupation, and marital status (Appendix U). Likewise, descriptive information from the familiar communication partner was also obtained by means of a separate biographical questionnaire (Appendix V).

4.11.2.2. Montreal Cognitive Assessment

The Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) was used as a standardised cognitive screening tool to describe the participant’s dementia severity. The MoCA is indicated for research in older adults and has demonstrated high reliability ($r=0.92$), high concurrent validity ($r = 0.87$) and high internal consistency ($a = 0.83$) (Nasreddine et al., 2005). The MoCA consists of 12 cognitive tasks related to visuospatial/executive functioning, naming, attention, language, abstraction, memory, and orientation. The severity of dementia was described by calculating a total score range out of 30, with 14-23 indicating mild dementia and 8-13 indicating moderate dementia (Chang et al., 2012).

4.11.2.3. Manual Ability Classification System

The Manual Ability Classification System (MACS) (Eliasson et al., 2006) was used as a tool to classify the participant's ability to use her hands in daily activities. The researcher asked questions to the familiar conversational partner as well as to care staff at the dementia care home regarding the participant's ability to handle objects in everyday activities. This descriptive information was used to assess the participant's ability to press the navigational tabs on the AAC device.

4.11.2.4. Dementia Communication Difficulties Scale

The Dementia Communication Difficulties Scale (DCDS) (Murphy & Gray, 2013) was used as a simple screening tool to obtain descriptive information about the specific communication difficulties experienced by the participant. The scale was completed by the familiar conversational partner, who descriptively rated the participant's communication difficulties on a 5-point option scale (never, sometimes, often, always, says too little for me to know). A score was assigned to 13 statements judged from the familiar conversational partner's perspective as follows: 0 (never); 1 point (sometimes); 2 points (often); 3 points (always) or 4 (says too little for me to judge). The tallied score ranges describe the communication difficulty in an associated stage of dementia: 0-10.5 (early stage); 11-19.5 (moderate stage); 20-39 (late stage).

4.11.3. Materials used during data collection

4.11.3.1. Procedures Checklist (Baseline Phase)

The Procedures Checklist (Baseline Phase) (Appendix W) consisted of five main steps related to venue set-up, greetings and introduction to each session, no scaffolding of the life story interpersonal interaction, closure, and obtaining of the participant's perspective. A score of 1 was obtained for a 'yes' (step implemented) and 0 for a 'no' (step omitted). Each step had sub-steps which tallied to give a score out of a total of 16 steps. A script for the baseline phase was embedded in this checklist to ensure the researcher delivered the greetings, introduction and closure consistently.

4.11.3.2. Procedures Checklist (Intervention Phase)

The Procedures Checklist (Intervention Phase) (Appendix X) also comprised five main steps with specific sub-steps related to equipment and set-up, greetings and introduction, AAC device familiarisation, application of PC-AAC scaffolding strategies, and obtaining the participant's perspective. A semi-structured script for the intervention phase was embedded in this checklist to guide the researcher's consistency in the greetings, introduction, and performing a familiarisation procedure of the AAC device. One point was scored to indicate 'yes' (step implemented) or zero for 'no' (step omitted). There was a total of 33 steps, 20 of which were assigned to the researcher's application of the PC-AAC scaffolding strategies in the intervention phases. A minimum of five life story sentences were included in each life story topic. A score was assigned each time the researcher applied the PC-AAC scaffolding with the use of the electronic life story conversational support.

4.11.3.3. AAC Outcome Measure for Persons with Dementia

The Augmentative and Alternative Communication Outcome Measure for PwD (AACOM-PwD), which was developed by the researcher (see Par. 3.6.1), consists of four turn taking domains categorised as Verbal turns (V), Gestural turns (G), Aided turns (A) and Multimodal turns (MM). Each of the four turn taking domains is divided further into eleven sub-domains to specify the type (form) of turn taking within the respective domain (Appendix F2). The AACOM-PwD is used as an observational tool by watching video-recorded interpersonal interactions between the researcher and participant. One point is assigned for each of the turn taking responses at a sub-domain level. Scores are then tallied at a domain level and a total score is tallied for the total turns (Appendix F1). The video-recordings were utilised by the researcher and the independent rater, for obtaining intra-rater and inter-rater scores respectively. Further information of the video-recordings and the interpretation of video-recorded data are found in Par. 4.13.2 and Par. 4.13.3 respectively.

4.11.3.4. Stakeholder Perspective Checklist

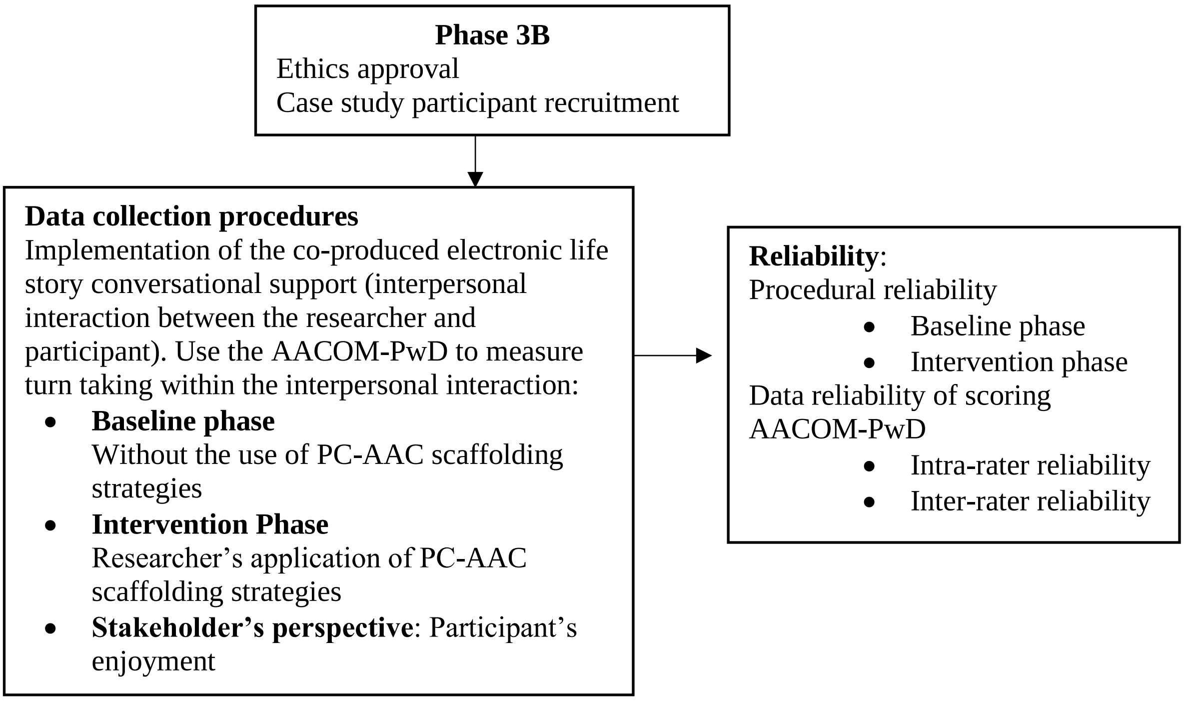
The Stakeholder Perspective Checklist (Appendix Y) contained two questions that helped the researcher to determine the participant's enjoyment of using the electronic life story conversational support. The two questions on the form were: *Did you enjoy talking about your life story today?* and *Did you enjoy talking about the life story a little or a lot*? The questions had corresponding picture symbols on cards to support the participant to express her responses.

4.11.4. Equipment

Video recording equipment included two Canon Legaria HF-R806 digital camcorders mounted on a tripod stand, back-up SD memory cards and camera batteries. These were used in the baseline, and intervention phases.

4.12. Phase 3B: Procedures

Data collection commenced once ethical approval (Appendix G1), permission from the dementia care home (Appendix N) and relevant informed consent from the legal guardian (Appendix P), participant (Appendix R) and familiar conversational partner (Appendix Q) had been obtained. An overview of the data collection procedures, and procedural and data reliability in Phase 3A is schematically depicted in Figure 4.5.



Phase 3B
Ethics approval
Case study participant recruitment

Data collection procedures
Implementation of the co-produced electronic life story conversational support (interpersonal interaction between the researcher and participant). Use the AACOM-PwD to measure turn taking within the interpersonal interaction:

- **Baseline phase**
  Without the use of PC-AAC scaffolding strategies
- **Intervention Phase**
  Researcher's application of PC-AAC scaffolding strategies
- **Stakeholder's perspective**: Participant's enjoyment

Reliability:
Procedural reliability
  - Baseline phase
  - Intervention phase

Data reliability of scoring AACOM-PwD
  - Intra-rater reliability
  - Inter-rater reliability

Figure 4.5: Schematic representation of Phase 3B data collection procedures and reliability

4.12.1. Data collection procedures

As shown in Figure 4.5, the main purpose of data collection in Phase 3B was to implement the electronic life story conversational support with the participant in a baseline phase and later in an intervention phase. In doing so, data collection allowed for the assessment of procedural reliability of implementing the electronic life story conversational support (Component 2 of the PC-AAC intervention for PwD), as well as for the assessment of data reliability of scoring turn taking on the AACOM-PwD. Additionally, data on the participant’s self-reported enjoyment of using the electronic life story conversational support was obtained. Data collection commenced when the researcher administered the MoCA (Nasreddine et al., 2005) screening tool with the participant and obtained observational information using the MACS (Eliasson et al., 2006).

The familiar conversational partner completed her own biographical questionnaire, assisted in completing the participant’s biographical questionnaire and completed the rating of the participant’s communication on the DCDS (Murphy & Gray, 2007). Thereafter, the co-production process of the PC AAC intervention for PwD was conducted according to the details described in Sections 3.3 and 3.4. All data was collected in the participant’s private room at the dementia care home. All sessions were video-recorded for data analysis. The video recording equipment was set up on each day of data collection prior to the participant entering the room. Two cameras were used so as to obtain footage of front and rear views of the interpersonal interactions between the participant and the researcher. The participant was brought into her room by the familiar conversational partner. Upon arrival, the participant was welcomed and made to feel comfortable before the process of ongoing consent was followed (see Par. 4.10.1). Data collection followed a specific sequence beginning with three baseline sessions and was followed by six intervention sessions described in the section below.

4.12.2. Baseline phase

The baseline phase entailed three consecutive days of data collection before the intervention began. The researcher and the participant engaged in a 10-minute interpersonal interaction using her electronic life story conversational support as developed in Par. 3.4. At baseline, the researcher responded to the participant in a neutral manner (e.g., “*Hmm”*) and the use of agreement or disagreement vocabulary was avoided. Furthermore, there was no familiarisation procedure on the use of the electronic life story conversational support, nor application of the scaffolded PC-AAC strategies by the researcher. During the baseline phase, interpersonal interaction was measured and scored with the AACOM-PwD developed in this study.

4.12.3. Intervention with PC-AAC scaffolding strategies

The intervention phase was implemented over six non-consecutive days, with an interval allowed on every alternative day. In this phase the researcher implemented the electronic life story conversational support according to the prescribed intervention protocol outlined in Par. 3.4.2.2. Similar to the baseline phase, interpersonal interaction was measured and scored using the AACOM-PwD as developed in Par. 3.6.1.

4.12.4. Stakeholder perspective

At the end of each baseline and intervention phase session, the participant's self-reported enjoyment of using the electronic life story conversational support was obtained. The researcher adhered to the Stakeholder Perspective checklist (Appendix Y) and asked the participant two questions related to her enjoyment of using the electronic life story conversational support. The researcher supported the conversation by using multimodal AAC strategies. She pointed to the written text of each question, used pictures to support the participant's understanding of the question, and expanded on the participant's responses that were supplemented with gestures (e.g., head nodding to indicate yes). The researcher also had three option cards available with picture symbols indicating 'yes', 'no' and 'not sure' to which the participant could point to indicate her responses (Appendix Y). These conversations were video-recorded and transcribed by the researcher to obtain qualitative data on the participant's self-reported enjoyment.

4.13. Reliability

Reliability refers to evidence that procedural reliability of implementing the electronic life story conversational support was maintained in the baseline and intervention phases in Phase 3B of this study, and that data on the AACOM-PwD was scored reliably by an intra-rater and inter-rater. A schematic illustration of the reliability of findings in this study was depicted in Figure 4.4.

4.13.1. Procedural integrity

Procedural integrity was evaluated for the procedures applied in the baseline phase as well as in the intervention phase. The researcher rated all video recordings for procedural integrity. An independent speech therapist who served as the inter-rater independently rated 33% (Schlosser, 2003) of sessions in the baseline and intervention phases by completing the respective procedural checklists (Appendix W and Appendix X).

4.13.1.1. Procedural integrity of the baseline phase

To ensure procedural integrity in the baseline phase, the researcher evaluated the procedures by using a Procedural Checklist (Baseline Phase) (Appendix W). One point was scored to indicate ‘yes’, the step had been implemented, and a zero was given to indicate the step had been omitted. There were a total number of 16 steps in each baseline session. Procedural integrity was expressed as a percentage by using the formula developed by Kuoch and Mirenda (2003, p. 222):

$$\frac{\text{Number of correct steps executed by the researcher}}{\text{Total number of possible steps}} \text{ x } 100$$

4.13.1.2. Procedural integrity in the intervention phase

Procedural integrity as adhered to by the researcher was evaluated by marking off the steps in the Procedural Checklist (Intervention Phase) (Appendix X). This required the participant to have been familiarised with the AAC device before the life story interpersonal interaction was implemented and ensured that the PC-AAC scaffolding strategies were applied by the researcher. Procedural integrity was also calculated by using the above formula of Kuoch and Mirenda (2003, p. 222).

4.13.2. Data reliability: Scoring the AACOM-PwD

Data reliability for scoring the AACOM-PwD (outlined in Par. 3.6.1) was deemed to be an important gauge of whether the outcome measure would be a reliable tool to measure turn taking during interpersonal interaction with a person with dementia. Data reliability was assessed through the scoring agreement reached at different points in time by the same rater (intra-rater) and by different raters (inter-raters) (Zapf, Castell, Morawietz, & Karch, 2016).

4.13.3. Intra-rater reliability

Intra-rater reliability was assessed by scoring the AACOM for PwD immediately after the sessions in the baseline and intervention phases, and again after a one-month interval. Scoring was performed a month apart to prevent scoring recall and carryover effects. The researcher watched the same video recordings and scored turn taking in the same way by using the turn taking coding scheme (Appendix F1) and operational definitions (Appendix F2) of AACOM for PwD. Raw scores were obtained at both a domain and a sub-domain level of the AACOM-PwD. The researcher generated two sets of intra-rater reliability raw scores which were compared on a point-by-point rating. Percentage agreement between intra-rating 1 and intra-rating 2 was calculated as follows (Tawney & Gast, 1984):

$$\frac{\text{Number of agreements}}{\text{Number of agreements + disagreements}} \times 100$$

A mean percentage of intra-rating agreement was then determined at a domain level (e.g., verbal turns) and at a sub-domain level (verbal turns with vocalisations).

4.13.4. Inter-rater reliability

An independent rater, a post-doctoral researcher in AAC registered as a Speech-Language Therapist with the Health Professions Council of South Africa, served as the independent rater. She had more than fifteen years of clinical experience of working with children and adults with severe communication disabilities. The independent rater was given a coding manual with operational definitions of the AACOM-PwD (Appendix F2). The researcher trained the independent rater on how to perform observational coding procedures using one video recording from the case study. The independent rater practised the coding and the researcher answered questions and provided further guidance before final independent scoring commenced. The rater was provided an electronic version as well as a hard copy of the AACOM-PwD to perform scoring. She randomly selected 33% of the video recordings in the baseline phase and 33% of the video recordings in the intervention phase (i.e., two intervention sessions), to score turn taking with the AACOM-PwD. This met the recommended criterion of 20-40% for inter-rater reliability set by Schlosser (2003). Inter-rater reliability was assessed by comparing the scores obtained by the researcher and the independent rater on the randomly selected video recordings. Percentage agreement was calculated by using the previously stated calculation by Tawney and Gast (1984) in Par. 4.13.3.

4.14. Data analysis

Raw data generated from procedural integrity and data reliability from scoring the AACOM-PwD was captured on a Microsoft Excel© 2016 spreadsheet. Although Cohen's Kappa was considered to be a suitable statistical measurement of the level of intra-rater and inter-rater agreement of turn taking data, a case study with one participant did not meet the minimum sample size of two participants for statistical interpretation of reliability results (Bujang & Baharum, 2017). Percentage agreement scores were tabulated and described descriptively. The participant's self-reported enjoyment elicited from supported conversations with AAC strategies were video-recorded and transcribed by the researcher. This generated qualitative data on the participant’s self-reported enjoyment which was described descriptively.

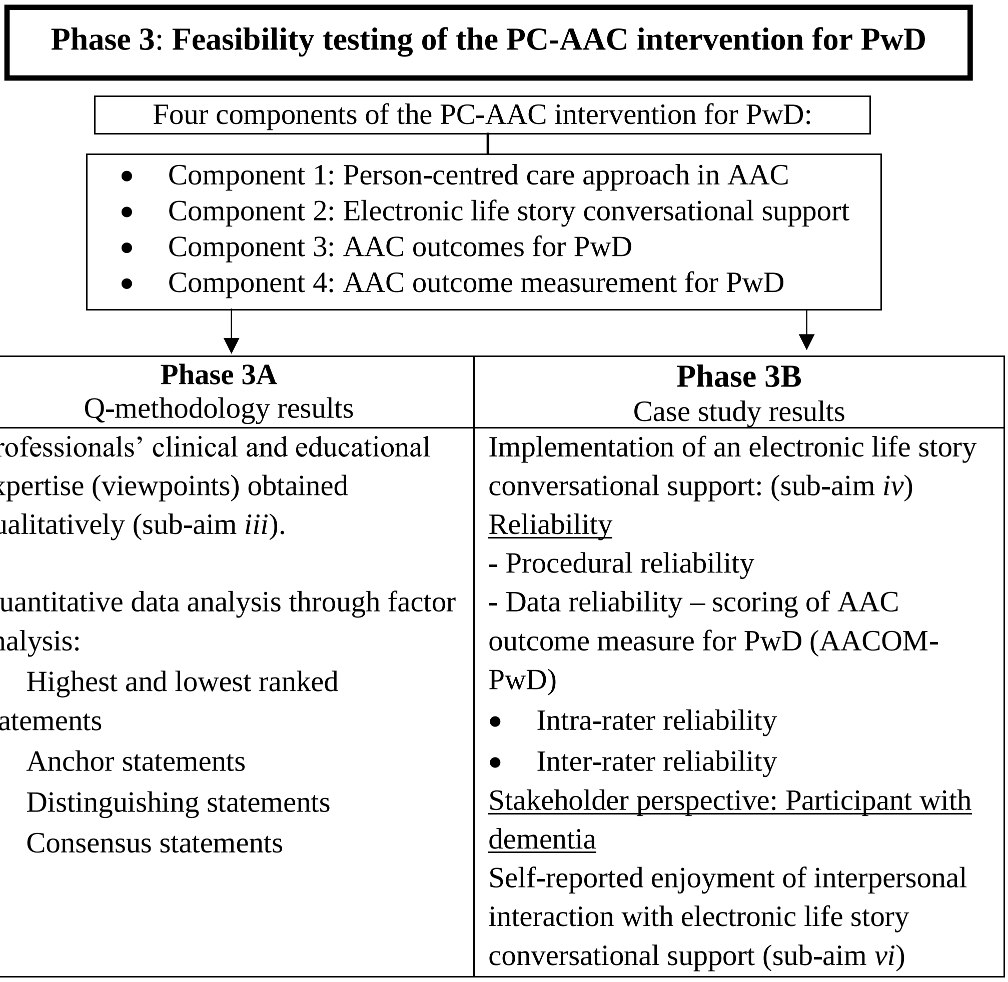
4.15. Summary

This chapter discussed the research methodology employed in this study. The main aim and sub-aims were presented, followed by an outline of the overall multimethod research design, and the three research phases. Research Phase 3 (feasibility testing) was next detailed in two parts in this chapter. Phase 3A detailed the four steps involved in Q-methodology. Each step was described separately by outlining concourse development with an e-Delphi panel, selecting a set of statements, the online ranking of the statements, and factor analysis. Phase 3B described the participant with dementia involved in the case study, the setting in which in-person data collection took place, the recruitment materials utilised, data collection procedures followed and reliability in implementing two components of the PC-AAC intervention for a PwD.

CHAPTER 5: RESULTS

5.1. Introduction

In this chapter, the results of Phase 3 of the main study are presented in two parts, namely in Phase 3A and Phase 3B. First, a description of terms is presented. Phase 3A reports on professionals' viewpoints regarding the four components of the PC-AAC intervention for PwD as attained from Q-methodology data and analysed using factor analysis (see Figure 5.1). Next, Phase 3B presents the case study results – first for the procedural reliability of implementing the electronic life story conversational support (component 2 of the PC-AAC intervention for PwD), and secondly for the data reliability of scoring the AACOM-PwD (component 4 of the PC-AAC intervention for PwD). Chapter 5 concludes with qualitative data related to the self-reported enjoyment of a participant with dementia when using the electronic life story conversational support.



Phase 3: Feasibility testing of the PC-AAC intervention for PwD

Four components of the PC-AAC intervention for PwD:

- Component 1: Person-centred care approach in AAC
- Component 2: Electronic life story conversational support
- Component 3: AAC outcomes for PwD
- Component 4: AAC outcome measurement for PwD

Phase 3A Q-methodology results	**Phase 3B** Case study results
Professionals' clinical and educational expertise (viewpoints) obtained qualitatively (sub-aim *iii*). Quantitative data analysis through factor analysis: • Highest and lowest ranked statements • Anchor statements • Distinguishing statements • Consensus statements	Implementation of an electronic life story conversational support: (sub-aim *iv*) Reliability - Procedural reliability - Data reliability – scoring of AAC outcome measure for PwD (AACOM-PwD) • Intra-rater reliability • Inter-rater reliability Stakeholder perspective: Participant with dementia Self-reported enjoyment of interpersonal interaction with electronic life story conversational support (sub-aim *vi*)

Figure 5.1: Schematic illustration of the results chapter

5.2. Terms

- **Anchor statements:** The statements that were ranked as strongly agree (+3) and strongly disagree (-3) in each factor (Bartlett & DeWesse, 2015).
- **By-person factor analysis**: Factor analysis condenses the entire set of data into a few factors (groupings of people) for analysis and interpretation (Valenta & Wigger, 1997).
- **Consensus statement:** A statement ranked with similar z scores across all factors (McKeown & Thomas, 2013).
- **Distinguishing statement:** A statement within a factor that is significantly different from its rank position in other factors based on its *z*-score (McKeown & Thomas, 2013). In this study, a distinguished statement is significant at $p < .05$.
- **Eigenvalues:** The sum of square factor loadings for each factor assesses the "statistical strength and explanatory power" of a factor's variance (Watts & Stenner, 2012, p. 122). Using the Kaiser-Guttman criterion, an eigenvalue greater than 1.00 is considered to be interpretable.
- **Factor**: In this study, a factor refers to a group of professionals with shared views based on their similar rank-order of statements related to the components of the PC-AAC intervention for PwD developed in this study (Valenta & Wigger, 1997).
- **Factor loading:** Shows a correlation or relationships between a professional's completed Q-sort to the factor onto which they loaded (Newman & Ramlo, 2015).
- **Highest- and lowest-ranked statement**: The highest-ranked statement is a statement with the highest *z*-score, indicating a factor's strongest agreement (+3). The lowest-ranked statement is a statement with the lowest *z*-score, which is ranked as strongly disagree (-3). The two statements are most useful for interpretation (Newman & Ramlo, 2015).
- **Participant**: A person with moderate to severe dementia, who was the participant in the case study in Phase 3B.
- **Professionals:** In this study, professionals include AAC researchers, clinicians and academic teachers who, based on their clinical and/or educational expertise, expressed their subjectivity on statements related to the components of the PC-AAC intervention for PwD through the completion of a Q-sort (Phase 3A).
- **Q-sorting:** Refers to professionals expressing their viewpoints by rank ordering 37 statements (Q-sample) on a forced-choice distribution grid according to a continuum

(i.e., +3 strongly agree, 0 neutral, and -3 strongly disagree) (McKeown & Thomas, 2013). In this study, Q-sorting was performed electronically on QMethod Software (Lutfallah & Buchanan, 2019), in other words through online Q-sorting.

- **Varimax rotation:** Refers to the statistical algorithm, which is a statistical procedure to indicate the maximum variance among the minimum number of factors to enhance the interpretability of each factor (Newman & Ramlo, 2015).
- ***Z*-scores:** Refers to a weighted average score that similar professionals give to a statement. *Z*-scores provide information about how strongly each factor engaged with a statement (Zabala et al., 2018).

5.3. Phase 3A: Q-Methodology results

5.3.1. Factor extraction

The number of factors to be extracted is not prescribed in the literature (Zalaba, Sandbrook, & Mukherjee, 2018). To employ a systematic and transparent approach towards determining the number of factors to be extracted, the researcher followed a factor extraction decision-making protocol as shown in Table 5.1.

Table 5.1: Factor extraction decision-making protocol

Selection criteria	Factors						
	A	B	C	D	E	F	G
1. Default factors generated by QMethod software	✓	✓	✓	✓	✓	✓	✓
2. Eigenvalue >1.0	✓	✓	✓	✓	✓	✓	✓
3. More than two Q-sorts loaded	✓	✓	✓	✓	✓	x	x
4. Perform factor rotation comparisons							
5-factor rotation	✓	✓	✓	✓	x		
4-factor rotation	✓	✓	✓	x			
3-factor rotation	✓	✓	✓				

As is evident from Table 5.1, four decision-making factor extraction criteria were applied. Firstly, factor extraction began with seven factors, because QMethod Software (Lutfallah & Buchanan, 2019) automatically generated seven factors (Factors A-G) as the default number of factors. These factors represented seven groups of similar viewpoints derived from 33 completed Q-sorts. The general characteristics of all seven factors were inspected.

As the second criterion, the eigenvalues of each factor were inspected. Table 5.2 shows that the eigenvalues for each factor were as follows: Factor A (6.37); Factor B (5.01); Factor C (4.680); Factor D (3.80); Factor E (2.75); Factor F (2.35); and Factor G (1.58).

Table 5.2: Overview of seven default factors initially generated

	Initial seven factors						
Characteristic	**A**	**B**	**C**	**D**	**E**	**F**	**G**
Eigenvalues	6.37	5.01	4.68	3.80	2.75	2.34	1.58
Number of loading Q-sorts	5	4	3	2	2	1	1
Total explained variance	5	4	3	2	2	1	1

According to the Kaiser-Guttman criterion, an eigenvalue greater than 1.00 is considered to be interpretable (Watts & Stenner, 2012; Yang, 2016). All seven factors satisfied this second criterion and were retained. While eigenvalues greater than 1.00 may be statistically interpretable, they do not provide meaningful information on the significance of each factor in providing an understanding of professional's views on the components of the PC-AAC intervention for PwD (Watts & Stenner, 2012). Therefore, the third criterion was applied. The number of factors with two or more loadings was retained (Watts & Stenner, 2005). As shown in Table 5.2, Factors F and G were therefore eliminated, leaving five potential factors to be extracted.

5.3.2. Factor rotations

To determine whether five factors offered the most variance, factor rotations with five, four and three factors were performed and compared on QMethod Software (Lutfallah & Buchanan, 2019). This was done iteratively before a decision on the final numbers of factors was made. Table 5.3 shows a comparison between the 5-factor, 4-factor and 3-factor rotation.

Table 5.3: Factor rotation comparisons

Factor rotation	Total explained variance	Total number of participants loaded	Decision
5-factor	58%	19	*Removed:* 58% variance explained, with the fewest number of professionals' views represented.
4-factor	67%	22	*Removed:* Although 67% of variance was explained, a smaller number of participants was represented compared to a 3-factor rotation.
3-factor	79%	26	*Retained:* The highest percentage of variance, with the minimum number of factors (Watts & Stenner, 2005).

As shown in Table 5.3, a 3-factor solution yielded the highest explained variance with the greatest number of professionals loaded on a minimum number of factors (Watts & Stenner, 2005). Hence, three factors were extracted for the interpretation of the results.

5.3.3. Characteristics of three extracted factors

The three final factors are shown in Table 5.4. The following characteristics of each factor were examined: average reliability co-efficient; number of loading Q-sorts; eigenvalues; total variance explained; composite reliability; and standard error of *z*-scores.

Table 5.4: Characteristics of the three extracted factors

Characteristics	Factor A	Factor B	Factor C
Average reliability coefficient	0.8	0.8	0.8
Composite reliability	0.98	0.97	0.97
Standard error of factor scores	0.16	0.16	0.19
Eigenvalues	8.5	7.2	6.8
Number of loading Q-sorts	10	9	7
Total explained variance	10 (38%)	9 (35%)	7 (27%)

The average reliability co-efficient is an estimate of test-retest reliability, which indicates that professionals completing successive Q-sorts would respond in a similar manner. In Q-methodology, this score is set at 0.8 and a composite reliability score higher than 0.8 is an estimate of good factor reliability (Zabala & Pascual, 2016). The composite reliabilities of 0.98 (Factor A), 0.97 (Factor B) and 0.96 (Factor C) are above 0.8. This suggests that the professionals' views defined in each factor are reliable (Brown, 1980).

As shown in Table 5.4, the high composite reliability scores and lower standard error of factor scores signify the level of consistency between the three factors (Watts & Stenner, 2012). Overall, the three factors represented the viewpoints of 26 professionals (79%) out of the 33 who had completed their Q-sorts. This means that 26 professionals loaded onto one of three factors, while seven professionals (21%) did not load onto any factor. Of the 26 professionals, 10 expressed similar viewpoints on the components of the PC-AAC intervention for PwD and were loaded onto Factor A. The total explained variance of viewpoints in Factor A was 10 (38%). Likewise, nine professionals loaded onto Factor B (35% variance), and seven onto Factor C (27% variance).

In each of the three factors, the significant factor loadings were automatically flagged on QMethod Software (Lutfallah & Buchanan, 2019) and appear in boldface in Table 5.5.

Table 5.5: Factor loadings for the three rotated factors

Professional ID	Factor A (10)	Factor B (9)	Factor C (5)
P654	**0.745 X**	0.389	0.29
P664	0.403	0.395	**0.71 X**
P665	0.384	**0.612 X**	0.40
P666	0.432	**0.616 X**	0.26
P675	0.200	**0.754 X**	0.22
P688	0.193	0.347	**0.77 X**
P700	**0.727 X**	0.084	0.40
P712	0.350	0.096	**0.71 X**
P718	**0.641 X**	0.439	0.33
P724	**0.774 X**	0.343	0.22
P746	0.557	**0.608 X**	0.20
P773	0.488	0.492	0.34
P816	0.232	-0.021	**0.51 X**
P846	**0.752 X**	0.250	0.42
P856	0.180	**0.755 X**	0.43
P858	0.537	0.342	0.55
P860	0.385	0.551	0.57
P869	0.589	0.509	0.46
P935	0.296	**0.631 X**	0.47
P002	**0.565 X**	0.309	0.36
P017	0.567	0.372	0.43
P068	0.249	0.119	**0.80 X**
P070	**0.619 X**	0.270	0.38
P121	**0.726 X**	0.248	0.49
P133	0.119	0.427	**0.68 X**
P139	0.084	**0.802 X**	-0.14
P166	**0.620 X**	0.438	0.25
P175	0.383	0.211	**0.62 X**
P216	0.385	0.463	0.51
P285	0.377	**0.720 X**	0.23
P296	0.363	**0.495 X**	0.31
P303	**0.826 X**	0.153	0.14
P345	0.595	0.602	0.15

Boldface X: Factor loadings greater than 0.42 (significant) showing a defining Q-sort.
Grey: Confounded (significantly loaded on two or more factors greater than 0.42) i.e., significance level p>.05.

Table 5.5 shows the rotated factor matrix in which significant factor loadings (either positive or negative) were greater than 0.42. A defining factor loading is presented in boldface and is considered to be most representative of the specific factor onto which it has been loaded. This means that 10 professionals' Q-sorts loaded significantly onto Factor A. For example, the first professional (i.e., P654) had factor loadings of 0.745 on Factor A, 0.39 on Factor B, and 0.29 on Factor C. This professional's highest loading was on Factor A and it was therefore a defining Q-sort in Factor A.

In the case of Table 5.5, the Q-sorts of seven professionals (21%) loaded significantly on more than one factor. For example, although professional P773 (highlighted in grey in Table 5.5) loaded significantly on two factors, namely 0.488 (Factor A), 0.492 (Factor B), their expressed views did not define a specific factor and is considered to be confounded. Therefore, all seven confounded Q-sorts were excluded from the factor interpretation.

In the next section, the results of each factor are described and interpreted individually. In each factor of the three factors, the professionals who shared similar views points are described first. Then, the statements in each factor are examined in four ways:

i. The highest and lowest ranked statements by *z*-scores

ii. Anchor statements, i.e., the statements ranked at extreme ends of the ranking scale (i.e., +3 strongly agreed, and -3 strongly disagreed)

iii. Distinguishing statements, i.e., statements that were statistically significant at a p-value < .05 as a unique view in each factor

iv. Consensus statements, i.e., statements that are ranked in a similar way across all factors with a non-significant difference in *z*-scores at a p-value > .05

At the end of the section, a summary of the three factors is provided, and each factor is given a label based on its most distinguishing characteristics (Zabala et al., 2016).

5.3.4. Factor interpretation

5.3.4.1. Factor A

Ten professionals ranked the statements on their Q-sorts in a similar way and together comprised Factor A. This factor represents the largest professional grouping with an explained variance of 10 (38%) (see Table 5.6). The professional (P303) with the highest factor loading (0.826) in Factor A was a Speech-Language Pathologist with specialisation in dementia studies, as well as an interest in person-centred care in adults with neurologically acquired communication disorders.

