Dementia and Communication: Supporting Family Carers in Wales and England

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December 2024

Abstract

This thesis investigates how Empowered Conversations (EC) (Morris et al., 2020), a communication course for family caregivers of people living with a dementia (PLwDs) that is currently only offered in Greater Manchester, could be adjusted to better suit the needs of family carers living in Wales.

The data comprises interviews with family caregivers in Greater Manchester who have participated in EC, carers in Wales who have not, and two supplementary focus groups of family carers who live in a rural area of North Wales. The interview data were analysed using a reflexive thematic analysis. The focus group data analysis used directed content analysis.

The analyses are interpreted through the lens of two frameworks that underpin EC, namely the Communicative Impact model (Wray, 2020) which focusses on how and why carers use communication, and Mentalization (Luyten & Fonagy, 2015), a psychological model of how carers understand others and themselves.

The findings suggest that strategies taught in EC for overcoming difficulties in dementia communication are likely to be as beneficial in Wales as in Greater Manchester. Specifically, mentalization training improves carers' ability to develop solutions to issues that emerge over time in the dementia trajectory, and it therefore meets a universal need. However, some issues particularly relevant to Wales were identified. In order for EC to better suit the need of carers in Wales, especially those living in rural areas, it should incorporate additional strategies for communicating with healthcare professionals and it should promote peer-support between participants to a greater extent. Consideration is also given to the value of offering EC through the medium of Welsh.

In discussing and conceptualising the outcomes theoretically, three new insights are offered. First, carers improve communication through changing their communicative goals. This is done by adjusting the perception of what communication realistically can do and learning to anticipate when similar adjustments will be needed, before anything goes wrong. Second, changes to communication are underpinned by information that stems from situations where carers are unsuccessful in achieving their goals. Mentalization aids in this process. Finally, the way third parties communicate with PLwDs can have impact *by proxy* on carers' experience of dementia and communication. In addition, the concept of social reserve, part of Wray's (2020) Communicative Impact model, is applied to empirical evidence, which has not been done before. The concept is shown to provide an excellent frame for mapping how carers' social support impacts on their experience of dementia communication.

Overall, the findings indicate that Wray's and Fonagy et al.'s frameworks can provide explanations for how and why dementia communication is so difficult. Moreover, they indicate that the communicative strategies taught in EC, inspired by these frameworks, can result in individually tailored long-term improvements to communication.

Acknowledgements

First, I want to express my deepest thanks and gratitude to my supervisor Professor Alison Wray. I am truly grateful for her keen interest in this research, insightful guidance, and unwavering support. I have especially valued our (often much longer than planned) meetings, where we have discussed theory, problems, and solutions, that reinforce the importance of the work that can help people living with a dementia and people who provide care for them. In addition, throughout this degree, Alison has continuously provided me with opportunities that have developed my skills as a researcher, and strengthened my confidence in academia. It has been an absolute privilege to learn from you, and work with you. I truly could not have wished for a better supervisor. Thank you so very much!

Thank you to all the staff at ENCAP who have been immensely supportive throughout my studies, always providing speedy and clear answers to just about any question you can think of. I would like to give special thanks to Dr Seán Roberts for your valuable insights and support.

Thank you to the Economic and Social Research Council Wales, Cardiff University College of Arts, Humanities and Social Sciences, and Health and Care Research Wales, for funding this 1+3 project. From undertaking the work in this degree, I have found a new way of looking at the world. I would also like to thank Empowered Conversations for being an external partner to this research project, and for everything that the lovely staff has done for me. I want to give a special thanks to Emma Smith. I am very grateful for her encouragement, support, and insightful reflections that she has brought to all our conversation over the last four years. Thank you.

To all my PhD-peers - Alex Carr (the British wizard), Ellie Bristow, Emma Collier, Aurora Goodwin, Katherine Young, Debbie Cabral, Mihaila Lukic, Nagla Alqaedi, Erin Mathias, Tom Fitz-Hugh and Susannah Paice – I am so very grateful for having been surrounded by people who are just as interested in what they do as I am, and for the privilege to call you friends. Thank you for all the discussions, insights, walks, lunches, trips to the pub, ‘fika’, and so many other fun things!

To all of my friends outside of the PhD in Stockholm, Linköping, Cardiff and elsewhere in the world (no one mentioned, no one forgotten – Swedish saying) – thank you all for being there for me. I appreciate your friendship to no end.

Finally, I want to extend a massive thank you to my family, and to my partner Hannah, for always being there, and for all of your support. Thank you, dad, for talking to me on the phone every morning as I made my way to the office, and for your constant encouragement. It mattered more than you think. Thank you, mum, for being an excellent conversational partner, and for generously sharing your amazingly empathetic ability to always relate even the most abstract research back to the person who can benefit from it. You are an inspiration! To my siblings Ebba and Arvid, I am not sure you know much about my research, but I am immensely grateful for you nonetheless! Finally, thank you Hannah for your constant support, for pushing me when I needed it, and for patiently listening to endless explanations of theoretical concepts – none of which you are probably all that interested in. I am extremely grateful for all of you.

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Transcription key

Symbol	Meaning
,	Short pause.
.	Slightly longer pause.
(x.x)	Long pause (detail of length of pause in transcription).
?	Marks a question where needed for context.
Cursive	Marks clear emphasis where necessary for context.
(( ))	Marks extralinguistic features, e.g. laughter, or comments from researcher, e.g., inaudible parts of utterances.
‘word’	Marks reported speech
[ ]	1. Marks retraction or supplement of information (chapter 7)

	2. Overlap between interlocutors (chapter 8)
	Where [ ] is used to indicate overlap between participants, ‘(word)’ is used to mark masking or supplementation of information (this only applies in chapter 8).
-	Marks cut off words
…	Represents omission of one or multiple words within transcription.

Chapter 1: Dementia communication - what is the problem?

Communication is often seen as a natural ability that we control effortlessly. In many cases, this is true. However, even in individuals with the highest of language proficiency, communication can go wrong. Everyone can relate to not finding a word, forgetting or mishearing what someone has said, and the frustration of feeling misunderstood. There are many conditions that can make communication a complicated process. In this thesis, I will focus on one such condition, dementia, that greatly impacts on the experience of communication for the people affected, and those close to them.

Dementia is an umbrella term describing different sets of cognitive, memory and language symptoms that progress and gradually increase (American Psychiatric Association, 2013). It constitutes one of the leading global conditions causing cognitive disabilities and dependency in older people (World Health Organization, 2020). Currently, one in eleven older people in the UK is living with a dementia (NHS, 2023b), a number that is likely to increase in the future due to the population getting older, since age is the greatest risk factor for developing dementia (World Health Organization, 2017). When a person is affected by a dementia, the way they experience the world will change. It is logical then, that interaction with others may be altered, since it is based on our thoughts and experiences. There are currently no cures for dementia, and considering the nature of the condition, an affected person will require increasing aid to deal with many aspects of life.

In many cases, that aid is provided by an unpaid family member, often termed ‘family carer’ (henceforth referred to as ‘carer’[1]). This term intrinsically refers to kin, but is in fact not restricted to this type of relationship (Gitlin et al., 2020, p. 13). That is, the term can also refer to a close friend, neighbour, or anyone else who provides unpaid care for a person living with a

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[1] ’Carer’ can also refer to people who provide support in a professional capacity. In this thesis, this type of carer is termed a ‘professional carer’, ‘healthcare professional’, or similar, indicating that someone is providing care in a professional capacity.

dementia (PLwD), whether it be “episodic, daily, occasional, or of short or long duration” (National Academies of Sciences Engineering and Medicine, 2016, p. 4). Being a family carer can be extremely difficult. In addition to the hardship of witnessing the person they care for progressively being affected by dementia, carers undertake massive support responsibilities, often forcing them to deprioritise other central parts of life, such as work (Brodaty & Donkin, 2009) and social interactions outside the ‘dementia dyad’[2] (Alzheimer’s Society, 2017, p. 16; Pinkert et al., 2021).

It follows that the PLwD and family carer spend a lot of time together, making the carer the primary source of and target for communication for a PLwD. Ensuring that communication works as well as it can is important. Where it does not, it is not uncommon for both the carer and the PLwD to experience high levels of stress and uncertainty, and feelings of isolation and depression (Feast et al., 2016; Savundranayagam et al., 2005; Savundranayagam & Orange, 2011).

The ways in which dementia affects communication, and how carers perceive its impact on interaction, have been studied extensively. Symptoms of dementia that directly affect communication are related to language, cognition and memory (Banovic et al., 2018), and vary in how they affect discourse depending on the person affected, and the context (Kempler, 1991, p. 104; Müller, 2010, p. 613). Many people living with a dementia are aware of contexts in which they are particularly vulnerable to communicative breakdowns, and develop sophisticated strategies for masking difficulties, or avoiding such situations (e.g., Maureen Littlejohn’s conversational behaviour reported by Davis, Maclagan and Cook (2013)). Wray (2020, pp. 198-199) notes that formulaic language is commonly used to hide dementia symptoms, perhaps because it seems to require less cognitive processing due to being recalled as one unit in language, despite potentially containing multiple words. Examples include pragmatically appropriate phrases that do not disrupt typical interaction patterns such as ‘yes dear’ and ones that carry little semantic content, e.g., ‘and all that kind of thing’ (Wray, 2010). Another way to disguise problems is with laughter (Lindholm & Wray, 2011). Therefore, in order to pinpoint how carers perceive communication with a PLwD, it is logical to approach communication framed by the contexts in which it happens.

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[2] That is, the carer and the PLwD.

Research examining core approaches for communicating well with a PLwD focuses on maintaining their status as a person and promoting wellbeing, where symptoms of dementia provide the frame by which unimpaired interlocutors should adapt *their* communication (Kitwood, 1997). However, for a family carer, this is not always easy to do. Communication can be an intimate and sensitive issue for carers. Contrasts in communicative practices over time can be painful markers of how long and loving relationships are changing (Braithwaite Stuart et al., 2021, pp. 1144-1146). During the course of this PhD, I visited a dementia support centre (which I will discuss in depth in chapter 8), where one spousal carer pulled me aside and said: "the thing I miss the most, Axel, are the conversations, but they're gone now".[3] For me, this captures how changes to communication play a significant part, at an emotional and practical level, in shaping carers' experiences of supporting a PLwD (Purves & Phinney, 2011).

Many theoretical approaches have been deployed to explain why dementia disrupts communication. One problem arising across these theoretical explanations is discrepancies in terminology, which make it hard to align studies for direct comparison (see chapter 1 of Davis & Guendouzi, 2013). Another problem relates to what theories attempt to explain. Ennis et al. (2019, p. 18) states:

> Most current theory focuses on communication as an interpersonal process. Societal- and individual-level explanations are currently relatively impoverished in terms of theory and may therefore benefit from further investigation into the basic mechanisms which underlie this complex phenomenon.

This thesis will draw on a recent pragmatically-oriented theoretical framework, developed specifically to explain how dementia can disrupt communication and why carers often find communication so challenging, namely the Communicative Impact model (Wray, 2020) (I will outline this framework in detail in chapter 5). The focus of this research will be how family carers perceive and manage communication difficulties with the person they care for in their everyday lives.

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[3] This person has given consent for me to use her comment in this thesis.

A first step towards investigating this issue is to examine what aspects of communication are disrupted by dementia, and how family carers perceive these changes to constitute challenges for communication. Therefore, the chapters in this thesis that review past literature will be guided by review questions targeting these issues (Wallace & Wray, 2016, pp. 179-180). In chapter 2, these are: (1) how does a dementia impact on language, and (2) how can impairments in memory and cognition impact on communication? Given the idiosyncratic nature of how symptoms of dementia manifest in communication, there is also scope to investigate what issues family carers perceive as difficult to circumvent. Therefore, there is need for a second literature review chapter, guided by the following questions: (3) what do family carers need to improve their management of communication difficulties, and (4) what can help carers meet their needs in relation to effective communication?

Over the years, there have been several initiatives aimed at helping carers overcome challenges in communication. In their systematic review of such interventions, Eggenberger et al. (2013) suggest that carer interventions that are individually tailored offer greater benefit than those that are not. One recent intervention that offers flexibility to carers' individual needs, which is built on Wray's (2020) Communicative Impact model, is a Empowered Conversations (EC) (Morris et al., 2020). This course provides carers with tools for developing solutions to their specific communication needs (a detailed outlining of EC and its outcomes will be presented in chapter 4) (Eastham et al., 2024; Innes et al., 2022; Morris et al., 2021; Morris et al., 2023). Current research outcomes indicate that indeed, participants develop such tools and reduce their stress levels after having participated in this course (Innes et al., 2022; Morris et al., 2021). This means that EC offers an interesting opportunity for investigating how carers perceive their communication needs, and what it takes to help them meet them.

Currently, EC is only offered in Greater Manchester. Insofar as EC carries potential benefit for all carers in some ways (which I will discuss in chapter 9), it would be desirable to see it rolled out to other locations, including Wales. Given the specifics of Greater Manchester as an urban, metropolitan area, however, there is scope to ask if the course would benefit from any changes, to make it more effective and suitable in other places. In this thesis, I will focus on precisely this. The central question of this thesis, which guides the already-listed review questions underpinning the literature reviews (chapters 2 and 3), the theoretical considerations (chapter 5), and research questions for the empirical study (chapters 7 and 8), is: how might EC be altered to suit the needs of family carers in Wales?

Two investigations will be reported, which jointly help pin down similarities and differences between the communication needs of carers in Greater Manchester and Wales. The findings will be combined with an exploration of the theoretical underpinnings of the EC approach, to offer a discussion (chapter 9) of why EC is so successful. The final chapter (10) will then offer an answer to the central question, as well as to a supplementary question arising from the intervening account, followed by a consideration of the limitations of the study and some suggestions for further research.

Chapter 2: Dementia and its impact on communication abilities

The first step towards investigating how carers perceive dementia and communication is to outline the root cause, that is, how dementia impacts on ability to communicate. This will provide the framework for establishing what distinguishes dementia communication from typical discourse.

To that end, in this chapter, I will first discuss the term ‘dementia’ and draw on a few relevant demographic figures. I will then ground my later accounts by considering how typical language production and comprehension work. After this, I will address how dementia affects language and how the impairments alter interaction. I will then turn to how dementia impacts on information processing, with attention to impairments of both language and memory.

Finally, in section 2.4, I will apply the combined information from this chapter to a brief analysis of an excerpt from the documentary “*You’re looking at me like I live here and I don’t*” (2012), directed by Scott Kirschenbaum, which presents much interesting spoken interaction from a person living with Alzheimer’s.

2.1 What is dementia?

According to the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) (2013), dementia is defined as a *Major Neurocognitive Disorder*, specified by etiologic subtype.

Approximately 50 million people in the world are currently living with a dementia, a number that is expected to increase to over 150 million by 2050 (World Health Organization, 2020), due to increased life expectancy (Rizzi et al., 2014; World Health Organization, 2017). The most common form of dementia in the UK is Alzheimer’s disease, followed by vascular dementia, and dementia with Lewy bodies, which often is associated with Parkinson’s disease (Alzheimer’s Society, 2020a). However, in many cases, the dementia is ‘mixed’, where features of multiple subtypes are displayed in a person who is affected (Alzheimer’s Society, 2018). Other, more uncommon, forms include the frontotemporal dementias, some variants of which often develop in individuals under the age of 65 (Bang et al., 2015, p. 1680).

Although much research has been carried out mapping the symptoms associated with specific subtypes of dementia, I will not strongly differentiate between types of dementia in this thesis. Wray (2020) states:

> While the subtypes of dementia are cognitively debilitating in different ways, they are socially debilitating in rather similar ways, undermining self-confidence and credibility, and disrupting relationships …[and]… the impact on communication is surprisingly similar, even though language and memory are differently affected (p. 9).

Therefore, in this thesis, I will often bundle together the different ways in which dementias affect cognition, language and memory, in order to sustain my focus on their impact on social interaction. Having said that, in this chapter, I will follow the research literature in describing and discussing the most commonplace symptoms, which are typically associated with Alzheimer's disease and vascular dementia. In what follows, I will outline some broad characteristics associated with the trajectory of dementia as a condition over time.

Dementia is typically characterised according to its stage, as mild, moderate, or severe. An individual in the early stages often experiences issues with word-finding, planning, and memory (Gale et al., 2018), e.g., remembering new people's names, and misplacing items. These symptoms are exacerbated in the moderate stage, where a PLwD may experience difficulties in recalling life events and personal information, such as their address (Szatloczki et al., 2015). According to the literature review by Førsund and colleagues (2018), dementia diminishes a person's ability to interpret their physical surroundings. The authors also note that this progression can impact negatively on the sense of belonging and can engender stress and anxiety. Anxiety and confusion can, in turn, lead to strong responses such as anger. Such changes in behaviour are sometimes labelled 'challenging' (Feast et al., 2016). This term will be explored in chapter 3, where I will address the potential for carers to interpret strong reactions of this kind as communicative expressions.

Late stage dementia is often associated with major limitations in using verbal language (Bayles et al., 2000). However, PLwDs in late stage dementia can still participate in communication using non-verbal language (Ellis & Astell, 2004). According to Bender, Savundranayagam, Murray, and Orange (2022) “eye contact, gestures, facial expression and touch” (p. 7) are the most used non-verbal strategies by others when interacting with people living with advanced dementia. In section 2.3.2, I will further consider the role of non-verbal communication in enabling the PLwD to participate in interaction.

Even though assigning typical symptoms to ‘stages’ of dementia can be useful, it is not an exact science. In research addressing symptoms and stage of dementia, the screening tools[4] used in determining progression have been noted to be unreliable for this purpose (Garin et al., 2014; Lim & Loo, 2018). One reason is that these screening tools rely on responses to visual and auditory cues in certain tasks. It is possible that some responses that indicate cognitive deterioration, when interpreted through the lens of screening tools, are actually the result of visual or auditory impairments (Lim & Loo, 2018) which are common in the older population more generally. Even though the association between stage of dementia and anticipated symptoms offers potential benefit – for instance, to inform carers of what they can expect in the future – it is not possible to do this with certainty. This is especially true in relation to communication, since there is great individual variation in how symptoms related to disease progression are displayed (Müller, 2010, p. 613).

In what follows I will briefly consider how typical language functions in interaction. From this, it will be possible to examine how symptoms of dementia disrupt typical processes.

2.2 What is communication?

Communication is a means for two or more individuals to share information, including facts, perceptions, beliefs and emotions. There are many signalling systems, including images, calls, noises, facial and body movements, etc. But humans also use language, a highly complex system that makes possible precise meanings. These systems work together in most contexts, according to what the medium permits, and in the context of dementia, their relative importance and usefulness can alter, as linguistic abilities recede (Ellis & Astell, 2018).

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[4] Common screening tools are the Mini-Mental State Examination (Folstein et al., 1975), and the Montreal Cognitive Assessment (Nasreddine et al., 2005).

In chapter 5, I will discuss one particular model of communication, the Communicative Impact model, which focusses as much on *why* we communicate as *how* we do so. Here, I offer a more basic overview of what is entailed in the linguistic aspects of communication, to prepare the way for outlining, in the later sections of this chapter, the ways that dementia affects communicative abilities.

A speaker begins with an idea of what they want to say, which must be held in working memory[5] for long enough to generate the output. The process of production includes the evaluation of the context, which informs the pragmatic decisions about what to say and how (Wray, 2020). This evaluation requires access to information in long and 'short term memory' and the ability to identify what is relevant (Baddeley & Hitch, 1974, p. 76; Baddeley, 2000) (for more on this see Chapter 5, section 5.2). Next comes the selection of lexical material, its assembly into a grammatical sequence or frame, and the activation of the articulators to generate the spoken output (Abbott, 2016). The speaker monitors the output to ensure that what is generated is what was intended.

A hearer receives the spoken input and must first decode it as an auditory signal before it can be mapped onto known lexical knowledge and grammatical markers, to generate a meaningful message. These processes require working memory. The message is then juxtaposed with the known context (drawing on long and short term memory), to pragmatically evaluate its plausibility as literal, figurative, humorous, fallacious, and so on (Calbi et al., 2017; Hupp & Jungers, 2013).

At all points in this process, non-linguistic signals can contribute to how information is conveyed and received. Comprehending and producing language is an ability that relies on

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[5] It is helpful to clarify here the difference between the concepts termed 'short term memory' and 'working memory', which are often interchangeable in the research literature. Aben, Stapert and Blokland (2012) note that these concepts are motivated by different theoretical positions, though at an empirical level they are fairly equivalent. I will refer to both concepts, drawing on Cowan's (2008) work when referring to working memory. He suggests that working memory can manipulate information drawing on both short and long-term memory. In this view, short term memory is distinguished from working memory in that the former stores information that the latter can process.

multiple processes that often happen in quick succession, and this is one reason why communication is badly impacted by cognitive decline.

In the following sections, I will outline how dementia affects these systems and how the changes impact on an individual's communicative abilities. I will begin with language production and language comprehension. Then I will briefly outline how sensory impairments can create problems for communication in a dementia context. After this, I will consider how impairments to memory and working memory capacity affect communication. Finally, I will turn to how symptoms of dementia change the dynamics of interaction.

2.3 Dementia and linguistic impairments

To some extent, the way a dementia impacts on language is related to its subtype. There are two reasons for this. First, some specific subtypes of dementia may affect language processing to a greater extent than other types (e.g., Gale et al., 2018). One such type is 'semantic dementia' (Mendez et al., 2021), which affects neurological areas (i.e., the temporal lobes bilaterally (although predominantly left), and the frontal lobe) associated with language processing, specifically those associated to language comprehension and word meaning (Kertesz et al., 2010). A person living with this subtype of dementia are likely to experience greater language comprehension, and word finding difficulties than people with other types of dementia (Hodges & Patterson, 2007). Another example is vascular dementia, which is caused by symptoms following damage to the brain caused by reduced blood flow (NHS, 2020). There is a wide range of potential aetiologies for such lesions (e.g., trauma, stroke, and transient ischaemic attacks (TIAs)), where symptoms displayed by a PLwD are linked to the areas of the brain that are affected.

The second reason why language impairments are linked to the subtype of dementia is that language is affected by impairments to cognition and memory. For instance, problems with working memory and attention can cause a PLwD to struggle with word retrieval even if there is no deficit in linguistic capacity itself (Bayles, 2003; Kempler & Goral, 2008, p. 75).

Common linguistic symptoms associated with dementia include problems with word finding, discourse cohesion, and language comprehension, especially in relation to complex language (Boschi et al., 2017; Kempler, 1991; Rapp & Wild, 2011; Taler & Phillips, 2008). As the condition progresses, PLwDs have also been noted to display changes to phonology and grammar (Szatloczki et al., 2015; Themistocleous, 2022). Across dementia subtypes, some of the most common symptoms that impact on linguistic abilities are related to semantics, such as word-finding, and language comprehension (Klimova & Kuca, 2016). Therefore, section 2.3.1 will focus on how a PLwD displays difficulties in finding words, and section 2.3.2 will address how the condition impacts on language comprehension. From these sections, it will also become clear how ‘memory’ impacts on a PLwD’s communicative abilities in several ways. I will discuss this term and the ways in which it affects communication in section 2.3.4.

2.3.1 Word- and meaning-finding

Difficulties related to word-finding are prevalent early in the dementia trajectory (Clarke et al., 2009; Henry et al., 2004). In clinical settings, where word-finding is tested by eliciting language phonologically and semantically, such changes are characterised by increases in time required to retrieve words (Bayles et al., 1992; Clarke et al., 2009), and a greater incidence of not finding target words (Adlam et al., 2006). A large body of literature reports that PLwDs over-utilise high-frequency words (e.g., animal) (Boschi et al., 2017), that substitute lower frequency words with more specific meaning (e.g., crocodile). Gumus et al. (2024) show that deteriorations in word-finding abilities are associated with producing fewer nouns in connected speech, and increasing the frequency of pronouns. Given that pronouns can make reference to objects and people in the same way that nouns do (e.g., ‘it’ referring to a specific object), provided there is a prior joint understanding of what entity is being referred to, pronouns can function as a substitution for nouns in many instances. However, in the absence of such joint understanding (e.g., ‘it is at home’ without providing any additional information), confusion can arise.

Word-finding difficulties have been suggested to be a consequence of deficits in semantic knowledge, reduced efficacy in searching for specific words in the mental lexicon (Taler & Phillips, 2008, p. 504; 512), and working memory impairments (Bayles, 2003). Symptoms associated with semantic impairments tend to be exacerbated as the condition progresses (Gumus et al., 2024; Szatloczki et al., 2015). In fact, it is not always clear if a person has the idea but cannot find the word, or cannot find the word because they do not have a firm grasp on the idea. Taylor (2007), wrote a book about his experiences about living with a dementia. In relation to finding words, he states:

> These days, I’m moving from searching for the right word, to searching for the thought! Increasingly, it is not a matter of waiting for the correct noun, verb, adverb, or adjective to pop up and out. It is a matter of waiting to discover an entire fact (Taylor, 2007, p. 95).

Taylor suggests that he not only struggled to find the name of an object, but also could not access the mental representation of it (Reilly et al., 2011, pp. 341-344). In other words, Taylor experienced issues in accessing information about an object, which can be a consequence of deficits in semantic knowledge.

2.3.2 Language impairments in discourse

It follows that needing more time to retrieve words, inaccuracies in naming, and an increased use of pronouns when referring to objects are all characteristics of how dementia affects single-word production. Finding specific words is just one aspect of how a dementia impacts on language in interaction. Multiple studies have investigated how a dementia impacts on utterances, and show that PLwDs tend to produce a higher frequency of indefinite terms (such as overarching words or pronouns, as exemplified above), and excessive details in narration, within which accuracy, and plausibility are often ambiguous (Boschi et al., 2017). A further well-known speech characteristic associated to dementia is repetition. However, this phenomenon is related to memory, and will be outlined in section 2.3.3.

Whilst these markers undoubtedly cause potential challenges in interaction, they do not necessarily prevent a PLwD communicating effectively. Wray (2020) suggests that it is often how other people respond to language that is the cause of suboptimal outcomes (I will discuss how this works from the perspectives of carers in chapter 3). For instance, a PLwD may request reassurance by displaying signs of anxiousness, but can be ignored if an interlocutor does not infer this request from their message, and does not probe for additional information. This loss of communication is particularly common in late-stage dementia, where PLwDs may not primarily communicate through speaking anymore (Alzheimer’s Society, 2021a; Hydén et al., 2024).

However, PLwDs’ abilities to engage in *interaction* are often retained in late-stage dementia (Hydén et al., 2024; Kindell et al., 2017), meaning that even if a PLwD cannot comprehend an utterance, or produce verbal responses, they can communicate in other ways (Ellis & Astell, 2004; Müller & Guendouzi, 2005). This communication often consists of non-verbal markers. Astell, Shoaran and Ellis (2022) show in a study that investigates the outcomes of a communication intervention (Adaptive Interaction). The authors show that carers who are equipped with tools for identifying such markers, and who respond to them by adapting to the communicative repertoire that the PLwD can use, can facilitate meaningful communication between the PLwD and other interlocutors, and help retain the PLwD's connection to the social world.

2.3.3 Language comprehension

Language that requires extensive cognitive processing is usually more difficult to produce for everyone, not just PLwDs. However, dementia undermines working memory capacity, which adds an impediment to language processing (Small et al., 1997). Specifically, Bayles (2003) suggests that reductions in information retention span and attention are salient aspects of working memory impairment related to language comprehension. This also means that any additional relevant or competing stimuli in the environment can be challenging for the PLwD, who might be required to pay attention to multiple strands of information at once (Alzheimer's Society, 2020b). There may be additional challenges in busy environments, where auditory stimuli are obscured or distorted by background noise (Arehart et al., 2014).

Difficulties in comprehending language have been observed early in the disease trajectory. At the single-word level, PLwDs have been noted to display impairments to semantic decoding (Smirnova et al., 2021), where both the accuracy and speed by which PLwDs link together words and their meaning are reduced, due to similar causes as those mentioned in section 2.3.2, i.e., impairments in the mental lexicon (Grossman et al., 1996) and working memory (Bayles, 2003). This means that utterances containing words that are difficult to process semantically (e.g., infrequent words) and/or strain the working memory, such as those that are excessively long, delivered at a high speed, or syntactically complex, may be challenging for a PLwD to comprehend (Kempler, 1991, p. 99; Savundranayagam & Orange, 2014).

One type of language that requires extensive processing, and has been noted challenging for PLwDs to process and comprehend is non-literal and abstract language, such as irony, sarcasm, and metaphors, and proverbs (Rapp & Wild, 2011). Comprehending such utterances requires abstract thinking and, to identify the speaker's likely intent, theory of mind abilities ('mind reading') (Chapman et al., 1997; Cummings, 2015).

One element of comprehension that can involve non-literal language, and carries important interactional functions, is humour, which can be an effective tool for both PLwDs and carers for relieving stressful situations in a dementia context (Wray, 2017). First, humour has been noted to function as a means for PLwDs and carers to share meaningful connections, where laughter generates positive emotions (Alsawy et al., 2019). Second, humour can be an effective tool for PLwDs to reframe situations in which communication breaks down (Wray, 2020, p. 173) – everyone says something wrong sometimes, and we do not need to have a dementia in order to laugh at it in lieu of the potential embarrassment that otherwise could constitute the outcome.

However, whether because of direct disruptions to pragmatics or because of reduced access to contextual information, dementia seems to change how humour is appreciated. According to Clark et al. (2016) carers perceive PLwDs to change in how they use and respond to humour, and what they find humorous, over the course of the disease progression, often leading to carers being unable to understand what the PLwD finds so amusing.

2.3.4 Memory and its impact on discourse in dementia communication

Arguably, when most people think about dementia, they think about memory loss and, more specifically, problems accessing traces of past events, particularly recent ones. We use language to describe memories, and we use memories to contextualise what language to use in communication. Therefore, our capacity to store and retrieve memories is central to communicating effectively. In this subsection, I will first outline what the term 'memory' entails, and then consider how impairments to its constituents can create barriers to communication.

In section 2.3, I defined the term 'working memory' and in sections 2.3.1 and 2.3.2 I showed how impairments to working memory greatly impact on language production and comprehension. However, though the working memory is essential for holding *retrieved* memories 'in mind' (Baddeley et al., 2020, chapter 8), this system is not used for information storage. Permanent information about events is stored in the long-term memory.

According to Squire (1992) the long-term memory is divided into two sub-sections, implicit and explicit. Explicit (or declarative) memory is split into two subsections, semantic and episodic memory (Tulving, 1972). The semantic memory consists of 'facts' (Baddeley et al., 2020, p. 14; Squire, 1992), for instance knowing that there are pyramids in Egypt. The episodic memory stores ‘events’ that we remember (e.g., getting married).

Some events and facts are paired and can exist in both episodic and semantic memory simultaneously. Baddeley and colleagues (2020, pp. 14-15) exemplify that “if you heard that an old friend had died, this would be likely to become part of your general knowledge of that person, hence part of your semantic memory” (p. 15), and that “if you subsequently recall the particular occasion when and where your had learned this sad news, then it would be an instance of *episodic memory* (…) hence, a given event can be registered in both types of memory” (ibid., p. 15).

The other part of the long-term memory is termed ‘implicit’ or ‘nondeclarative’ memory. This module of memory includes knowledge underpinning skills, conditioning and priming (Squire, 1992), which refers to the “retrieval of information from long-term memory through performance rather than explicit conscious recall or recognition” (Baddeley et al., 2020, p. 14), such as knowing how to ride a bike without actively recalling information to that end. Within this branch of memory is also ‘conditioning’, which refers to how some stimuli in the world evoke specific response patterns, e.g., “the involuntary association of one thing with another, such as looking for the phone when we hear it ring” (Wray, 2020, p. 35).

Two common symptoms of dementia, especially in relation to the Alzheimer’s type, are the impaired storage of new memories, and the decay of previously stored episodic memories. For example, a PLwD might struggle to remember what they did earlier in the day because the memory has not been stored. But they might also no longer accurately recall personal details, such as their age, and specific events, such as getting married (Alzheimer’s Association, 2021b). These difficulties impact on a range of situations in daily living. For instance, a PLwD may misplace items because they did not lay down a memory of where and when they moved it, or repeat a particular piece of information because they cannot remember already having said it (Cullen et al., 2005; McKhann et al., 2011). There are many potential consequences related to such impairments. For instance, without personal information to hand, a PLwD can become lost and may be unable to get help to find their way home, or risk upsetting friends and relatives where they cannot recall the relationship.

In section 2.3.1 I reported that PLwDs often struggle to describe objects in narration tasks, using ambiguous or inaccurate language. In turn, such language may reduce the amount or accuracy of contextual information in a PLwD's utterance so that other interlocutors cannot infer its meaning (Boschi et al., 2017; Carlomagno et al., 2005). Memory plays a significant part in this issue. First, the cognitive ability to judge how much information a hearer needs may be impaired. Second, a dementia often impacts on the ability to recall contextual information related to specific memories (El Haj & Kessels, 2013).

This means that whilst it is possible to make links between memory impairment and its impact on PLwDs' communicative abilities in research settings, the characteristics of such issues in clinical trials do not necessarily match those that are problematic when interacting in the real world. Whilst impairments to the PLwD's ability to provide accurate and sufficient information for a hearer to infer a message is likely to impact on communication, there are many more processes that happen simultaneously. El Haj an Kessels (2013) point out that one aspect of memory impairments associated with Alzheimer's disease is recalling contextual information related to episodic memories, such as when or where something happened, who something happened to, or what people were there, etc. Issues in any of these processes, and indeed, in generating the language to express them, can impact on the intelligibility of a description.

A secondary problem that can emerge as a result of these difficulties is the gradual eroding of the PLwD's confidence. Pointing out to the PLwD that they are not being clear, or have mistaken some fact, may be very undermining (Wray, 2020, p. 52). In turn, it could reduce the extent to which the PLwD participates in social encounters due to uncertainties in what they are supposed to know, and anxiety about how people might react (Alzheimer's Association, 2021b).[6]

Although PLwDs' awareness levels of their cognitive symptoms appear to differ in early stages (Cacciamani et al., 2021), Vogel, Waldorff and Waldemar (2015) studied how PLwDs display awareness of their condition over time, and found that awareness is not associated with cognitive decline in mild-to-moderate stages. Rather, the level of awareness between baseline, and follow-up measurements over 36 months often remained stable, and for some participants,

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[6] It is possible to question whether not commenting on inaccuracies in a PLwD's statement would entail deception. Deception and its management lie within the frame of moral philosophy, which is outside of my knowledge. Therefore, it is outside of the scope of this thesis. See Wray (2020, pp. 219-228) for an in-depth discussion of deception in dementia communication.

awareness improved over time. These findings are consistent with another longitudinal study examining awareness conducted by Alexander and colleagues (2022), who note that psychiatric (e.g., prevalence of depression) and personality traits or level of wellbeing do not offer convincing grounds for explaining the variance in participants' awareness over time.

Naturally, a PLwD's awareness of symptoms of dementia impacts on how they communicate. For instance, a PLwD might explicitly attempt to make others aware that they experience difficulties in storing and recalling memories in order to mitigate the potential negative impacts that this impairment can have on communication (Wray, 2020). However, this is not always the case. Jones (2015) carried out a conversation analysis study using data from 70 telephone calls between a woman living in a residential care home, 'May', and her daughter and son-in-law. May experienced severe difficulties in storing memories and could often not remember details of her day. Jones notes that May established a number of formulaic phrases to mask her memory issues. For instance, when asked what she had been doing, she often said 'nothing special', regardless of whether something 'special' had happened that day or not, such as family members visiting. Whilst formulaic phrases are useful strategies that PLwDs can use for producing pragmatically appropriate responses, and potentially mask symptoms of dementia, they also serve a cognitive purpose. Formulaic phrases are considered to be retrieved as 'entire units' in the mental lexicon, and therefore require less cognitive effort than formulating a more nuanced response (Wray, 2020, p. 152).

Linguistic, cognitive, and memory impairments are all factors that alter how a PLwD interacts. We are now in a position to look more broadly at the nature of communication when someone is living with a dementia.

2.4 Dementia communication in context: what does it look like

In order to illustrate how a dementia can impact on communication, I will analyse a short passage from the movie 'You Look at Me Like I Live Here and I Don't', directed by Scott Kirschenbaum (2012). This documentary follows 'Lee', an older woman with Alzheimer's disease, living in a care home. Although there is no direct statement in the film about the severity of Lee's condition, her dementia has progressed to the extent where she requires assistance with aspects of daily living, and it is evident that although her language is fluent and superficially grammatical, her communicative behaviour is atypical. In the selected passage (timestamps 14.41 – 15.52), Lee and the camera crew are in Lee's room, where she is showing them two pieces of clothing: one turquoise jacket, and one purple suit. In the transcription below, parentheses mark non-verbal, extralinguistic features related to the conversation, and pauses.

Extract 1 – Conversation between Lee and Scott

1 Lee: I've always loved this one (reads on label) Lee (looking at camera crew with
2 anticipation for 11 seconds but does not get a response)
3 This is getting to be rather heavy for a little old lady (laughs)
4 This is mine. That's where it's going, and here's another one
5 Oh this is the one where I, I got married in (showing purple suit)
6 (9.0)
7 Scott: How old were you?
8 Lee: Oh it was a year after this, because I was, I had been doing the other things,
9 you see what you could see there. But that's the way he did it himself
11 Scott: Why did you decide to get married in that outfit?
12 Lee: Because I do not like what I see

I am going to consider this exchange from two different perspectives. The first one is how Lee's impaired language abilities impact on communication. The second is how Scott's turns contribute to the development of the conversation. I will address these issues in turn.

Looking at the transcript as a whole, we can see that Lee is not using any specific nouns, and she substitutes information-carrying units with pronouns and determiners (see below for examples), which is common in people living with a dementia (Gumus et al., 2024). From a linguistic perspective, this behaviour could prove problematic, as there is not sufficient information to infer what Lee is referring to (Boschi et al., 2017). However, in the context of her conversation, this deficit is not particularly problematic since Lee can provide additional information, that help a hearer to infer what she means, by showing two articles of clothing (lines 1 and 5).

In line 4, Lee describes where the clothes should hang: 'that's where it's going'. She does not produce nouns for 'jacket', 'suit', or the overarching term 'clothes', or 'closet' when referring to where the clothes ‘go’ (Adlam et al., 2006; Taler & Phillips, 2008). Nonetheless, Lee still produces functional communication by referring to objects in her surroundings.

Similarly, in Line 8, when Lee is responding to Scott’s question ‘How old were you [when you got married]?’ her response contains no distinct semantic content, and she refers to objects using determinants like ‘this’, and unspecific overarching words (Taler & Phillips, 2008) such as ‘other things’, which can relate to *any* object.

Scott’s question specifically addresses *when* Lee got married. Even though Lee’s language does not contain semantic information units, it is possible to claim that the way she shapes her answer is consistent with the information that Scott is requesting. Lee responds with a temporal measurement, ‘*a year after* this’ (line 8), even though it is not possible to infer what year it is, considering that there are no indications to what ‘this’ means. Here, it is possible that Lee cannot pin down the amount of information necessary for Scott to understand her response (Carlomagno et al., 2005), or that working memory impairments limit her ability to simultaneously recall information, and retrieve words, that accurately convey what she means (Bayles, 2003). But it is also possible that Scott’s question has limited meaning for her, if she has little memory of getting married (Alzheimer’s Society, 2021a; El Haj & Kessels, 2013).

On line 12, Lee responds ‘Because I do not like what I see’ to Scott’s question about why she got married in that outfit. The type of outfit that Lee is showing Scott is a purple suit. One way to understand her response is that she is referring to not liking traditional wedding dresses, or other possible outfits. It is also feasible that grammatical impairments to Lee’s language cause her to substitute ‘saw’ for ‘see’, meaning that she meant to say ‘I did not like what I saw’. However, grammatical impairments typically come in advanced stages of Alzheimer’s disease, where verbal communication is disrupted to the point well beyond Lee’s capabilities for fluent speech production (Alzheimer’s Society, 2021b; Szatloczki et al., 2015). Lee’s answer reflects typical pragmatic conventions as she replies to a ‘why’ question with ‘because’, indicating that ascriptive abilities are retained. Nonetheless, it is not possible to infer exactly what Lee means by her response.

Turning now to Scott’s communicative practices, he withholds a response to Lee in lines 1 and 2. Lee is clearly waiting for him to react, but he remains silent for 11 seconds. Considering that he is filming a documentary, he probably aims to speak as little as possible. Therefore, this situation is atypical in terms of interaction. However, we easily see the detrimental impact on

Lee's experience. In line 2, Lee displays anticipatory facial expressions after finishing her turn. This indicates that Lee's ability to apply interactional patterns functions well, which is common in dementia of the Alzheimer's type (Kindell et al., 2017). However, she does not get a response. In line 3, she therefore utilises humour as a way to repair communication (Orange et al., 1998). Humour can be an effective technique for PLwDs to avoid some negative outcomes of communication, e.g., embarrassment (Alsawy et al., 2019; Baumgartner & Renner, 2019; Wray, 2017; 2020, pp. 196-198), and this may very well be what Lee is doing at this point, since a lack of response can be interpreted as a misstep in the communication. Naturally, then, Lee will attempt to repair this situation.

Another characteristic of Scott's participation is that he asks specific questions, as if interviewing her. He does not ask any follow-up questions for clarification, or try to help Lee communicate more effectively. In this, he is behaving differently from the norm, because supporting the PLwD's language production is generally considered effective and beneficial (Braithwaite Stuart et al., 2021). Although motivated for understandable reasons, his failure to support Lee, and the withholding of a response altogether, is reminiscent of the malignant psychological behaviour of 'ignoring' (Kitwood, 2019, pp. 52-53) (see section 3.2 for an account of Kitwood's contributions to the field and definitions of relevant terminology). However, due to Lee's anticipatory facial expression, it is likely that she and Scott share joint attention, e.g., through eye-contact. If so, Scott's failure to offer a response does not mean he is ignoring Lee.

Even though Scott's communicative behaviour does not impact negatively on how the interaction proceeds, it is possible that similar behaviours can invoke negative consequences in other contexts. Other communicative patterns by unimpaired interlocutors that constitute of malignant psychology are disempowerment (where a PLwD is not enabled to use their skills), and withholding (where a communicative partner do not pay attention to, or meet an obvious need) (Kitwood, 2019, pp. 52-53), which may apply to Lee in that she clearly displays an effort to discuss and show her clothing, which is not acknowledged. From this short extract, it is clear that others' choices play a role in how successful a PLwD experiences an exchange to be, with potential onward impact on their wellbeing.

It will be a recurrent theme in this thesis that others can both enhance and diminish a PLwD's abilities to contribute to communication. It is not easy for interlocutors to know what to do, however. A dementia's impact on language, memory and cognition does not necessarily directly translate into the level of success experienced, because so much depends on the frame of interaction. Consequentially, carers find it difficult to navigate a clear route from identifying which aspects of communication are challenging for a PLwD, through the ways they are reflected in interaction, to an understanding of what they can do to improve the outcomes. In the next chapter, therefore, I will turn more fully to the matter of how others communicate with a PLwD, and focus on how carers attempt to support the PLwD through communication.

Chapter 3: Dementia communication from the perspective of family carers

In chapter two, I suggested that the way in which carers respond to a PLwD can greatly impact on the outcomes that they can achieve. In this chapter, I will focus on how carers perceive and manage communication difficulties in dementia. As outlined in chapter 1, this chapter is driven by the following topics: what family carers need if they are to improve their management of communication difficulties, and what can help carers meet those needs.

A first step in answering these questions is to review the characteristics that define the term 'carer' (3.1). Following this, I will consider what individuals who identify as carers experience in their role (3.2), and outline what they find challenging (3.3). Then, I will explore what carers do to promote communication and what barriers they face (3.4). Next, I will review some approaches to managing communication breakdowns (3.5). Finally, I will consider whether there are particular situations in which carers experience communication difficulties (3.6).

3.1 What is a dementia carer?

A PLwD will increasingly require support in managing daily living. Often, this help is given by an unpaid carer, typically a family member. Therefore, the term 'family carer' is often applied in literature in dementia and communication. However, there are many different relationship bonds between PLwDs and carers. Therefore, in this thesis, I will not limit my consideration of unpaid carers to family members. Instead, a broad definition will be adopted, where a carer is considered someone (a) who "live[s] with, nearby, or far away from the person receiving care" (National Academies of Sciences Engineering and Medicine, 2016, p. 4), and (b) whose "involvement is determined primarily by a personal relationship rather than by financial remuneration. The care they provide may be episodic, daily, occasional, or of short or long duration" (ibid., p. 4).

In the UK, approximately 700,000 people provide unpaid care for people living with a dementia. It is estimated that about 540,000 unpaid carers live in England, 30,000 live in Wales, and the remaining 130,000 in Scotland and Northern Ireland (Alzheimer's Association, 2021a; Carers Trust Wales, 2016; Carers UK, 2021; NHS, 2021). Since dementia is more common in older age (NHS Digital & Adult Social Care Statistics Team, 2017) and unpaid care is often provided by a spouse or sibling, many carers are older people themselves (Carers UK, 2019). However, care is also often provided by the next generation(s) down: the PLwD's children or grandchildren. Next-generation carers live separately to a higher extent than older carers (Carers UK, 2021), which can add travel to their caring responsibilities, along with underlying concern for the welfare of the PLwD who might be living on their own.

The forecasted cost of dementia care in the UK in 2024 is £42 billion (Alzheimer's Society, 2024), out of which unpaid care comprises between 42-60% (Alzheimer's Society, 2024; Wittenberg et al., 2019). As such, unpaid carers are undeniably essential not only for a PLwD, but for minimising the costs of dementia care as well.

The responsibilities that carers undertake are related to daily living, medical and social aspects of life, including cooking, cleaning, the management of medicines, personal care, and enabling social encounters for the PLwD (Dementia Carers Count, 2023). Carers often report changes in the relationship between them and the person they are caring for, psychological strain, and financial hardship (Alzheimer's Research UK, 2019). One in three carers in the UK report that their mental health is bad, and that they cannot access the support they need (Dementia Carers Count, 2023). Although this account paints a negative picture of the caring responsibilities, we will see later that caring responsibilities are not only related to negative experiences. In what follows, I will investigate how aspects of the caring experience impact on carers' lives.

3.2 What is it like to be a dementia carer?

Given the high demands of unpaid dementia care, carers display elevated levels of stress, anxiety, and depressive symptoms relative to people who are not carers (Brodaty & Donkin, 2009), and caring often impacts negatively on carers' perceived quality of life (Farina et al., 2017). The extent of the caring responsibilities can also affect carers' social lives. It is not uncommon for carers to experience loneliness because they cannot find time to access social environments (Older People's Commissioner for Wales, 2016, pp. 11; 18; 21; Pinkert et al., 2021). At the heart of the challenge of caring is trying to support the PLwD in a sustainable and humane way.

Kitwood (1997) coined the term ‘personhood’, “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (ibid., p. 8). Acknowledging personhood ensures that a PLwD remains a member of society and can authentically contribute to communication (Brooker, 2004). This stance helps ensure that PLwDs can draw on their abilities to achieve positive communitive outcomes, minimising behaviours in others that risk excluding them (Sabat, 2018, pp. 179-184). Communicative behaviours that reinforce personhood target listening to the PLwD, validating their contributions, and adapting language so that it is meaningful to them (which extends to interactions in which verbal communication is no longer the primary form of communication (Ellis & Astell, 2004)).

Kitwood also identifies the risks of undermining personhood, which can result in a range of behaviours on the part of carers (e.g., infantilization, invalidation, or objectification), that are jointly termed ‘malignant social psychology’. This term “signifies something very harmful, symptomatic of a care environment that is deeply damaging to personhood, possibly even undermining physical well-being” (Kitwood, 2019, p. 52). With regard to communication in particular, carer behaviours like ‘outpacing’ – speaking too fast or using language too complex for the PLwD to follow– withholding information, or disrupting their interactive contributions are particularly damaging to the PLwD’s wellbeing. However, Kitwood (1997) notes that carers rarely intend to be unkind. Rather, they are responding to the inherent challenges of dementia care.

Not all aspects of caregiving are perceived negatively. Carers also report positive experiences, such as feeling useful, and developing closeness with the PLwD (Pinquart & Sörensen, 2003). Sanders (2005) asked 85 carers to answer open ended questions in a survey about their caregiving experience. She found that 81% reported both positive and negative outcomes of caring, where positive aspects were related to spiritual growth and feelings of accomplishment. The main negative effects of caring were worries and a sense of being overwhelmed by the care demands.

A way of capturing the extent to which caring responsibilities put strain on the carer’s life is the measurement of ‘carer burden’ (Pinquart & Sörensen, 2003; Sörensen & Conwell, 2011). This is a potentially important metric for conceptualising impact on the carer’s perceived Quality of Life (Contreras et al., 2021). Naturally, stress, anxiety and similar psychological states contribute to carer burden, and, importantly, their level typically increases in relation to the severity of experienced communication difficulties, and the extent to which they perceive the PLwD's behaviour to be challenging (Clare et al., 2013; Lee et al., 2013; Savundranayagam et al., 2005).

Communication difficulties impact negatively on the perceived quality of the dyadic relationship between carers and PLwDs (Rippon et al., 2020). Although there is some evidence to suggest that the way carers perceive the relationship between themselves and the PLwD dictates how they approach interpreting and circumventing communication difficulties (Ablitt et al., 2009) (see section 3.3), it remains unclear whether communication difficulties cause changes to the relationship or vice versa. In what follows, I will address how the relationship can impact on communication, and consider how improvements to communication might improve carers' perceptions of the quality of relationship with the PLwD.

3.3 Communication as a tool for managing a changing relationship

PLwDs and carers often experience significant changes to relationship roles across the dementia trajectory (Steenfeldt et al., 2021). These changes can be extremely difficult to deal with, and can engender a sense of loss and grief (Braithwaite Stuart et al., 2021). Cooper, Pitts and Harwood (2021) examined how the relationship changes over time in spousal carers, and homed in on broad relational changes constructed by what they term 'turning points'. The authors identified four overarching changes that shaped the nature of the relationship: (1) the initial realisation that 'my spouse has dementia', (2) the transition of the spouse into a carer, (3) the sense that the spouse is 'lost', and (4) transcending dementia through love.

Cooper et al (2021) mention multiple ways in which communication plays a role in identifying and managing these vital relational turning points. A particularly salient example in the second turning point was conversations about 'losing driving privileges', which is often a detrimental change for many older people (Chihuri et al., 2016). Cooper et al (2021) state: "loss of driving privileges contributed to the change from spouse to caregiver because conversations around monitoring or removing driving privileges diminished caregiving spouses' sense of partnership in the relationship" (p. 16). In other words, a significant constituent of this second turning point was conversations about reducing the PLwD's autonomy and making them more reliant on others, as well as signalling lack of confidence in their capabilities and judgement. One communicative factor that contributed to the third turning point was ‘losing intimate conversations’. Here, the link between communication and the changing relationship is very direct. Depending on how carers approach the relationship with the PLwD, their emotional response to changes in the relationship can vary. For instance, carers who experience a sense of detachment from the PLwD are likely to experience less negative emotions related to changes in their relationships than carers who do not (Ablitt et al., 2009). I will expand on this notion later in this subsection.

Cooper, Pitts and Harwood (2021) also identified ‘communication strategies for maintaining relationships’ across the dementia trajectory. These were: (1) having open and intimate conversations; (2) avoiding confrontation; (3) avoiding bringing attention to symptoms; (4) engaging in daily conversations and activities; and (5) communicating love.

Arguably, these are not communication strategies in themselves, but rather behavioural decisions that would be delivered using communication. The distinction might seem unnecessarily precise, but it is helpful to tease apart, because this thesis engages at the interface of behaviour and communication, exploring the means by which changes to the former can catalyse new outcomes in the latter. For instance, in order to ‘avoid confrontation’, the carer needs to have developed an awareness of markers signalling the risk of it. While a general capability to spot such markers would be part of core life skills, dementia often causes changes to how a PLwD interacts with their world, causing behavioural responses that carers must learn to understand (Feast et al., 2016). Thus, changing communication is unlikely to be successful without changing other things first. I will expand on this topic in section 3.5.