Table 5.6: Factor A – Description of professionals

Professional *#	Factor loading	Profession, specialisation	Type of work	Focus of work Δ	Area of interest
P654**F**[d]	0.745	SLP (AAC)	Research	Adults	PCC[v]
P700**F**[e]	0.727	Other (AAC)	Research, teaching	CWDD	Interaction
P718**F**[e]	0.565	SLP (Dementia)	Research, clinical, teaching	Adults	Dementia communication
P724**F**[c]	0.774	SLP (Dementia)	Research, clinical, teaching	Adults	Interaction
P846**F**[c]	0.752	SLP (AAC)	Research, clinical, teaching	Adults	Interaction
P002**M**[e]	0.565	SLP (AAC)	Research, teaching	Adults	Interaction
P070**F**[b]	0.619	SLP (AAC)	Clinical	Adults	PCC[v]
P121**F**[b]	0.726	SLP (AAC)	Research	Both	Instrument development
P166**F**[d]	0.620	SLP (AAC)	Other	Both	PCC[v]
P303**F**[e]	0.826	SLP (Dementia)	Research, teaching	Adults	PCC[v]

Participant ID: participants' non-identifiable code followed by their *gender (**F** denotes Female. **M** denotes Male); #years of experience: **a** (0-5 years), **b** (6-10 years), **c** (11-15 years), **d** (16-20 years), **e** (> 21 years).
ΔFocus of work: Adults (adult neurologically acquired communication disorders); CWDD (children with developmental disorders); Both (adults and CWDD).
[v] PCC (Person-Centred Care).

As displayed in Table 5.6, all but one of the professionals in Factor A were Speech-Language Pathologists (SLPs) who mainly specialised in AAC or in dementia studies. One professional classified their profession as a researcher who specialised in AAC. The viewpoints expressed in Factor A were principally from professionals involved in research (2), research and teaching (3), or a combination of research, teaching and clinical work (3). While one professional was involved only in clinical work, another professional was involved in neither clinical work nor research, but focused on assistive technology and AAC consultation for adults and children with communication disorders. The nine females and one male in Factor A all had a range of years' (6- 21 years) worth of experience, mainly in adults with neurologically acquired communication disorders. Professionals in Factor A were equally interested in person-centred care (4) and interpersonal interaction generally (4), followed by instrument development (1) and dementia-related communication specifically (1).

Table 5.7: Factor A – Highest- and lowest-ranked statements

Statement #		Statement	
		z-score	Ranking
Highest-ranked statements			
24	Persons with dementia should be supported in authoring the content of their life story based conversational supports.	1.7035	+3
28	Successful interaction should be rated from the perspectives of both the person with dementia (patient-reported) and the conversational partner (proxy-reported).	1.5494	+3
30	Social connections are important goals of AAC interventions and designed to support interpersonal interaction with a person with dementia.	1.4888	+3
23	Conversational supports with personalised life story content of a person with dementia is a useful scaffold for reminiscence-based conversations with a person with dementia.	1.3202	+3
Lowest-ranked statements			
31	Enjoyment and motivation (as engagement outcomes) within an interpersonal interaction are not important to include in an outcome measure for persons with dementia.	-1.4898	-3
36	It is not necessary to include participation outcomes (frequency of taking part in everyday interactions) in an AAC interaction outcome measure for persons with dementia.	-1.5845	-3
27	Person-centred care as a philosophy of care (e.g., one that promotes the independence of persons with dementia and values their life history) in AAC interventions is not clinically achievable.	-1.6076	-3
29	It is not necessary to measure the satisfaction of the person with dementia in using AAC strategies within an interpersonal interaction.	-1.6605	-3

Grey coding indicates the statements ranked extremely high (at +3) and low (at -3) in Factor A.

As shown in Table 5.7, statement 24 was ranked the highest (*z*-score of 0.7035), which reflects the views of Factor A on the person-centred care component of the PC-AAC intervention for PwD. Statement 29 (*z*-score of -1.6605) was the lowest ranked statement that reflected Factor A's views on AAC outcome measurement for PwD. Professionals in Factor A strongly agreed with statements related to person-centred care components on personalised content of life-story-based conversational supports (statements 24 and 23), measuring the perspectives of PwD and their conversational partners (statement 28), and social connections as AAC outcomes for PwD (statement 30).

Factor A showed strongest disagreement with statements on AAC outcome measurement (statement 29), person-centred care as a philosophy of care in AAC interventions for PwD (statement 27), and in two statements concerned with AAC outcomes for PwD (statements 36 and 31). Notably, the negative *z*-scores of these statements do not infer a negative opinion. Instead, as shown in Table 5.7, they denote a negatively worded statement. The strong disagreement with these negative worded statements indicates that professionals expressed their support to the contrary wording of the lowest-ranked statements.

Five statements were found to be statistically significant and distinguished in Factor A (see Table 5.8). The distinguished statements are listed in a way that shows their composite factor ranking, rather than the numerical order of statements.

Table 5.8: Factor A – Distinguished statements

Statement #	**Factor A Distinguished statements ***	**Statement *z*-scores and factor rankings** A	B	C
1	Electronic AAC systems (e.g., tablet computers with applications [apps]) can be useful to support interpersonal interaction between a conversational partner and a person with moderate to severe dementia.	-1 **(-0.498)**	0 (0.420)	0 (0.20)
34	The most important domain to measure in an AAC interaction outcome measure for persons with dementia is turn taking (e.g., frequency of turn taking exchanges).	-1 **(-0.247)**	-2 (-0.993)	-2 (-1.39)
13	By repeating the utterances of the person with dementia, a conversational partner shows an understanding of what the person with dementia is expressing within an interpersonal interaction.	0 **(0.118)**	-1 (-0.803)	-1 (-0.53)
35	An AAC interaction outcome measure must include the modality of turn taking (e.g., turn taking with gestures).	+2 **(0.872)**	-1 (-0.113)	-1 (-0.55)
24	Persons with dementia should be supported in authoring the content of their life-story-based conversational supports.	+3 **(1.704)**	0 (0.317)	1 (0.80)

*Significant at p<.05

As displayed in Table 5.8, the group of professionals comprising Factor A was distinguished by their prominent views on five statements. Factor A shared a clearly defined and distinguished agreement that PwD should be supported in authoring the content of their own life story conversational supports (statement 24). However, they did not agree that the use of electronic AAC systems is useful for interpersonal interaction in persons with moderate to severe dementia (statement 1). Furthermore, Factor A was differentiated in their neutrality towards repeating of utterances as a useful conversational partner strategy to aid understanding in an interpersonal interaction with a PwD (statement 13). Professionals in Factor A had two defined views on an AAC outcome measure for PwD. They were of the view that an AAC outcome measure for PwD must include measurement of the modality of turn taking (statement 35). This view was validated as they were more inclined to agree that the frequency of turn taking was the most important measurement domain.

5.3.4.2. *Factor B*

Nine professionals made up Factor B and are described in Table 5.10. The professional (P139) with the highest factor loading of 0.802 was a Speech-Language Pathologist with specialisation in technology, as well as an interest in person-centred care for both adults and children with disabilities.

Table 5.9: Factor B – Description of professionals

Professional$^{*\#}$	**Factor loading**	**Profession, specialisation**	**Type of work**	**Focus of work** $^{\Delta}$	**Area of interest**
P665**F**^{a}	0.612	SLP (AAC)	Clinical	Adults	Interaction
P666**F**^{e}	0.616	SLP (AAC)	Research, clinical, teaching	Adults	PCC^{v}
P675**F**^{e}	0.754	SLP (AAC)	Research, clinical, teaching	CWDD	Interaction
P746**F**^{e}	0.608	OT (AAC)	Research, teaching	Both	Other
P856**F**^{b}	0.755	SLP (AAC)	Clinical	Adult	PCC^{v}
P935**F**^{b}	0.631	Psychologist (AAC)	Research	Adult	Instrument development
P139**F**^{d}	0.802	SLP (Technology)	Research, clinical, teaching	Both	PCC^{v}
P285**F**^{b}	0.720	SLP (AAC)	Research, teaching	CWDD	Interaction
P296**F**^{d}	0.495	SLP (Other)	Clinical	Both	Interaction

Participant ID: participants' non-identifiable code followed by their *gender (**F** denotes Female. **M** denotes Male); and #years of experience: **a** (0-5 years), **b** (6-10 years), **c** (11-15 years), **d** (16-20 years), **e** (> 21 years).
ΔFocus of work: Adults (adult neurologically acquired communication disorders); CWDD (children with developmental disorders); Both (adults and CWDD).
^{v}PCC (Person-Centred Care).

As reported in Table 5.9, Factor B represented a multidisciplinary group of female professionals with seven SLPs, one Occupational Therapist and one Psychologist. Five SLPs specialised in AAC, one in technology and one described their specialisation as 'other' (i.e., communication interventions). Four SLPs were interested in interpersonal interaction and three in person-centred care through their research, teaching and clinical work with either adults and/or children with disabilities. The Occupational Therapist specialised in AAC research and teaching focused on the participation of adults and children with communication disabilities. The Psychologist was an AAC researcher with an interest in instrument development in adults with neurologically acquired communication disorders.

Factor B was represented by the greatest number of clinicians (3) whose clinical work focused on adults with neurologically acquired communication disorders (2), or both adults and children with disabilities (1). Professionals in Factor B had diverse work experience, ranging from one early-career clinician (0-5 years) to three well-experienced professionals with more than 21 years of research, teaching and clinical experience. The highest and lowest ranked statement in Factor B based on their *z*-scores are shown in Table 5.10, along with the statements ranked at the extremes with strong agreement (+3), and strong disagreement (-3).

Table 5.10: Factor B – Highest- and lowest-ranked statements

Statement #		**Statement** *z***-score**	**Statement Ranking**
	Highest-ranked statements		
26	A patronising style of language (e.g., an exaggerated tone of voice typical of talking to an infant) used during interpersonal interaction with a person with dementia undermines personhood of a person with dementia.	1.6875	+3
15	A person with dementia must be supported in decision-making in all aspects of their AAC intervention.	1.4776	+3
18	AAC interventions to support interpersonal interaction in persons with dementia must be tailored to the strengths of the person with dementia.	1.2946	+3
16	A person with dementia must be consulted about their personal preferences for interpersonal interaction.	1.2124	+3
	Lowest-ranked statements		
29	It is not necessary to measure the satisfaction of the person with dementia in using AAC strategies within an interpersonal interaction.	- 1.5611	-3
27	Person-centred care as a philosophy of care (e.g., one that promotes the independence of persons with dementia and values their life history) in AAC interventions is not clinically achievable.	- 1.6944	-3
31	Enjoyment and motivation (as engagement outcomes) within an interpersonal interaction are not important to include in an outcome measure for persons with dementia.	-1.7593	-3
37	It is not important to include the behaviour displayed by persons with dementia (e.g., their level of frustration, agitation or avoidance) as an AAC interaction outcome measure for persons with dementia.	-1.7984	-3

Grey coding indicates the statements ranked extremely high (at +3) and low (at -3) in Factor B.

As shown in Table 5.10, statement 26 was the highest-ranked statement by Factor B with a *z*-score of 1.6875. The lowest-ranked statement with a *z*-score of -1.7984 (statement 37) concerned the lack of importance of including a behaviour domain in an AAC interaction outcome measure for PwD. Professionals in Factor B expressed their strongest agreement with statements related to person-centred care components of the PC-AAC intervention package for PwD (statements 26, 15, 18 and 16) and were ranked as +3 (strongly agree) on the ranking scale. Factor B expressed their strongest disagreement with negatively worded statements related to a behavioural domain of an AAC outcome measure for PwD (statement 37), person-centred care in AAC interventions (statement 27) and measurement of engagement in and satisfaction in respect of an AAC interpersonal interaction with a PwD (statements 31 and 29). Factor B had eight statements that distinguished their views from those of Factor A and C (see Table 5.11).

Table 5.11: Factor B – Distinguished statements

Statement #	**Factor B Distinguished statements***	**Statement *z*-scores and factor rankings**		
		A	**B**	**C**
36	It is not necessary to include participation outcomes (frequency of taking part in everyday interactions) in an AAC interaction outcome measure for persons with dementia.	-1 (-1.584)	-2 **(-0.990)**	-2 (-1.69)
5	Non-electronic AAC systems (e.g., paper-based communication books with pictures) are the most beneficial communication supports for interpersonal interaction with a person with mild to moderate dementia.	-1 (-0.905)	-1 **(-0.123)**	-2 (-0.89)
4	Legacy messages (i.e., unique words or phrases used by a person with dementia digitally recorded in their own voice in the early stages of dementia) stored as voice output on electronic devices (e.g., iPad) are useful to facilitate social connection with a conversational partner as dementia severity progresses.	0 (-0.129)	0 **(0.447)**	-1 (-0.24)
30	Social connections are important goals of AAC interventions and are designed to support interpersonal interaction with a person with dementia.	+3 (1.489)	0 **(0.111)**	+3 (1.63)
6	Combining picture pointing with spontaneous speech (i.e., augmented input) is a useful strategy to support auditory comprehension of spoken language in persons with dementia.	0 (-0.085)	1 **(0.582**)	-1 (-0.40)
9	The unique set of communication behaviours of a person with severe dementia (e.g., vocalisations, facial expressions, gestures) should be used as the basis for interpersonal interaction with a conversational partner.	-1 (-0.225)	+2 **(1.161)**	0 (0.22)
16	A person with dementia must be consulted about their personal preferences for interpersonal interaction.	+1 (0.475)	+3 **(1.212)**	0 (0.27)
26	A patronising style of language (e.g., an exaggerated tone of voice typical of talking to an infant) used during interpersonal interaction with a person with dementia undermines the personhood of a person with dementia.	+2 (0.877)	+3 **(1.688)**	+2 (0.95)

*Significant at p<.05

As shown in Table 5.11, Factor B distinguished their views regarding the use of specific AAC strategies and techniques in interpersonal interaction with persons with dementia. Factor B felt that augmented input was a useful AAC strategy to aid comprehension in persons with dementia (Statement 6). While they slightly disagreed that non-electronic AAC systems were the most beneficial support for persons with mild to moderate dementia (Statement 5), they also affirmed their agreement that the unique set of unaided communication behaviours should be used as a basis for interpersonal interaction with persons with severe dementia (Statement 9). Although neutral in their view on legacy messages (Statement 4), they statistically distinguished themselves in their collective view on the possible usefulness of using digitally recorded legacy messages as a voice output in the own voice of the person with dementia.

Factor B was distinguished by their neutral view towards social connection as a goal in AAC interventions for persons with dementia (Statement 30). However, they inferred their agreement to participation outcomes on an AAC outcome measure in persons with dementia (Statement 36). They also strongly believed that persons with dementia must be consulted about their personal preferences for interpersonal interaction (Statement 16) and that personhood is undermined (Statement 26) through a patronising language style during interpersonal interactions with persons with dementia.

5.3.4.3. Factor C

The viewpoints in Factor C were defined by seven professionals (two males and five females) and are next described in Table 5.12.

Table 5.12: Factor C – Description of professionals

Professional$^{*\#}$	**Factor Loading**	**Profession, specialisation**	**Type of work**	**Focus of work** $^{\Delta}$	**Area of interest**
664**F**^{d}	0.71	SLP (AAC)	Research, clinical, teaching	Both	Interaction
688**M**^{e}	0.77	Other (AAC)	Research, teaching	Both	Interaction
712**F**^{e}	0.71	SLP (Dementia)	Research, clinical	Adults	Dementia Communication.
816**F**^{e}	0.51	SLP (AAC, Dementia & Technology)	Research	Both	Interaction
068**M**^{e}	0.80	Psychologist (Other)	Research, clinical, teaching	Adults	PCC
133**F**^{e}	0.68	SLP (AAC)	Clinical	CWDD	Interaction
175**F**^{e}	0.62	SLP (AAC)	Research, teaching	CWDD	Interaction

Participant ID: Participants' non-identifiable code followed by their *gender (**F** denotes Female; **M** denotes Male) and #years of experience: **a** (0-5 years); **b** (6-10 years); **c** (11-15 years); **d** (16-20 years); **e** (> 21 years).
ΔFocus of work: Adults (adult neurological acquired communication disorders); CWDD (children with developmental disorders); Both (adults and CWDD)
^{v}PCC (Person-Centred Care)

As displayed in Table 5.12, the professional (P068) with the highest factor loading (0.80) was a psychologist with expertise in disability studies and an interest in person-centred care in adults with neurologically acquired communication disorders. Collectively, professionals in Factor C were all well-experienced, with the majority having more than 21 years of work experience individually, and one with 16-20 years' experience. There were five SLPs, specialising in AAC, dementia studies or in a combination of AAC, dementia and technology. These SLPs were primarily interested in interpersonal interaction in general – in both adults and children with disabilities. Only one of them was a clinician, while the work of the other six professionals focused on a combination of research, clinical work or teaching. The highest- and lowest-ranked statements in Factor C obtained a *z*-score of 1.6284 (Statement 30) and -1.7324 (Statement 29) respectively (see Table 5.13).

Table 5.13: Factor C: Highest- and lowest-ranked statements

Statement #		**Statement *z*-score**	**Rank**
	Highest-ranked statements		
30	Social connections are important goals of AAC interventions designed to support interpersonal interaction with a person with dementia.	1.6284	+3
8	A conversational partner should never correct off-topic utterances made by a person with dementia.	1.2984	+3
18	AAC interventions to support interpersonal interaction in persons with dementia must be tailored to the strengths of the person with dementia.	1.1941	+3
23	Conversational supports with personalised life story content of a person with dementia is a useful scaffold for reminiscence-based conversations with a person with dementia.	1.0734	+3
	Lowest-ranked statements		
31	Enjoyment and motivation (as engagement outcomes) within an interpersonal interaction are not important to include in an outcome measure for persons with dementia.	-1.4720	-3
27	Person-centred care as a philosophy of care (e.g., one that promotes the independence of persons with dementia and values their life history) in AAC interventions is not clinically achievable.	-1.6684	-3
36	It is not necessary to include participation outcomes (frequency of taking part in everyday interactions) in an AAC interaction outcome measure for persons with dementia.	-1.6921	-3
29	It is not necessary to measure the satisfaction of the person with dementia in using AAC strategies within an interpersonal interaction.	-1.7324	-3

Grey coding indicates the statements ranked extremely high (at +3) and low (at -3) in Factor C.

As revealed in Table 5.13, the highest-ranked statement reflected Factor C's view on social connection as an important AAC goal in interpersonal interaction (Statement 30). The lowest ranked statement in Factor C was Statement 29 (*z*-score of -1.7324). This statement expressed Factor C's views on the necessity of AAC outcome measurement relating to the level of satisfaction of a person with dementia with an interpersonal interaction.

The professionals grouped in Factor C expressed their strongest agreement in respect of statements aligned with AAC outcome measurement (Statement 30), conversational partner strategies (Statement 8), personalisation of conversational supports (Statement 23) and person-centred care in AAC interventions for persons with dementia (Statement 18). They expressed their strong disagreement with negatively worded statements related to participation and engagement outcomes of interpersonal interaction with a person with dementia (Statements 36 and 31 respectively), as well as person-centred care (Statement 27). Factor C's viewpoints were defined by four distinguished statements shown in Table 5.14.

Table 5.14: Factor C – Distinguished statements

Statement #	**Factor C Distinguished statements***	**Factor**		
		A	B	C
20	Adapted participatory methods (e.g., co-production) should be employed to include persons with dementia as collaborators in the co-design of AAC interventions.	+1 (0.705)	+2 (0.967)	0 **(0.17)**
21	Working collaboratively with the family of a person with dementia and other stakeholders throughout the AAC intervention process is important, but not necessary.	-2 (-1.296)	-2 (-1.271)	+1 **(0.91)**
11	A conversational partner should display empathy by mirroring the emotion of the person with dementia to facilitate interpersonal interaction with a person with dementia.	0 (-0.092)	0 (0.049)	+2 **(0.99)**
8	A conversational partner should never correct off-topic utterances made by a person with dementia.	-1 (-0.936)	-1 (-0.539)	+3 **(1.30)**

*Significant at p<.05

As displayed in Table 5.14, Factor C had distinguished views on the role of a conversational partner in supporting interpersonal interaction with a person with dementia. These professionals felt strongly that a conversational partner should never correct the off-topic utterances made by a person with dementia (Statement 8) and should display empathy to mirror the emotion of a person with dementia (Statement 11). Factor C felt that although collaboration with persons with dementia and other relevant stakeholders was important, it was not necessary (Statement 21). They further expressed a neutral view towards adapted participatory methods that involve persons with dementia as co-designers of their own AAC intervention (Statement 20).

Before proceeding to the consensus statements across all three factors, a summarised overview of each factor is provided in Table 5.15. The summary presents the composite *z*-score of each of the three factors' highest- and lowest-ranked statement, and statements that notably distinguished each factor.

Table 5.15: Summary of Factors: Factors A, B and C

Factor description	Highest-ranked statements (+3)	Lowest-ranked statements (-3)	Distinguished statements	
Factor A Person-centred authorship with a focus on directly reported outcomes and turn taking outcome measures	24. Persons with dementia should be supported in authoring the content …	29. It is *not* necessary to measure the satisfaction of the person with dementia …	• Electronic AAC systems can be useful to support interpersonal interaction (-1) • By repeating the utterances of the person with dementia, a conversational partner shows an understanding (0)	• Persons with dementia should be supported in authoring the content of their life story …(+3) • The most important domain to measure … is turn taking (-1) • An AAC interaction outcome measure must include ... modality of turn taking (+2)
Factor B Person-centred language style with a focus on AAC strategies and techniques	26. A patronising style of language … undermines personhood …	37. It is *not* important to include the behaviour displayed by persons with dementia … as an AAC interaction outcome ...	• Legacy messages … are useful to facilitate social connection …(0) • Non-electronic AAC systems … are the most beneficial … (-1) • Augmented input is a useful strategy to support auditory comprehension ...(+1) • Social connections are important goals of AAC interventions (0)	• The unique set of communication behaviours of a person with severe dementia … should be used … for interpersonal interaction (+2) • A person with dementia must be consulted … personal preferences (+3) • It is not necessary to include participation outcomes…on an AAC outcome measure…(-2)
Factor C AAC outcomes and outcome measures with a focus on empathetic interpersonal interactions	30. Social connections are important goals of AAC interventions ...	29. It is *not* necessary to measure the satisfaction of the person with dementia …	• A conversational partner should never correct off-topic utterances …(+3) • A conversational partner should display empathy by mirroring the emotion of the person with dementia … (+2)	• Adapted participatory methods … should be employed to include persons with dementia … in the co-design of AAC interventions (0) • Working collaboratively with the family… and other stakeholders ... is important, but not necessary (+1)

- 3 (strongly disagree), 0 (neutral), +3 (strongly agree)

5.3.5. Consensus statements

Consensus statements are statements that were scored similarly in two or more factors and were non-significant at a p-value <.05. Overall, there were 12 consensus statements (see Table 5.16), and complete consensus was reached on five of them, which were negatively worded statements (i.e., Statements 3, 22, 27, 29 and 31). This meant that all three factors expressed their strongest agreement with the notion that person-centred care as a philosophy of care for persons with dementia was clinically achievable (Statement 27). They also strongly agreed on the necessity of measuring the satisfaction of a person with dementia in using AAC strategies within an interpersonal interaction (Statement 29). All factors indicated that enjoyment and motivation of persons with dementia within an interpersonal interaction (Statement 31) are important AAC outcomes to measure. All factors disagreed that the immediate interactional context was not important to consider when designing AAC interventions for persons with dementia (Statement 22). Additionally, all factors disagreed with Statement 3 in that intelligent assistive technologies should be not explored to support interpersonal interaction in persons with dementia.

Between Factors A and C, there was consensus of agreement on three statements. These two factors held a strong view that AAC strategies for persons with dementia are flexible, depending on the stage and type of dementia (Statement 17), and that pausing to give a person with dementia time to respond is important within an interpersonal interaction (Statement 14). They also agreed that personalised music and digital photographs on electronic devices increased enjoyment in interpersonal interaction with a person with dementia (Statement 25).

Similarly, there was consensus of agreement on three statements between Factors B and C. These factors disagreed to a lesser extent that it was not necessary to train persons with dementia in navigating electronic AAC systems before their use in real-time interpersonal interaction (Statement 2). Factors B and C held a strong view that AAC interventions should be tailored to the strengths of persons with dementia (Statement 18), but they did not have a definitive view on whether interpersonal interaction was analysed best through qualitatively observations (Statement 32).

The last consensus statement was shared by Factors A and B, which revealed their agreement that involving persons with dementia in co-designing their own interventions promoted self-determination (Statement 19).

Table 5.16: Consensus statements across factors

Statement #	Consensus statements	Factors A	Factors B	Factors C
2	Training persons with dementia on the use of electronic AAC systems (e.g., navigating on tablet computers with apps) before they use them in real-time interaction settings is not necessary when the purpose is interpersonal interaction.	-2 (-1.194)	-1 (-0.877)	-1 (-0.74)
3	The use of intelligent assistive technologies (e.g., artificial intelligence) to support communication and interpersonal interaction in persons with dementia should not be explored for persons with dementia.	-2 (0.0335)	-2 (0.223)	-2 (0.190)
14	A conversational partner can support interpersonal interaction by pausing to give a person with dementia time to respond.	2 (0.3685)	1 (-0.084)	2 (-0.452)
17	AAC strategies for a person with dementia are flexible, depending on the stage and type of dementia.	2 (0.2214)	1 (-0.059)	2 (-0.281)
18	AAC interventions to support interpersonal interaction in persons with dementia must be tailored to the strengths of the person with dementia.	2 (1.250)	3 (1.295)	3 (1.19)
19	The self-determination of a person with dementia is promoted by facilitating their involvement in co-designing their own AAC interventions.	1 (0.501)	1 (0.644)	0 (0.42)
22	The immediate interaction context (e.g., the time of day in which an interaction occurs) does not play a vital role in the success of interpersonal interaction with a person with dementia.	-2 (-1.036)	-2 (-1.036)	-2 (-1.13)
25	Life-story-based conversational supports that include personalised music and digital photographs on electronic devices (e.g., iPad) enhance the enjoyment of interpersonal interaction for persons with dementia.	1 (0.865)	2 (0.854)	1 (0.92)
27	Person-centred care as a philosophy of care (e.g., one that promotes the independence of persons with dementia and values their life history) in AAC interventions is not clinically achievable.	-3 (1.608)	-3 (-1.694)	-3 (-1.67)
29	It is not necessary to measure the satisfaction of the person with dementia in using AAC strategies within an interpersonal interaction.	-3 (-1.661)	-3 (-1.561)	-3 (-1.73)
31	Enjoyment and motivation (as engagement outcomes) within an interpersonal interaction are not important to include in an outcome measure for persons with dementia.	-3 (-1.490)	-3 (-1.759)	-3 (-1.47)
32	AAC-supported interaction in persons with dementia is best analysed qualitatively from observation of spontaneous interaction.	-1 (-0.163)	0 (0.017)	0 -0.15

Grey coding shows consensus between two factors.

5.4. Phase 3B: Case study results

5.4.1. Reliability

In this section, the reliability results are presented first for procedural integrity of implementing procedures in the baseline and intervention phases, and secondly for reliability of scoring the AACOM-PwD (intra-rater reliability and intra-rater reliability).

5.4.1.1.1. Procedural reliability

Procedural reliability was evaluated to provide evidence that the procedures in the baseline and intervention phases were implemented in a reliable and consistent manner as intended. The results are presented next.

5.4.1.1.2. Procedural integrity in the baseline and intervention phase

Procedural integrity in the baseline phase was scored using the Procedural Checklist: Baseline Phase (Appendix W). There were 16 procedural steps in each baseline session. One point was scored for each procedural step implemented and a zero if omitted. The raw score out of 16 was converted to a percentage and is reflected in Table 5.17.

Table 5.17: Procedural reliability percentages – Baseline and intervention phases

Phase	Baseline			Intervention					
Session	1	2	3	4	5	6	7	8	9
Procedural integrity Researcher Mean 98.3%	100%	94%	94%	100%	97%	100%	100%	100%	100%
Independent rater			94%			100%		100%	

As shown in Table 5.17, the researcher's procedural integrity in all three baseline phase sessions (sessions 1, 2, 3) ranged from 94% to 100%. Procedural integrity of the intervention phase sessions (sessions 4, 5, 6, 7, 8, 9) was measured using the Procedural Checklist: Intervention Phase (Appendix X). In total, there were 33 procedural steps in the intervention phase. The raw scores were converted to a percentage and are shown in Table 5.17. Procedural integrity in the intervention phase ranged from 97% to 100%. Overall, a high mean procedural reliability percentage of 98.3% was obtained. This is considered to be good reliability and indicates that the baseline and intervention procedures were executed with high consistency and reliability (McMillan & Schumacher, 2014).

The independent rater followed the same scoring instructions as the researcher and evaluated three randomly selected video recordings for procedural integrity – 33% in the baseline phase (session 3), and 33% in the intervention phase (sessions 6 and 7).

5.4.2. Data reliability: Scoring of the AAC Outcome Measure for PwD

The Augmentative and Alternative Communication Outcome Measure for PwD (AACOM-PwD) was developed as Component 4 of the PC-AAC intervention for PwD. The AACOM-PwD was administered as an observational tool to score the turn taking of the case study participant during her interpersonal interaction with the electronic life story conversational support (Component 2) (see Sections 3.4 and 3.6 respectively). Interpersonal interaction between the researcher and case study participant took place in two phases (base line and intervention) and were video recorded. The researched watched all video recordings to assess the reliability of scoring the AACOM-PwD. The video-recorded data used for reliability of scoring ranged from 5 minutes 24 seconds in the baseline phase to 10 minutes 11 seconds in the intervention phase. An independent rater (described in Par. 4.13.4) watched 33% of the video recordings and scored the turn taking independently.

Cohen’s Kappa is considered a suitable statistical measurement of the level of intra-rater and inter-rater agreement. However, a case study with one participant did not meet the minimum sample size of two participants for the statistical interpretation of reliability results (Bujang & Baharum, 2017).

The researcher and independent rater used electronic formats of the turn taking coding scheme and score sheets of the AACOM-PwD to score the turn taking of the case study participant (Appendix F1). In the sections that follow, intra-rater and inter-rater scoring agreement results are presented for overall number of turns, four turn taking domains (verbal turns; gestural turns; aided turns; multimodal turns), and 11 turn taking sub-domains (verbal turns, such as vocalisations or verbal utterances).

5.4.2.1.1. Intra-rater reliability

The researcher scored nine video recordings (i.e., three baseline sessions and six intervention sessions) twice. The first scoring occurred subsequent to each baseline and intervention session with the participant. Following a one-month interval, the second scoring was performed. The researcher assigned a score on the AACOM-PwD contingent to the case study participant’s turn taking responses in each session. Each turn taking response was coded and scored in one of four turn taking domains (verbal, gestural, aided or multimodal) and the overall number of turns was counted. The modality of each turn was then coded as a turn taking sub-domain. The researcher scored the participant's turn taking in the same manner each time by utilising the same turn taking coding scheme and electronic formats of the scoring sheets (Appendix F2). The raw scores of these intra-rater datasets are displayed as ratings 1 and 2 in Table 5.18.

Table 5.18: Intra-rater reliability of scoring the AACOM-PwD – domain level

	Phase	Baseline			Intervention						Mean percentage agreement
	Session	1	2	3	4	5	6	7	8	9	
Total turns	Rating 1	27	27	29	79	85	89	62	83	85	
	Rating 2	29	28	31	81	87	93	64	85	83	96%
% agreement		93	96	94	98	98	96	97	98	98	
Verbal turns	Rating 1	11	13	13	36	35	39	29	32	30	
	Rating 2	12	12	14	35	36	41	30	32	30	96%
% agreement		92	92	93	97	97	95	97	100	100	
Gestural turns	Rating 1	3	3	4	4	4	9	7	6	8	
	Rating 2	3	3	4	3	6	10	7	7	8	91%
% agreement		100	100	100	75	67	90	100	86	100	
Aided turns	Rating 1	1	1	1	3	4	3	3	4	3	
	Rating 2	1	1	1	3	4	3	4	4	3	97%
% agreement		100	100	100	100	100	100	75	100	100	
Multimodal turns	Rating 1	12	10	11	36	42	38	23	41	44	
	Rating 2	13	12	12	40	41	39	23	43	42	93%
% agreement		92	83	92	90	98	97	100	95	95	

All percentage (%) agreement scores were rounded off to the nearest whole.

To report on the reliability of the intra-rater datasets, the raw scores were compared on a point-by-point rating, which resulted in a percentage agreement between ratings 1 and 2. A mean percentage of intra-rater agreement was subsequently determined. Intra-rating of the AACOM-PwD scores is reported on a domain level (Table 5.18) and on a sub-domain level (Table 5.19).

As reflected in Table 5.18, the total turns on the AACOM-PwD ranged from 93% (Session 1) to 96% (Session 2) in the baseline intra-ratings. For total turns in the intervention sessions, intra-rater agreement ranged from 96% (Session 6) to 98% (Sessions 4,5 8 and 9). The mean percentage agreement for the total turns in all sessions scored was 96%. Intra-rater agreement scores for verbal turns ranged from to 92% (Sessions 1 and 3) to 100% (Sessions 8 and 9). The mean scoring of total verbal turns was 96%. Agreement for the gestural turns in each session varied from 67% (Session 5) to 100% (Sessions 7 and 9). The mean intra-rater agreement for gestural turns was 96%.

All intra-rating agreements for aided turns were 100%, except for a 75% agreement in Session 7. Overall, this consistently high agreement resulted in a mean intra-rater agreement of 97% for total aided turns. The agreement for multimodal intra-rater turns ranged from 83% in Session 2 to 100% in Session 7. A mean percentage of 93% was obtained for all intra-ratings of all multimodal turns. Collectively, at a domain level on the AACOM-PwD, intra-ratings for the total turns (96%), verbal turns (96%), gestural turns (91%), aided turns (97%) and multimodal turns (93%) met the acceptable minimum agreement of 80% (McHugh, 2012).

Similar to the domain level, the reliability of intra-rating data is reported as the percentage agreement and mean percentage agreement in each sub-domain. At a sub-domain level, a raw score of zero indicates that the specific modality of the turn was not observed by the rater (i.e., the sub-domain turn did not occur). This applies to the baseline phase for aided turns (with assistance), as the researcher did not provide any support with the AAC device (see baseline procedures found in Appendix W). In this instance, the agreement refers to a non-occurrence agreement (Ledford, Dane, & Gast, 2018). The intra-rating reliability for the 11 turn taking sub-domains is reported in Table 5.19.

Table 5.19: Intra-rating reliability of scoring the AACOM-PwD – sub-domain level

***AACOM-PwD* domain**	***AACOM-PwD sub-domain***		**Baseline phase**			**Intervention phase**						**Mean % agreement**
			Session									
			1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
Verbal turns	Vocalisations	Researcher rating 1	2	1	1	5	2	6	1	1	1	94%
		Researcher rating 2	2	1	1	5	2	6	2	1	1	
		% agreement	100	100	100	100	100	100	50	100	100	
	Verbalisations	Researcher rating 1	9	12	12	31	33	33	28	31	29	96%
		Researcher rating 2	10	11	13	30	34	35	28	31	29	
		% agreement	90	92	92	97	97	94	100	100	100	
Gestural turns	Body movement	Researcher rating 1	1	1	1	1	2	1	1	1	1	100%
		Researcher rating 2	1	1	1	1	2	1	1	1	1	
		% agreement	100	100	100	100	100	100	100	100	100	
	Head nod	Researcher rating 1	1	1	1	2	1	5	5	4	6	85%
		Researcher rating 2	1	1	1	1	3	5	5	5	6	
		% agreement	100	100	100	50	33	100	100	80	100	
	Facial expressions	Researcher rating 1	1	1	2	1	1	3	1	1	1	97%
		Researcher rating 2	1	1	2	1	1	4	1	1	1	
		% agreement	100	100	100	100	100	75	100	100	100	
Aided turns	With assistance	Researcher rating 1	0	0	0	2	3	2	2	3	2	96%
		Researcher rating 2	0	0	0	2	3	2	3	3	2	
		% agreement	100	100	100	100	100	100	67	100	100	
	Without assistance	Researcher rating 1	1	1	1	1	1	1	1	1	1	100%
		Researcher rating 2	1	1	1	1	1	1	1	1	1	
		% agreement	100	100	100	100	100	100	100	100	100	
Multimodal turns	Verbal +Gestural	Researcher rating 1	9	9	8	32	39	35	20	23	31	93%
		Researcher rating 2	10	11	9	36	38	36	20	25	31	
		% agreement	90	82	89	89	97	97	100	92	100	
	Verbal + Aided	Researcher rating 1	1	1	1	1	1	1	1	13	2	88%
		Researcher rating 2	1	1	1	1	1	1	1	13	2	
		% agreement	100	100	100	100	100	100	100	100	100	
	Gestural + Aided	Researcher rating 1	1	0	1	1	1	1	1	1	1	100%
		Researcher rating 2	1	0	1	1	1	1	1	1	1	
		% agreement	100	100	100	100	100	100	100	100	100	
	Verbal + Aided + Gestural	Researcher rating 1	1	0	1	2	1	1	1	4	10	98%
		Researcher rating 2	1	0	1	2	1	1	1	4	8	
		% agreement	100	100	100	100	100	100	100	100	80	

As reported in Table 5.19, all 11 turn taking sub-domains met the acceptable intra-rater agreement of 80% (McHugh, 2012). The mean percentage of intra-rating is reported on at a sub-domain level. This was noted in a 100% agreement in three sub-domains, namely gestural turns with body movements, aided turns without assistance, and multimodal turns (i.e., a combination of gestural and aided turns). Mean intra-ratings of 94%, 96%, 97% and 93% were obtained for verbal turns with vocalisations, aided turns with assistance, gestural turns with facial expressions, and multimodal turns with a combination of verbal and gestural turns respectively. In four other sub-domains, an acceptable level of mean intra-rater agreement was obtained. For verbalisations (96%), head nods (85%), and the two multimodal sub-domains (i.e., combined verbal and aided turns; and combined verbal, aided and gestural turns), agreement was at 88% and 98% respectively.

5.4.2.1.2. Inter-rater reliability

One session in the baseline phase (Session 2) and two in the intervention phase (Sessions 8 and 9) were randomly selected to assess inter-rater reliability of scoring the AACOM-PwD. An acceptable level of inter-rater mean agreement above 80% (McHugh, 2012) was obtained for the total turns observed (93%), as well as for turn taking in the gestural domain (91%) and multimodal domain (83%). A mean percentage of inter-rater agreement for the verbal domain (79%) and aided domain (72%) did not meet the minimum acceptable level of 80% (McHugh, 2012). The inter-rater reliability raw scores, percentage agreement and mean percentage agreement are displayed in Table 5.20.

Table 5.20: Inter-rater reliability of scoring the AACOM-PwD – domain level

		Total scores of turns on *AACOM-PwD* domains				
Inter-rated session	**Inter-raters**	**Total turns**	**Verbal turns**	**Gestural turns**	**Aided turns**	**Multimodal turns**
Session 2	Researcher	27	13	3	1	10
	Independent rater	29	12	3	1	13
	% agreement	93%	92%	100%	100%	77%
Session 8	Researcher rating	83	32	6	4	41
	Independent rating	88	26	7	2	48
	% agreement	94%	81%	86%	50%	85%
Session 9	Researcher rating	85	30	8	3	44
	Independent rating	78	19	7	2	50
	% agreement	92%	63%	88%	67%	88%
Mean % agreement		93%	79%	91%	72%	83%

All percentage (%) agreement scores were rounded off to the nearest whole.

Further inter-rating reliability scoring results for the 11 turn taking sub-domains are reported in Table 5.21. In this table, the percentage agreement in each sub-domain is presented horizontally, while mean agreement across three inter-rated video-recorded sessions is presented vertically. The mean inter-rater agreement for vocalisations (67%) and verbalisations (76%) were found to be below the accepted minimum level of 80% for inter-rater agreement (McHugh, 2012).

Table 5.21: Inter-rater reliability of scoring the AACOM-PwD – sub-domain level

AACOM-PwD		**Phase**	**Baseline**	**Intervention**		**Mean % agreement**
Domain	**Sub-domain**	**Session**	**2**	**8**	**9**	
		Inter-ratings				
Verbal turns	Vocalisations	Researcher	1	1	1	67%
		Independent rater	1	2	2	
		% agreement	100	50	50	
	Verbalisations	Researcher	12	31	29	76%
		Independent rater	11	24	17	
		% agreement	92	77	59	
Gestural turns	Body movement	Researcher	1	1	1	100%
		Independent rater	1	1	1	
		% agreement	100	100	100	
	Head nod	Researcher	1	4	6	82%
		Independent rater	1	5	4	
		% agreement	100	80	67	
	Facial expressions	Researcher	1	1	1	83%
		Independent rater	1	1	2	
		% agreement	100	100	50	
Aided turns	With assistance	Researcher	0	3	2	61%
		Independent rater	0	1	1	
		% agreement	100	33	50	
	Without assistance	Researcher	1	1	1	100%
		Independent rater	1	1	1	
		% agreement	100	100	100	
Multi-modal turns	Verbal + Gestural	Researcher	9	23	31	79%
		Independent rater	11	35	35	
		% agreement	82	66	89	
	Verbal + Aided	Researcher	1	13	2	49%
		Independent rater	2	9	7	
		% agreement	50	69	28	
	Gestural + Aided	Researcher	0	1	1	100%
		Independent rater	0	1	1	
		% agreement	100	100	100	
	Verbal + Aided + Gestural	Researcher	0	4	10	97%
		Independent rater	0	4	9	
		% agreement	100	100	90	

The mean inter-rater percentage agreement for the gestural sub-domains were 100% (i.e., body movements), 82 % (i.e., head nods), 83% (i.e., facial expressions). In the aided sub-domain, inter-rater agreement scores were 100% (aided turns without assistance) and 61% (aided turns with assistance). Two multimodal sub-domains met the minimum acceptable level of 80% (McHugh, 2012). These sub-domains were 100% (i.e., multimodal turns with gestural and aided turns) and 97% (i.e., multimodal turns with verbal, aided and gestural turns).

One sub-domain (i.e., multimodal turns with verbal and gestural turns) obtained an inter-rater agreement score of 79%, falling slightly below the 80% threshold of acceptable inter-rater agreement. Multimodal turns with combined verbal and aided turns (49%) was the sub-domain with the lowest mean inter-rater percentage agreement (McHugh, 2012). In summary, inter-rater agreement scores in six sub-domains met the minimum acceptable level of 80% (McHugh, 2012), while five sub-domains fell below this threshold.

5.5. Stakeholder's perspective: Participant with dementia

The researcher adhered to the Stakeholder Perspective Checklist (Appendix Y) as a guide to ask the participant two questions related to her enjoyment of using the electronic life story conversational support. This process unfolded in a conversational manner and was recorded on video. The researcher transcribed the participant's verbatim responses, which are shown in Table 5.22 as qualitative data.

Table 5.22: Stakeholder's perspectives – Self-reported enjoyment of a PwD

Session	***Did you enjoy talking about your life story today?*** **(Yes, No, Unsure)**	***How much did you enjoy talking about your life story today?***	**Other verbal information**
1	Yes	"Hmm"	*"It was good"*
2	Yes	Off-topic response	
3	Ok	"A lot, I guess"	*"I liked it amazingly"*
4	Yes	"A lot"	
5	"Oh, I don't know"	Off-topic response	
6	Off-topic response		
7	Yes	"Yes"	
8	Oh, yes		*"This is lovely…I haven't done anything like it, like it before"* (during the video recording)
9	Off-topic responses		*"That is very difficult"*

As shown in Table 5.22, the researcher asked the first question verbally: "*Did you enjoy talking about your life story today*?". The researcher supported each question as well as the conversation that was elicited from the questions by using AAC strategies (outlines in Par. 4.14). Although the researcher provided the participant three option cards with symbols to indicate 'yes, no, unsure' responses, the participant provided verbal responses to Question 1. The participant responded verbally and in the affirmative to the first question in sessions 1, 2, 4, 7 and 8. She also produced off-topic responses (Sessions 2 and 5) or did not respond (Sessions 6 and 9). Although the researcher attempted to elicit meaningful responses in these instances, she was sensitive to the participant's body language, which indicated fatigue or restlessness.

Based on the participant's response to Question 1, the researcher asked the second question using the same AAC strategies as applied in the first question. The use of multimodal AAC strategies supported the participant in expressing her opinion in a natural conversational manner. For instance, in Session 3, when the researcher expanded on the participant's response, the latter made a further contribution to confirm her enjoyment of the session, as noted in her response, "*I liked it amazingly*".

Although the participant did not self-report her enjoyment in Session 9, observational information from the video recording of the entire session provided anecdotal information. For instance, it was evident that the participant laughed many times during Session 9 and used hand movements to express enjoyment whilst listening to music on the voice output.

5.6. Overview of results: Phases 3A and 3B

In Phase 3A, professionals' viewpoints on the components of the PC-AAC intervention for PwD were obtained. Professionals in Factor A viewed person-centred authorship and directly reported outcomes from the perspective of a person with dementia as important components. Professionals in Factor B, with more clinical expertise, viewed person-centred language style as a way to uphold the personhood of a person with dementia and believed that this may be achieved through AAC strategies and techniques such as augmented input. Professionals in Factor C valued person-centred communication strategies such as displays of empathy but expressed a neutral view on adapted participatory methods to involve persons with dementia in developing their AAC interventions.

In Phase 3B, the feasibility of implementing the electronic life story conversational support and scoring reliability of the AACOM-PwD was tested. The electronic life story conversational support was reliably implemented by the researcher. Acceptable levels of scoring agreement were noted in the intra-rater and inter-rater reliability of scoring the AACOM-PwD at a domain level (e.g., overall turns). However, inter-rater reliability was not at an acceptable level of scoring agreement in the multimodal sub-domain. The participant with dementia self-reported her enjoyment in using the electronic life story conversational support with the researcher.

5.7. Summary

The results of the feasibility phase of the main study were presented in this chapter in two parts. Firstly, Q-methodology data was collected qualitatively and analysed quantitatively through by-person factor analysis. Three factors (A, B and C) emerged as the viewpoints of professionals on the components of the PC-AAC intervention for PwD. The results of ranked statements by *z*-scores were reported in distinguishing and consensus statements. Secondly, the case study results were presented for procedural reliability and for data reliability of the intra-rater and inter-rater scoring of the AAC Outcome Measure for PwD developed in this study. Finally, the perspective of the participant on her enjoyment of using the electronic life story conversational supported was reported. Collectively, the results presented in this chapter provide a variety of findings on the four components of the PC-AAC intervention for PwD developed in this study. These findings will be discussed in the next chapter.

CHAPTER 6: DISCUSSION

6.1. Introduction

This chapter discusses the results presented in Chapter 5. The discussion unfolds in accordance with the three viewpoints that emerged via Q-sort data. As illustrated in Figure 6.1, the viewpoints of professionals are discussed according to the following four components of the PC-AAC intervention package for PwD:

i. Person-centred care approach within AAC interventions for PwD
ii. Electronic life story conversational support for PwD
iii. AAC outcomes
iv. AAC outcome measure for PwD

The results of the procedural and scoring reliability of an AAC outcome measure for PwD, developed as part of Component 4, are also discussed. In each section, the findings of this study are compared to those of previous research studies. Pertinent literature is also consulted to highlight important implications of this study.

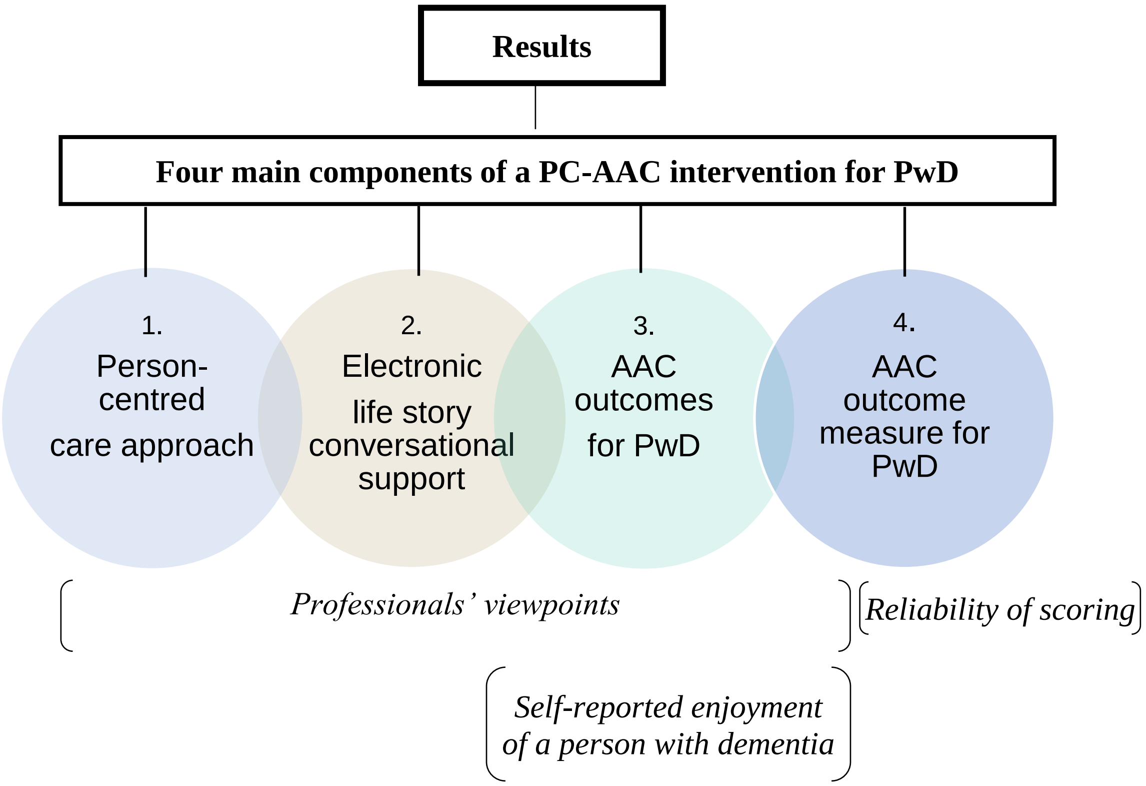


Figure 6.1: Schematic illustration of the discussion chapter

In addressing sub-aim *iii* of the main study (see Figure 6.1), the researcher examined the patterns of professionals' clinical and educational viewpoints on the four components of the PC-AAC intervention package for PwD developed in this study. The professionals were not informed of this intervention package or of its specific components or sub-components. During concourse development (Par. 4.5.1.4), professionals answered open-ended questions and contributed their unique opinions on elements of person-centred care, AAC strategies for PwD, AAC outcome and AAC outcome measurement. In the collection of Q-sort data, professionals had full control of how they interpreted and subsequently ranked each statement, based on their unique opinion.

Based on the study results, three distinct factors (viewpoints) emerged. These three factors provided an idea of how researchers, clinicians and academic teachers viewed various components of the PC-AAC intervention package for PwD, based on their subjectivity towards statements. In accordance with Q-methodology, the statements that distinguished each factor, and the highest- and lowest-ranked statements of each factor were brought to the forefront of the discussion (Zabala et al., 2018). Consensus statements across all three factors were used to highlight significant components.

6.1. A person-centred care approach in AAC interventions for persons with dementia

The concept of person-centred care is often questioned in the literature, with even wider speculation about the validity of its clinical application (Edgar et al., 2020; Dewing, 2019; Dewing & McCormack, 2017; Gibson et al., 2019; McCance et al., 2011; McCormack et al., 2011; Røsvik et al., 2013; Swaffer, 2019). However, in this study there was a commonly held strong agreement across all factors that person-centred care as a philosophy of care for persons with dementia is clinically achievable (Table 5.16). This view was further substantiated from the data that emerged as specific person-centred care statements were the highest-ranked statements in Factors A and B (Tables 5.7, and 5.10 respectively). In fact, it is noteworthy that Factor B prioritised all of their strongest agreements with statements on person-centred care (Table 5.10). Factor B offered a strong collective view that persons with dementia must not only be spoken to in a manner that upholds their personhood, they must be supported in decision making and consulted about their preferences (Bourgeois et al., 2016; Chang, 2015; Chang & Bourgeois, 2020; Fazio et al., 2018; Reitz & Dalemans, 2016). Tailored AAC interventions for persons with dementia should also be introduced according to strengths.

Factors A and B represented the majority of professionals (Table 5.5) in the Q-sort data. Therefore, it can be inferred that the majority of professionals expressed their strongest agreement with, and indicated a possible validation of person-centred care components and sub-components of the PC-AAC intervention package for PwD developed in this study.

A fine-grained analysis revealed that professionals with the highest factor loadings and most defined views in Factor A (Table 5.6), Factor B (Table 5.9) and Factor C (Table 5.12) indicated a special interest in person-centred care for adults or for both adults and children with disabilities. Taken together, their views may suggest that professionals have a strong view of person-centred care as part of AAC interventions for persons with dementia. Further specific statements related to the concept of person-centred care are integrated and discussed in the sections that follow.

6.2. PC-AAC scaffolding strategies

This study found that conversational partners play a significant role in positively affirming the unique identity of a person with dementia (Brooker, 2004; Kitwood, 1997). According to Webb (2017), person-centredness within interpersonal interactions is mostly operationalised as a relational concept achieved through the manner and style of a conversational partner. The professionals making up Factor B strongly agreed that talking to a person with dementia in an infant-like manner was patronising. This view is important for two reasons. Firstly, it validates how person-centredness within AAC-supported interpersonal interactions lies not only with a person with dementia, but extends to the relationship that develops between conversational partners (Alm et al., 2004; Astell et al., 2010; Davis & Shenk, 2015; Ellis & Astell, 2017; Hamel et al., 2016; Hydén, 2011; Kindell et al., 2013; Purves et al., 2015; Webb, 2017; Wong et al., 2009). The current finding endorses the relational attribute of upholding the personhood of a person with dementia (Kitwood, 1997; Webb, 2017).

A complementary aspect of the relational focus of person-centred interpersonal interactions was introduced by Factor C's very strong agreement that a conversational partner should never correct off-topic utterances of a person with dementia. However, this view stands in contrast to previous studies where the effect of non-electronic memory and communication supports focused on increasing on-topic statements and reducing the number of off-topic responses in a person with dementia (Aitken, 2015; Andrews-Salvia et al., 2003; Bourgeois et al., 2001; Chang, 2011; Dynes, 2018; Fried-Oken et al., 2009; Fried-Oken et al., 2012; Gomèz-Taibo et al., 2014; McPherson et al., 2001; Reitz & Dalemans, 2016; Ruiz, 2015). Whilst reducing off-topic responses may be an appropriate outcome of interventions focused on improving the quality of language competency, it may arguably be of less importance when the AAC outcome is aimed at building a social connection with a person with dementia (Alant, 2017; Hung et al., 2019). Furthermore, this result presents an interesting clinical insight. As professionals primarily interested in interpersonal interaction, the views of Factor C appeared to pose an important consideration to AAC interventionists in terms of how researchers are measuring the competency of a person with dementia in using AAC. It may be inferred that if a conversational partner views communication competence as a meaningful contribution by a person with dementia within an interpersonal interaction, and if the goal is social connection (Light, 1988), then off-topic responses may be assumed to be irrelevant.

Related to other relational aspects of person-centred care, the findings of the current study indicated that empathy may be an important construct to apply within AAC-supported interpersonal interactions with persons with dementia (Alant, 2017; Alant et al., 2015; Broughton et al., 2011; McEvoy & Plant, 2014). This was reflected in the firm agreement by professionals in Factor C that conversational partners should display empathy by mirroring the emotion of the person with dementia as a means to facilitate interpersonal interaction. Furthermore, Factor A expressed agreement that a conversational partner could support interpersonal interaction by pausing to give a person with dementia time to respond.

These findings support previous research on person-centred communication which emphasises the importance of a conversational partner to listen, observe, and validate the responses of a person with dementia (Alant, 2017; Alant et al., 2015; Broughton et al., 2011; Dynes, 2018; McEvoy & Plant, 2014; Savundranayagam et al., 2020; Savundranayagam & Moore-Nielsen, 2015; Savundranayagam et al., 2016). Perhaps this finding may further suggest that person-centred communication strategies may be a vehicle through which developing friendships and a social connection with persons with dementia could possibly be achieved in PC-AAC interventions for persons with dementia (de Medeiros et al., 2012; Perion & Steiner, 2017; Sabat & Lee, 2012; Ward et al., 2012).

Augmented input was evidenced in previous case studies to be a useful multimodal conversational partner strategy to support auditory comprehension in persons with semantic dementia (Cress & King, 1999) and thereby to improve conversational turn taking in a person with frontotemporal dementia (Gibbons et al., 2012). In the current study, professionals in Factor B expressed their agreement with the use of augmented input as a strategy to support auditory comprehension of spoken language in persons with dementia. Upon closer inspection of the biographical data, Factor B was represented by three clinicians with work-related experience in adults with other neurologically acquired communication disorders (Table 5.9). It may be plausible to infer that this view may suggest the clinical relevance of augmented input for persons with dementia.

Whilst the effect of augmented input on persons with aphasia was investigated in previous studies (Dada et al., 2019; Wallace et al., 2012), there are few studies that systematically explored this strategy in AAC interventions for persons with dementia (May et al., 2019). Augmented input using high-context visuographic support was found to support comprehension of narratives in persons with aphasia in a pilot study conducted by Dada et al. (2019). This finding potentially suggests the clinical relevance of augmented input as a strategy to support comprehension of life story content in an electronic format on an AAC device in the AAC intervention developed in this study (Cress & King, 1999; Gibbons et al., 2012).

Furthermore, Factor B strongly agreed about the importance of supporting the decision making of persons with dementia. Previous studies found evidence that visual and verbal support in understanding and reasoning related to the decision-making capacity of persons with mild to moderate dementia had a positive effect on their end-of-life care (Bourgeois et al., 2016; Chang, 2015; Chang & Bourgeois, 2020; Murphy & Oliver, 2013; Reitz & Dalemans, 2016). In summary, the results of the current study support previous studies (Dada et al., 2019; Dada et al., 2020) that exemplify the potential of aided input as a multimodal strategy to support language comprehension in persons who require AAC.

6.3. Electronic life story conversational support

The implementation of assistive technology with artificial intelligence capabilities to support communication in persons with dementia is a timely topic in the field of AAC (Dada et al., 2020). Congruently, in this study professionals across all factors agreed that intelligent assistive technology and AAC devices using artificial intelligence should be explored to support communication and interpersonal interaction in persons with dementia (Table 5.16). Whilst this is an optimistic finding, the adoption of both assistive technology with artificial intelligence and electronic AAC devices for persons with dementia is generally influenced by their design (Waller, 2019).

The literature highlights the importance of supporting persons with dementia to be included in research by using adapted participatory methods (Hydén et al., 2018; Keady et al, 2018; Kullberg & Odzakovic, 2018). In this regard, Mooney et al. (2018) developed an AAC application that comprises computerised processing of human language (natural language processing) and just-in-time principles using personalised vocabularies co-constructed with persons with semantic dementia. In the current study there was shared agreement among the three factors that facilitating the involvement of persons with dementia in co-designing their own AAC interventions promotes their self-determination. This finding is an important one, as it is aligned with current discourses on participatory design methods that involve persons who use AAC as collaborators of their own intervention (Dewing, 2008a; Kindell et al., 2017; Murphy & Oliver, 2013; Murphy et al., 2010; Johnson, 2020; Moulam et al., 2020; McLaughlin, 2020; Taylor & Balandin, 2020). Perhaps this finding further suggests that involving persons with dementia as co-producers of their own electronic AAC interventions, technology abandonment may potentially be reduced and acceptability of the interventions may be increased (McConnell et al., 2019; Realpe & Wallace, 2010; Waller et al., 2005; Waller, 2019).

Regardless of the benefits that participatory methods may hold for promoting person-centred care, it is professionals who ultimately decide whether such methods actually are employed in research and clinical practice (Giezendanner et al., 2019; Hickey et al., 2018; Hopper, 2003; Mahendra et al., 2011; Mahendra et al., 2013; Saccasan & Scerri, 2020). The results of the current study show that there may be a professional hesitancy with regard to adopting participatory design methods in research with persons with dementia. This finding may be problematised in the literature by the limited research on person-centred AAC interventions and the need for professional training on how to involve persons with dementia in decision-making (Bourgeois et al., 2016; Crete-Nishihata, 2012; Douglas et al., 2018; Dynes, 2018; Saccasan & Scerri, 2020).

Moreover, this finding was also evident in the distinguished neutral view of professionals in Factor C towards co-production as a participatory method with persons with dementia in the design of an AAC intervention (Table 5.14). Furthermore, Factor C also affirmed their distinct view that while working collaboratively with persons with dementia and other stakeholders was important, it was not necessary (Table 5.14).

Notably, professionals in Factor C were the most well-experienced of all factors in their overall work-related experience (i.e., > 21 years) in the areas of AAC, dementia studies and technology (Table 5.12). As a factor, they collectively had an interest in interpersonal interaction rather than in person-centred care per se. What their neutral view may suggest, is that the cognitive and communicative challenges of persons with dementia and ethical issues related to informed consent make participatory design methods difficult to implement. Furthermore, Johnson (2020) asserts that there is a general lack of guidance to AAC professionals on how to implement participatory research with persons who use AAC. While this may explain Factor C's neutrality on participatory methods, Taylor and Balandin (2020) are of the opinion that AAC researchers should be obliged to justify their reasons for excluding persons who require AAC (such as persons with dementia) from the intervention design process.

The paradigm of participatory research, experiential knowledge and lived experience, in which persons with dementia are viewed as experience-based experts, is significantly underscored in the literature (Boivin et al., 2018; Davies et al., 2019; Hubbard et al., 2003; Harding et al., 2019; Lepore et al., 2017; Mann & Hung, 2019; McLaughlin, 2020). In the current study, Factor A expressed their strong distinguished agreement that persons with dementia should be supported in authoring the content of their own life story conversational support. Notably, this statement obtained the highest *z*-score (1.704), making it the highest-ranked statement of all 37 statements in the Q-sort data. Importantly, this finding resonates with current literature and has two main implications.

i. Firstly, it extends the essence of person-centred care to one of empowerment, control and autonomy, where persons with dementia are viewed as experts of their own lives and therefore should be authoring their own life stories from their unique perspective (Bartlett, 2014; Bartlett et al., 2017; Crete-Nishihata, 2012; Fazio et al., 2018; Hydén & Antelius, 2017; Keady et al., 2018; Yeandle et al., 2012). These elements possibly lean towards person-centred care being an evolving concept and potentially becoming nuanced with a more contemporary understanding of its operationalisation in research with persons with dementia (Alsawy et al., 2019; Bosco et al., 2019; Hennely & O'Shea, 2017; Hung & Chaudhury, 2011; Jesus et al., 2019; Terkelsen et al., 2020).

ii. Secondly, when persons with dementia are supported with adapted methods through the use of AAC support, a new understanding of their own life story may potentially be introduced into the design of electronic life story conversational supports (Critten & Kucirkova, 2019; Kindell et al., 2014; Nedlund & Bartlett, 2019; Subramaniam & Woods, 2016). The current study also supports literature that advocates the creation of a 'conversational space' into which persons with dementia should be invited, and where adapted methods may be used to enable the sharing of their stories (Antelius et al., 2018; Hydén et al., 2018; Kindell et al., 2014; Kullberg & Odzakovic, 2018). Furthermore, it supports previous AAC studies in which researchers utilised adapted interview methods to co-construct meaning with persons with use AAC to facilitate their communicative autonomy to convey their own stories in research (Smith et al., 2018; Dada, Tönsing & Goldbart, 2020). As such, the results of the current study may possibly point towards pertinent guidance of how AAC research and the design of electronic conversational supports could be further explored with persons with dementia.

Electronic AAC systems with multimedia support have been evidenced in previous studies to promote enjoyment for both the conversational partner and persons with dementia in an interpersonal interaction (Alm et al., 2004; Astell et al., 2010; Hamel et al., 2016; Hung et al., 2020; Ferm, Ekström, Larsson, & Samuelsson, 2020; Purves et al., 2015). This finding was confirmed in the current study. Both Factors A and C shared a distinct agreement that life-story-based conversational supports with personalised music and digital photographs on electronic devices (e.g., iPad) enhance the enjoyment of interpersonal interaction for persons with dementia. However, on closer analysis of the findings, mixed professional views were noted on whether electronic AAC systems were useful for persons with more severe dementia.

Factor B tended to slightly disagree that non-electronic AAC systems were the most beneficial communication supports for a person with mild to moderate dementia. Furthermore, the viewpoints of the professionals making up Factor B indicated a possible agreement with the notion that electronic legacy messages (i.e., digitally recorded by the person with dementia in their natural voice in the early stages of dementia) stored as voice output on electronic devices (e.g., iPad) were useful to facilitate social connection with a person with dementia. This finding is in contrast to a previous exploratory pilot study by Fried-Oken et al. (2012) in which voice output was found to have a negative impact on communication in persons with dementia.

It may be plausible to suggest that, based on their collective clinical experience, the professionals in Factor B may value the clinical utility of using electronic AAC systems with specific web-based applications (Aitken 2015; Alm et al., 2004; Astell et al., 2010; Dynes, 2018; Hamel et al., 2016; Purves et al., 2015). This is supported in a previous study in which an application, Computer Interactive Reminiscence and Communication University of Sheffield (CIRCUS), showed to have a positive effect on interpersonal interaction with persons with dementia (Samuelsson & Ekström, 2019).

Conversely, Factor A notably disagreed that electronic AAC systems such as tablet computers with applications (apps) may be useful to support interpersonal interaction in a person with moderate to severe dementia. This view may be due to concerns raised in the literature that the novelty of technology use and unfamiliarity with electronic AAC systems within interpersonal interactions may present challenges for persons with dementia as their cognitive and communication difficulties advance (Fried-Oken et al., 2012; Fried-Oken et al., 2009; Hung et al., 2020). The views of Factor A were from a majority of professionals who were researchers and academic teachers employed at educational institutions. It may be reasonable to infer that their views are due to the limited research evidence that exists of communication intervention for persons with moderate to severe dementia in general (Swan et al., 2018). Electronic AAC systems as a conversational support for persons with moderate to severe dementia in particular is under-researched (Dynes, 2018; Ekström et al., 2017; Fried-Oken et al., 2012; Hung et al., 2020; Swan et al., 2018). As the evidence base of electronic AAC systems for persons with moderate to severe dementia expands and new insights are discovered, professionals' views in this regard may evolve.

A possibly cautionary reminder was the distinguished strong agreement of professionals in Factor B that persons with dementia should be consulted about their personal preferences for interpersonal interaction. This may indicate that any customisation and personalisation of electronic conversational supports should be in accordance with the personal preferences of persons with dementia (Bourgeois et al., 2016; Brooker, 2004; Fazio et al., 2018; Kitwood, 1997). The literature also suggests that consulting persons with dementia in the design process allows for the personalisation of electronic life story supports (Hashim et al., 2013; Subramaniam & Woods, 2016).

6.4. AAC outcomes for Persons with Dementia

A decade ago, Bourgeois et al. (2010) cautioned AAC professionals that whilst advancements in electronic AAC systems would create new interactional possibilities for persons with dementia, goals that have a human and social impact on persons with dementia and their conversational partners must remain. Findings in the current study support AAC literature, as Factor A and C strongly agreed that a social connection was an important goal of AAC interventions (Alant, 2017; Granlund et al., 2008) for persons with dementia, while Factor B held a neutral view in this regard. This finding suggests that social connection as a valued goal and as determined by a person with dementia should possibly be at the forefront of a person-centred AAC intervention (Birt et al., 2020; Haapala et al., 2019; Hancock et al., 2006; Patterson et al., 2017; Perion & Steiner, 2017; van der Roest et al., 2009).