There is some research which associates relationship quality with personality differences. Ablitt, Jones and Muers (2009) identify four types of carer personality. The first is termed ‘Continuity’, which describes carers trying to maintain the past identity of a PLwD and actively seeking out responses from the person that align with their former behaviours. Carers with this personality type may experience a sudden and delayed realisation about the cognitive deterioration of the care recipient. The second type is ‘Reciprocation’, where a carer recognises the emotional impact that the dementia has on the PLwD, and primarily display motivation to provide care because they believe the PLwD would have done the same for them. Carers with this type of personality will make ongoing changes to their communicative approach across the disease trajectory. The third is ‘Detachment’, where carers perceive the PLwD as a different person from who they were prior to developing dementia. Carers in this frame offer support without expecting anything back, and often maintain a more clinical approach with less emotional attachment. Finally, ‘Duty’ is where a carer’s ongoing care is fuelled by beliefs or a moral code, rather than emotion.

It follows that carers’ capacity to communicative effectively is a crucially important factor in achieving these outcomes. Carers who are skilled communicators are likely to be in a better position to shape communication towards desired outcomes (I will address in chapter 5 the theoretical mechanisms that may underpin these skills). Therefore, communication is an important tool in relational and emotional management for both the carer and the PLwD. However, dementia communication does not always go as the carer wants. In what follows, I examine what aspects of communication carers perceive challenging.

3.4 What contributes to communication challenges in a dementia context?

The language, memory and cognitive symptoms of dementia, outlined in chapter 2, that impact on the PLwD’s communication (Bayles, 2003; Clarke et al., 2009; Szatloczki et al., 2015) do not operate in isolation.

Small, Gledart and Gutman (2000) ran focus groups to find out what situations family carers find difficult, and report that the most challenging activities were those that (1) relied on conversations to a high degree, such as talking about one’s personal life or managing finances, and (2) those that were susceptible to dementia symptoms, such as navigating through language the process of finding lost objects. These situations are related to everyday life and arise frequently, making them important for the extent to which carers and PLwDs perceive communication as successful (Vasse et al., 2010). The interactions that Small et al. (2000) describe are often characterised by clear functional outcomes, such as locating specific objects, and as such may be particularly susceptible to dementia symptoms.

Nguyen et al. (2022) carried out a survey asking what carers find difficult in communication. Out of the 286 responses from carers, 83.3% reported difficulties in making themselves understood by the person living with a dementia, and 69.8% difficulties in understanding the PLwD. Furthermore, 50.4% of the respondents reported that they recently had experienced an instance of not knowing what to do. There is scope, then, to ask what factors contribute to the difficulties in reciprocal understanding.

Even where carers are aware of how a dementia impacts on a PLwD's communication, they do not always understand how the PLwD experiences the world (Steenfeldt et al., 2021). This can be a source of frustration for the PLwD, who may have awareness of carers' difficulties in understanding their perspective. Taylor (2007), who was living with Alzheimer's, noted: "I do want them to know how I think and feel, from my perspective, which they can never be in a position to fully realize; I also can't ever see our interactions from their perspective". It is well accepted in the literature that carers recognise changes in relationship roles and attempt to adapt to the PLwD's needs across the dementia trajectory accordingly. Taylor reminds us that the PLwD will often also be trying to adapt, to meet the needs of the carer.

Due to dementia progressively causing damage to the brain, the PLwD can change in how they perceive the world, and alter how they interact with it accordingly. Some commonly resulting behavioural changes are apathy, aggression, anxiety, and agitation (Lyketsos et al., 2002). These neuropsychiatric symptoms are well-recognised in the literature, and are often termed 'Behavioural and Psychological Symptoms of Dementia' (Feast et al., 2016) (BPSD).

This concept has, however, been challenged. Cunningham, Macfarlane and Brodaty (2019) review the arguments put forward by '#banbpsd', a movement to ban the use of the term 'BPSD'. One concern is the risk of making a direct link between a behaviour and changes in the brain, when PLwDs' behaviours can also be interpreted as natural reactions to their surroundings (Sabat, 2018). There are at least two benefits to not promoting the BPSD interpretation. One is that it reduces the risk of over-medication as a response to behavioural changes, since environmental triggers are more likely to be sought and addressed. Another is that it avoids unnecessary 'labelling', which Kitwood (2019, p. 52) lists as a type of malignant social psychology (see section 3.2), and thus a threat to personhood.

Seen this way, behaviours such as aggression and agitation can be interpreted as signalling unmet needs (Warren, 2022). Indeed, Ferreira, Dias, and Fernandes (2016) show that the frequency and severity of behaviours that often fall under the term BPSD correlate with the extent to which a PLwD experiences unmet needs, and, as a consequence, depressive symptoms. It follows that the way others respond to such behaviours, and identify the PLwD's needs, is a central component for improving the PLwD's world. As such, the extent to which such behaviour manifests is likely to be determined by how carers approach the situation (Cunningham et al., 2019). But what does this mean in practice?

Given that 'problematic' behaviours can be a reflection of negative emotions generated by communicative breakdowns (Savundranayagam et al., 2005; Warren, 2022), it follows that carers' capability to manage communication effectively plays a key role in mitigating such outcomes (Savundranayagam & Orange, 2011). Braithwaite Stuart et al. (2021) suggest that 'helpful' communication is characterised by empowering the PLwD to engage in conversations, and circumventing the symptoms of dementia that constitute barriers to this end. In contrast, 'unhelpful' strategies are characterised by failing to accommodate for symptoms of dementia, hence limiting PLwD's ability to engage in communication. For instance, where a PLwD inaccurately recalls information, such as giving an old address when asked for their current one, or misnaming someone in a photograph during a reminiscence activity (Astell et al., 2010) a carer's desire for "getting things [information] right" (Braithwaite Stuart et al., 2021p. 1148) can motivate drawing attention to the PLwD's memory impairment. There are two potential risks associated with correcting the PLwD. One is that it undermines their personhood (Kitwood, 1997), by negating the validity of their statement (which they might believe is the truth). The other is that persistent correction by the carer damages the PLwD's self-esteem, which, ultimately, may result in them avoiding participation in communication (Alsawy et al., 2019).

Then, it is important to consider the drivers underpinning carers' perceptions of how to operationalise communication. As we shall see in chapter 5, developing skills for better understanding the underpinning mechanisms of the PLwD's behaviour through 'Mentalization' (Fonagy & Target, 1997; Luyten & Fonagy, 2015) seems to mitigate negative communicative outcomes. Two catalysts of mentalization are targeted interventions for communication skills development (which I will discuss in section 3.5), and advice from healthcare professionals and other carers. As a result, a further part of the holistic picture is how easily carers can access, and be ready to receive, such input.

In section 3.2, I pointed out that time spent outside of caring responsibilities is often extremely limited for carers. In order to access opportunities for acquiring information and advice that can improve their communicative abilities, they need respite, which is often not available (Oliveira et al., 2020; Sanders, 2005). Even where carers can attend appointments where information is offered, not all information is helpful. Carers report that guidance from healthcare professionals is unhelpful when it is too general, and where it is not tailored to how the dementia impacts individually on that PLwD (Bressan et al., 2020, p. 61; Older People's Commissioner for Wales, 2016).

Receiving and discussing information relevant to the caring experience in a group setting, with peers, is noted to be beneficial for carers in that it is a social encounter (Bressan et al., 2020) which can promote resilience to depressive symptoms (Thompson et al., 2007). This latter point is relevant to communication for two reasons. First, the carer's mental health is central to their perceived quality of life (Farina et al., 2017), which, as we have seen, has bearings on the quality of the relationship between them and the PLwD, and the communication difficulties. The second reason is that the carer's psychological state shapes how they respond emotionally to communicative breakdowns. In chapters 4 and 5, I will outline the mechanisms that underpin this relationship, and highlight carers' emotional management as a relevant factor for how they develop ways to improve their dyadic communication.

Naturally, all PLwDs are different, and all carers respond differently to the changes to communication that they experience as a dyad. In the next subsection, I will flip the question of why communication in a dementia context is difficult on its head. I will ask what factors contribute to meaningful communication, and outline some of the ways that communication can be improved.

3.5 What contributes to meaningful communication in a dementia context?

What do people typically do when they want to find out something? While academics might search for research articles, most of the general population would turn to the internet, looking for guidance in terms they can easily understand. Not surprisingly, then, for many carers, a first stop in identifying ways for improving their communicative practices is by searching on the internet. Harris et al. (2024) investigated the extent to which online communication advice aimed at PLwDs, carers, and healthcare professionals is evidence based. They found that out of 164 strategies identified, only 48% were based on research evidence. However, a Personal and Public Involvement group, consisting of four people with lived experiences of dementia, considered

73% of the strategies helpful, and only 11 to be unhelpful, suggesting that research might be unable to capture some aspects of what is effective. Across all strategies, two strands of advice, ‘Providing Emotional Safety’ and ‘Working together’, were frequently featured, which indicates that much advice on websites promotes respect and kindness as central concepts for successful communication.

Harris et al. (2024) divided the online recommendations into nine themes, and sorted the themes into two groups based on the inferred outcomes, informed by recent theoretical frameworks (Morris et al., 2020; Wray, 2020). One outcome was ‘Communicating a message’, which is characterised by practical aspects of communication. The other was ‘Creating a connection’, which relates to interactional and interpersonal factors (Harris et al., 2024, p. 13). The former set included: supporting communication strengths; working together; adapting communication for the situation; and developing carer communication skills. The second contained strategies related to: valuing the interaction; prioritising needs; providing emotional safety; knowing the individual; and focusing on a broader meaning.

Whilst these results are encouraging, the number of strategies offered can easily be overwhelming for a carer. Bangerter et al. (2019, p. 1308) note: “caregivers’ needs are often complex and hold different levels of priority, and affected by individual resources as well as the demands of the stage of illness.” For instance, as noted in section 3.3, many carers experience potentially distressing relational turning points (Cooper et al., 2021). In these moments, the primary focus may not be on communication framed by the PLwD’s current communicative abilities, because of the carer’s need for adjustment, as they experience grief (Braithwaite Stuart et al., 2021) and loss (Stedje et al., 2023). In these situations, the carer might instead fight to retain past communicative patterns. This indicates that examining how carers can improve their communication should take into account their emotional state.

Eggenberger and colleagues (2013) carried out a literature review investigating the constituents of dementia communication training for paid and unpaid carers. They found that current interventions targeted seven categories: (1) verbal skills, such as announcing one thing at a time; (2) non-verbal and emotional skills, e.g., active listening and making eye-contact; (3) attitudes towards people with dementia, for instance non-infantilisation; (4) behavioural management skills, such as avoiding confrontations; (5) usage of tools, e.g., constructing custom memory aids; (6) self-individual experiences, e.g., being mindful about one’s own communicative behaviour, and (7) theoretical knowledge, such as recognising behavioural symptoms as a consequence of the disease (Eggenberger et al., 2013, p. 352-353).

There is much literature suggesting the first two, and the fifth categories as helpful for alleviating the impact of dementia on communication in empowering the PLwD to participate in communication (e.g., Bayles, 2003; Fried-Oken et al., 2012; NHS, 2023a). The third, fourth, and sixth category overlap in their characteristics and strongly resemble themes from Kitwood's (1997) person-centred care, which promotes the PLwD's personhood, and reduces the likelihood of carers *over*estimating the impact that a dementia has on a PLwD's communicative abilities (Sabat, 2018, pp. 50-52). As outlined in section 3.4, mismatches between the carer's assumptions about what a PLwD can and cannot do, and the PLwD's actual capabilities can lead to detrimental communicative outcomes. Indeed, as will be shown later, an important element of training carers is helping them question their assumptions about how meaning can be conveyed (McEvoy & Plant, 2014).

According to Small et al. (2002; 2003), carers select communication strategies that they believe to be effective. However, the authors note that carers' choices do not always reflect what research suggests is most empirically effective, a finding also confirmed by Harris et al. (2024) in their systematic review of the evidence base for online communication guidance for dementia carers. Where carers are not exposed to or informed of other options for achieving specific communicative goals, it is unlikely that they would change a communicative behaviour which they associate with successful communicative outcomes. This means that they can be trapped inside their own limited experience, unless they can access new sources of advice. This is the purpose of many communication interventions that are delivered in the form of educational courses.

There are multiple established approaches for improving dementia communication (see Wray, 2020, pp. 107-113 for an overview). Some are delivered as 'frameworks', such as reminiscence therapy (Woods et al., 2018) and Specialized Early Care for Alzheimer's (SPECAL) (Contented Dementia Trust, 2023; McCrae et al., 2020), that give carers 'rules' for how to interact with a PLwD successfully. Others are delivered as courses, for instance RECAPS and MESSAGE, that help carers develop generic communicative strategies by watching videos. Most communicative interventions show positive outcomes. However, Eggenberger et al. (2013) note that out of the 12 empirically supported interventions included in their review study, most lacked mechanisms for maintaining improvements to communication when the intervention is completed. Whilst it would not be sustainable to develop an intervention that follows up with all participants indefinitely, there is scope to ask whether interventions ought not to equip carers with skills that enable them to sustain and further develop their communication independently. In chapter 4, I will show how one intervention method, Empowered Conversations (Morris et al., 2020), attempts to do this.

In addition to frameworks and courses, a third type of intervention that has been noted to improve PLwDs' quality of life (Astell et al., 2018) concerns supplementary tools for facilitating communication, which are perhaps most useful when the PLwD has lost some of the powers of comprehensible speech. Research suggests that using personalised image banks on digital tablets can help PLwDs participate in communication (Fried-Oken et al., 2012). PLwDs produced a higher number of utterances when using a tablet than in situations where they did not. Similar outcomes have been reported in relation to talking mats (Murphy, 1998; Murphy et al., 2007), which were noted to boost levels of satisfaction in discussions of the PLwD's daily life management (Murphy & Oliver, 2013).

The discussion in this section reminds us that different strategies will be suitable for different types and stages of dementia, and highlights the importance of adapting such strategies to suit the individuals, both PLwD and carer. In order to understand how carers might go about choosing and using communication strategies, I next consider which situations they can successfully alleviate communication difficulties in, and in which situations are beyond their scope to improve.

3.6 What are the challenges in developing carers' communication?

Nguyen et al. (2022) report that the two most common ways in which carers attempt to mitigate communication difficulties are to (1) find and (2) minimise the causes/triggers of behaviour changes. They also show that amongst their 286 participants, the most common approaches to address communication difficulties were trying different ways to communicate (96.1%) and taking carer education courses (89.1%) (Nguyen et al., 2022). This indicates that despite the enormous challenges that dementia communication can entail, carers can often identify ways in which they can improve communication.

The authors note that participants in their study population who were younger and had less experience of caring measured in years of experience, generally reported a greater need for courses on dementia communication than older carers with more caregiving experience. This does not mean that more experienced carers actually encountered fewer difficulties. However, it may indicate that carers who have less experience have higher expectations of what communication courses can truly offer. Carers with more experience perhaps do not perceive that communication can improve to the same extent as younger carers, or doubt whether communication courses can actually do much to improve their communicative behaviour. Whilst the caregiving experience undoubtedly does build knowledge in its own right (Frith & Frith, 2006), a potential challenge for those offering communication training can be that carers do not consider that there is more to learn. Williams (2011) notes:

> If caregivers perceive that they are knowledgeable about communication (when they are not), they may be unmotivated to learn new strategies or to seek information that could help them (Williams, 2011, p. 32).

A further barrier to carers seeking communication training would be when they do not consider their own communicative behaviours to be contributing to communication breakdowns. In extreme cases, carers can withdraw emotionally from a PLwD, who cannot communicate verbally anymore, and claim that they do so because the PLwD is rejecting them (Williams, 2011). This pattern has been noted elsewhere as well. Savundranayagam et al. (2005) suggest that it is not uncommon for carers to interpret 'challenging' behaviour in a PLwD as malicious rather than as a marker of distress. Where carers make such inferences, education about the ways in which dementia impacts on communication and behaviour could be beneficial (Eggenberger et al., 2013; Leung et al., 2021), yet carers would need to recognise its potential value.

Recent reviews of literature addressing carer needs point out that this body of research lacks clarity and rigour. First, there is a need for more qualitative research that addresses what carers perceive difficult, and what strategies truly help them with communication (McCabe et al., 2016), which can serve as a central aspect guiding developments in carer interventions (Orgeta et al., 2015, p. 58). Many studies that generate information to this end are characterised by inconsistencies in theoretical underpinning (Cummings, 2005, 2009). This is an issue since choice of theoretical framework can greatly influence the interpretations of how carers and PLwDs experience communication (Ennis et al., 2019). For instance, there are problems regarding the definition of the term ‘needs’, and how needs are measured (Bangerter et al., 2019).

In an effort to fill this knowledge gap, I will draw in later chapters on Wray’s (2020) Communicative Impact model to investigate what carers perceive to be challenging in communication, and the strategies that they use to combat such challenges. This framework takes into account the ways in which a dementia impacts on communication, and how carers respond to such changes, including the underpinning mechanisms for such responses. By this means, I will be in a position later, to offer some new insights into what it takes to develop carers’ communicative abilities, and to compensate in some small way for the lack of qualitative research into effective carer interventions (Orgeta et al., 2015, p. 58).

But first, I will introduce Empowered Conversations, the cornerstone of the later empirical research questions, and explain how its approach offers practical support and hope for dementia carers.

Chapter 4: A novel approach to supporting communication: Empowered Conversations

Many of the interventions developed to support communication in PLwDs and carers focus on generic pragmatic strategies and speech modification (Eggenberger et al., 2013), such as establishing eye contact and speaking slowly (Broughton et al., 2011; Smith et al., 2011). Vasse et al. (2010) point out that the most important focus for improving communication must be everyday activities, which have also been noted as the most challenging situations for carers to manage communication, e.g., situations related to hygiene and eating (Nguyen et al., 2022; Small et al., 2000). In other words, the most useful improvements to communication will relate to outcomes in everyday life activities that are perceived as challenging by carers and PLwDs.

As mentioned in section 3.5, there are multiple frameworks in the literature that outline specific approaches for increasing successful outcomes in everyday communication. They include Validation therapy, which emphasises "the acceptance of the reality and personal truth of another's experience" (Neal & Wright, 2003, p. 1), Reminiscence therapy, which involves conversations focussing on the PLwD's past, facilitated by prompts from others (Kiernat, 1979; Woods et al., 2018), and, albeit limited in empirical support (McCrae et al., 2015), SPECAL (James, 2008), where carers are encouraged to use "selected intact memories from the person's pre-dementia past and [link] these to their activities in the present" (Contented Dementia Trust, 2025).

Interventions like Reminiscence therapy and SPECAL have been reported to impact positively on carers' experience of communication, particularly their sense that the PLwD's communicative abilities and mood have improved. Additionally, some evidence, although limited, suggest that these methods can relieve carers' stress and anxiety (Faw et al., 2022; Woods et al., 2018).

SPECAL rests on three 'golden rules' (Contented Dementia Trust, 2023; James, 2008; McCrae et al., 2020), which are (1) do not ask direct questions; (2) listen to the expert which is the person with dementia and learn from them, and finally (3) do not contradict. McCrae et al. (2015) note that whilst 'choosing' specific memories for a PLwD may replicate some positive outcomes from reminiscence therapy, there has been substantial negative pushback from stakeholders advocating for PLwDs and their rights. Wray (2020, pp. 229-236) notes that

SPECAL carers are encouraged to develop personalised and premediated deception as part of using communication strictly guided by this framework. First, embedding deception causes limitations to information that the PLwD can acquire to understand the world. Second, the carer is likely to be entangled in lies that may be difficult to escape.

A common denominator in approaches such as SPECAL and Reminiscence therapy is that they are driven by specific assumptions and procedures (Eggenberger et al., 2013, p. 346) and engage in communication in particular ways. For example, carers are not encouraged to use all the available information to achieve the optimal outcome in a given situation. In chapter 5, I will argue that carers are experts in how to achieve success in communication with the person they care for (though, this does not mean they cannot improve their practices), and therefore, methods that limit their options may offer suboptimal potential for improving communication.

Mentalization Imagery Therapy (Yang et al., 2022) is one recent type of intervention that approaches communication from the perspective of individual carers developing communication improvements relevant to their specific situation and needs. This therapy is theoretically framed by 'mentalization' (see chapter 5, section 5.1 for a description of this term) and it works on the premise that communication can be improved by carers developing their ability to interpret the PLwD's and their own emotions and behaviours. Approaches of this type are reported to reduce stress and anxiety in carers, and potentially improve the quality of relationship with the PLwD, which I will expand on in the next subsection. As noted earlier, there is a direct link between improvements in communication and how carers perceive the quality of their relationship with the PLwD (Rippon et al., 2020; Savundranayagam et al., 2005; Savundranayagam & Orange, 2014).

However, Mentalization Imagery Therapy does not explicitly incorporate communicative strategies. In contrast, the approach focussed on here, *Empowered Conversations* (EC), combines mentalization with practical tools for carers to improve communication with a PLwD (Morris et al., 2020).

4.1 What is Empowered Conversations?

EC is a communication course where a small group of carers (4-9 participants) meets for two-hour sessions over six consecutive weeks. The purpose of the course is to train carers so they can ‘enabl[e] people with dementia to live as well as they can by keeping channels of communication and connection open’ (https://empowered-conversations.co.uk/). This is done by introducing carers to *empathic curiosity*, which entails listening with an active consideration to feelings in another person, and remaining curious about behavioural or emotional patterns in a speaker (McEvoy et al., 2013). Thus, in EC, carers are helped to gain insight into the emotions, motives and beliefs that drive how a PLwD reacts and interacts.

EC has emerged from the integration of three theoretical frameworks. These are (1) the Communicative Impact model, (2) Perceptual Control theory, and (3) Mentalization Theory (Morris et al., 2020). As outlined in more detail in Chapter 5, the Communicative Impact Model holds that we use communication to change our own world through others’ agency, e.g., asking for a glass of water when we are thirsty. The way a hearer reacts, and thus changes, or fails to change, our world in the desired way, will determine whether the communicative act was successful (*high* communicative impact), or unsuccessful (*low* communicative impact) (Wray, 2020).

Perceptual Control theory (Powers, 1973, 2005) focusses on how the frustration of speakers’ interactive goals can arise as a consequence of a mismatch between what is envisaged (internal goal representation) and what is possible (the extent to which the real life situation can furnish that outcome) (Mansell, 2009). As Morris and McEvoy (2023) note, Perceptual Control theory and the Communicative Impact model (Wray, 2020) overlap, in that both perspectives put “personal goals as central to sustaining a sense of control over one’s life” (Morris & McEvoy, 2023p. 239). Finally, ‘Mentalization’ explains the “imaginative mental activity that enables us to perceive and interpret human behaviours in terms of mental states (e.g., needs, desires, feelings, beliefs, and goals…)” (Fonagy & Luyten, 2009). This psychological ability can be applied to understanding both others’ and own behaviour (Fonagy, 1991; Fonagy & Allison, 2012).

The Empowered Conversations Framework underpinning EC, set forth by Morris et al. (2020), draws on strengths from the three theories mentioned above, to create a means for carers to appreciate the perspective of the person they care for. Central to the EC approach is the belief that carers can be taught to identify effective communicative goals and improve their chances for achieving them.

However, carers are also taught to interrogate their own reactions when communication is unsuccessful. This is important because strong emotions can diminish a carer’s ability to apply curiosity in interpreting behaviour (Allen et al., 2008, p. 70), I will expand on this topic in chapter 5. As such, EC promotes techniques allowing carers to better understand not only the PLwD but also themselves. This understanding should improve their chances of experiencing successful communicative outcomes (Wray, 2020).

4.2 What does Empowered Conversations look like?

EC consists of six weekly two hour meetings. Whilst the manual (Empowered Conversations, 2022), outlining the course in detail, is not publicly available, I have obtained permission from the project manager of the course to outline the general content of each week (see Table 4.1). It shall be noted that the content and week are stated in the manual, but that the connection to the framework is not. Therefore, I will refer to relevant points in the EC framework (Morris et al., 2020).

Table 4-1: Content of each week in the Empowered Conversations course

Week 1- Introducing Curiosity
• Participant introductions. • Breathing exercise to promote mindfulness (this exercise is featured in the start of every session). • The bookcase analogy – a framework for explaining differences between emotions and episodic memory (Dementia Friends, 2023). • Participants generate a list of information on what dementia is, what it means. • Participants generate a list of ‘what it feels like to speak with a PLwD’, and ‘what it feels like for a PLwD to speak with them’, in order to explore emotions associated with dementia communication. • Animated video outlining what dementia and communication is.[7]
Commentary: Participants generate existing knowledge on dementia as a condition and consider how emotions may be connected to how dementia disrupts communication. In other

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[7] All animations mentioned in this table are based on the works of – and produced by – Professor Alison Wray.

words, participants generate a knowledge base which constitutes the fundament of starting to practice mentalization (Frith & Frith, 2006).

Week 2 – What gets in the way of a conversation?

- Investigating contextual factors which might contribute to communicative breakdowns (e.g., background noise, or not being in the same room).
- Introduction to ‘invitation to respond’, a tool for using comments to start a conversation, e.g., “lovely weather today”, instead of a question, e.g., “do you remember when…?”
- Videos of interactions between a PLwD which participants are invited to reflect on.

Commentary: Contextual aspects of communication build on participants’ knowledge of how to alter their environment to increase success rates of communication (see chapters 7 and 9).

‘Invitation to respond’ is not a total replacement for questions but it avoids the need for a PLwD to recall specific information and gives them a choice about whether to engage or not.

Week 3 – Stop, Listen and Look

- Listening to other participants and summarising what they have said to the group (promoting active listening, and emulating what it is like to be spoken for).
- Exploring non-verbal communication. Participants generate different types of non-verbal communicative markers and reflect on what they can mean.
- Exploring the concept of humour in dementia.
- Animated videos on the complexity of communication in a dementia context, and on coping and humour.

Commentary: Active listening is core to empathic curiosity (McEvoy et al., 2013), and a prominent characteristic in what PLwDs perceive as contributing to good communication (Alsawy et al., 2019). Improving empathic curiosity is beneficial for improving mentalization abilities (Luyten et al., 2020).

Identifying new non-verbal markers that carry meaning may fortify participants’ ability to detect the PLwD’s mental state (Ellis & Astell, 2018, pp. 55-58; 89-96; Fonagy et al., 2007).

Humour is often retained far into the dementia trajectory, and is therefore an important pragmatic skill to promote and explore in dementia communication (Stedje et al., 2023; Wray, 2016).

Week 4 – Memory and Identity

- Introducing notions of brain reserve, cognitive reserve, social and emotional reserve (Wray, 2020).
- Exploring the concept of empathy and introducing response-based empathy (i.e., ‘what would have to happen to me to react the same way someone else is reacting’) illustrated in an animated video.
- Brief theoretical overview of ‘memory’ as outlined by Baddeley and colleagues (Baddeley et al., 2020; Squire, 1992).

Commentary: Brain, cognitive, social and emotional reserve provide an explanatory framework for participants about the effects of dementia, and how their and the PLwDs’ reactions to them, vary (Wray, 2020).

Outlining of memory theory (Baddeley et al., 2020) expands on carers’ knowledge about why a PLwD may struggle more with certain aspects of memory than others.

Week 5 – Build on Strengths and Resources

- Self-care tools using visual representations and analogies.
- Participants encouraged to map the most important things in their lives (e.g., family) to help illustrate their options for prioritising aspects that provides positive experiences, which can build resilience to negative change.
- Participants use a visual tool called ‘The Control Continuum’, which helps them reflect on situations where they do not have sufficient levels of control, and practical ways of increasing control in such contexts.

Commentary: Self-care tools are meant for carers to improve their emotional management and resilience. Improving these abilities can reduce barriers impeding active self-mentalization (see section 5.1).

Reflecting on the notion of control is an integral part of Perceptual Control Theory (Mansell, 2009) and can help participants formulate realistically achievable communicative goals (Morris & McEvoy, 2023). This ability also carries into the later stages of dementia, where carers may need to recalibrate the roles of verbal and non-verbal communication.[8]

Week 6 - Summing up and Learning through Sharing

- Reflections on the course.
- Animated video summing up previous weeks and discussing how carers' communicative practices influence communication.
- Looking at drawings of situations where communication is difficult, followed by participants drawing illustrations of situations where they experience communication difficulties in their own lives.
- Revisiting 'what it feels like to speak with a PLwD' (see week 1).

Commentary: Participants are asked to reflect on the course as a whole, and exchange resources and experiences.

Participants are also given a method of externalising a situation (drawing) in order to better understand the reasons for potential communicative breakdowns.

Finally, participants are tasked with revisiting the feelings-exercise from week 1. This exercise promotes empathic curiosity (McEvoy et al., 2013). Where carers can expand on, or deepen their understanding of how emotions are associated with communication, it can validate and empower them in developing and applying mentalization skills in communication.

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[8] EC offers a follow-up course called 'Moving Beyond Words' (https://empowered-conversations.co.uk/moving-beyond-words-how-to-communicate-without-speech/), developed in collaboration with Maggie Ellis, which targets how carers can improve their communication in late-stage dementia.

4.3 Effects of Empowered Conversations

EC is designed to increase quality of life in family carers over time, by improving communication between them and the person they care for (Morris et al., 2020). One aspect of EC that distinguishes it from other courses is its focus on finding solutions to situations that participants identify as problematic. Generating information about situations where communication is difficult expands on carers' knowledge base. This knowledge underpins the extent to which carers understand the PLwD's behaviour using active mentalization (Collins et al., 2006; Frith & Frith, 2006).

Participants are offered multiple ways of identifying information and associating that information with mental states. At the beginning of each session, they are asked to reflect on knowledge gained in the previous week, and whether that information has led to new observations or communicative practices. They are also invited to practice all communicative strategies and information identification strategies with each other. This means that course attendees exercise active participation, where skills taught in an intervention are also practiced within the frame of that intervention, and at home. This has been found to improve intervention effects (Morris et al., 2018, p. 878).

Innes and colleagues (2022) used interviews to investigate what EC facilitators and participants found useful in the course[9], and what aspects of the course could be improved. Twenty-one out of the twenty-eight participants interviewed found the weekly structure useful because they could put content covered in the course to use between sessions. Regarding the course content, a third of the participants found the animated films (which currently is used in sessions one, three, and six, see table 4.1) particularly useful. Over half of the participants commented that speaking to other carers was beneficial, and that it offered a safe space to discuss their experiences. Previous studies report that accessing such contexts is beneficial for emotional and informational aspects of caring (McCabe et al., 2016).

Most EC facilitators delivering the course have personal experience of dementia. Innes and colleagues (2022) comment that it "appeared to be particularly poignant for participants that the facilitators had their own lived experience of caring for someone with dementia as this

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[9] At the time of conducting interviews in that study, EC was four sessions long where each session lasted for 2.5 hours. Now, the course is six weeks long, and each session is two hours long.

created mutual understanding" (Innes et al., 2022, p. 109). The authors suggest that this lived experience connection created an inclusive and accepting group dynamic. However, some participants suggested that in order to further the benefit from others' perspectives, it would be helpful to meet and get to know each other prior to the first course session. They also requested facilitators to avoid one or more participants dominating the conversations.

Morris et al. (2021) conducted a feasibility study investigating the psychometric effects of EC, involving 159 course attendees. They measured multiple factors relevant to psychological wellbeing and communication at three time-points: before the course, immediately after the course finished, and fourth months later. Two key findings were that carers perceived the quality of their communication[10] with the PLwD to have significantly improved, and that the carers' stress levels were reduced immediately after the course, and at the four-month follow-up. This latter improvement extended to carers who reported low stress levels at the beginning of the course, suggesting that EC is beneficial for all carers, regardless of their stress-responses to the demands of caregiving. Stress is an important factor because it can generate significant barriers for carers in identifying and interpreting the PLwD's mental states (Luyten et al., 2020). Thus, reducing stress levels is beneficial for generating information that contributes to enhanced communicative success.

Indeed, Morris and colleagues (2021) comment on how reduced stress levels can be beneficial for communicative outcomes over time. Reducing barriers for utilising active mentalization "encourages carers to adapt how they find solutions in light of changing contexts and goals" (Morris et al., 2021, p. 2846). McEvoy et al. (2020) suggest that increasing the extent to which carers can draw on active mentalization in communication is beneficial for (1) exploring links between their own emotions and experiences; (2) creating mental space to reflect on their own state of mind as a response to fluctuations in the PLwD's state of mind; and (3), cultivating cognitive space for developing mentalization abilities that are helpful to communication over time.

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[10] This was measured by using a questionnaire developed by the authors, that address specific outcomes targeted by EC. This instrument is not empirically validated, but contains questions informed by the theoretical approach that underpins EC. As such, this instrument measures communication within the frame of EC.

Despite the claims above that active mentalization can underpin improvements in communication, it should be noted that the feasibility study (Morris et al., 2021) did not show improvements in global mentalization abilities. However, this is not necessarily problematic. First, let us consider the way in which mentalization is measured. Morris et al. (2021) capture mentalization using the Reflective Functioning Questionnaire (Fonagy et al., 2016). The authors note that this instrument has "primarily been validated as a 'trait measure' (i.e., not a measure of change) on individuals with severe mental health problems (e.g., borderline personality disorder)" (Morris et al., 2021, p. 2846). Thus, it might not reflect changes in high-functioning mentalization. Furthermore, a distinction can be drawn between the extent to which a participant *can* mentalize in dementia communication and what they use their mentalization abilities *for*, the latter being more important. As such, carers would benefit from strategies that promote their use active mentalization in everyday activities for understanding the PLwD, which is precisely the goal of EC.

In summary, EC is targeting the development of insightful general knowledge and awareness about dementia symptoms and their effects, as a means for catalysing carers to take control of their language and behaviour, within the context of their surroundings and specific situation. Thus, it has a strong focus on participants' individual difficulties, and ways of overcoming them. The content of the course is designed to give participants tools for developing solutions that result in successful communicative outcomes over time. These rely on "foster[ing] the ability of carers to reflect upon their communicative interactions, so that they can support their relatives with dementia in less reactive, more responsive ways" (McEvoy et al., 2020, p. 237). This is done by providing tools for accommodating dementia symptoms (as outlined in 4.1 and 4.2), and for managing their own emotions so that they can clearly evaluate which approach will best circumvent negative outcomes. Dementia is a progressive condition, where some strategies that carers employ may work at one point, but not at another. Therefore, equipping participants with tools to identify and construct solutions to potential future difficulties is of utmost importance for the prolonged wellbeing of both the carer and the PLwD.

Two additional reports on EC have been published recently. They cover how participants perceive their communication practices, and the psychological mechanisms that underpin them, to have changed following EC (Morris et al., 2023); and how these changes are implemented in communication (Eastham et al., 2024). Since they were published after the empirical studies in this thesis were completed and therefore did not contribute to the framing of the investigations, their findings will be discussed in chapter 9 during the interpretation of the empirical findings.

Chapter 5: The Route to (in)effectively solving communication problems

So far, I have outlined ways in which dementia impacts on communication (chapter 2) and how such communication difficulties are experienced by family carers (chapter 3). I have also looked in depth at a communication course that is designed to help carers facilitate communication with the person they provide care for (chapter 4). I have, however, not yet directly examined theoretical notions of what communication is, what communication is for, and what processes are involved when communication is 'done'. This chapter will explore these questions drawing on two theoretical frameworks that underpin EC, namely 'mentalization' (Fonagy & Allison, 2012), and the 'Communicative Impact Framework' (Wray, 2020).

Before this, it is necessary to briefly consider the reasoning behind approaching communication through the lens of these specific frameworks, and not others. From a practical point of view, EC was a partner in this research project, which was designed to explore the potential for EC to be rolled out in Wales. On that basis, it was logical to adopt the theoretical frames that underpin the course, so that the interpretation of data in this thesis would be consistent with other research that informs EC. Nevertheless, it is useful to position the work here in relation to some other theoretical approaches.

A useful starting point is Ennis et al. (2019) who reviewed and thematically analysed literature on the theoretical underpinnings of dementia and communication. They found that most accounts focus on 'mutuality' (understanding the PLwD by means of 'emotional', 'temporal' and 'cognitive attunement'), and 'personhood' (prioritising the PLwD's identity and autonomy), and that several 'perspectives' for analysing communication – psycho-social, psychoanalytic, relational, and linguistic frameworks such as 'The Communicative Effectiveness Framework' (Wong et al., 2009), and an earlier instantiation of Wray's CI model (Wray, 2012) – are, together, viable tools for understanding communication in a dementia context. This suggests that theories explaining dementia communication need to need to consider a broad range of aspects of human cognition and behaviour. The authors comment that the most useful future theorising of dementia communication would benefit from collaboration across disciplines and specialisms. They also note that most theories focus on the relational level, with less attention to the individual at one end or society at the other (Ennis et al., 2019). This observation is perhaps not surprising, given that most communication is between two individuals, but it does support the selection here of two theoretical models that do accommodate those aspects of communication as well.

There are several frameworks in pragmatics that might seem capable of helping interpret carers' perceptions of communicating with a PLwD. Two prominent ones are Politeness Theory (Brown & Levinson, 1987) and Relevance Theory (Sperber & Wilson, 1995). However, as Cummings (2005) points out, these models are focussed on understanding typical communication, by means of central concepts in pragmatics, e.g., 'implicature' (a speaker's intentions), and 'inference' (a hearer's perception of the speaker's intentions), and on how neurotypical interlocutors manipulate each other's assumptions and beliefs in how to present ideas. This approach, Cummings argues, is problematic when applied to communication characterised by pathological conditions, because the patterns of interaction are shaped by how PLwDs deviate from 'typical' communication norms (Cummings, 2020).

Whilst the CI model and mentalization draw on several features of previously developed frameworks, they also accommodate analysing communication that is not neurotypical. In addition, Wray (2020, pp. 167-168) argues that, even at the normative level, the CI model captures greater flexibility in explaining the relationship between what is said and what is understood: "while hearers are, indeed, subject to the rules of the pragmatic game, speakers have the potential to create a distinction between the intention *contained* within the communicative event and the foundational intention that *drives* it (*what I want to achieve*)" (p. 168). I will expand on this distinction in section 5.2, and its implications for family carers in a dementia context in section 5.4.

Because both models prioritise motivations, they offer, in combination, the scope to interpret communication in a dementia context through the lens of what carers and PLwDs respectively are aiming to achieve with communication (rather than just how they achieve it). This means that, together, they can address not only *what* happens in communication but also *how* and *why,* at both a psychological and a social level. In so doing, they can account for how communicative outcomes affect speakers and hearers, and thus address the limitations identified by Ennis et al. (2019) in theoretical approaches to dementia and communication. This is particularly useful since dementia, as a condition that progresses, has a range of different impacts on the form of communication over time, while the core motivations for communicating are likely to be relatively stable.

In this chapter, I will first describe the concept of ‘mentalization’, and outline trait-like individual and state-like situational factors that can impact on how an individual ‘mentalizes’. I will then turn to the Communicative Impact framework, and offer a view of what communication is for, and how communication is done. Then, I will juxtapose central ideas from these two frameworks and propose that mentalization is an integral part of dyadic communication when interpreted using the Communicative Impact framework. Finally, I will draw on ideas from these models to conceptualise how family carers use information from communicative breakdowns to inform their approaches to communication over time.

5.1 Mentalization

'Mentalization' is a term originally coined by Peter Fonagy (1991) to describe the psychological processes by which we interpret the 'mental states' of ourselves and others – that is, the motivations underpinning our behaviours. Bateman and Fonagy (2010) state that “mentalization, or better mentalizing, is the process by which we make sense of each other and ourselves, implicitly and explicitly” (p. 11), by inferring needs, desires, feelings, beliefs, goals, and reasons that underpin behaviours (Fonagy et al., 2007, p. 288).

Mentalization encompasses a range of mental capacities. One is Theory of Mind, which concerns how an individual understands the state of mind of other people (Leslie, 2001). Other capacities include perspective taking, curiosity towards understanding others, and, as a basis for individuals to understand themselves, mindfulness (Luyten et al., 2020). A core driver for an individual’s mentalization capacity is their ‘attachment style’ (Allen et al., 2008; Fonagy, 1991). ‘Attachment style’ refers to behaviours used in forming a connection with an ‘attachment figure’, who can be a parent during childhood, and in later life, a friend, romantic partner, or group of particular importance to the individual.

The concept of attachment styles stems from ‘Attachment theory’ (Ainsworth & Bowlby, 1991; Bretherton, 1992). These styles derive, to a large extent, from an individual’s upbringing and early relationships (Cassidy et al., 2014), and can be categorised as: secure; anxious-ambivalent; anxious-avoidant; and a later addition, disorganised/disoriented (Shaver &

Mikulincer, 2010).[11] The clinical features of all four are not relevant in this thesis. However, the distinction between secure and insecure attachment styles impact on their behaviour in close relationships (Simpson & Rholes, 2018), and has been suggested to play part in how adults use mentalization (Luyten et al., 2020).

People who display secure attachment styles can effectively form stable and loving relationships. This ability is believed to correlate with a greater capacity to mentalize. Insecure attachment styles are characterised by difficulties in forming stable relationships. Using this style is often a consequence of negative past experiences, such as childhood trauma. This trait-like behaviour can influence how individuals respond emotionally to interactions in the wider social world. Two state-like abilities (meaning psychological responses related to a specific situation, as opposed to the more permanent psychological 'traits' underpinning such responses) determining the capacity for mentalization are stress and experiencing strong emotions (Luyten et al., 2020; Luyten & Fonagy, 2015, p. 366). I will describe how these responses can impact on interaction in section 5.3.

Luyten and Fonagy (2015, p. 367) note that mentalization is a "fundamentally bidirectional or transactional social process." This means that the speaker's responses to interactions are stronger determinants of mentalizing effectively than their personality or behaviour associated to attachment style (Luyten et al., 2020). As a result, mentalization can be a catalyst for change in behaviours. We can now ask what mechanisms underpin active mentalization as part of interaction.

5.1.1 The dimensions of Mentalization

According to Luyten and Fonagy (2015), mentalization is built on four distinct dimensions, each a continuum with two poles, constituting the bases for understanding one's own and others' mental states. The four dimensions are 1) automatic-controlled, 2) internal-external, 3) self-other, and 4) cognitive-affective. Dimension 1 is founded on evidence from neurobiology, that our instinctive and volitional behaviours are controlled by different processing mechanisms. Automatic mentalization refers to the behaviours we adopt by instinct, such as fight or flight

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[11] Attachment theory and attachment styles are fields of research in psychotherapy on their own. It is outside this scope of this thesis to explicitly investigate these concepts or their empirical foundation.

response, or situations where we do not need to actively make a decision. This latter point also captures ‘implicit mentalization’ (Davidsen & Fosgerau, 2015), i.e., information we automatically process based on previous experiences. An example of this is going for a walk, where we do not have to make active decisions about not saying hello to all strangers that we pass. Controlled mentalization refers to behaviours characterised by active reflection and decision making, either during or prior to an action.

The second dimension, internal-external, refers to the types of cues used to inform a judgement. Internal cues are inferred, whereas external cues are stimuli outside of the mind, such as appearance, or body posture. The third dimension, self-other, refers to our capacity to understand our own and/or others’ behaviours based on our understanding own or other’s mental states in a given situation. Finally, the fourth dimension, cognitive-affective, relates to the distinction between an individual’s ability to assign cognitively logical reasons for their own/other’s behaviour on the one hand, and emotional reasons on the other (Luyten et al., 2020, p. 302). The dimensions are further discussed and exemplified in section 5.4.1.

Whilst the poles of each dimension are “subserved by relatively distinct underlying neural circuits” (Luyten et al., 2020, p. 301) they are not entirely disconnected from each other. All dimensions individually provide information that informs a person about their own and others’ mental states, which, together, contributes to balanced mentalization. However, the first dimension, regulating automatic versus controlled behaviours (dimension 1) can greatly impact on the information generated through the other dimensions. Where a person’s capacity to utilise controlled mentalization is inhibited, e.g., due to strong emotions such as fear or embarrassment, they will draw on automatic mentalization, which may result in “overly simplistic and biased assumptions about self and other” (Luyten et al., 2020, p. 301), even in close relationships where interlocutors have extensive knowledge about one another (Fonagy & Luyten, 2009).

In extreme cases, where a person experiences excessive stress and anxiety, inhibitions to their capacity to oscillate between automatic and controlled mentalization can result in distortion between real and inferred mental states that underpin behaviours (Chevalier et al., 2023). Luyten and Fonagy (2015) outline that this a consequence of either (a) considerable limitations in utilising controlled mentalization, where a speaker cannot recognise, or discard evidence about mental states from social cues (Fonagy et al., 2017); and (b) assigning excessive importance to social cues, resulting in “assumptions about other people’s mental states that go so far beyond observable data that the average observer will struggle to see how they are justified" (Sharp et al., 2013, p. 4).[12]

Tanzilli et al. (2021) note that individuals with insecure attachment styles are more prone to display inhibitions to mentalization in stressful social situations than those who have secure attachment styles. Returning to section 5.1, I point out that the type of attachment style that a person develops greatly depends on their upbringing and early relationships. In similar vein, children's mentalization capacity is in part determined by the extent to which parents display effective mentalization in interaction with them, such as mimicking, verbalising, and discussing emotions in themselves and in the child (Fonagy et al., 2017; Fonagy & Target, 1997). However, childhood experiences are only one source of learning for mentalization, since mentalization is an ability that can be introduced through training in later life (which I will discuss in section 5.4).

5.1.2 The role of information in mentalization

Information that contributes to making inferences of others' mental states have been suggested to comprise two sources: 'immediate' and 'stored' (Achim et al., 2013). The former relates to observations of physical and linguistic cues displayed by a particular person (e.g., facial expressions, and verbal information), and the current contextual environment. The latter refers to previously acquired knowledge that contributes to a general understanding of a particular context - e.g., general expectations and behaviours associated with a specific situation - and specific information attributed to the particular interlocutor(s), i.e., "all that we already know about the agent or the particular context in which the agent is encountered" (Achim et al., 2013, p. 118).

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[12] In addition, there is extensive research showing that switching between automatic and controlled mentalization is affected by pathological conditions such as autism (Bliksted et al., 2018) and bipolar disorder (Luyten et al., 2020), or inflicted conditions with permanent psychological consequences, such as childhood trauma (Luyten & Fonagy, 2015). In extreme cases, Luyten and colleagues (2012) suggest that a person can engage in 'non-mentalization modes', and describe three modes of this state where a person's inferences of mental states deviate from reality (see Luyten et al. 2020). Although important, discussing non-mentalizing modes is beyond the scope of this thesis, and will therefore not be discussed further.

However, the authors also point out that speakers assign some aspects of other's behaviour greater importance than others for understanding them (ibid., p. 124). A term that encapsulates the extent to which a speaker considers information displayed by other interlocutors relevant for mentalization is *epistemic trust*. This term (see Sperber et al., 2010 for a discussion of epistemic trust in pragmatics) refers to "an individual's willingness to consider new knowledge from another person as trustworthy, generalizable, and relevant to the self" (Fonagy & Allison, 2014, p. 373), and is closely linked to attachment style, in that a secure attachment style correlates with increased epistemic trust (ibid., pp. 4-5). High levels of epistemic trust mean that an individual considers much information in the social world to be potentially relevant for understanding others. In turn, knowledge about the social world in general is considered to contribute to a higher mentalization capacity (Frith & Frith, 2006). In contrast, an individual with an insecure attachment style may find it harder to accept knowledge from someone else as trustworthy and to see it as applicable to their own lives. Consequently, they will generate less information about the social world, which reduces the information base contributing to their potential mentalization capacity (Frith & Frith, 2006; Luyten et al., 2020, p. 303).

In the research literature concerning pathology, mentalization has primarily been investigated within the frame of borderline personality disorder. There is, to date, little research investigating how mentalization works (and can change) in a dementia context. However, there is great potential in this field. Mentalization theory can help carers understand how exposure to dementia can distort their own beliefs and behaviours, and those of the PLwD. As such, it can be used to explore how carers interpret their, and the PLwD's, new behaviours, including in social encounters with third parties. Where carers are able to access an accurate understanding, it will inform them of the PLwD's needs, wants, and wishes. This knowledge will shape the interactive choices they make to fulfil those needs, with increased chances of empowering the PLwD to participate successfully in communication. The next section considers these aspects in more detail.

5.1.3 Mentalization in a Dementia Context

Mentalization in the dementia context is not widely researched. One constituent of this framework, namely Theory of Mind (Fonagy & Allison, 2012, p. 12; Leslie, 2001) is increasingly being investigated in research concerning pragmatics and pathological conditions affecting language (Cummings, 2017). In contrast, research concerning self-related mentalizing in dementia is limited. There is undoubtedly work to be done on developing mentalization in PLwDs themselves, to better understand how they interact with the world. For example, Lipinska (2009, chapter 7) offers several examples of how psychotherapy can help PLwDs reflect on and voice inferences about their own and others' communication. Authors living with a dementia (e.g., Taylor, 2007) also demonstrate the capacity to draw on controlled mentalization in communication in, at least, the earlier stages of dementia. However, my focus here will be on building mentalization skills in carers.

In chapter 3, I outlined Ablitt, Jones and Muers' (2009) four types of approach to the relationship with a PLwD: Continuity, where the "carer works to maintain the past identity of the person with dementia and actively seeks out small positive responses from the person" (ibid., p. 504); Reciprocation, where "the carer perceives the person as changed, but is motivated to care because they have received care from this person in the past or believe that 's/he would have done the same for me'" (ibid., p. 504); Detachment, where the carer distinguishes between themselves and the PLwD, and provide care without expecting anything in return (where carers often are more factually oriented and reduce interactions of a personal and emotional nature); and Duty, where the carer undertakes their caring responsibilities based on that it is morally right to do so, which is often characterised by "minimal or no mutuality in the relationship" (ibid., p. 504). There are notable links between characteristics defining these approaches, and the cognitive-affect based dimension of mentalization.

From the definitions of Ablitt and colleagues (2009), it is clear that carers approach and interpret emotional aspects of interaction differently. For example, a carer using a Continuity interaction style see the PLwD within a long-term narrative of their relationship, and may lead to "a sudden and delayed realisation of the actual level of severity of the dementia" (Ablitt et al., 2009, p. 504). Carers who approach communication from this perspective may then rely more heavily on affective-based explanations of the PLwD's behaviour, and potentially suppress cognitive explanations. For instance, they might think that specific changes in the PLwD's communication are related to feeling sad, tired, and stressed (potentially because of their diagnosis), and not to how the condition is altering the neurological foundation of their communicative abilities. This may indicate that only when the carer is forced to exclude emotional explanations for the PLwD's abilities, will they attribute the changes in the PLwD's communication to cognitive difficulties.

In contrast, a carer who operates in the Detachment category feels neutral in their caring role, and "their distanced role may serve to protect them from the intensity of emotional experience required in sharing the journey of the person with dementia" (Ablitt et al., 2009, p. 504). In contrast to the prior example, a carer approaching the relationship this way might rely more heavily on cognitive explanations and overlook emotional drivers for some of the PLwD's behaviours.

In section 2.6 I mentioned a study by Williams (2011). In her study, she gives an example of a family carer who avoids communicating with her husband, who is living with a dementia, because he struggles to communicate with her. The carer "viewed his lack of response as a rejection of her" (p. 32) rather than as a reflection of how dementia affects their ability to communicate. We can conjecture the carer is drawing to a great extent on emotional mental states to understand the PLwD's behaviour. By leaning more towards explaining this behaviour from a cognitive point of view, she might feel less hurt. Moreover, she could potentially adjust her communication to better suit her husband, to increase the positive outcomes from their communication.

At the beginning of this chapter, I stated that mentalization consists of multiple mental processes, one of which is curiosity (Luyten et al., 2020). Deployed in a dementia communication context, the ability of carers to be curious takes into account both cognitive and emotional aspects of communication, and has therefore been termed 'empathic curiosity' (McEvoy et al., 2013; McEvoy & Plant, 2014). This mindset is characterised by carers scrutinising their assumptions about which behaviour observed in PLwD is relevant to inferring meaning. In this way, the carer learns to use controlled mentalization to a greater extent, questioning their prior automatic interpretations, and becoming curious about easily overlooked cues as to the PLwD's mental state and intended meaning.

Empathic curiosity is heavily integrated with multiple dimensions of mentalization, as it draws on both self- and other-oriented perspective taking. It encourages a listener to pay attention to "felt meanings and the emotions a person is experiencing" (McEvoy et al., 2013, p. 274) and non-verbal disruptions (which relates to dimension 2, inner-outer cues), e.g., "someone scratching their head, or shifting their position in the chair they are sitting on as they respond to something that has been said" (Morris & McEvoy, 2023, p. 233).