Findings in the current study indicate that professionals supported the measurement of intra-personal outcomes such as enjoyment within an interpersonal interaction (Table 5.16). Electronic life story conversational support, such as the one developed in this study, has the potential to not only facilitate turn taking during interpersonal interaction, but also to create opportunities for enjoyment during such interaction. This was substantiated by the direct self-report from the participant with dementia in the case study (Table 5.22). The self-reported enjoyment from the case study participant supports previous studies which indicate that electronic conversational supports with life story content are enjoyable and may serve as a means to overcome the social isolation experienced by persons with dementia (Astell et al., 2005; Astell et al., 2010; Ekström et al., 2017; Elfrink et al., 2018; Ferm et al., 2020; Hamel et al., 2016; Hung et al., 2020; Samuelsson & Ekström, 2019). The anecdotal evidence from video recordings, showing that the participant displayed behaviours that indicated enjoyment although she did not express this enjoyment verbally, is an important finding. This may suggest that supplementing the self-reports of a person with dementia (Crete-Nishihata et al., 2012; Mooney et al., 2018a; Mooney et al., 2018b), with proxy reports of enjoyment from a familiar conversational partner may provide a holistic understanding of AAC outcomes in persons with dementia.

6.5. AAC outcome measurement for Persons with Dementia

Sharing meaning and participating in everyday interactions may arguably be the most optimal outcomes for persons using AAC systems (Alant, 2017; Fried-Oken & Granlund, 2012; Kindell et al., 2017; Savundranayagam, 2013). Findings in this study have supported this argument. Professionals in Factor B felt that an AAC outcome measure for persons with dementia should measure not only the frequency of turn taking exchanges, but also the modality of turn taking (e.g., turn taking with gestures). It should possibly also include participation outcomes, in other words how frequently a person with dementia takes part in everyday interpersonal interactions.

In the current study, professionals across all three factors agreed about the necessity of measuring the satisfaction of a person with dementia when using AAC strategies within an interpersonal interaction. Importantly, this possibly suggests that a satisfaction domain should be included in an AAC outcome measure, but it may also shed light on whose perspective should be sought to measure satisfaction of an AAC intervention (Broomfield et al., 2019; Cohen & Hula, 2020; Swaffer, 2015). In the current study, the person with dementia self-reported her enjoyment of using the electronic conversational support within an interpersonal interaction with the researcher. This was an important finding for further development of AAC outcome measures for persons with dementia, as it places value on self-reported satisfaction expressed from their own perspective. The finding further supports previous literature which highlight that AAC interventions for persons with dementia should have meaningful real-life outcomes, and their satisfaction in using electronic systems must be self-reported (Mooney et al., 2018a; Mooney et al., 2018b). The self-reported enjoyment in using the electronic conversational support from the perspective of the participant with dementia provides a complementary source of evidence to the reliability of scoring the AACOM-PwD as discussed in the next section (Cohen & Hula, 2020).

6.6. Reliability

6.6.1. Procedural reliability

Reliability is central to evidence-based practice in AAC as it provides a way to measure the accuracy of data collection and sheds light on the validity of research findings (Kent-Walsh & Binger, 2018). Within the AAC literature, Koul, Petroi and Schlosser (2010) suggest that AAC professionals rely on evidence of electronic AAC systems benefiting persons who use AAC, before they consider implementing technology in clinical practice. Since research on electronic AAC systems for persons with dementia is still developing (May et al., 2019), the procedural reliability results in this study may provide preliminary evidence to support further research into electronic AAC interventions for persons with dementia.

The high procedural integrity results indicate that the electronic life story conversational support developed in this study can be reliably implemented by the same individual and with a different individual (Barton, Meadan-Kaplanksky, & Ledford, 2018). This infers that AAC clinicians could possibly be trained in implementing the PC-AAC scaffolding strategies to support turn taking in persons with dementia. As shown in previous literature (Kent-Walsh & Binger, 2018; Morin et al., 2018), high procedural integrity increases the confidence that AAC outcomes resulting from the use of electronic AAC systems may be due to the accuracy and reliability of implementing procedures as intended (Barton et al., 2018). Given the neurodegenerative nature of dementia (Bourgeois & Hickey, 2018; Mahendra et al., 2011; Mahendra et al., 2013), the preliminary procedural integrity results in this study may provide an avenue to propel further research to demonstrate the effect of person-centred AAC interventions for persons with dementia.

6.6.2. Reliability of scoring the AAC Outcome Measure for PwD (AACOM-PwD)

According to Enderby (2014) an outcome measure must be used in the same manner on more than one instance before it is considered to be effective in detecting changes over time. In this study, intra-rater reliability was scored in the same manner at different time points and showed acceptable levels of agreement on a domain level (Table 5.18). This acceptable intra-rater reliability is of clinical importance as it indicates the preliminary consistency of ratings of the AACOM-PwD across different time points (Enderby, 2014; Ledford, et al., 2018).

Similarly, at a sub-domain level (Table 5.19), there was acceptable intra-rater reliability on all eleven sub-domains. Given the degeneration of the expressive language, family members and other conversational partners of persons with dementia might be inclined to focus only on the loss of communication (Bourgeois & Hickey, 2018; de Medeiros et al., 2012; Hopper, 2003; McEvoy & Plant, 2014). With a loss of expressive language and progression of dementia, the AACOM-PwD may have clinical utility to provide conversational partners with an observed quantified picture of the specific type of turns that are used by a person with dementia (Cohen & Hula, 2020). This may be specifically important for the multimodal turn taking domain (Brock et al., 2019). The literature shows that there is limited evidence of the use of multimodal AAC systems for persons with progressive cognitive-communicative conditions (Broughton et al., 2011; Cress & King, 1999; Mooney et al., 2018a; Rebstock & Wallace, 2020; Wong et al., 2009).

Therefore, in this study, multimodal turns as captured on the AACOM-PwD show that the combined use of verbal utterances, vocalisations with head nods, or body movements within turn may be a valuable indicator of the overall communicative strengths that a person with dementia possesses (Brock et al., 2019; Broughton et al., 2011; Cress & King, 1999; Enderby, 2014; Kindell et al., 2013; Trahan et al., 2014; Wong et al., 2009). This finding supports current research on outcome measurement tools in persons with dementia, which focus on the preserved strengths of persons with dementia (Hickey et al., 2018; Lanzi, et al., 2020). The AACOM-PwD may therefore serve as a strength-based measure of the various types of turn taking that the person with dementia still utilises in interpersonal interaction, instead of focusing on communication deficit and loss.

Acceptable inter-rater scores were found in respect of the level of agreement with the total number of turns at a domain level (Table 5.20), which potentially suggests that the turn taking coding scheme may be used to train other raters. Importantly, however, inter-ratings were not at an acceptable level for verbal turns (e.g., verbalisations), aided turns (e.g., with assistance) and multimodal turns (e.g., verbal and aided) at a sub-domain level (Table 5.21). In this vein, it could be inferred that the observation and coding of subtle multimodal turn taking behaviours are open to interpretation (Ledford et al., 2018). Therefore, further training of raters in coding and refinement of the existing coding definitions may be an important consideration for any future studies (Gast & Ledford, 2018).

Reliability of scoring was ensured owing to video analysis that allowed repeated viewings of turn taking. Previous studies show that the coding of subtle behaviours based on video analysis is a time-consuming process (Williams et al., 2017). Given that certain sub-domains, e.g., multimodal turns, did not meet the acceptable agreement level of scoring at an intra-rater level, it may be inferred that the scoring reliability of multimodal turns could be enhanced by supplementing coding with conversational analysis procedures (e.g., transcriptions and analysis of turns) (Ekström et al., 2017; Hydén, 2011; Kindell et al., 2013; Spilken & Bethlehem, 2003) or with computer-based microanalytic video coding of turn taking (Ellis & Astell, 2017; Spriggs, et al., 2018).

While this was an exploratory study into the reliability of scoring the AACOM-PwD, it is important to consider anecdotal information that may shed light on the possible clinical utility of this measure (Zaga et al., 2020). Scrutiny of the surface-level turn taking data of raw scores revealed that the number of total turns increased sharply from the baseline to the first intervention session when the researcher applied the PC-AAC scaffolding strategies to the interpersonal interaction. Firstly, this infers that the measure was able to establish a baseline or stability of turn taking (Gast & Ledford, 2018). Secondly, this provided plausible evidence to suggest that the AACOM-PwD may be sensitive to measuring a change in turn taking in a person with dementia (Brock et al., 2019; Cohen & Hula, 2020; Spriggs et al., 2018). This anecdotal finding – albeit in a small way – indicates that the AACOM-PwD may show possible improvement in the turn taking of a person with dementia when using an electronic life story conversational aid and being supported by a conversational partner with AAC strategies.

This is a vital anecdotal finding of this study and has important clinical implications that may warrant further research. In sum, the AACOM-PwD could potentially benefit AAC clinicians and support them in measuring the effect of the AAC intervention – pre-intervention, during intervention and as a post-intervention maintenance measure with other conversational partners (Brock et al., 2019; Spriggs et al., 2018).

6.7. Summary

This chapter discussed and interpreted the results of the study. Discussions were aligned to the four components of the PC-AAC intervention package for PwD developed in this study by highlighting the significance of three distinct professional viewpoints from Q-methodology data. An understanding of how expert professionals view person-centred AAC strategies, techniques, AAC outcomes and outcome measures for PwD can provide valuable insights into current thinking on intervention development. Furthermore, knowing which specific components professionals ranked as most or least important is a vital indicator of the validity of the PC-AAC intervention developed in this study. Findings related to procedural reliability of implementing the electronic life story conversational support and the scoring reliability of the AACOM-PwD were also discussed.

CHAPTER 7: CONCLUSION, EVALUATION AND RECOMMENDATIONS

7.1. Introduction

This final chapter presents a summary of results and conclusions regarding the exploration of the PC-AAC intervention package for interpersonal interaction with PwD that was developed in this study. Next, the clinical implications of the research findings are outlined, followed by an evaluation of the strengths and limitations of the study. The chapter concludes with an outline of recommendations for future research.

7.2. Summary of the findings

This study was a scientific endeavour to develop and explore the PC-AAC intervention package for interpersonal interaction with PwD. The package comprised four main components, namely the person-centred care approach in AAC interventions, electronic life story conversational support, AAC outcomes, and AAC outcomes measurement. The study followed an evidence-based practice triad of inquiry.

i. Firstly, the assembly of the four components was based on current research evidence that resulted from the researcher's findings of a research review on AAC interventions for persons with dementia. These findings were supplemented with the findings from a second scoping review of intelligent assistive technology devices for persons with dementia.
ii. Secondly, based on professionals' clinical and educational expertise, three viewpoints on the components of the PC-AAC intervention for PwD were obtained. Professionals viewed person-centred authorship and directly reported outcomes from the perspective of a person with dementia as important components of the PC-AAC interventions for PwD. Professionals with more clinical expertise viewed person-centred language style as a way to uphold the personhood of a person with dementia and believed that this may be achieved through AAC strategies and techniques such as augmented input. The results showed that some professionals view adapted participatory methods as a means to facilitate the inclusion of persons with dementia in the design of their AAC interventions, whereas others do not have a clear view on this concept.
iii. Thirdly, the researcher conducted a process of co-producing an electronic life story conversational support with a person with dementia and implemented it in a real-life context with the same individual. The feasibility of procedural reliability related to the

implementation of the electronic life story conversational support and intra-rater and inter-rater reliability of scoring the AACOM-PwD was tested. Procedural integrity results indicated that the electronic life story conversational support was reliably implemented by the researcher. Acceptable levels of scoring agreement were noted in the intra-rater and inter-rater reliability of scoring the measure, especially at a domain level. Inter-rater reliability was not at an acceptable level of scoring agreement in some sub-domains. Furthermore, a direct stakeholder's perspectives were obtained from the self-reported enjoyment of a person with dementia who used the electronic life story conversational support with the researcher.

To summarise, this study drew evidence from three evidence-based practice cornerstones. Accordingly, the results suggest that person-centred AAC interventions could mean more than just integrating the preferences of the person with dementia once-off. Instead, professional views point towards other integral elements that include persons with dementia in playing vital roles throughout the process of designing AAC interventions. Involving persons with dementia as decision makers creates the possibility to promote greater autonomy, control and authorship of their AAC interventions. It is possible to infer that the findings of this study herald a renewed perspective on how professionals could move the field of AAC forward in re-thinking traditional ways of developing AAC interventions with persons with dementia.

7.3. Clinical implications of the study

Three main clinical implications of this study emerged:

i. Firstly, the results suggest possible clinical guidelines for AAC professionals on the participatory processes that could be considered when developing AAC interventions for persons with dementia. They emphasise the involvement of persons with dementia at various stages of the development and feasibility-testing phases. Accordingly, this introduces clinical insights that may suggest the different roles persons with dementia could play as co-producers of their own interventions. With the current rise in dialogue on involving persons with dementia in AAC intervention research, the results of this study could possibly serve as a reference point from which AAC researchers and clinicians may consult for evidence-based decision making for persons with dementia.

   Despite the co-production process being challenging, given the cognitive-communicative difficulties of persons with dementia, AAC is in itself a vital strategy to support the participation of persons with dementia in this intervention process. Taken together, the adapted methodologies, processes and ways of facilitating the involvement of persons with dementia within this study are of significant clinical relevance to AAC professionals.

ii. Secondly, to the researcher’s knowledge, the AACOM-PwD is the first attempt of an outcome measure of interpersonal interaction with persons with dementia in the field of AAC. The AACOM-PwD makes an important clinical contribution in providing initial psychometric testing on the reliability of scoring. Specifically, this adds to possible ways of measuring aided conversations in persons, which is a vital aspect of evidence-based decision making.

iii. Thirdly (and also as far as the researcher knows), this study is the first to bring together various international AAC professionals with a range of clinical and educational expertise in expressing their viewpoints on AAC interventions for persons with dementia. Discourses of this nature are not only an important avenue to charter the way forward in the field of AAC, they are also an integral aspect of developing the evidence base for persons with dementia.

7.4. Evaluation of the study

In view of the scientific impact of this research study in contributing novel evidence to the field of AAC, the most salient strengths and limitations are highlighted next.

7.4.1. Strengths

Methodologically, this study had two main strengths:

i. Q-methodology enabled patterns of professionals’ viewpoints to be obtained qualitatively based on their own biases. When combined with the statistical sophistication of quantitative analysis, three unique professional views on the components of the PC-AAC intervention package for PwD emerged. This would not have been possible to be elicited with traditional ranking scales. Hybrid research methodologies such as Q-methodology add to the robustness of the results obtained in this study.

ii. The inclusion of views from an e-Delphi panel of international AAC professionals during concourse development added breadth and diversity of professional input to the Q-sort data. This would not have been likely with an in-person focus group as is typical of traditional Q-sorting. As far as the researcher currently knows, this study is the first to focus on AAC interventions for persons with dementia by employing Q-methodology as a research method. The combination of Q-methodology with an e-Delphi panel, specifically during concourse development, further contributes to the methodological innovation applied in the current study.

Conceptually, the study contributed important information to the three cornerstones of evidence-based practice as applied to AAC. It was the first to review and synthesise the current literature on AAC interventions in persons with dementia. The research review conducted in Phase 1 of the study spurred the need for a secondary scoping, which provided a synthesis of current evidence on electronic AAC systems for persons with dementia. In Phase 2 of the study, the researcher presented a preliminary organising framework of how to potentially involve persons with dementia in the co-production of their own electronic conversational support. The attempt was not to be prescriptive and there was no inference to involve persons with moderate to severe dementia in all roles at all times during the design of the AAC intervention. Instead, in the absence of documented guidelines on how to promote the involvement of persons with dementia in co-producing electronic AAC interventions, this study should contribute to the current dialogue on incrementally increasing involvement of persons with dementia in AAC research.

Phase 3 added a novel contribution by offering a nuanced examination of the diversity of viewpoints held by AAC professionals on the PC-AAC intervention developed in this study. In sum, all three phases of this study offered an innovative contribution to the field of AAC for persons with dementia. As such, the study has generated valuable insights for expanding the knowledge base and making progress in the field of AAC for persons with dementia.

7.4.2. Limitations

i. Firstly, given the exploratory nature of the research aim, Q-methodology extrapolated viewpoints of professionals from a purposive sample. In an attempt to increase the variances of views, only 26 Q-sorts were used in the final factor analysis after factor rotations. Whilst these viewpoints may provide an understanding of the patterns of different views on the components of the PC-AAC intervention for PwD, they do not represent all viewpoints on the topic. Therefore, conclusions reached in this study cannot be generalised. The online administration of the Q-sort may also have been challenging for some professionals due to their being unfamiliar with Q-methodology and the unexpected technical difficulties that accompany online data collection. This may have potentially affected how professionals ranked the statements on the online platform.

ii. Further reliability testing of scoring the AACOM-PwD with a larger participant sample was impeded by the COVID-19 pandemic. Scoring reliability was limited to a single participant with moderate to severe dementia. Consequently, the exploratory results for the intra-rater and inter-rater reliability of scoring the AACOM-PwD in this study are not conclusive.

iii. Family members afford unique perspectives to shaping evidence-based person-centred AAC interventions for persons with dementia. Although the researcher managed to obtain the perspectives of a person with dementia, family perspectives were distinctly underexplored in this study.

7.5. Recommendations for future research

The recommendations for future research arising from this study include the following:

i. The effect that the PC-AAC scaffolding strategies for electronic life story conversational support developed in this study had on interpersonal interaction in a person with dementia is an avenue for further investigation. This matter could be investigated further by using a single-case experimental design. Consequently, this study may assist in expanding treatment efficacy studies related to electronic AAC systems for persons with dementia.

ii. Further refinement is required of the turn taking codes on the AACOM-PwD and in-situ training of inter-raters is recommended to improve the inter-rater reliability at a sub-domain level.

iii. Reliability of scoring of the AACOM-PwD should be further improved through training a larger number of raters and using a larger sample size of participants. This may result in greater accuracy of inter-rater scores through more sophisticated statistical measures (i.e., inter-class coefficients) to establish the psychometric properties of the AACOM-PwD.

iv. Further investigation into the content validity of the AACOM-PwD, together with a panel of AAC content domain experts, is needed as an independent validation study. This will contribute to the refinement and psychometric properties of the AACOM-PwD.

v. Further refinement is required of a PC-AAC co-production organising framework for persons with dementia as applied in this study. Importantly, the involvement of family members in the process of co-producing AAC interventions for persons with dementia should be explored further in future studies.

vi. Finally, further research on PC-AAC interventions *with* persons with dementia, based on their personalised life stories, must involve diverse persons with dementia, especially from non-Western countries.

7.6. Summary

Chapter 7 summarised the results and presented the conclusions of the study. The significant contributions of the study results were highlighted, followed by a presentation of the strengths and limitations of the study. Finally, important recommendations that emerged from the current research suggested possible avenues for further study.

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Appendices

Appendix A: Co-Production Process: Observation Form

	Multiple Stakeholder Interview and Observations			
Guiding Questions	**Music Therapist**	**Occupational Therapist**	**Nursing Staff**	**Familiar Conversational Partner**
What does Mrs Brown enjoy talking about?				
What are Mrs Browns' personal preferences, things she enjoys doing?				
Are there phrases Mrs Brown says often?				
Is there anything else that could assist in getting to know Mrs Brown?				
Observations:				

Appendix B: Co-Production Process: Participant's Information from the Family

Dear family,

With your help, I will write short sentences on *Mrs. Brown's life story. This will serve as the basis for our interpersonal interaction in the research study.

Would you kindly provide any (i) **family photographs** (other than those in her private bedroom) depicting interesting and happy times in Mrs Brown's life (incl., her travels, family and friends) and (ii) **information in the table below**?

Thank you for your time.

Warm Regards,
Adele May

Note:

- All bullet points may not be applicable to Mrs *Brown, they only serve as a guide.

Childhood and family	▪ Where did she grow up? ▪ Who were her parents? ▪ Her position in the family (e.g., youngest daughter) ▪ A distinctive family trait ▪ Childhood interests ▪ She was really good at.... ▪ She didn't like.... ▪ School stories… ▪ Special early memories	**Mrs Brown's career:** ▪ first job ▪ last job Interesting work experiences
Achievements/things she was good at	▪ Special skills ▪ Milestones ▪ Highlights in personal life or career	**Hobbies/pastimes** ▪ Activities of interests (e.g., dancing, art, crafts, play sport, cooking, gardening) ▪ Who are her best friends, people she socialised/socialises with most of the time?
Personal preferences	▪ Clothing preferences ▪ Fashion and style ▪ Signature perfumes ▪ Nicknames/special names she likes to tease or calls others ▪ Personal expressions, sayings/phrases that's associated with her ▪ Favourite colours ▪ Favourite recipes/dishes ▪ Favourite TV shows, actors, movies ▪ Celebrities ▪ Music genre's	**Religious/cultural/spiritual** ▪ Community/associations ▪ Cultural celebrations ▪ Birthdays ▪ Spiritual beliefs ▪ Values

*Mrs Brown is a pseudonym used for the case study participant

Appendix C: Life Story Framework and Themes

Participant's life story centred around the high points and milestones related to three themes:	
LIFE EVENTS	
	Description
Upbringing	Places where you lived, growing up (with your family) preparing meals, helping others, shopping.
Jobs, occupation, career	Previous employment, work or educational experiences.
Education	Personal grooming and taking care of your health.
Travel	Places you have travelled, went on vacation, places of interests
Special events	
Hobbies and pastimes	Hobbies or fun activities done during in spare time or for relaxation e.g., cooking
PEOPLE	
	Description
Family life Immediate family Extended family Friends Community	Relationships with a partner or spouse, family, special friends, neighbours, carers.
VALUES	
	Description
Religion and spirituality	Religious beliefs, going to specific religious activities. Affirm identity through the participants core values

Adapted from Skinner, Bonnet, Schlundt, and Karlekar (2019)

Appendix D: Life Story Vignette and Example Script

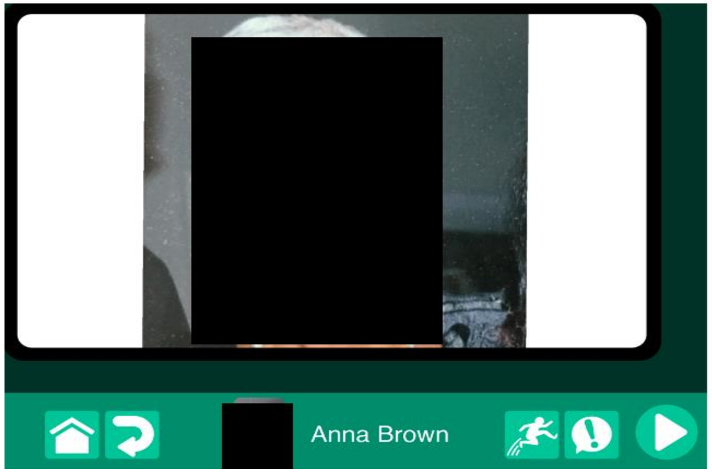
Life story 1: Family Meals

1. I am Anna Brown and I am Jewish
2. Every Friday night we celebrate Shabbat
3. We always have a lot of food at Shabbat dinner
4. Lala does all the cooking in the home
5. I am not good at cooking or baking
6. Rosh Hoshana is my favourite time of year
7. We dip apple slices in honey to celebrate the Jewish new year

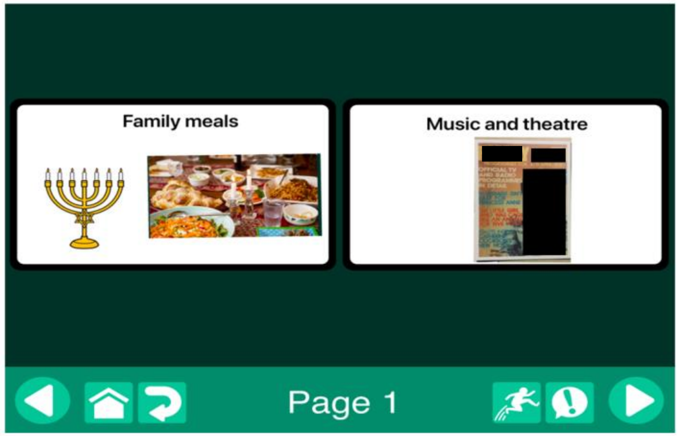
- Life story screen shots from the AAC device are on the next page (Appendix E)

	Intervention Phase (semi-structured script)
Cover Page	*Mrs Brown, these are your stories. You helped me write them.*
Page 1	Researcher: Aided modelling: point to symbols on the AAC device: *You have two stories to choose from.* *Would you like to talk about family meals, OR* *Would you like to talk about music and theatre?*
Page 2	**I am Anna Brown, and I am Jewish.**
Page 3	*Mrs Brown, this is a picture of a beautiful synagogue. I am sure this is a special place for you?*
Page 4	Multimodal responses (option for the participant to point to pictures if she prefers)
Page 5	Aided modelling: point to symbols on the AAC device: *Yes, Mrs Brown, you are Jewish. The synagogue is a special place*
Page 6	**Every Friday night we celebrate shabbat.**
Page 7	*Mrs Brown, this is a picture of your family. Nelly looks so happy to be at Shabbat dinner.*
Page 8	Multimodal responses (option for the participant to point to pictures if she prefers)
Page 9	Aided modelling: point to symbols on the AAc device *Your family, and Nelly are happy to be at Shabbat dinner.*
Page 10	**We always have a lot of food at shabbat dinner.**
Page 11	*Mrs Brown, in this is picture, there is bread, soup, and salad at Shabbat dinner. The soup looks delicious.*
Page 12	Multimodal responses (option for the participant to point to pictures if she prefers)
Page 13	Researcher: Aided modelling: point to symbols on the AAC device *At Shabbat dinner, the soup and salad were delicious.*
Page 14	**I am not good at cooking or baking.**
Page 15	**Lala does all the cooking in the home.** Researcher: Aided modelling: point to symbols on the AAC device *Mrs, Brown, so Lala does all the cooking at home?*
Page 16	Multimodal responses (option for the participant to point to pictures if she prefers) Researcher: Aided modelling: point to symbols on the AAC device
Page 17	**Rosh Hoshana is my favourite time of year.**
Page 18	**We dip apple slices in honey to celebrate the Jewish new year.**
Page 19	*Mrs, Brown the apples slices and honey must be a sweet treat!*
Page 20	Multimodal responses (option for the participant to point to pictures if she prefers)
Page 21	Researcher: Aided modelling: point to symbols on the AAC device *Yes, Mrs Brown, you dip apple slices in honey to celebrate the Jewish new year, and you love it!*

Appendix E: Electronic Life Story Conversational Support on AAC device (Example)

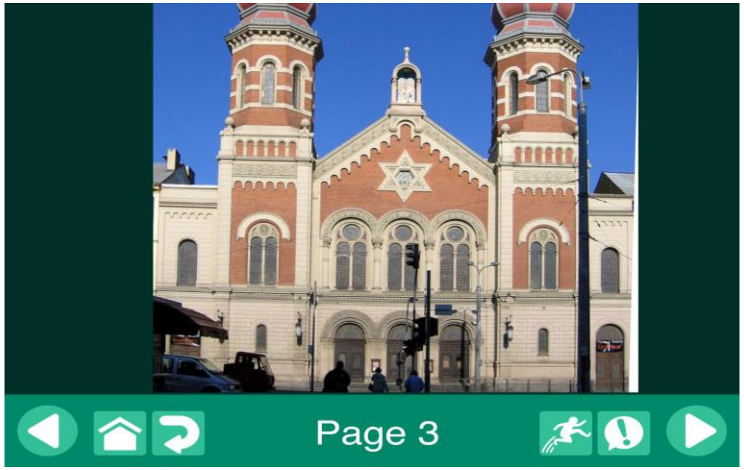

[redacted]

[redacted]

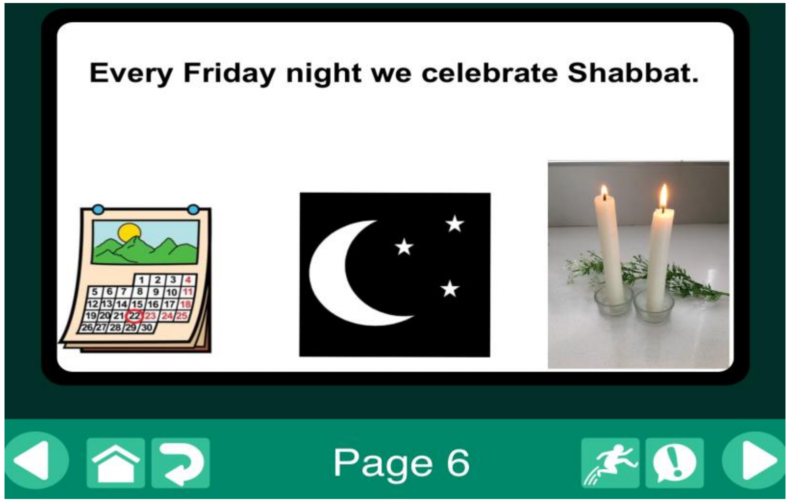

[redacted]


[redacted]

I am Anna Brown and I am Jewish.

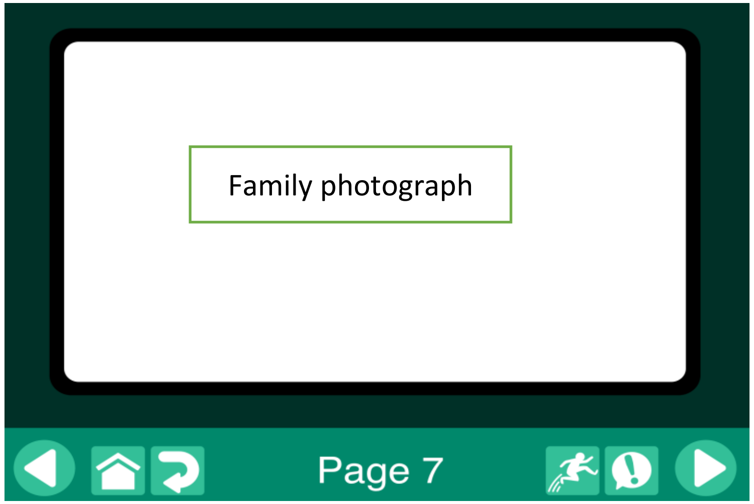


All names are pseudonyms. All personal photographs are blanked out.



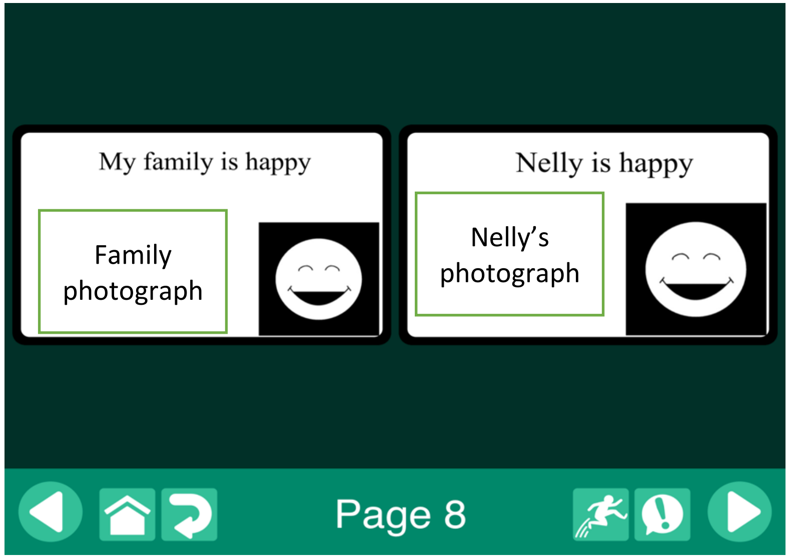
Every Friday night we celebrate Shabbat.