This latter point is particularly salient for people with late-stage dementia, who may rely almost exclusively on non-verbal communication (Ellis & Astell, 2017, 2018). In this setting, outer communicative signs are crucial for making inferences about inner communicative messages. For instance, a PLwD might be able to express verbally that they are in pain during most of the disease trajectory, which might not be possible in the late stages. Experiencing pain might then be observed only through changes in respiration, a tense body posture and so on. The PLwD's emotional and physical needs might also be inferred indirectly, when anticipated responses are not forthcoming - for instance, where a compassionate gentle touch or squeeze of the PLwD's hand does not seem to offer consolation, or an action or comment is unable to distract the PLwD due to discomfort (Warden et al., 2003).

Empathic curiosity effectively works as a strategy for carers to help them consider more information as potentially relevant for understanding the PLwD's behaviour, and develop their other-mentalization abilities. Ballespí and colleagues (2021) show that higher levels of other-mentalization in the general population are associated with perceived happiness, and argue that this relationship is a product of positive social experiences. Moreover, they argue that a greater mentalization capacity (both self and other) is associated with several aspects relevant to increasing general and role-based social functioning. This suggests that increases to knowledge and mentalization capacity have a positive impact on the outcomes of interactions, and in turn on quality of life and general wellbeing (Ballespí et al., 2021; Kwasky et al., 2010).

Rogoff et al (2021) show that global mentalization can be improved by extended training, such as studying and practising psychotherapy. However, generalised levels of mentalization might not be sufficient. If one is to improve one's communicative abilities through increased mentalization, knowledge about a specific person, and how to understand their individual expression patterns, may be of greater significance than general knowledge about the world.[13] In a dementia setting, this argument is particularly relevant, as communication difficulties are often addressed rather generically, and can be difficult for people to relate to their own lived

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[13] Bączkowski and Cierpiałkowska (2015) confirm this, though they note that secure attachment is required for it to be effective.

experience (Eggenberger et al., 2013; Vasse et al., 2010), which was discussed in section 3.4 and in the introduction to chapter 4.

Later in this chapter, it will be possible to show how communicative approaches aiming to gain insight into a PLwD's thoughts and feelings through mentalization can help carers alleviate the effects of some dementia symptoms on communication. A model that articulates this relationship – the Communicative Impact Model (Wray, 2020) – has already been integrated, alongside mentalization, into the EC framework (Morris et al., 2020), described in Chapters 3 and 4. In what follows, I will outline the central concepts of this model, as they are relevant to creating and construing utterances.

5.2 The Communicative Impact Framework

The Communicative Impact (CI) model (Wray, 2020) is a novel approach to explaining communication from two perspectives, (1) what communication is for, and (2) how communication is done. In this section, I will first discuss the origins of the CI model and outline central terms and definitions. I will then describe how the model functions and offer some notions about how the model works in a wider societal context. Finally, I will juxtapose the theoretical framework of the CI model with Mentalization and point to where the two frameworks overlap.

At a fundamental level, the CI model addresses the question of what communication is for. A speaker will use communication to enlist others to change their world when they cannot do so themselves. Wray proposes that the impulse to continually modify one's world is founded in the survival drive, because of the imperative to protect oneself from harmful situations. Wray notes, however, that "survival" needs to have a broader definition than merely staying alive. Therefore, survival as a concept is expanded to "maintaining one's place amongst others, sustaining a desired quality of life, and protecting valued relationships" (Wray, 2020, pp. 137-138). Whilst we can achieve many things contributing to our survival independently, many desirable changes are beyond our capability to achieve without the assistance of another person. It follows that, in many cases "our capacity to mould our experiential world towards an ideal state depends in significant measure on our communicative skills" (Wray, 2020, p. 138).

Two key factors for the speaker are, first, their communicative goals, i.e., what changes to their world they want to achieve (Wray, 2020, p. 141), and, second, the extent to which those changes happen. Where the outcomes of a communicative message reflect the speaker's intentions, the communicative event is successful. This means that the speaker can gauge the success of their communication by comparing its outcome against what they were aiming for. Wray calls this concept 'communicative impact'. Where the outcomes of communication match the speaker's goals, communicative impact is high. Where they do not, communicative impact is low.

Wray makes the assumption that speakers always attempt to achieve high CI. This means that all messages are formulated with that intention, and will display choices that the speaker anticipates will maximise the chances of success. However, since success is determined by the hearer's response, the speaker cannot single-handedly achieve CI, only generate CI *potential.* The choices made in this process are heavily reliant on the speaker's beliefs about what the hearer knows, assumes and expects. This set of information is part of what Wray considers 'context'.

Wray approaches the notion of context by drawing on definitions from sociolinguistics, pragmatics, and cognitive linguistics, stating that context is a combination of the speaker's own knowledge, their perception of their hearers' knowledge, and a range of situational variables, including setting, relationships and previous events. One key aspect is the speaker's mental representation of what the hearer knows about the world, since this is the best way to anticipate how the hearer will interpret the message. This information stems from a speaker's past experiences and interactions, and observations made within current interactions. It is against this backdrop that speakers determine the content and form of messages so as to maximise their potential for achieving a desired change.

The way in which speakers incorporate this knowledge into constructing messages that can achieve their desired changes to their world is conceptualised as a module within the CI model called 'the Communicative Demand Management System' (Wray, 2020, p. 142). This concept represents the processes that determine how a carer formulates an utterance that they perceive has the highest CI potential. We now turn to how this module of communication functions.

5.2.1 Producing communicative messages

The communicative demand management system chains three tasks together. These are (1) *assessing the context* and defining the best potential path to reaching a defined change, (2) *gathering resources* where the speaker assigns lexical units and structures to their message, and (3) *applying processing* where the speaker generates the spoken output (Wray, 2020, p. 142). In this section, I will focus on the first step, 'assessing the context'. The reason for this is that 'gathering resources' and 'applying processing' are related to psycholinguistic and motor processes that follow the decisions about what to say and how (assessing the context). In the dementia context, it is the decisions associated with step one that lie at the core of improving communication for both carers and PLwDs.

By means of 'Assessing the context', the speaker will determine "which of the many possible (linguistic and non-linguistic) ways of conveying a message is most likely to result in a desired outcome (high Communicative Impact)" (Wray, 2020, p. 142). This assessment is made up of two components, (1) 'information sources', which inform (2) 'parameters'.

Information sources are banks of knowledge and sets of cognitive processes that underpin a speaker's evaluation of what information they need to include in a given message to maximise their chances of achieving their desired goals. The knowledge includes awareness of past events, observations of surroundings, relationships between interlocutors, cultural information, and interpretations of non-verbal markers. Cognitive processes include, but are not limited to, working memory and long-term memory (episodic and semantic – see section 2.3.4).

This information helps the speaker assess what the hearer is likely to expect them to say, given where they are and what (the hearer knows) has already happened. Thus, the speaker's choices are dependent on the ability to infer what knowledge a hearer has and assess the hearer's frame of mind, as already discussed in terms of Theory of Mind (Leslie, 2001) and 'other-oriented' mentalization (Fonagy & Luyten, 2009; Luyten & Fonagy, 2015). The extent to which a speaker's map of the hearer's perceived knowledge matches their actual knowledge can help predict the efficacy with which the speaker can steer their message through expected and easily processed cognitive routes that facilitate decoding by the hearer. A message based on a good match will reduce the cognitive effort for the hearer and maximise chances of them responding in the desired way rather than misunderstanding, refusing to do something, or ignoring the speaker. Since the context is constantly shifting, including being updated by previous conversational turns, a speaker's success in achieving their desired goals lies in keeping up with the ever-changing context, not only from their own perspective, but also from that of the hearer.

In the speaker's mapping of the hearer's knowledge, some information is assumed to be expected and shared, whereas other information is not. This information, along with other relevant contextual considerations, is the foundation for setting 'parameters'. Parameters in this context are "considerations relevant to formulating the message" (Wray, 2020, p. 149), i.e., what the speaker needs to mention, and how, given what the hearer already knows and believes. Parameters include aspects of a communicative message such as focus, explicitness and implicitness, the rate of delivery, formal or informal language, and clarity (Wray, 2020, p. 146). Parameters enable the speaker to point the hearer towards a specific interpretation that the speaker believes will have the best communicative impact potential.

The other two components in the Communicative Demand Management System ('Gathering Resources' and 'Applying processing') relate to the specific formulation of the message and then its delivery. On the basis of the speaker's model of the context, certain decisions will be made about lexis and grammar, from speaking in a particular language that the hearer is believed to know or prefer, to selecting certain words and morphemes that will signal social alignment, power relationships, etc. Similarly, the speaker may choose phonological forms (e.g., dialectal, informal) that signal group membership, intonational features that deliver emphasis, measure of certainty etc, and voice quality that indicates attitude, relationship etc.

An additional aspect of resource selection can be the management of the hearer's cognitive load, such as using preformulated familiar word-strings, at the potential expense of semantic novelty. Conversely, the speaker might select novel, high-load formulations in order to convey an exact meaning that the hearer will recognise as significant (as a poet or comedian does, to achieve specific CI outcomes in an audience) (Wray, 2020, pp. 150-151).

5.2.2 Hearers determine communicative impact

Once an utterance is constructed and expressed, a hearer will react (or refrain from reacting). At this point, a speaker will be able to judge whether they have achieved higher or lower communicative impact. If a hearer reacts in a way that changes the speaker's world in the way the speaker desired, the communicative impact is high. If a hearer does not change the speaker's world in the way the speaker desired, the communicative impact is low.

Three things should be noted, however. First, even where the hearer's response does not reflect what the speaker anticipated, it could still lead to a desirable outcome. Technically, the CI is low, because the speaker did not achieve what they set out to. However, the speaker may easily adjust and accept this alternative. Second, speakers are rarely pursuing only one goal at once, and there may be a different level of CI for each one (Wray, 2020, pp. 14; 139). For example, the speaker may intend to ask someone politely to turn down their radio, in order to reduce noise, but want to do so in a way that does not annoy the hearer. The hearer might, despite the polite approach, be annoyed (low CI for the speaker) but grudgingly still turn the radio down (high CI). Third, Wray recognises that a listener's reactions may reflect something other than what a speaker thinks they do. We might, for instance, believe that we have successfully explained a concept to a child, and when they say they have understood, we assume we have achieved high CI. Yet we do not know that we have: "perhaps communicative impact is *always* about the changes we *believe* we have effected rather than what actually changes" (Wray, 2020, p. 154).

This notion raises two points regarding the speaker's capacity to achieve CI. First, a speaker may experience discrepancies between their perceived CI, and the changes they actually have achieved over time. For instance, where a hearer makes a promise with no intention to fulfil it. Second, speakers in strongly disadvantageous power dynamics can find it hard to influence hearers. I will first discuss them in turn, and then bundle them together and briefly consider how they apply to communication in a dementia context.

In relation to the first, let us consider the example above. Asking someone to make a promise and expecting them to fulfil their promise comprises two communicative goals. The first is for the hearer to make the promise, and the second for them to carry it out. The speaker will achieve high CI in relation to the first goal where they infer from the hearer's response that they will attempt to make a specific change to the world in the future.[14] The CI in relation to the second goal (and indirectly, to the first) is conditional to whether this change happens later. Where it does not, the speaker's inference of the hearer's mental states did not reflect their

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[14] Not all promises are based on intended future actions. For instance, a speaker can promise a friend in distress that 'everything will be alright' despite lacking knowledge of whether this future outcome is possible. Instead, this promise is likely intended to provide reassurance. In many cases, the hearer and speaker likely overlap in acknowledging this being the primary function, and therefore, neither party form expectations related to its literal meaning.

intentions, and the CI is low altogether (I will expand on this notion in section 5.3). The speaker will likely feel uncertain of what social cues they may have overlooked, and question the hearer's intentions in future responses.

The second point is related to how power can constitute part of the context, and restrain what outcomes a speaker can achieve. For instance, where a doctor suggests two different possible interventions, neither reflecting the speaker's mental representations of what an optimal solution should look like. In these situations, the speaker will not have the power to conjure drastically different outcomes than those suggested. The power that determines the extent to which a carer can change their world lies in an institutional voice. The stated potential outcomes, determined by the institutional voice, becomes part of the speaker's contextual knowledge. Where available outcomes contrast with a speaker's wishes, the speaker is forced to reframe what they realistically can achieve with communication in that setting.

Furthermore, as Heffer (2018a, 2018b) explains, in situations of social power imbalance, speakers can find themselves effectively 'without voice' in that the hearer is not much disposed to pick up cues and respond in a collaborative way. Hearers in positions of power can become blind to a speaker's intentions. For instance, a doctor who is focussed on factual responses might fail to pick up the emotional goals embedded in a carer's questions about how to obtain certain information and support, and thus not provide the desired reassurance or sympathy. Power imbalances can also degrade the value of the speaker's intervention, if that intervention appears ill-informed or inappropriate. The speaker is disadvantaged in not having social entry to the knowledge base that could better inform their evaluation of the context and improve the match. The hearer fails to recognise that comments and questions still have a purpose, even if they are founded in inaccurate information.

Dementia disrupts some aspects of the communicative demand management system, which leads to imbalances between PLwDs and unimpaired interlocutors. A PLwD may not always be able to form the messages they want to or accurately identify suitable goals to pursue. As pointed out in chapter 3 and 4, others' communicative approaches determine, in part, the extent to which the PLwD can use communication to improve their world.

Where other interlocutors shape communication in a way that is difficult for the PLwD to comprehend, such as talking at a pace that is too fast for the PLwD's cognitive processing speed, they effectively remove contextual components that underpin their CI potential. This puts the

PLwD at a considerable disadvantage for contributing to communication on the same terms as other unimpaired interlocutors. Unimpaired interlocutors not recognising this fact, and using communication that is inaccessible to the PLwD may lead to potentially diminishing the PLwD's wellbeing (Kitwood, 1997), and undermine their self-confidence.

This means that there is considerable risk that unimpaired interlocutors will negatively affect the PLwD's ability to achieve communicative impact, not just by using language that restrict their participation in interaction (Braithwaite Stuart et al., 2021), but also because of their beliefs. Where people do not believe that the PLwD has anything to contribute, their opinions will not be given as much weight as those of others. This brings us full circle, in that carers' capacity to identify and meet the PLwD's communicative needs (that is, act as an agent for desired change in the PLwD's world) will depend on their ability to recognise and engage with the PLwD's internal mental states. Moreover, as we shall see in chapters 7 and 8, carers often bridge communication breakdowns between a PLwD and other external interlocutors. This means that the carer's capacity to utilise controlled mentalization is relevant for both their own, and the PLwD's communicative impact potential. In the next section, therefore, I bring the CI model and Mentalization together, to consider how they interface.

5.3 Mentalization as part of Context Assessment and Communicative Impact

Wray recognises that mentalization plays a role in contextual assessment: "the integration of information into a mental map of the other's emotional state and knowledge is termed mentalizing" (Wray, 2020, p. 147). Whilst mentalization certainly does constitute a big part of the contextual assessment, insofar as it integrates the knowledge we have about the world (Achim et al., 2013; Frith & Frith, 2006), I will argue that mentalization functions beyond contextual assessment in Wray's CI Model. To describe how this process works, I will show how mentalization can constitute part of assessing the context, and evaluating the degree of communicative impact in the CI model, by functioning as a continuous information source across multiple communicative acts in prolonged interaction.[15]

As described earlier, in Wray's view, communication is driven by the speaker's need to engage another person to help them change their world in a way beneficial to their physical, mental, emotional and/or social 'survival' (Wray, 2020, p. 137-138). Wray does not mention mentalization in relation to goal formation, but it could play a role, insofar as a person notices their current situation and their reactions to it, and uses that information as a reference point for determining what they want to change (or keep stable). Since the capability to mentalize efficiently differs between individuals, we might expect to find a difference in the nature of the goals that are formulated by good and poor mentalizers. In particular, there might a difference in the extent to which people access and deploy awareness of the self within the wider context. Goals informed by high levels of mentalization might be more alert to internally conflicting desires, more socially sensitive and/or more observant of longer-term objectives, even at the expense of some immediate pay off.

To explore this further, let us consider the conditions that characterise successfully achieving communicative goals by means of mentalization. Where a speaker manages to generate a desired change to their world, they have likely displayed accurate mentalization skills in a number of ways. First, effective self-mentalization skills may help pin down more accurately what material or psychological changes are most likely to achieve the desired change. For example, if a person is feeling sad, and wants to feel better, controlled self-mentalization might help them distinguish between options with different short and long-term benefits, such as eating a tub of ice cream versus going for a walk.

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[15] The communicative impact from earlier parts of a conversation will constitute the context in later attempts to achieve communicative impact (provided the speaker is capable of storing the new information – thus, memory impairments are an impediment for PLwDs, eroding the quality of their contextual information over time, relative to that of the family carer). Therefore, the output generated continuously throughout one or multiple interactions, will, to some extent, constitute the grounds on which a speaker formulates their goals, and how they go about achieving them. Thus, the CI model does not end with communicative impact. The communicative impact directly feeds back into goals and context assessment.

This means that a person’s capacity to understand their own reactions to their situational context is directly relevant to the goals that they formulate. This raises two considerations, of which the second has not been discussed previously in this chapter. The first regards the interconnectedness between mentalization and that context. While mentalization is needed for formulating maximally beneficial goals (in other words, for understanding what one most needs), in contexts of emotional and mental strain, controlled mentalization will be difficult to harness and operationalise. This is because, as noted in section 5.1, strong emotions and stress inhibit access to controlled mentalization (Luyten & Fonagy, 2015).

The second consideration follows from the first, and points to the value of mentalization training. If an individual can only recognise the shortcomings in their capacity to draw links between their surroundings and their feelings of discomfort, they might gain enough traction to formulate goals focussed on regaining control over their situation. Communication gives them the opportunity to harness the help of others in achieving those goals.

Arguably, most people oscillate between accessing controlled and automatic self-mentalization during goal formulation. Where a person cannot draw accurate links between their situational context and their reactions to it, they are less likely to be able to pinpoint what, in that context, needs to change in order for their reactions to be altered. However, they may still attempt to change it, and doing so can still be beneficial in the end. Failing to achieve the change, and experiencing low CI, can indicate that they gauged some aspect of the situation inaccurately, and that provides new information that could improve the outcome next time.

In section 5.1.1, I linked trait-like factors that impact on a person’s ability to utilise mentalization as part of their contextual assessment, to attachment style and type (Luyten et al., 2020; Tanzilli et al., 2021). Meanwhile, state-like reactions that inhibit controlled mentalization (dimension 1) are strong emotions, and high stress levels (Luyten & Fonagy, 2015). Where a speaker draws less on controlled mentalization, their decisions will, to a higher extent, rely on automatic reactions. I do not intend to suggest that the extent to which a speaker can apply controlled mentalization is the sole determinant of which communicative goals they formulate. Many situations do not require controlled mentalization, e.g., greeting a loved family member with a hug when we see them. I will return to the relationship between self-mentalization abilities and how speakers formulate goals and evaluate communicative impact later in this subsection.

Let us turn to the next step of the CI model – the construction of an utterance to best achieve a desired change through the agency of another person. Wray points out that mentalization is key to constructing a knowledge map (Wray, 2020, p. 147), on which an individual may determine what information to include, leave out and focus on when constructing a message. This information is generated by the speaker's contextual knowledge, which, in Wray's definition of context, includes the speaker's knowledge, perceptions of others' knowledge, and perceptions of how others will utilise contextualisation cues (Gumperz, 1992).

Two important determinants of the outcome of mentalizing, involved in generating sufficient contextual knowledge, are the type of relationship between interlocutors (Bączkowski & Cierpiałkowska, 2015), and the hearer's behavioural tendencies in close relationships (Simpson & Rholes, 2018). These tendencies have been reported to constitute a part of an individual's 'personality' (Noftle & Shaver, 2006).[16] The relationship between a speaker and a hearer and their respective personalities can have significant impact on how a speaker anticipates and understands their behaviour. For instance, a speaker would likely not address their member of parliament in the same way they address their child. Similarly, they would likely not suggest topics or activities that they know would generate discomfort in a hearer. Therefore, these factors are important for how a speaker predicts a hearer's use of contextualisation cues across contexts, and they constitute part of the speaker's other-mentalization (Luyten & Fonagy, 2015).

A speaker's developing understanding of the mental states that underpin others' behaviour will also be part of the speaker's reflections on the causes of low communicative impact (Wray, 2016, p. 43). Morris and colleagues (2020) propose that 'good mentalizing' for the speaker is "an accurate and effective understanding of (a) his or her [the speaker's] personally important goals and (b) the other person's perspective that takes into account what is really important to them" (p. 1745). This suggests that evaluating where a speaker's and hearer's respective communicative goals overlap, and where they differ, is a particularly important

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[16] The notion of 'personality' is a substantial field of psychological research. Discussing this concept is outside of the scope of this thesis, and my knowledge. I am not attempting to outline the exact functioning of attachment style in the concept of personality, nor outline how the dimensions of any definition of 'personality' impact on how an individual may go about communicating. I am merely pointing out that knowledge about a person's 'personality' (in whichever way it is interpreted) will be a factor influencing the way interlocutors interact with each other.

consideration during effective mentalization in communication. It may be argued, then, that for a speaker to understand why their communicative impact is low, they need to not only understand the determinants of their own communicative goals, but also and where others' goals are in conflict and thus raise barriers for the speaker to achieve high CI.

The way in which a speaker may orient themselves when assessing low CI can be illustrated by a continuum between: (a) lacking knowledge about others in a given context, where the speaker's goal may be realistic, but the construction of their message might not be optimal for achieving it; and (b) lacking knowledge about what is possible to achieve in a given setting, rendering the goals unrealistic. When a speaker is leaning more towards (a) in interpreting the reasons to why they achieved low CI, they will, to a higher extent, be confident of their self-mentalization assessment. In other words, there is a high level of certainty that their world would have been better if changed in the way they plan, that this change was possible, and the undesired outcome is the result of their other-mentalization being insufficient to anticipate what was required (in terms of gaining the agency of the hearer) to achieve this change. Then, the speaker may reframe their understanding of the hearer's behaviour, and try again with a new formulation, informed by their new understanding of the hearer, to achieve the same outcome.

Where the speaker is leaning more towards (b), they are less certain of their self-mentalization assessment. Towards this end of the continuum, the speaker may question to what extent their cognitive representation of a given change was ever likely to result in that change to their material or psychological world. In other words, the speaker may question their perception of the outcomes a hearer is capable of delivering, or whether any communication that the speaker can produce is likely to result in achieving the originally formulated goal. For instance, a hearer might not be able to go to lunch with a speaker – not because they do not want to, but because they do not have time. In another instance, a hearer might be inclined to go to lunch with a speaker but cannot understand their request because the speaker has limited capabilities in their shared language. In this latter example, the speaker would acquire additional contextual knowledge about what it takes to achieve their goal. This would, however, come at the high cost of, say, getting advice on how to formulate a comprehensible and pragmatically appropriate lunch request in that language.

Both ends of this continuum constitute important sources of information for a speaker and contribute to understanding why high CI may not be achieved. However, this continuum is only relevant in instances when a speaker can actively reflect on communicative outcomes, i.e., apply *controlled* mentalization. Insofar as strong emotional reactions can affect this ability negatively (Allen et al., 2008, p. 70; Luyten & Fonagy, 2015), learning techniques for emotional management and resilience could be key to improving outcomes.

Wray proposes, as part of her CI model, the notion of ‘emotional reserve’.[17] This idea aims to describe the sources of ‘emotional resilience’ in speakers and provides an explanation for why it is easier for some people to ‘bounce back’ from negative experiences than others. Factors that contribute to emotional reserve can be “life experience, personal philosophy, spirituality, role models, learning opportunities, and cultural input conducive to developing the ability to override the lower brain’s response to threat, which prevents a more reasoned response to a situation” (Wray, 2020, p. 104). Wray suggests that individuals with high emotional reserve are more likely to “stay in touch with their feelings and work with them in a mature and constructive manner” (Wray, 2020, p. 104). This means that when someone with high emotional reserve experiences low CI, even though they might experience the same negative emotions as people with low emotional reserve, the experience might be differently perceived.

It follows that where emotion is overpowering, a person is less likely to be able to apply controlled mentalization. Where they can cope with such feelings, they are more likely to understand the situation by means of controlled mentalization. It is possible that this pattern induces a positive spiral, where a person can calibrate the third dimension (affect-cognitive) of mentalization, meaning that they can assign both emotional and cognitive explanations to the aspects of others’ behaviour that elicit strong emotional reaction in them.

So far, I have proposed ways of integrating mentalization as part of contextual assessment, and evaluating the extent of communicative impact within Wray’s CI model. Specifically, mentalization can play a part in determining goals, shaping the content in communicative utterances, gauging the communicative impact, and learning from communicative outcomes. In this account, I have focussed on how a single speaker and hearer attempt to change their world with communication. However, in many situations, there are

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[17] Linked to emotional reserve, Wray also introduces the concept ‘Social Reserve’ which refers to ”the currency of resilience located in a person’s cultural and social context” (Wray 2020, p. 76). This concept will be outlined and applied in chapters 8 and 9.

multiple interlocutors. Wray notes that speaking to several hearers can significantly impact on communication, as a speaker will have to assess their context taking multiple interlocutors into account (Wray, 2020, p. 153). Different hearers will have different perspectives, needs and priorities and might well have different existing knowledge and expectations and/or might not all infer the same things from a given message. Meanwhile, a speaker may be trying to achieve different changes to their world in respect of different hearers (e.g., inform person A, reassure person B so that they are willing to inform person A, avoid upsetting person C). All such factors will affect the speaker's utterance construction, subject to their capacity to manage multiple agendas, something easily compromised by emotion and stress (e.g., in a carer) and cognitive decline (in a PLwD).

In the next section, I will focus on how mentalization functions in dementia communication as an underpinning ability informing carers of PLwDs' behaviour.

5.4 Determinants of Choosing Communication Strategies and Contextual Reassessment following Low Communicative Impact

So far in this chapter, I have outlined the theoretical underpinnings of Empowered Conversations, namely, through outlining the concepts of Mentalization (e.g., Allen et al., 2008; Fonagy & Allison, 2012) and the Communicative Impact model (Wray, 2020). I have also pointed to the interface between these theoretical frameworks, and shown that mentalizing is relevant in (1) formulating communicative goals and (2) interpreting communicative outcomes.

But there is still a puzzle. Given the potential for the underpinning psychological, cognitive and societal resources to enable effective communication, why (in the context of dementia) is a speaker's CI so often lower than intended? And given that the communicative context changes as dementia deteriorates, how can CI be improved? We have established, of course, that carers are often stressed, which would dampen their access to mentalization. But I will propose that another part of the answer lies in the capacity of a speaker to deploy mentalization in navigating their, or their interlocutor's, negative emotional reactions to mismatches in contextual knowledge, expectations and discursive power.

I will explore this matter in relation, now, to the specific challenges of dementia communication. To that end I will first consider how a dementia can disrupt mentalization abilities, and impact on the trajectory of typical interaction. I will also point to how changes in mentalization are of particular importance to interaction in close relationships. Following this, I will outline how the four dimensions of mentalization individually, and in combination, can work to limit, and improve communication in the context of dementia. Lastly, in section 5.4.2, I will suggest a way in which instances of low CI can be turned into high CI by recontextualising communicative goals by means of mentalization.

We already saw that mentalization is an intrinsic part of communicating effectively (Morris et al., 2020). But which aspects associated with higher or lower mentalization contribute to this outcome? Previous research suggests that higher levels of self-mentalization are associated with increased levels of self-confidence, and better social and role-functioning (Ballespí et al., 2021; Rogoff et al., 2021), which, in turn, have been noted to play a role in the extent to which a speaker experiences positive communicative outcomes (Erozkan, 2013). Speakers who experience positive communicative outcomes achieve their communicative goals (Wray, 2020). If self-mentalization helps speakers accurately estimate the social context within which they are communicating, it follows that they will be adept at constructing realistically achievable communicative goals, which will further bolster their security in their social setting.

However, this can only be part of the story, since, as we have seen, the extent of a speaker's communicative success is not always within their own control. It is, in part, determined by other interlocutors. Sometimes, the lack of control is explicit, as in a doctor's surgery, where, as I have suggested in section 5.2.2, societal roles determine the communicative manoeuvrability of interlocutors, and ultimately, can affect the outcomes (Heffer, 2017). Limitations in outcomes can also stem from implicit perceptions of how a person generally communicates, something that may be of particular importance in a dementia setting. Wray (2020, p. 164) states that "people living with a dementia may find they have no credibility, because interlocutors classify whatever they say as shaped by the dementia." In terms of mentalization, unimpaired interlocutors may assume that the PLwD's abilities to express reflections of their mental states through communication are permanently distorted. If unimpaired interlocutors have low expectations of a PLwD's mentalization abilities, their behaviour could easily undermine the PLwD's confidence in their mentalized insights, erode their willingness to estimate the context and, in consequence, reduce their CI. Therefore, the communicative suppression of the PLwD, in this instance, is due to the hearer’s assumptions which, in turn, are underpinned by their (limited) other-mentalization abilities.

In a dementia setting, understanding others’ mental states - and accessing information that contribute to that understanding - is of particular importance for both PLwDs and their interlocutors. Since dementia alters communicative practices (see chapter 2), a PLwD may not be able to interpret or express information to the same extent or with the same accuracy as they did prior to diagnosis. To compensate for any such changes, much responsibility must fall on other interlocutors. They need to find new ways to facilitate the PLwD in producing and comprehending communication (Ennis et al., 2019; Kitwood, 1997). To do so, unimpaired interlocutors may need to employ strategies such as curiosity (McEvoy et al., 2013; McEvoy & Plant, 2014) for identifying and interpreting compensatory information sources. Before discussing information sources (see the next section), I will turn to two different types of contextual information that are of importance to mentalization.

As mentioned earlier, effective mentalization and communication, respectively, are to a great extent built on knowledge about the world (e.g., Frith & Frith, 2006; Wray, 2020). One important knowledge source for effective communication is the wider cultural frames which determine what is perceived as appropriate, and inappropriate, behaviour across different types of situations. For instance, a speaker would likely act differently when having supper with friends than at a Nobel Prize dinner. However, the specific interlocutors populating a context also matter. Therefore, knowledge about present interlocutors may be of great significance. Where a speaker and a hearer have an affect-based relationship (i.e., know each other), a speaker will adopt a specific type of communication pattern based on their attachment style (Simpson & Rholes, 2018) and knowledge they have about that person. This model of interaction is called a ‘working model’ (Collins et al., 2006), which will “guide how individuals orient to their attachment figures” and “influence the way in which relationship-relevant information and events are filtered, interpreted, and acted upon” (Simpson & Rholes, 2012, p. 283). Ballepsí and colleagues (2021) have suggested that ‘working models’ are important in mentalization. The authors found that speakers utilise other-mentalization more efficiently in situations where they know the participant (e.g., a friend) than where they do not, such as when describing and explaining the feelings and reactions of a character in a movie.

5.4.1 Mentalization as a mechanism for efficient communication

In section 5.1.1, I noted that mentalization consists of four different dimensions: (1) automatic-controlled; (2) self-other; (3) inner-outer; and (4) cognitive-affective (Fonagy & Luyten, 2009). These dimensions explain the processes by which speakers utilise mentalization to understand their own, and others' mental states, and can also potentially be applied to how speakers attempt to change their world through communication. I have already outlined the significance of the first dimension of automatic-controlled mentalization in section 5.3, where the controlled end of the dimension, to some degree, dictates to what extent other dimensions of mentalization can be used. So now, let us turn to the self-other dimension. Earlier in this section, I pointed out how higher levels of self-mentalization are associated with social functioning, indicating a direct link between communication and self-mentalization. I also pointed out how other-mentalization is crucial for identifying others' needs in communication. Thus, both self and other-mentalization are linked to determinants of efficient contextual assessments, which in turn constitute the basis for CI potential (Wray, 2020, p. 146).

It follows, then, that the greater a speaker's understanding of their own and others' mental states, the more likely they are to produce efficient communication. But what methods do speakers use to generate this information? Some cues that indicate emotional states are global, such as smiling to show happiness. In close relationships, such cues are more refined. Interlocutors can routinely make inferences from specific cues in others, as part of their 'working models' (Collins et al., 2006). The way in which speakers generate and understand this information is outlined in the internal-external dimension of mentalization.

The external part of this dimension constitutes what a person observes and perceives to be relevant for understanding someone else's behaviour. The internal part is defined as "inferences based on external features of others (e.g., facial expressions) or direct assumptions about one's own mind or the mind of others (externally-internally based mentalizing)" (Fonagy & Luyten, 2018, p. 125). Whilst abilities that let someone infer information about others do not necessarily rely on mutual familiarity (e.g., one can understand that someone is tired because they yawn and have bags under their eyes), being familiar with someone can reveal further external and internal cues.

For instance, an individual might know that someone is undergoing a particularly stressful period. On this basis, they will anticipate and recognise signs of tiredness, both external (e.g., bags under their eyes), and internal (e.g., they seem less energetic than usual), and be able to link their observations more to a known cause (e.g., not simply assume that the person had a bad night). Here, the last dimension of mentalization, cognitive/emotional, would also be deployed, to further inform them of the person's mental states. For example, suppose someone wants to invite their friend to dinner, but the friend is too tired and so declines the invitation. The cognitive end of the mentalization dimension accounts for logical reasoning, i.e., 'they want to rest because they are tired from work, so I understand they do not want to go to dinner tonight'. Meanwhile, the affective end of the dimension accounts for "self-affective state-proposition" (Fonagy & Luyten, 2009, p. 1360), where one's own emotions are drawn up on to connect with someone else's emotional state, e.g., 'I feel bad for them because they have to work so hard so that they are too tired to see friends'.

In this example, mentalization provides a way of understanding current situational behaviours. Mentalization can also provide an interpretation of behaviours that have happened in the past, something that is undeniably important for information generation with relevance to communication. In Wray's CI model, the catalyst for communication is one or more proactively formulated desired outcomes. But each new goal is, to a greater or lesser extent, also a reaction to previous change. Mentalization is predominantly a way of making behavioural interpretations of reactions, that is, in retrospect. This suggests that when a speaker completes a communicative gesture, they draw on their mentalization skills to gauge the level of CI. In other words, mentalization underpins the efficacy with which a speaker can make sense of communicative outcomes and generate information for the future (including their next goal). But what determines the efficacy with which this is done?

Mechanisms in mentalization that limit information generation are, first, the type and amount of information that one person can generate from another (Fonagy & Allison, 2014; Fonagy & Luyten, 2009), and their willingness to accept the information as relevant to their own lives, i.e., their 'epistemic trust' (Sperber et al., 2010). Second, as mentioned earlier, state-like features such as stress or frustration can reduce the speaker's ability to utilise their total mentalization capacity in that situation (but not necessarily in retrospect) (Luyten & Fonagy, 2015).

It follows that if it is desirable to utilise mentalization to its greatest extent in the interests of effective communication, there are two main opportunities for change: to increase a person's fundamental capacity for mentalization, and to reduce, where possible, the current impediments to greater mentalization by addressing the limitations. In clinical literature on therapy designed to improve mentalization, two cornerstones are (1) "stabilization of emotional expression" (Daubney & Bateman, 2015) (which reduces the conditions that prohibit controlled mentalization) and (2) "taking time to identify differences in perspectives, legitimising and accepting different perspectives" (ibid.), i.e., expanding the range of acceptable inferences. Therefore, improving mentalization may stem from broadening the ways in which information is generated, and processed. That is, to improve mentalization, a person might be assigned the rather difficult task of actively deviating from their usual communicative inferences. At a global level of interaction with unknown or partly known people, this might be easier since there would not be any 'usual' inferences. Within specific 'working models' based on existing relationships, however, a speaker might be used to the ways in which they and another interlocutor interact with each other (for example in a long-term marriage). In such cases, changing routine-based interaction patterns may be extremely difficult.

The necessity of altering working models is particularly salient when it comes to dementia communication. As a PLwD's cognitive processing abilities deteriorate, a carer may not be able to generate information from the PLwD in the same way they have in the past. The PLwD may change the way in which they draw on mental states related to emotions or cognition, to determine communicative goals for themselves, or react to others' communicative requests. Therefore, as mentioned above, a carer will have to explore new ways of generating information that informs them of the PLwD's mental states, since the current working model will no longer support the links between expression and mental states. Identifying new sources of information, and changing interpretations of generated information, requires self-monitoring. For instance, a carer may need to question their own assumptions (McEvoy & Plant, 2014). They may have to change the way they gather information, e.g., through active listening (Alsawy et al., 2019), and utilise certain information sources, e.g., non-verbal communication, to a greater extent than they previously have (NHS, 2023a). All these techniques are introduced within Empowered Conversations, as outlined in chapter 4, and have been shown to impact positively on communication efficacy (Morris et al., 2021).

Doing all of this is no easy task. Experiencing change to a long-established working model due to a dementia can be extremely painful and upsetting. Even carers with exceptionally good mentalization skills, who can change their communication with ease in most settings, may not be in a mental space where this is possible.

Even though the above account suggests how mentalization practices can alter communication on a general level, it does not explain how mentalization practices take shape in communication on a micro level, i.e., the instances in which a speaker is forced to employ new strategies and accept new inferences. In what follows, I will turn to this issue and suggest that situations in which a speaker experiences low CI can function as a source of information for improving communication in future turns.

5.4.2 Interpreting communication breakdowns: can communicative impact change?

Before addressing the ways in which a speaker can approach low CI, and determining potential causes of communicative breakdowns, let us consider the conditions which determine when CI is high. Wray (2020) states that "high communicative impact occurs when the outcome of the communicative act corresponds with the intentions" (p. 141). She emphasises that multiple desired outcomes can exist simultaneously (ibid., p. 143). That is, depending on the relative importance of the goals, CI might not be considered high for an event altogether if not all desired outputs are met. For instance, imagine wanting a light to be turned on, and needing to get someone else to do it, but not wanting to annoy them. The request is made but without adequate mitigation of the hearer's emotional response. The light is turned on (high CI) but the person is annoyed about having to do it (low CI). If the relationship is important, there will be an overall sense of failure to achieve high CI, even though the outcome was partly successful.

When a speaker experiences low communicative impact, they will have generated information about not having met all the desired communicative outcomes to a satisfactory extent. This information becomes part of their contextual assessment and can alter parameters shaping future utterances (see Wray, 2020, p. 143). As suggested in section 5.3, a speaker may retain previous communicative goals and attempt to meet them with new strategies. When this happens, previously formulated desired outputs must (still) be perceived as possible to achieve. For example, if the light is not switched on, there is still scope for that to happen. Conversely once the hearer has been annoyed, it is no longer possible to pursue the goal of not annoying them, only a new one of pacifying them. Where a speaker makes multiple unsuccessful attempts to reach a goal, they will ultimately run out of methods by which their goal feasibly can be achieved. When this happens, the speaker can either (a) leave the situation feeling frustrated, or (b) retroactively alter their communicative goals to fit the situation.

For instance, they might repeat a message that, originally interrupted by a loud noise, had not been received by the hearer. Whilst a loud noise is an obvious factor impacting on the speaker's CI potential, many factors that condition CI are less discernible. For example, the hearer might not focus on the speaker because they are stressed or may not register immediately that the speaker is speaking, due to hearing loss. This contextual information might not be known to the speaker, and therefore a conflict could arise between what the speaker thought they would be able to do with communication, and the outcome they achieve. In situations where a speaker cannot achieve a goal they perceive as possible, it is common for frustration to arise (Morris et al., 2020). Frustration, being a strong emotion, can prevent the speaker from using controlled mentalization, and thus from reflecting on the situation fully (Luyten & Fonagy, 2015). In other words, they may not have the mentalization capability, at that moment, to interpret the situation in a way that will that generate a full range of possible explanations for the low CI; instead, they might favour an automatic inference. They may, however reflect on the situation later, since controlled mentalization can happen retrospectively (Luyten & Fonagy, 2015).

Not all instances of low CI result in frustration. In cases where the speaker does not resort to automatic mentalization, they may determine that their currently formulated desired output was not possible in that context. As before, the experience of low CI becomes part of future contextual assessments. However, instead of employing new strategies to achieve unchanged goals, the speaker may draw on the knowledge generated by the low CI (at the time, or retrospectively (Luyten & Fonagy, 2015)) and recalibrate the potential outcomes they realistically can achieve – in other words, modify their goals. This means that the carer updates their frame of reference to better match the situation.

In what follows, I will develop this argument further, to show that feeding information arising from low CI into one's contextual assessment can enable one to recontextualise what a successful communicative outcome looks like. I will also show that it is possible to retrofit past outcomes to this new frame, which ultimately can transform low CI to high. This is the purpose of model in Figure 5.1. The model presents three ways in which carers can react to low CI.

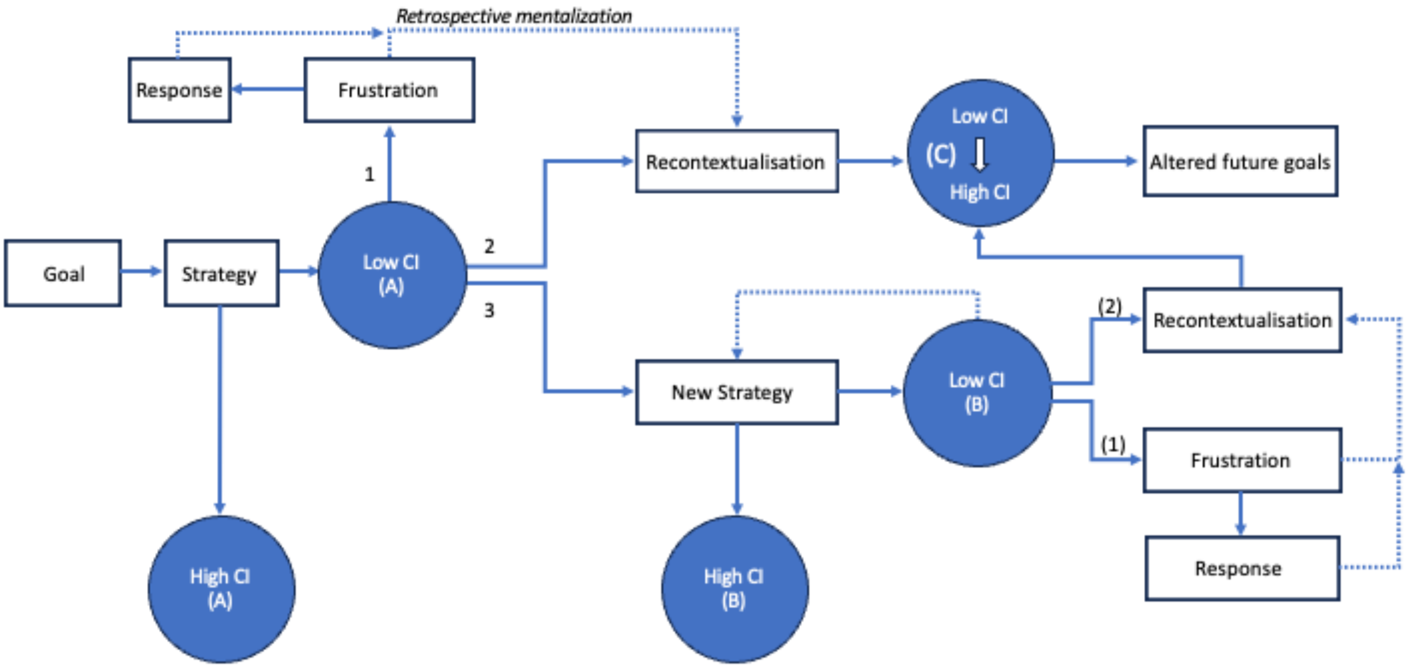

Figure 5-1: Temporal process of outcomes following low communicative impact

To read through the processes in the model it is best to start on the far left, middle, with the communicative 'goal' that a carer will attempt to achieve with a 'strategy'. Either they achieve high, or low CI, marked by the circles (A) under, and to the right of 'strategy'. In agreement with the account already outlined in this section, the information from low CI can lead to three outcomes, i.e., 'frustration'; 'recontextualisation'; and 'new strategy' (marked 1, 2 and 3). First, above 'low CI' is *frustration*, and can, in turn, lead to two outcomes. The first is ambiguously termed 'response', which is intended to encompass all responses that do not result in carers reframing their goals. As we have seen in chapter 3, when carers perceive communication to not be working well, they experience more anxiety, depressive symptoms (Brodaty & Donkin, 2009), and caregiver burden (Savundranayagam et al., 2005). The latter two factors have been noted to correlate with how frequently carers report using 'harsh language', e.g., shouting and scolding the PLwD, but can also result in withdrawal (Petrovsky et al., 2020), that is, avoiding communicating with the PLwD (e.g., Williams, 2011). Such behaviours can undermine the wellbeing of the PLwD (Kitwood, 1997) and, in affecting the experience of interaction negatively, can ultimately deprive the PLwD of exposure to social encounters (Wray & Bergström, 2024).

The second outcome of frustration (still part of route 1 in the model) is the carer reflecting on the outcome, which requires controlled mentalization, and can happen before, during or after a 'response'. Since feeling frustrated likely will inhibit the use of controlled mentalization at the time, carers will need to engage in 'retrospective mentalization'. This is indicated by the dotted line that originates from 'frustration', and 'response' to 'recontextualisation'.

This brings us to the second route. 'Recontextualisation', located to the right of 'Low CI' (route 2), refers to a process where carers observe low CI, and make a change to the contextual frame that determines what goals are realistically attainable. This new frame, can be retrospectively applied to the original goal. Then, the low CI outcome can be reinterpreted as high, as indicated by the circle (C) 'Low CI → High CI', located to the right of 'recontextualisation'. This can either be entirely contained within the immediate event, e.g., accepting the PLwD wearing a different pair of shoes from those that the carer has requested, or it stretch over future turns in the same interaction (I will provide an example of this later). The consequence of 'altered future goals', marked by the arrow and box top right, applies when carers extrapolate from this situation to similar contexts in the future.[18]

We now turn to the third route, which is marked 'new strategy'. As mentioned earlier in this section, carers can attempt to achieve a communicative goal again even if they failed last time. In doing so, the carer can, again, end up achieving high or low CI. In the case of the latter, the carer may repeat the process, and attempt to reach their goal again, indicated by the dotted line emerging from 'low CI (B)' to 'new strategy'. However, where they do not, the carer will repeat routes 1 and 2, as indicated by these numbers in parenthesis in the far right of the model. Next, I will consider an example of this.

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[18] There are, of course, additional ways in which goals can change that are not related to the immediate processing of information following low CI. I will discuss how carers formulate goals, and additional factors that can change them further in chapters 7, 9 and 10.

Consider a carer wanting to have a pleasant conversation with the PLwD about them having gone to a restaurant the night before (goal). She asks the PLwD what they liked best about the visit (strategy). However, the PLwD does not appear to recall this event, and seems a little flustered. Instead, the PLwD mention foods that they generally like, which is not what the carer was aiming for. The carer's CI is low (A), in relation to not managing to discuss that specific topic, and also regarding several emotional goals: the carer did not intend to fluster the PLwD and did not intend to feel the consequential sadness about how the dementia is impacting the PLwD, and did not intend to feel disappointed about not achieving these various goals.

In route 1, the frustration could come out in a sharp 'response' to the PLwD, or the feeling of frustration could subside, allowing the carer to draw on *retrospective mentalization* to reframe their perception of what communication can do in that context. This is one way into *recontextualization* (route 2). However, for convenience, before exemplifying *recontextualization,* let us turn to an example of a *new strategy* (route 3).

In order to help the PLwD recall the restaurant visit, the carer shows photos she took that night (new strategy). The PLwD is still struggling to recall the event (low CI (B)), but remains engaged in talking about food. Rather than succumbing to frustration and possibly an unsupportive response, the carer recontextualizes.

This recontextualization (a way into route 2) is to accept that it might not be possible to talk about the restaurant visit, but that they can talk about the closely associated topic *food*. This means that the status quo is updated, and that the original goal 'having a pleasant conversation *by talking about restaurant visit*', is changed to 'having a pleasant conversation'. Whilst the outcomes of 'asking the PLwD about the restaurant visit' did not meet the conditions that determine a successful outcome related to the first goal, it did in the second. Where the carer accepts the original outcome as successful within the boundaries of what they (now) perceive attainable, their CI can retrospectively change, which in indicated by circle (C) 'Low CI → High CI' in Figure 5.1. To increase the CI potential in future turns, the carer may broaden the topic to align with their new goals, and talk on food that the PLwD likes in general (Altered future goals). In chapters 7, and 9, I will expand on this idea, and discuss how carers change their goals longitudinally.

One aspect that is not captured in Figure 5.1 is the possibility of a speaker unnecessarily changing their communicative goals despite being able to achieve them using alternative methods, e.g., when a carer assumes a PLwD cannot do something because they failed once, and therefore draws the conclusion that they are incapable of completing that task altogether. Using retrospective mentalization, however, they may realise that a goal they determined impossible was, in fact, possible (e.g., realising that there was a reason why the PLwD could not complete the task on that occasion). In instances when this happens, the carer may regret abandoning the goal too soon, but enable themselves to achieve that goal in the future. Thus, both goals, and CI, can shift retroactively depending on evidence generated from instances in which CI is low, making those with mentalization skills much more agile in their responses to situations.

A clear difference between 'typical' communication and communication in a dementia setting is that dementia disrupts the conditions for high CI. As a dementia can change the production and comprehension capabilities in a PLwD, a carer must recognise these changes, and adapt accordingly. Otherwise, they may experience a high frequency of lower CI than they are used to. Therefore, carers are, to some degree, forced to draw on observations of communicative change, to shift their goals - both in the moment and retrospectively.

In a dementia context, communication difficulties often arise in situations related to daily life (Bressan et al., 2020; Small et al., 2000), such as when carers want to assist the PLwD in making every-day decisions, e.g., choosing what to eat. Commonly reported strategies for dealing with communication challenges around choice are reducing the number of options, and making a choice on the PLwD's behalf (Samsi & Manthorpe, 2013). Carers are clearly changing their communicative pattern in trying to achieve their goal of a decision having been made, one way or another. However, another goal that carers are often pursuing when they take decisions out of the hands of the PLwD is avoiding situations they anticipate will cause unnecessary difficulties for the PLwD, and for themselves. Indeed, Polenick at al. (2020), who conducted a focus group study investigating how family carers manage behavioural and psychological symptoms of dementia, point out that "caregivers adapted their interactions with the PLWD to fit his or her current functioning" and note that "such approaches may help to prevent distress for both care partners by avoiding unnecessary confrontation" (ibid., p. 9). As such, carers adapt their situational communicative goals not only in the moment, but in a temporal frame whereby they predict and manage future events. This is in itself a method for modifying their world in beneficial ways (without the help of an agent), one goal being self-preservation.[19]

Polenick et al. (2020) suggest that as communication challenges increase, carers become more reliant on noticing what worked last time, as a frame of reference for what will work next time. This contrasts with what is likely to have been the carers' former, more global, view of what generally works with people in similar situations. That is, they become more conscious of the micro-environment and use it as their dominant frame of reference.

The carer's new perspective will in turn modify the range of options they are willing to invoke for making changes to their personal world through the PLwD's agency (Wray 2020). While in some ways that range will be narrower (there are things the PLwD simply cannot help them alter in their world) it can also break open the tight grip they previously had on what counts as an acceptable experiential world, and this offers new opportunities. For instance, whereas before they might have only considered a *suitable and informative* linguistic response from the PLwD to be adequate for improving their world, they might now consider *any* response to be sufficient for high CI. Similarly, where before they might have interpreted a lengthy silence from someone as evidence of having been ignored (low CI) they might now interpret it as potential evidence of processing what they said, which could be associated with success (high CI).

In chapters 7 and 9 I will explore this notion further. There, I will draw on my empirical data to illustrate how carers broaden their scope for successful communicative outcomes. I will also show how mentalization underpins this change and demonstrate that while it can happen naturally for some carers, a significant catalyst is the Empowered Conversations programme.

Thus, the empirical investigation in chapters 6 to 9 aims to examine how closely informants' perceptions of the challenges of communicating with a PLwD match the theoretical models outlined in this chapter. Given the need, as discussed in this subsection and in 5.4.1, for carers to find ways to extricate themselves from low CI, particular attention will be paid in the

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[19] One way in which this 'adaptation' may be expressed, which is part of Polenick and colleagues' paper title, is to 'go with the flow'. This exact phrase appears in multiple non-academic sources from both first- and second-hand reflections, in relation to managing behavioural and psychological symptoms of dementia e.g., White (2019); Ninkatec (2020), and in dementia training, e.g., Area Agencies on Aging Association of Michigan (2023); Dementia Caring (2023).

analysis and interpretation to the sorts of solutions that the informants report, for getting communication back on track when it is perceived to be unsuccessful.