Page 6



Family photograph

Page 7



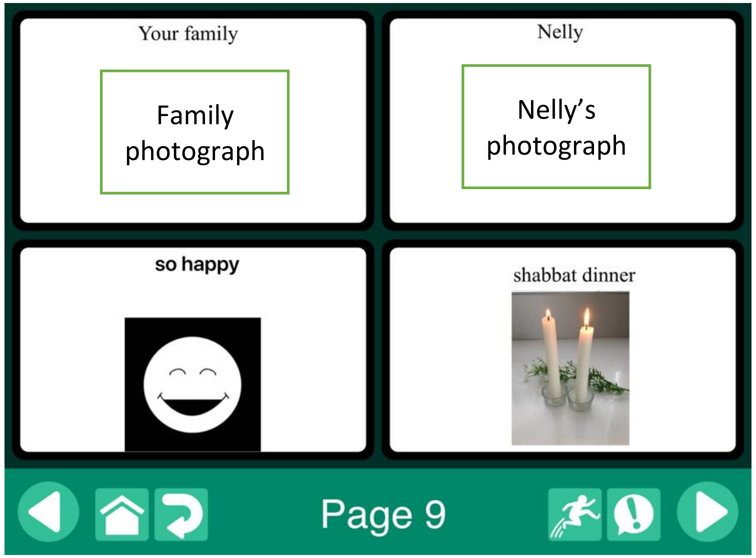
My family is happy

Family photograph

Nelly is happy

Nelly's photograph

Page 8



Your family

Family photograph

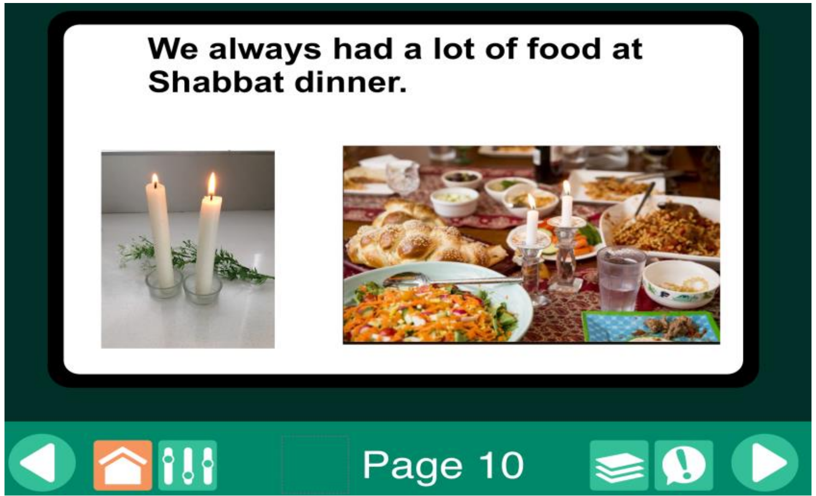
Nelly

Nelly's photograph

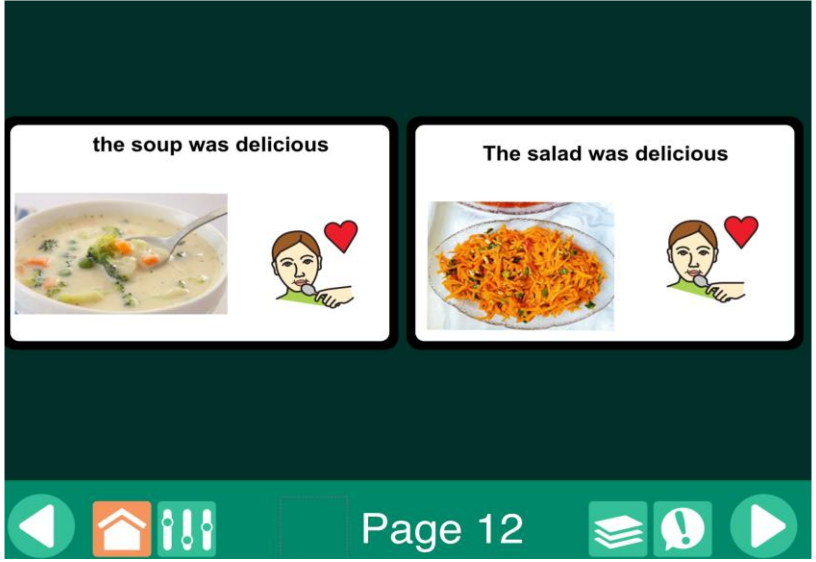
so happy

shabbat dinner

Page 9



We always had a lot of food at Shabbat dinner.



the soup was delicious

The salad was delicious

at shabbat dinner

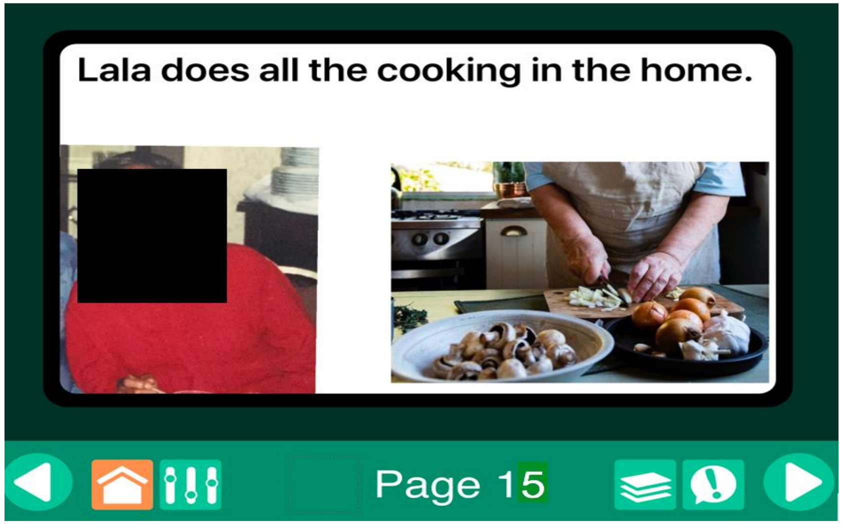
soup

salad

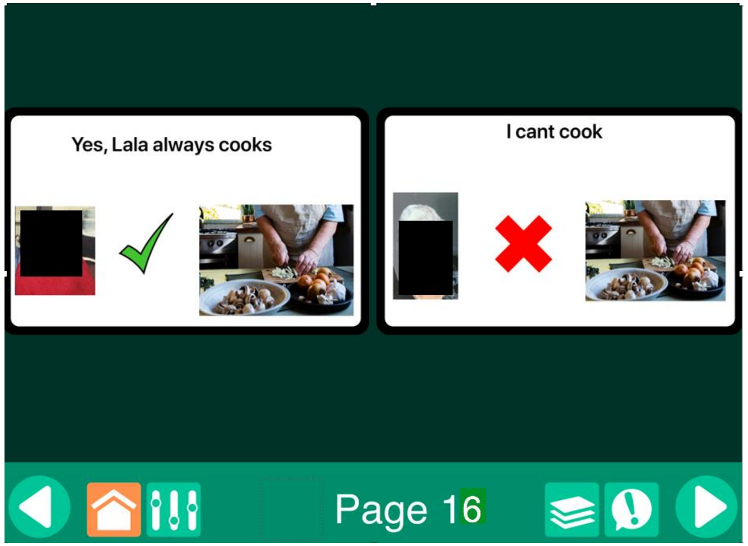
was delicious


I am not good at cooking or baking.

[redacted]


Lala does all the cooking in the home.

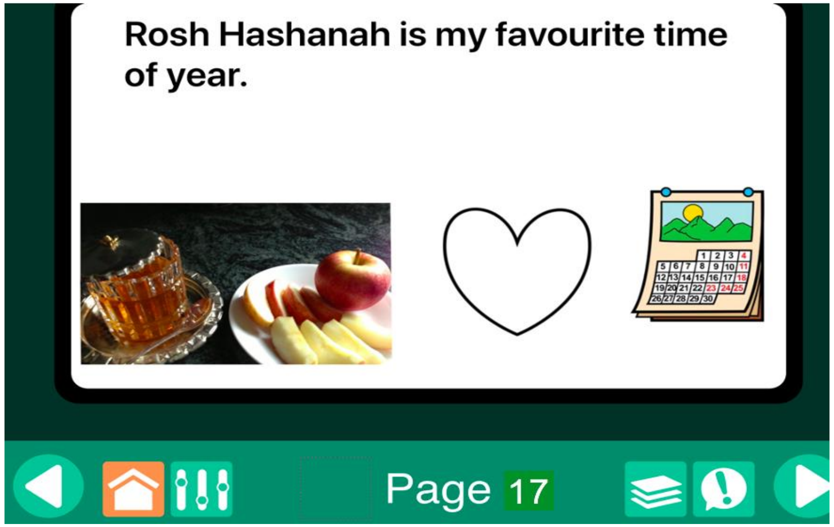
[redacted]

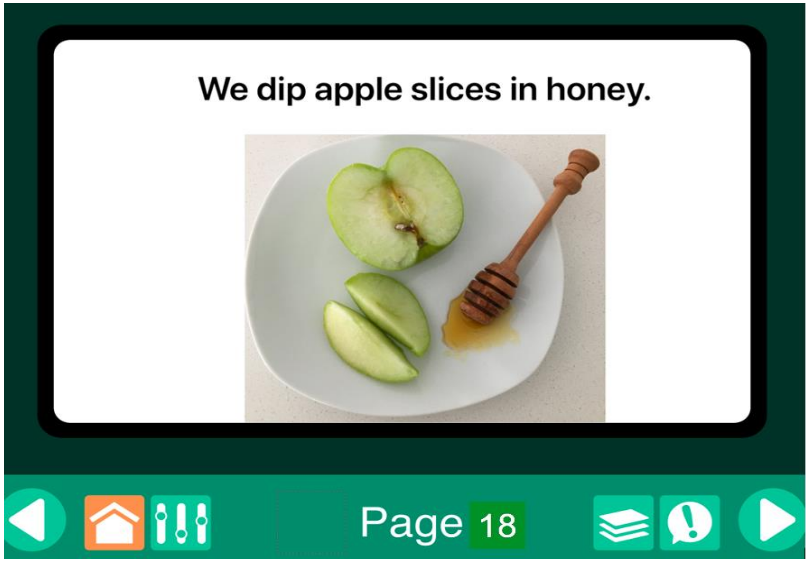

Yes, Lala always cooks

[redacted]

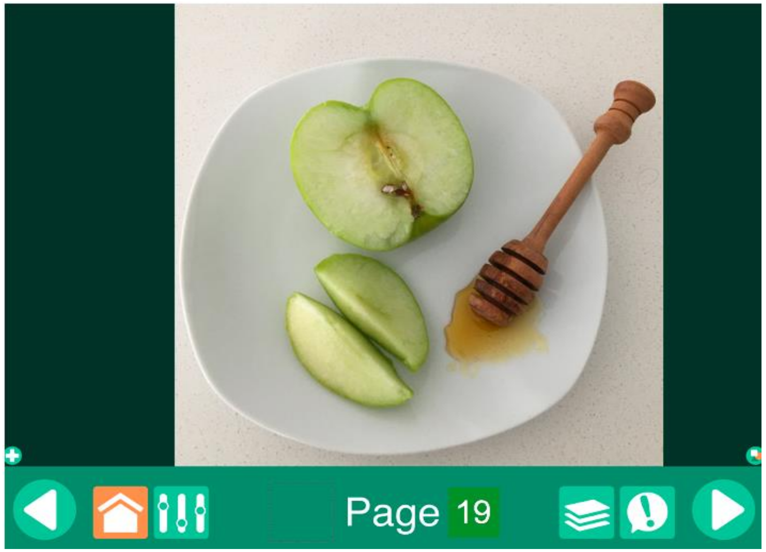
I cant cook

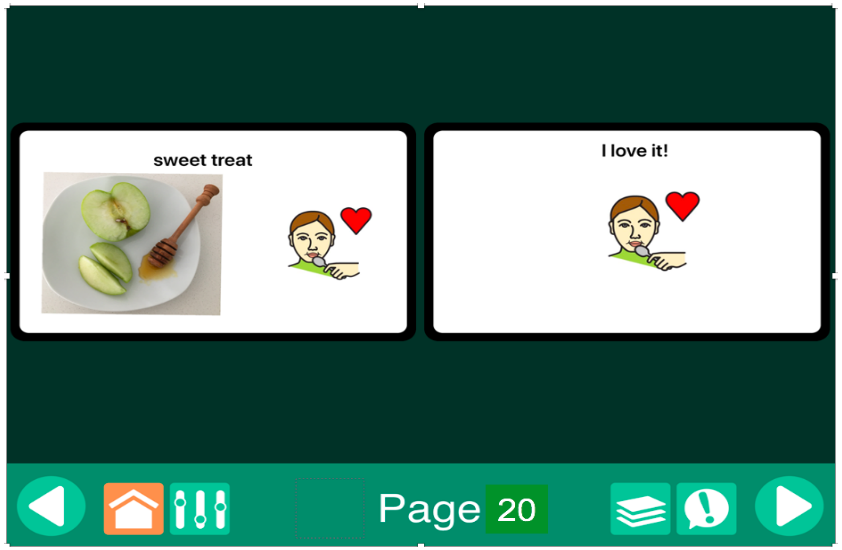
[redacted]


Rosh Hashanah is my favourite time of year.



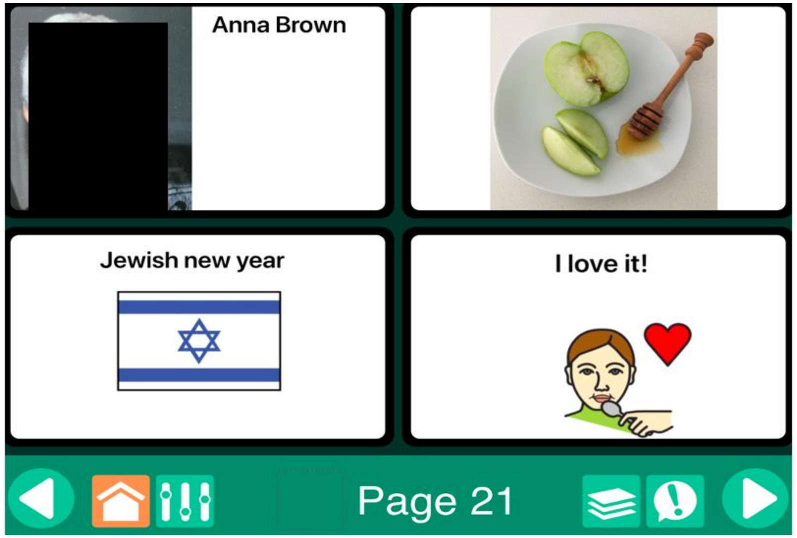
We dip apple slices in honey.





sweet treat

I love it!



[redacted]

Anna Brown

Jewish new year

I love it!

Images: Google Images and researchers own.

Appendix F1: AAC Outcome Measure for Persons with Dementia (AACOM-PwD)

Augmentative and Alternative Communication Outcome Measure for A Person with Dementia (AACOM-PwD)

CODING SHEET (example)

Name of coder: Session coded: Date:

Instruction:

1) Watch the 10-minute video-recording to score turn taking responses of the participant only.
2) Turn taking is scored within the boundary of an interaction opportunity (labelled as interaction on the scoring sheet, e.g., interaction 1). Each participant has a minimum of 5 interaction opportunities for each 10-minute interaction.
3) Begin by familiarising yourself with the coding definitions and coding colours in the coding guide.
4) Stop scoring when the ten-minutes is completed

	Turn taking Domains											
Interaction 1	**Verbal (V)**		**Gestural (G)**			**Aided (A)**		**Multimodal (MM)**				**Turns**
	Turn taking Sub-domains											
	a	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	**c**	**d**	
Offer Choice	✓											
PCC+wait		✓										
Model choice	✓								✓			
Subtotal	2	1							1			4
Subtotal	3							1				

Interaction 2	**Verbal (V)**		**Gestural (G)**			**Aided (A)**		**Multimodal (MM)**				**Turns**
	a	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	**c**	**d**	
Offer Choice		✓										
PCC+wait								✓				
Model choice	✓		✓									
												4
Subtotal	1	1	1					1				
Subtotal	2		1					1				

Interaction 3	**Verbal (V)**		**Gestural (G)**			**Aided (A)**		**Multimodal (MM)**				**Turns**
	a	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	**c**	**d**	
Offer Choice	✓	✓ ✓										
PCC+wait								✓				
Model choice						✓						
Subtotal	1	2				1		1				5
Subtotal	3					1		1				

Interaction 4	**Verbal (V)**		**Gestural (G)**			**Aided (A)**		**Multimodal (MM)**				**Turns**
	a	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	**c**	**d**	
Offer Choice		✓						✓				5
PCC+wait									✓ ✓			
Model choice										✓		
Subtotal		1						1	2	1		
Subtotal	1							4				

SCORE SHEET: TALLY THE ABOVE SUB-TOTAL SCORES ON THE SHEET BELOW

Total Turns count (horizontally) all turns in each interaction (pink block)	**Turn taking Domains** ***Total:** count all sub-totals (vertically) in each interaction 1-8 in their respective colour	**Turn taking Sub-domain** **Total:** count all sub-totals (vertically) in each interaction 1-8 in their respective colour		
14	Verbal Turns 9	(a)Vocalisations	4	🟩
		(b) Verbalisation	5	🟩
	Gestural Turns 1	(a) Body movement		🟨
		(b) Head nod	1	🟨
		(c) Facial expression		🟫
	Aided Turns 1	(a)With assistance	1	🟦
		(b)Without assistance		🟦
	Multi-modal Turns 7	(a)Verbal +Gestural	3	🟧
		(b) Verbal + Aided		🟧
		(c) Gestural + Aided		🟧
		(d)Verbal + Aided+ Gestural		🟫
***note:** an off -topic turn is counted as a turn				

Appendix F2: AACOM-PwD Operational Definitions

AACOM-PwD: TURN TAKING OPERATIONAL DEFINITIONS	
DOMAIN	**SUB-DOMAIN**
	Score: 1 Point for each occurrence within a turn opportunity
Verbal (V) Turn A verbal turn is a vocalisation (sound) or verbalised (utterance) response or contribution to an interaction	This score is given when a participant uses a: **(a)** ***communicative vocalisation*** i.e., vocalisation/sound (e.g., ooo), or a verbal agreement (e.g., uh-huh, Hmm). **(b)** ***verbal utterance:*** i.e., single-word (e.g., "right" /pause/) or multi-word utterance ("let me see"../pause/). * One score is given if there is a verbal repetition of the same utterance ("me too-me too").
Gestural (G) Turn A gestural turn indicates that the participant used a body movement, head-nod or part of the body as a turn taking response	A gestural turn is a response to an interaction initiated by the researcher, or (b) after the 5 sec expectant delay, (c) or 5 seconds after the final modelling by researcher. This score is given when a participant uses the following gestures: (a) **Body movement** (e.g., handwave, shoulder shrug) (e.g., moves shoulders to indicate "perhaps") (b) **Headnod** (e.g., head moving side-to side to indicate "no") (c) **Facial movements or eyebrow raising** (e.g., to indicate shock)
Aided (A) Turn An aided turn indicates that the participant used the AAC device or AAC symbol selection during a turn	This score is given when participant is: (a) Physically touching or pointing to AAC symbols or using the iPad **with assistance** within a turn (b) Physically touching, pointing or using the iPad **without assistance** within a turn.
Multi-Modal (MM) Turn A multimodal turn indicates that the participant used a combination of any two turn taking domains during a turn	Dual turn: ***(a) Verbal + Gestural*** i.e., vocalisation or verbal utterance [single or multi-word] + gesture] (e.g. saying "yes + moving head up and down) ***(b) Verbal + Aided*** i.e., vocalisation or verbal utterance [single or multi-word] + pointing touching, body orientated to the AAC device. *The pointing/touching body orientation can be done simultaneously with vocalisation or verbal utterance *(c)* ***Gestural + Aided*** i.e., gesture (before, during or followed after) + physically touching, pointing, body orientated to AAC device or AAC symbols. *The pointing/touching body orientation can be done simultaneously with the gesture, OR before OR after the gesture. Triadic turn: *(d)****Verbal + Aided+ Gestural*** vocalisation/verbal utterance +gesture + pointing/touching/body orientated to the AAC device (e.g., "me too-me too+ raise eyebrow+ thereafter looking at the AAC device) *The pointing/touching body orientation can be done simultaneously with vocalisation/verbal utterance or gesture, OR before OR after vocalisation, verbal utterance or gesture. * Aided includes AAC symbol selection using the legacy message (voice-output) with or without assistance from the researcher.
Note: An off-topic turn: is scored as a turn: i.e., the participant asking an unrelated question or making an inappropriate comment that is not related to the life story content (e.g., says " *I lost my keys*" in response to "which story would you like to talk about")	

Appendix G1: Ethics Approval (original study)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Research Ethics Committee

18 September 2019

Dear Mrs AA May

Project Title:	The effect of an AAC intervention on the social interaction and engagement of persons with dementia
Researcher:	Mrs AA May
Supervisor:	Prof S Dada
Department:	CAAC
Reference number:	16389256 (HUM005/0719)
Degree:	Doctoral

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 29 August 2019. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

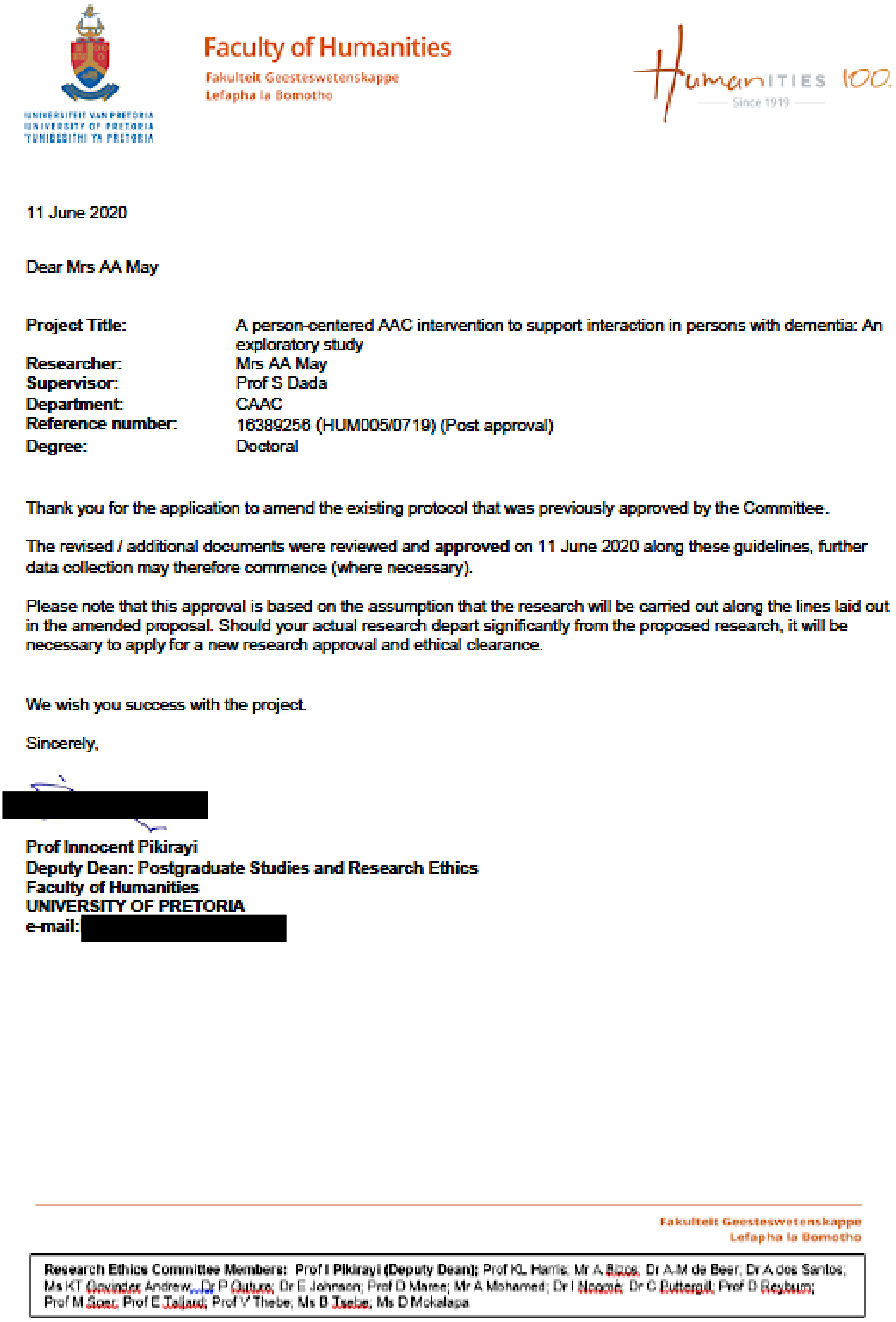
Sincerely

Prof Maxi Schoeman
Deputy Dean: Postgraduate and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: [redacted]

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Mr A Bizos; Dr L Blokland; Dr K Booyens; Dr A-M de Beer; Ms A dos Santos; Dr R Fasselt; Ms KT Govinder Andrew; Dr E Johnson; Dr W Kelleher; Mr A Mohamed; Dr C Puttergill; Dr D Reyburn; Dr M Soer; Prof E Taliard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

Appendix G2: Ethics Approval (amended study)



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YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100.
Since 1919

11 June 2020

Dear Mrs AA May

Project Title:	A person-centered AAC intervention to support interaction in persons with dementia: An exploratory study
Researcher:	Mrs AA May
Supervisor:	Prof S Dada
Department:	CAAC
Reference number:	16389256 (HUM005/0719) (Post approval)
Degree:	Doctoral

Thank you for the application to amend the existing protocol that was previously approved by the Committee.

The revised / additional documents were reviewed and **approved** on 11 June 2020 along these guidelines, further data collection may therefore commence (where necessary).

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the amended proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely,

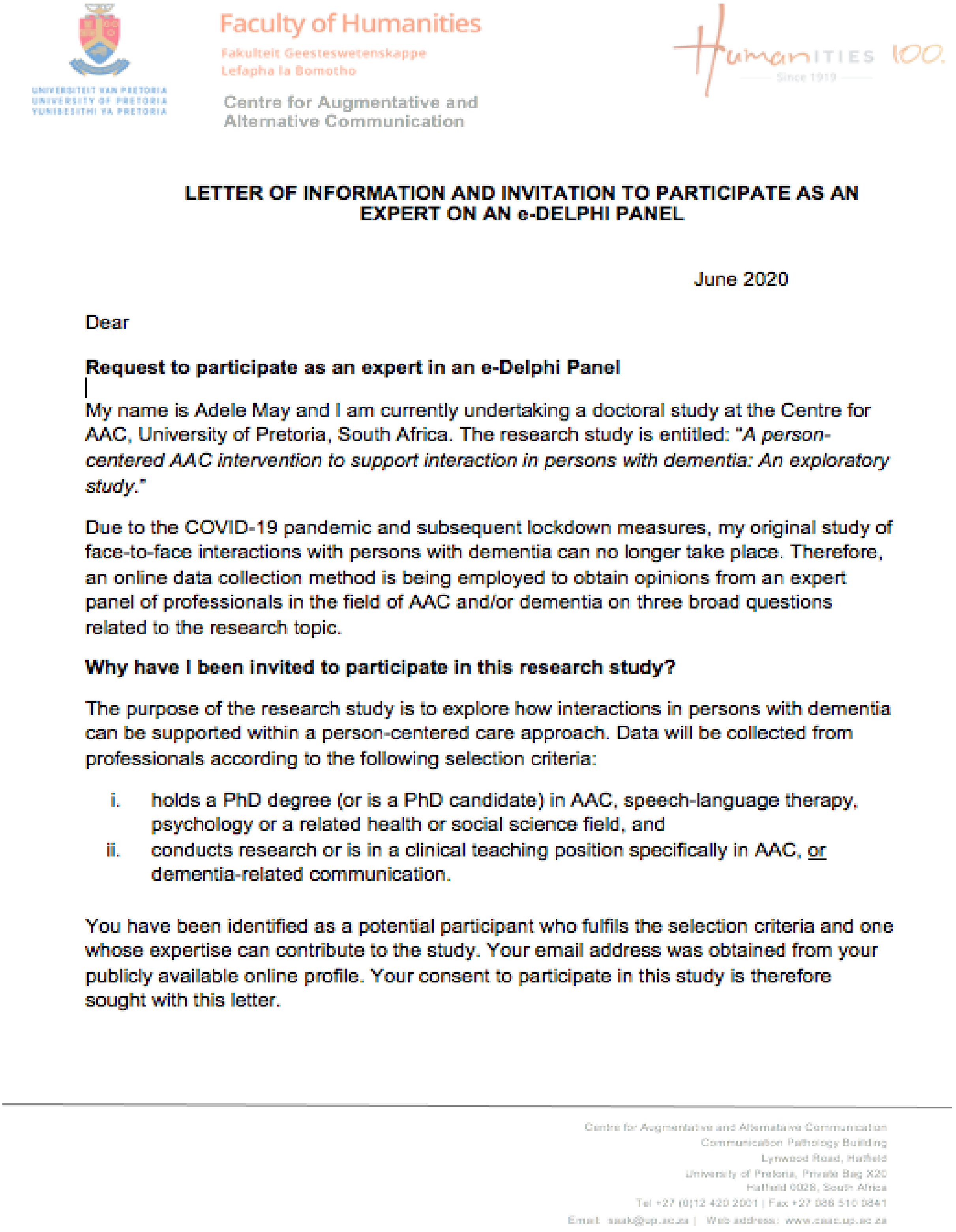
[redacted]

Prof Innocent Pikirayi
Deputy Dean: Postgraduate Studies and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: [redacted]

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Research Ethics Committee Members: Prof I Pikirayi (Deputy Dean); Prof KL Harris; Mr A Bizos; Dr A-M de Beer; Dr A dos Santos; Ms KT Govinder Andrew; Dr P Gutura; Dr E Johnson; Prof D Maree; Mr A Mohamed; Dr I Noomé; Dr C Buttergill; Prof D Reyburn; Prof M Soer; Prof E Taljard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

Appendix H: Concourse Development: Letter of Information to Participate as an Expert on an e-Delphi Panel



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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Centre for Augmentative and
Alternative Communication

Humanities 100.
Since 1919

LETTER OF INFORMATION AND INVITATION TO PARTICIPATE AS AN EXPERT ON AN e-DELPHI PANEL

June 2020

Dear

Request to participate as an expert in an e-Delphi Panel

My name is Adele May and I am currently undertaking a doctoral study at the Centre for AAC, University of Pretoria, South Africa. The research study is entitled: "*A person-centered AAC intervention to support interaction in persons with dementia: An exploratory study.*"

Due to the COVID-19 pandemic and subsequent lockdown measures, my original study of face-to-face interactions with persons with dementia can no longer take place. Therefore, an online data collection method is being employed to obtain opinions from an expert panel of professionals in the field of AAC and/or dementia on three broad questions related to the research topic.

Why have I been invited to participate in this research study?

The purpose of the research study is to explore how interactions in persons with dementia can be supported within a person-centered care approach. Data will be collected from professionals according to the following selection criteria:

i. holds a PhD degree (or is a PhD candidate) in AAC, speech-language therapy, psychology or a related health or social science field, and
ii. conducts research or is in a clinical teaching position specifically in AAC, or dementia-related communication.

You have been identified as a potential participant who fulfils the selection criteria and one whose expertise can contribute to the study. Your email address was obtained from your publicly available online profile. Your consent to participate in this study is therefore sought with this letter.

Centre for Augmentative and Alternative Communication
Communication Pathology Building
Lynwood Road, Hatfield
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001 | Fax +27 086 510 0841
Email: saak@up.ac.za | Web address: www.caac.up.ac.za

What is an e-Delphi method?

A Delphi method obtains consensus of opinion in a structured manner from a panel of professionals (participants), traditionally completed through face-to-face meetings. In this study, opinions will be obtained online through electronic questionnaires, i.e., e-Delphi (Keeney, Hasson, & McKenna, 2006).

What is expected of me should I consider participating in this study?

In round 1, participants will be asked to provide responses to three, open-ended questions. Participants will have two weeks in which to complete the online questionnaire. An email will be sent after one week of sending the invitation as a courtesy reminder for potential participants to complete the online questionnaire. The online responses from round one will be collated and analyzed by the researcher. The researcher anticipates completing this process over three to four weeks, after which the second round will begin with your consented participation.

In round 2, the researcher will provide summarized feedback of round 1 responses to all participants. Participants will then be asked to rate the importance of statements derived from themes in round one.

What are the ethical considerations guiding this study?

Participation in this e-Delphi panel is completely voluntary. There is no obligation to complete the online questionnaire or continue with the study in round 2 (i.e., second questionnaire). Informed consent procedure will be obtained in each of the two rounds of the study.

All biographical information will be obtained for descriptive purposes only. All information will be kept strictly confidential and will not be disclosed at any stage of this study or to anyone outside of this study. Should participant responses be included for the interpretation of the study results, in the thesis, all responses will be anonymised by using a generic non-identifiable coding system.

All online questionnaire responses will be administered, and downloaded via Qualtrics.com for data analysis. All data will be stored on a password protected computer which will only be accessible to the student researcher and supervisor of this study. Once the research study has been completed, all data will be stored at the Centre for AAC, Faculty of Humanities, for a period of 15 years, as per policy at the University of Pretoria

There are no tangible or financial incentive attached to your participation in this study. A foreseeable minimal discomfort may be associated with the estimated 20-30 minutes to complete each questionnaire. The benefit of participation is your contribution to advancement of developing communication interventions to support persons with dementia.

Thank you in advance for considering this request. Please click on the web-link attached to this email should you wish to participate in this study. This will direct you to the start of the questionnaire. Your acknowledgement of informed consent is made by clicking on the yes option to confirm that you have read and understood the contents of this informed consent letter. Further questions regarding the research study are welcome and can be addressed to the researcher or supervisor using the contact details provided below.

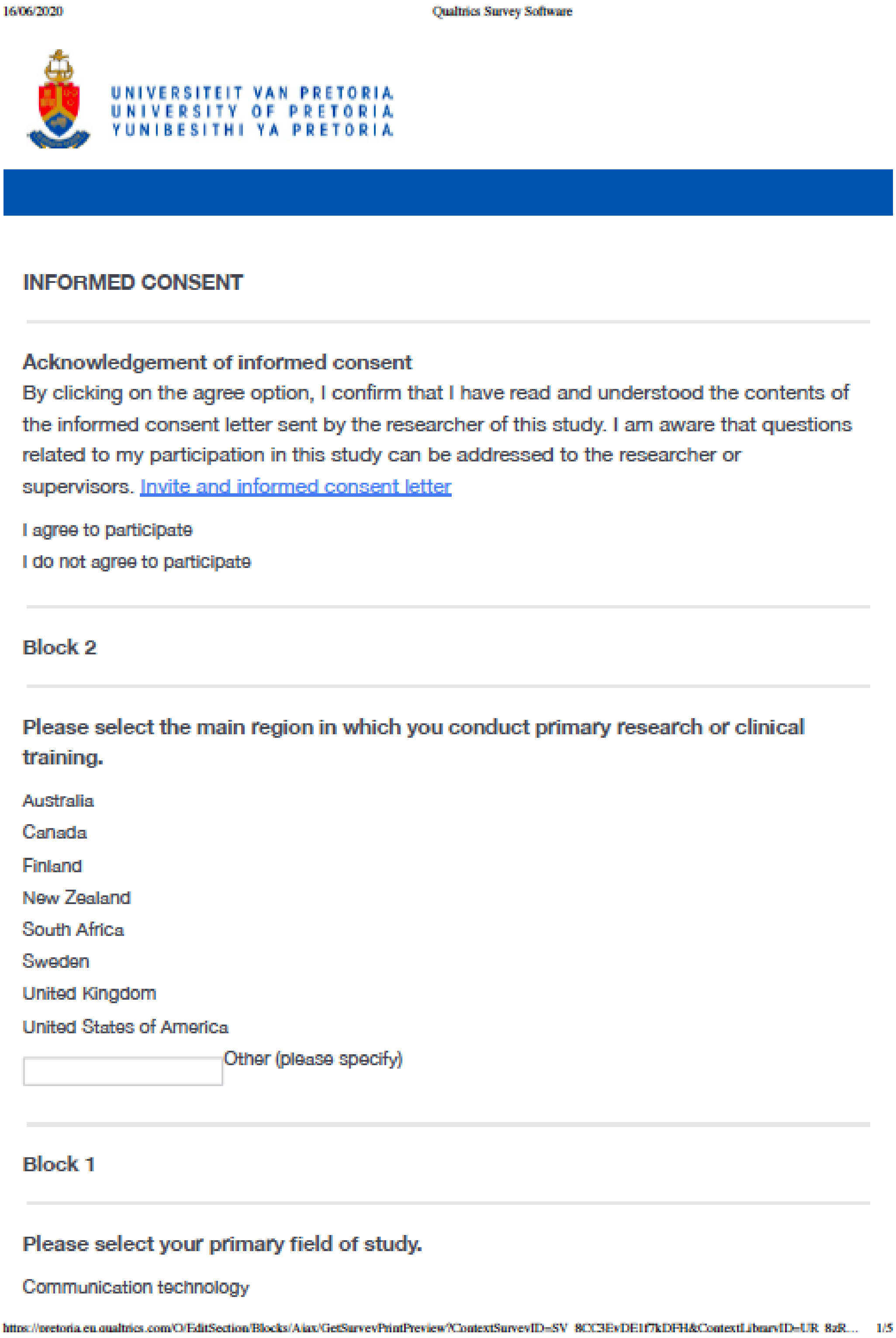
Yours sincerely,

Adele May
PhD Candidate
[redacted]

Prof Shakila Dada
Primary Supervisor
[redacted]

Prof Janice Murray
Co-supervisor
[redacted]

Appendix I: Concourse Development: Online Questionnaire for e-Delphi Panel



16/06/2020 Qualtrics Survey Software

INFORMED CONSENT

Acknowledgement of informed consent

By clicking on the agree option, I confirm that I have read and understood the contents of the informed consent letter sent by the researcher of this study. I am aware that questions related to my participation in this study can be addressed to the researcher or supervisors. [Invite and informed consent letter]

I agree to participate

I do not agree to participate

Block 2

Please select the main region in which you conduct primary research or clinical training.