Chapter 6: Methodology

The account so far has set the scene for the empirical study, which explored how appropriate EC would be for meeting the needs of carers in Wales. As already noted, EC is founded on the two theories outlined in chapter 5, namely the Communicative Impact model and Mentalization, and so these theories were used to evaluate the extent to which carers who had attended an EC course had different capabilities and understandings from those who had not. The vocabulary associated with the theories, which the EC input might have introduced to its participants, was not used in collecting the data, so as not to bias the findings. Rather, carers were asked questions about how well communication worked between themselves and the person they were caring for, and what might improve their experience. It was possible to infer from these accounts their understanding of what communication is for and their potential to mentalize about it.

Two studies were conducted. The first directly focussed on the role of EC in distinguishing participants (in Greater Manchester) from non-participants (in Wales). The second was a follow-up study to provide additional information about the sort of carer most likely to be first targeted for a roll out of EC in rural North Wales.

In this chapter, I motivate and discuss the choices of method for these investigations. In the first investigation, the research questions were:

1. What do family carers in Greater Manchester and Wales say that they need in order to improve communication with the person they are caring for?
2. What carer-identified factors enable or prevent carers acquiring skills/strategies/knowledge about how to realise improvements in communication?

And in the second:

3. What factors associated with living in rural North Wales are prominent for managing communication with respect to people living with a dementia and their unpaid carers?
4. What aspects of communication are perceived as important to include in communication training for carers in North Wales?

5. What successful communication strategies do unpaid dementia carers report having observed when ‘third parties’ (e.g., GPs, nurses, hairdressers, shop assistants etc.) interact with PLwDs?

In section 5.1.2, I suggested that, in order to understand what improvements to communication carers ‘need’, it is necessary to pinpoint what they want communication to do, what barriers dementia symptoms pose, and what carers do to circumvent such issues. The investigations reported here acknowledge that circumstances related to the progression of dementia, and how symptoms of dementia are perceived by carers vary, and many of the reasons underpinning such variations have pointed out in chapter 5.

Given the need to gather personal views and insights about an emotive topic, it is, first, necessary to consider what methods can capture data of that kind. The choice of method should take into account the research questions, and the extent to which various methods can generate data that inform them (Busetto et al., 2020). In this case, the research questions explored a complex social phenomenon related to perceptions of communication, and the ambiguity surrounding the social and psychological aspects of the caring experience. Since quantitative surveys would not be able to capture this sort of nuance, qualitative methods were more appropriate (Lim, 2024).

Braun and Clarke (2013, pp. 33-34) suggest that data can come “through *production*, where we generate it ourselves by what we get participants to do”, e.g., surveys, interviews, focus groups, structured observations, etc., or “through *selection* from existing material such as media reports or blogs” (ibid). The former was more appropriate for this research, since the sort of information sought did not exist in more than piecemeal form in existing sources.

Next, the method for generating data must appropriately target the information sought, and offer flexibility in how participants can express their experiences. There are several ways to capture information about others’ experiential world, such as observations (e.g., ethnographies or structured observations of specific pre-determined phenomena), interviews, and questionnaires (Russell & Gregory, 2003; Sutton & Austin, 2015). While all would offer potential benefits, observation and questionnaires would have several drawbacks compared to interviews for this study. For instance, observation studies, despite being lengthy, may generate only a small number of instances of the target phenomenon. They also require the researcher to make extensive inferences and extrapolations, relative to simply asking the carer for their view. While, conversely, observation can reveal patterns that the informant is not aware of or not willing to mention, in this study the primary purpose was to find out what carers believed, since this is the driving force for their potential to change. Therefore, the method adopted in the first study was qualitative interviewing. This method has previously been used in applied linguistics to generate information about attitudes, beliefs, and emotions (Talmy, 2010).

In order to collect data likely to inform the research questions, semi-structured interviews were used because, "[due to their] flexibility and relative spontaneity, interviews can not only corroborate or challenge knowledge that the researcher has formed about the topic at hand prior to the interview, but they can also bring to light entirely new information" (Karatseras, 2022, p. 101). I will offer additional observations related to the role of the researcher in interview settings in section 6.4.

The second study was introduced to compensate for an imbalance in the data from Wales due to the Covid pandemic (see sections 7.5 and 10.3) and was conducted using focus groups (see section 6.2.3). Focus group data are generated from multiple people, who may hold various opinions (though they are not guaranteed to voice them) (Al Ghazali, 2014). A key strength of using focus groups is in exploring issues that involve complex and varied beliefs and behaviours, as multiple participants can validate and challenge views within the session (unlike one-to-one interviews where only the perspective of the interviewee is generated) (Hornsby, 2022). However, inherent limitations lie in how participants engage with each other, especially where one or more participants dominate the discussion, potentially suppressing the contributions of others (Smithson, 2000). This makes the role of the focus group moderator particularly important. Hornsby (2022) suggests several important factors regarding the moderator's role, such as topical knowledge, some degree of relatability to the participants, and an ability to steer the focus group without display obtrusiveness. I will expand on some considerations of how the focus groups were constructed against this backdrop in section 6.1.2.

In what follows, I outline how the studies were structured, the instruments used, how the research was carried out, how the data were processed, and finally, the motivations and procedures for how the data were analysed to address the research questions.

All details of the design, including the recruitment procedures, interview and focus groups questions and data management, were reviewed by the Research Ethics Committee of

Cardiff University's School of English, Communication and Philosophy, and formal permission to proceed was received. The Participant Information Sheets are provided in Appendix A (Greater Manchester), and Appendix B (Wales), and Consent Forms in Appendix C.

6.1 Research design

The data in this research come from three different population samples, that were purposely selected to meet criteria for informing the research questions (Russell & Gregory, 2003), and to satisfy the conditions set out by the funding bodies for this research. The interview study sampled carers who had participated in EC – all from Greater Manchester, since this was the only place where EC was available – and carers in Wales who had not attended EC. The original intention was to recruit an additional group from Greater Manchester, made up of carers who had not yet taken the EC course. This would have enabled triangulation, by helping separate out differences between the EC group and the group in Wales that reflected EC versus the difference in location. However, the EC staff were unable to facilitate the recruitment of a pre-course group, because of the timeline used for entry to EC provision during the Covid pandemic. In effect, if I had had to interview people before they attended EC, it would have significantly delayed their attendance, which was viewed as unethical, given the stress that the pandemic was causing. It is recognised that the absence of this third group makes it more difficult to interpret the findings (see section 10.3), though, as it happens, there was relatively little difference between the two groups in relation to many of the factors examined (see chapter 7), suggesting that, in the end, little more would have been learned from having the third group.

I will outline the inclusion criteria and participant characteristics in section 6.2 Originally, I planned on interviewing participants in Greater Manchester before and after they attended EC so as to establish how their thinking changed as a result of the course. However, this turned out not to be possible for logistical reasons (see chapter 10, Limitations section (10.3), for details, and for the impact of this change).

The focus group sample consisted of carers attending a dementia support hub in a town in North Wales. Again, the recruitment process is described in section 6.2. To make clear differences between participants and data generated for each study, methods, participants, data, and analysis will be discussed under separate headings, since, as we shall see, the approach differed significantly at times.

6.1.1 Interviews

Two sets of semi-structured interview guides were created (see Appendix D). Both interview guides were designed to generate information about what carers want to achieve with communication, perceptions of communication difficulties, ways of overcoming them, and other factors influencing communication. The questions focused on the carers' personal experiences of care, with particular emphasis on communication challenges, and the ways in which these challenges were addressed. The Greater Manchester participants were additionally asked about skills, insights and any differences in communication that they had identified after the course (see Appendix D, 'Set 2 – Sample A(2)', questions 2, 4, and 5). Multiple follow-up probes were available for each interview question in order to create possibilities for investigating each carer's perception of what they perceived to be important, without sacrificing systematicity. A pilot study was carried out to ensure that the interview guide targeted relevant areas of information.

6.1.2 Focus Groups

The focus group protocols, including questions, were constructed to explore general thoughts on dementia and communication, and specifically addressed what challenges the participants experienced associated with their rural location in Wales (see Appendix H). The method and focus group protocols were continuously discussed with staff at the dementia centre in North Wales, where the focus groups were carried out, to ensure that the anticipated data would best target the research questions. Some consideration was given to the role of moderator and to whether focus groups could be conducted in the absence of the researcher. However, for practical reasons, it was not possible or desirable for anyone other than myself to take this role. It would have had ethical implications to ask staff to conduct focus groups, as they would need to take time away from their commitments at the dementia centre, potentially disadvantaging all carers who attended the centre but did not participate in the focus groups.

Since the decision to conduct focus groups was the consequence of finding gaps in the interview data once it was analysed, the findings of study 1 could be used to shape the focus group topics, so as to directly fill those gaps. This was done in two ways. First, in addition to questions that would enable an evaluation of the general compatibility of the study 2 participants with the two groups in study 1, key questions targeted the information that had not been obtained in study 1. Second, a card-sorting exercise was introduced, requiring the participants to discuss and order by importance, key themes generated from study 1. This rendered an additional, collective perspective on what had been individual responses in study 1. In this exercise, participants were each given a set of eight cards, each listing a different communicative goal generated from accounts presented in chapter 7 (see Appendix I), and asked to put them in order of importance and then discuss their decisions together.

6.2 Participants

For each participant group related to the interviews, the number of participants required was set at 10-20, totalling between 20-40 family carers (see section 6.2.2 for an outline of participant characteristics). The reasoning behind this number was to ensure data saturation in both samples, and compensate for eventual dropouts. Guest, Namey, and Chen (2020) suggest that about 80% of themes are saturated within 6-7 interviews, and that 11-12 interviews are needed for a 95% data saturation rate. Hennink and Kaiser (2022) support this suggestion in a review paper addressing how data saturation is accommodated in qualitative interviewing. Therefore, a minimal number of 10 participants seemed likely to ensure that most relevant themes would arise.

The number of participants for the focus groups was not decided in advance. In part, this was because review studies report a wide range of group sizes as effective (three to twenty-one participants) (Nyumba et al., 2018). As for the number of focus groups to use, Hennink and Kaiser (2022) suggest that data saturation in focus groups is reached between four and eight. However, it was recognised early on that it might not be possible to organise that many groups. In addition to the lingering impact of Covid, carers had challenges with transport and limited access to someone to stay with the PLwD, if they were not in a position to come to the centre with the carer. So, the main determining factor in the number of focus group discussions conducted (which ended up being two) was the opportunity to hold them in a centre that carers were already attending. Further information on the recruitment follows in section 6.2.3.

6.2.1 Inclusion criteria

The central inclusion criteria that applied to all participants in both interview and focus group studies were that they identified as unpaid carers of someone living with a dementia. Furthermore, all participants needed to have sufficient conversational English proficiency (since I do not understand Welsh).

Wray (2020) argues that people living with dementia, and people providing unpaid care for them, generally experience similar communication difficulties, regardless of the type of dementia. Therefore, type of dementia did not constitute a basis for inclusion or exclusion. The term ‘carer’ was taken to encapsulate not only family, e.g., spouse or child of a PLwD, but also friends, neighbours or anyone else who provides substantial unpaid care to a PLwD (Gitlin et al., 2020, p. 13; National Academies of Sciences Engineering and Medicine, 2016). While these definitions were used to recruit participants, the type of relationship was not a variable of interest in the analysis. Although relationship, and also gender and age, could usefully be examined in future studies, it was not possible to control for them here, because the challenges of recruiting participants during Covid (see section 10.3) meant I had to rely on opportunity sampling.

The main additional criterion for inclusion in the interview group in Greater Manchester was having completed an EC course. EC has its own criteria for participation, but they mapped closely onto those already mentioned.

One obvious criterion applied by EC was that participants should currently be caring for a PLwD. In recruiting for the non-EC group in Wales, however, this criterion was not applied in all cases, so as to include people who had recently ceased to be a carer, due to the PLwD passing away. This opened the way for hearing from people who had lived through the entire dementia trajectory, and made recruitment, which was extremely challenging due to Covid, easier. As it turned out, however, only one participant was no longer caring for a PLwD and since the points raised by them were so similar to everyone else’s, it was decided that there was no need to take this difference into account in the analysis.

Largely, the same inclusion and exclusion criteria were applied to participants in the focus groups as those in the interview sample. However, all participants in the focus groups were currently carers. They were identified and recruited through a dementia support centre (see section 4.4.2) with help from the centre coordinator. Therefore, carers who were not linked with the support centre were not included.

6.2.2 Recruitment – Interview participants

Participants in Greater Manchester were identified and approached by representatives of EC. Originally, I also had a collaborative partner supporting family carers in central Wales, who offered to help identify and approach potential participants. However, Covid increased the workload of that partner who was forced to prioritise vital service provision over supporting this research. Therefore, participants in Wales were identified with help of clubs and organisations associated with dementia carers across the country and, in a few cases, through personal contacts.

Intermediaries were informed about the study, and asked to distribute an invitation letter to any potential participants that they identified. This could be delivered to participants by email, or by hard copy via post (however, no participants requested this). When distributed via email, intermediaries were asked to send a reminder to potential participants who did not respond after ten days. A lack of response past this point was interpreted as not being interested in participating.

In the invitation letter, participants were asked to report to the intermediary that they were interested in receiving additional information. The letter also explicitly stated that doing so constituted an agreement for the intermediary to share contact information with the researcher. Upon receiving this information, I sent out a participant information sheet and a consent form for participants to review, and offered to answer any queries. Where participants expressed interest in participating, an interview time was scheduled.

In total, ten participants from Greater Manchester and ten from Wales were recruited (see chapter 7, Table 7.1 for details).

No immediate risks were identified in relation to the design of the interviews in this research project. However, dementia can be an emotive topic to discuss. Therefore, all carers were informed in the beginning of the interview that they could take a break in case they were upset, or for other reasons such as sudden events related to their caring responsibilities. Only in one instance did a carer need to momentarily pause the interview. When this happened, the recording was paused so to not accidentally capture any audio unrelated to the research.

Participants were also reassured that if the PLwD were to accidentally appear during the interview, they would be subject to the same confidentiality and privacy criteria as the participant. However, in practice, this eventuality never arose.

6.2.3 Recruitment – Focus groups

Potential participants were identified by the centre manager of a dementia support centre. Carers, and the people they care for, attended this centre weekly. However, separate activities were organised in different rooms for carers and PLwDs. The centre manager was sent information about the focus group research, including planned aims, and focus groups questions, along with a gatekeeper permission form (see Appendix J). This form specified procedures for contacting participants, and for providing information about the focus groups. The details were largely the same as for interview recruitment, but the invitation letter was presented in hard copy at the centre. This approach was determined best fitting for the participants based on discussions with the centre manager. Where participants showed interest and agreed to be contacted, they were sent additional information via email, or, if they preferred, could receive information in physical format on the day of the focus groups. The focus groups were scheduled at a time when participants regularly attended the centre.

All participants were given a participant information sheet and a consent form on the day. Once they had read through the documents, they were offered an opportunity to ask questions, or discuss any aspect of the research. Even though some participants had previously expressed interest in participating, all carers were again asked if they wanted to participate. I was sensitive to the possibility that some carers attending the dementia support centre might feel obliged to participate in the focus groups when they did not want to. There were, however, many carers attending the centre that day who did not participate, which suggested that there was no undue pressure. Moreover, asking carers whether they consented to participate verbally, even after they had signed a consent form, was intended to function as a safeguard against this risk.

The participants were organised into two groups, and in turn, invited into a separate room. Before the focus groups commenced, all participants were, again, given chance to discuss any aspects of the research, in case they felt uncomfortable raising issues in the bigger group. Before commencing focus groups, all carers were asked verbally whether they consented to participate, even though they had signed a consent form. Finally, participants were offered the opportunity to discuss any issues with the researcher in a separate room after the focus group concluded, so that any concerns or potentially strong emotions elicited through the discussion could be addressed. In practice, no participants made any requests to this end.

In total, ten people participated in focus groups (see Chapter 8, Table 8.1 for details).

6.3 Data

The personal data collected about participants in the interview study were their names, age, gender, relationship to the person with dementia that they are caring for and type of dementia (where known)[20] (see Appendix G). Additional identifying data were the consent form and an audio recording of their interview.

The personal data collected about participants in the focus group study were similar to the data collected in the interview study. However, the focus groups were also video recorded, meaning that the participants' image and voice was also collected. These recordings were securely stored and were not shared with anyone. They were only used as back-up for the audio recording in case the researcher could not confidently match specific comments to participants. It also helped with the analysis of the card-sorting task.

All data were treated confidentially, and interview and focus group data were anonymised (see section 6.7, 'Ethical Considerations' for further details.)

6.3.1 Data processing and storage

As laid out on the Participant Information Sheet and Consent Form, any data collected could be accessed directly only by the researcher. However, the researcher could allow access to specific sections for supervisors where necessary for monitoring or support purposes.

All data collected by participants in both studies were anonymised apart from the consent form. Each participant was assigned a generated participant ID which was used instead of their name on any document containing data about that participant (i.e., participant forms and

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[20] As mentioned earlier, Wray (2020) argues that the social experience of dementia is often shared across dementia subtypes. Type of dementia was not viewed as a major influence on the carers' experiences at the level examined in the research and so is not part of the analysis.

interview transcripts). Potentially identifying information appearing elsewhere was omitted or anonymised.

All data were stored on the researcher's computer, which was password protected, and on the Microsoft 'OneDrive' Cardiff University cloud service. The latter functioned as a back-up storage place, in case any technical errors were to compromise the data stored on the computer. All files uploaded to OneDrive were private, meaning that only the researcher could access them. In case the supervisors needed to view the files (i.e., the sound recordings of interviews, which cannot be anonymised, or the interview transcripts), the files would be encrypted and emailed to the supervisor, where a password would be required to access them. The password would be emailed in a separate email to protect the files. In some cases, where discussions were necessary in relation to transcripts, supervisors could also receive a hard copy of the transcript, which had been anonymised.

6.3.2 Transcription of data

The data transcription drew on features of Jefferson's (2004) orthographic transcription conventions. The transcription conventions were generally the same for both interview and focus group data, except in the marking of supplements (e.g., specifying a subject) or masking (e.g., names of people and places) of information. Clear emphasis, and pauses were marked. For procedural reasons, other information relevant for inferring meaning (e.g., prosodic markers of reported speech, or pragmatic implications such as sarcasm) was marked in closed brackets in the interview data, and rounded brackets in the focus group data (see Transcription key on pages x-xi). After checking how any uploaded data would be used by Microsoft, all interview data were transcribed verbatim using Microsoft automated transcription which is included in the university's subscription of the Office-package and cloud storage on OneDrive. The focus group data were transcribed verbatim. All interview and focus group transcriptions were then monitored for accuracy, and, where applicable, corrected, by reviewing each transcript whilst listening repeatedly to the corresponding interview and focus group audio recordings.

6.4 Coding and Analysis – Interviews

The interview data were analysed using ‘Reflexive thematic analysis’ (Braun & Clarke, 2006; 2013, pp. 202-203; 2019). As with the selection of the best methodology for a study (see the start of this chapter), the approach to data analysis is dependent on the research questions. In this study, the aim was to identify details about dementia carers’ experiences of communication, their views on how communication could be improved, and what barriers stood in their way. Ideal for this sort of project are analytic approaches that can capture complex ideas and show how they relate to each other. One such approach is reflexive thematic analysis, which operates by generating ‘themes’ representing broad and overlapping ideas. This method accommodates both similar and contrasting ideas between participants (Braun & Clarke, 2014, 2019) and takes into account both deductive and inductive interpretations of the data, where the former relate to theoretically driven interpretations, and the latter to understandings driven by the data (Braun & Clarke, 2022, p. 10). These characteristics match those outlined in section 6 as necessary to produce answers to the research questions. Moreover, as pointed out earlier, interview research in linguistics benefits from reflexive accounts (Mann, 2010).

Alternative analytical approaches that were considered included discourse analysis (Lupton, 1992), which could inform the emotional and ideological reasoning behind participants’ accounts, but not necessarily marshal the individual comments to reveal broader ideas across the data set, as required for answering the research questions, and Framework analysis (Gale et al., 2013). Like reflexive thematic analysis, framework analysis constructs ‘themes’. However, this framework was less suitable because of two design features that risked it being overly deductive for the purposes of this study: (1) codes from one transcribed interview are automatically applied to all remaining ones, even though (as discourse analysis demonstrates) people do not always mean the same things when they use the same words; (2) participant data are summarised (Gale et al., 2013; Parkinson et al., 2016) which was not necessary here, and could remove important details.

The reflexive thematic analysis framework contains six phases: (1) Familiarisation with the data; (2) Generating initial codes; (3) Generating themes; (4) Reviewing potential themes; (5) Defining and naming themes; and (6) Producing the report. In what follows, I will outline the recommended procedures for each phase, and how I approached them.

Familiarisation with the data (phase 1) was achieved by listening to all recordings, and reading all transcripts multiple times. Following this, codes were assigned to all information potentially relevant to the research questions (phase 2). The codes assigned to the data were both semantic, which referred to overt statements made by the participant (e.g., ‘frustration’ coded for the statement ‘I get frustrated that I cannot redirect him’), and latent, which referred to a researcher-derived understanding of underlying processes or implicit ideas (e.g., ‘controlled mentalization’ where a carer mentions actively reflecting on a specific behaviour) (Braun & Clarke, 2022, p. 57; Braun & Clarke, 2013, p. 207). All excerpts that were assigned codes were compiled in a separate document, organised by participant ID, so that comments and participants could be matched. This document was reviewed multiple times. Where codes were altered, they were assigned an additional comment. Altogether, the coding was reiterated multiple times, which is necessary for acquiring sufficient understanding of the data (Braun & Clarke, 2022, pp. 70-71).

To identify themes (phase 3), the document containing the excerpts and codes was printed out, placed on a big surface, and reviewed extensively by the researcher, making notes on the document, and in a separate notebook, to keep track of the analytic process. As a result, multiple separate digital documents were created, containing codes with overlapping meaning. Each document was reviewed multiple times and ultimately assigned descriptions that captured characteristics shared by the various sets of codes, that is, generating initial themes (Braun & Clarke, 2022, pp. 79-81).

These documents provided the basis for phase 4 and 5, which concerned exploring potential analytic interpretations of the data, and ultimately deciding on how all themes together constituted an overall analysis that could answer the research questions underpinning it (Braun & Clarke, 2022, pp. 108-110). The finalised definitions and named themes and subthemes are presented in chapter 7.

6.5 Coding and Analysis – Focus groups

Stewart and Shamdasani (2015, chapter 7) state that “the nature of the analyses of focus group interview data should be determined by the research questions and the purpose for which the data are collected.” As described in the introduction to this chapter, the research questions driving the focus group study were partially derived from the outcomes of the interviews (see chapter 7) and used different approaches, in order to benefit from that starting point. For example, the questions used in the focus groups more directly examined the salience of the two theories underpinning EC, namely, Mentalization and the Communicative Impact Model. One angle was how 'social reserve', as part of Wray's (2020) CI model, was impacting on carers' experience of communication. Given these differences, an analytical framework was needed that was suitable for linking participants' comments to theoretical constructs. Meanwhile, in contrast to many focus group studies, no analysis was needed of how the focus groups generated opinions, e.g., by analysing co-construction of messages (Smithson, 2000), or what ideologies or processes could be extracted from the participants' individual discursive patterns (Doody et al., 2013).

One deductive analytic framework that fit the purpose of the study, guided by research questions, was Directed Content Analysis (Hsieh & Shannon, 2005). The goal of this framework is to "validate or extend conceptually a theoretical framework or theory" (Hsieh & Shannon, 2005, p. 1281). This framework is useful where a theory can suggest specific key concepts relevant for informing the answer to a set of research questions. These predetermined key concepts will, at the beginning of the analytic process, constitute what information is relevant to code in a dataset. Directed Content Analysis has been suggested as particularly useful for investigating qualitative data related to healthcare due to the framework being strictly guided by research questions, but offering flexibility in reporting relevant factors to the research questions that were not identified in preparatory phases (Elo & Kyngäs, 2007). The combination of priming topics coming into this study, namely, the two theoretical models and the findings of the interview study meant that the Directed Content Analysis was a good choice (though see the Limitations section in chapter 10 for some caveats).

Assarroundi et al. (2018) review how directed content analysis has been used in the literature. They suggest that good practice is split into three phases (consisting of 16 steps altogether), which are 'preparation', 'organisation' and 'reporting'. In the first phase, the study and data are prepared for analysis, e.g., establishing research questions, gathering data, and data transcription. I outline how I approached this phase in section 6.3.2. In the second phase, the data are organised. The authors suggest developing a 'categorisation matrix', which outlines the categories most helpful for organising the information needed to answer the research questions, and from this, pre-determining what characteristics in the data warrant coding to this end.

Following this, relevant identified data extracts are matched to the main categories outlined in the categorisation matrix. Data extracts that are particularly clear examples of categories in the matrix are marked. Where potential new categories are identified in the data, not anticipated from the chosen theoretical frame, they are added.

Some reflections (i.e., a ‘Reflexive Account’ (Braun & Clarke, 2022; Braun & Clarke, 2019)) of the advantages and drawbacks of the chosen analytical approaches are offered in Chapter 10, section 10.3.

Chapter 7: A snapshot of what communication strategies do: interviews with family carers in England and Wales

The data for this first study consists of 20 interviews across two settings. Ten participants had taken an EC course and lived in the Greater Manchester area (GM), and 10 had not undertaken EC and lived in (Cymru-)Wales (CW). In the GM sample, six participants provided care for a parent (GM0611 cared for both parents living with a dementia), one was caring for their grandmother, and two for their spouse (see tables 7.1 and 7.2). In the CW sample, seven participants cared for a parent, one for their grandmother, one for their spouse, and one for a neighbour. The length of the interviews ranged between 41 and 78 minutes, with an average of 58 minutes. In the GM sample, the total length of all interviews was 595 minutes (9 hours and 55 minutes), and in the CW sample 614 minutes (10 hours and 14 minutes), making the total duration of all interviews 1209 minutes (20 hours and 9 minutes).

Table 7-1: Participant Characteristics Greater Manchester

Participant	Relationship to PLwD	Type of dementia in PLwD	Interview Length
GM1101	Granddaughter	Alzheimer’s Disease	64 minutes
GM1103	Daughter	Lewy Body	70 minutes
GM1104	Daughter	Alzheimer’s Disease	52 minutes
GM0201	Daughter	Mixed Alzheimer’s Disease and Vascular Dementia	61 minutes
GM0202	Daughter	Unknown	55 minutes
GM0203	Spouse	Unspecified - associated with Parkinson’s Disease	54 minutes

GM0302	Son	Mixed Alzheimer’s Disease and Vascular Dementia	48 minutes
GM0303	Partner	Alzheimer’s Disease	60 minutes
GM0306	Spouse	Vascular Dementia	58 minutes
GM0611	Daughter	Vascular Dementia (mother), Alzheimer’s Disease (father)	73 minutes

Table 7-2: Participant Characteristics Wales

Participant	Relationship to PLwD	Type of dementia in PLwD	Interview Length
CW0201	Neighbour	Unknown	51 minutes
CW0202	Wife	Alzheimer’s Disease	66 minutes
CW0501	Daughter	Mixed Alzheimer’s Disease and Vascular Dementia	78 minutes
CW0502	Daughter	Alzheimer’s Disease	57 minutes
CW0503	Granddaughter	Unknown	55 minutes
CW0504	Daughter	Alzheimer’s Disease	65 minutes
CW0505	Daughter	Mixed Alzheimer’s Disease and Vascular Dementia	54 minutes
CW0611	Daughter	Mixed Alzheimer’s Disease and Vascular Dementia	76 minutes
CW0711	Son	Mixed Alzheimer’s Disease and Vascular Dementia	41 minutes

CW0712	Daughter	Mixed Traumatic and Lewy Body	71 minutes

The study set out to answer the first two research questions presented in chapter 6, namely:

1. What do family carers in Greater Manchester and Wales say that they need in order to improve communication with the person they are caring for?
2. What carer-identified factors enable or prevent carers acquiring skills/strategies/knowledge about how to realise improvements in communication?

In line with Braun and Clarke's (2022) guidance, the reflexive thematic analysis used in this chapter is explicitly oriented towards these questions. In this chapter, the information addressing the questions will be essentially descriptive. A more interpretative approach to the answers will be provided in chapter 9, where the findings of both studies are interpreted in relation to the theoretical frame.

A persistent challenge in qualitative analysis is reliability. In quantitative research, a common solution is to use more than one rater and aspire to a high inter-rater reliability value. However, McDonald, Schoenebeck and Forte (2019) found that in qualitative research the use of multiple raters is relatively uncommon (one in nine of the studies they researched), and for valid reasons: "[Inter-rater reliability] can be confusing because it merges a quantitative method, which has roots in positivism and objective discovery, with qualitative methods that favor an interpretivist view of knowledge" (p. 72:2).

As they point out, where fine-tuned qualitative judgements are concerned, neither differences nor consensus between raters guarantee accuracy. Arguably, in practice, the rater likely to make the most insightful judgements is the one with most investment in, and familiarity with, the data, provided they approach the analysis with an open mind and with research questions that can be answered successfully in more than one way.

Were another rater used, any disagreements would prompt a return to the data for another look. On that basis, the approach taken here to ensure reliability and consistency was for the sole researcher to code the data more than once, and to return regularly to it to check the judgements still seemed valid.

The interview accounts generated five overarching themes. A theme is defined as a broad, complex idea, where participants may have similar, or contrasting ideas (Braun & Clarke, 2014, 2019). The five themes generated were (1) Communication Difficulties (2) Desired communicative outcomes, (3) Opportunities for communicative change, (4) Strategies for alleviating communication challenges, and (5) other factors causing communicative breakdowns.[21]

Before exploring the themes individually, it is useful to give an overview of the data as a whole. The coded ideas that underpinned the themes were broadly similar across the two participant groups, suggesting that the carers had more in common than differentiated them. Overall, 537 comments from the interviews were coded (many in multiple ways), with three-quarters of them (347) being split relatively evenly between communicative difficulties (theme 1) and strategies (theme 4). The first theme, related to communicative goals, was generated from 94 codes whereas the second theme was the smallest, and only has 50 comments associated with it. Some participants contributed many more observations relevant to the analysis than others. This seemed, impressionistically, to be because they were more attentive to the purpose of my questions, while others preferred to talk generally about their experiences, without much attempt to directly address the topics.

Overall, comments that were coded for the themes most closely associated with the EC content were more likely to be provided by the GM group, who, of course, had recently completed EC. However, the Wales-based participants also had insights to offer across the full range of topics, indicating that EC probably builds on ideas and beliefs that carers are already somewhat familiar with.

I have not attempted to make generalised claims in this chapter about differences between the two groups, tempting as it might seem to do a ‘before’ and ‘after’ comparison of CW and GM participants. This is because the data, being rather nebulous, were not suitable for the quantification that such a comparison would require. Without the ability to count up how many

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[21] The fifth theme contains little data and mainly consists of quotes that do not fit into other themes but are related to communication. This theme will not be directly presented in this chapter because the content does not contribute to the narrative in a significant way. However, examples from this theme are used within the rest of the thesis as and when they are relevant.

times one or another sort of viewpoint was held (at least, not without extensive inference), the most I would have been able to do is note that there was no directly quotable example of, say, a CW participant expressing an idea associated with EC. Nevertheless, there were instances of GM participants specifically indicating the impact of EC on their perceptions and knowledge, and they are reported in the final part of section 7.4.

As is common with interview data, even contributions that seemed well-aligned with a theme did not always furnish the perfect quote – or at least one that would be meaningful without a lot of contextual notes. As a result, the discussion of the themes below has relied on those examples that were most suitable for the purpose. It does not mean, however, that they alone represent the body of evidence for the point made.

When presenting a thematic analysis, the themes "need to be both fully developed in their own right and in relation to other themes" (Braun & Clarke, 2022, p. 128). Therefore, in what follows, I will briefly discuss the structure of how the themes will be presented.

As outlined in chapter 5, this thesis adopts assumptions of what communication is, and what it is for, from Wray's (2020) communicative impact model. This means that the data presented in this chapter are interpreted within this frame.

Thus, aligned with Wray, I will assume that communication is driven by the ways in which a speaker wants to change their world. Dementia significantly changes the way in which communication is used, both for the PLwD and for the carer. Therefore, to set the scene within which carers formulate the goals that they want to achieve, I will first, in section 7.1, discuss the changes to communication that participants associate with dementia and perceive as problematic (theme 1). These changes are the most likely to impact carers' capacity to achieve their communicative goals, which is the focus of the second theme, discussed in section 7.2. In this section, it will become clear that carers attempt to achieve communicative goals despite the changes to communication that inhibit their attempts.

Before I move on to explaining how theme 3 (opportunities for changes to communication) fits into the account, it is important to mention that theme 4 (strategies) serves as an integrated part of how carers formulate and attempt to achieve their goals. As a result, one often cannot report one without the other. Therefore, 'strategies' that are intrinsically linked to specific communication difficulties (7.1) or to formulating goals (7.2) will constitute part of the account (with explicit marking).

As mentioned earlier, theme 3 concerns the changes that carers felt would improve communication. After having discussed themes 1 and 2, we will know what carers want to achieve with communication, what challenges they face doing so, and some of the ways in which they attempt to circumvent them. We will then be in a position to appreciate what the desired changes are a response to, and why these particular changes are viewed as important.

Finally, in addressing theme 4, having already presented the strategies that carers adopt when presented with communication challenges, I will focus on what carers say drives their choices of communicative strategies. In other words, I will explore how they see specific issues in communication, and the cognitive underpinning that guides how they combat those issues to improve the chance of achieving their communicative goals.

As will become clear, it was not only the strategies that were relevant to more than one section. It was, more generally, difficult to report on the themes without some overlap. My aim has been to manage that overlap rather than totally avoid it, so that, in any one section, the account is comprehensible and rounded.

7.1 Theme 1: Communication Difficulties

The first theme concerns the things that carers perceived to be challenging in communication. As seen in chapter 5, a challenge in communication can be understood as a barrier to a speaker achieving a change to their own world through the agency of another person (Wray, 2020). Under this definition, not all deviations in communication constitute communication challenges. A challenge emerges only where a speaker cannot achieve their communicative goals.

In order to contextualise the findings, I will first briefly recap some symptoms that impact on communication, originally presented in chapters 2 and 3, and, based on existing research, reflect on the likely fit between scientific descriptions of dementia symptoms and what carers tend to talk about. After this, I will report how the participants in this study talked about communication difficulties, and discuss what symptoms they considered to cause challenges to communication, and why.

Many ways in which dementia impacts on communication patterns were presented in chapter 2 and 3. These deviations are related to memory, cognition and linguistic abilities, and are relevant for both language production and comprehension. It is important to state that carers are unlikely to directly report symptoms as the central communication challenge. They are more likely to report the effects of symptoms in preventing them doing things in their lives. This was exemplified in chapter 5 from the work of Small, Gledart and Gutman (2000) who reported that mentions of communication difficulties tended to relate to activities in daily living that rely on interaction. We also saw that carers and PLwDs experienced changes in their relationship and respective identities, which Cooper and colleagues (2021) suggest is often a result of difficulties in communication.

In relation to memory, it is important to distinguish the technical term 'memory' from the way a carer is likely to talk about it. Whilst the term 'memory' includes – amongst other types - working, semantic, and episodic memory (see Baddeley et al., 2020), most carers associate the term 'memory' with only episodic memory, for example, not remembering a specific event, or not recalling what has been said earlier in a conversation (even though this is not necessarily strictly episodic memory by definition). Problems with semantic memory and working memory are more likely to be indirectly invoked, through the way they affect the PLwD's capability to participate in communication. For example, a carer might say that a communication problem comes about because the PLwD does not understand what a specific object is anymore (semantic memory) or struggles to keep track of multiple things at once (working memory).

Much literature that describes linguistic issues associated with dementia focuses on the mental lexicon. Two widely reported issues are (1) the speed and accuracy of matching lexical units to concepts (Bayles et al., 1992), and (2) the knowledge of concepts altogether (Reilly et al., 2011, pp. 341-344). Arguably, some of these symptoms are associated with memory impairments, albeit in relation to semantic and working memory. However, it is unlikely that a carer would utilise such terms. It is likely that carers would mention linguistic issues as problematic where an interaction depends on a PLwD successfully retrieving or comprehending specific words.

I will now turn to how the participants described issues that impact on communication. This will provide the framing for seeing how the succeeding themes in this chapter interact with each other. In line with the observation earlier, that strategies, despite being a theme in their own right, cannot easily be separated out, in what follows, I will first point to aspects of communication that carers perceive difficult, and then, where applicable, illustrate techniques (i.e., strategies) that carers adopt for modifying or circumventing them.

7.1.1 What are the issues in dementia communication?

Reported by all participants in some way, the most frequently mentioned manner in which dementia impacted negatively on communication was that the carer could not understand the PLwD and vice versa. In the broadest sense, GM0202 comments “it can be almost [like the PLwD is] speaking a different language [in] that the words just don't, they're all a bit of a jumble”. This experience is shared by GM0303, who states that “I have absolutely no idea of what he is saying so you just tend to agree … if in his mind, you haven’t answered correctly you can tell because he tends to go a bit off.”

These comments chime with Nguyen et al. (2022), who found that disrupted linguistic capabilities were one of the most common symptoms that carers perceive challenging in everyday communication. GM0611 and CW0503 further this notion and provide reasons to why such linguistic barriers constitute a difficulty: “she knows me and she remembers stuff, but you can't … have a proper conversation with her” (GM0611); “She gets confused as well … she'll ask a question and you explain something to her. She's not able to understand that … she struggles to follow what you're saying” (CW0503).

For GM0611, the issue likely lies in the linguistic and cognitive factors that underpin the capacity to *have a proper conversation*. Even though she does not elucidate what those factors are, it is possible to infer some common processes that are likely relevant for having a ‘proper conversation’, such as the capacity to retrieve words, and working memory for using words appropriately in a given context. CW0503 points to a similar issue and specifies that the PLwD’s struggle to retain linguistic and contextual information is undermining communication.

In a similar vein, CW0712 has experienced many instances in which her father does not understand her, which has led to avoiding some topics altogether “I don't … tell him about my day … because I don’t think he understands what I'm saying”. I will now turn to some strategies that the participants mentioned using to directly manage these kinds of issues. Then, I will turn to how memory impairments can constitute challenges to everyday communication.

Almost all participants reported ways of minimising the impairment to communication that such difficulties entail. Generally, the carers recognised and accommodated the changes to language comprehension in the person that they care for: “it is that realisation… that the level of comprehension is going to deteriorate and that you have to adjust things to be simpler” (GM0302). As for their own comprehension of the PLwD’s impaired output, in many instances, carers had to look beyond verbal language for information: “I know if she wants the toilet she can't tell me, but I know it from what she does and how she moves, that she started to get a little bit agitated” (GM0611). GM1103 has a slightly different view, suggesting that comprehension can often be improved by working harder: “if she was trying to say things [that are difficult to comprehend], you know there's always that either you you've missed it because you've been busy doing other stuff, or I'm not … really listening enough.”

The examples so far have focussed on linguistic issues associated with problematic communication, and strategies that carers adopt to manage them. However, other levels of challenge to comprehension were also identified. CW0201 comments “I think she has trouble keeping hold of the context of the question or the conversation and then by the time she's processed it and then said it back to that person, she's lost the thread.” Retaining information was also mentioned as problematic by CW0503, who reports telling her mother: “you can find out what day it is by looking at your calendar”, from which we can infer that her mother frequently asks what day it is. CW0503 continues: “it’s almost like she’s has forgotten what the concept of a calendar is, so she both forgets that she has one and forgets that she can use it to help herself.”

CW0503 is focussed on the problem being either (1) diminishing knowledge of the concept of ‘calendar’, or (2) her mother not remembering of to use a calendar. As a result, her search for strategies revolved around finding a method for her mother to independently identify what day it is. We will see in later chapters how carers can inadvertently blind themselves to other explanations and strategies by not being able to stand back enough. In this case, it could be that her mother is really trying to communicate something else, such as a need for reassurance and orientation (e.g., because she is worried about missing appointments), and is asking what day it is for that reason.

An inherent factor in the quotes above, that bridges communication difficulties and specific symptoms, is memory. The ways in which memory impairments can be disruptive to communication was variously reported by 16 out of the 20 participants. For instance, GM1101 states: “so a lot of the time now she's struggling uhm with where she lives so … if somebody says, ‘oh where do you live now?’ she's saying her old address”. We would typically consider our address to be lodged in semantic memory. However, it is possible that GM1101’s grandmother cannot recall any events that are related to her current address, or moving from her old address. If so, the issue could reflect difficulties with her episodic memory. If you can only remember events related to an old address, why would you provide a different one? But a third explanation could be linguistic: that the old address is strongly imprinted as a formula in her lexicon, easy to retrieve as the response to that question, while a more recent address, much less often rehearsed, would not be stored holistically in such a strong form, if at all. Whilst providing an inaccurate fact, such as the wrong address, is not a problem on its own, CW0201 draws together how impairments in episodic memory can trigger negative emotional outcomes for the PLwD: "mum, tell [me] what you did yesterday … she can't remember what she did yesterday, so I think she instantly thinks 'ah shit what did I do yesterday? I must have done something wrong what have I done wrong?' so we're off on a bad foot."

Something that is important to point out in relation to CW0201's comment is that the PLwD's memory impairment only seems to be become problematic when she is confronted by her memory limitations, even if it was not the carer's intention to mention them. If so, then one could argue that the issue lies not with the PLwD, but with how the carer manages impairments to memory. Indeed, even talking about memories which ought to be solid ground for a conversation can be challenging for carers. GM0303 comments, "it's hard to start a conversation without saying *do you remember when."* This example indicates a practical difficulty that carers can encounter – the past would be an excellent topic of conversation, but only if the PLwD is able to harness the necessary memories. The impact on carers can be deeply emotional, if they need to connect with the PLwD about certain events, and cannot.

This latter point is also illustrated by CW0611, who wanted to discuss memories by looking a picture with her father: "many … pictures are really painful for me because I remember what was happening at the time … my father can't recognise … the people in the pictures, even though it's him and my mother and me and my sister." Here, it can be inferred that CW0611 is showing her father pictures of family despite knowing that he cannot recognise them. It is likely that the underpinning reasons for this are related to wanting her father to remember the events displayed in the photos, and that his memory impairments constitute barriers for doing so. In a study investigating how generic and family photos stimulate communication in PLwDs and their family carer, Astell and colleagues (2010) found that PLwDs generally produced less information than the family carer when presented with family photos, and that none of the stories elicited by these photos overlapped between the PLwDs and their carers. PLwDs produced a much higher number of stories in response to generic photographs. The authors suggest that

PLwDs may hold back from commenting on family photos because they recognise faces but fear not being able to identify them. Generic photographs eliminate this risk.

Taken together, the nature of communication difficulties related to memory impairments is twofold. First, participants may be uncertain how the PLwD's memory is affected at any given time. CW0504 states: "my dad knows [that he has dementia] … that there's something not quite right, but he doesn't always remember what it is or how it affects things." Even though he knows that "something [is] wrong…he doesn't always articulate that." It follows then, that identifying what the PLwD can remember (which is an integral part in contextual assessment (Wray, 2020)) often falls on the carer, which, according to CW0504, means that: "you could be starting at lots of different points every time you start communication". The second aspect of memory-based communication difficulties is the restrictions they impose on what conversations carers perceive are available to them. We can infer from CW0611 above that the main challenge to communication is not that her father displays memory impairments in general, but rather, the emotional impact on CW0611 arising from the PLwD not being able to remember *that* memory in particular (I will outline additional considerations of how memory impairments can impact on communication in section 7.4.1).

Fourteen participants recognised that the emotional effects of memory impairments on the PLwD could be managed by general modifications to their communicative practices, for instance: "I'll talk about things that I know my mom will know, so I'll say, oh, the priest was really good today" (GM0202). However, as we have seen, this type of behaviour cannot solve the potentially detrimental emotional effects that memory impairments can have on everyday communication.

To sum this subsection up, we have seen that the challenges arising from linguistic and memory impairments are complex, and often require carers to adjust their communication to navigate both functional and emotional factors. At this point, it is important to make two observations, which set the scene for the next parts of the discussion. First, the way carers approach managing communication in a dementia context can greatly impact on their own and the PLwD's communicative success. Second, the carer's desires regarding what they want communication to do in a given context (discussed in section 7.2) play a role in the extent to which their compensatory strategies can effectively circumvent linguistic and memory impairments. In short, the ways in which carers approach managing communication difficulties can be the cause of communicative breakdowns.

7.1.2 The impact of carers (not) knowing how to respond

It takes two to have a conversation. While the dementia was the cause of carers changing their communicative practices, it was not always the reason why communication was perceived as challenging. Certainly, more than half of the participants stated that they sometimes struggled with understanding a PLwD's utterance or behaviour. For example, when CW0504 commented "my dad does certain things that I- I wonder what's going on in his brain", she points the finger clearly at his disability. In a similar vein, GM0611 described feeling uncertain about how to respond to her mother because her mother could not generate responses: "I struggled with … mum because she doesn't always respond and communicate … you sort of think sometimes you're having a one-way conversation and that's how I felt at the beginning [of the dementia trajectory]".

However, often, the carers blamed their own inability to respond appropriately. GM1101 relates a conversation with her (unimpaired) grandfather about her grandmother, stating: "she [the PLwD] said, 'oh, she's [the dog] got no shoes on' and he [the grandfather] kinda said to me 'what am I supposed to say to that?'" (GM1101). Even though the clear deviation in this example is that something nonsensical has been said, the grandfather's focus is on not knowing how to reply. He seemed to feel that if he knew how to respond, there would not be a problem.

In this example and others in the data, the communicative issue is not attributed to the PLwD's interactional contributions but from the limited choice the carer has for responding to them. In GM1101's example, there are multiple potential factors contributing to her grandfather not knowing how to respond. Perhaps he does not want to undermine the PLwD by pointing out that dogs are not supposed to wear shoes. Perhaps he suspects that she did not mean to produce the word 'shoes', but cannot work out, using pragmatic means, what she is likely to have meant, and so cannot help. In other words, he does not want to induce negative emotions in the PLwD, and by extension, himself.

One way in which changes to communication become an issue, then, is where carers fail to accommodate them. In many cases, carers can retrospectively identify mismatches between their inference and a PLwD's implications: "I keep reminding myself about that oh, you know, my dad's not ignoring me or he's not deliberately misunderstanding" (GM0302). From this comment, we can infer that GM0302, at some point, must have felt that her father was ignoring or misunderstanding her deliberately - since she needs to remind herself that he is not. However, where this sort of insight does not materialise, carers might interpret this type of behaviour in the PLwD as deliberate. In turn, this can lead the carer into responding detrimentally, such as with anger and shouting.

No informants reported any such behaviours themselves.[22] However, four participants provided examples of other family members employing detrimental communicative styles, presumably based on limitations in pinpointing the underlying drivers of the PLwD's behaviour. For instance, GM1103 explains how her stepdad's responses to delusional episodes in her mother have changed over time: "when she [PLwD] has the delusions, he [stepdad] goes from zero to a hundred like that ((claps)) and he gets really angry and shouts at her". However, there was a turning point when her stepdad observed such behaviour was affecting the PLwD. During a family dinner, GM1103's sister was shouting at her mother, who "started withdrawing to herself … she looked sad and she wasn't talking to anybody, and I think it was just because she was constantly getting yelled at and it really upset [stepdad]… he said 'I just don't like watching her [sister] shout at her [PLwD]' and as he said it he looked at me and … I could see the penny drop". From this example, we can conclude that observing undesirable features in others' communication can facilitate identifying aspects of one's own communication with similar characteristics.

In many cases, the participants displayed awareness of what aspects of their communication could invoke undesired effects. This awareness was often used to develop new strategies. For instance, CW0201 comments on avoiding discussing some topics with the PLwD: "no way that you could openly say to her 'listen, [PLwD], you've got dementia' or 'we think you've got dementia' because that would totally devastate her" (CW0201). On the other hand, it was clearly difficult to get out of certain habits: "I go, 'I know what you're gonna say dad' … and

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[22] One way to break through the barrier of informants' reluctance to admit to behaviours in themselves is to give them opportunities to comment on what *other* people do, as reported in what follows. Their ability to identify detrimental actions in others is a signal of their capacity to notice them in themselves, even if they are not divulging them.

actually it's wrong ’cause then I am trying to predict what he's going to say, and that's the wrong way to treat it really” (CW0502).

The context can affect how strategies intended to avoid negative outcomes are employed. In the following example, GM0201 states that her father often experiences stress related to processing new information, and therefore, she adopts a general rule in her own communication: “don’t tell him [PLwD] anything you don’t need to … just tell him things you need to if it’s new information”. Here we can see that the condition GM0201 adopts for breaking her rule of ‘not telling him anything new unless you have to’ is where her father *needs* to know something. Furthermore, in the situations where she needs to relay new information to her father, she engages in the proactive management of anticipated negative effects:

> No point in telling him now, you’re gonna go into the doctors and I’m gonna take you up there for a blood test. What’s that for he’ll, say? And how do you know? And how? How come you’re organising that for me? I just leave it till an hour before, and I say ‘we’re going for blood test in a bit dad we’re going to go up to the doctor’s office’ (GM0201).

Here, GM0201 successfully delivers new information to her father that he needs to know. However, she also displays awareness of her father being likely to experience stress related to processing this information. So, in order to ensure her father receiving this information, while minimising the anticipated negative effects, she finds a compromise by providing this information close to the time it happens. In doing so, she limits the time her father may experience stress. Whilst a strategy like this can decrease the negative effects of communicating important information, it is likely impossible to avoid them altogether. As we shall see in the next section, one reason is that carers often need to manage multiple anticipated communicative outcomes simultaneously.

To sum up Theme 1, the core of the communication issue is twofold. First, dementia alters the way in which an affected individual can communicate. Second, the carer, as the other party in the interaction, needs to figure out appropriate ways to respond. This involves dealing with not understanding, not reacting with frustration and anger, and not creating stress in the

PLwD. All of these changes entail a realisation of the carer's role in the outcomes, and the development of strategies to achieve better outcomes.

Such alterations on the part of the carer are only needed where the carer is dissatisfied with one or more outcomes of the interaction – that is, where they encounter barriers to achieving desired changes to their world (or preventing undesired ones). This brings into the frame the carers' beliefs about what changes are realistically achievable. This is the focus of theme 2.

7.2 Theme 2: Desired communicative outcomes

In this second theme, I will outline the factors that guide the changes carers attempt make to their world using communication. In the data, two main perspectives are offered: what they want to achieve and what impedes their achievement of it. As with the previous theme, this section will also describe strategies that carers employ. Again, I will mark where strategies are part of the narrative to distinguish information related to theme 2 (communicative goals), and theme 4 (strategies).

As outlined in chapter 5, Wray (2020) proposes that communication with others is driven by the speaker's desire to get the hearer to act as an agent in changing something in their experiential world (or preventing a change). Carers want to manage their world in two main ways: achieve outcomes that are directly beneficial to themselves and achieve outcomes that benefit the PLwD, with indirect benefits to themselves. One outcome that is relevant to both is *Quality of Life* (Hockley et al., 2023). Even though it is unclear exactly to what extent communication alone contributes to quality of life, it arguably plays an important role. There are multiple studies reporting improvements to communication being associated with positive changes in quality of life, such as supporting PLwDs to engage in social interaction (Moyle et al., 2015), enabling the PLwD to participate to a greater extent (Fried-Oken et al., 2012) and maintaining the quality of the relationship (e.g., Rippon et al., 2020), which can be characterised by e.g., experiencing positive emotions, and satisfactorily reaching a decision in a discussion. Situations counterproductive to these two outcomes are to be avoided.

The participants talked about what communication should result in, from two different perspectives. The first one was achieving outcomes perceived as positive. The second one was avoiding outcomes considered negative. I will discuss these two perspectives in turn. However, carers' perceptions of positive or negative outcomes could change over time. Therefore, I will also report how participants said that they modified their perception of communicative outcomes in the light of growing experience.

7.2.1 What carers want to achieve

All informants stressed that communication should support and preserve the PLwD's wellbeing and sense of self. They differed to some extent in how they thought this was optimally achieved, but there was a common sentiment that is worth mentioning. It is well illustrated by a comment from CW0201: ”if you sit down and speak to someone that's 80 or 90 years of age, whether they've got dementia or not, the stories they have to tell you about their lives are incredible and the knowledge that they can pass on is unbelievable.” This comment illustrates an underpinning attitude of valuing older people's contributions to communication. As we shall see, many of the characteristics of the communication that carers perceive successful relate to valuing, validating, and empowering the PLwD's contributions to communication, despite the ways in which a dementia disrupts their abilities for making such contributions.

The ideas guiding what outcomes carers perceived important widely resonated with the concept of personhood (Kitwood, 1997) in validating the PLwD and minimising detrimental social effects of dementia on the person affected: “take a step back and think you know … some things just don't matter anymore … get the bigger things into perspective, that my mum and dad are human. They still need that love and attention- that's more important than some other things” (GM0611). Facilitating the PLwD's communication helped sustain agency for both parties: “the things is you still want that strain of conversation … you don't want to feel like a person [PLwD] becomes almost invisible” (GM0202).

The most common priority, reported by 15 participants, was to facilitate the PLwD's achievement of positive emotional outcomes, by enabling them to participate in communication. No informants mentioned expecting alterations in the PLwD's communicative abilities as a condition for optimal communicative outcomes. On this basis, participants approached describing successful outcomes from two perspectives. First, in recognising the PLwD's contributions, they would actively avoid signalling that an utterance was unimportant or incomprehensible, when they could not understand: “it's [the utterance] important to him, it doesn't have to make sense to me, you know" (CW0712); "you might not think it's meaningful, the conversation you end up having, but it will be to them … sometimes we have rather nonsense conversation … but my mum has got something out of it, so for her it's meaningful" (GM1104). Second, the carer practising patience – which, here, is a strategy, given that it is something actively employed to improve communication – was helpful for identifying ways in which they and the PLwD could achieve positive communicative outcomes: "keep patience at the forefront of communications … I guess it's that it's the emotional impact … on everyone that's involved, on the carer and the person, on the other person with dementia, the … person, dementia can't help how they are" (CW0503).

In many instances, positive emotional outcomes were reciprocal. Over half of the informants reported that achieving positive emotions in themselves would often reflect improvements in the PLwD's interactive participation. One reason why was that positive emotional outcomes from communication allowed them to more easily adopt state-like mindsets that would benefit future communicative events e.g., "If you're calm with him … he responds better as well" (CW0712); "so having … patience, listening and putting yourself in their shoes and thinking of that bookcase analogy[23] really worked for me" (GM1104). Participants noted that having some agency over their own emotional state created the conditions for adapting their communication to suit the PLwD's abilities, e.g., "relax and lighten up, [not] make a big issue out of communication … and join them in the conversations where they are at, not where you are at" (GM0201).[24]

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[23] The Bookcase Analogy is an idea developed by Alzheimer's Society (https://www.youtube.com/watch?v=kkvyGrOEIfA). It aims to explain the relationship between episodic and 'emotional' memory in a person living with a dementia. The analogy depicts memory as two bookshelves, one representing episodic memories, which is tall and flimsy, and one representing emotional memory, which is short and sturdy. Dementia shakes these bookcases. The tall flimsy bookcase is more prone to lose books than the short and sturdy one. Therefore, even though a PLwD might not remember a specific episode, they are more likely to retain an emotional outcome. This concept is presented in week 1 of Empowered Conversations (see chapter 4).

[24] Both GM1104 and GM0201 touched on ways in which mentalization can enhance communication, and this will be discussed in depth in chapter 9.

Often, a PLwD cannot remember the content of an interaction, but can retain the emotional outcome (James, 2008), making negative feelings important to avoid. For instance, GM0611 observed that even though her mother often could not remember the content of a conversation, it was important to be mindful of the emotional impact that the content might have had on her: “that’s a big thing for me.” GM0611’s insight – “the big learning” – was that “the feelings and the emotions” are “a different [type of capability] and it is not affected as much.” Similarly, promoting their own positive emotional response to interactions was valued, e.g., “Just enjoy [the] time with them. That's probably- the- it's a hard thing to do sometimes, and tiring, but yeah, enjoying time with them.” (CW0502). It is significant that participants recognised the importance of sustaining their own positive emotions as well as those of the PLwD. If the carer feels positive, it will have beneficial impact on the subsequent interactive events.

CW0504 offered insights about successful communicative outcomes based on her particular previous experience and guided by her perceptions of what communication should do. Earlier in life, she worked as a professional carer, and states that her training made her prioritise maintaining PLwDs’ independence. In caring for her father, she perceives communicative outcomes that empower his autonomy in deciding how he wants to be supported as successfully contributing to retaining his independence. This is exemplified in the following account of asking her father whether he needs assistance in going to the bathroom:

> There is a reason I’m asking him that [wanting to go to the bathroom], and I try to find gentle ways to remind him without being bossy or without saying he can’t do it himself (…) a lot of my training in that [professional care] was … their independence … their own decisions, so I’m very aware that I should do that wherever possible (CW0504).

Carers are guided, then, by broad ideas about what communication should do, when they evaluate the communicative outcomes. In the next section, I will explore this idea further by asking what factors contribute to evaluating the success of outcomes, and how, over time, this learning changes the goals that they pursue.

7.2.2 Learning to change to communication over time

As discussed in section 7.1, the PLwD brings to every interaction certain limitations in their linguistic ability, memory, and processing capacity, which constitute a blanket threat to how successful an interlocutor can be in achieving communicative goals. In chapter 5, I reviewed Wray's (2020) suggestion that any given attempt at communicating a message is limited in its scope for success by how the hearer receives it. This means that carers need to develop a mental map of what goals the PLwD is trying to achieve, how their limitations of expression might affect their ability to express messages appropriate for achieving them, and what it will take for the carer to successfully interpret the message as intended. Similarly, they need a map of how the PLwD is most likely to fail to interpret *their* (i.e., the carer's) messages and thus not be able to act as an agent for them to achieve their goals (Wray, 2020, pp. 261-263). I will expand on this topic in section 7.5, and in chapter 9.

One might imagine that when carers are asked about the things that impede effective communication, they would home in on misunderstandings or failures to align knowledge and expectations (i.e., context) but in fact there was relatively few comments on this. As a result, the data invites a rather sideways approach to exploring this issue, where it is necessary to consider at a broad level the sorts of goals that the carers and PLwDs had, and look at what they talked about in terms of impediments to them. One factor modulating this perception was the carer's perception of their relationship with the PLwD.

Multiple participants reported that they had needed to learn how to avoid unnecessary conflict, something that entails the development of strategies.[25] CW0501 advised carers to "avoid any pressure [that would] make [the PLwD] anxious." This might involve experimentation: "say something and if you don't get any response, … divert or just let it be." In short, she advised against fighting the situation: "Go with the flow, I would say". The idea of 'going with the flow' is recognised in research on dementia communication, and functions as a means of avoiding conflict in communication (Polenick et al., 2020). GM0611 reports what this can look like in interaction:

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[25] This involves adopting new mental states. I will argue in chapter 9 (section 9.1.2) that such mental states in part underpin the extent to which carers can generate communicative impact potential, and therefore constitute an integrated part in what communicative goals carers perceive that they can achieve.

> Yeah, try to just go with it, and don't try to shortcut the journey, so my father gets to a place where he can understand something. He does get there, but it may take him- You know, he may take a really circuitous path to that point. So, in normal conversation you would want to get there. What I try and do now is to allow him to go on his journey, and to go on that journey with him, but then try and bring him back to where he says he feels safe (GM0611).

GM0611 distinguishes between normal conversation, where she might negotiate meaning actively with the interlocutor, and conversations with her father, whom she needs to tolerate taking the long way round to expressing his meaning. This indicates an adaptation on her part that aims to improve the PLwD's experience and avoid unhelpful responses to his style of communication. Likely, this adaptation is underpinned by an attempt to sustain calm in herself. Responses such as stress or frustration will diminish the carer's capability to provide the time necessary for adapting to the PLwD's abilities.

However, this approach was only applicable where the carer's inferences about the PLwD's goals aligned with their own ideas of how the world should improve. Sometimes, that was not the case. For instance, CW0504's father needed help but was resistant to accepting it: "he's a very proud man and he doesn't always, well, like accepting help". This was a potential source of conflict because his goal (not to accept help) clashed with hers (to help him). There was risk of a consequent impact on a key goal for her, namely, to sustain a positive approach to her role. If she felt powerless, that would likely have knock-on effects for their interaction. Fortunately, in this case, all she needed to do was sustain her availability to help if he needed her. As he gradually recognised that he could not operate independently, "he accepted it and the fact that he accepted it… really makes me happy because he needs help" (CW0504).

Such conflicts are not always going to be resolved by a change in the PLwD's viewpoint, however, and where they are not, the carer risks a permanent state of failing to achieve important goals. To break this spiral, carers can remove impediments to effective communication by redefining what they wanted out of the interaction. For example, CW0711 commented that "you don't want to take away people's independence", indicating that the desire to empower – or, at the very least, not diminish – the PLwD's independence partially determined what communicative outcomes to prioritise in improving her world. Part of her mental flexibility lay in her recognition that: “we all need help somewhere down the line, and you know, it's recognising that when that point comes”. In the end of this chapter, I will offer ideas to explain interactions between carers’ perceptions of good communication and successful communicative outcomes over time.

As indicated in chapters 2 and 3, communication, and of the sense of what communication should do, is closely linked to the speaker's sense of personal identity and to their perception of the identity of (e.g., their relationship with) the other person. Not surprisingly, then, the question of changes in role and relationship came up in the informants’ responses. Six participants made some sort of comment about how dementia altered their relationship, e.g., “I guess our relationship is changing … I felt like I was helping him as a carer as well as a daughter” (CW0504). Changes in identity and role over time are common for carers, with pivotal points often marked by painful experiences within communication. Cooper et al. (2021, p. 232) show that these experiences, together, can “contribute to the sense that the [spousal] partner was gone”, and, further, suggest that “to the extent that communication constructs the meaning of relationships, its loss also contributed to their deconstruction” (ibid., p. 232). This means that changes the interlocutors’ communicative patterns or ‘working models’ (Collins et al., 2006; Simpson & Rholes, 2012, see chapter 5 of this thesis) enforce alterations in the PLwD’s and carer’s respective roles.

Even though conversations that draw attention to relational changes are unavoidable, it is likely that carers attempt to steer away from them, or only reluctantly engage with them. Carers who experience strong negative emotions in relation to changes caused by a dementia are probably more likely to avoid outcomes that draw painful attention to the situation, resulting in delayed realisations of the extent to which the dementia impacts on communication (Ablitt et al., 2009). For example, CW0505 comments “I think people are in denial at the start, I really do. You know, you don’t want to think [about changing relationships], and it becomes that parent-child relationship, it really flips on its head.” It is inevitable that a shift in roles as extreme as parent-child reversal will affect the patterns of interaction, encompassing what goals are sought, what is viewed as appropriate context for framing messages, what assumptions about the other person’s likely response need to be taken into account, etc.

Taking a step back, the relationship between achieving high communicative impact and identifying of the changing needs of the PLwD is symbiotic. A carer may be extremely adept at adapting their communication to fit the capabilities of the PLwD and be able to use that method to generate information about what the PLwD needs. However, this information is likely unhelpful if the carer cannot then achieve the communicative outcomes that they want. Where they achieve only low communicative impact, the carer can question two things. First, was their contextual assessment sufficient for generating a credible understanding of what the PLwD was trying to convey? Second, did their perception of the PLwD's needs reflect reality? Thus, identifying needs in dementia care is an interactive phenomenon. In the next section, I will turn to this issue, and outline how the carers, wishing their communicative experience was different, looked for opportunities to make changes.

7.3 Theme 3: Recognising opportunities to improve communication

The third theme explores in more detail how carers perceived a need for change in the patterns of communication, if outcomes were to be better, and how they tried to take opportunities to make such changes. Interestingly, these ideas appeared in two forms, both entailing a sense of failure. The first relates to specific changes that participants could not make, but believed would contribute to overarching communicative goals. The second regards communicative changes that participants believed they ought to be able to achieve, but on that occasion had not, for some reason.

In the previous section, I noted that carers' communicative goals often concern reciprocal emotional outcomes. In section 7.3.1 I build on this notion, by considering how improving some outcomes reciprocally can amplify the carer's and PLwD's communicative impact potential respectively. Then, I will address how changes to some interactive characteristics – ranging from specific linguistic issues to overall settings in which communication takes place – could work to improve communication, and how such changes are connected to the PLwD's communicative abilities. I will also address how memory impairments in dementia can constitute grounds for a particular type of communicative need that marks changes in how the carer perceives the relationship between them and the PLwD.

In section 7.3.2, I will consider some ways in which carers' self-reflection capabilities can be useful for identifying needs in the PLwD. Finally, in section 7.3.3, I will touch on potentially beneficial changes made outside of the dementia dyad, e.g., in communication with healthcare professionals. Here, I will also comment on how such challenges differ in England and in Wales.

7.3.1 Better for you means better for me

As noted in 7.2, all participants felt that minimising the direct impact of poor communication would help avoid the secondary negative effects of frustration and disappointment for both parties. But they also had aspirations about what they would ideally see in their communication. For example, CW0501 commented: "to be completely selfish, I would like a little bit more depth in our conversations." Here, she regrets how the interaction is increasingly transactional and functional, and thus less satisfactory than their conversations in the past. CW0712 also wished that things were different: "I suppose it would be nice to work on his- like just being able to do a sentence, I guess it sounds silly but just getting him… to- like you know, once he's had a drink or whatever 'that was nice', I know it sounds silly, but hearing him say something like that" (CW0712). In this example, CW0712 displays wanting feedback of her father appreciating what she is doing, which would confirm that she is accurately evaluating her father's wants, needs, and wishes.

Eight out of twenty participants reported that reducing negative emotions would impact positively on communication. GM1104, for example, commented: "so to make her feel totally at ease with the world would be the one thing I'd want to do, 'cause then half the barriers to having conversations would go". In particular, GM1104 wanted to "get rid of that feeling that she's under threat, that paranoia … because 80% of the conversation is around those … trying to reassure about those threats and those barriers." Here GM1104 construes her mother's distressful feelings as barriers to maximising positive emotional outcomes in communication. Finding ways of manging her mother's anxiety would not just reduce problematic episodes, but dramatically reduce the overall frequency of low CI – where one or other of them is unable to successfully signal to the other what help they need in making a change to their world.

A common strategy for improving a PLwD's emotional state was to engage in joint activities that had generated a similar emotional shift in the past. However, this was not always successful. Four participants reported mismatches between the communication they anticipated would result in a positive emotional impact, because it had in the past, and present outcomes that deviated from this anticipation, for instance: “he’s experiencing something in a way that I don’t understand and I keep trying to work out what the best way is because … I got that from him … I know he enjoys looking at photos, so I want to show him them” (CW0504). In this example, CW0504 cannot achieve a reciprocal positive emotional outcome with her father, and indicates feeling uncertain of the reasons why.

Another participant reported how her husband’s memory impairment was a barrier for recognising that he had children and grandchildren. Even though she, and her family, tried to tell him, they could not achieve an outcome where he recognised them:

> We couldn't get him to accept the fact that [daughters] were married and had grandchildren, and when they used to come over here, I mean he'd be polite but sort of, uhm ‘well, when are these people going away’, you know, and ‘what are you doing that for them for’ (CW0202).

Here, the primary issue is the failure of the family to find a way to use communication to get a desired outcome – the PLwD acknowledging who the guests are and welcoming them. CW0202 feels that her husband’s behaviour is socially inappropriate since other interlocutors expect him to know his grandchildren. This is likely distressing for CW0202 and for her daughters and grandchildren and it could result in the family not visiting as much, which would be an undesirable outcome for CW0202 and her husband. There may be a second even less attainable goal in CW0202’s mind, however. Quite possibly, she really wants to get back the husband who recognised his own family. Her attempts to ‘get him to accept’ that these were his daughters and their families suggests an attempt to restore him to his previous state of knowledge.

As mentioned earlier, the abnormal communicative conditions imposed by the Covid 19 lockdowns co-occurred with this data collection. Therefore, I will dedicate some space to discussing how this crisis impacted on carers’ wish that communicative practices between them and the PLwD would change.

Family members who did not live in the same house as the PLwD often communicated at least in part over the telephone or, where possible, via video-calling software. Covid imposed significant additional pressure on families to set up and sustain this sort of communication. Research into the role of telephone and video[26] in the lives of PLwDs and carers confirms its social acceptance and its versatility for improving and reinforcing social inclusion. However, the potential benefit is tied to individual needs (Ambegaonkar et al., 2021). Topo et al. (2002) interviewed six PLwDs and their families who considered the phone beneficial for staying in touch with friends, family, and healthcare professionals. In one case, a PLwD's mood was reported to positively improve after talking to their children. However, all family carers noted that long phone conversations could elicit irritation in the PLwD, that the ringing sound of the phone could cause confusion or nervousness, and that the PLwDs could feel embarrassed about dialling the wrong number.

Consistent with Topo et al.'s (2002) research, telephone contact was mainly seen as a positive way of allowing carers and PLwDs to stay in touch when it was not possible to meet face to face. However, three limitations were outlined when compared to in-person settings. One related to body language: "there's just so many things missing in a phone call communication wise, you know you can't see the person, there's no body language … everything's got to be gleaned through what he [PLwD] is saying and how he is saying it" (GM0201). The second was tactile communicative markers: "you get a better interaction if you're actually with someone than doing it on a on a phone or on a video screen … it's not the same and you know not being able to give her a hug or … holding her hand if she gets upset" (GM1103). The third was that tele-communication could not generate the same overall emotional effect as face-to-face interaction: "he is not getting that daily love and support that he needs, it's just over the phone and it is not enough for somebody with dementia" (GM0201).

Furthermore, some aspects of telecommunication may exacerbate the dementia symptoms that impact on communication. For instance, if a carer cannot provide practical help with a task, and instead has to explain to the PLwD how to do it, the PLwD might not be able to carry the task out due to impairments in cognition and/or memory. This could lead to the PLwD becoming

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[26] Research into the role of video-calling in dementia care has lagged behind that of telephony, given the relatively recent adoption of video calling in general households, particularly those of the older generation.

less confident about independently carrying out tasks in their home, or using the phone, since it could be associated to negative emotions such as failure, embarrassment, or frustration.

Indeed, interaction over a distance can be particularly complex, with goals embedded in each other. For example, the PLwD might have a goal (e.g., finding a lost object) but need the agency of the carer in achieving it. Since the carer is not there, the carer must generate their own goal of trying to get sufficient information to help the PLwD solve the practical problem themselves – thus getting the PLwD to act as agent by providing more context – and, as already noted, all of this within the constraints of the impairments caused by the dementia.

It is clear, then, that informants saw tele- and video-communication as a poor second best to face-to-face interaction, albeit better than nothing. Just what it is about face-to-face communication that makes it better is difficult to pin down in terms of cognitive or sociointeractional mechanics. What we can see, however, is that the obvious differences between these media – physical presence, opportunity for visual as well as auditory connections, quality of sound, etc. – were playing a major role in how informants evaluated their relative value.

7.3.2 Communicative outcomes as markers indicating how the person living with a dementia perceives the world

As we saw earlier, a PLwD's communicative capability changes over the course of the condition. It follows that PLwDs will often respond to communication differently over time. This makes the carer's capacity to modify their own communicative behaviour central to successfully identifying the PLwD's needs. However, this ability requires carers to actively question their own assumptions. One such assumption regards what communication can do, since this perception underpins the communicative goals that carers formulate.

For example, CW0501 comments: "it [communication] hasn't improved, it's just changed … 'cause I've learned to accept less … I think I've learned to accept the condition, so then my expectations from her are different." The changes in how dementia impacts on communication between CW0501 and her mother underpin what she perceives communication to be able to do.

One inherent part of carers formulating effective goals is identifying where theirs and the PLwD's goals overlap, so that communication can result in high CI for both parties (Wray, 2020, p. 165). A consideration that participants raised in relation to this question was distinguishing between their perceptions of what the PLwD *ought* to think, and evidence informing them of what they *actually* thought. In the earlier discussion of theme 2, this issue was mentioned in the context of outlining realistic goals. In this section, we focus on a different aspect of it: carers' difficulties in making such distinctions. Participants described strategies for trying to develop insights: (1) self-reflection: "I think build in some more skills and tools for self-reflection, cause I think communication is automatically gonna come into that" (GM1101), (2) monitoring whether the carer's communication generated productive output, and (3) the ability to question whether the carer's assumptions about the PLwD's wishes, wants, and needs, reflected reality: "[I had to] learn how to communicate in a way that I can sort of push those things [own assumptions] aside and get to what it is he actually wants and needs" (GM0611). I will discuss the factors that underpin these abilities, and how they can improve carers' communicative impact potential, within the frame of mentalization (e.g., Allen et al., 2008) in chapter 9.

One particular comment illustrates how a carer's developing self-reflection both helped identify the needs and preferences of the PLwD, and challenged her own assumptions about them: "I'd say, well, look dad, you know 'Feel the sun on your face this is lovely', isn't it? Well, it wasn't lovely for him it was- It was me wanting it to be lovely" (CW0611).

Here, CW0611 shows that communication is a key driver in realising that her father did not enjoy the sunshine, even though she thought he might. CW0611 tells her father to do something in an attempt to elicit a positive response, which she does not get. What we see here is that CW0611 deploys the communicative strategy of pointing to a benefit of the sunshine and seeking her father's agreement (I will expand on the drivers of such strategies in section 7.4.2 and 7.4.3). If he had agreed, her statement would have had high communicative impact. When he indicates that he is not enjoying the sunshine, she has, at that level, not gained that impact. However, we can see that she has actually gained high communicative impact in another way. She has put out a feeler, to gauge whether her assumption about what he will like is correct. She has learned that her assumption was incorrect, and, insofar as she is reflexive in her interaction and thus willing to learn, she has achieved her objective. Here, then, we see an example of how interlocutors can improve their wellbeing by pursuing learning goals in their communication that will give them success whenever the immediate goal is not achieved.

One consideration integrated in how carers changed their practices to suit the capabilities of the PLwD was recognising changes in how the PLwD perceived the world. Often, participants were clearly aware of such changes and, as we have just seen with CW0611, needed to change their assumptions, once they became aware that they were inaccurate. Therefore, in addition to modifying their language to suit the capabilities of the PLwD, carers are also tasked with monitoring whether the PLwD's responses challenge their assumptions about how the PLwD experiences their world. This is done through communication.

The final subsection takes a wider view of the carer's experience of communication, by considering what can be learnt from observing others.

7.3.3 Communicative Needs Outside of the Dementia Dyad

In chapter 5, I outlined Wray's (2020, pp. 76-78) concept of social reserve. This concept explains how society can impact on communication for carers and PLwDs. I will not engage with this concept in depth here. However, I will draw on a few quotes from the data that illustrate the role of people outside of the dementia dyad in shaping the carer's and PLwD's experiences of communication, both good and bad.

Two frequently mentioned ideas were related to communicating with healthcare professionals. Seven participants raised issues concerning various aspects of communication in this domain, particularly feeling overlooked as the primary unpaid carer: "I think with medics it it's not just a medical problem, you know, and that they don't, I don't I don't feel that they really take note of the carer" (GM0203), and not taking the PLwD or their symptoms seriously: "I went to the doctor and he said, 'oh we will do a mini mental score thing with him', but he said '[PLwD] you know what a fork is?', and he [PLwD] says 'yeah' and he says 'do you know where to use it' and he said 'yeah', 'well come back when you don't know when to use it'" (CW0712). CW0505 draws on a similar experience where a doctor's communication had a direct negative emotional impact on her mother:

> There was a doctor, I mean obviously was very hectic A&E, and she'd [PLwD] had breast cancer some years ago, and she had this funny rash. And I remember him saying to me, 'oh, that's probably just the breast cancer returned' over her head, with this frightened old lady sat on a chair in a cubicle … I was shocked, actually it turned out to be shingles, so he wasn't even correct with his medical assumption (CW0505).

However, four informants also outlined positive outcomes from interacting with healthcare professionals, for instance, in accessing reliable medical information: “when we had the diagnosis you could ask the doctor there and then we had carers coming in who obviously had experienced the dementia” (CW0711). GM0302 mentioned how professionals could achieve outcomes that a carer couldn’t: “the doctors, you know, if they say something … they carry more authority… I still think he'd be a little bit [hesitant to receiving help], but would accept it because he realised ‘this is for my own good’”.

GM0201, who was not living with her father, reported that being in touch with the professional carers attending her father gave her important information about his wellbeing when she could not visit him. However, she suspected their reports were not fully accurate: “I'm sure he's [PLwD] not miserable all the time and I have good reports from the carers, but then, he's still got enough ability to put on a face for somebody. I see it happen when they come in”. This comment suggests that it might take more than occasional professional visits to truly evaluate how her father feels, given his ability to hide his emotions from strangers.

Another participant highlighted a different aspect of the qualitative difference between what professionals know about a PLwD and what close family members know. Her concern was safeguarding the PLwD’s rights:

> Make sure you’ve got power of attorney for your health and wealth. And so, if there’s a decision to be made health wise, medication wise, you’re making it. Not the professional person making it, so you don’t lose control of that person’s life. Because you just get left behind and everyone’s making decisions for you, but it might not be what you want or what he [PLwD] wants (GM0303).

GM0303 makes clear the importance of knowing a person well, given that the time will come when they cannot communicate their wishes for themselves. She also points to how institutional power differences can be a significant factor in the extent to which a family carer can exercise knowledge about a PLwD to ensure that major choices reflect what the PLwD would have wanted in that situation.

Beyond the frame of healthcare, participants mentioned several ways in which their wider social environment impacted on communication. We can separate out two main scenarios: how others interact with the PLwD directly, and how they interact with the carer and/or disrupt the communicative relationship between carer and PLwD.

Regarding the first, two perspectives are offered in the data. First, GM1101 felt that third persons – whether family members or outsiders – had a less effective communicative style than she had developed herself. She quotes a conversation she had with her sibling about their mother: “that’s your mum, so like I don't understand how you wouldn't want to do something that would improve your communication with your mum.” In a similar vein, GM0203 reported one of the PLwD’s friends communicating in a manner that she found frustrating: “she [PLwD] has a friend who's a total opposite [to friend 2] and who frustrates me no end … I wish she would listen [to PLwD] ’cause she answers for [PLwD] all the time”. The second friend, in contrast, is “really good and they've [friend 2 and PLwD] been friends for a very long time … they spend time just just talking to each other … and she just carries on normal conversations, she has everyday conversations.” GM0203 considers that the reason for these successful conversations is “because they've known each other for so long and I think also because [friend] doesn't try to get [PLwD] to give the right answer” (GM0203).

Participants were aware that outsiders sometimes approached communication in a less intense way, which could be beneficial for the PLwD, as well as giving the carer a rest. For instance, CW0502, who, together with her mother, was providing care for her father, wished the PLwD could interact with more people: “I'd like him to be involved with a few more clubs to help with that communication. To help with just- and even to help my mum.” When PLwDs and carers draw on their social environment as a beneficial resource it is an example of accessing social reserve.

The second type of intervention from outsiders could be more problematic, however. Carers develop a sensitivity about how to handle the challenges of communication, and others coming into the situation might not have the same skills, nor recognise and be sympathetic to the toll that caring takes. Again, CW0502, had a view on this, putting herself, in this instance, into the role of outsider, since she is not the primary carer for her father. She admits to finding it difficult to offer her mother the emotional support she needs as primary carer, particularly when her mother expresses her frustrations: “she needs an outlet to talk to somebody, but we're maybe not in the right frame of mind at that point to hear it from her and it just feels like it's a moan all the time… and it's a really hard thing to be positive about something" (CW0502). Thus, we see that where a main carer has daily challenges, likely to include communication problems, they will bring their frustrations into other interactions but not necessarily get a sympathetic hearing, even when the interlocutor is personally very aware of the pressures they are under. Ideally, carers and third parties would bring a measure of controlled mentalization (Luyten & Fonagy, 2015) to the situation, but doing so is rarely easy or natural. Training and support are thus likely to be helpful (see chapter 9).

Finally, CW0501 brought up that the use of Welsh by third parties was an important issue for carers living in Wales (I will expand on this topic in chapters 8, 9 and 10). In her comment, she makes a point about how accessing healthcare in the medium of Welsh would be beneficial for reasons related to identity:

> Preferably yes, a Welsh speaking carer, you know, because they [i.e., the social workers] say … 'so yes, but does your mom understand, does your mom understand then English?' I said yes of course, she is fluent, you know, she used to teach and everything. She's fluent, she understands, but I'm trying to tell staff at hospitals and things who have no Welsh at all. Well, if you could just get some phrases, it's- because it's more than the language. I can't get them to understand that it's much more than a language (CW0501).

7.4 Theme 4: Strategies

The fourth theme addresses communicative strategies that carers employ to increase the chances of achieving a desired outcome. As mentioned in the beginning of this chapter, multiple strategies have already been mentioned under the first three themes. Those examples have illustrated ways in which carers adjust their language to accommodate dementia symptoms, and how they adapt their frame of mind, e.g., patience.

In this theme, I consider strategies from a slightly different angle, by focussing on their different macro-functions. Thus, in 7.4.1, I consider the participants' approaches for matching appropriate strategies to aspects of communication that are perceived problematic (where many examples have already been presented). In 7.4.2, I look at strategies intended to suppress or eliminate negative communicative outcomes. Section 7.4.3 focusses on how carers learn to fine-tune strategies to the specific PLwD and situation.

The final subsection, 7.4.4, sets the scene for Chapter 8, by drawing out strategies only mentioned by those who had participated in Empowered Conversations. This gives us a snapshot of how EC seems to heighten awareness and offer practical approaches for improving communicative outcomes.

7.4.1 Matching strategies to their intended function

In this section, I draw together the strategy-related observations from earlier in the chapter, as the basis for a discussion. In section 7.1.1 and 7.3.2, we saw three foci for using strategies. The first was aimed at circumventing symptoms of dementia: “you have to adjust things to be simpler” (GM0302). For example, GM0202 would deliberately avoid mentioning events that the PLwD could not recall: “I'll talk about things that I know my mom will know, so I'll say, oh, the priest was really good today” (GM0202). Another aspect of this strategy type, not mentioned in the account thus far, concerns establishing joint attention as a preparatory action: “like the first time you say something to him it's like a prompt to him to to- ‘Oh, I've got to listen to something now’” (GM0302); and “yeah you have to make sure that they’re looking at you when you’re talking because they’re so easily distracted” (GM0303). Although not widely illustrated in the data, this strategy also includes ensuring that background noise is minimised, and limiting environmental stimuli to reduce the amount of information that the PLwD will have to process. For instance, CW0201 noted: “if we’re in a room with lots of other people, she tends to look around. That is a sign to me that she’s just totally lost track of what’s going on” (CW0201). This would be a signal to her that she needed to act.

The second focus was steering away from anything upsetting: e.g., “well, I try and choose a topic about something, usually about something in the past. Events I know he’s enjoyed, people I know he- events- some people I know that he will remember and be able to contribute something to the conversation” (GM0201). Another aspect of this strategy was consoling the PLwD if they were stressed (as we saw in section 7.3.2). The third focus was developmental, where carers questioned their own assumptions and attempted to pick up feedback from the PLwD to help them hone their use of strategies in the future.

So far, I have depicted the strategies as discrete. But now we are in a position to begin conceptualising how they are integrated. One example of this is provided by GM1101, who adopts both the first strategy type (avoiding the impact of symptoms) and the second (emotional protection) when she reduces the speed of utterances: “I'd probably say I do talk a little bit slower, but not like, not a really kind of condescending slow” (GM1101).

The adoption of one strategy could also sometimes compromise another desired outcome. Multiple carers mentioned circumventing memory impairments by avoiding topics that the PLwD potentially could not recall, e.g., asking what the PLwD had for dinner yesterday. However, this strategy could undermine the PLwD’s emotional experience, given that memories and experiences, when they can be recalled, are important. As we saw in 7.1.1 with CW0611 and in 7.3.1 with CW0504, however, even adopting the additional strategy of using photos to support eliciting memories was not always successful. CW0611’s father could not recall information about her and her sister when presented with pictures of them as children, CW0504 could no longer achieve reciprocal positive emotional outcomes with her father when looking at photos, something that had been a common interest for them.

Another strategy for supplementing verbal communication was suggested by CW0505, who mentioned using music as a way of eliciting memories, without risking putting the PLwD into a situation where she could not respond: “I'd play it [music] and then we’d talk about it and maybe we might remember how she used to love country dancing when she was young” (CW0505). Here, CW0505 avoids demanding too specific a content response from her mother. As a result, she creates a wider range of potential for her communicative goals to be achieved by acknowledging that she cannot control what her mother will remember on that occasion. Whilst this strategy may not be efficient for eliciting desired emotional outcomes from *specific* memories such as those important to CW0505, it may lead to generating reciprocal positive emotional outcomes from discussing *a* joyful memory.

The third strategy type related to how carers progressively learnt to manage situations better. One participant gave a particularly clear example of how her communicative strategies changed, and how their outcomes were monitored:

> I still have expectations, I guess that's just way human brains work, but uhm, what my dad needs and needs to communicate to me, is not necessarily what

> I'm expecting. I might be asking the wrong questions, I might not be taking the right approach, uhm, yeah, so I guess if I have more time then I would be able to try more different strategies, types of ways of questioning him, ways of finding out what he still can enjoy, and allowing that to happen (CW0504).

From CW0504's comment, we can identify at least three factors that are relevant to the development of strategies over time. The first is monitoring "*what he can still enjoy*". This shows that CW0504 continuously updates her frame of what communicative outcomes she realistically can achieve relative to the dementia progression. By extension, those potential outcomes dictate what strategies she will use. The second factor relates to how she construes her father's way of communicating his needs. CW0504 is mindful that her own assumptions of reality may not reflect her father's: *"what my dad needs and needs to communicate to me, is not necessarily what I'm expecting"*. The third factor is a strategy for interrogating the extent to which her existing portfolio of options is large enough: *"more different strategies, types of ways of questioning him".* Here, CW0504 points to how relying on previously established communicative patterns may prevent her achieving her goals. Effectively, she is searching for new ways to generate and validate information about her father's perception of the world. I will discuss the psychological underpinnings of this in chapter 9.

7.4.2 Steering the interaction to increase communicative impact

The second strategy type that participants reported was ways of avoiding making communication worse. The ideas discussed earlier were mainly proactive. This means that the carers often considered potential pitfalls in communication ahead of time when employing strategies. The ideas I will discuss in this section are reactive. In other words, they are strategies that carers employed when, in the course of a communicative event, they realised they were not on a trajectory to the outcome they wanted. One example would be the PLwD signalling agitation or uncertainty, which could indicate that the carer's communicative attempt would result in a suboptimal outcome. Often, when this happened, the participants said that they attempted to correct the communicative trajectory by means of 'deflection'.

GM1101 provides an example of markers her mother might display that warrant using deflection: “there are definitely certain topics we avoid and if she kind of touches on a certain topic, we’ll jump to something else and try and change the topic”.

When participants identify markers that indicate an undesired communicative trajectory, they could employ linguistic strategies to divert the person they care for: “sometimes you'll say ‘we've had that conversation let's move on’ and then others it will be ‘really, you think so? Oh well, hopefully not’ and then just change the subject again, and constantly trying to deflect” (GM1104). In this example, GM1104 demonstrates two ways in which she uses deflection. The first is by overtly telling the PLwD that they are repeating themselves, which, although potentially face-threatening and undermining of their self-confidence (Alsawy et al., 2019), is handled with a positive impetus towards a new topic. The second, “really, you think so?”, validates the PLwD’s utterance, but sidelines it, in that GM1104 does not request any additional information about the PLwD’s message. As a form of deflection, this latter example may not work as effectively in terms of changing topics. This is because this response signals interest and indicates the PLwD has provided new information (even though that might not be the case). However, it does reduce the risk of threatening face.

Being mindful of not threatening face was also evident in other forms of deflection. One such method the use of humour, though it was important not to fall into ridicule. CW0201 observed: “You don't have to use humour to highlight the fact she's made a mistake. To skip over it, you just use humour to move her away from it” (CW0201). A difference between CW0201 and GM1104 above is that CW0201 attempts to reduce the risk of exposing a mistake, while GM1104 is more direct about the fact that repetition has occurred, yet without explicitly attributing it to her mother.

However, it is not only the carer who can steer communication to avoid detrimental outcomes. GM1103 comments on her mother using humour to steer the conversation away from a possible mistake: “she will now kind of just laugh and say ‘oh that's my dementia’ like, you know, if she can't remember something” (GM1103).

The markers that trigger deflection strategies presented so far have been in the form of overt statements from the PLwD. Other markers that could alert a carer to use a reactive strategy to avoid negative communicative outcomes were non-verbal:

> I think the key thing is to learn to read their body language. If they don't look like they're relaxed and comfortable, change the topic, because it's normally, it's usually an outward expression of them not understanding the concept that you're trying to discuss with them (CW0201).

The focus of CW0201's quote is on the function of body language as a compensatory form of expression. However, CW0201 also points out that this is something a carer has to *learn*, hence indicating a shift in the ways she gathers and interprets information. This suggests that the way carers construe information displayed by the PLwD underpins the strategies they employ. Then, it is possible to claim that carers' capability to extract information from the PLwD's behaviour, and consider its potential relevance to communication, are core mechanisms for carers' shaping of communicative strategies.

7.4.3 Fine-tuning the selection of strategies

As outlined in section 7.3, and in the preceding subsection, a core aspect of identifying and generating strategies is eliciting information from the PLwD that informs carers of their needs. However, the way this information is displayed is not constant across the disease trajectory, nor static across situations. Therefore, carers need to develop flexibility in the way they select strategies.

In the data, 13 out of 20 participants mentioned ways in which they acquired information from the PLwD beyond the direct linguistic exchange. Effectively, they were combining a range of different information strands to home in on an accurate appraisal of what was going on at this specific point in time and situation. The information they drew on included external markers of mood, for instance: "I like to be tuned into his feelings or whether he's relaxed, happy or whatever, but I don't necessarily get that through what he's saying to me anymore" (CW0611). This kind of tuning in was presented as something of increasing importance when language diminished.

A second information source was an evaluation, using evidence of their memory and cognitive problems, to determine the PLwD's construal of the world, e.g.,: "you've got to find where they are and that's usually about 50 years ago" (GM0201); "go into her world instead of trying to drag her back into ours because she's got no concept of our world" (CW0201). A third information source, built on the second, was to assess how the PLwD's world perception was impacting on how they perceived the roles and identities of their interlocutors. This would inform the carer of what communication the PLwD might expect in that context: "the only sort of question mark in my mind then is he did say that and then sometimes not know me, so I think, who does he think he's saying this to?" (CW0611).

The second and third strategies entail a fine-tuned evaluation, based on the ever-changing state of that specific person who is living with a dementia. For instance, in order to make inferences about a given PLwD's belief about what year it is, where they are, or the identities of other interlocutors, the carer needs to have detailed information of the PLwD's life. Only then is it possible for carers to match cues in the PLwD's communication to this knowledge, and make accurate inferences.

To give one example, CW0712 draws on several factors important for 'tuning in' to the PLwD. She reflects on the age her father believes he is, and how he might perceive her based on her actions in that context:

> He used to think I was his wife. He didn't do anything but he would act like I was his wife because I was the one doing all the care. Yeah, he's called me [mum's name] once because I look like my mum so that was at a stage I think where he was going back into thinking he was probably my age but now he's further back (CW0712).

One aspect of these situations that has not been discussed so far is that the PLwD often displays uncertainty about their perception of the world. This adds an extra layer of communication that carers have to manage. GM1104 mentioned consoling her mother when she expressed concern about her dementia symptoms: "trying to reassure her [mother]", was "a hard conversation to have when she's lucid [but] when she's not lucid ... actually, quite an easy conversation to have because you can just divert it off and talk about something else, but when she's quite with it on the days that she is with it, it's a harder conversation to have" (GM1104). This shows that the extent to which GM1104 could infer her mother's level of 'lucidity' determined her strategy in trying to 'provide reassurance'.

Similarly, CW0501 needed to manage her mother's own perception of her problems:

> I think she realises every now and then what she cannot do so there's a lot of frustration and anger and sadness there, well, you know I'm trying to keep it upbeat and give us some quality of life as far as we can. And she doesn't really admit it but you can read it in her body language you can read it in her eyes. Uhm, she will be head down in her chair (CW0501).

Given the contrast in what information CW0511, GM0611 and CW0712 foreground to make inferences about the PLwD's emotional state, it seems likely that carers are able to select, from among the different information sources (e.g., verbal language, body language, tone of voice etc), those that will provide the most reliable information *on that occasion*. And this raises a consideration with greater potential, namely (as outlined in chapter 5), that carers often do not explicitly process all information available to them.

In section 5.4, I noted that humans generally understand people that they have closer relationships with better than those with whom they do not. In relationships of familiarity, some behaviours that are useful for inferring mental states *in that person* constitutes a 'working model' (Collins et al., 2006; Simpson & Rholes, 2012, 2018). By this logic, carers would primarily base their inferences of the PLwD's mental states based the behaviours that are prominent in their working model. However, as we have seen earlier in this chapter, this does not mean that carers unable to consider behaviours outside of this behavioural set. They will, however, need a measure of emotional reserve and cognitive flexibility to do so (see chapter 9).

In section 7.2, several participants suggested that 'patience' is a useful state of mind for amplifying communicative impact potential. Arguably, 'patience' is a word that is associated with a high level of reflection (controlled mentalization (Luyten & Fonagy, 2015)). Without patience, the scope for accurate inferencing is reduced: "I think sometimes we don't think really. We just act, so we act on what they say and their behaviour" (CW0502). To just 'act', in situations where "we don't think", likely indicates relying to a higher extent on automatic mentalization rather than controlled (Luyten & Fonagy, 2015). However, familiarity, and an accurate working model, increase the chances of an appropriate response even when carers are using less controlled mentalization. This is because the working model is associated with that specific person, and encodes patterns of behaviour that the carer can identify without controlled mentalization, e.g., “I know what his triggers are [for a successful conversation], you know, something about my mother or maybe something about a family holiday we've had or something like that” (GM0201).

7.4.4 Empowered Conversations and changes to communication

In some instances, participants in the Greater Manchester group specifically pointed out how insights developed as a result of Empowered Conversations changing their communicative behaviour. These changes were of two types: things they had learnt to do, i.e., techniques taught in the course, and new ways of thinking, that provided information useful for informing strategies. This latter point applied both to improvements in understanding the PLwD, and in understanding how their communicative approaches could impact on communication.

Three participants commented on the usefulness of a strategy taught in the course called ‘invitation to respond’. In this strategy, the carer attempts to initiate a conversation with a statement or comment instead of a question, e.g., ‘I’m feeling a bit hungry’, where the PLwD is simply invited to respond if they want to.

> Actually, just talking about your experience with something and waiting for what the, uhm, impact or the response to that is, rather than giving a direct question where you have a bit more of a yes no and a bit more of a direct static conversation with someone (GM1104).

GM1104 compares the conversations that invitation to respond can generate to a ‘direct static conversation’ and suggests that this technique is useful in generating new conversations.

Four participants mentioned that the animated videos by Alison Wray (see table 4.1) were particularly helpful for understanding how dementia impacts on communication. For example, GM1103 observed: “the videos that we were watching I’ve found incredibly useful, and I’ve been sharing them with my family … because of the way they were very simplistic, the cartoon style just explaining everything really clearly, I thought that would really help him [stepdad] to understand what she's [GM1103’s mother] going through” (GM1103). Another participant liked how the videos expanded the range of communicative cues relevant for understanding the

PLwD: “I thought the videos are really good … ‘cause it’s obviously not also not just verbal communication, it’s the non-verbal [too]” (GM0202).

Another strategy introduced on the course was empathy: “she [EC facilitator] gave us some really good techniques about thinking of how the mind is when you've got dementia” (GM1104). In turn, empathy helped carers figure out the root of a problem with communication, for instance: “I could be in the kitchen and my mom was in the front room, and I'm saying ‘would you like a cup of tea’ and she can't see me. And then I'm having to, say, ask the question again and I'm getting frustrated, but I'm actually in a different room, so I actually come in now and speak to her, you know face to face sort of things” (GM0202).

Most strikingly, then, the participants who had attended EC had learned the strategy of standing back and actively reflecting on about what might be going on:

> This is from the course actually … when he [dad] doesn't reply, I don't really think he was ignoring me or something like that … he doesn't understand maybe and … everything [perceived by the PLwD] is more simplified really, I think, so that's you know I definitely modified from that point of view. (GM0302).

In the two other cases, participants reported that they could derive emotions from the PLwD’s communication more accurately, for instance:

> she was frustrated … but because she couldn't tell me and say those things it was coming out in this way [frequent negative remarks]. But I just didn't have the the tools to recognise that ... whereas if I'd had those things from that course a lot earlier … I [would have] picked [it] up a lot quicker (GM0611).

Similar insights were reported by GM1104, who noted that EC had helped her with interpreting information in new ways, and so that she relied less on her assumptions: “one of the big things I took away from the course was … not to assume too much and also some things like body language and giving them a reason to contribute to the conversation rather than directing it” (GM1104). This shift in thinking was also mentioned by GM0203: “when you do the

Empowered Conversations you … have to start off from a different place, from the not knowing place” (GM0203). These quotes indicate that EC has shifted the way participants assess their own knowledge as a contextual factor in communication. The concepts of ‘the not knowing place’ and ‘not to assume to much’ tell us that participants consider a broader set of information relevant to communication than what she has considered in the past, which improves the information base that underpins inferring the PLwD’s mental states. In practice, this means that previously automated communicative patterns between them and the person they care for could be scrutinised, and new communicative patterns could be analysed for efficacy.

By questioning assumptions, a carer effectively acquires tools to create and inform *new* assumptions rather than relying on ‘general’ beliefs that they have about the person they care for. Even if this approach does not always end in success, it broadens their range of options, because when carers analyse communicative outcomes by observing what *is* possible, rather than through their pre-existing beliefs about what *ought to be* possible, they can adjust their frame of reference for what successful communication looks like.

What EC appeared to have achieved with the GM participants was a greater flexibility than before, to reflect and build on the communication they engaged in. On this basis, not being able to achieve something that they had achieved in the past was not a failure but a point of learning. They were able to adjust the criteria viewed as constituting a successful outcome as the PLwD’s abilities diminished. For example, where, before, success might have been the PLwD putting on all their clothes before going out, the carer might now recognise that success lay in the PLwD tolerating having their clothes put on for them.

From the comments made by the GM participants about EC, it is clear that the course was beneficial in several ways. First, multiple informants comment on techniques taught in the course that had a direct relationship with managing symptoms of dementia. Perhaps more importantly, several participants commented that they had developed a better understanding of how communication works in a dementia context generally, and, in many cases, with the particular person that they care for. Although the carers residing in Wales did have some of the same insights, they tended to be less focussed and the participants could not talk *about* them in the same way. In chapter 9, I will evaluate the potential for EC to work successfully in Wales, should it be introduced there.

7.5 Low communicative impact and needs in communication

Throughout this thesis, I have made reference to approaching communication through the theoretical lens of Wray's (2020) CI model. In this model, the starting point for all communicative messages is what outcomes the speaker optimally would achieve through the agency of someone else. It is well-recognised in the literature, and shown throughout this chapter, that carers often struggle to reach high CI in a dementia context. As we have seen in section 7.2, and 7.3, successful communicative outcomes are often subject to multiple agendas, and even where there are no functional barriers to communication (see section 7.1), and carers and PLwDs appear to understand each other perfectly, carers can still experience low CI by failing to achieve their goal of protecting, boosting or changing the PLwD's emotional state.

In this section, I will assume that carers attempt to achieve communicative outcomes that they perceive possible to achieve. If they knew that something is impossible, why attempt it? Given that carers accept dementia as the culprit of the changes in the PLwD's communicative capabilities (and not the person who is affected), we can now ask how they navigate the experience of low CI and, indeed, exploit it. I will build on my argument from section 5.4.2 outlining that carers can recycle information associated with low CI. This information guides whether they attempt to achieve that goal again, or recontextualise their perception of what goals are realistically attainable in that context. In section 5.4.2, I also argued that carers can retroactively reevaluate past communicative outcomes against a new frame that determine what goals they realistically can achieve. This means that outcomes where CI previously was perceived low can be changed to high. This lens offers a way towards understanding how carers (still) attempt to improve communication, and find ways to achieve high CI, despite knowing that the dementia will progress, which affects what outcomes they can achieve using communication.

Figure 7.1 (see below) captures the set of interactions between the themes presented in this chapter. However, it also makes an addition, concerning one small part of the entire process of creating communicative impact, by homing in on the feedback mechanism from low CI. In the CI model, the communicative goal is the starting point of communication. But here, 'communicative goals' are both the instigator and the *result* of the process, which is cyclical. Specifically, the model in Figure 7.1 contributes, based on the findings in this chapter, is a new conceptualisation of what people do when they find that they are not achieving their goals using the communicative strategies that they have previously found effective.

In a nutshell, two pathways are depicted. To the left, the speaker's perception of what is possible to achieve reflects reality since they achieve high CI. This process reinforces the future use of the strategies that led to this outcome, subject to a sufficiently similar context. In other words, carers tend to gravitate towards what worked last time (Polenick et al., 2020). To the right, the speaker's perception of possible outcomes does not reflect what they can realistically achieve, which results in perceived low CI. Where the carer experiences low CI, they can draw on this information in three ways, that reflect those outlined in section 5.4.2 (figure 5.1). First, the carer can experience frustration (Morris et al., 2020), second, they can have another attempt at achieving their goal, and third, they can modify their goal retrospectively to fit the current context. However, in describing figure 7.1, I will offer additional considerations to those presented in chapter 5. First, I will consider that carers often pursue more than one goal at a time (Wray, 2020, p. 139). Second, that carers' perceptions of how dementia impacts on communication underpin what adaptations they make to their communication to increase their CI potential. As such, I will discuss how achieving one goal, but not another, impacts on the speaker's overall CI. The following sections will unpack the stages of these processes.

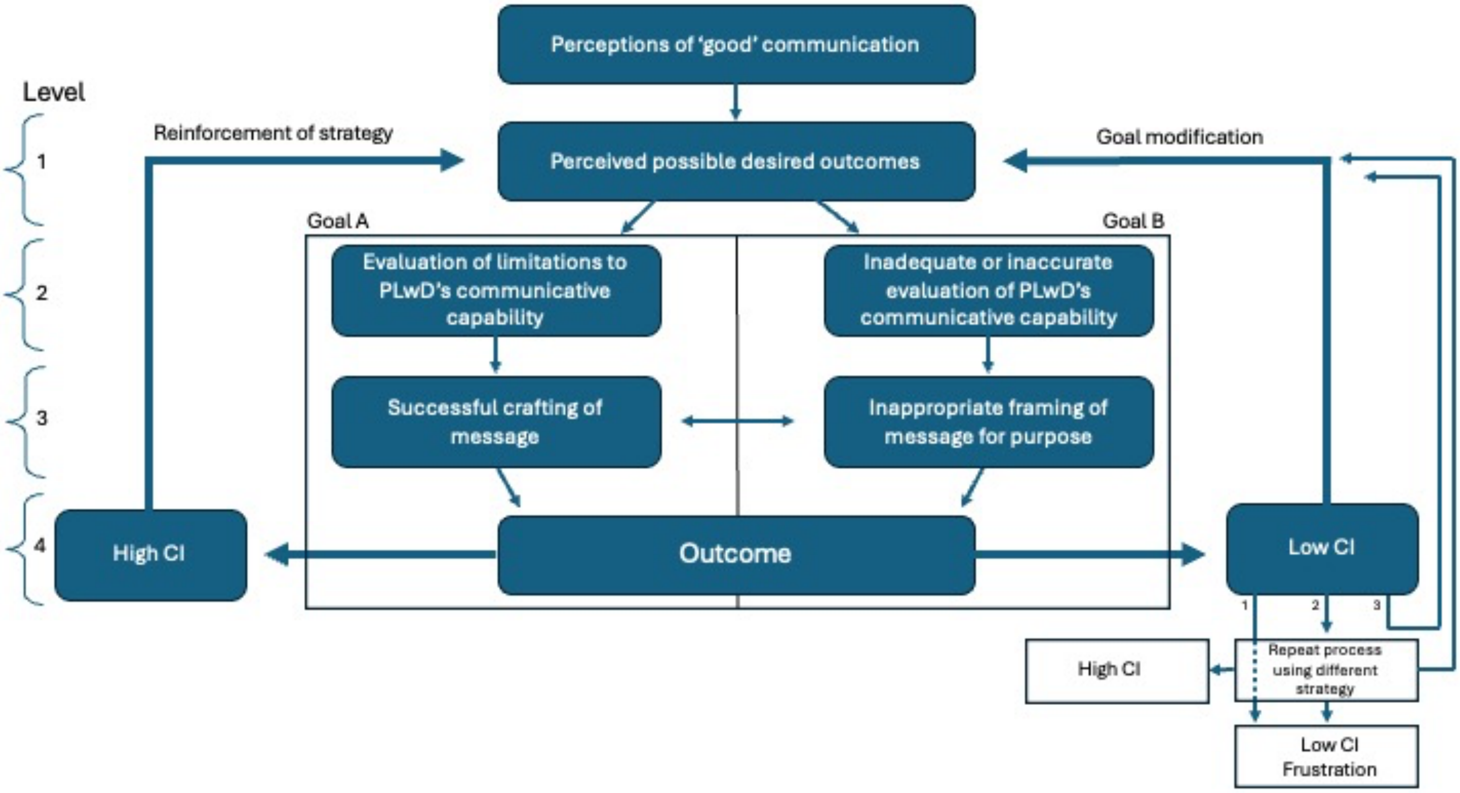

Figure 7-1: The function of interpreting information following communicative impact when pursuing more than one goal

In this figure, carers formulate 'perceived possible desired outcomes' in a context (level 1), which is informed by what 'good communication' should do (see central top modules). These are the speaker's goals, and in this figure, two are tracked (Goal A, which turns out to be successful) and Goal B (unsuccessful). For example, we saw in 7.2 how CW0504, a former carer, was keen to balance assisting her father when he went to the bathroom with letting him be independent, given that he said he didn't want help. She had two goals. At a functional level she wanted to ensure her father could manage. At an emotional level she wanted to avoid him feeling that he had lost personal agency. In this particular instance, she was managing to gain high CI for both goals (left-hand route), by expressing herself carefully, so that her father acted with the desired mixture of autonomy and caution and felt empowered. However, each time she started out to pursue these goals, she would not know if one or both of them would be unsuccessful (right-hand route).