Australia
Canada
Finland
New Zealand
South Africa
Sweden
United Kingdom
United States of America
☐ Other (please specify)

Block 1

Please select your primary field of study.

Communication technology

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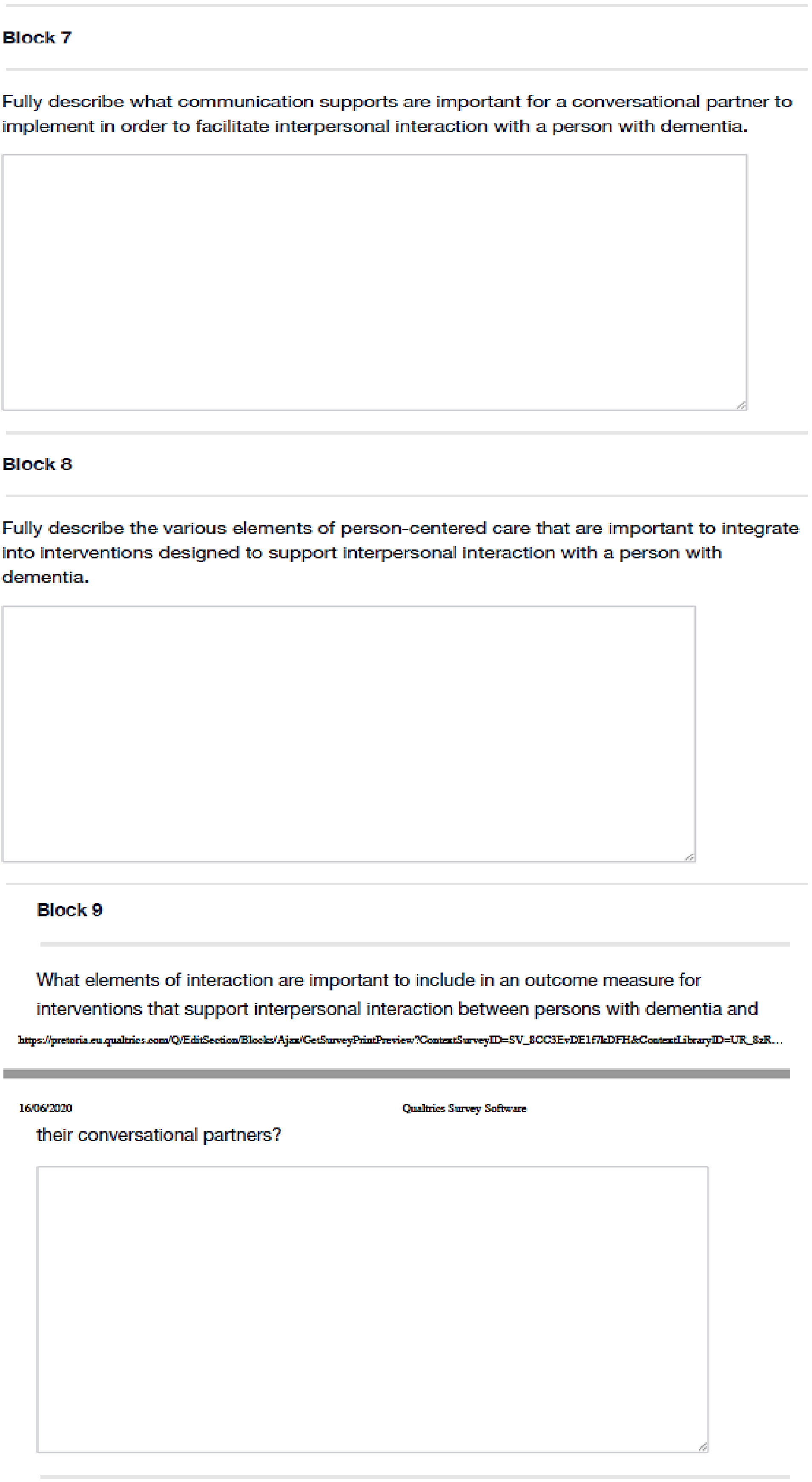

Block 7

Fully describe what communication supports are important for a conversational partner to implement in order to facilitate interpersonal interaction with a person with dementia.

Block 8

Fully describe the various elements of person-centered care that are important to integrate into interventions designed to support interpersonal interaction with a person with dementia.

Block 9

What elements of interaction are important to include in an outcome measure for interventions that support interpersonal interaction between persons with dementia and their conversational partners?

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16/06/2020 Qualtrics Survey Software

Appendix J: Concourse Development: Content Analysis

Themes	**Code Category**	**Codes***	**Instances**
Theme 1: **PwD Characteristics** The personalised characteristics of the PwD must be considered when designing AAC interventions for PwD: including personal preferences, use of life history, adapting to changes in dementia severity, consistency and tailored around individualised strengths.	Personhood principle	Personhood and dignity	8
	Uniqueness of the PwD	Personal biography	14
		Personal preferences	26
		Personal words	2
		Personal goals	3
	Dementia diagnosis	Neuro-cognitive profile	8
		Dementia-changes	13
		Signals of distress/comfort	3
	Adapted to abilities	Strengths-based	9
		Individualised/tailored	16
		Consistency	3
Theme 2: **Working with the PwD** Different ways of working with the PwD and those close to them, including supporting communication partners' (CPs) communication goals and needs.	Collaboration	Relational (with PwD)	4
		Collaborative (involving others)	9
		Key relationships (familiar communication partners)	11
	Supporting independence	Decision-making	6
		Inclusion	9
		Self-determination	5
Theme 3: **Use of Communication supports (AAC)** Related to the various features, and attributes of communication supports for PwD	Unaided supports	Gestures, eye-contact etc	11
	Unaided (other features)	Proxemics	5
		Touch	3
		Prosodic	1
	Non-electronic supports	Visual/pictorial support	23
		Paper-based books/boards	8
		Objects, remnants, keywords, topic setters	11
	Electronic supports	Technology and apps	4
	Combined supports	Combination of supports	7
	Communication support features	Level of complexity, knowledge of use, availability	7
	Specific strategies	Augmented input	1
		Visual scene	1
	Language and memory support	Language based support	14
		Memory support	10
		Cues and prompts	3
	Meaningful content	Specific activities	9
		Music and signing	5

Themes	**Code Category**	**Codes**	**Instances**
Theme 4: **Empathetic Communication** A meaning-making process in which the CP's uses empathy within an AAC interaction to establish, maintain and co-construct meaning with the PwD	Co-construction	Co-construction of meaning	9
		CP co-construction characteristics (enabling)	20
		Attunement	7
		Attentiveness (of CP or Dyad)	6
		Emotional resonance	1
		Empathy	2
		Observant	3
		Being Present	2
		Interest shown by CP in	3
		Listening skills	2
		CP co-construction strategies	7
		Questions	7
Theme 5 **Temporal-sequential interaction features** Relates to the stops, silences, pauses and structure of an interaction that must be considered when interacting with a PwD	Interaction structure	Initiate interaction	2
		Maintain interaction	3
	Temporal aspects	Pauses and delays	3
		Pacing and time of the interaction	12
		Silences	1
Theme 6 **Interactional context** The association between the context, PwD and communication support, including the changes in the immediate context and purpose of the interaction	Interaction context	Context (immediate/situated)	14
		Context (comm support in context)	7
	Purposes of an AAC- interaction	Interaction of needs and wants, etiquette and information transfer	4
		Interaction for social closeness	7
Theme 7 **Interactional environment** Features of the external environment which hinders or supports an AAC interaction with a PwD	External environment	Interaction environment	7
Theme 8 **Features of an AAC interaction outcome measure for PwD** Relates to all features necessary for developing an AAC interaction outcome measure for PwD, including the constructs that should be measured, domains to be measured and types of outcome	Constructs and overarching frameworks to be measured	Engagement	12
		Participation	12
		Quality of Life and wellbeing	5
		ICF/other	3
	Types of outcome measures	Spontaneous interaction measure	1
		Performance-based measures	2

Theme 8 (continued)	Domains to be measured	Turn taking	21
		Timing	3
		Verbal and vocalisations	1
		Language	18
		Multimodal communication	1
		Body Language	2
		Gestural domain	2
		Silences	1
		CP Domain	5
		Social closeness	3
		Focus and joint attention	2
		Behavioural and emotional domain	11
		Other domains	1
	Analysis of Interaction	Video-recorded analysis	2
		Interaction analysis types	1
	Measure interaction in various contexts	Use of comm supports in context	15
Theme 9 **Social validity of AAC interaction outcomes in PwD** Assessing the importance and relevance of interaction outcomes from various stakeholders	Intrapersonal outcomes	Satisfaction of the interaction	8
		Feelings about the interaction	2
		Confidence in the interaction	2
		Success of interaction	5
		Control and choice	3
	Interpersonal outcomes	Fun/Enjoyment	1
	Stakeholder's Perspective	Proxy and PWD reported	5
		Proxy-reported perspective	2
Theme 10 **Inhibitors to an AAC interaction with a PwD** Specific CP characteristics that undermine personhood within an AAC interaction	Inhibiting CP characteristics	Patronisation and disruptions	4
Theme 11 **Diversity of perspectives on approaches to AAC interventions with PwD** Opposing expert opinions on usefulness or applicability of specific approaches in AAC interventions with PwD	Person-centred care does not work	PCC does not work	1

Appendix K1: Q-set: Statements (pre-pilot)

1.	Electronic AAC systems (e.g., mobile technology, tablet computers with applications [apps]) can be useful to support interpersonal interaction between a conversational partner and person with dementia.
2.	Training persons with dementia on the use of electronic AAC systems (e.g., navigating on tablet computers with apps) before they use them in real-time interaction settings is not necessary when the purpose is interpersonal interaction.
3.	The use of intelligent assistive technologies (e.g., using artificial intelligence) to support communication and interpersonal interaction in persons with dementia should not be explored for persons with dementia.
4.	Combined AAC systems (e.g., clarifications with head nods, verbal comments by pointing to photographs) are most useful communication supports for persons with dementia
5.	Combining picture pointing with spontaneous speech (i.e., augmented input) is a useful strategy to support auditory comprehension of spoken language in persons with dementia.
6.	Meaningful high-context photographs (e.g., visual scene displays) support joint reference during interpersonal interaction with a person with dementia.
7.	A conversational partner should never correct off-topic utterances made by a person with dementia.
8.	A conversational partner should assume that all communication attempts made by a person with dementia is meaningful.
9.	A conversational partner can co-construct meaning with a person with dementia by using language that enhances social emotional connection.
10.	A conversational partner should display empathy by mirroring the emotion of the person with dementia to facilitate interpersonal interaction with a person with dementia.
11.	Active listening shown by paying attention conveys respect for the contributions of a person with dementia.
12.	Silences within an interaction promotes moments of companionship with a person with dementia.
13.	A conversational partner can support interpersonal interaction by pausing to give a person with dementia time to respond.
14.	A person with dementia must be supported in decision-making in all aspects of their AAC intervention.
15.	A person with dementia must be consulted about their personal preferences for interpersonal interaction.
16.	AAC strategies for a person with dementia are flexible depending on the stage and type of dementia.
17.	AAC interventions to support interpersonal interaction in persons with dementia must be tailored to the strengths of the person with dementia.
18.	The self-determination of a person with dementia is promoted by facilitating their involvement in co-designing their own AAC interventions.
19.	Adapted participatory methods (e.g., co-production) should be employed to include persons with dementia as collaborators in the co-design of AAC interventions.
20.	Working collaboratively with the family of a person with dementia and other stakeholders throughout the AAC intervention process is important, but not necessary.
21.	The immediate interaction context plays a vital role in the success of interpersonal interaction with a person with dementia (e.g., time of day in which interaction occurs).

22.	Conversational supports with personalised life-story content of a person with dementia is a useful scaffold for reminiscence-based conversations with a person with dementia.
23.	Persons with dementia must be supported in authoring the content of their life-story based conversational supports.
24.	Life-story based conversational supports that include personalized music and digital photographs on electronic devices (e.g., iPad) enhances the enjoyment of interpersonal interaction for persons with dementia.
25.	A patronising style of language (e.g., an exaggerated tone of voice typical of talking to an infant) used during interpersonal interaction with a person with dementia undermines personhood of a person with dementia.
26.	Person-centered care as a philosophy of care (e.g., one that promotes the independence of persons with dementia and values their life history) in AAC interventions is not clinically achievable.
27.	Satisfaction of an interaction should be rated directly from the perspective of a person with dementia.
28.	Intra-personal outcomes such as a sense of connection experienced within an interpersonal interaction must be measured by asking the person with dementia.
29.	Successful interaction should be rated from the perspectives of both the person with dementia (patient-reported) and conversational partner (proxy-reported).
30.	Social connections are important goals of AAC interventions designed to support interpersonal interaction with a person with dementia
31.	Enjoyment and motivation (as engagement outcomes) within an interpersonal interaction is equally important to include in an outcome measure for persons with dementia.
32.	AAC-supported interaction in persons with dementia is best analysed qualitatively from observation of spontaneous interaction
33.	AAC-supported interaction in persons with dementia must be analysed using a combination of qualitative measures and standardised, quantitative outcome measures.
34.	The most important domain to measure in an AAC interaction outcome measure for persons with dementia is turn taking (e.g., frequency of turn taking exchanges).
35.	An AAC interaction outcome measure must include the modality of turn taking (e.g., turn taking with gestures).
36.	Participation outcomes (frequency of taking part in everyday interactions) are important to include in an AAC interaction outcome measure for persons with dementia.
37.	It is important to include the behaviour displayed by persons with dementia (e.g., their level of frustration, agitation or avoidance) as an AAC interaction outcome measure for persons with dementia.

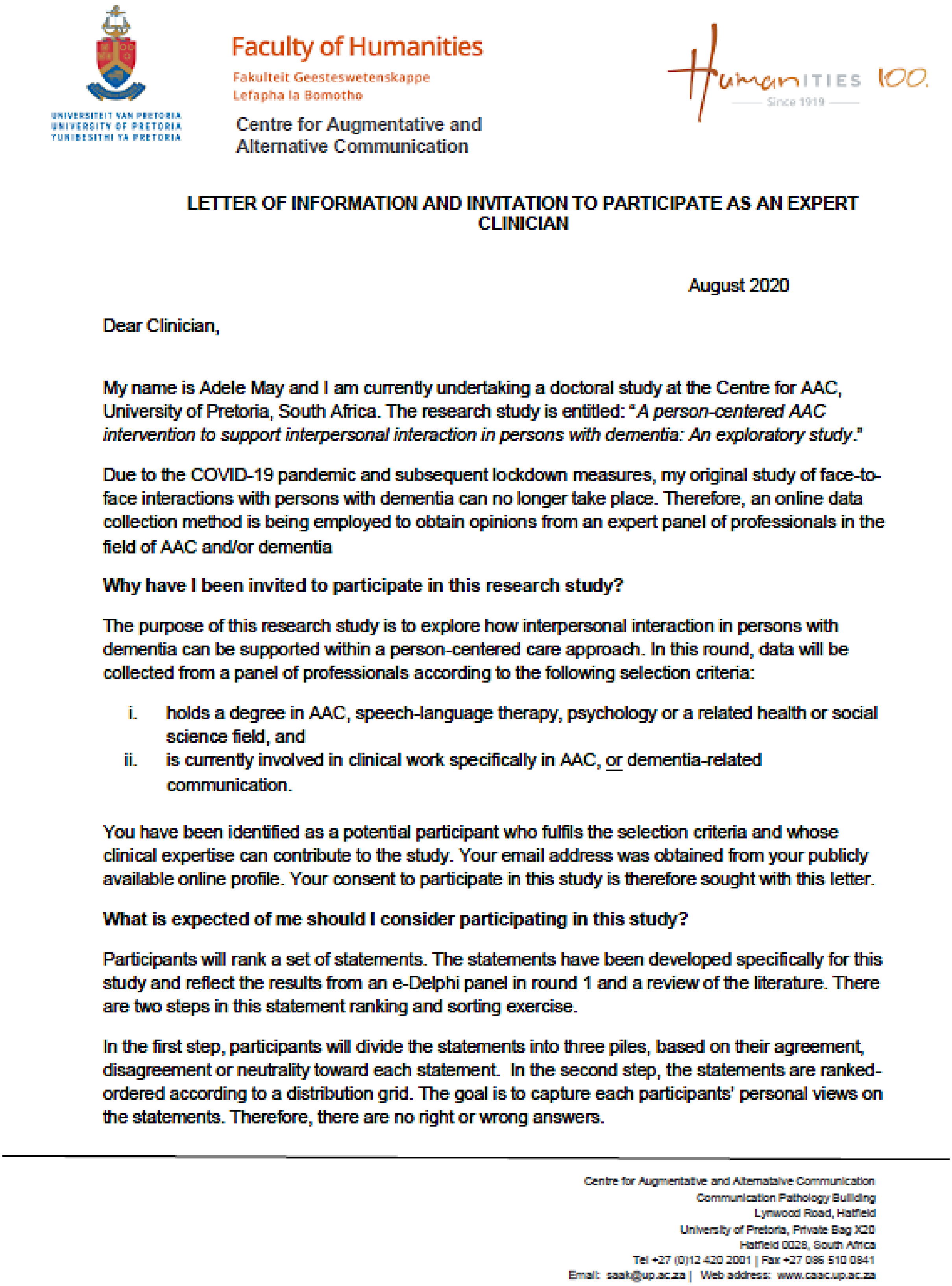
***blue font denotes statements recommended to be adjusted**

Appendix K2: Q-set: Statements (post-pilot)

AAC scaffolding strategies to support interpersonal interaction in person with dementia	
Electronic AAC systems	
1.	Electronic AAC systems (e.g., tablet computers with applications [apps]) can be useful to support interpersonal interaction between a conversational partner and a person with moderate-severe dementia.
2.	Training persons with dementia on the use of electronic AAC systems (e.g., navigating on tablet computers with apps) before they use them in real-time interaction settings is not necessary when the purpose is interpersonal interaction.
3.	The use of intelligent assistive technologies (e.g., using artificial intelligence) to support communication and interpersonal interaction in persons with dementia should not be explored for persons with dementia.
4.	Legacy messages (i.e., unique words or phrases used by a person with dementia digitally recorded in their own voice in the early stages of dementia) stored as voice output on electronic devices (e.g., iPad) are useful to facilitate social connection with a conversational partner as dementia severity progresses.
AAC techniques and strategies	
5.	Non-electronic AAC systems (e.g., paper-based communication books with pictures) are the most beneficial communication supports for interpersonal interaction with a person with mild-moderate dementia
6.	Combining picture pointing with spontaneous speech (i.e., augmented input) is a useful strategy to support auditory comprehension of spoken language in persons with dementia.
7.	Meaningful high-context photographs (e.g., visual scene displays) support joint reference during interpersonal interaction with a person with dementia.
"Empathetic Communication" strategies	
8.	A conversational partner should never correct off-topic utterances made by a person with dementia.
9.	The unique set of communication behaviours of a person with severe dementia (e.g., vocalisations, facial expressions, gestures) should be used as the basis for interpersonal interaction with a conversational partner.
10.	A conversational partner can co-construct meaning with a person with dementia by using language that enhances social-emotional connection.
11.	A conversational partner should display empathy by mirroring the emotion of the person with dementia to facilitate interpersonal interaction with a person with dementia.
12.	Active listening shown by paying attention conveys respect for the contributions of a person with dementia.
13.	By repeating the utterances of the person with dementia, a conversational partner shows an understanding of what the person with dementia is expressing within an interpersonal interaction.
Silences and expectant delays	
14.	A conversational partner can support interpersonal interaction by pausing to give a person with dementia time to respond.
Person-Centred Care elements in AAC interventions that support interpersonal interaction in persons with dementia	
Personalisation and independence	
15.	A person with dementia must be supported in decision-making in all aspects of their AAC intervention.
16.	A person with dementia must be consulted about their personal preferences for interpersonal interaction.
17.	AAC strategies for a person with dementia are flexible depending on the stage and type of dementia.
18.	AAC interventions to support interpersonal interaction in persons with dementia must be tailored to the strengths of the person with dementia.
Person-centered methods and ways of working	
19.	The self-determination of a person with dementia is promoted by facilitating their involvement in co-designing their own AAC interventions.

20.	Adapted participatory methods (e.g., co-production) should be employed to include persons with dementia as collaborators in the co-design of AAC interventions.
21.	Working collaboratively with the family of a person with dementia and other stakeholders throughout the AAC intervention process is important, but not necessary.
22.	The immediate interaction context (e.g., the time of day in which an interaction occurs) does not play a vital role in the success of interpersonal interaction with a person with dementia.
Life story	
23.	Conversational supports with personalised life-story content of a person with dementia is a useful scaffold for reminiscence-based conversations with a person with dementia.
24.	Persons with dementia should be supported in authoring the content of their life-story based conversational supports.
25.	Life-story based conversational supports that include personalized music and digital photographs on electronic devices (e.g., iPad) enhances the enjoyment of interpersonal interaction for persons with dementia.
Person-centred care as a practice/other	
26.	A patronising style of language (e.g., an exaggerated tone of voice typical of talking to an infant) used during interpersonal interaction with a person with dementia undermines personhood of a person with dementia.
27.	Person-centered care as a philosophy of care (e.g., one that promotes the independence of persons with dementia and values their life history) in AAC interventions is not clinically achievable.
Outcome measurement for AAC-supported interpersonal interaction with persons with dementia	
Intrapersonal outcomes	
28.	Successful interaction should be rated from the perspectives of both the person with dementia (patient-reported) and conversational partner (proxy-reported).
29.	It is not necessary to measure the satisfaction of the person with dementia in using AAC strategies within an interpersonal interaction.
Interpersonal outcomes	
30.	Social connections are important goals of AAC interventions designed to support interpersonal interaction with a person with dementia.
31.	Enjoyment and motivation (as engagement outcomes) within an interpersonal interaction are not important to include in an outcome measure for persons with dementia.
Interaction analysis	
32.	AAC-supported interaction in persons with dementia is best analysed qualitatively from observation of spontaneous interaction.
33.	AAC-supported interaction in persons with dementia must be analysed using a combination of qualitative measures and standardised, quantitative outcome measures.
AAC outcome measure domains	
34.	The most important domain to measure in an AAC interaction outcome measure for persons with dementia is turn taking (e.g., frequency of turn taking exchanges).
35.	An AAC interaction outcome measure must include the modality of turn taking (e.g., turn taking with gestures).
36.	It is not necessary to include participation outcomes (frequency of taking part in everyday interactions) in an AAC interaction outcome measure for persons with dementia.
37.	It is not important to include the behaviour displayed by persons with dementia (e.g., their level of frustration, agitation or avoidance) as an AAC interaction outcome measure for persons with dementia.

Appendix L: Q: Sort: Letter of Information to Experts



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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho
Centre for Augmentative and
Alternative Communication

Humanities 100.
Since 1919

LETTER OF INFORMATION AND INVITATION TO PARTICIPATE AS AN EXPERT CLINICIAN

August 2020

Dear Clinician,

My name is Adele May and I am currently undertaking a doctoral study at the Centre for AAC, University of Pretoria, South Africa. The research study is entitled: "*A person-centered AAC intervention to support interpersonal interaction in persons with dementia: An exploratory study*."

Due to the COVID-19 pandemic and subsequent lockdown measures, my original study of face-to-face interactions with persons with dementia can no longer take place. Therefore, an online data collection method is being employed to obtain opinions from an expert panel of professionals in the field of AAC and/or dementia

Why have I been invited to participate in this research study?

The purpose of this research study is to explore how interpersonal interaction in persons with dementia can be supported within a person-centered care approach. In this round, data will be collected from a panel of professionals according to the following selection criteria:

i. holds a degree in AAC, speech-language therapy, psychology or a related health or social science field, and
ii. is currently involved in clinical work specifically in AAC, or dementia-related communication.

You have been identified as a potential participant who fulfils the selection criteria and whose clinical expertise can contribute to the study. Your email address was obtained from your publicly available online profile. Your consent to participate in this study is therefore sought with this letter.

What is expected of me should I consider participating in this study?

Participants will rank a set of statements. The statements have been developed specifically for this study and reflect the results from an e-Delphi panel in round 1 and a review of the literature. There are two steps in this statement ranking and sorting exercise.

In the first step, participants will divide the statements into three piles, based on their agreement, disagreement or neutrality toward each statement. In the second step, the statements are ranked-ordered according to a distribution grid. The goal is to capture each participants' personal views on the statements. Therefore, there are no right or wrong answers.

Centre for Augmentative and Alternative Communication
Communication Pathology Building
Lynwood Road, Hatfield
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001 | Fax +27 086 510 0841
Email: saak@up.ac.za | Web address: www.caac.up.ac.za

Participants will have two weeks in which to complete the online survey. An email will be sent after one week of sending this invitation as a courtesy reminder of the submission date.

What are the ethical considerations guiding this study?

Participation in this study is completely voluntary. There is no obligation to complete the survey. Your informed consent is required before initiating the online survey.

All biographical information will be obtained for descriptive purposes only. All information will be kept strictly confidential and will not be disclosed at any stage of this study or to anyone outside of this study. Should participant responses be included for the interpretation of the study results, in the thesis, all responses will be anonymised by using a generic non-identifiable coding system.

The online responses for this round will be administered, and downloaded via https://qmethodsoftware.com/ for data analysis. All data will be stored on a password protected computer which will only be accessible to the student researcher and supervisors of this study. Once the research study has been completed, all data will be stored at the Centre for AAC, Faculty of Humanities, for a period of 15 years, as per policy at the University of Pretoria.

There are no tangible or financial incentives attached to your participation in this study. A foreseeable minimal discomfort may be associated with the estimated 30-45 minutes to complete this survey. The benefit of participation is your contribution to advancement of developing communication interventions to support persons with dementia.

Completion of this round will conclude your participation in the study.

Please click on the web-link in the email to confirm your consent to participate. Copy and paste your unique participant code to login.

Thank you in advance for considering this request. Should you have further questions related to the study, please contact me or my supervisors using the contact details provided below.

Yours sincerely,

[redacted]

Adele May
PhD Candidate
Centre for AAC
University of Pretoria
[redacted]

[redacted]

Prof Shakila Dada
Primary Supervisor
Centre for AAC,
[redacted]

[redacted]

Prof Janice Murray
Co-supervisor
[redacted]
[redacted]

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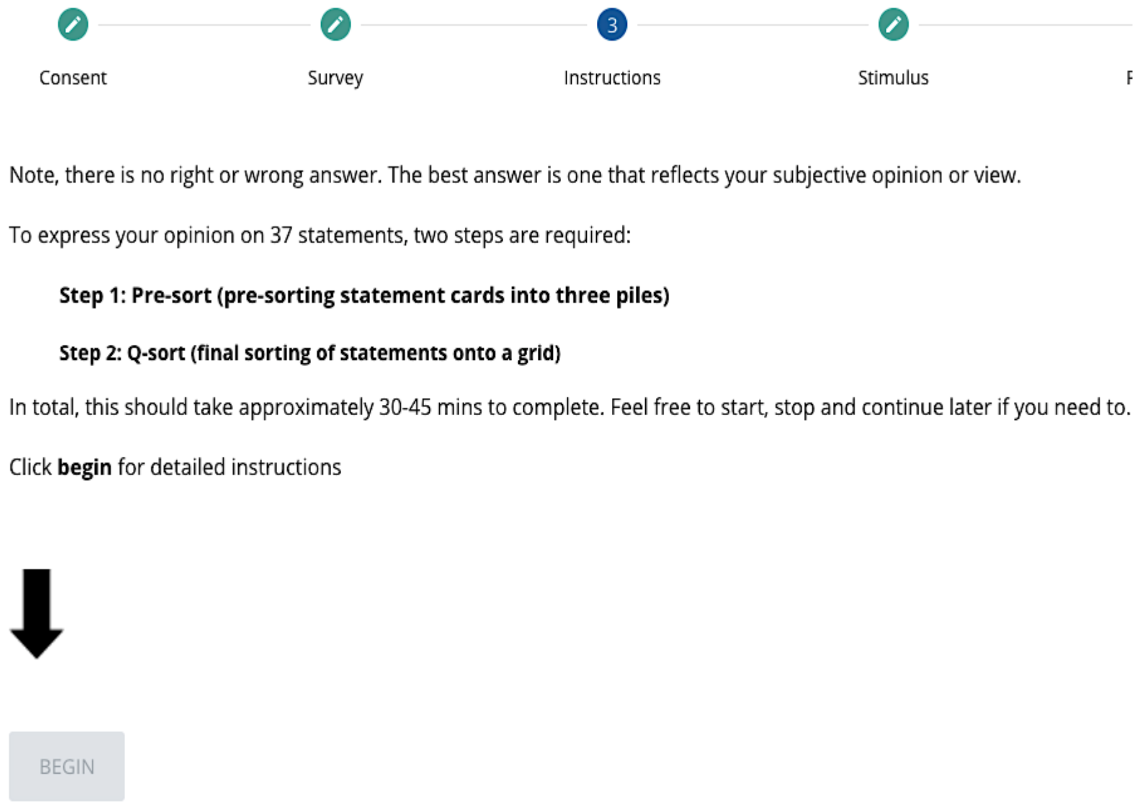
Appendix M: Online Q-sort

Online instructions on QMethod Software (Lutfallah, & Buchanan, 2019)



Note, there is no right or wrong answer. The best answer is one that reflects your subjective opinion or view.

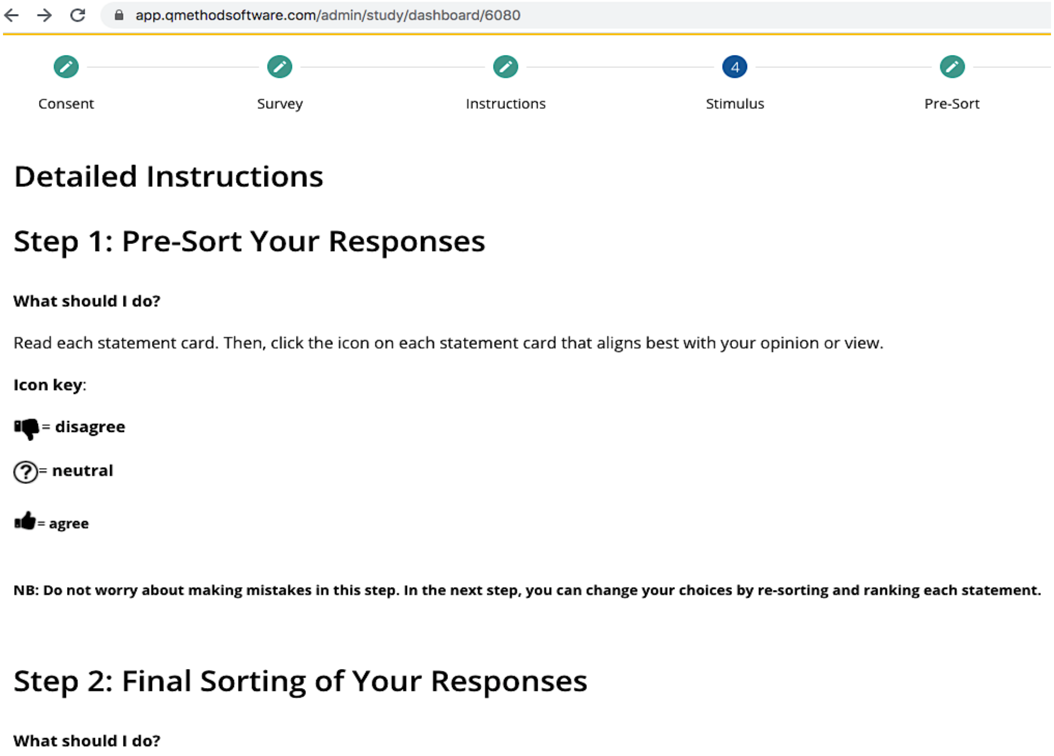
To express your opinion on 37 statements, two steps are required:

Step 1: Pre-sort (pre-sorting statement cards into three piles)

Step 2: Q-sort (final sorting of statements onto a grid)

In total, this should take approximately 30-45 mins to complete. Feel free to start, stop and continue later if you need to.

Click **begin** for detailed instructions



Detailed Instructions

Step 1: Pre-Sort Your Responses

What should I do?

Read each statement card. Then, click the icon on each statement card that aligns best with your opinion or view.

Icon key:

👎 = **disagree**

? = **neutral**

👍 = **agree**

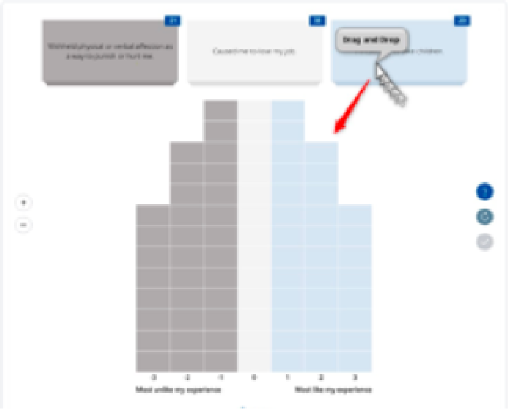
NB: Do not worry about making mistakes in this step. In the next step, you can change your choices by re-sorting and ranking each statement.