Many goals are certainly (but probably not primarily) other-centred (Wray 2020), and so, we can also recognise that carers have goals relating to their own welfare. For instance, we saw in section 7.1.1 that CW0611 found looking at family pictures with her father painful, because he could not remember the people depicted. One of her goals was to create a pleasant experience for both parties. Even if her father seemed content to look at pictures of people he could not recognise, her own sadness would mean that she experienced (some) low CI from the event.

We now move on to level 2. This level (and the next) are heavily inspired by 'assessing the context' as part of the communication demand management system in Wray's (2020) CI model. In Wray's account, this assessment can be based on any knowledge the speaker has about the world. The focus of Figure 7.1 is narrower, however, as we are modelling, specifically, how carers evaluate symptoms of dementia in the PLwD. First, the left-hand side, 'Evaluation of limitations to PLwD's communicative capability' covers knowledge about how symptoms of dementia are likely to affect the PLwD's communicative capacity in a given context, e.g., what they are likely to remember at that time, or the extent to which limitations in cognitive processing might be problematic in this context. Second, the right-hand side, 'Inadequate or inaccurate evaluation of PLwD's communicative capability' concern what aspects of the PLwD's emotions that the carer perceive could impact on how they receive a message. For instance, we saw in section 7.3.2 how CW0601 thought her father would enjoy being in the sunshine, but concludes: "it wasn't lovely for him … It was me wanting it to be lovely" (CW0611).

In level 3, the carer uses the information derived at level 2 to make alterations to their communication. The left module, 'successful crafting of message' relates to ensuring that the message is linguistically and cognitively adjusted to fit the PLwD's communication capacity. For instance, by accommodating for reduced processing speed: "I'd probably say I do talk a little bit slower, but not like, not a really kind of condescending slow" (GM1101), and memory impairments: "I do try to take him back to nice memories, but I don't do it by saying, 'do you remember'" (CW0611). The right side describes how an inaccurate evaluation can lead to an 'inappropriate framing of message for purpose', e.g., inadequate adjustments related to cognition and linguistics: "she gets confused as well … she'll ask a question and you explain something to her. She's not able to understand that" (CW0503), or in displaying emotional intentions in a way that the PLwD can infer: “and she [PLwD] always felt when I was helping her that I was trying to control her, and so it was very challenging to help somebody who's so fiercely independent“ (CW0505).

In addition to changes made to verbal communication, modules in level 3 also concerns any supplementary information strategies that the carer uses. For instance, playing music in attempting to elicit communication from the PLwD, as exemplified by CW0505 in section 7.4.1. The arrow between the two modules at level 3 reflects the fact that a single utterance is often being produced on the basis of more than one goal (e.g., Wray, 2020, p. 139), so the choices made need to accommodate all the relevant considerations across goals.

Now, we turn to level 4, ‘outcomes’. Here, the carer will gauge the communicative impact of the utterance. Where all goals are achieved, communicative impact is high, and when they are not, the CI may be considered high, low or somewhere in between, depending on the relative importance of the goals. A consistent theme in the interview data was a sense of frustration, sadness or failure when emotional goals were not met, even if more functional ones were. But now we can dig deeper.

Figure 7.1 identifies three pathways, that overlap with those outlined previously in section 5.4.2. First, the carer can leave the situation feeling frustrated, abandoning the attempt to achieve that goal. This is indicated by the descending line emerging from ‘low CI’, numbered 1. For instance, CW0505 states: “if she [PLwD] was challenged, she could get very angry … and that wasn't very pleasant, and I do remember one or two occasions leaving and thinking ‘I'm not going tomorrow’ because it was so difficult.” Second, the carer can retain the goal, and repeat the process using new strategies, which describes line 2.[27] In other words, where a carer achieves low CI, but perceives that the goal can be achieved with a different method, it is possible for them to reach high CI via a different strategy.

The third pathway (line 3 from ‘low CI’) involves modifying the communicative goal, often based on an altered perception of what they can achieve with communication in that context. This will generate a new level 2 evaluation and level 3 selection, since the fit between the new goal and the context must be established and acted upon.

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[27] Technically, the second and third pathways should entail a loop back to the top of the diagram. For clarity, however, the second attempt is represented as a local modification at the bottom.

So far, we have seen how the outcome of a communicative event can be compromised if the carer has unfeasible goals or fails to adequately evaluate the context, so that the message is not optimally formulated. But this model offers us the opportunity to consider two additional factors. First, since carers need a range of strategies for managing unanticipated barriers, a further risk factor for them is not having at their disposal the strategies that they need to do so. A major purpose of the EC training is developing those strategies. Second, there is a risk of low CI if there is a mismatch between what the carer believes is a feasible goal and what turns out to actually be so. While individuals might generally be fairly good at anticipating which goals are possible to achieve, dementia adds a significant layer of uncertainty. Over time, goals that were previously possible may not be anymore. CW0502 experienced this in relation to a material goal: e.g., “I asked him [PLwD] to make a box for my plants, which I thought would be really easy. He really struggled, so now I don't ask him to do those kinds of things” (CW0502). Meanwhile, as we saw in section 7.3.1, CW0501 aspired to more in-depth conversations than her mother could now manage.

In short, the model makes it easier to identify the different potential weak points in the chain that links a goal to an outcome. Instead of only being able to observe that communication failed, we can pin down what failed and why, and, thus, how a change in strategy, or alteration to communicative goals might reduce the risk of low CI in future similar contexts. To illustrate this, let us return to the example of CW0611 finding it painful to talk about family memories with her father because he no longer recalled the family members. The problem lay in a mismatch between what she wanted to achieve and what was possible. We can infer that, as depicted in the right-hand route through Figure 7.1, she gave up the effort, feeling frustrated. However, there were other options too. She could have developed a new strategy and/or modified her definition of ‘success’. A combination of the two options might be to open the conversation up, to elicit from her father comments about anything related to family, rather than pinning it down to the recall of specific events and people. This would not make it any less painful that he had such poor recall of the specifics. However, by widening the scope of ‘talking about memories of family’, e.g., by asking her father much broader questions about their past, she might have been able to (1) generate part of the emotional outcome that she associates with discussing memories of family, and by doing so (2) eliminating the risk for achieving low CI in relation to the prior goal.

To sum up, this chapter has drawn on the interview study data to provide preliminary answers to the first two research questions.

Question 1 was: What do family carers in Greater Manchester and Wales say that they need in order to improve communication with the person they are caring for?

Carers wanted techniques and strategies to help them circumvent barriers to achieving functional and emotional communicative goals. They also wanted support in learning how to reframe their goals, as a means of increasing the success of their communication (high CI).

Question 2 was: What carer-identified factors enable or prevent carers acquiring skills/strategies/knowledge about how to realise improvements in communication?

Carers believed that understanding the PLwD was key in developing improvements to communication, and they linked their emotional reactions and capacity for self-reflection to being able to do so. The participants also commented on how the complexity of pursuing and prioritising several goals at once was a potential impediment to improving their practices. There is more to say with regard to question 2, but it requires an explanation of how carers interpret information from their experiences of negative CI. That explanation will be presented in chapter 9.

In the course of the account, it was also possible to extrapolate patterns at a more theoretical level, and they have been captured in a model of how high and low CI occur (Figure 7.1).

The need for the second study became clear when the interviews had been completed and reviewed: the data were insufficient to address the matter of regional, demographic and/or other factors impacting on carers' experiences with communication. Specifically, due to the travel restrictions of Covid and the temporary suspension of the support services in Powys (a rural part of central Wales, where interviews had been planned), most interviews in Wales had been with participants in the more populated south of the Principality. Thus, there were few accounts describing the experience of dementia communication in rural settings in Wales. Since the central question of this thesis regarded how EC can best meet the needs of carers in Wales, it was necessary to expand the data collection to include views of carers beyond South Wales. For this reason, I augmented my data with targeted input from Welsh dementia carers living in a rural context, with the purpose of placing a more direct focus on their needs. The next chapter reports the results.

Chapter 8: Challenges to communication associated with living in North Wales

In the last chapter, I outlined evidence concerning how and why carers perceive some communication strategies as more useful than others. As part of this discussion, I also noted some differences in how carers approached communication strategies, according to whether they lived in England or in Wales. However, the data from chapter 7 were not sufficient to make any convincing claims in this regard. As a result of the challenges with recruitment during the pandemic, the Welsh participants in chapter 7 primarily lived in urban settings in South Wales and could not speak for the experience of being a dementia carer in other parts of the country. To better understand the experience of being a dementia carer in Wales, I wanted to also access the views of Welsh carers in rural settings. Gathering information from such carers would provide (1) information related to the experience of caring for a PLwD in a rural setting (whether in Wales or not), and (2) a more complete picture of the caring experience for carers living in Wales. In this chapter, I will address these issues by presenting data from two focus groups of carers residing in North Wales. I will answer the following questions:

> RQ 3: What factors associated with living in rural North Wales are prominent for managing communication with respect to people living with a dementia and their unpaid carers?
> RQ 4: What aspects of communication are perceived as important to include in communication training for carers in North Wales?

In addition, I took the opportunity of accessing a new set of informants to expand on my findings with regard to third parties in communication, to ask:

> RQ 5: what successful communication strategies do unpaid dementia carers report having observed when 'third parties' (e.g., GPs, nurses, hairdressers, shop assistants etc.) interact with PLwDs?

In section 8.1, I will present some ideas from the two focus groups (FGs) regarding general challenges in dementia communication. These observations will ground the data, by triangulating to the interviews reported in chapter 7. As we shall see, there is overlap between the ideas from participants in the FGs, and the interviews. On this basis, I will make the assumption that people in North Wales, South Wales, and England do not think fundamentally differently about communication. Therefore, any differences emerging are likely related to their place of residence, and any associated factors.

After this, I will turn to the research questions and start by presenting findings related to how participants felt that living in North Wales impacted on their experience of dementia communication (8.2). These ideas inform research question one. In section 8.3, I will then turn to participants' perceptions of interventions that ought to improve communication, which will inform research question two. In 8.4, I will present some examples of what the informants perceived as successful communicative strategies, related to living in a rural setting, which will inform the third research question. In this final subsection, I will also set the scene for later discussions of what changes could be made to Empowered Conversations for better meeting the needs of carers in rural Welsh settings, should it be delivered in Wales in the future (which will be discussed in chapters 9 and 10).

Table 8-1: Participant characteristics Focus Group 1

Participant	**Relationship to PLwD**	**Hours caring per week**	**Place of residence**
P1	Wife	Full time	Rural
P2	Wife	Full time	Rural
P3	Husband	Full time	Rural
P4	Wife	Full time	Urban
P5	Wife	Full time	Rural

Table 8-2: Participant characteristics Focus Group 2

Participant	Relationship to PLwD	Hours caring per week	Place of residence
P7	Wife	Full time	Urban
P8	Civil partner	Full time	Urban
P9	Daughter	40 hours per week	Semi-urban
P10	Daughter	Full time	Urban

All participants except for one provided live-in care for the PLwD. Seven participants provided care for a partner, and two provided care for a parent. The support centre is located in a town adjacent to the often quite remote countryside in North Wales. Four participants said that they lived in rural settings, four in an urban area, and one in a semi-urban setting. However, this does not reflect the meaning of 'urban' as in the context of living in big cities such as London or Manchester. There are no particularly large towns in that area of Wales, and it is likely that many aspects of living rurally applied to all participants, not only those who state that they live 'rurally'. All participants had to arrange transport to and from the centre, no matter their residential setting, and accessed (for the most part) the same healthcare provision. Therefore, the data from these focus groups will be construed as sufficient for pinpointing the key aspects of dementia care relevant for carers who live in North Wales both rural and 'urban'. The first focus group lasted 71 minutes, and the second 53 minutes.

The participants in both FGs all attended the dementia centre where the data were collected on a weekly basis. During these sessions, the carers and the PLwDs were separated, with each group having a staff member. For the PLwDs, staff organised various stimulating activities that fit the participants' ability to participate, such as crafts, music and games. Activities in the carer group were predominantly focussed on information and social support. Staff facilitated sessions encouraging carers to discuss specific topics related to caring responsibilities and to talk to others in a similar situation generally. Often (as we shall see later), participants found that speaking to each other, and sharing best practice solutions, helped them with communication problems. This means that attending the centre, and the factors that enabled carers to do so, can be causally linked to improvements in communication between them and the

PLwD. In addition, the communication that carers had with others at the centre helped with maintaining their own wellbeing.

In the FGs, participants were invited to discuss four topics: first, if they believed that living in North Wales was associated with any particular challenges related to dementia communication; second, what they thought would be beneficial to include in a dementia communication support course, if one was to be delivered; third, what good communication with the person they care for looked like; and fourth, whether they had observed examples of others communicating successfully with the PLwD. The third topic also regarded what communicative goals they had. They were given eight pieces of paper, each with a communicative goal that the informants in the interviews (chapter 7) had mentioned as important, and asked to decide on an order of importance, explaining why they preferred that order.

The topics just listed were, of course, intended to elicit answers to the research questions, but they were formulated in a manner likely to encourage discussion and surface additional information. In regard to the sorting task, I will therefore not directly report the ‘results’, since getting firm and final decisions from the groups about which goals were more important than others was not the purpose of setting the task. Rather, the aim was to create a basis for discussion, in which participants would come up with justifications from their own experience for why they held a particular view. The eight stimuli are listed in Appendix I.

The questions asked in the FGs were broader than in the interviews. There are three reasons for this. First, FGs do not offer scope to ask each individual participant about their experiences in depth. Second, the participants in the FGs were recruited to supplement the data from the interviews, so the questions focussed on probing areas not previously covered. This augmentative approach was based on the assumption that the FG participants would have similar general perceptions about the experience of communicating with a PLwD. Indeed, participants raised ideas overlapping with those in chapter 7 (see section 8.1), confirming this assumption to be accurate. Third, the aim of the FGs was to generate information relevant to the dementia communication experience in rural North Wales. Therefore, it was appropriate to facilitate a wider ranging discussion, so as elicit responses that related to the interface between personal day to day experiences in the home and the role played by (limitations in) infrastructure, transportation and opportunities for social encounters.

With the last of these considerations in mind, I will interpret the FG findings in relation to Wray's concept of 'social reserve', which is one aspect of her (2020) communicative impact model, the main theoretical perspective of this thesis. For this reason, I briefly revisit here, with reference to relevant research literature, the key features of the concept, as advance markers for the structure of the later discussion.

'Social reserve', which I introduced in chapter 5, is defined "the currency of resilience located in a person's cultural and social context, both local and global" (p. 76). Social reserve is built on four elements, *infrastructure*; *attitudes*; *social groups*; and *social credibility*. For further explanation of these elements, please see chapter 5. Social reserve is relevant to how the experience of communication is shaped on a day-to-day basis. Wray notes:

> Accounts from family members bear witness to the gulf between wanting to add social richness to their lives and the difficulties of doing so if they cannot get care cover, or if they find those they meet to be unsympathetic and lacking in understanding about their needs and their stressful lives (Wray, 2020, p. 80).

In this quote, Wray shows that improving social richness whilst caring for a PLwD can be challenging. Even though carers likely want to retain or improve their, and the PLwD's social lives, there are multiple factors that may prohibit them from doing so. For instance, it may not be possible for a carer to spend time with friends unless they find respite care, or arrange transportation. Even though they may have a rich social network, the potential benefits are rendered ineffective if the carer, or PLwD, cannot access it.

Carers may also, for similar reasons, struggle to access services such as medical or social interventions (Velloze et al., 2022). For some carers, such services are vital for managing the care of the PLwD. A potential consequence of inadequate medical and social support is that the carer increasingly will struggle to meet all the needs of the PLwD. This may present a number of issues related to communication, as a consequence of greater carer stress and carer burden (Petrovsky et al., 2020; Savundranayagam et al., 2005), which also is associated with increased levels of anxiety in the PLwD (Clare et al., 2013).

Furthermore, as pointed out by Wray, there are interpersonal factors beyond the dyadic communicative setting that impact on the longitudinal experience of dementia communication.

Where family or friends of the carer and/or PLwD are “unsympathetic and lacking in understanding about their needs and their stressful lives” (Wray, 2020, p. 80), the communication issues in the dementia dyad may be exacerbated. Therefore, in this analysis, it is important to take into account the carers’ experiences regarding attitudes from people in their social vicinity. As we shall see later in this chapter, people who understand dementia and the caring experience display particularly helpful communicative behaviours towards the carer and the PLwD.

We turn now to the data, which I will interpret by identifying links between Wray’s concept of ‘social reserve’ and the reported experiences of the FGs, who are family dementia carers in North Wales. As already indicated, I will begin by dedicating a brief section to the core similarities between how carers in the interviews (chapter 7) and those in the FGs perceived communication. Recognising these similarities can give us confidence that the *differences* between what is said by participants in the two studies are attributable to their area of residence.

8.1 Common experiences of communication

In this subsection I aim to briefly show that informants in the FGs and the interviews thought about communication in a similar way. This will be demonstrated by presenting a few excerpts from the FGs where participants discuss communication difficulties and solutions to such difficulties that are similar to those reported from the interviews in chapter 7. I will also show that underpinning factors can depend on both their relative’s dementia symptoms, and the carers’ own responses to behaviours in the PLwD. However, where applicable, I will also point to aspects of communication that may have particular relevance to being a carer in Wales.

Multiple participants agreed that dementia can be unpredictable in relation to its impact on communication and that it can negatively affect carers’ capability to carry out day-to-day tasks:

P1: you understand what’s happening and you base your behaviour on how they behave, and you modify things. With dementia you have no idea what the next day or the next moment
P5: It’s trial and error
P1: totally

P5: [to try one thing and if it works it works, and if it doesn't]
P1: [when putting pyjamas on or something]

P1 points out that making modifications to behaviour and communication based on how the PLwD acts is a useful communicative strategy. P1 also comments that symptoms of dementia can make it difficult for the carer to judge how to adapt their behaviour. P5 agrees and notes that they sometimes do not achieve their goals, but that they learn from it by 'trial and error'. In other words, it is only in hindsight that the carer will know whether the outcome of a modification is helpful or not, which strongly resonates with outcomes from interviews in chapter 7. In other words, adopting a 'trial and error' mindset means that information generated from situations where carers experience low communicative impact can be harnessed to reshape communicative goals.

The participants mentioned several symptoms of dementia that can lead to the carer changing their behaviour. The symptoms most commonly mentioned in the FGs were those related to language and memory. One challenge in language was difficulties finding the right word, which is common for a PLwD (Alzheimer's Society, 2021b; Taler & Phillips, 2008):

P8: I mean the thing I don't understand, (husband) will try and tell me something, and doesn't make sense
R: okay
P7: or stops halfway through a sentence
P8: I mean if I say to him, you know 'can you think of another word', he'll go to another language
R: okay
P8: and I find that really strange and he speaks to me in another European language, and then he seems to be able to explain himself better

In this example, P8 demonstrates that his partner sometimes struggles to find words. However, he also points out that even though the PLwD has a strategy for solving this issue when prompted to do so, understanding the word the PLwD is trying to produce remains a challenge. P8's partner speaks multiple languages, some of which P8 cannot understand. Therefore, there are two separate reasons for P8 not understanding what his partner is trying to say. P8 attempts to circumvent the PLwD's word-finding issue, and is, to some extent, successful. The PLwD attempts to 'think of another word' when asked to do so, but in a language that does not makes sense to P8. Therefore, P8 is not successful in his request even though his partner in fact changes the form of a word. This issue may be of particular importance to the Welsh context, even though P8's example does not concern Welsh. In many Welsh households, one person speaks English and Welsh where the other person does not.

At another point, P7 comments that his husband is "starting sentences but he forgets then what he's talking about", and P9, who provides care for her Welsh-English bilingual mother agrees: "I found that with my mother as well."

Of course, switching languages to facilitate word-finding is only problematic when the carer does not understand the language. Indeed, in many family situations worldwide it would be standard to switch between languages to enhance nuance in communication (Myers-Scotton, 2006). In north Wales, it would not be uncommon for both the PLwD and the carer to be comfortable in Welsh and English. Although the same could certainly have been the case for the interviewees (chapter 7), it happens that none mentioned any challenges or opportunities associated with more than one language. Because the UK is a multilingual society, it would not be accurate to claim that the availability or barrier of an additional language is a specific feature of rural Wales, to the exclusion of other places. However, it is a factor that emerged in the data as being associated with north Wales, where Welsh is widely spoken.

Similar to carers in the interviews, the FG participants recognised that not all communication issues can be attributed to the dementia, and that the way the carer acts, and responds, is relevant to communicative outcomes. Often, this was reported through personality traits that carers wished they had to a greater extent, for instance, being more tolerant, which was suggested to decrease negative behaviour, such as shouting:

R: is there anything there which could help how to go about those things when it's just really difficult to know what to do?
P3: [depends on the individual]
P5: [I would like to learn tolerance]
P1: ((laughter)) rescue remedy

P4: instead of just shouting

P5: you know just be tolerant and to su- the memories ((inaudible)) what did you call it, rescue pill?

P1: rescue remedy ((laughter))

Preceding this quote, participants were discussing challenges associated with communication that are difficult to overcome, and what they do to address them. There are multiple important factors mentioned in this excerpt. P5, P1, and P4 discuss 'tolerance'. P1 is referring to the homeopathic medicine 'rescue remedy' (Nelsons, 2024). This may indicate that in his view, there are no particular methods that can provide the 'help' that I ask about.

One situation in which being calm is necessary is where carers' and PLwDs' perceptions of the world differ. In such situations, P9 states, it is important to recognise the PLwD's way of understanding the world:

P9: and I've got to respect that and if she tells me that 'no it's so and so, so and so' then I have to let- whatever I'm thinking, she's got to do

P10: yeah

P9: she has her decision as well. I think that's the big learning curve that I've had to take on board

R: yeah yeah yeah

P9: that she still has got her own self-will at the end of the day

P10: yeah

In this excerpt, P9 indicates that she and her mother can differ in how they perceive the world. Despite this, P9 makes clear that it is important to validate her mother's world view. This is something she has had to learn, which indicates that this approach to communication is a product of her caring experience.

Altogether, there was no evidence in the data of fundamental differences between participants in the FGs and in the interviews in terms of their experiences with communication.

The following account targets the factors associated with living in rural Wales, as this is the only factor identified, within the scope of this thesis, that distinguished the participants in the two studies.

8.2 Challenges in Dementia Communication associated with living in North Wales

Bauer and colleagues (2019) conducted focus groups with carers and PLwDs in rural Australia in order to identify whether their place of residence was associated with any particular support needs. They found that, out of 12 identified aspects of support, the three most important for carers were related to (1) early diagnosis that enables accessing services and information; (2) improvements in training for healthcare professionals so that carers can receive best practice advice; and (3) increased awareness of dementia in the community in order to reduce stigma, and more opportunities for carers to communicate with peers to share best practice advice.

Carers in rural settings often face greater challenges in accessing healthcare and specialised services than carers who reside in urban areas (Campbell-Enns et al., 2023). Such challenges may be related to infrastructure such as what services are available, distances and transportation (Innes et al., 2005; Szymczynska et al., 2011). They can also reflect stigma in the community (Herrmann et al., 2018), leading to potential reluctance about being seen to access healthcare (Szymczynska et al., 2011).

It seems that rural life can have both positives and negatives for family dementia carers. On the one hand, it can shape the nature of the available provision, with family feeling excluded. For example, Orpin et al. (2014), interviewing 18 family carers residing rurally, reported that "primary carers [in this study] are not involving even the closest family and friends in the provision of direct care of the person living with a dementia" (p. 201), because they try instead to rely on professional care. The authors also found that family members and friends provided more assistance in terms of emotional support than practical (pp. 195; 197). On the other hand, carers in rural settings often speak of their community as tight-knit, which generally is perceived positively (Campbell-Enns et al., 2023, p. 14). If these two perspectives both apply, it could mean that in rural settings, the core role of family and friends is to build and sustain a social network. If so, this could be a significant positive benefit to the PLwD, who might encounter many people who are not worn down by the responsibility of daily care. However, the research on dementia carers in rural settings is limited (Campbell-Enns et al., 2023; Innes et al., 2011) and it is important not to assume all 'rural' settings are the same.

In what follows, I will report some factors that impacted on how family carers living in rural Wales experienced communication. As indicated in the quote below, there was consensus that the rural setting does need considering in its own right:

R: do you think there is a difference living in this particular area, than for example living in Manchester, would it be different to provide care for someone living with a dementia?
P 1-5: [everyone agreeing]

All informants believed that the experience of caring for someone living with a dementia would differ depending on whether the carer lived in an urban or a rural setting (note that the focus was on the carer, not the PLwD, who might live in a town or city). As we shall see later, the participants suggested multiple specific reasons for such a difference. However, one factor relevant for dementia care directly related to the residential setting.

Interestingly, notwithstanding the potential assumption that rural locations offer, or have less take-up of, support services, P7 and P10 believed the opposite. Whilst P7 make a general comparison between Wales and bigger cities in England, P10 grounds her perception in contrasting support provision in a personal experience of previously living in London but having moved to North Wales to care for her mother. For her, the dementia centre in North Wales that all the FG informants attended was markedly different from anything she experienced when living in London:

P10: I come from London, I definitely don't think I'd have the same (experience)
P7: The support we have had I think is only here, in Wales. I think Wales is better organised with a lot of things than what you would get in Manchester or in Liverpool or wherever
P10: because I used to go there (dementia support centre in London) when I was-first with mum's dementia, they (memory clinic) … used to tell me to go

to this dementia thing, and I'd turn up and nobody would be there, and I'd be all psyched up, and my first time going (to the London support centre), taking mum, and I go here, and ring (call) the lady (healthcare professional) who was like a 'it's not on' or- it was very unreliable, that's what I found

P7: this place has been a [godsend]

P10: [godsend]

P8: absolutely yeah

Clearly, P10's experiences of dementia support groups in urban and rural settings differ. P7, and P8 emphasise P10's positive attitude towards the social support that she is receiving through the dementia care centre in North Wales. Of course, we cannot infer much from this single comment, about the general level of support for carers in London. Individual centres must vary, along with the personalities of those who run and attend them. Nevertheless, there may be a difference in attitudes towards attending care groups in cities compared to North Wales. Dementia carers who reside in rural areas were found in one study to report a greater sense of community (Herrmann et al., 2018, p. 323), which might contribute to more positive attitudes towards support resources, such as carer groups. This would mean that collective attitudes towards utilising social support are relevant for carers' and PLwDs' wellbeing, and contribute to communication support.

However, there are other considerations that may explain why the support centre (and possibly others) in North Wales was well-visited whereas the one in London that P10 refers to, was not. In order for carers to attend carer groups, they need to acquire information about such services. P10 indicates that she received information about the London support group from healthcare professionals directly involved in her mother's care. P3 found out about the centre by encountering the centre manager in a medical context: "I think I was lucky that (person running the centre) was the first person through the door and we came virtually from the time of diagnosis. Without her we wouldn't be here today" (P3). In both cases, and no doubt others, the centre was ensuring its visibility to carers. Perhaps that would be harder to achieve in a more densely populated place where, ironically, greater choice of provision might reduce the sense that there was a particular place that would be beneficial.

8.2.1 Healthcare access and its implications for communication

A factor directly relevant to healthcare professionals' practices, and how care is delivered to PLwDs and carers, is the organisation of healthcare. The way healthcare is organised directly impacts on how carers interact with healthcare providers, and available services. P3 comments on what is often referred to as the 'postcode lottery' of health provision:

> In (town) on the other side of the blue bridge… it's (healthcare provision) done by (name), so that side of the bridge, it's somebody else, they have a completely different service, and they offer a completely different set of courses (P3).

Often, the participants had multiple experiences of healthcare provision. In addition to the memory clinic that participants had been referred to, their GP was an important gateway for accessing social care:

P1: well, yours is different ((referring to P5)) but you're (with memory clinic), you're (with memory clinic)
P3: no, well yes, I'm (with other memory clinic)
P4: well, I think it (social care provision) depends on the doctor that you see at your general surgery
P3: yes, also at your GP
P4: that's what I mean

Since carers in rural settings may have greater distances to travel to access healthcare services, transportation becomes a vital factor. After all, having access to healthcare provision is of little use unless you can get there – particularly if the only alternative is online support:

P3: if you don't have a computer, and you don't have a driving licence, living with somebody with dementia in Wales-
P5: -is impossible

In urban areas, public transport is often available, whereas in rural areas, accessing public transport can constitute a challenge. P3 states: “you can’t catch a bus here, there aren’t any buses”, and P5 comments: “a bus every three hours, there’s nothing coming back. If you want to go to (town) we’re stranded there, maybe till tomorrow … we have no buses”. Indeed, public transport has been identified as a wider issue in rural Wales:

> For older people in some parts of Wales, particularly those living in rural areas, limited public transport options and reductions in public transport provision mean they must rely upon community transport to access primary health services (Older People’s Commissioner for Wales, 2021, p. 13).

Indeed, the carer’s ability to provide transport for the PLwD was crucial for their wellbeing, especially because the various sources of healthcare were not always in the same place. For instance, P2 made a point of commenting how lucky she was that the specialist *was* in her local town rather than further away: “because if he [PLwD] didn’t have any transport, how do you get there?”

This makes transportation a wider issue. Where carers cannot provide transport themselves, or have access to other reliable transport solutions, they may struggle to benefit from medical and social support. As Wray (2020) points out, such challenges may impact on communication in several ways. First, limitations in accessing social settings and healthcare are likely to create stress. Second, they may impact on how easily the carer can acquire tools to manage dementia symptoms and improve communication. Third, limitations in accessing transport may result in a lower number of social opportunities for the carer and the PLwD altogether. This can increase the risk of carers experiencing loneliness and isolation (Older People’s Commissioner for Wales, 2016, pp. 11; 18; 21; Pinkert et al., 2021), which, in turn, has been noted to increase the risk of negative psychological outcomes such as depression (Snowden et al., 2015). All of these factors will contribute to ‘carer burden’, which has been noted to negatively impact on carers’ perceptions of communication difficulties (Savundranayagam et al., 2005), and may contribute to them responding to such difficulties in detrimental ways (Petrovsky et al., 2020). Therefore, even though transportation is not directly related to communication, it underpins many factors that are.

In the beginning of this chapter, we saw P8 and P9 discussing how the PLwDs they care for sometimes switched languages when trying to circumvent communication issues. P8 points out how this can be an issue where he does not understand the language. This can be extrapolated towards healthcare. If a PLwD who is a first-language Welsh speaker prefers to speak Welsh, where healthcare professionals cannot understand, the communication will be problematic. In what follows, I will outline issues related to healthcare provision in the medium of Welsh, a topic that did distinguish the North Wales FG comments from the interview data.

8.2.2 Healthcare provision in Welsh

Although the laws about the use of Welsh apply equally across the whole of Wales, the preference for Welsh as the medium of choice is not uniform, due to variations in the percentage of Welsh speakers and in how Welsh is used. According to the 2021 census (Welsh Language Commissioner, 2025), while only 17.8% of those living in Wales speak Welsh, two local authority areas in the north west – Gwynedd (64.%) and Anglesey (55.8%), along with the central western area of Ceredigion (45.3%) have a substantial proportion of Welsh speakers. Although, of course, there are speakers of many different languages in Wales (north and south) as well as in Greater Manchester and the rest of England and the UK, only Welsh and British Sign Language are explicitly mentioned in policy regulating healthcare professionals' approaches for providing care in languages other than English (Welsh Government, 2022a).

Only one person (P9) in the focus groups stated that Welsh was the first language of the person they provide care for, and obviously one person's account cannot tell us about the general experience of Welsh-medium healthcare. However, it is possible, at least, to look at P9's account within the context of the multiple examples in the literature of how carers experience accessing healthcare in the medium of Welsh. One source of evidence that there is a problem with Welsh-medium provision is the Older People's Commissioner for Wales' report 'Dementia: more than just memory loss' (2016, pp. 48; 53). Even though "the experience of carers in this respect [accessing Welsh in healthcare] varied widely" (p. 48), "concerns emerged about the lack of Welsh-speaking services available" (p. 53); one participant "felt lucky that the person for whom she cared was not a Welsh-speaker" (p. 53). Even though the need for Welsh-medium healthcare is far from universal, it is important to address the issue, as it can matter greatly to those who would benefit from it.

In the FGs, P9 cared for her mother who is a native Welsh speaker. Even though P9's mother was very proficient in English, she would at times find it easier to mobilise words in Welsh:

P9: she (mother) will forget 'oh I've got to tell you now' … we are bilingual as well, we speak Welsh and English, and you know if she forgets 'oh what's the word for it', 'be 'sa chi'n ddeud' ('what would you say') … Welsh is our first language, so we have a little bit of similarity there

In P9's comment, it is possible to infer that even though she has no problem using the English language, it is sometimes beneficial to speak Welsh with her mother. This benefit would ideally extend beyond their dyadic communication, but evidently that was not always possible.

P9: yes, we have been told that it is possible to have [healthcare in Welsh], but we haven't had as of yet, and that's the same- applies to when we've had home visits from hospital carers, but they can't have a Welsh speaking- somebody to come …
R: okay
P9: that hasn't really come about, it's all been in English

P9's quote strongly resonates with the way participants describe the role of Welsh in the interviews in chapter 7. Even though few participants in the interviews and focus groups spoke Welsh as a first language, or cared for a relative that did, citizens in Wales do have the right to healthcare through the medium of Welsh (National Assembly for Wales, 2011) and its limited availability is therefore a problem.

8.3 Improving communication – the individual and their social context

Multiple participants expressed difficulties in accessing formal training in tasks associated with being a family carer, including communication. In fact, no participants had been offered, or received, communication training. However, the informants identified multiple benefits that communication training could offer. This is the focus of the second research question. In what follows, I will outline some of the factors important to consider if a communication course was to be designed to suit the needs of carers residing in North Wales. The participants displayed two types of general thoughts. The first was improving communication between them and the person they care for, which I will discuss in section 8.3.1, and the second was improving communication with services, including potential benefits from communication courses, which I will address in section 8.3.2.

Some of the information in this discussion comes from the sorting task described earlier in this chapter. The statements capturing what the carers in chapter 7 perceived important, or central to this end were: (a) making the person [living with a dementia] feel positive; (b) creating meaningful conversations; (c) accepting change by adapting to the person; (d) maintaining the person's independence; (e) 'reading between the lines' to figure out what the person really needs and wants; (f) providing reassurance; and (g) making sure you can be empathetic and patient. Thus, the outcomes of this task can serve as a good starting point for understanding what aspects of communication the participants want to improve.

8.3.1 Desired changes to communication in the dementia dyad

In focus group 1, two participants, P1 and P3, thought that 'reading between the lines' was the most important communicative skill for them at that time. P2 introduced a second option, that it was important to display empathy and patience:

> P1: I think this is probably important to me at the moment 'Reading between the lines to figure out what they really need and want'
>
> R: okay

P3: I think ‘reading between the lines’ is the most important for me ((laughter)) because you don’t really know, you don’t really understand, so you have to really read between the lines to know what they are really wanting and needing
P2: G ((refers to item number on piece of paper)), ‘making sure you can be empathetic and patient’
P4: ((laughter)) yeah, because it’s so easy to lose your cool, we’re only human aren’t we
P1: Yeah

Whilst P1 and P3 do not provide any further explanation to why they think that reading between the lines was the most important thing, P2 develops her thoughts on the importance of displaying empathy:

P2: People say, and specialists and doctors and that, ‘walk away and have two minutes for yourself’, try going into the bathroom and just ((big exhale)) calm down, and come back out again and start again
P1: does he follow you around all the time?
P2: oh gosh yeah ((putting head in hands)), (animating conversation between her and PLwD) ‘where are you?’, ‘I’m in the bathroom’

Here, P2 directly relates communication priority to an issue that she is experiencing with her husband. In this example, it is possible to infer that P2 sometimes cannot display the level of patience that she would like. Thus, she seems to believe that improving her patience would improve communication between her and her husband.

In a similar vein, P3 provides a reason to why he thinks some statements are less important:

P3: I’m not so sure about ‘Providing reassurance’ because they forget what you’ve said two minutes later, so you … you’ve lost your temper because she has asked me four times in the last ten minutes the same damn question, and eventually you just turn around and say ‘you’ve asked me that, not again’

P4: I know but sometimes-

P3: you snap, it’s going to happen

R: yeah yeah

P3: but two minutes later, she’s completely forgotten it

In this excerpt, P3 explains that providing reassurance is not as important as the other concepts. Although he concedes that there is sometimes a need to provide reassurance, since frustration in a carer can lead to sharp remarks (Petrovsky et al., 2020), ‘you’ve asked me that, not again’, his experience is that even when he succeeds in providing reassurance, his wife does not stay reassured. What P3 does not acknowledge here, however, is that he may contribute to his wife’s unease. He implies that his wife forgets not only that she has asked a question before, but also how he reacted to it. It has been suggested, however (e.g., James, 2008) that PLwDs register negative emotions for longer than facts, so they are left feeling upset, without remembering why. If it were the case that P3’s wife was left more uneasy because of his snapping, then, in the absence of recalling why he snapped, her approach to gaining reassurance might be to ask the question again. A vicious circle would be created, and the way to change it into a virtuous one would be for P3 to enable her to achieve her goal, by answering her question. Even if she could not retain the information, it could reduce her anxiety level for a while.

Although it is not possible to say whether it applies to P3 from his account, the absence of any reflection on his part about what he says could suggest that his mentalization abilities in that setting are inadequate for avoiding this vicious circle.

In FG 1, there seemed to be a pattern in how the participants chose which statements were important and which statements were not. Where a participant felt strongly about one or more statements, they often linked that statement to an example from their life. Where the statement could function as a solution to improve their communication, the statement was perceived as important. However, as in the case of P3, ‘providing reassurance’ was clearly important to him, but difficult to achieve. Therefore, significantly, he downplayed the importance of that goal. However, this was a goal that he chose to talk about, and he linked it to a real communication challenge that he faces. This suggests that carers might at times filter their perceived options for dealing with problems, so as to sideline anything that appears intractable.

In the following example from FG 2, P8 outlines his choices based on what he thinks good communication should look like, and what he wants to achieve with the person he cares for by means of communication:

P8: I've got 'maintaining the person's independence'
R: okay
P8: as much as you can
P10: yeah I think so
P9: yeah I agree with that as well
R: yeah, which other ones did you, can I have a-
P8: yeah go through them
R: and then you had a 'providing reassurance', is it okay that I'm reading out?
P8: yeah of course yeah
R: 'creating meaningful conversations', and 'making the person feel positive', so very focussed on (partner)
P8: yes
P10: I had the same as you, I've put them in pretty much the same yeah
P8: yeah that's all I've got, it's only the two of us
R: okay yeah m
P8: and I do think, and it has nothing to do- ((chuckles)) I just think I would find it easier if I would have had brothers and sisters
P7: yeah family, if he has got family
P10: I mean I've got a brother and he doesn't- he doesn't really do much to be honest, I do everything sometimes
P8: I just think to myself it must be nice to have brothers and sisters, you know, someone you can fall back on, talk to

Here, P8, in parallel with participants in FG1, states multiple things that he perceives important to achieve through communication, but he also points to the difficulties in achieving these goals without anyone supporting him. Specifically, P8 feels that having family members for emotional support would have helped him achieve his communicative goals with the person he provides care for.

In the same FG, P10 has ordered her statements similarly to P8, but provides different reasons for that ordering:

P10: I'm the same ((referring to P8's order)), so I think the first one is maintain the person's independence, make the person feel positive, provide reassurance, and meaningful conversations, but then hand in hand, you also want to know at the same time how the disease impacts on how you communicate better with them

R: m

P10: And I think obviously, mum- would be the most important to make her feel comfortable, independent, cause that's got to help you in the long run isn't it

In this excerpt, P10 first talks about what she perceives as important to achieve with communication. However, the statements she then chooses to talk about are actually not the ones that she proposes as most important. In fact, she compares all goals to one core need: understanding the way dementia affects communication. This, she implies, underpins the potential to achieve positive communicative outcomes. Thus, P10 follows the same pattern as P1, P3 and P8. In all cases, the statements that they felt were most important were the ones that they could not provide an easy solution to. The statements they spoke about were the ones they could provide an example of, along with either a solution or a pathway to a potential solution. Being able to do this seemed to downgrade the importance of the situation described in the sorting-task statements.

In other words, the carers identified issues that they found challenging, but also produced potential solutions to those challenges. This was an unexpected finding. It is possible that sorting tasks similar to this one could facilitate carers' identification of changes that could improve communicating with a PLwD.

8.3.2 Local support to improve communication

Multiple participants spoke about the benefits of learning how best to engage with stakeholders in the community, to facilitate one or more tasks associated with their caring responsibilities. Here, a primary source of information was peer support and the sharing of best practice solutions:

> P10: I think a top tips, you know what you said, the labelling, what we get from this group is little tips that you can, I don't know
>
> P9: it's sharing best practice, I know that's a bit of jargon thing

Whilst there were few examples of how sharing best practice works conceptually, there was one instance in which sharing best practice was directly demonstrated. In FG 2, P7, P9 and P10 discussed the difficulties of finding a helpful chemist.

> P10: like these blister packs, and I keep going on about uhm tablets and mum, she's got breast cancer and stuff so she takes quite a lot of tablets, and I really struggle to find a chemist who will just give me a blister pack so I just have one less job to do
>
> P7: did you not try Boots at (place)
>
> P10: tried it, had to go to (place) on the Friday, and it's always coming on a Saturday morning, waited 40 minutes to see them … but then when I said that I administer the tablets they said they wouldn't do it, so now I went to the one in the shopping centre, they've got a wait list, I've literally gone around to every chemist, I spoke to doctors, and for me, it's just, I just want one less job
>
> (…)
>
> P9: And I'm lucky like that, although sometimes it can be frustrating, and the chemist I use uhm isn't oh
>
> (…)
>
> P9: is in (place), and it's (pharmacy name) and they do the blister pack, but there are some things they haven't put in the blister packs, and if they run out, then it's up to me to communicate to them

P10: ((writing down information from P9))
(…)
P9: but (pharmacy name) I can only praise them for the help that they give, and I can go through my doctor, put in a repeat prescription, but I can also go into the chemist and say ‘do you mind sorting the whatever is running out’ she’s on another couple of different tablets extra to what’s already in the pack
P10: so (Pharmacy name)
P9: So (spelling out pharmacy name)
P10: where is it
P9: It’s in (place) which is a bit further than (town), it’s a bit far, but there may be (pharmacy chain) in (town)

This excerpt demonstrates how conversations of this kind can provide practical help to carers. This sort of interaction arose incidentally during the focus groups, suggesting that it characterised the kinds of exchange occurring at this dementia care centre. P3 confirms that this is the case: “and that’s what’s important coming to these meetings… I learnt more from the people who had been in the system for, let’s say, a year … than anyone else … and that’s because (project manager) facilitated discussions around the table of this type.” Similar benefits were related to how knowledge in centre staff could be helpful in navigating local healthcare provision:

> That was one of the things that changed in the early days, we had lots of people coming, but since (project manager) got promoted, we don’t have that sort of this-is-what-you-need-to-know, a single point of access for (county), which is, I think it’s (branch of Alzheimer’s Society). None of them have got cards, it’s a phone number in (town), they put you in touch with (local caring organisation), they can do home visits, they’ll assess your living accommodation. (P3)

Indeed, other research has shown that carers greatly value accessing ‘single-point contacts’ who have knowledge about the healthcare infrastructure, and who can help direct carers to appropriate instances (Bamford et al., 2014; Smith et al., 2021).

The benefits from interactions with peers and staff presuppose that there are spaces where such conversations can take place, that carers can make time to attend such social events, and that they can arrange for transportation. Thus, this is not a resource all carers may be able to access, unless via electronic interaction.

Although the participants were specifically asked what they would like to see from a communication course, relatively few of their responses directly addressed that question. It could be that they had little conception of what a good course might actually offer. What they certainly did provide, though, was a wealth of examples of difficulties in accessing the sort of information and ideas that such a course might in fact offer. No participants felt that they knew where to turn for information about communication support:

> R: can I ask, have you been supported with communication in any way you feel, do you have any sources where you can find information about communication?
>
> P8: no, no
>
> P7: no
>
> P9: nothing

P3 pointed out that it is not just communication courses that are lacking. He observed that the healthcare system in relation to dementia care is confusing, and that information from healthcare professionals is lacking:

> P3: yeah there is no roadmap about who talks to who, there is no roadmap saying the memory clinic talks to the GP, the GP talks to the social services. (Centre project manager) talks to everybody, or did, or now, all the funding has been split, we're treated as- we're treated as customers- like patients rather than customers … if this was a private system we would be treated as customers
>
> R: okay
>
> P3: that would be a different way of communicating

In addition to difficulties in orienting the healthcare system, one participant also commented that the GP might often only be available on the phone rather than face to face. One issue with this is that if the GP was speaking directly to the PLwD, the carer might not be able to listen to the call and help interpret medical advice, unless the GP called back to talk to them:

P9: and if you are able to get through to the doctor it's only a telephone conversation
P10: yeah same
P9: very very difficult to get someone and actually see you like they should, so I think the doctors now are either referring to a nurse, a practice nurse if there are issues … they come around to see to sort of pressure sores and things like that so it's not the doctor. Sometimes you know you need to have the doctor to see the patient rather than just to talk to them
P10: yeah yeah
P9: … and very often when that happens, when my mother needs to have a call from the doctor, he will call her, and then meet afterwards which is quite good
P10: yeah that's good
P7: m
P9: that's that I know exactly, because she might now remember everything, it's been going on for a while really, but she may not know everything, or understand especially if it's uhm a doctor with an accent, and that not able to understand everything that they've said, so then I- part of that conversation so that the doctor will phone me you know again and they will be only limited to a certain amounts of time I think so uhm

It appears that it was generally perceived difficult to understand the structure of healthcare, and to get in touch with doctors. By extension, this impacts on how the carers can help the PLwD receive the care that they need. Although this type of information might not be appropriate to include in a communication course as such, it would certainly help if a facilitator delivering communication courses was familiar with the local situation. Moreover, we can see from the blister pack example, that simply ensuring a communication course includes general opportunities for chatting can lead to the sharing of important information.

8.4 What is good communication?

In the previous sections of this chapter, there have been some examples of communication *difficulties* with people outside of the dementia dyad. In this section, I will present examples of what *good* communication looks like outside of the dementia dyad, and explore some of the underpinning factors that the participants saw as contributing to good communicative practice. This discussion complements that from the interview data, in 7.3.3 (communicative needs outside of the dementia dyad).

In many instances, the participants associated positive communication with specific personal traits. First, I will outline some of these traits, then I will describe what it is that people who have such traits do, and why the participants perceive their communication to work well. Finally, I will point to some of the positive outcomes that the participants thought skilled communicators could achieve.

In both FGs, participants considered that having experience with dementia communication was beneficial for communicating well. P4 makes this point in the next extract. P2 then recounts an instance from her own experience and P7 offers an explanation:

P4: it's usually people who've had ((inaudible)) or a friend or

P2: the lady at the at the paper shop, I don't know her from Adam ((idiom, not referring to a specific person)), he's (P2's husband) been going in there once twice a week, hello and come out, and there was one day she said 'how is your husband' and I was so surprised, he was standing behind me, and I said 'not too bad' and she said 'if ever you need to talk', she said 'my mother had dementia'. She recognised that, and I never ever told her anything

P7: and it sounds awful doesn't it, but they do know, one or two do know that he has dementia problems but they treat them like I say as normal, they latch onto him, they talk to him, he has a laugh with them. I mean sometimes, you wouldn't think that he did have dementia

The example above draws attention to two important things. First, the experience of having been in a caring situation can provide knowledge about how best to empower the PLwD to contribute to communication. Second, there are styles of communication that can get the best out of the PLwD.

Meanwhile, there are communicative behaviours that, if not managed, are likely to exclude a PLwD from participating in communication. P7 contrasts, below, those who accept the PLwD's challenges in communication with those who unhelpfully draw attention to them:

> P7: but it's only later when you've sat with him for about an hour when it starts coming out, and then that's when they realise, but a lot of them carry on, they just don't- they take him as he is
> P10: yeah
> R: yeah
> P7: which is great, whereas if you go out anywhere in a crowded place, and he starts talking they look at him as if to say 'what's wrong with you?' you know that type-

Another point of importance was the way healthcare professionals addressed a PLwD. P5 exemplifies a positive experience, in which her husband who is living with a dementia is having his eyes tested. The healthcare professionals first attempt to ask him questions and give him the opportunity to communicate. P5 is only brought in to help answer questions when the PLwD struggles to do so. Thus, the situation is 'normalised' in relation to communication to the greatest extent possible:

> P5: That's at (place), and we've had no problems at all. They sort of accept that he can't answer questions, and they go straight back to me and bring me into the room. He had his eyes tested last week and I was brought into the room to answer questions, no problems

Here, P5 displays a positive attitude towards being asked to contribute information to healthcare professionals, because their request was delayed until it became necessary. Other participants had similar views:

> P7: and if they can't answer the question, well then that's what we're there for
> R: mm
> P7: is to answer for them. But they should ask them first, shouldn't they
> P9: yeah
> P8: no I agree I agree

Asking the PLwD and assuming that they have knowledge of their own health concerns, and can communicate these to some extent, is therefore viewed as important.

Carers felt that only other carers could really understand the challenges. Knowledge of what it was like could not be acquired in any other way than a lived experience:

> P7: unless you're living with it 24 hours a day, 7 days a week, nobody knows
> P8: nobody knows
> P7: you've got no idea. And even with all your information ((refers to Researcher)), you will never know unless you have to live with it

One way in which this lack of knowledge is displayed by others is not recognising the impediments that carers experience, regarding how freely they can speak:

> P1: but lots of phone calls you get offering support come when your partner your husband, whatever, is there. You can't speak
> P4: You can't speak, no
> P1: You can't, you can't say most of the things you need to say if they're [PLwD] actively around

As we have seen throughout this chapter, the carers in the FGs valued peer-support, and particularly information that came from peers with similar experiences to them. This was recognised by the centre where the FGs took place, and carers regularly were given the opportunity to talk to each other without the presence of the people they care for. Staff helped facilitate discussions about emotional support and communication, and this was considered helpful by almost all participants. In addition, the centre intermittently offered courses for carers:

> P3: we had a lady in the early days who came in and gave us a series of lectures for about oh- six weeks on resilience, and she was really good. Apparently she cost an arm and a leg, it was while we were you know in (place) down there you know. And the resilience was more about you need to support each other

Moreover, the centre offered benefits beyond momentary emotional support and a space for discussion. Many carers were returning to the centre regularly. Below, two participants in FG 2 comment that they have developed a long-lasting friendship from attending the centre. This suggests that opportunities to speak with peers within the context of structured, institutional support can have lasting benefits. The group had just been asked if they wanted to raise any additional points in the end of the session. P8 promoted the personal benefits that he gets from attending the centre:

> P8: absolutely
> P10: yeah, really has helped
> P7: because I was like whether to do it, but I'm glad now I did
> P8: but we (P8 and P7) always do things together
> P10: oh that's lovely that's so nice
> R: ((laughter)) that's lovely
> P10: you're so good friends, it's lovely to see
> R: yeah yeah
> P10: is that because you've met through this group?
> P7/P8: yes
> P10: that's lovely
> P9: that's excellent

Overall, in the participants' accounts, there are many useful comments that could help inform adaptions to a communication course designed to fit the needs of carers in North Wales. In particular, it would be important to embrace the good practice solutions that are identified by participants, as they are examples of successful communication. As we have seen, they particularly highlighted the value of meeting with peers. However, it is important to recognise that the participants may not have knowledge of all benefits a communication course can offer. The participants in focus group 2 overtly stated that they did not know where to turn, to get support with communication. We saw in chapter 7 that people who had attended Empowered Conversations training learned skills that they did not realise they lacked previously.

The question, then, is how Empowered Conversations could be altered to better suit the needs of carers that reside in North Wales. I will make two considerations to this end. First, one issue that is closely related to Wales is healthcare provision in the medium of Welsh. Whilst this was mentioned by only one participant in section 8.1, and one participant in chapter 7, it is possible to extrapolate from these accounts and suggest that offering EC in the medium of Welsh would be beneficial to many carers in Wales.

Second, multiple extracts from participants indicate that face-to-face communication is greatly beneficial in the context of attending the centre. In section 8.3.2, several examples show that participants link interactions with peers and staff in the centre to improvements in their general wellbeing, and to alleviating aspects of their caring responsibilities. On this basis, there is scope to ask whether delivering EC in person would integrate additional benefits compared to online, which is its current mode of delivery.

I will address both considerations in section 9.5, and draw on theory and literature in pinning down what factors that impact on these issues. Later, in section 10.1, I will offer some suggestions of changes to EC that could help target the needs of carers in North Wales.

In the next chapter, I will expand on the findings of chapters 7 and 8 by combining them with the theoretical underpinnings of effective communication that were explored in chapter 5.

Chapter 9: Discussion

In chapters 7 and 8 I addressed a series of research questions using the data from the two empirical studies. In this chapter, I broaden the discussion, by combining my answers to those questions with a wider consideration of the data and previous research. Given my interest in evaluating the potential for Empowered Conversations (EC) to be successfully introduced in Wales, the final section offers some observations about factors related to carers' place of residence that might be of importance in changing EC to better suit the needs of Welsh dementia carers.

The account begins with an evaluation of the direct experiences of carers in communication (9.1), then broadens to consider what is actually happening when there is a third person in the conversation (9.2). Next, I consider EC's role in helping carers reframe their approach (9.3), before unpacking the methods that EC uses to do that (9.4). Finally, against the backdrop of the preceding sections, I consider which factors from this research contribute to understanding the communication needs in carers in Wales (9.5).

9.1 Carers' perceptions of how to improve dyadic communication

In chapters 5, I made suggestions about the mechanisms that underpin improvements to communication, and in chapters 7 and 8 I outlined how communication improvements are experienced by carers. In this section, I will expand on these topics by targeting how such improvements happen in a dyadic setting. I will frame this discussion by drawing on the literature and the data provided by participants in chapters 7 and 8.

One of the themes in chapter 7 concerned opportunities for improving communication that carers had identified (section 7.3). This information pinpoints the changes to communication that carers thought would increase their achievement of high CI. Thus, there is scope to ask whether these observations represent solutions to what is traditionally termed 'communication needs' in the literature. As a first step, I will consider what constitutes a communicative need for a carer. This will be framed by addressing some ways in which dementias typically impact negatively on communication, and how carers typically respond to them in an effort to achieve their desired communicative goals.

In order to bring the key aspects of context back into focus, it will be useful to briefly recap on the main underlying reasons why communication is challenging for carers. As already noted in chapter 2, notwithstanding general features of aging such as impaired hearing, many difficulties in reciprocal understanding result from symptoms of dementia. For instance, a PLwD may struggle to comprehend and produce language due to impairments that affect their linguistic skills, e.g., decoding complex language, and word-finding (Szatloczki et al., 2015; Taler & Phillips, 2008). Communicative issues can also arise due to difficulties in memory and cognition (American Psychiatric Association, 2013; Bayles, 2003). Even though memory and cognition do not necessarily change the PLwD's linguistic capabilities, they impact on how language is used in interaction (Orange, 1996).

However, it is not only the PLwD's own capacities that impact on dyadic communication. We saw in section 7.2.2 that the way a carer engages with dementia symptoms can significantly shape the experience, both for the PLwD and for the carer. Ablitt, Jones and Muer (2009) suggested that carers can be described using one of four adjectives (Continuity; Reciprocation; Detachment; Duty) depending on how they perceive the relationship between themselves and the PLwD (see section 2.3). One factor that distinguishes carers in the different types is how they respond emotionally to symptoms of dementia disrupting communication. Carers who can healthily detach themselves emotionally from the situation may experience a lesser negative emotional response when communication does not work. Meanwhile, carers who actively try to sustain or reinstate the relationship with the PLwD to what it was before the disease may experience stronger negative emotional reactions as they observe how the dementia is progressing. This means that carers' emotional responses to low communicative impact (Wray, 2020) partially depend on their relationship with the PLwD.

The way carers respond emotionally to communication may greatly impact on their strategies for dealing with its challenges. In chapter 5, I discussed the concept of 'mentalization' in relation to how carers understand the PLwD and themselves (Fonagy & Allison, 2012). I showed that mentalization can be a useful theoretical framework for mapping how carers utilise contextual information to increase their communicative impact (CI) potential (Morris et al., 2020; Wray, 2020). Luyten and Fonagy (2015) argue that strong emotional reactions significantly inhibit a person's capacity to analyse information relevant for understanding others' intentions in interaction. Therefore, carers who respond to low CI with strong negative emotions may struggle to find new communicative strategies to a greater extent than carers who do not.

Furthermore, if instances of low CI occur frequently, that will create additional problems. It must be challenging both emotionally and practically to continually find one's intended outcomes failing to materialise. However, there are several layers to the story. The first thing to note is that while it is often, and rightly, observed that all carers (and PLwDs) have unique personalities that impact on the way they communicate (Noftle & Shaver, 2006), Ablitt et al. (2009) nevertheless suggest that despite individual differences, it may be possible to categorise general interactional patterns according to how carers approach the relationship with the PLwD. This in turn gives us a means to understand the variation in how carers respond to low CI (and how often it occurs). Anticipated CI is built on assumptions about what is possible and reasonable, and these, in turn, depend on the carer's expectations of the PLwD. Family members struggling to accommodate how the PLwD is changing in terms of, for example, authority, capability, dependency, capacity to give and support, etc., may be locked into a perception of the relationship that is no longer fit for purpose and that sets up unreasonable expectations of the interaction, leading, repeatedly, to the disappointment and frustration of low CI.

However, the causality between relationship and communication can also be reversed. In chapter 3 (see section 3.5), I point out that frequent experiences of low CI increase the risk of carers experiencing psychological symptoms such as anxiety and depression (Brodaty & Donkin, 2009). In turn, such feelings may increase carers' social isolation and loneliness (Older People's Commissioner for Wales, 2016, pp. 11; 18; 21; Pinkert et al., 2021). The more a carer is socially restricted to only interacting with the PLwD (or with others only *about* the PLwD), the greater the need for high CI to be achieved within that dyad – there is no opportunity for them to experience the pleasure, and sense of relief, of high CI elsewhere.

Thus, it is possible to argue that the relationship itself is not the only factor dictating how a carer approaches communicating with a PLwD. Instead, I argue that carers who perceive the relationship with the PLwD negatively are likely get into a cycle of repeated low CI and consequentially strong negative emotions when communication breaks down. This increases the risk of them experiencing depression, anxiety, frustration and, completing the cycle, an urgent need for the affirmation arising from high CI.

This suggests that any tools that will help the carer experience high CI - such as communicative techniques to circumvent the impact of dementia symptoms, to build their emotional management capacity, or to reassess their communicative goals - would be beneficial for the carer's perceptions of the quality of their relationship with the PLwD, and lead to improvements in their perceived Quality of Life.

Given the observations just made, three key themes can now be developed, namely, how carers can benefit from analysing why they do not achieve the communicative outcomes they wanted (9.1.1), how such analyses generate information for generating new goals (9.1.2) and how they might be helped to do so using mentalization (9.1.3).

9.1.1 Benefits of analysing (undesired) communicative outcomes

In chapter 7, there are several examples of participants commenting that the goals they want to achieve have practical and emotional elements. For instance, in section 7.4, I presented examples where the carers attempt to facilitate the PLwD's engagement in conversations. These examples often featured markers that indicated, to the carer, that the PLwD was participating in communication by (1), communicating by whichever means that they could, and (2) experiencing positive emotions. For instance, CW0505 stated "I'd play it [music] and then we talk about it and maybe we might remember how she used to love country dancing when she was young". There were clearly at least two goals for CW0505 here: to enable the PLwD to contribute to communication, and to elicit memories of positive life experiences and make the PLwD feel good.

In contrast, another example demonstrated how carers avoided communicative styles that potentially could cause negative emotions in the PLwD, e.g., "I try not to say, 'do you remember', I do try to take him back to nice memories, but I don't do it by saying, 'do you remember'" (CW0611). In this example, CW0611 actively chooses to not use specific formulations that interact negatively with symptoms of her father's dementia, as doing so might lead to her father experiencing stress in mobilising an appropriate response. For her, it is immaterial whether her father's problem is with bringing memories to mind or choosing between multiple memories. This is because CW0611 has developed strategies that seek to circumvent her father's memory impairments entirely, by modifying her linguistic choices. That this is likely to be a valuable support to many PLwDs is evidenced by Taylor (2007), who was living with Alzheimer's and who, as already noted in chapter 2, observed:

> These days, I'm moving from searching for the right word, to searching for the thought! Increasingly, it is not a matter of waiting for the correct noun, verb, adverb, or adjective to pop up and out. It is a matter of waiting to discover an entire fact (Taylor, 2007, p. 95)

Searching for 'entire facts' is likely to impede effective communication. By adopting strategies that can avoid this sort of hold up and the associated negative feelings, the carer will create the conditions for both parties to experience higher CI. This is because they craft the interactional demands into ones that the PLwD is more likely to fulfil and because they knowingly reduce the frequency of communication outcomes that will trigger negative emotions for the PLwD. In short, they take control over steering towards outcomes that they perceive as 'good communication'. In turn, increasing the proportion of situations in which strategies successfully reduce negative emotional outcomes – or contribute to positive emotional outcomes in the PLwD, will contribute to higher levels of secondary CI – where it is not only the direct, tangible outcome that is achieved (e.g., provision of information, compliance in a task), but also the hoped for emotional outcome for both carer and PLwD.

Achieving this outcome is, however, pushing against the tide, as evidenced by an extensive body of literature outlining the many symptoms of dementia that can impact on communication (see chapter 2), the way carers may perceive such changes to communication as challenging (see chapter 3). Morris et al. (2020) suggest that frustration is a typical result, when the outcome of interaction does not match the carer's expectations (i.e., they achieve only low communicative impact (Wray, 2020)). In chapter 5, I suggested that experiencing frustration following low CI may impede the carer's ability to analyse the communicative outcome (Allen et al., 2008; Luyten & Fonagy, 2015). This response may create barriers for carers to reframe their communicative goals in relation to that situation. By extension, carers may find themselves trapped a vicious circle of low expectations about communicative outcomes, and this in turn could limit their capacity to develop, without external help, the mentalization skills that could have helped them reframe the situation. Without some measure of controlled mentalization, the carer's understanding of the PLwD's emotional states underpinning their behaviour will be limited (Ballespí et al., 2021; Collins et al., 2006), creating ever greater frustration.

9.1.2 Communicative goals and conditions for successful outcomes

In section 9.1, I briefly suggested that communicative goals can be categorised based on what types of outcomes characterise them as successful. Wray (2020, p. 196) argues that carers can pre-emptively alter what they attempt to achieve with communication, where they perceive there is a risk of the PLwD losing face, or where they anticipate that they cannot achieve a given desired outcome. Here, I want to explore and extend this idea with some new observations.

In a series of diagrams, Wray (2020, pp. 193-195) maps out, for a range of different problems with communication, the potential pre-emptive and post-hoc solutions that a PLwD or carer might adopt. These solutions are sited in different parts of the generative process, including changing choices in processing (e.g., repeating something or speaking more loudly), selecting different resources (e.g., using simpler words and grammar), modifying the context (e.g., pre-emptively warning the interlocutor about the content or delivery of the message to come), or changing the goal to match what is more likely to be attained.

Of all of these, changing the goal is the most significant, in that it sometimes entails a resetting of communicative ambitions and the sacrifice of tangible desirable changes to the speaker's world. However, it often also involves the identification of an interim goal, that will pave the way for achieving the desired effect by a different means. For instance, GM0201 wanted the PLwD to take a shower and so she put instructions up on the wall for him to look at and supported this information with verbal communication by calling to him through the bathroom door. This way, she could avoid imposing on her father, without sacrificing supporting him in maintaining his hygiene. This created the conditions for achieving high CI for the goal of conveying key information to the PLwD in a recoverable format, available at the right time. And, in turn, this set up the potential for higher CI for her original goal of getting the PLwD to eat her meals.

I want to suggest, by extrapolating from this example, that goals are likely to get changed or augmented for two main reasons. First, the carer wants to ensure a *functional* goal is achieved, such as the shower or the eating of a meal. But second, carers want to protect themselves and the PLwD from any *emotional* fallout of low CI. Moreover, I propose, in line with several participants in section 7.2.1, that it is this antipathy towards negative emotional outcomes that most often drives carers' decisions, e.g., "take a step back and think … get the bigger things into perspective, that my mum and dad are human. They still need that love and attention- that's more important than some other things" (GM0611); "it's that it's the emotional impact … on everyone that's involved, on the carer and the person, on the other person with dementia, the … person, dementia can't help how they are" (CW0503).

Indeed, many examples in the data directly related to difficulties in managing emotions in the PLwD and the carer (see sections 7.1 and 7.3). Generally, the carers wanted to reduce negative emotions and promote positive ones in the PLwD. Similarly, carers attempted to avoid situations that would cause negative emotions for themselves, though this was discussed by the participants far less than emotions related to the PLwD.

Although there might be reasons to question whether distinguishing goals based on what they are intended to achieve covers the entire story, it is a useful view for investigating why communication in dementia is particularly challenging. In relation to communication generally, Wray (2020) states:

> We typically want to manage several different changes to our world, or the avoidances of change (…) We must try to gain Communicative Impact on all these fronts at once. We make complex social judgements about the parameters of the context so as to navigate the best path towards these multiple goals and, indeed, to establish whether there is any possible outcome that can serve them all. If there is not, we will have to choose (p. 139).

In a dementia context, managing different agendas simultaneously might be particularly difficult. Carers likely often have both functional and emotional goals that they want to achieve (see figure 7.1). For example, we saw in section 7.3.2 how CW0611 wanted the PLwD to sit in the sun, so she told him: "Feel the sun on your face this is lovely', isn't it?". However, she comments: "Well, it wasn't lovely for him it was- It was me wanting it to be lovely."

In the context of chapter 7 (see section 7.3.2), I interpreted this quote as CW0611 identifying a strategy for challenging her own assumptions. However, if we examine this quote from the perspective of functional and emotional goals, we can come to a different realisation.

From this comment, we can infer that CW0611 wanted to make her father feel good (emotional goal 1), which would make her feel good (emotional goal 2), by taking him out in the sunshine so that he can feel it on his face (functional goal 1) and so that she can feel the sun on her face (functional goal 2). CW0611 achieves high CI in relation to her functional goals. However, she achieves low CI in relation to her emotional goals. We can infer from CW0611 that she does not perceive the communicative outcome as high CI. Therefore, the emotional outcomes appear to be more important to achieve in this situation.

A major challenge for carers, then, is to acknowledge the different goals that contribute to their CI in a given situation. Arguably, carers who are adept at pinning down which goals are most important to prioritise will have a greater chance of experiencing high CI more frequently – and reducing the negative impact of low CI. Furthermore, where carers can identify all their goals, and prioritise them, they will be better equipped to explain the reasons for why they do, or do not, attempt to achieve specific goals. For instance, CW0712 comments in section 7.1.1 “I don't … tell him about my day … because I don’t think he understands what I'm saying”. When interpreted from a perspective of goal prioritisation, CW0712 seems to anticipate that the functional goal of having her father understand her explaining her day will result in low CI. It is also possible that she avoids putting her father in the position of not understanding since exposure to such situations can lead to sadness, anxiety and feelings of shame and embarrassment in the PLwD (Aldridge et al., 2019; Kitwood, 1997; Wray, 2020, p. 186). This means that she feels it is more important to avoid eliciting negative feelings in her father (and indeed, in herself) than to achieve the functional goal of telling him about her day.

In the following section, I will outline how mentalization can function as a tool for carers to develop their understanding of how to prioritise goals in communication. I will also argue that this skill is helpful for carers in forming goals that they realistically can achieve (in which goal prioritisation is a constituent). At a later point in this chapter (section 9.4), I will also present some examples of how carers can change their communicative practices over time by changing how they approach communicative goals.

9.1.3 Mentalization as a support for fulfilling communication needs

How might mentalization be a useful support for improving communication? We saw in chapter 5 that one way for carers to utilise their mentalization skills to the highest extent possible involves the capacity to detach from strong emotional responses (Luyten & Fonagy, 2015; Morris et al., 2020). And the discussion above (see section 9.1.1) outlined the potential vicious circle of poor communication, low CI and strong emotional responses. The circle needs to be broken and there at least three ways that might be done.

First, Carers could develop their emotional management skills (e.g., by increasing emotional reserve (Wray, 2020)), so they can take a calmer approach to understanding the situation, thus increasing their capacity to apply controlled mentalization. By learning how to manage their own emotions, carers create the conditions for drawing on mentalization to break that circle. Second, carers could improve their mentalization skills, so that they have new techniques for observing and understanding their emotions. Finally, carers could independently identify, or experience, an improvement in CI, such that the pressure on emotions is relieved and the need for active mentalizing is reduced. Evidence suggests that this option is difficult for carers to operationalise, because they enter communication with their status quo of emotions and beliefs. However, in section 9.2, I will show how the involvement of a third person can potentially break the vicious circle via that route.

McEvoy and colleagues (McEvoy et al., 2020, p. 244) propose that mentalization training can benefit carers who experience particularly high levels of stress: “Mentalization provides a point of orientation that gives an insight into the channels of communication that may be helpful in enhancing the emotional resilience”. Indeed, participants who had attended EC provided some examples of how the course had improved their communicative abilities, and emotional responses to low CI (see section 7.4.4) – which, unsurprisingly, could not be inferred to the same extent from the accounts of carers living in Wales. Therefore, in anticipation of my further consideration of EC in the later sections of this chapter, I want to focus on how the vicious circle can be broken by training to improve mentalization skills. Since it is difficult to deal with strong emotions at the time, and also difficult to replicate them in a workshop setting, mentalization needs to engage elsewhere. The most effective place to start will be with what carers already know and can work with. Chapter 7 showed that carers have a sense of what ‘good communication’ is like, and strive for it. The discussion above aligned ‘good communication’ with high CI. Insofar as that is the case, mentalization techniques can gain traction by helping carers understand what they need to do, in order to achieve high CI.

Although, as the carers in chapter 7 and 8 point out, all dementia dyads' needs are unique, their communication challenges often revolve around reciprocal understanding, and situations where vital practical outcomes, such as eating and hygiene, are determined by communicative outcomes (Nguyen et al., 2022). Thus, in teaching mentalization, high CI can be pegged to necessary daily activities, creating a buffer from *direct* emotional goals, while creating the conditions for achieving the indirect ones associated with feeling good at the end of an interaction. With these techniques developed, carers should also be able to engage more successfully in communication in situations that are particularly prone to communication breakdowns, such as conversing as a form of enjoyment, planning agendas, and managing finances (Small et al., 2000; Small et al., 2003).

Because dementia symptoms change over time carers' communication needs are difficult to fulfil using static, generic guidance on what to say and how. Indeed, as suggested in the preceding section, carers in both chapter 7 and 8 could likely not rely on generic strategies only to achieve *all* their communicative goals (which is conceptualised in section 7.5). Mentalization, being rooted in the carer's own awareness, is much more flexible and responsive to the changing patterns of individual experiences. The carer is equipped to continuously reexamine and reevaluate what they can (and cannot) achieve with communication, and the strategies that they might employ to achieve their goals.

In chapter 7, I suggested that carers tend to identify communication challenges related to dementia when they achieve low CI in situations where they previously achieved high CI. Mentalization training, then, needs to target such contrasts, because they reveal carers' inherent capacity to analyse and interpret information following situations where they experience low CI. If they are given the tools to work with this information, carers will be equipped to anticipate likely future outcomes using accurate contextual assessments, and thus increase their CI potential.

Key to the success of mentalization, then, is that it builds on what carers naturally try to do, since, as we saw in section 7.2.2, carers evidently do eventually find solutions to new challenges over time (Cooper et al., 2021; Polenick et al., 2020). In section 8.4, participants pointed out that the lived experience of dementia caring can play a major role in learning how to achieve good communication with a PLwD. This experience is likely important for generating information that inform carers of needs, wants and wishes in the PLwD, which guides their perceptions of what communicative goals are possible to achieve. However, some carers gain more information than others over time. One factor that determines the extent to which carers can generate information relevant to communication is their mindset, and mentalization training focusses on developing one mindset in particular: empathic curiosity (McEvoy et al., 2013; McEvoy & Plant, 2014). Where carers utilise empathic curiosity, they actively search for new information and ways to interpret that information. This helps them build on their understanding of the factors that underpin the PLwD's, and their own, behaviour (Achim et al., 2013; Frith & Frith, 2006).

Thus, as shown in section 7.4.4, someone who can generate a lot of information by observing the PLwD, themselves, and the context, who can use it efficiently, and who can understand why a certain communicative action works or does not - based on their own, and others' reactions - will experience low CI less often, and be less negatively affected when they do.

A second factor is the role of the individual differences and styles. Where carers achieve low CI, it can often be attributed to their personality (Noftle & Shaver, 2006) and the type of relationship they have with the PLwD (Ablitt et al., 2009), since both will shape their emotional responses.

Finally, the carer's attitude towards communication determines the potential bandwidth of information that they can generate (McEvoy & Plant, 2014). It may not be possible to alter the carer's personality or how they approach their relationship to the PLwD. However, it is possible to alter carers' emotional management, experience and knowledge about dementia communication, and mindset.

The value of mentalization training as an intervention, then, is that it increases the carer's knowledge about dementia and communication and teaches them how to improve their emotional management.[28] Moreover, it promotes beneficial mindsets that are likely to have a positive

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[28] Emotional management is not a clearly defined ability. There are many factors that can impact on the way carers manage their emotional responses to communication in particular situations, and over time. Some psychological states such as stress, anxiety, and depression can impact on how carers manage their emotions, as discussed earlier in this chapter and in chapters 3 and 5. However, there are many sociopsychological factors that are relevant to this concept, such as the carer's financial situation, which are often directly related to stress levels. Some aspects related to the carer's psychosocial situation will be

impact on how information relevant for improving communication in a given situation is generated and interpreted. Mentalization can also help reduce psychological factors that inhibit information generation and interpretation (and thus combat the risk of low CI), such as high levels of stress and anxiety, which carry an onward risk of developing pathological conditions such as depression (Brodaty & Donkin, 2009; Savundranayagam et al., 2005; Savundranayagam & Orange, 2011). If carers can understand why their CI is low in a given situation, they are better equipped, through extrapolation and generalisation, to reduce the frequency of experiencing low CI in future similar situations. Where carers do not have this capacity, they may well gradually withdraw from the PLwD, which is detrimental to the wellbeing of both parties (Kitwood, 1997).

In sum, it has been suggested that unmet communicative needs represent barriers that prohibit the carer from achieving high CI. Carers who are better equipped at finding solutions to their issues should in time reduce their needs, leading to greater satisfaction in communication. Mentalization is a method for achieving this outcome.

9.2 Improvements to communication beyond the dementia dyad

In the previous section, I pointed out that not all factors that impact on dementia communication are related to dyadic interactions between the carer and the PLwD. Other interlocutors are also important for the carers' and PLwD's experience of communication. They include family and friends who provide social support (Donellan et al., 2016), and healthcare and social care professionals (Adams & Gardiner, 2005; Carter et al., 2020). All contribute to their social reserve (Wray, 2020, pp. 76-78).

We saw in chapter 8 how social reserve can be a lens for investigating determinants of carers' experiences of communication in Wales. In what follows, I will focus on factors that carers in the two empirical studies identified as relevant to their experience of social reserve, and point to how resources associated with their residential geographical location affected the opportunities for strengthening social reserve. I will also consider how others' communication can shape the carers' experiences.

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outlined in section 9.2 and 9.5. However, an in-depth discussion of all potential biopsychosocial constituents of potential relevance to 'emotional management' is beyond the scope of this thesis.

9.2.1 Social reserve in practice: how does it impact on communication?

To the best of my knowledge, no previous research has examined carer accounts of dementia and communication through the lens of the concept of social reserve. In this subsection, I review how my data exemplifies the different elements of social reserve and use that to set up the context for developing, in 9.2.2, a new proposal about the role of individuals beyond the dyad in shaping carers' wellbeing, access to insights, and experience of CI. The starting place is considering how participants draw on their social vicinity as a resource to enhance their social and emotional resilience.

In chapter 8, all focus group participants praised the support centre they attended. This centre may be a particularly strong example of how carers' wider social facilities can reinforce emotional and social resilience. In the carers' accounts, there were examples that relate to each of the four elements in social reserve, (1) infrastructure, (2) attitudes, (3) social groups, and (4) social credibility. I will address them in turn.

The centre was a clear example of infrastructure beneficial to carers in the local area. The centre had sufficient funding to employ staff who ensured that the centre was maintained and offered helpful activities. The centre was split into two sections, one for PLwDs, and one for carers. This meant that carers who attended the centre could access respite, benefiting from peer-support without the presence of the person they cared for. Peer-support is often insufficient in rural settings, but is an important element to social support (Alzheimer's Society Cymru, 2017, pp. 10; 17). It provides social connection with others who understand the challenges of their life and has been noted to be associated with reductions in carer burden (Kishita et al., 2018).

The second aspect of social reserve, "attitudes, assumptions, beliefs and priorities that determine an individual's experience within society" (Wray, 2020, p. 76) was clearly identified by attendees who found acceptance and understanding at the centre. For instance, P7 states that it is impossible for someone to understand the nature of the caregiving experience unless they are "living with it 24 hours a day, 7 days a week" (P7) and values people who, on meeting the PLwD, are not fazed: "they treat him … as normal, they latch onto him, they talk to him, he has a laugh with them" (P7).

The third aspect of social reserve, 'social groups' concerns "the existence of supportive family, friends, and social groups … [that] make a huge difference to a person's resilience to dementia, or their experience as a family carer" (Wray, 2020, p. 76). A particularly salient example is reported in section 8.3.1, where P8 believes that having brothers or sisters could constitute a source of support. However, in section 8.4, I showed that P8 and P7 have developed a close and supportive friendship from attending the centre, which likely constitutes some form of support for P8, albeit not in the shape of that which he associates with having siblings. We also saw, in section 8.3.2 where P9 helped P10 find a pharmacy that could issue blister packs, that social groups characterised by positive and supportive attitudes t can generate knowledge that directly impacts on functional aspects of the caring responsibilities.

Finally, the fourth aspect of social reserve is 'social credibility' which is "the extent to which a person is listened to and taken seriously" (Wray, 2020, p. 77). Wray notes that "[its] level will be determined in part by the other three types of social reserve as well as interlocutors' emotional intelligence." Thus, in Wray's conceptualisation, 'social credibility' is a product of the considerations already discussed: positive attitudes, empathy, experience and – referring back to the account of mentalization in section 9.1 – having the 'emotional intelligence' to understand one's own and others' behaviours in interaction (Luyten et al., 2020, p. 302). Throughout both chapter 7 and 8, we can see that carers valued being recognised and heard, and perceived the absence of these factors detrimental.

Two aspects of social credibility, as an integral aspect of the first three constituents of social reserve, concern the carers' experiences of how others interact with a PLwD, and their manoeuvrability in improving their own and the PLwD's life by means of communication through the agency of a third party. Related to the first, GM1101 commented that it was frustrating to hear family members, who were less involved with the care, making unsupportive judgements about the value of trying to improve communication outcomes. Related to the second, in section 8.3.2 P3 comments that healthcare would adapt to carers to a greater extent if they were treated as customers, and not patients. A possible inference is that where a product is not satisfactory, a customer has the power of comeback, e.g., to return a product or get it repaired. In healthcare, they feel less empowered. This suggests that carers' perceptions of credibility are determined, to some extent, by their ability to make changes to their world through the agency of parties with particular support to offer.

This evidence suggests that social credibility lies at the heart of sustaining high social reserve, because it is the basis on which people will consider it worthwhile investing resources and effort into building and sustaining infrastructure and reaching out to PLwDs and their carers in positive ways.

I have demonstrated above that there is a direct connection between the social reserve that carers are able to access and how they manage communication. But there is one more component to the story. So far, in line with Wray's account, third parties have been depicted as supporters of the carer and PLwD. But in section 9.2.2 I will suggest that third parties can play a greater role too – in both disrupting and improving the carers' opportunity to achieve CI.

9.2.2 Social reserve supporting successful interactions with a PLwD

As mentioned in chapter 5, carers are likely to have a more accurate and complete map about how to communicate information and what outcomes are possible and desirable in a dementia context than others. They may also perceive what potential a third party has for achieving a type or level of CI that they know they cannot achieve themselves (e.g., explaining a medical procedure or giving the PLwD specialist advice). Conversely, they may strongly suspect that a third party will fail to achieve a desired outcome. As a result, carers can become heavily invested in the contributions that third parties make.

Where the third party generates a communicative outcome with the PLwD that the carer perceives as suboptimal, the carer may experience frustration as a consequence of discrepancies between their expectations and the actual outcome (see chapter 2, 5 and section 9.1.1), even though the carer did not produce this outcome. There could be an important consequence of this: that the carer feels it necessary to intervene and increase the CI. For instance, GM0202 comments: "I'm quite mindful that, if it was just my mum and this person, the conversation would end pretty quickly, the person... might just get up and go... whereas I think it's important for mum to socialise and have some form of conversation." Here, GM0202 intervening in the interaction achieves two things. First, she facilitates sustaining an interaction between the PLwD and a third party, which likely increases CI for her mother, and potentially also for GM0202, insofar as her mother displays positive emotions from this encounter, which can have a knock-on effect on GM0202. Second, GM0202 achieves her mother 'socialising', which, as can be inferred from GM0202's comment, is only attainable where a third party is present.

However, two problems could arise here. First, an intervention from the carer will only be perceived as helpful by the third party insofar as it aligns with the third party's perception of the communicative situation. Where the alignment is poor (that is, the carer and third party have different beliefs about the purpose of the conversation and the best goals for it), the interaction may, from the point of view of the third party, be undermined by the carer's 'interference'. That is, the third party believes the CI was high, and so does not welcome the carer meddling with that outcome. Second, where such an intervention is interpreted negatively by the other interlocutor, the carer may feel confused, even more frustrated, and undermined. If it happens a lot, they might start to feel a tension between their genuine desire to help improve someone else's CI and a sense of impotence, rejection and alienation, increasing the risk of social isolation and reducing their willingness to engage with others who should be offering support.

One further observation can be made at this point. As just noted, and briefly considered in section 7.3.3, carers are so invested in how well communication works, that they can become frustrated when third parties do not achieve the desired outcomes, e.g., "[friend to PLwD] frustrates me no end … I wish she would listen [to PLwD] 'cause she answers for [PLwD] all the time" (GM0203). In Wray's model, CI is always tied to the speaker-hearer dyad. But in instances where the carer is an onlooker while a friend or healthcare worker, say, fails to engage satisfactorily with the PLwD, we might say that the carer's emotional reaction is caused by low CI *by proxy*. This is a small addition to Wray's model, but it could be beneficial in tying in the role played by third parties, who are not strongly represented in her own account. To that end, I expand on this idea below.

On what basis would we want to attribute an ownership by proxy of the CI outcome? That is, under what circumstances might a carer identify, indirectly, as the person affected by the level of CI? Where would that sense of ownership come from?

Even where the carer and an external interlocutor have similar communicative goals (e.g., completing an important transaction with the PLwD), the primary carer is likely to have more information to feed into an effective contextual assessment, to help them understand the PLwD's behaviour (Collins et al., 2006; Simpson & Rholes, 2012; Wray, 2020, pp. 174-175). As such, where external interlocutors communicate with the PLwD, and provide outcomes that the carer cannot (e.g., general chat between the PLwD and a family member, or having a medical consultation), they may feel that if they had the specific information or role to undertake the interaction themselves, they could have done it a lot more effectively. Viewed this way, we can see why carers would be quick to intervene where the third party does not have much to offer, and thus head off low CI, but have to endure low CI by proxy when they are not in a position to stand in for the third party. Several examples demonstrating this are presented in section 7.3.3, e.g., carers' perceptions of hospital consultants having vital expertise and knowledge but displaying poor communication skills towards the PLwD.

However, CI by proxy is not solely relevant to carers experiencing low CI. It is also possible that the carer can experience high CI when the PLwD and another interlocutor experience an outcome that the carer perceives positively. In this situation, a third party may achieve outcomes that are aligned with the primary carer's goals, or that exceed them. There are two sides to the latter point. The carer can react positively and reframe their own goals to suit the outcomes that they now know can be achieved. However, it is also possible that the carer might react negatively, feeling frustrated that someone else can achieve a specific communicative outcome, where they cannot. In this situation, the carer would experience two reactions simultaneously. They would recognise and appreciate by proxy the high CI but would experience a sense that the third party had achieved only low CI in relation to the carer's own emotional outcomes (i.e., the third party has inadvertently upset the carer, which likely was not a desired outcome).

It follows from all of this that the role of others, and how they talk about and to the PLwD, is relevant for shaping the carer's experience of dementia communication when interpreted through the lens of Wray's (2020) CI model. Based on the assumption that carers want to experience high CI to the highest extent possible, it is reasonable to argue that all interventions that increase others' capacity to interact positively with a PLwD (e.g., promoting knowledge about dementia in the public) are indirectly beneficial to the carer. For instance, increasing public knowledge about dementia could have a positive impact on the dementia dyad: "educate people about it, dementia, I think, if we do that, then … your communication will better because people have a much better understanding of it, and, you know, people who are looking after them [PLwDs] will feel a lot more empowered" (GM0611). But this will only be the case when the carer has the mental space to stand back from their own emotions – something that they may need explicit training to learn to do.

9.3 Empowered Conversations: reframing outcomes from communication courses

In this section and the next, I will draw on findings from chapters 5, 7, and 8 to demonstrate why carers seem to benefit from EC. There is currently limited research on the effects of EC on family carers. However, as noted in section 4.3, Morris and colleagues (2021) found that EC reduced stress levels in carers after the course, and that this effect was sustained, even where carers did not display high stress levels at baseline. They suggest that the reason for this is that the course "provides techniques and understandings that can help manage and reduce stress" (Morris et al., 2021, p. 2846). Previously in this chapter, I have argued that increasing the frequency with which carers achieve high CI could be expected to result in decreased stress levels. Therefore, this metric may in part reflect the extent to which participants perceive that they are experiencing successful communication, after having learned techniques for doing so.

In each EC session, the participants are taught new techniques for facilitating effective communication, and/or developing new perspectives on communication with the person they care for (see chapter 4). However, in addition, the course indirectly offers peer-support. Many of the tasks in the course are focused on managing communication in everyday life. This entails carers sharing information from their own lives, and participants often do so.[29] Therefore, the participants form a social peer group, with consequential benefits for communication (see section 9.5). Moreover, almost all facilitators of EC have personal experience of caring for a PLwD. As we have seen in chapters 7 and 8, this appears to improve the authenticity of information for carers. Innes and colleagues report in a study investigating the experiences of EC participants: "[it was] particularly poignant for participants that the facilitators had their own lived experience of caring for someone with dementia" (Innes et al., 2022, p. 109). Therefore, EC offers not only communication techniques but also a supportive social context in which participants can explore communication with peers. It is likely that positive outcomes are interpreted as authentic to a higher extent when they are discovered amongst peers rather than people who do not have

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[29] My personal experience as an EC facilitator confirms to me that sharing experiences is an intrinsic part of the course. Participants are under no obligation to share if they do not want to, but almost always do at some stage in the course.

experience of dementia care, e.g., “a health care person can only give you, well, ‘you could do this, you could do that, you could do this’, whereas someone who's lived it will say, ‘well, I tried that and it didn't work well, I tried this and this is what happened so next I did that’ and that's just a bit more tangible for you.” (GM1104).

In the week 5 session, participants are introduced to the ‘Control Continuum’. In this exercise, participants are asked to discuss how they can improve situations in which they have little control, and perhaps more importantly, how they can recognise where they cannot. In the former, carers identify what aspects of a situation can be altered by means of communication, and review how modifying those factors might improve the situational outcomes.

This activity addresses the common experience of having little control over the changes that dementia is causing in daily life (Cooper et al., 2021), which can engender feelings of not only distress and anxiety but also grief (Morris et al., 2020). EC helps carers approach situations where there is little that they can change, giving them more choices about how to respond.

In the next section, I will combine aspects of the discussion so far, to show how EC can help carers achieve greater communicative success over time by improving their self-mentalization abilities.

9.4 Mindset matters: Empowered Conversations and improvements to communication over time

As already mentioned, one core constituent of EC, which all participants are encouraged to adopt, is ‘empathic curiosity’ (McEvoy et al., 2013). At the beginning of each EC session, participants practice curiosity in a reflection exercise, which has been noted to have a positive impact on course attendees (Innes et al., 2022). In this activity, they are asked to reflect on the content of previous course weeks and relate it to communication issues or solutions in their everyday lives during the past week. Curiosity is related to active mentalization (Luyten et al., 2020) and characterised by examining other interlocutors’ communication and behaviour for new and potentially relevant information.

In chapter 5, I suggested that mentalization is enhanced by the ability to accept as potentially relevant information that previously seemed irrelevant. This is because it broadens the range of input from the PLwD that carers bring to interpreting their behaviour (Luyten et al., 2020; Luyten & Fonagy, 2015), and modifies the context that the carer assesses when planning how to achieve their next goals (Wray, 2020, p. 147). Mentalization benefits from this due to carers broadening their understanding of the dynamics in the relationship over time (Collins et al., 2006).

In section 4.3, I noted that two additional reports of EC had been published since this project was carried out (Eastham et al., 2024; Morris & McEvoy, 2023). Both arose from funded research directly aimed at evaluating the EC programme, and they were carried out in collaboration with the EC team. As such, the focus was on investigating the nature and quality of the learning. The results confirm the conclusion in this project, that EC is a gateway to new understandings of how communication works. Eastham et al. (2024) found that mentalization techniques provided greater understanding of how a PLwD is affected by a dementia. This included how they understand and respond to the carer's communication (Morris et al., 2023).

In turn, this helped carers "to move negative feelings about the person's presentation away from the person and on to their dementia" (Eastham et al., 2024, p. 5), something that resonates with the principles of good communication through prioritising personhood (Kitwood, 1997).

Now we can ask what this looks like in communication. I suggested earlier in this chapter (see also chapters 5 and 7), that when carers achieve low CI, one of their responses can be to modify their contextual assessment, making it easier for them to accurately appreciate what can be achieved as a future goal (see figures 5.1 and 7.1). As it turns out, recalibrating goals is something that carers can do better following EC (Eastham et al., 2024). I will present evidence below that that it is curiosity that catalyses the identification of instances where it will be beneficial to reframe a communicative goal.

Even though curiosity is a central concept taught in EC, this mindset was not exclusive to the carers in my study who had attended EC. Certainly, those who had attended the course showed signs of utilising curiosity to a greater extent or of developing a mindset of curiosity earlier in the dementia trajectory than carers who had not. However, my data show that carers who had not attended EC could also deploy curiosity effectively – a valuable observation, in understanding how easily carers will be able to tune into the content of EC. Therefore, I will draw on comments from across my dataset, that is, carers who both have and have not attended EC.

With this in mind, in what follows, I will first remind the reader of some key observations made earlier, and outline some of Wray's (2020) thoughts regarding the underpinning drivers of altering communicative goals. This background will enable me to make a new link, to the concept of 'going with the flow', which was presented in section 7.2.2, and point to how this concept may be related to reframing communicative goals.

It should also be noted that, so far, I have implied that carers change their communicative goals only *after* they experience low CI. Whilst this may be true for situations they have not encountered before (how could they pre-empt what they have not experienced?), situations that are repeatedly difficult for carers, or instances with similar characteristics, allow carers to anticipate that they, or the PLwD, will experience difficulties in communication. Where carers identify risk factors, they can pre-emptively modify their goals (Wray, 2020, pp. 196-197), such as expecting less, or reordering the relative priority of functional and emotional aims (see figure 7.1, and section 9.1.2).

CW0201 exemplifies this process and outlines both the changing of goals, and how she knows needing to change her communication for avoiding undesired outcomes:

> I think the key thing is to learn to read their body language. If they don't look like they're relaxed and comfortable, change the topic because … it's usually an outward expression of them not understanding the concept that you're trying to discuss with them (CW0201).

In this quote, CW0201 gives a clear example of how she reframes a communicative goal. First, she identifies a marker (the PLwD not looking relaxed and comfortable) which indicates that the PLwD might be struggling to follow what she is saying. By changing the topic, there is a shift in functional goal (i.e., talking about something else), employed to avoid achieving low CI in relation to an emotional goal (not wanting her mother to feel uncomfortable because she cannot follow the conversation). If she needs to retain her original goal, she will need to find ways to help the PLwD participate, such as by rephrasing and providing additional contextual information. Nevertheless, her comment suggests that, in her experience, the risk of low CI is greater with retaining the goal than with changing it. CW0201's awareness, drawn from experience, that the PLwD's body language functions as a marker of impending low CI, gives her a reasonably reliable method for evaluating the current situation. There is evidence showing that body language is a particularly strong source of information in late-stage dementia, where verbal language is no longer the primary form of communication (Ellis & Astell, 2017, 2018) and there is no reason to assume that it does not play a major role earlier on as well, though, in the absence of other cues, it needs to become more important as the dementia progresses.

While we do not know why CW0201 acts this way, we can certainly recognise that she would be unlikely to do so without some measure of calm curiosity. The interview protocol did not probe into why carers adopted certain communicative patterns when they experience low CI, because the importance of this aspect of insight was not evident in advance of the study design. This matter would, however, be interesting to address in future research, both through interviews and observation. Anticipating the discussion in chapter 10 on future research possibilities, a study of this type could seek to establish the relationship between patterns in communication and the framing and reframing of goals. However, there would be significant methodological challenges, given the difficulties of identifying (through self-awareness in interviewees and reliable insights in observation) just what is happening at the level of motivation and intention.

With all of this in mind, it is possible to make a new connection between ideas. In section 7.2.1, I noted that carers often talk about reframing communicative goals in terms of ‘going with the flow’. Polenick et al. (2020) suggest that this notion is associated with avoiding unnecessary conflicts. Since it is not possible to avoid something that has already happened, avoiding conflicts presupposes that a speaker can identify cues indicating that conflict may soon arise – which requires active mentalization (Luyten et al., 2020). Just as with the case of CW0201, such anticipation requires learning to identify reliable markers that can trigger strategies for averting conflict. It follows that when carers talk about ‘going with the flow’ they are actually capturing the quite complex process of reframing their communicative goals based on information acquired in previous situations resulting in low CI.

Multiple carers mentioned how ‘going with the flow’ is useful, and one participant explained how this works in interaction for her:

> Yeah, try to just go with it, and don't try to shortcut the journey, so my father gets to a place where he can understand something … he may take a really circuitous path to that point. So, in normal conversation you would want to get

> there. What I try and do now is to allow him to go on his journey, and to go on that journey with him, but then try and bring him back to where he says he feels safe (GM0611).

Having said all of that, one thing that carers know is that they will not be able to avoid all communication problems. Importantly, for most family carers (as indeed for PLwDs), the persistent point of comparison will be how communication functioned prior to the condition. Therefore, rather than focussing on whether carers feel that they can achieve better outcomes by reframing their goals, we should ask if they can reduce the frequency of negative outcomes. In the context of support and training like EC, this perspective would tie in well with self-mentalization, because they would be examining, head-on, the situation they are in, rather than sustaining unattainable desires based on the past.

I have aimed to show in this thesis that the benefits of EC reported in recent studies extend beyond improvements to functional communication. I have argued that because carers prioritise emotional goals over functional ones (see section 9.1.2), and the evaluation of emotional goal success is dependent on mentalization in a way that the evaluation of functional ones is not, what EC is doing is making it possible for carers to revolutionise their approach to communication, to achieve the outcomes that are most important to them. The psychological benefits of improved mentalization; and improvements to the dyadic relationship are reflected in both this current research, and in the outcomes of both Morris et al. (2023), and Eastham et al. (2024).

9.5 The experience of dementia communication for carers in Wales

We turn now to the particular needs of dementia carers in Wales, and here two related difficulties with the data must be acknowledged. As will have become evident in the previous chapters, the Welsh participants did not provide much direct information relevant to how the needs of carers in Wales are different from those in Greater Manchester. Nor did those in Greater Manchester provide an abundance of information about how EC alters approaches to communication. This is perhaps, in part, due to weaknesses in how the questions that generated data in chapter 7 were asked (see chapter 10, limitations) but there may be more to it than that. If, as seems intuitively reasonably, we continue to assume that carers in Wales, particularly in rural areas, do have particular challenges, and if we also accept the evidence from Innes et al.'s (2022) and Morris et al.'s (2021) studies that EC has beneficial effects, why might participants not have spoken about these things more?

All participants in chapter 8 thought that the experience of carers living in Greater Manchester would be different to their own, living in North Wales. However, details that underpinned this opinion were not offered, perhaps because it was not salient for the participants to compare themselves with others elsewhere. Only one participant (P10) illustrated contrasts between living in an urban and a rural area. This participant felt more positively about living in North Wales than in London, in relation to providing care for her mother. The only other voiced distinction between rural and urban areas related to transport, where P3 firmly believed that transport was easier to access in urban areas.

The relevance of transport in making carers' lives easier cannot be overstated. Multiple participants mentioned that they were limited in what healthcare services they could access, which is a known consequence of long distances, travel time and limited availability of public transport (NHS Confederation, 2018). As reported in section 8.2.1, focus group participants identified problems accessing transport beyond what they could arrange privately, something they felt put them at risk of being able to meet neither their own nor the PLwD's health and social needs. Such risks would be likely to increase carers' stress and anxiety levels, with the previously outlined potential onward impact on their relationship with the PLwD and, thus, communication (Wray & Bergström, 2024).

As we have seen, carers often access more than just services when they attend hospital, centres and support groups. The evaluation of EC by Morris and colleagues (2023) found that carers' social networks improved following the course. Where this happened, it was the result of facilitators informing participants about additional support they were entitled to. Arguably, where such support is accessed successfully, it will help alleviate carer burden, and unlock more time for carers to tend to their own social needs. Through social encounters for both themselves and the PLwD they reduce the risk of loneliness, which is a significant problem in Wales (Older People's Commissioner for Wales, 2016, pp. 11; 18; 21), and elsewhere in the UK (Victor et al., 2021). Whilst there are many psychological factors that can contribute to the carer and PLwD withdrawing from social settings and experiencing loneliness or social isolation (see chapter 3), geographical isolation certainly must play a role. That role extends beyond the proximity of services. Where family members and friends have to travel long distances, particularly on small roads or over difficult terrain, live-in carers are more likely to be ‘home alone’ with the PLwD for more of the time, while PLwDs living alone are more likely to have only limited carer support.

An obvious question to consider in relation to communication experiences for PLwDs and carers in Wales is the use of Welsh (see section 8.2.2). NHS Wales states: “The issue of language choice/need must be put at the core of the patient's pathway through the health system” (2023), and PLwDs have been identified as a particularly important group for accessing healthcare in Welsh (Welsh Government, 2022b, p. 8). Thus, it is notable that the participants interested in Welsh medium healthcare (CW0501, chapter 7; P9, chapter 8) had not been able to access it. The Older People’s Commissioner in Wales points out in a report investigating the experiences of living with a dementia, and providing unpaid care in Wales that “the experience of carers in this respect [accessing healthcare through the Welsh language] varied widely” (2016, p. 48).

With only two participants in this study expressing a need for Welsh language provision, it is not possible to generalise. It is perhaps more telling that, even in a rural part of North Wales, where Welsh is widely spoken, particularly by the older generation, there was not *more* said about it. It could be a generational matter, with younger carers less concerned about the absence of Welsh, or indeed with the current cohort of older people no longer part of the earlier generations who were uncomfortable using English. But there is a wider point to make here. The UK has first language speakers of many different languages, and it is not only Welsh that is poorly provided for. There is a risk for many marginalised groups in the UK, who already encounter language barriers, that their lives will be made harder still by not being able to access vital information from public services (Welsh Government, 2018).

In sum, it must be admitted that the information gleaned in this study about the particular needs of carers in Wales was limited. Nevertheless, the original question remains: how might EC be altered to suit the needs of family carers in Wales? In the final chapter, I take a step back, to offer a rounded answer to this central question posed in chapter 1, to reflect on the challenges of undertaking this study, and to offer some pointers for future research.

Chapter 10: Conclusions

The central question driving this thesis, as laid out in Chapter 1, was: 'How can Empowered Conversations be altered to optimally suit the needs of carers in Wales?' This question was inspired by the awareness that Empowered Conversations (EC) was very well-received in Greater Manchester, and that there was nothing similar available for family carers in Wales.

In the course of the study, however, three things became clear. The first was that very little needed changing *within* the EC content, which seemed well able to meet the needs of the participants living in Wales. The second was that most of the considerations relevant to introducing EC effectively in Wales were not about Wales as such, but rather about accommodating carers in locations that were more rural than Greater Manchester and providing for carers who preferred to use a language other than English. The third element arising from the research was that it was not enough to ask *if* EC would be effective in Wales (or anywhere else). Much more important, and interesting, was to ask *why* it might be. This realisation led to an in-depth consideration of how communication works and what it takes for a carer to develop new and more effective approaches to it.

With all of this in mind, section 10.1 focusses on the central question as originally posed and section 10.2 addresses a subsidiary question pertinent to the remainder of the findings: 'What does it take for a family dementia carer to become an effective communicator?' Both themes will be drawn upon in section 10.4, to propose ideas for future research. However, that discussion will be preceded by some reflections on the limitations of the work (10.3), since these play a role in identifying what is desirable and possible for follow-on research.

10.1 How can Empowered Conversations better suit the needs of carers in Wales?

Overall, the comments from the interview participants (chapter 7) and focus groups (chapter 8) indicated that carers' needs are likely to be well met by EC in Wales, just as they are in Greater Manchester. EC provides carers with solutions to existing problems and equips them with tools to generate new strategies for combatting issues that emerge across the dementia trajectory. In regard to the general experience of caring, the Welsh and Manchester populations were very similar, indicating that EC would be beneficial if introduced in Wales. There were, however, two factors identified, that distinguished the experience of dementia communication in the two populations. The first relates to bilingualism, and the second to how a carer's place of residence, and by extension, access to social reserve, impacts on their experience of dementia communication. I will recap each in turn, and then outline how EC might be modified to meet these needs.

10.1.1 Appropriate language provision

Welsh is an official language in Wales, with a protected status. The Welsh Language (Wales) Measure (National Assembly for Wales, 2011) stipulates that making key public services in Wales accessible through the medium of Welsh as well as English is a legal requirement. Even though only two participants in this study stated that they needed to access healthcare in Welsh, they had found it problematic. They reported difficulties in being assigned healthcare professionals proficient in Welsh, and they were unsure how to go about requesting this service. One participant felt that even the use of a few phrases in Welsh could be beneficial for a PLwD, since language is associated with identity, hence extending beyond a functional level.