Step 2: Final Sorting of Your Responses

What should I do?

How do I perform the final sorting?

- Drag and drop each statement from the pile into a grid cell of your choice as illustrated below.



- The grid runs on a continuum as follows:

-3 =strongly disagree,

-1 =disagree,

0 = neutral

+1 =agree,

+3 = strongly disagree

To **expand** the view, click + Zoom In

To **minimise** the view, click − Zoom Out

help

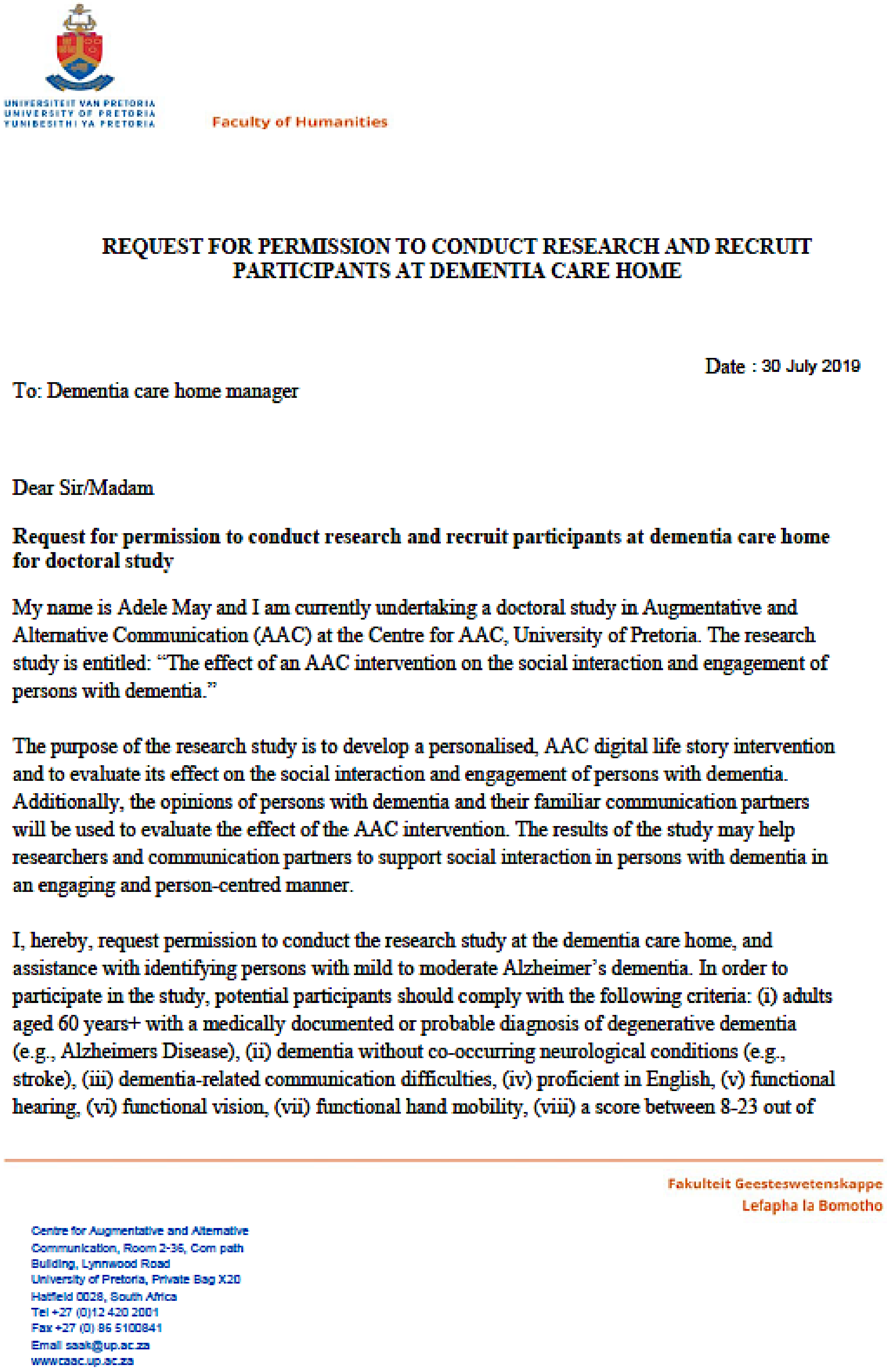
- If you need **help**, click ?

- If you want to re-sort all the statements into three piles and **start over**, click: reset

- When you are done placing the statements onto the distribution grid, review your Q-sort. Drag and drop the statemen

When you are done with your final Q-sort, click Submit Q-Sort ✓

Appendix N: Permission Letter to Dementia Care Home



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REQUEST FOR PERMISSION TO CONDUCT RESEARCH AND RECRUIT PARTICIPANTS AT DEMENTIA CARE HOME

Date : 30 July 2019

To: Dementia care home manager

Dear Sir/Madam

Request for permission to conduct research and recruit participants at dementia care home for doctoral study

My name is Adele May and I am currently undertaking a doctoral study in Augmentative and Alternative Communication (AAC) at the Centre for AAC, University of Pretoria. The research study is entitled: "The effect of an AAC intervention on the social interaction and engagement of persons with dementia."

The purpose of the research study is to develop a personalised, AAC digital life story intervention and to evaluate its effect on the social interaction and engagement of persons with dementia. Additionally, the opinions of persons with dementia and their familiar communication partners will be used to evaluate the effect of the AAC intervention. The results of the study may help researchers and communication partners to support social interaction in persons with dementia in an engaging and person-centred manner.

I, hereby, request permission to conduct the research study at the dementia care home, and assistance with identifying persons with mild to moderate Alzheimer's dementia. In order to participate in the study, potential participants should comply with the following criteria: (i) adults aged 60 years+ with a medically documented or probable diagnosis of degenerative dementia (e.g., Alzheimers Disease), (ii) dementia without co-occurring neurological conditions (e.g., stroke), (iii) dementia-related communication difficulties, (iv) proficient in English, (v) functional hearing, (vi) functional vision, (vii) functional hand mobility, (viii) a score between 8-23 out of

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www.caac.up.ac.za

30 on the Montreal Cognitive Assessment [MoCA] screening tool to confirm mild to moderate dementia.

The study aims to recruit eight participants who meet the above criteria along with their familiar communication partner (spouse, adult child, friend, professional carer). All interactions with the participants will be video-recorded. It is preferable that the interactions be undertaken in an unoccupied, quiet room at the dementia care home.

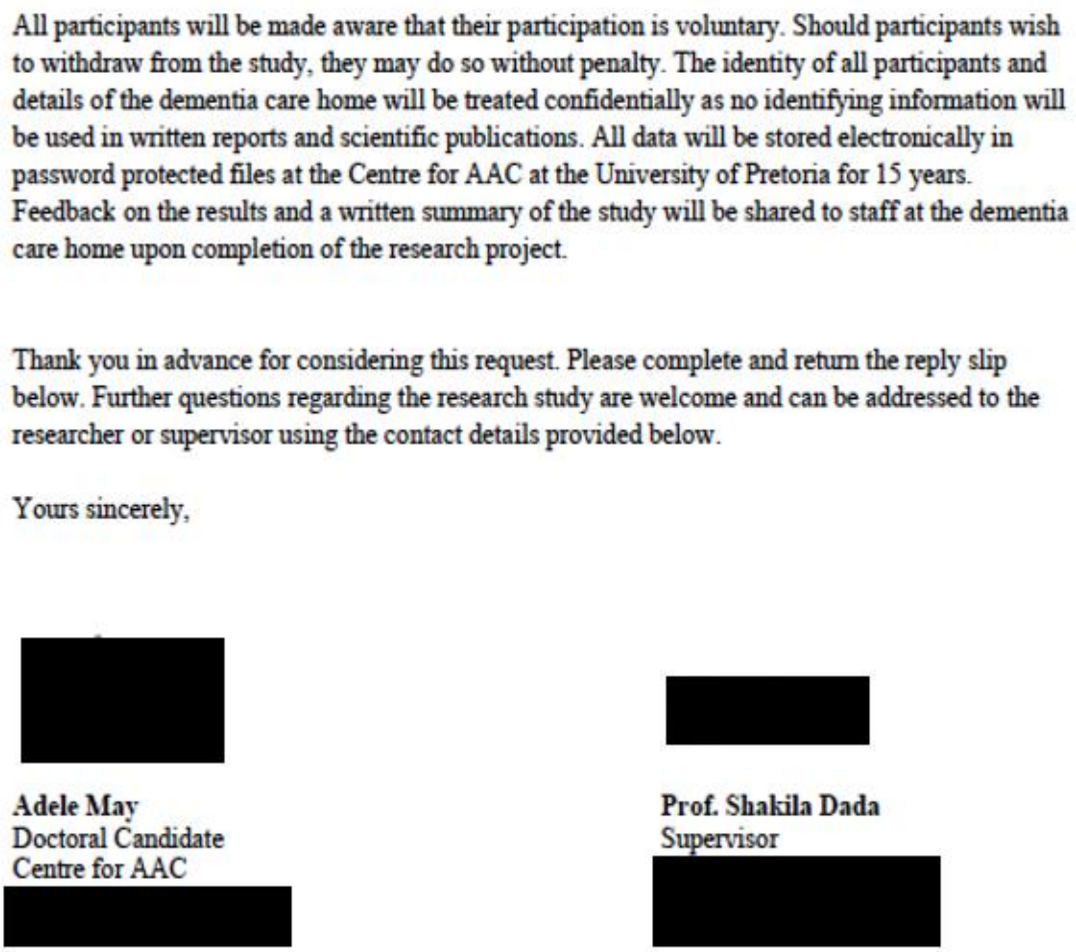
Should permission be granted, I will drop off copies of recruitment flyers at the dementia care home for distribution to legal guardians and family members (attached). The recruitment flyer may also be electronically distributed to potentials participants' legal guardians or family (via e-mail). A simplified information flyer for potential participants will illustrate the nature of the study and seek their voluntary participation.

Legal guardians (or family members) who express interest in the study will be contacted directly and individual meetings will be arranged at their convenience. The purpose of the research study will be explained to the legal guardian (or family member). Written informed consent for the participant to be involved in the research study will be obtained from the legal guardian. The legal guardian will also identity a potential familiar communication partner and their written informed consent will be requested.

Each participant will be met individually at the dementia care home along with their familiar communication partner. Simple language and pictures will be used to support the participant in understanding the purpose of the study and in requesting their informed consent. The informed consent process will be observed by the familiar communication partner to ensure that the participant was not coerced into participating. The participants' consent will be requested each time contact is made with the researcher. Should the participant tire or express discomfort, research will discontinue for that specific day.

Initially three to five sessions of 30-45 minutes each will be conducted to focus on building trust and establishing rapport with the participant, prepare materials for the digital life story and complete the Montreal Cognitive Assessment [MoCA] screening tool. Potential participants meeting all the criteria will then commence with the intervention sessions.

Thereafter, nine intervention sessions with each of the eight potential participants is planned. Each intervention session should take 20 minutes of video-recorded interaction. Each participant will interact with the researcher using the AAC device (iPad) in two ways. Firstly, the participant will discuss a digital life story topic with the researcher without being trained on how to use the AAC device. Thereafter, the researcher will train the participant to use the AAC device and will apply supportive strategies to encourage interaction with the participant. The familiar communication partner will watch the video-recordings and rate the interactions.



All participants will be made aware that their participation is voluntary. Should participants wish to withdraw from the study, they may do so without penalty. The identity of all participants and details of the dementia care home will be treated confidentially as no identifying information will be used in written reports and scientific publications. All data will be stored electronically in password protected files at the Centre for AAC at the University of Pretoria for 15 years. Feedback on the results and a written summary of the study will be shared to staff at the dementia care home upon completion of the research project.

Thank you in advance for considering this request. Please complete and return the reply slip below. Further questions regarding the research study are welcome and can be addressed to the researcher or supervisor using the contact details provided below.

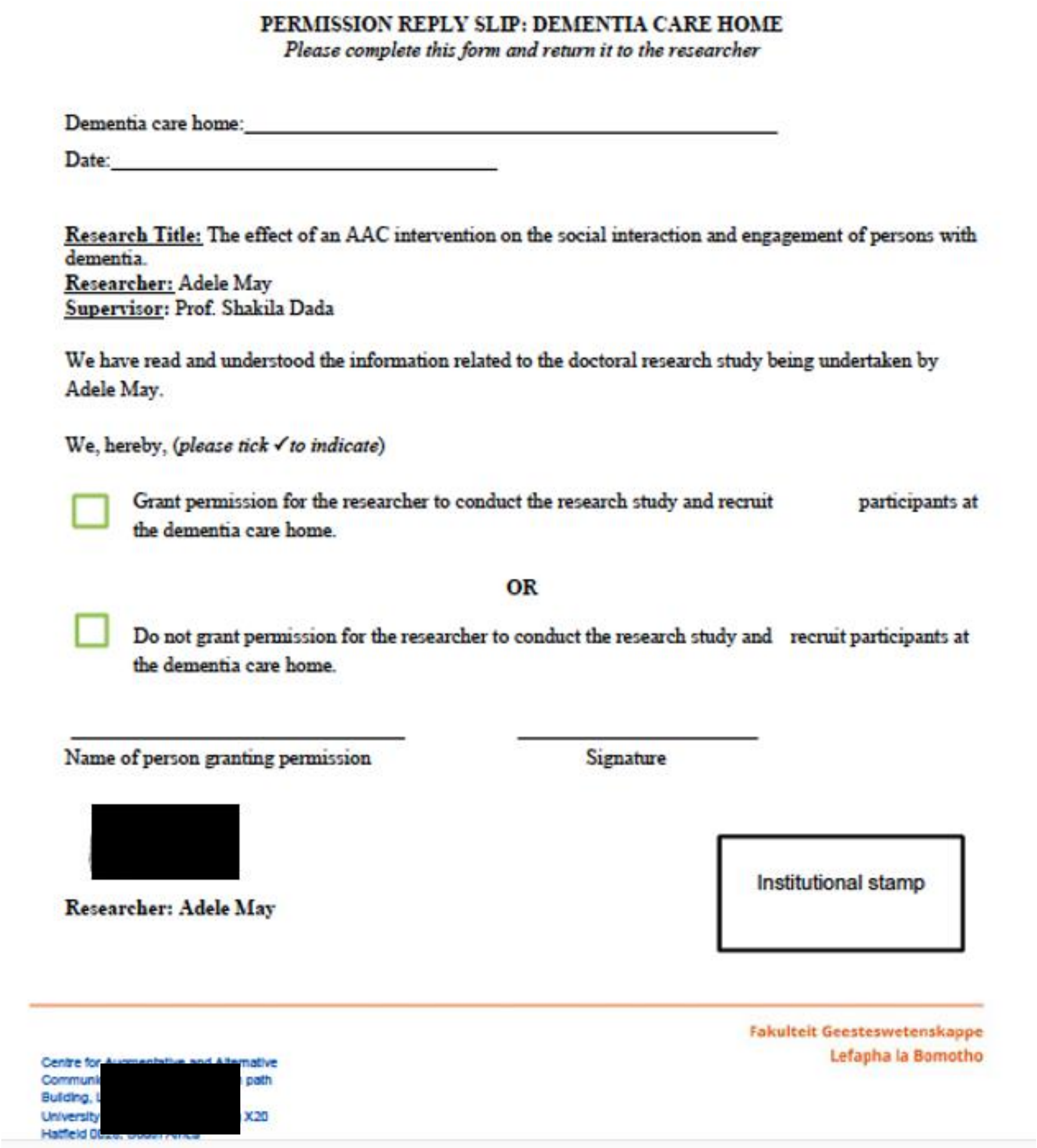
Yours sincerely,

[redacted]

Adele May
Doctoral Candidate
Centre for AAC
[redacted]

[redacted]

Prof. Shakila Dada
Supervisor
[redacted]



PERMISSION REPLY SLIP: DEMENTIA CARE HOME

Please complete this form and return it to the researcher

Dementia care home:____

Date:_______________________________

Research Title: The effect of an AAC intervention on the social interaction and engagement of persons with dementia.
Researcher: Adele May
Supervisor: Prof. Shakila Dada

We have read and understood the information related to the doctoral research study being undertaken by Adele May.

We, hereby, (*please tick ✓ to indicate*)

☐ Grant permission for the researcher to conduct the research study and recruit participants at the dementia care home.

OR

☐ Do not grant permission for the researcher to conduct the research study and recruit participants at the dementia care home.

____________________________ ____________________

Name of person granting permission Signature

[redacted]

Researcher: Adele May

Institutional stamp

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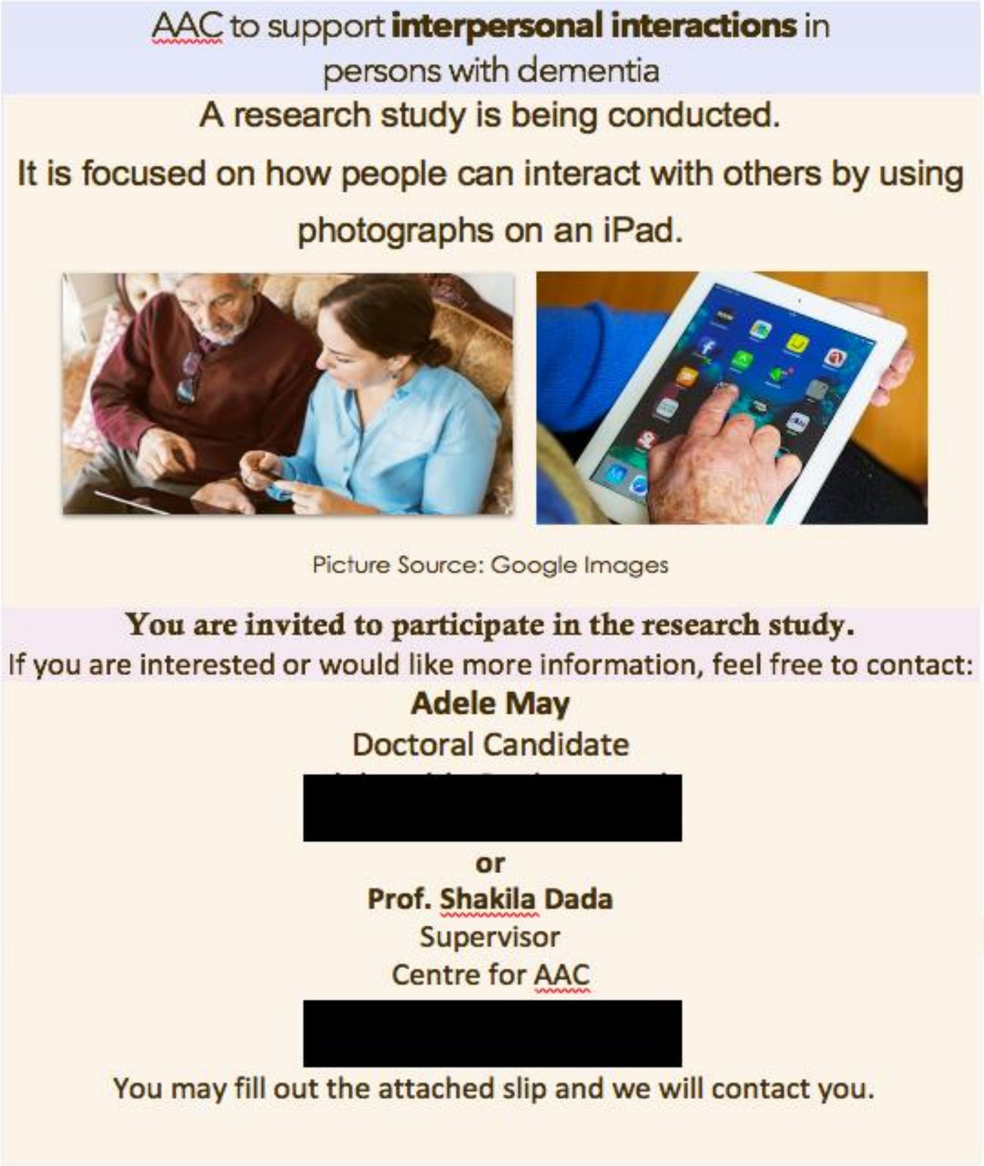
Communi [redacted] path
Building, L
University X20
Hatfield

Appendix O: Recruitment Flyer (for persons with dementia)



AAC to support **interpersonal interactions** in persons with dementia

A research study is being conducted.

It is focused on how people can interact with others by using photographs on an iPad.

Picture Source: Google Images

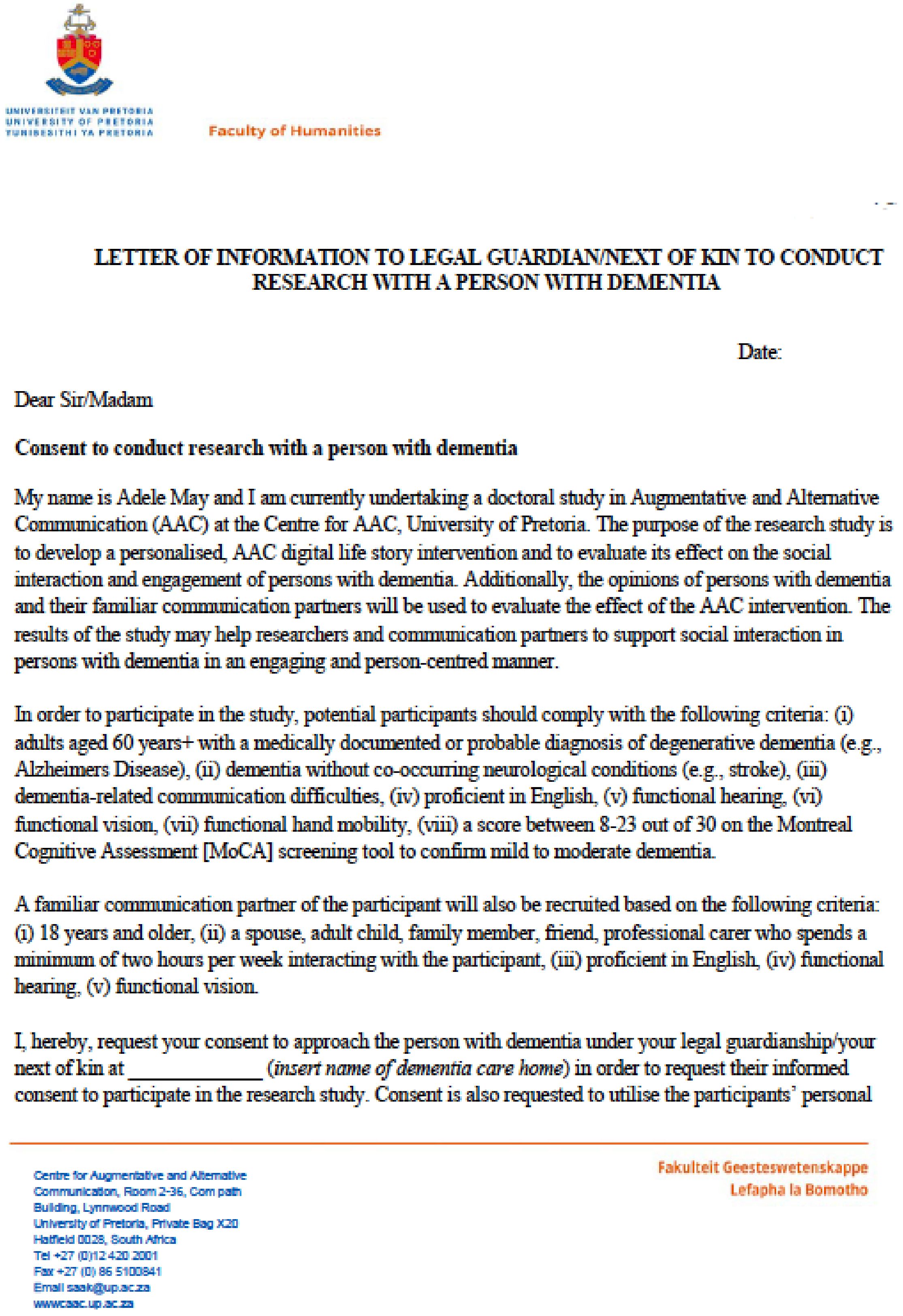
You are invited to participate in the research study.

If you are interested or would like more information, feel free to contact:

Adele May
Doctoral Candidate
[redacted]
or
Prof. Shakila Dada
Supervisor
Centre for AAC
[redacted]

You may fill out the attached slip and we will contact you.

Appendix P: Case study: Letter of Consent to Legal Guardian of the Participant with Dementia



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LETTER OF INFORMATION TO LEGAL GUARDIAN/NEXT OF KIN TO CONDUCT RESEARCH WITH A PERSON WITH DEMENTIA

Date:

Dear Sir/Madam

Consent to conduct research with a person with dementia

My name is Adele May and I am currently undertaking a doctoral study in Augmentative and Alternative Communication (AAC) at the Centre for AAC, University of Pretoria. The purpose of the research study is to develop a personalised, AAC digital life story intervention and to evaluate its effect on the social interaction and engagement of persons with dementia. Additionally, the opinions of persons with dementia and their familiar communication partners will be used to evaluate the effect of the AAC intervention. The results of the study may help researchers and communication partners to support social interaction in persons with dementia in an engaging and person-centred manner.

In order to participate in the study, potential participants should comply with the following criteria: (i) adults aged 60 years+ with a medically documented or probable diagnosis of degenerative dementia (e.g., Alzheimers Disease), (ii) dementia without co-occurring neurological conditions (e.g., stroke), (iii) dementia-related communication difficulties, (iv) proficient in English, (v) functional hearing, (vi) functional vision, (vii) functional hand mobility, (viii) a score between 8-23 out of 30 on the Montreal Cognitive Assessment [MoCA] screening tool to confirm mild to moderate dementia.

A familiar communication partner of the participant will also be recruited based on the following criteria: (i) 18 years and older, (ii) a spouse, adult child, family member, friend, professional carer who spends a minimum of two hours per week interacting with the participant, (iii) proficient in English, (iv) functional hearing, (v) functional vision.

I, hereby, request your consent to approach the person with dementia under your legal guardianship/your next of kin at _____________ (*insert name of dementia care home*) in order to request their informed consent to participate in the research study. Consent is also requested to utilise the participants' personal photographs (e.g., from family albums) depicting interesting and happy times to develop their personalised, digital life story.

You may choose to participate as the familiar communication partner, or you may identify an individual who could be a potential familiar communication partner. Contact will be made with the familiar communication partner that you identify, and their signed written informed consent will be required should they wish to participate in the study.

The participant will be met individually at the dementia care home along with their familiar communication partner. The purpose of the study will be explained to the participant using simple language and their informed consent will be requested. During the informed consent process the participant will be asked to place pictures on a mat to indicate their choices. The familiar communication partner will observe this process to ensure the participant was not coerced into participating. The participants' consent will be requested each time contact is made with the researcher.

Initially three to five sessions of 30-45 minutes each will be conducted to focus on building trust and establishing rapport with the participant, prepare materials for the digital life story and to complete the Montreal Cognitive Assessment [MoCA] screening tool. Potential participants who meet all the inclusion criteria will then commence with the intervention.

In the intervention phase, nine intervention sessions are planned and will take place at the dementia care home. Each intervention session will take 10-20 minutes of video-recorded interaction. In the intervention phase, the participant will interact with the researcher using the AAC device (iPad) in two ways. Firstly, the participant will discuss a digital life story topic with the researcher without being trained on how to use the AAC device. Thereafter, the researcher will train the participant to use the AAC device and will apply supportive strategies to encourage interaction with the participant.

At the end of the intervention phase, the familiar communication partner will be requested to come to the dementia care home at a convenient time to watch five of the video-recordings. The familiar communication partner will rate the video-recordings and answer three short questions about what they thought about the interactions. This will help to get an idea of whether the AAC intervention was effective. This entire process should take no longer than one hour.

Participation in this study is completely voluntary. Participants may withdraw from the study at any time without giving a reason. Participants will be given a printed copy of their completed life story at the end of the study. All information will be treated confidentially as no identifying information will be used in written reports and scientific publications. All data will be stored electronically in password protected files at the Centre for AAC at the University of Pretoria for 15 years. A one page written summary of the findings of the research study can be emailed to you upon completion of the study.

Thank you in advance for considering this request. Please complete and return the reply slip below. Questions or queries regarding the research study are welcome and can be addressed to the researcher or supervisor using the contact details below.

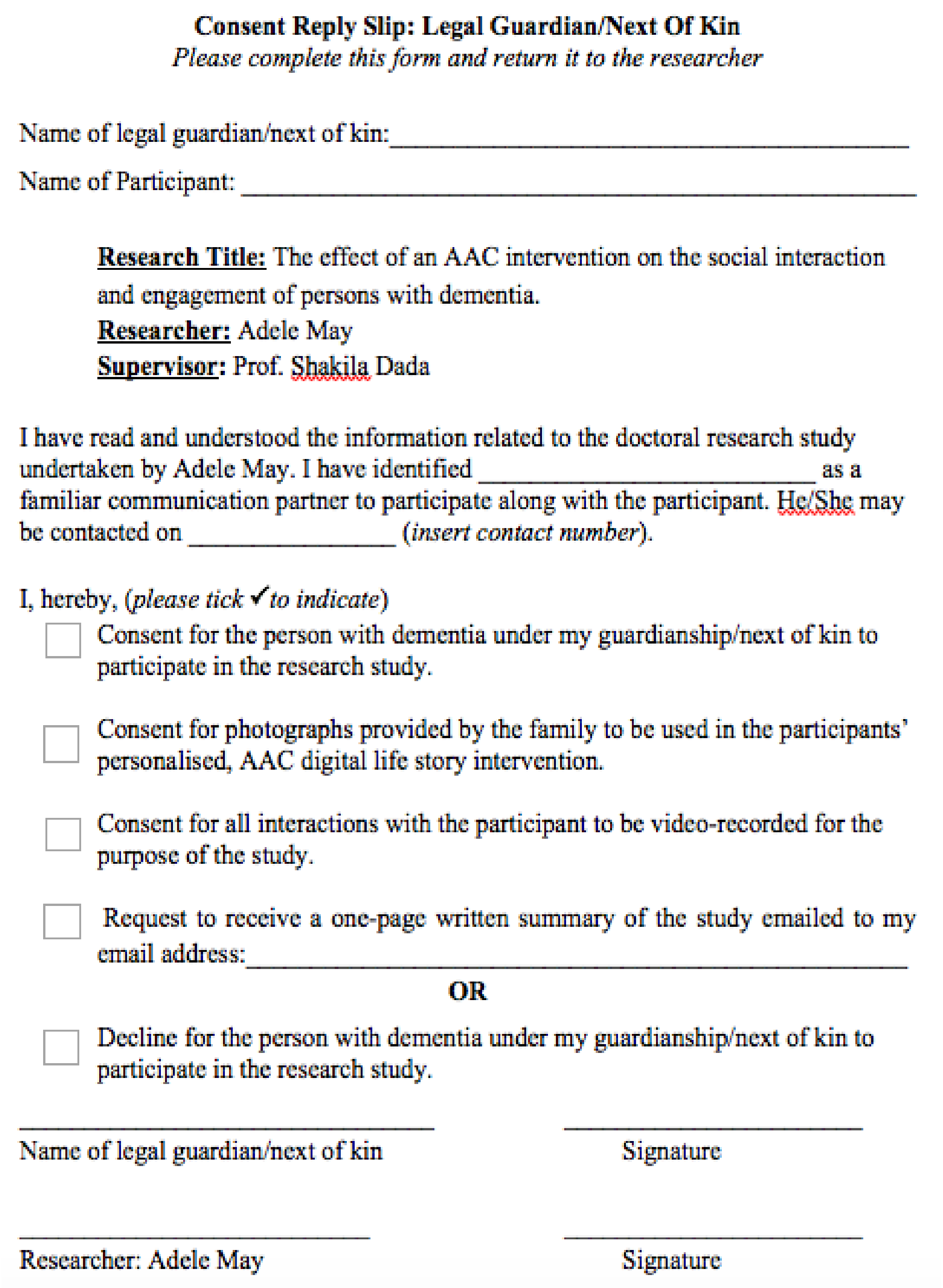
Yours Sincerely,

[redacted]

Adele May
Doctoral Candidate,
[redacted]

[redacted]

Prof. Shakila Dada
Supervisor
[redacted]



Consent Reply Slip: Legal Guardian/Next Of Kin

Please complete this form and return it to the researcher

Name of legal guardian/next of kin:____

Name of Participant: ____

Research Title: The effect of an AAC intervention on the social interaction and engagement of persons with dementia.
Researcher: Adele May
Supervisor: Prof. Shakila Dada

I have read and understood the information related to the doctoral research study undertaken by Adele May. I have identified __________________________ as a familiar communication partner to participate along with the participant. He/She may be contacted on ________________ (*insert contact number*).

I, hereby, (*please tick ✓to indicate*)

☐ Consent for the person with dementia under my guardianship/next of kin to participate in the research study.

☐ Consent for photographs provided by the family to be used in the participants' personalised, AAC digital life story intervention.

☐ Consent for all interactions with the participant to be video-recorded for the purpose of the study.

☐ Request to receive a one-page written summary of the study emailed to my email address:____

OR

☐ Decline for the person with dementia under my guardianship/next of kin to participate in the research study.

________________________________ _______________________
Name of legal guardian/next of kin Signature

___________________________ _______________________
Researcher: Adele May Signature

Appendix Q: Case study: Letter of Consent to a Familiar Conversational Partner

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LETTER OF INFORMATION AND REQUEST TO PARTICIPATE IN STUDY AS A FAMILIAR COMMUNICATION PARTNER

Date:

Dear Sir/Madam,

Request to participate in a study as a familiar communication partner of a person with dementia

Thank you for agreeing to meet me in order to get more information about the research study. I would like to repeat and present the information discussed with you today in written format.

My name is Adele May and I am currently undertaking a doctoral study in Augmentative and Alternative Communication (AAC) at the Centre for AAC, University of Pretoria. My research topic is entitled: “The effect of an AAC intervention on the social interaction and engagement of persons with dementia.”

The purpose of the research study is to develop a personalised, AAC digital life story intervention and to evaluate its effect on the social interaction and engagement of persons with dementia. The study also aims to gain an idea of how persons with dementia and their familiar communication partners felt about the interactions. The results of the study may help researchers and communication partners to support social interaction in persons with dementia in an engaging and person-centred manner.

You have been identified as a potential familiar communication partner of a person with dementia. In order to be selected for the study, the following criteria must be met: (i) 18 years and older (ii) either a spouse, adult child, family member, friend or professional carer who spends a minimum of two hours per week interacting with the participant, (iii) proficient in English, (iv) functional hearing and (v) functional vision.

I, hereby, request your consent to participate in the study as a familiar communication partner of a person with dementia. Should you wish to participate in the study and meet the criteria, you will be asked to complete two short questionnaires. One is a biographical questionnaire and the other, a Dementia Communication Difficulties Scale related to the person with dementia. These should take 10 minutes to complete.

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You will be met at the dementia care home with the participant at an arranged time. This may take place over three to five sessions of 30 - 45 minutes each. You may be requested to observe the process of informed consent with the participant to ensure they were not coerced into participating. You will be required to sign an observer form. Once written informed consent has been granted from the participant, you will be required to assist the participant in selecting photographs to prepare their digital life story. This process may be audio-recorded.

Then, the participant and I will have scheduled time to interact by using the personalised, AAC digital life story intervention. These interactions will be video-recorded. You will be requested to come to the dementia care home at a convenient time to watch five of the 10-minute, video-recordings. A scoring sheet will be provided to score the video-recordings. You will also be asked three short questions on what you thought about the video-recordings. Your rating of the video-recordings will be helpful to get an idea of whether the AAC intervention was effective. This entire process should take no longer than one hour.

Participation in this study is completely voluntary. All personal information will remain confidential. You may withdraw from the study at any point without giving a reason. All data will be stored electronically in password protected files at the Centre for AAC at the University of Pretoria for 15 years. A one page written summary of the findings of the research study can be emailed to you upon completion of the study.

Thank you in advance for considering this request. Please complete and return the reply slip below. If you have any questions, please contact me or the supervisor using the contact details provided.

Yours Sincerely,

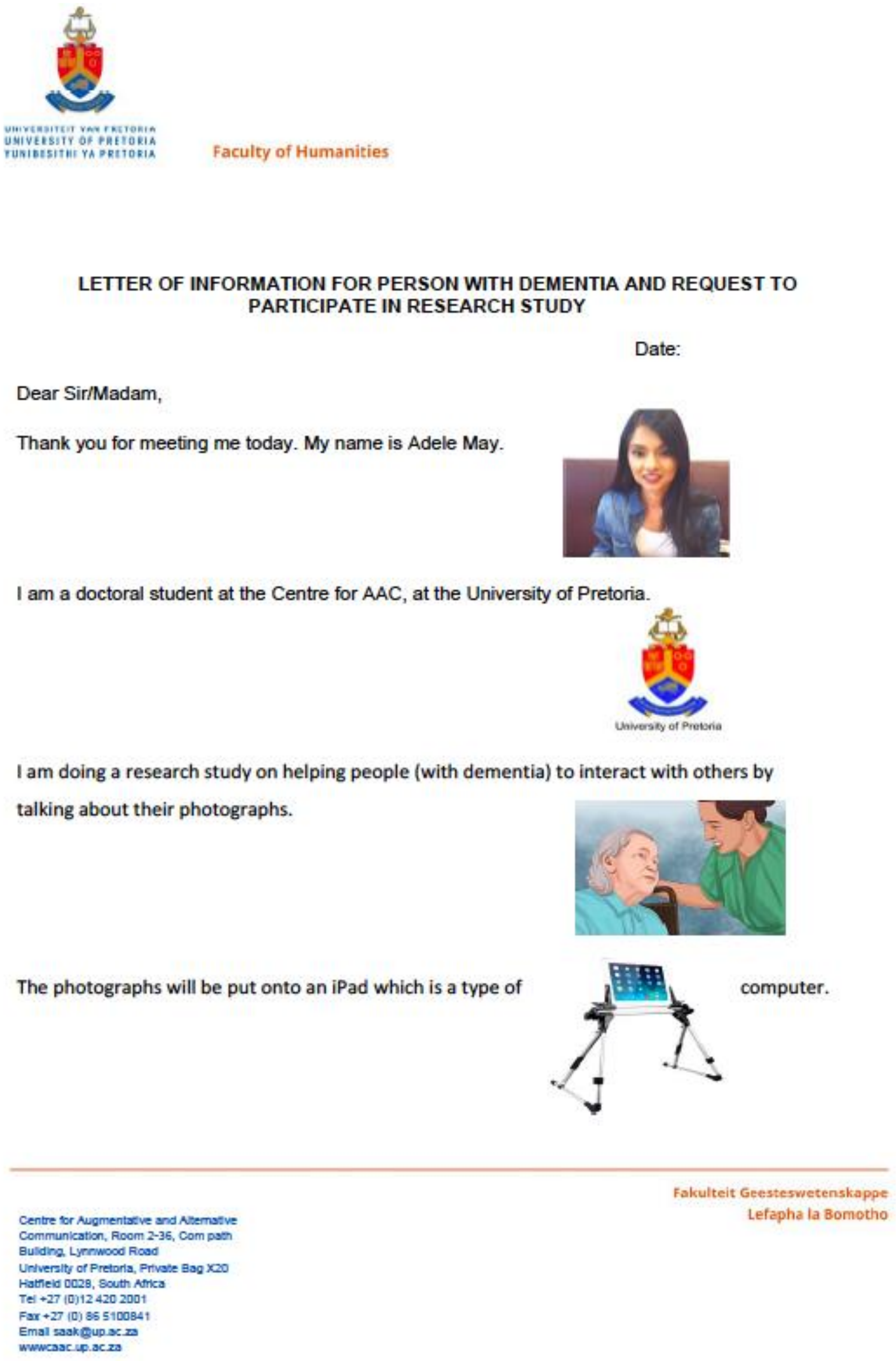
[redacted]

Adele May
Doctoral Candidate,
Centre for AAC
[redacted]

[redacted]

Prof. Shakila Dada
Supervisor
[redacted]

Appendix R: Case study: Letter of Consent to Participant with Dementia (adapted)



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LETTER OF INFORMATION FOR PERSON WITH DEMENTIA AND REQUEST TO PARTICIPATE IN RESEARCH STUDY

Date:

Dear Sir/Madam,

Thank you for meeting me today. My name is Adele May.

I am a doctoral student at the Centre for AAC, at the University of Pretoria.

University of Pretoria

I am doing a research study on helping people (with dementia) to interact with others by talking about their photographs.

The photographs will be put onto an iPad which is a type of computer.

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Fax +27 (0) 86 5100841
Email saak@up.ac.za
wwwcaac.up.ac.za

If you choose to take part, I will first do a short test on you. In the test, you will be asked a few questions, for example the date and time.

You will choose the photographs from your family albums.
I will ask you some questions about your photographs.
This will help to write a short story about the interesting and happy times in your life.

I will see you for 10 minutes for about 3 weeks. In this time we will talk about your photographs.

I will use a video-recorder to record our discussions. This will help me remember what we spoke about.

Taking part in the study is voluntary.
This means that you can choose to take part.

During the study you can use the stop card at any time.
This will say that you want to stop the study.
You don't have to give a reason for why you want to stop.

If you feel tired, you can use the break card.

This will say that you need a break.

You can take a break or continue on another day.

Your name will not be used in the study. All your information will be kept confidential. This means it will not be shared with anyone.

The video-recordings of us will be kept safe at the Centre for AAC at the University of Pretoria for 15 years.

Nobody outside of the study will see your life story photographs.
You may keep a copy of the life story photographs at the end of the research project.

I would appreciate if you would think about taking part in the study. I, or my supervisor, can be contacted directly (details below) if you would like more information on the study.

Yours Sincerely,

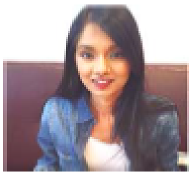
[redacted]

[redacted]

Adele May
Doctoral Candidate
Centre for AAC
[redacted]

Prof Shakila Dada
Supervisor
[redacted]

Informed Consent Reply Slip (Adapted)

	I understand that information about my personal photographs and life story will be kept safe and will not be shared with anyone outside the research study.			
	I understand that I can stop taking part in the research study at any time. If I stop, I do not have to give a reason.			
	I understand that Adele May is the researcher and she will be interacting with me. I know how to contact her if I want more information on the study.			

Do you want to take part in the study?	☺ 👍 yes ☐	✗ 👎 no ☐

Name: ______________________ Signature: ______________________

Date: ______________________ Place: ______________________

Researcher:

I have explained the research study to the participant before requesting his/her signature above.

An observer has observed the consent process being undertaken with the participant.

A copy of this form will be given to the participant or his/her legal guardian/next of kin.

Adele May (researcher)

Signature: ______________________

Date: ______________________ Place: ______________________

Appendix S: Observer to Informed Consent Form

Observer to informed consent

Office use: participant nr

Name of observer:

____

Relationship to participant:

____

I have observed the research project being explained to: (*insert name of person with dementia)*

____

Please tick ✓ the options that apply:

	Yes	No
I feel that he/she understood what was required of him/her for participation		
I feel that he/she was happy to participate in the study without being coerced by the researcher.		

Additional comments on the informed consent observed.

____

____

____

Signature of Observer: ________________________________

Date: ____

Place: ____

Researcher: Adele May

Signature: ______________________________________

Date: ______________________________________

Appendix T: On-going Informed Consent Form and Picture Booklet

Process of on-going consent form (participant with dementia)

Office use: participant nr

Date: ___________________________________

Research site: ____________________________

I know what the research study is about		yes ☐ no ☐
I know that I can take a break if I feel tired.		yes ☐ no ☐
I know I can stop at any time if I don't want to be in the study any longer.		yes ☐ no ☐
I am happy to continue with the research study today with Adele May.		yes ☐ no ☐

Participants name: ______________________________________

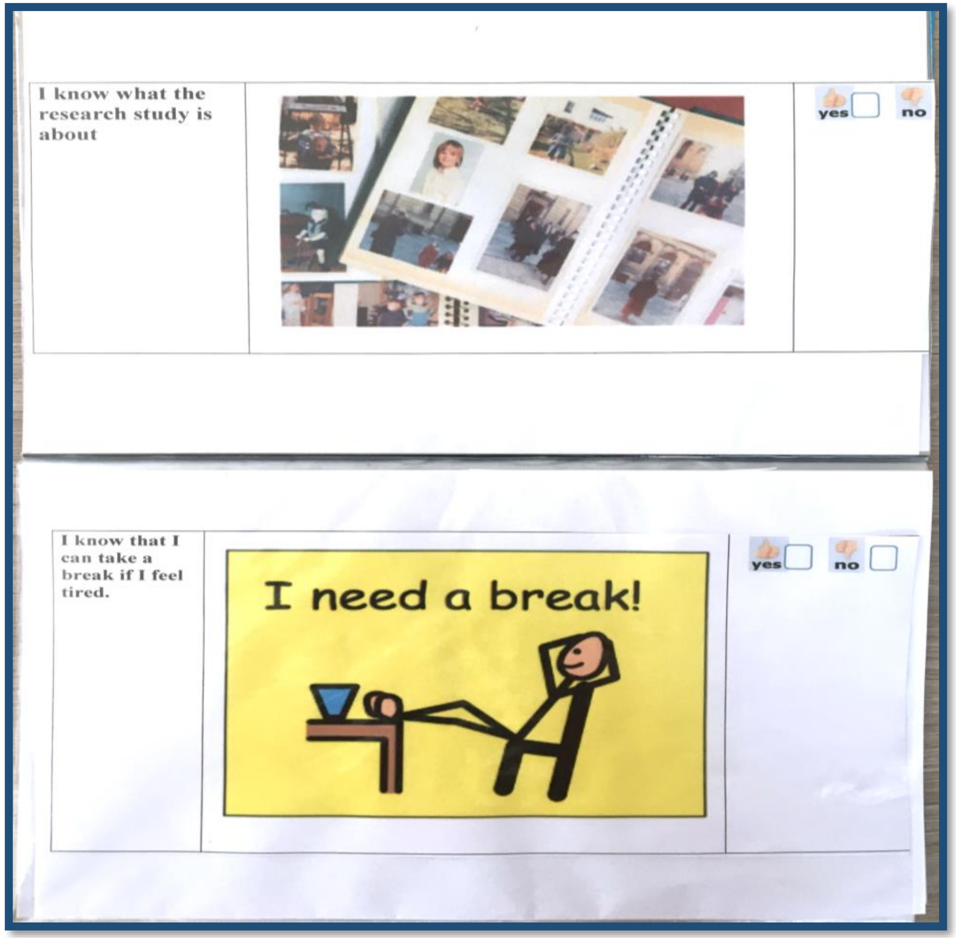
Participants signature: __________________________________

Adele May (researcher) Signature: ______________________

Date: ____

Place: ____

Process of on-going consent: picture booklet



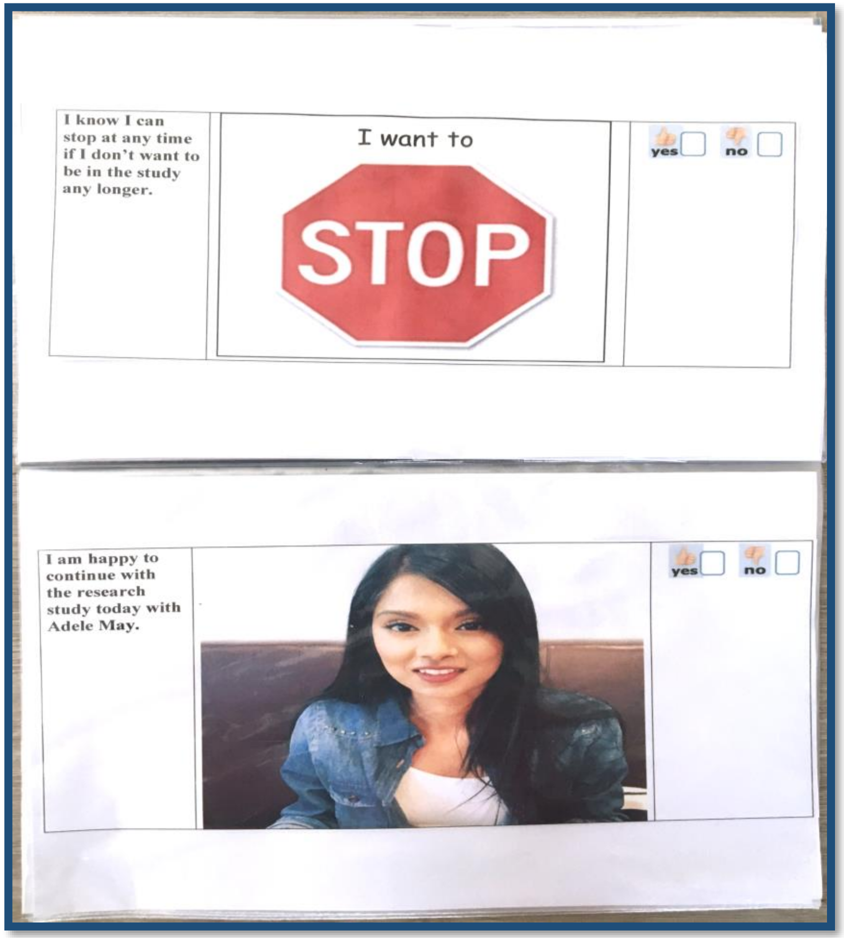
I know what the research study is about

yes ☐ no

I know that I can take a break if I feel tired.

I need a break!

yes ☐ no ☐



I know I can stop at any time if I don't want to be in the study any longer.

I want to

STOP

yes ☐ no ☐

I am happy to continue with the research study today with Adele May.

yes ☐ no ☐

Appendix U: Biographical Questionnaire: Participant with Dementia

Biographical Information Form for the participant

Office use: participant nr

Please complete this questionnaire by writing the information in the spaces provided or ticking the boxes where appropriate. The legal guardian, next of kin or the researcher, may assist the person with dementia to complete this form.

1. What is your date of birth? ________/_________/______
2. What is your age? _________________________________

Please tick ✓ the appropriate box.

3. What is your gender?

Male ☐

Female ☐

4. Do you speak English as your first language?

Yes ☐

No ☐

5. What other languages do you speak?

English	☐	isiZulu	☐
Afrikaans	☐	isiXhosa	☐
Other	☐		

Specify ________________

6. What was your highest level of education**?**

Primary School	☐	Diploma	☐	Matric	☐
High School	☐	Degree	☐	Post-graduate	☐

7. What was your last occupation?

____

8. What is your marital status?

Single ☐

☐

Married
Divorced ☐
Widow/widower ☐
Other: ☐

9. Do you have any problems with your vision?

Yes ☐
No ☐

10. Do you wear spectacles?

Yes ☐
No ☐

11. Do you have any problems with your hearing?

Yes ☐
No ☐

12. Do you wear hearing aids?

Yes ☐

No ☐

13. Which is your dominant hand?

Left ☐

Right ☐

14. Do you have any problems with your dominant hand?

Yes ☐

No ☐

If yes, please elaborate: ________________________

Completed by:

Thank you for taking the time to complete this form.

Appendix V: Biographical Questionnaire: Familiar Conversational Partner

Biographical information form for familiar communication partner

Office use: participant nr ☐

Please complete this questionnaire by writing the information in the spaces provided or ticking the boxes where appropriate.

1. What is your date of birth? _______/________/______
2. What is your age? _______________________________

Please tick ✓ the appropriate box.

3. What is your relationship to the participant (person with dementia)?

Spouse	
Child	
Family member	
Professional Caregiver	
Other: Specify	

4. What is your gender?
   Male ☐
   Female ☐

5. Do you speak English as your first language?
   Yes ☐
   No ☐

6. What other languages do you speak?
   English ☐ isiZulu ☐
   Afrikaans ☐ isiXhosa ☐
   Other ☐
   Specify ________________

7. What was your highest level of education?
   Primary School ☐ Diploma ☐ Matric ☐
   High School ☐ Degree ☐ Post-graduate ☐

8. Do you have any problems with your vision?
   Yes ☐
   No ☐

9. Do you wear spectacles?

Yes ☐
No ☐

10. Do you have any problems with your hearing?
Yes ☐
No ☐

11. How many days in a week do you interact with the person with dementia?
1 day a week ☐
2-3 days per week ☐
3 days or more ☐
Everyday ☐

12. How much time is spent interacting with the person with dementia
15 minutes or less ☐
15-30 minutes ☐
30-45 mins ☐
60 mins ☐

13. Do you struggle to find things to talk about with the person with dementia?
Yes ☐
No ☐

If yes, please elaborate:
____
____
____

14. List the three things that the person with dementia enjoys talking about?
1:_____________________________
2: ____________________________
3: ____________________________

Thank you for taking the time to complete this form.

Appendix W: Procedural Checklist: Baseline Phase

Procedural Checklist: Baseline Phase

Procedural integrity

Initials of Observer: **Date: - - 2020** **Session:** Baseline

Instructions to the observer:

- Insert a ✓ to indicate a 'yes' -the step was followed
- Insert a X to indicate a 'no' -the step was not followed

Procedure	**Yes**	**No**
Equipment and set-up		
Video-camera switched on and set-up prior to participant entering the room		
AAC device placed on the table with adjustable stand in front of the participant		
Researcher and participant are seated next to each other facing the AAC device		
Life story content is loaded onto the AAC device (visible on video recording)		
Audio for voice-output plays during life story interaction		
Greetings and introduction		
Greet participant and orientate her to the task at hand: *"Good day Mrs…, My name is Adele and I am a speech-therapist. I doing a doctoral study…"*		
Before the start of the life story, the researcher reiterates that the lifestory belongs to the participant "*Mrs…these are your stories. You helped me write these stories for you….*"		
In each interaction opportunity with the electronic life story conversational support: The researcher does the following…		
Begins the interaction **without** demonstrating use of AAC device		
Reads a pre-selected (researcher selected) life story topic (**no choice offered to the participant)**		
Reads life story on AAC device (**without pointing** to AAC symbols)		
Provides **general prompts** "tell me about this..."		
Responds to the participant **neutrally** e.g. "Oh", "Hmm" (no elaborations, no comments)		
Speaks naturally (**no prosodic emphasis**)		
Refers to the participant generally (during life story interaction there is **no specific** or intentional use of participants name)		
Closure		
End the interaction (**no pointing** to AAC symbols) "*Thank you…., we have come to the end of the story today*."		
Stakeholder Perspective		
Obtain stakeholder perspective immediately after interaction		

Total steps: 16

Total steps researcher adhered to: ____

Appendix X: Procedural Checklist: Intervention Phase

Procedural Checklist: Intervention Phase

Procedural integrity

Initials of Observer: **Date:** - - **Intervention Session:**

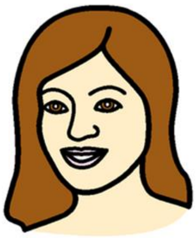
Instructions to the observer:

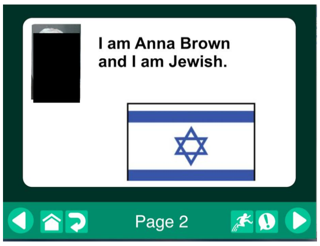
- Insert a ✓ to indicate a ‘yes’ -the step was followed
- Insert a X to indicate a ‘no’ -the step was not followed

Procedure	**Yes**	**No**
Equipment and set-up		
Video-camera switched on and set-up prior to participant entering		
AAC device placed on table with adjustable stand in front of participant		
Researcher and participant are seated next to each other facing the AAC device		
The content of the life story is loaded onto the AAC device (visible on video)		
Greetings and introduction		
Greet participant and orientate to the task at hand and says: *“Good day Mrs…, My name is Adele and I am a speech-therapist. I doing a doctoral study…”*		
Before the start of the life story, the researcher reiterates that the life story belongs to the participant “*Mrs …these are your stories. You helped me write these stories for you….”* *Your stories are on a type of computer called an iPad.* *Let me show you how the iPad works”*		
AAC device familiarisation: Does the researcher *Your stories are on this computer. I will show you how the computer works.*		
Demonstrate: light, single touch with pad of finger on the AAC device		
Demonstrate: Press Home Button		
Demonstrate: Press GoTalk app icon		
Provide at least 3 opportunities for the participant to navigate AAC device (with or with assistance)		
General: Audio plays for voice-output during life story interaction		
PC-AAC Scaffolding Strategies: Did the research apply the following (consistently for a minimum of 5 times in the life story)		
1. **Aided Modelling:** Researcher points to AAC symbols on AAC device while simultaneously reading life story (introduces story topic)		
2. **Person-centred comment or question with Aided Modelling**: Researcher uses (person recognition, person elaboration, empathetic responses) while pointing to AAC symbols on AAC device		
3. **Expectant delay**: Researcher turns toward participants, wait 5 seconds		
4. **Respond with Aided Modelling**: responds by repeating the participants responses by pointing to AAC symbols on the AAC device		
If no response= no verbal, no non-verbal or inappropriate: Repeat using aided modelling and wait 5 secs before moving on. Responds to participant initiation, elaboration, repairs contingently with aided modelling before moving on.		
Sub-total: PC-AAC Scaffolding strategies	/20	
Ending: Say” End of story” to signal end of the life story by pointing to AAC symbols “*Thank you Mrs …., we have come to the end of the story today*.”		
Stakeholder Perspective		
Obtain stakeholder perspective immediately after interaction		
Total score out of 33	/33	

Appendix Y: Stakeholder Perspective Checklist

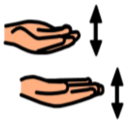
Question 1: Mrs, Brown, did you enjoy talking about your life story today?





[redacted]

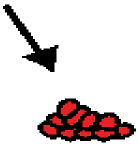
I am Anna Brown
and I am Jewish.

 ☐	 ☐	**not sure** 

Based on the participants response, ask the second question.

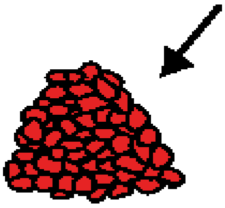
Question 2: Did you enjoy talking about your life story?

a little?



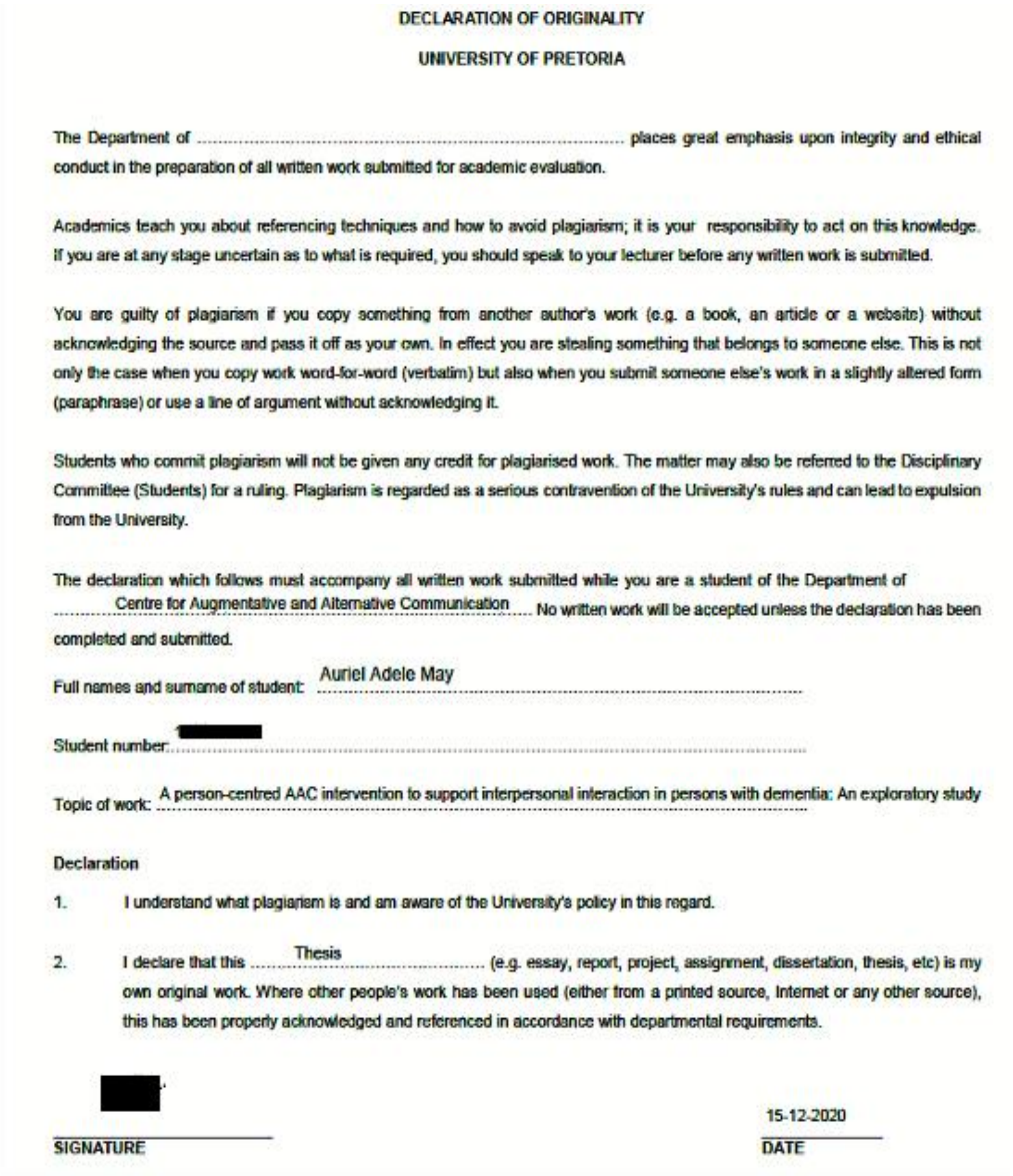
Or

a lot?



To support this conversation with the participant, the researcher should use multimodal AAC strategies:
-Point to symbols while reading each question verbally
-Wait for the participant to respond
-Use natural gestures (hand gestures) to enhance meaning of the question
-Repeat or expand on participants responses
-Point to symbols to show an understanding of what the participant responds

Appendix Z: Declaration of Originality



DECLARATION OF ORIGINALITY

UNIVERSITY OF PRETORIA

The Department of .... places great emphasis upon integrity and ethical conduct in the preparation of all written work submitted for academic evaluation.

Academics teach you about referencing techniques and how to avoid plagiarism; it is your responsibility to act on this knowledge. If you are at any stage uncertain as to what is required, you should speak to your lecturer before any written work is submitted.

You are guilty of plagiarism if you copy something from another author's work (e.g. a book, an article or a website) without acknowledging the source and pass it off as your own. In effect you are stealing something that belongs to someone else. This is not only the case when you copy work word-for-word (verbatim) but also when you submit someone else's work in a slightly altered form (paraphrase) or use a line of argument without acknowledging it.

Students who commit plagiarism will not be given any credit for plagiarised work. The matter may also be referred to the Disciplinary Committee (Students) for a ruling. Plagiarism is regarded as a serious contravention of the University's rules and can lead to expulsion from the University.

The declaration which follows must accompany all written work submitted while you are a student of the Department of ....Centre for Augmentative and Alternative Communication..... No written work will be accepted unless the declaration has been completed and submitted.

Full names and surname of student: Auriel Adele May

Student number: [redacted]

Topic of work: A person-centred AAC intervention to support interpersonal interaction in persons with dementia: An exploratory study

Declaration

1. I understand what plagiarism is and am aware of the University's policy in this regard.

2. I declare that this ....Thesis.... (e.g. essay, report, project, assignment, dissertation, thesis, etc) is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.

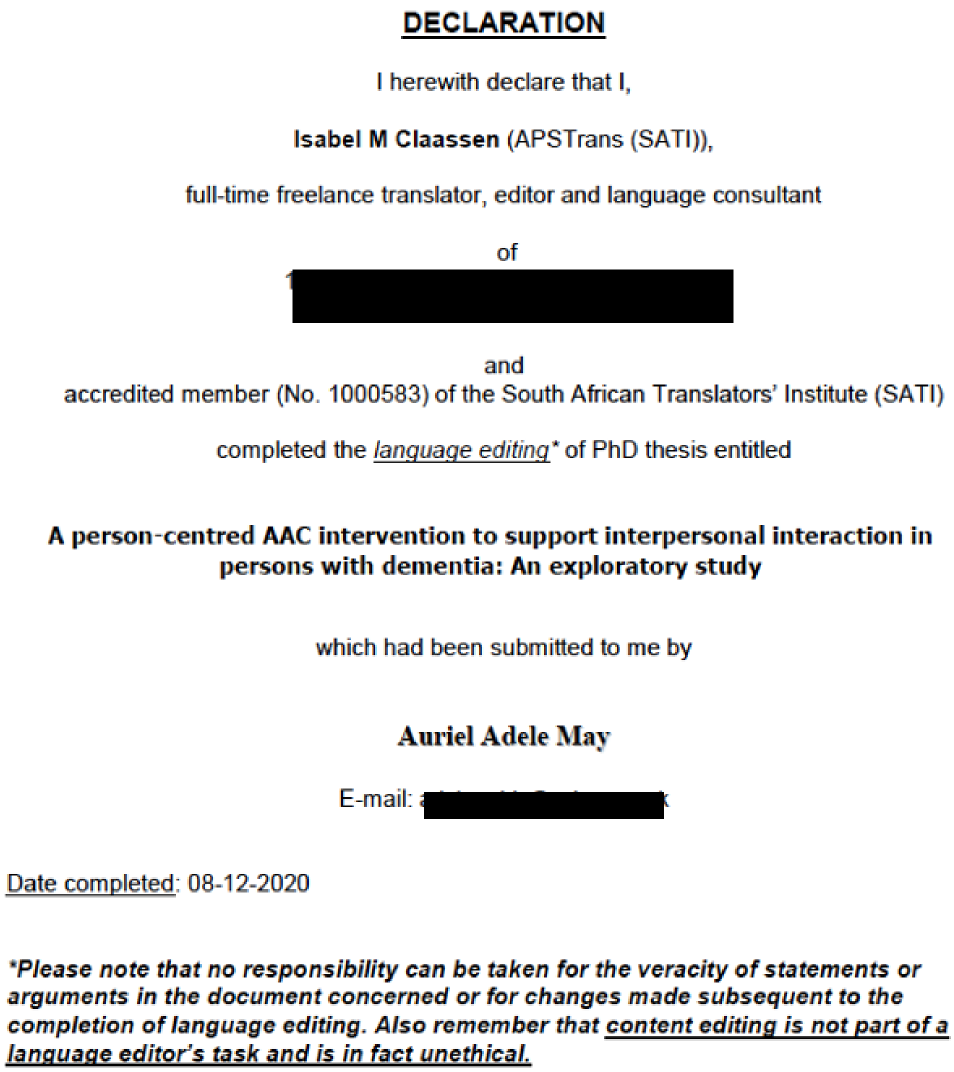
[redacted]

SIGNATURE

15-12-2020

DATE

Appendix AA: Declaration from Language Editor



DECLARATION

I herewith declare that I,

Isabel M Claassen (APSTrans (SATI)),

full-time freelance translator, editor and language consultant

of

[redacted]

and
accredited member (No. 1000583) of the South African Translators' Institute (SATI)

completed the *language editing** of PhD thesis entitled

A person-centred AAC intervention to support interpersonal interaction in persons with dementia: An exploratory study

which had been submitted to me by

Auriel Adele May

E-mail: [redacted]

Date completed: 08-12-2020

Please note that no responsibility can be taken for the veracity of statements or arguments in the document concerned or for changes made subsequent to the completion of language editing. Also remember that content editing is not part of a language editor's task and is in fact unethical.