With all of this in mind, it would be helpful for Empowered Conversations, if introduced in Wales, to include in the input some guidance on how to access Welsh language care and support. More radically, EC would ideally be available in the Welsh medium, for those carers who prefer to use Welsh. The latter would be a very significant modification, of course, entailing the training of Welsh speaking facilitators, rewriting of the materials, translating and re-making videos etc. Before any such plans were made, it would be important to undertake market research into the potential uptake of such an offering.

An additional benefit would be the opportunity for interacting with other Welsh speakers in similar situations, which could build additional social reserve in at least two ways: new social relationships in their preferred language, and the experience of feeling acknowledged and valued as Welsh speakers, with their wishes for Welsh-medium support respected and met. Notwithstanding the typically high level facility with English that Welsh speakers have, they might well find the course content more meaningful at a personal level.

In turn, however, the case of Welsh draws attention to a wider issue related to dementia and bilingualism. There are many PLwDs and carers in the UK who would feel more comfortable getting communication training in a language other than English. Could EC be adapted to the needs of such minority communities as well? Patterns of communication are culture-dependent, meaning that, in some cases, more might be entailed than simply translating English advice into other languages, because of differences in relationships, expectations and what it is possible and appropriate to say and do when communication breaks down. While developing EC in many languages might seem implausibly optimistic, it is important to remember that carers who are not comfortable using English may be amongst the most lonely and isolated, and consequently need the most support. Furthermore, offering EC in minority languages could help increase the currently low take-up of wider dementia support services in some minority communities, by destigmatising dementia and legitimising it as topic of conversation. Training minority language speakers as facilitators would also engrain expertise within the community and might act as a catalyst for individuals into careers in healthcare.

10.1.2 Accommodating rural carers' needs

Carers' residential setting impacts on how they experience caring for a PLwD. This study gathered insights from people in Wales living in both urban and rural areas, with the latter, particularly represented in the focus groups, raising two key points: (a) that they needed access to infrastructure, including formal and informal support, and (b) that opportunities to regularly discuss issues and solutions with peers made a positive impact. While the latter is relatively easy to link to the existing design of EC, the former stands partly outside of its remit. I will recap on the main challenges and then suggest ways in which EC might, nevertheless, be able to bridge the gap to an extent.

Regarding (a), as we saw in chapter 8 and 9, formal infrastructure includes many different types of provision, including transport and hospitals, information, affordability, and accessibility. The extent to which carers can access such services is often linked to aspects of deprivation. Even though deprivation can be found in both urban and rural areas in Wales, its impact within the local area differs. Rural areas have been noted to experience 'opportunity deprivation', meaning insufficient service availability, and 'mobility deprivation' which refers to limits in accessing services (Public Policy Institute for Wales, 2016, p. 10). The Alzheimer's Society Cymru (2017) states that "there are fewer services and points of information available for people affected by dementia in rural areas", and that such services "are not usually dementia specific" (p. 10). According to the Older People's Commissioner (2021), one way in which this is displayed, and impacts negatively on older people, is limits in public transport: "over the course of a year, hundreds of older people living in rural areas in Wales are at risk of missing crucial health appointments due to lack of transport options" (p. 20).

Not surprisingly, then, two main issues related to infrastructure raised in the focus groups were transportation, and identifying and accessing healthcare services. Carers experienced anxiety related to the very limited availability of public transport. For example, accessing vital services relied on them being healthy (and wealthy) enough to drive, arrange a lift or book a taxi. Many carers also found identifying and accessing relevant healthcare services confusing, perhaps because they did not frequent relevant places often enough. As noted in section 8.3.2, having access, and speaking to people who know how the local healthcare system works could mediate this issue, and was highly valued (Bamford et al., 2014). Finally, one important aspect of infrastructure that was often mentioned in the focus groups was the value of the centre they were attending (and where the focus groups were held).

This takes us to (b), the value of peer support. Participants in both studies valued how other carers, who regularly experienced similar challenges, could often offer solutions that were more easily implemented in the daily life of dementia care than those offered by healthcare professionals. They also appreciated how other dementia carers did not stigmatise dementia in the way that those less directly affected often do. While it is probably true that carers in any location, urban or rural, can lack access to sympathetic others, the Welsh participants certainly felt that the centre was a vital aspect of support for people who, perhaps living some distance from neighbours or from a village or town, are at considerable risk of feeling lonely or isolated (Older People's Commissioner for Wales, 2016; Pinkert et al., 2021).

Loneliness is an important factor to keep firmly in mind when developing support services for carers, since it is associated with how carers rate their sense of satisfaction and quality of life (Pinkert et al., 2021; Victor et al., 2021). In turn, experiencing low quality of life is related to increased stress and anxiety levels (Farina et al., 2017; Lee et al., 2013). As we have seen in chapters 5 and 9, these factors can reduce the extent to which carers are able to utilise mentalization in dyadic communication, so that they are less able to find their way out of challenging situations.

Taking all of this into account, the following are further recommendations for using EC to improve dementia communication support in Wales, with evident potential application to populations of carers in other parts of the UK who share similar characteristics.

The first recommendation is training *local* facilitators, ideally ones who have experience of caring for a PLwD. We have seen in chapters 7, 8 and 9 that personal caring experience contributes to the authenticity of discussions of dementia, something also noted by previous EC participants (Innes et al., 2022). But in particular, caring or having cared, for a PLwD in the same geographical area means that facilitators will bring experience in navigating local healthcare, which can contribute to satisfying the pronounced need of this information. To further address this aspect of the caring experience, EC might dedicate a workshop exercise to developing carers' ability to communicate with healthcare professionals in order to identify and access relevant support services.

The second recommendation is grounded in the benefits we saw in chapter 8 regarding in-person interaction as a way of alleviating aspects of the caring responsibilities, and for widening carers' social networks. On this basis, in addition to current standard online offering of EC, courses might also be offered in-person, to increase the opportunity for additional interaction and social support. Before addressing how this mode of delivery could amplify the benefits of peer-support, there are several practical considerations associated with this suggestion that are presented in Table 10.1 (see below).

Table 10-1: Examples of advantages and disadvantages in online and face to face course provisions in rural areas

Online Course provision		**Face to face course provision**	
Disadvantages	*Advantages*	*Disadvantages*	*Advantages*
Requires technical equipment and sufficient internet connection	Comfort of own home	Limited transportation	In-person interaction
Low confidence using technology	Saving time	Long distances	No need for technology
Caring for the PLwD during course sessions	Not arranging respite	Time commitment	Easier to engage in some course exercises (e.g., nonverbal communication)
PLwD in the room	Greater flexibility in course time arrangements	Finding respite care	Socialising and exchanging information with peers

Table 10.1 shows that there are advantages and disadvantages to both online and face-to-face modes of delivery, such that EC would ideally offer both. There are several advantages in using an online format, primarily in relation to the time flexibility that is unlocked for carers in (1) eliminating transport needs and (2) arranging respite care. However, there are also drawbacks. Where carers do not possess devices that enable them to participate in online meetings, or an adequate internet connection to enable such participation, they will not be able to attend the course. Moreover, they need to have confidence in using technology, including knowledge in how to identify and employ solutions to any technical problems that arise. This includes navigating software functions such as muting speakers or using headphones for avoiding

potentially detrimental effects that can arise from a PLwD feeling upset from overhearing discussions about communication problems.

The advantages and disadvantages of in-person courses are somewhat complementary (Table 10), and, arguably, if the logistics of getting to meetings can be addressed, the in-person option might be beneficial to many carers. Albeit potentially challenging given the geographical size of the catchment area, if there were ways for the EC programme to facilitate transport, that would be ideal for enabling rural carers who cannot arrange transport themselves. As for those who do drive or access public transport, they also could benefit, because of reduced anxiety associated with total reliance on their own health (see section 9.5).

It would be beneficial for EC to run, where possible, from a centre that offers a range of other services to carers. The single most valuable one would be, as with the centre used for the focus groups, a separate meeting place for PLwDs, so that the carers do not need to arrange care cover, which often difficult to achieve (Oliveira et al., 2020). Arranging EC sessions in settings similar to the centre would mitigate this need, and potentially generate additional beneficial effects related to the PLwD's wellbeing: "she [PLwD] really enjoys this group. Nothing makes me more happy than leaving [i.e., going home after] this group and she's like 'I've had such a great time'" (P10).

Finally, carers who attend EC often remain part of each other's support networks. It follows that if EC were introduced in Wales, there would be a particular benefit in facilitating networks and ensuring a good flow of helpful information. On this basis, EC could reinforce the value of peer-support, by accommodating opportunities before and/or after sessions, for carers to converse, and create the means for them to stay in touch after the course has finished, whether in person, or online (e.g., virtual meetings or WhatsApp groups). Innes et al. (2022) report that many EC participants valued the peer-support offered within the course. In rural settings, where finding a service or some information can involve time and travel, EC participants would likely function as important information sources for each other. Emphasising the benefit of peer-support would be a small - and potentially powerful - adjustment to how facilitators deliver the course. Furthermore, although a bigger change, it would possibly be beneficial to scaffold the establishment of ongoing peer-support for participants. This could be done by facilitating a follow-up meeting one month after the final workshop session. EC facilitators would not have to be present but could help the participants get established as a permanent group. EC could also produce a list of topics that the carers might find beneficial to discuss, based on the issues that were brought up in the course.

10.2 What do carers need to improve their communication?

My approach to pinning down what dementia carers need to know, if they are to feel that communication with their loved one (and with health professionals) is effective, was to first consider the two theoretical accounts that underpin Empowered Conversations: Wray's (2020) Communicative Impact model of how communication works, and Mentalization, which is Fonagy and colleagues' (Allen et al., 2008; Fonagy, 1991; Luyten & Fonagy, 2015) model of how to make it work better. In a nutshell, Wray's model holds that communication is about effecting change in one's experiential world. High Communicative Impact arises when the speaker successfully achieves the various outcomes that they intended, including changes or lack of change in their own and/or the other person's knowledge, behaviour and/or feelings. Building on mentalization capability can heighten a person's awareness of their own and others' mental and emotional states, such that they are better informed about the dynamics of the interaction (part of what Wray refers to as 'context' (see Wray, 2020, pp. 173-174)).

I aimed in this study to combine existing findings from previous research with information from my participants and with new insights of my own. Jointly, these offer two key points relevant to understanding the nature of the carer's challenge:

1. What carers want to achieve with communication.
2. Ways in which carers change their communicative goals.

Wray (2020) states that communication functions as an instrument that can improve our world through others' agency. This presupposes that a speaker knows how such improvements will materialise. Wray also notes that speakers often have multiple agendas, for all of which they want to achieve high communicative impact. In many instances, a speaker is unsuccessful in one or more of their communicative goals. Sometimes, carers identify markers that inform them of this risk, such as noticing that the PLwD is tired or looks confused. Wray (2020, p. 196) suggests that when this happens, carers can pre-emptively change their goals to avoid negative outcomes. However, she does not outline how they know *which* goals to reframe, or how they decide how to change them. In this thesis, I have suggested that more often than not, carers prioritise generating positive emotions in the PLwD. Evidence supporting this suggestion can be found in carers' explanations of changes in their communicative behaviour that happen over time, where they often deviate from functional outcomes in favour of emotional ones.

Dementia alters communication. Therefore, changes made by carers that relate to dementia must come from experience. No carer will be able to pinpoint the exact ways in which they might in future optimally modify their perception of what language can and should do, until they have come to know how dementia impacts on communication in general, and in the person they care for in particular. In chapters 5 and 7, I suggested that information underpinning changes to communication comes from situations where carers experience low CI. The efficacy with which carers can identify such information, and assign it to a PLwD's mental states is, in part, determined by their mentalization capacity (Allen et al., 2008; Rogoff et al., 2021).

As a result, it is possible to claim that there is an order to the process that results in carers changing their communicative goals. First, they must know that communication does not work in some settings. Information that underpins this realisation comes from experiencing low CI. The carer's capacity to utilise active mentalization contributes to their identification of what aspects of communication are most likely to cause negative outcomes. This information is helpful in two ways. First, it helps them with determining whether a goal is achievable using different methods, or if recontextualising the goal will be more beneficial, i.e., reevaluating what communication can do in a given context. Second, it heightens their capacity to identify markers in a hearer or in themselves that signal a risk of low CI. Some such signals are, of course, intuitive (e.g., frowning when expressing unhappiness, or shouting when angry), but some are more closely aligned with changes to communication caused by dementia symptoms. Wray (2020, p. 200) states, on this topic: "integrating into the context component an awareness of the anticipated impact of dementia on patterns of communication will make it easier for the interlocutor to decide which way to jump when more than one solution is feasible". That is, in order for a carer to pre-emptively avoid potential negative outcomes with confidence, they need knowledge about (1) how this person's dementia, at this stage, is likely to impact on the default patterns associated with the planned communicative act (e.g., are they likely to acknowledge a comment? will they answer a question?), and (2) how this particular individual's personality, preferences and anxieties shape the decision about how to generate the best outcome (for them and the carer).

Then, it is possible to claim that for carers to develop strategies for avoiding low CI, they need to know what markers characterise it, and this stems from experience. That means that all carers must experience failure in achieving certain goals. No wonder, then, that carers sometimes find it difficult to relate to generic advice about communication, given it is not anchored in their own lived experience.

There is one final corollary of this argument. I have suggested that mentalization is an effective way for carers to track the trajectory of communication changes over time, and that the learning is dependent on experiencing low CI, that is, failure. However, we have seen that low CI very easily leads to frustration (Morris et al., 2020) and that strong emotions block the ability to use controlled mentalization. Throughout the dementia trajectory, carers experience significant transition points in terms of their relationship with the PLwD, associated with changes in the efficacy of communication as the symptoms become worse (Cooper et al., 2021). These transitions often relate to responsibilities that the carer must take over from the PLwD (e.g., cooking and driving) and the associated alteration in the balance of dependency. But some transitions are directly about the relationship, as the carer becomes less of a spouse or child, and more of a ‘parent’, or ‘carer’.

Such transition points can be particularly emotionally stressful (Braithwaite Stuart et al., 2021; Stedje et al., 2023), reducing the capacity of carers to operationalize controlled mentalization, just when it might be of particular use to them. Meanwhile, during transitions, carers might be least able to access or engage positively with support, such as EC workshops. If so, then it might be an argument for getting carers into programmes like EC earlier rather than later, so they have at least practised mentalization and have a chance of remembering its value. And it might also mean that there is value in inviting past EC participants back for a refresher session sometime later, when they may well have been through a transition and lost some of their confidence about managing the communication challenges. Alternatively, as proposed earlier, EC cohorts might be helped to stay in contact after the end of the course, so that those undergoing new challenges have support from people who fully understand what they need.

10.3 Limitations

Research rarely goes completely to plan, and there were several aspects of this project that ended up not being optimal, so that I had to find solutions and, occasionally, make adaptations.

The most significant challenge was Covid 19. Some of the UK Covid-lockdowns coincided with my data collection period. This had significant impact on identifying and recruiting participants, especially in relation to the interviews. Because of the lockdowns, many organisations I had hoped to utilise for identifying participants did not operate normally. Even though I managed to recruit a sufficient, albeit low, number of participants, it is possible that the sample is skewed and excludes participants who were not comfortable with taking part in research online, since almost all interviews – again, due to the pandemic – were conducted over Zoom.

This had two implications for my findings. First, the participants in this study were probably more adept in using technology than other carers in Wales, meaning that, with regard to infrastructure, they might have had less to say about the challenges of finding information. Second, in relation to social connection, carers who did not feel confident in using technology may have experienced a different set of issues socialising with others than the participants in this study. Therefore, I have been careful not to overgeneralise my findings in these regards. It must be said, of course, that UK residents in general were experiencing significant challenges during Covid, in relation to most aspects of social reserve. This study was, then, conducted at a particular historical moment that might not always reflect standard patterns.

A clear example of how the pandemic impacted negatively on data collection was my difficulty recruiting Welsh participants in rural areas. Due to Covid, many potential participants were unable to travel to centres in Powys and North Wales, which I originally intended to collaborate with in participant recruitment. My solution to this was to supplement my interview set with focus groups after restrictions were lifted, capitalising on the participants' regular visit to the centre, and enabling me to hear from more people relatively quickly. As it turned out, this provided additional benefits over those originally anticipated, because I was able to develop the protocols using information from my already-analysed interview findings and also introduce a new method (card sorting) to find out more about the relative importance of themes that emerged from the interviews.

One unanticipated challenge in the empirical work was that even though I had carefully planned my interview questions and focus groups prompts, participants did not always give me direct or relevant replies. It became clear that it can be hard for people to suddenly come up with answers to questions they have not thought about before, something borne out by the fact that the GM interviewees, who had discussed similar topics in EC, were often more articulate and focussed in their responses than the participants in Wales. In principle, one solution would have been to give participants the questions in advance. However, I was, and would still be, cautious about doing so, because of the risk of losing spontaneity. Rather, my conclusion about this conundrum is that much can be learned from what interviewees and focus group members fail to say. As noted in chapter 8, the sorting task generated a fascinating incongruity between which communication goals participants identified as most important (those they could not achieve), and which goals they then actually talked about (those they had found ways of achieving).

Originally, as mentioned in section 6.1, I planned on interviewing participants in Greater Manchester before and after they attended EC and comparing these accounts, including measurements of communication (2021), and quality of relationship (Sebern & Whitlatch, 2007). However, this plan was not carried out for two reasons. Firstly, it turned out that the time required to undertake the consent procedures, schedule, and conduct interviews was greater than the window between EC facilitators relaying information about potentially interested participants, and the start of the course. As a result, the limitations for ‘catching’ EC participants before they began the course posed a significant risk to data collection within the frame of the original plan altogether. Second, Covid exacerbated this issue, primarily through the additional demands to potential participants’ caring responsibilities, which considerably reduced the possibility to slot an interview within the short time frame prior to the course.

The obvious impact of this change was that I was reliant, for insights into how EC changed people’s thinking, on a different population (in Wales) for the equivalent of the ‘before’ data. Since I was also interested in differences between Wales and Greater Manchester, I minimised making strong claims about the reasons for differences between the two groups, only attributing contrasts to either location or having done EC where there was direct evidence to that effect.

I elected early on in my project design to adopt the methodologies of Reflexive Thematic Analysis and Directed Content Analysis. Although I had good reason to believe the latter would be an appropriate approach, particularly considering how its deductive nature (Assarroundi et al., 2018; Hsieh & Shannon, 2005) could allow comparisons across the data and systematically reduce potential researcher bias (Belzile & Öberg, 2012), it turned out to be a rather unwieldy method to use, occasionally causing difficulties with pinning down answers to my research questions. In retrospect, it might have been better to use another approach to the data analysis, such as discourse analysis, which would offer a greater opportunity for exploring the dynamics of how carers talked about their caring responsibilities (Doody et al., 2013), and from that, extrapolate what their biggest challenges appeared to be. On the other hand, given the theoretical framing of this thesis, directed content analysis did offer an angle that effectively tied together the data and theory, something that is an intended outcome from this analytic framework (Assarroundi et al., 2018). It also allowed me to draw links between Wray's (2020) concept of 'social reserve' and the focus group data, which constitutes an important finding in this thesis.

Braun and Clarke (2022; 2019) argue that an important part of a Reflexive Thematic Analysis (but I apply it here also to the direct content analysis process) is to provide a 'reflexive account' informing the subjective decisions that can influence the results of qualitative analyses, and thus impact on claims that follow.

Over the course of reviewing the data, I acquired more knowledge, and more perspectives for interpreting it, as the thesis work progressed. Where knowledge becomes deeper and wider, a greater range of information can become relevant to a set of research questions. This likely impacts more on latent codes than overt ones, as the researcher has greater capacity to see patterns in what is not explicitly said. One such factor was my developing insights to mentalization (see chapter 5), which occurred in parallel with the analytical process. Mentalization is central to Empowered Conversations and so comments directly and indirectly relevant to it were important to find. It is possible that I did not spot everything relevant to mentalization during the earlier parts of my analysis, compared to the later.

Moreover, the accounts from carers in England and Wales indicated relatively small differences between the two settings. This aspect of the research therefore risked being relatively thin. In order to alleviate this issue, and deepen the account contained in the thesis, I investigated the theoretical models underpinning EC (chapter 5), to create a context for considering how the two settings might differ conceptually. By applying the theoretical notions to the empirical findings, I was able to develop new insights about how the participants' reported experiences might be translated into new developments for EC.

Finally, a notable limitation of this research is that although it was about communication between carers and PLwDs, none of the latter were involved. Ideally, research about PLwDs should give them a voice (Alsawy et al., 2017). However, it was decided early on that the additional challenges of ethics and permissions to work with PLwDs could jeopardise the study by holding up the data collection. As it turned out, even if I had planned to include PLwDs, the pandemic would have rendered it impossible in practice. Nor would it have been appropriate to lay any additional burden on PLwDs at a time of huge confusion and isolation. It was, indeed, difficult enough to recruit carers, as already mentioned.

In sum, this study has several limitations, some of which have been points of learning for me, but others of which were probably never things I could have avoided. Research on topics of this type is inherently challenging and often compromised, and one can only do one's best.

10.4 Future research

In the course of the preceding chapters, there are multiple potential opportunities for future research to expand on the findings or explore new angles. In this section, I will draw on some suggestions to this end, and construct three holistically conceived opportunities for future work.

The first relates to Communicative Impact by proxy. In chapter 8, I introduced the idea that carers might derive satisfaction from observing others achieving high CI and, by extension, frustration from observing others achieving low CI. A future project might ask: What is the role of a third person in a conversation with a PLwD and a family carer? In particular, how does the level of CI achieved by that third person influence the behaviour of the carer? To find this out, an observation study might be undertaken, investigating carers' behavioural responses in settings where others speak to a PLwD. Alternatively, a researcher could show carers examples of communication with a PLwD, e.g., from 'You Look at Me Like I Live Here and I Don't' (Kirschenbaum, 2012) (from which I analysed an excerpt in chapter 2), or staged examples from 'The World Turned Upside Down: Using theatre to take a realistic look at dementia' (Jepson, 2022), and then conduct interviews, or use a Think Aloud approach (Leighton, 2017; Someren et al., 1994).

A second opportunity for future research concerns how carers generate and prioritise communicative goals. In chapter 9, I observed that carers who had had the opportunity to develop their mentalization capabilities seemed to be better at talking about their functional and emotional goals. The research literature suggests that mentalization is generally viewed as a tool for generating understanding of one's own/other's behaviour, rather than as a mechanism for 'training' people to provide a body of information about their thoughts and feelings. As such, there is scope for developing research to establish how effective mentalization training is for this purpose, and, insofar as it is, to generate a new kind of detailed database of insightful observations about the experience of being a carer. One approach to such work could be comparing what such outcomes are generated from mentalization training with one or more other methods for helping carers understand their experiences. For instance, by compiling and delivering generic information about how the PLwD's communication and behaviour may change (Alzheimer's Society, 2022), and what communication strategies believed to facilitate these changes that are available on websites targeting carers (Harris et al., 2024).

Finally, it would be interesting to address practical approaches to mother tongue support for dementia carers and PLwDs. I have suggested earlier that the paucity of Welsh language provision in health and social care support in Wales is just one instance of a broader phenomenon in the UK (as in many other countries) where people would be more comfortable receiving support in a language other than English. Welsh and British Sign Language have the official status that ought to attract such provision – though in both cases there is a lack of skilled users of those languages within the relevant professions. Meanwhile, there are probably several other languages with greater user populations for which provision would be valuable. A research study could investigate the potential benefits of providing healthcare to a PLwD in their mother tongue, and, likewise, of offering support to carers in their preferred language. A possible method would be a combination between observations of PLwDs and/or carers in healthcare settings as they communicate in English and/or another language, and interviews with the PLwD, family carer(s) and healthcare professionals involved. Pragmatic and sociolinguistic analytic frameworks would offer a theoretical basis for conceptualising how first language healthcare provision impacts on the individual's wellbeing in general, and communicative abilities in particular.

10.5 Concluding remarks

As of now, one out of eleven of us is likely to develop dementia (NHS, 2023b), and that figure is likely to increase (World Health Organization, 2017). A much greater proportion of us are likely to have to support a loved one who is living with it. Although the voices of carers are heard, to an extent, the research presented in this thesis has shown that carers have very specific things to say about their experience of communication, and a strong desire to receive support in learning how to achieve better communicative outcomes.

It is in the interests of everyone in society to champion ways of helping dementia carers to learn how to be good communicators, whether they be in Greater Manchester, Wales, or elsewhere. This research has shown that Empowered Conversations is one excellent approach for providing the training that dementia carers need, and there is every reason to promote its use across the UK.

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Appendix A – Participant information sheet: Greater Manchester

PARTICIPANT INFORMATION SHEET

Facilitators of dementia communication from the perspective of family carers in urban England and rural Wales

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish.

Thank you for reading this.

1. What is the purpose of this research project?

This study is part of a PhD at Cardiff University looking into how communication can be improved between family carers and people living with a dementia. It is well known that a dementia can create difficulties in communication. However, there has not been much research on what carers feel they might need to facilitate communication and overcome communication difficulties. Therefore, the main aim of this study is to investigate what any such needs might be. An additional aim is to investigate whether communication needs might differ between people living in Greater Manchester and Wales. Therefore, this study will have two sets of participants, one in Greater Manchester and one in Wales. The outcome of this research will help us understand whether an existing communication course (Empowered Conversations) offered in greater Manchester needs to be altered to suit the needs of carers in Wales.

2. Why have I been invited to take part?

You have been invited because you are a family carer to someone living with a dementia and am attending or have completed an Empowered Conversations course.

3. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part, the researcher will answer any questions you might have about the project, and ask you to sign a consent form. If you decide not to take part, you do not have to explain your reasons.

If you do take part, you will still have an opportunity later to withdraw your contribution. The procedures for how to do this are outlined under point 9c ‘What if I change my mind about the data I give?’.

4. What will taking part involve?

Taking part will involve filling out two short forms and participating in an interview about communication with the person with dementia whom you know best. The forms concern (1) how you perceive the communication and (2) relationship with the person you are caring for. These forms will be emailed to you shortly before the interview. You will be asked to email the filled-out forms back to me prior to the interview, or report your answers verbally during the interview session.

The interview will be conducted over Zoom and will be audio-recorded. It is estimated that the session will take about 60 minutes. Assistance with using Zoom will be provided if needed.

In order to protect confidentiality, if there are any interruptions during the interview (e.g. someone else enters the room) the recording will be paused until it’s possible to continue.

5. Will I be paid for taking part?

No. You should understand that any information you give will be a gift and you will not benefit financially in the future, even if this research leads to the development of a new product or treatment.

6. What are the possible benefits of taking part?

Although this research is not designed to give specific benefits, many people find it helpful and enlightening to talk about their experiences. Furthermore, the information you provide will help contribute to the understanding of how communication difficulties can be addressed.

7. What are the possible risks of taking part?

The topic of dementia can be sensitive. Therefore, if you get upset at any point during the interview, you can choose to end the session or take a break. If you want to continue the interview after that, it will be continued whenever is convenient for you.

8. Will my taking part in this research project be kept confidential?

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see ‘What will happen to my Personal Data?’ (below) for further information.

9. What will happen to the data in this research project?

Any data from or about you will be kept in line with Cardiff University’s data retention guidelines. These guidelines state that all identifying data should be kept until five years after the end of the project, which, at earliest, will be September 2028. However, data that is anonymised may be retained indefinitely where it is deemed beneficial for further research. In addition, your consent form will be kept for as long as the anonymised data to serve as proof that you have given consent for this data to be used. In order to ensure that I will not keep your anonymised data and consent for longer than necessary, I will review annually whether it is still needed.

a. What will happen to my personal data?

The personal data collected about you will be your:

- Name
- Email address
- Age
- Gender
- Relationship to the person with dementia
- Interview recordings containing your voice
- Consent form

This data will be stored on a password protected computer and backed up on a secure web-based cloud service called OneDrive which is provided by Cardiff University. Only I will have direct access to these files.

In order to ensure participant confidentiality, your name will not appear on any documents other than the consent form. Instead, all documents about you will be assigned a participant number which will be used instead of your name to protect your identity. The only document containing both your name and participant number will be the consent form. This is necessary to prove that you consent for the data to be used.

b. Other identifying information

In the course of your interview, you are likely to disclose names, places and other information that you don't particularly want to be shared in the public domain. To ensure confidentiality, I will change all such information when I transcribe the interview. I will do all of the transcription and analysis. Thus, the original recording will be kept, but not shared, other than, as necessary, with my supervisors as they support my research. In such a case, they will honour your confidentiality the same way as I do, and will not share or disclose information to anyone else.

c. What if I change my mind about the data I give?

Should you say something in the interview that you would like to withdraw or change you will have an opportunity to do so. You can either let me know at the end of the interview or send me an email up to one week after the interview (at which point the anonymisation of the interview will have begun) and disclose what you would like to omit or change. I will then find that section and delete or change it in line with your wishes. You will be reminded of this at the start of the interview.

d. What else do I need to know?

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

10. What happens to the data at the end of the research project?
The data collected from you will appear in the results of a PhD-thesis and possibly publications, presentations, or other similar outputs stemming from the thesis. However, names, places, and other identifying information have been changed, as described earlier. Nothing will be used that is likely to enable someone else to identify you. The information you put on the two short forms will be combined with that of other participants and if anything from your form is reported in the write-ups of the research, it will be anonymised. Verbatim quotes from you might appear in the PhD-thesis or other publications, but, again, with any identifying information changed.

11. What if there is a problem?
If you wish to complain, or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Axel Bergstrom (Bergstromae1@cardiff.ac.uk) or Professor Alison Wray (supervisor, WrayA@cardiff.ac.uk). If your complaint is not managed to your satisfaction, please contact Tereza Spilioti (encap-researchintegrity@cardiff.ac.uk) who is the head of the ethics committee at the School of Communication, English and Philosophy at Cardiff University.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

12. Who is organising and funding this research project?
The research is organised by Axel Bergstrom at Cardiff University, supervised by Professor Alison Wray.

The research has been made possible through a Collaborative Doctoral Award jointly funded by the Economic and Social Research Council, Health and Care Research Wales and Cardiff University's College of Arts, Humanities and Social Sciences. The research is being conducted in collaboration with Empowered Conversations.

13. Who has reviewed this research project?
This research project has been reviewed and given a favourable opinion by the School of English, Communication and Philosophy Research Ethics Committee.

14. Further information and contact details
Should you have any questions relating to this research project, you may contact me during normal working hours:
Axel Bergstrom
Bergstromae1@cardiff.ac.uk
School of English, Communication and Philosophy, John Percival Building, Colum Drive, Cardiff.

Thank you for considering supporting this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a signed consent form to keep for your records.

Appendix B – Participant information sheet: Wales

PARTICIPANT INFORMATION SHEET

Facilitators of dementia communication from the perspective of family carers in England and Wales

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish.

Thank you for reading this.

1. What is the purpose of this research project?

This study is part of a PhD at Cardiff University looking into how communication can be improved between family carers and people living with a dementia. It is well known that a dementia can create difficulties in communication. However, there has not been much research on what carers feel they might need to facilitate communication and overcome communication difficulties. Therefore, the main aim of this study is to investigate what any such needs might be. An additional aim is to investigate whether communication needs might differ between people living in Greater Manchester and Wales. Therefore, this study will have two sets of participants, one in Greater Manchester and one in Wales. The outcome of this research will help us understand whether an existing communication course (Empowered Conversations) offered in greater Manchester needs to be altered to suit the needs of carers in Wales.

2. Why have I been invited to take part?

You have been invited because you are a family carer to someone living with a dementia living in Wales.

3. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part, the researcher will answer any questions you might have about the project, and ask you to sign a consent form. If you decide not to take part, you do not have to explain your reasons.

If you do take part, you will still have an opportunity to later withdraw your contribution. The procedures for how to do this are outlined under point 9c ‘What if I change my mind about the data I give?’.

4. What will taking part involve?

Taking part will involve participating in an interview, and filling out two short forms about how you perceive the communication and relationship with the person with dementia whom you know best. The forms will be emailed to you when the consent form is signed. You will be asked to email the filled-out forms back to me prior to the interview, or report your answers verbally during the interview session. The interview will be conducted over Zoom and will be audio-recorded. It is estimated that the session will take about 60 minutes. I may ask you to participate in an additional interview and do the questionnaires again about two months after the first session. However, if so, I will get in contact with you again so that you can choose whether you want to participate or not.

Assistance with using Zoom will be provided if needed.

In order to protect confidentiality, if there are any interruptions during the interview (e.g. someone else enters the room) the recording will be paused until it's possible to continue.

5. Will I be paid for taking part?

No. You should understand that any information you give will be a gift and you will not benefit financially in the future, even if this research leads to the development of a new product or treatment.

6. What are the possible benefits of taking part?

Although this research is not designed to give specific benefits, many people find it helpful and enlightening to talk about their experiences. Furthermore, the information you provide will help contribute to the understanding of how communication difficulties can be addressed.

7. What are the possible risks of taking part?

The topic of dementia can be sensitive. Therefore, if you get upset at any point during the interview, you can choose to end the session or take a break. If you want to continue the interview after that, it will be continued whenever is convenient for you.

8. Will my taking part in this research project be kept confidential?

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see 'What will happen to my Personal Data?' (below) for further information.

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a. What will happen to my personal data?

The personal data collected about you will be your:
- Name
- Email address
- Age
- Gender
- Relationship to the person with dementia
- Interview recordings containing your voice
- Consent form

This data will be stored on a password protected computer and backed up on a secure web-based cloud service called OneDrive which is provided by Cardiff University. Only I will have direct access to these files.
In order to ensure participant confidentiality, your name will not appear on any documents other than the consent form. Instead, all documents about you will be assigned a participant number which will be used instead of your name to protect your identity. The only document containing both your name and participant number will be the consent form. This is necessary to prove that you consent for the data to be used.

b. Other identifying information

In the course of your interview, you are likely to disclose names, places and other information that you don't particularly want to be shared in the public domain. To ensure confidentiality, I will change all such information when I transcribe the interview. I will do all of the transcription and analysis. Thus, the original recordings will be kept, but not shared, other than, as necessary, with my supervisors as they support my research. In such a case, they will honour your confidentiality the same way as I do, and will not share or disclose information to anyone else.

c. What if I change my mind about the data I give?

Should you say something in the interview that you would like to withdraw or change you will have an opportunity to do so. You can either let me know at the end of the interview or send me an email up to one week after the interview (at which point the anonymisation of the interview will have begun) and disclose what you would like to omit or change. I will then find that section and delete or change it in line with your wishes. You will be reminded of this at the start of the interview.

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- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

10. What happens to the data at the end of the research project?

The data collected from you will appear in the results of a PhD-thesis and possibly publications, presentations, or other similar outputs stemming from the thesis. However, names, places, and other identifying information have been changed, as described earlier. Nothing will be used that is likely to enable someone else to identify you. The information you put on the two short forms will be combined with that of other participants and if anything from your form is reported in the write-ups of the research, it will be anonymised. Verbatim quotes from you might appear in the PhD-thesis or other publications, but, again, with any identifying information changed.

11. What if there is a problem?

If you wish to complain, or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Axel Bergstrom (Bergstromae1@cardiff.ac.uk) or Professor Alison Wray (supervisor, WrayA@cardiff.ac.uk). If your complaint is not managed to your satisfaction, please contact Tereza Spilioti (encap-researchintegrity@cardiff.ac.uk) who is the head of the ethics committee at the School of Communication, English and Philosophy at Cardiff University.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

12. Who is organising and funding this research project?

The research is organised by Axel Bergstrom at Cardiff University, supervised by Professor Alison Wray.

The research has been made possible through a Collaborative Doctoral Award jointly funded by the Economic and Social Research Council, Health and Care Research Wales and Cardiff University's College of Arts, Humanities and Social Sciences. The research is being conducted in collaboration with Empowered Conversations.

13. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the School of English, Communication and Philosophy Research Ethics Committee.

14. Further information and contact details

Should you have any questions relating to this research project, you may contact me during normal working hours:
Axel Bergstrom
Bergstromae1@cardiff.ac.uk
School of English, Communication and Philosophy, John Percival Building, Colum Drive, Cardiff.

Thank you for considering supporting this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a signed consent form to keep for your records.

Participant ID no:

Appendix C – Consent form interviews

CONSENT FORM

Title of research project: Facilitators of dementia communication from the perspective of family carers in urban England and Wales

SREC reference and committee: ENCAP/Bergstrom/21-10-2021

Name of Chief/Principal Investigator: Axel Bergstrom

Please initial box

I confirm that I have read the information sheet dated 20/10-21 version 4 for the above research project.	
I confirm that I have understood the information sheet dated 20/10-21 version 4 for the above research project and that I have had the opportunity to ask questions and that these have been answered satisfactorily.	
I understand that my participation is voluntary and I am free to withdraw without giving a reason and without any adverse consequences.	
I consent to the processing of my personal information: name, email address, age, gender, relationship to the person with dementia, and consent form for the purposes explained to me. I understand that such information will be held in accordance with all applicable data protection legislation and in strict confidence, unless disclosure is required by law or professional obligation.	
I understand who will have access to personal information provided, how the data will be stored, and what will happen to the data at the end of the research project.	
I consent to being audio recorded for the purposes of the research project and I understand how the recording will be used in the research.	
I understand that anonymised excerpts and/or verbatim quotes from my interview, potentially appearing together with my questionnaire results, may be used as part of the research publication.	

Participant ID no:

I understand that if, during the interview, there is any interruption that would impact on confidentiality, the recording will be paused until the interruption is over.	
I understand how the findings and results of the research project will be written up and published.	
I agree to take part in this research project.	

________________________	__________________	__________________
Name of participant (print)	Date	Signature

Axel Bergstrom	__________________	__________________
Name of person taking consent (print)	Date	Signature

PhD-student
Role of person taking consent (print)

THANK YOU FOR PARTICIPATING IN OUR RESEARCH

YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

Appendix D - Interview-guide

Sample A(1): Empowered Conversations, Greater Manchester, Time point 1
Sample A(2): Empowered Conversations, Greater Manchester, Time point 2
Sample B: Family carers living in Powys

Set 1 – Sample A(1) and B

1. Could you tell me a bit about yourself and your mum/dad/wife/husband[30]?
    a. Do you know what sort of dementia your [relative] has?
        i. Does he/she have a formal diagnosis?
        ii. Do you know how long ago he/she got that diagnosis roughly?
    b. Does your [relative] live on his/her own?
        i. How long has that been the arrangement?
        ii. Is there anything you wish was different about where you/they live?

- *Follow-up questions might change to adequately address the participant's living situation*

As you know, I'm interested in how family members and people with dementia communicate with each other. So I'm going to ask you a few things about how you feel communication works with your [relative].

2. For a start, are there any aspects of your communication that you feel are challenging?
    a. Is there anything that still seems to work well?
    b. Going back to what you said about *[replies to 2 and 2a]*, do you have any thoughts about why that happens/works okay?

3. What did your communication used to be like before your [relative] had dementia?

---

[30] Henceforth referred to as '[relative]'

4. Do you feel like you have had to adapt your communication to handle the way things have changed, and if so, how?
    a. Could you give me an example of how you adapt your communication?
        i. [depending on answer] is this something that happens all the time or occasionally?

In case participant does not talk about communication strategies:

In my research so far I've been putting together a list of different things that people have said they do to help with the communication. Now, some of these won't be relevant to your situation because not all dementias are the same, but could I try some of them out on you and see if they apply to you?

- Talking more slowly
- Using simpler words
- Not even trying to talk about some topics [*if yes*: which topics? Why?]
- Being prepared to repeat yourself (and using different words)
- Taking a deep breath rather than getting angry

There is a lot of interest these days in trying to help people in your situation cope better with the daily challenges of communicating with their loved one.

5. I was wondering if there's anything you think the people trying to help should pay more attention to that would make your life easier?

Prompts

- More things to read about what to expect as dementia progresses
- Someone you could phone for advice
- A list of dos and don'ts for effective communication
- Courses you could attend
- Ways to help the person with dementia change what *they* do

I wonder what advice you'd give to yourself if you could go back to the start of all this.

6. What key things do you wish you'd realised earlier, or done sooner, or known how to do?

7. There are quite a few technical things that can make communication easier. Do you use any technology for communicative purposes with your [relative]?

    a. Did you use any technology to talk to friends and family during the pandemic (e.g. Zoom)? How did you find it, using that?
    b. Do you use any voice controlled devices (e.g. Alexa/Google Home etc.)? How did you find it, using that?
    c. Do you use any computers or tablets to stimulate communication through pictures or video? How did you find it, using that?
    d. Some researchers have been developing robots that would talk to people living with dementia, for company. What do you think about that?

It’s easy to overlook the role of other people around you in how they might make things harder or easier.

8. Have you been able to notice whether your [relative] is able to communicate well with people like neighbours, shop assistants, the dentist, hairdressers and so on?
    a. Is there anyone in particular who makes an effort to communicate with him/her?
        i. What is it that they do that other don’t?
        ii. Do you think others could do that too?

9. Is there anything else you feel is important to talk about?

Set 2 – Sample A(2)

1. How have you been since last time and how are you feeling?
    1. Since last we spoke, I know you have taken the Empowered Conversations course and I'll ask you about that in a minute. But first, I was wondering if anything else major has happened in your life?
    [if anything from last interview: last time you mentioned (insert from prior interview), has that happened yet/how was it?]

2. How did you find the Empowered Conversations sessions?
    1. Why do you think it was useful/so and so/bad etc.?

I know that the Empowered Conversations team have already asked you for feedback on the course. My questions are a little different. I'm interested in what Empowered Conversations isn't yet covering.

3. So, I wonder if there's anything you'd hoped you'd learn from the sessions but didn't?

Prompts

Is that because it wasn't covered?

What would you have liked to see them do to cover it?

Let's move away from Empowered Conversations and [potential support the carer has received and addressed].

4. If you could wave a magic wand and make one thing happen that would improve communication between you and your [relative], what would that be?
    1. Can you talk me through how that would help?
    2. Is there anything else you'd like to see that would improve communication?

Do you do anything different since having attended Empowered Conversations?

[if carer sees communication different since taking the Empowered Conversations course]…

5. Is there anything different you notice in how others communicate with your [relative]?

Or [if the carer does not see communication differently] Even if you don't feel like you do many things differently after Empowered Conversations, do you think that…

… it’s easier to identify good practice in what others do when they communicate with your [relative]?

    i. What is it that they do that other people don’t?
    ii. Do you think others could do that too?

6. What do you think are the most important things for a family carer to know to make communication with someone living with dementia as easy as possible?
    a. Why do you think that is?

7. Is there anything else you would like to mention?

8. Did I bring up question that you thought I would ask in this interview, or did you expect something else

Appendix E – Participant information sheet: Focus groups

PARTICIPANT INFORMATION SHEET

Facilitators of dementia communication from the perspectives of carers to people living with a dementia in England and Wales

You are being invited to take part in a research project conducted by me, Axel Bergstrom. Before you decide whether or not to take part, please read the information below, so you are aware of the purpose of the research, and what it will involve. You are welcome to discuss this information with others if you wish.

On the first pages, the most important things you need to know about the project are outlined in summary. On the pages that follow, the same headings are listed, but contain more information. In case there is something you are wondering about but that you cannot find, please ask the lead researcher Axel Bergstrom on Bergstromae1@cardiff.ac.uk

1. What is the purpose of this research project?

- This study is part of a PhD at Cardiff University
- The research looks into how communication works between you and your loved ones
- It also investigates what it is like to be living with a dementia in North Wales

2. Why have I been invited to take part?

- You have experience of supporting a family member or friend living with a dementia
- You are familiar with what it is like for someone to deal with the challenges of dementia in North Wales

3. Do I have to take part?

- No, participation is completely voluntary
- If you do not want to participate, you do not have to say why
- I, Axel, am happy to answer any questions
- If you feel unsure whether you want to take part you may discuss it with whoever you want, e.g., a close family member

4. What will taking part involve?

- Discussing what it is like to support a person living with a dementia in North Wales
- Discussing whether there are any advantages or disadvantages to supporting someone living with a dementia in North Wales
- Talk about what the goals of communication are for you, and if a communication course might help you achieve them

5. What are the possible benefits of taking part?

- A positive talking experience
- Getting your voice heard

6. What are the possible risks of taking part?

- Talking about dementia may be upsetting for you or might upset someone else. If that happens, you are welcome to leave the room for a bit if you like.

7. Will my taking part in this research project be kept confidential?

- All your data will be confidential, and anything you say will be anonymised

8. What will happen to my Personal Data?

- Any information that could potentially identify you (see **9a** in the 'further information'-section), like your name, or if you say something including specific places, will be changed (anonymised)
- The only document that will continue to identify you is the signed consent form, which I have to keep, securely, so I can prove that I only gathered information from people with their agreement.
- All data that has been anonymised will be kept for a minimum of five years after the research project is completed (see 9 below for further information)
- The data will be stored securely on my computer, and in a private folder (OneDrive) on the internet. The university subscribes to this service, and it is deemed a safe place to store the data.
- If, during or after the session, you change your mind about participating that is completely fine. Just let me know. However, I will not be able to remove your comments after the data analysis has started (see 9c for further information)

9. What happens to the data at the end of the research project?

- Information that you provide will appear in a PhD-thesis and possibly in published research articles
- You might be quoted in this research, but if so, your comments will be anonymous

10. How can you express any concerns about this research?

- If, during the session, you have any concerns, please either mention them to me, or feel free to simply leave the room.
- If you have any concerns after the session is complete, you can speak to me or email me later. You can also email my supervisor or the Chair of the ethics committee. All contact details are given below.

FURTHER INFORMATION

1. What is the purpose of this research project?

This study is a part of a PhD at Cardiff University looking into how communication can be improved between family carers and people living with a dementia. It is well known that a dementia can create difficulties in communication. However, there has not been much research on what unpaid carers of people living with a dementia living in North Wales feel might impact on dementia communication. Participants in this study will be asked to discuss some questions in a group-setting, focussing on what it is like to support a person living with a dementia in North Wales, and if dementia communication might be different for carers living in that setting to carers living elsewhere. The outcome of this research will help us develop, pinpoint, and understand challenges to and facilitators of dementia communication that might be specific to individuals living in North Wales and similar locations.

2. Why have I been invited to take part?

You have been invited because you are a family member, neighbour, or friend of someone living with a dementia, for whom you provide regular support.

3. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part, the researcher will answer any questions you might have about the project, and ask you to sign a consent form. If you decide not to take part, you do not have to explain your reasons.

If you do take part, you will still have an opportunity later to withdraw your contribution. The procedures for how to do this are outlined under point 9c ‘What if I change my mind about the data I give?’.

4. What will taking part involve?

Taking part will involve joining a small group of people similar to you, in a room in the Centre. You will be asked to discuss topics related to your experiences of supporting someone living with a dementia, whether your experiences in North Wales might be different from elsewhere, and what might be done to help with any challenges you have experienced with communication.

The session will take at least 30 minutes, but we might carry on talking longer if we wish to. The session will be video and audio recorded (please see section 9 below for a detailed account of how these recordings will be handled to ensure that your identity and contributions are anonymised). The video recordings are carried out to make sure that I have a recorded copy of a sorting task which I will ask you to do, and to ensure that I know who said what in the group.

5. Will I be paid for taking part?

No. You should understand that any information you give will be a gift and you will not benefit financially in the future, even if this research leads to an outcome with commercial potential.

6. What are the possible benefits of taking part?

Although this research is not designed to give specific benefits, many people find it helpful and enlightening to talk about their experiences. Furthermore, the information you provide will help with understanding how communication difficulties can be addressed, and specifically pinpoint any challenges that may be particularly prominent in North Wales. This information could benefit people like you in the future.

7. What are the possible risks of taking part?

The topic of dementia can be sensitive, and you might get upset. If that happens any point during the session, you can choose to exit the room and return at your convenience. You may also choose to end your participation at any time. If you do, the data you have contributed to the session up to that point will be included in the data analysis unless you ask that it is excluded.

8. Will my taking part in this research project be kept confidential?

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see ‘What will happen to my Personal Data?’ (below) for further information.

9. What will happen to my Personal Data?

Any data from or about you will be kept in line with Cardiff University’s data retention guidelines. These guidelines state that all identifying data (I am outlining what data this is in the list below, see 9a) should be kept for as long as the project is ongoing, which, at the very earliest, will be September 2023. The consent form is retained for longer, in order to prove that you have consented to participate in the research. In exceptional circumstances concerning research integrity auditing, individuals from Cardiff University or from regulatory authorities might have access to the consent form and/or other data and information that has been retained for that purpose.

Data that is anonymised will be retained for at least five years after the end of the research project (September 2028 at the earliest), but may be retained for longer where it is deemed beneficial for further research. In addition, your consent form will be kept for as long as the anonymised data to serve as proof that you have given consent for this data to be used. To ensure that I will not keep your anonymised data and consent for longer than necessary, I will review annually whether it is still needed.

a. What will happen to my personal data?

Directly identifying information

- Consent form – kept securely, as long as the anonymised data

- Name, Email address, phone number (if applicable) – deleted five years after the end of the PhD-project (i.e. in September 2028 at the earliest)
- Video and audio recordings of you – deleted five years after the end of the PhD-project (I.e. in September 2028 at the earliest)

Anonymised information – will be retained to at least September 2028, but may be retained for longer. I will review annually if the information might be needed. If not, it will be deleted.

- Age
- Gender
- General place of residence
- Relationship to person living with a dementia
- Amount of regular support given per week
- Transcripts of audio and video recordings

Data will be stored on a password protected computer and backed up on a secure web-based cloud service called OneDrive, which is a private file repository associated with Cardiff University. Only I will have direct access to these files. However, audio files may be sent to an auto-transcription program run by Microsoft, to which Cardiff University subscribes. This service uses an external server. The file is kept secure while it is sent to this server and the transcription, which is fully automated, takes place. In other words, no person will hear the audio file. Once the transcription is complete, the text file with the transcription is sent back to me, and as I check it for accuracy, I will remove any identifying information, such as your name (as outlined below). The audio file is automatically deleted from the external server.
To ensure participant confidentiality, your name will not appear on any documents other than the consent form. Instead, all documents about you will be assigned a participant number which will be used instead of your name to protect your identity. The only document containing both your name and participant number will be the consent form. This is necessary to prove that you consent for the data to be used.

b. Other identifying information

During the group discussion, you are likely to disclose names, places, and other information that you might not particularly want to be shared in the public domain. To ensure confidentiality, I will change all such information in the transcription. Meanwhile, the original recording will not be shared, other than that I might play a short extract to my supervisors if I need advice on how to interpret it. In such a case, they will honour your confidentiality the same way as I do, and will not share or disclose information to anyone else.

c. What if I change my mind about the data I give?

Should you say something in the group discussion that you would like to withdraw or change you will have an opportunity to do so. You can either let me know at the end of the focus group or send me an email up to one week after the session and disclose what you would like to omit or change. I will then find that section and delete or change it in line with your wishes, subject to what is feasible for the data from the group as a whole.
You will not be able to withdraw any data once the analysis of the discussion is under way (approximately 1-2 weeks after the data collection), because of the way in which different people’s comments impact on each other, and will be used together.

d. What else do I need to know?

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

10. What happens to the data at the end of the research project?

The information gathered from the discussion will be described in a PhD-thesis and possibly publications, presentations, or other similar outputs stemming from the thesis. However, names, specific places, and other identifying information will have been changed, as described earlier. Nothing will be used that is likely to enable someone else to identify you. Verbatim quotes from you might appear in the PhD-thesis or other publications, but, again, with any identifying information changed.

11. What if there is a problem?

If you wish to complain, or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Axel Bergstrom (Bergstromae1@cardiff.ac.uk) or Professor Alison Wray (supervisor, WrayA@cardiff.ac.uk). If your complaint is not managed to your satisfaction, please contact Dr Tereza Spilioti (encap-researchintegrity@cardiff.ac.uk) who is the chair of the ethics committee at the School of English, Communication, and Philosophy at Cardiff University.

Cardiff University reminds you that if you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

12. Who is organising and funding this research project?

The research is organised by Axel Bergstrom at Cardiff University, supervised by Professor Alison Wray.

The research has been made possible through a Collaborative Doctoral Award jointly funded by the Economic and Social Research Council, Health and Care Research Wales and Cardiff University's College of Arts, Humanities and Social Sciences. The research is being conducted in collaboration with Empowered Conversations (Age UK), a communication course currently given in Greater Manchester.

13. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the School of English, Communication and Philosophy Research Ethics Committee, SREC-reference 221129ENCAPBergstrom.

14. Further information and contact details

Should you have any questions relating to this research project, you may contact me during normal working hours:

Axel Bergstrom
Bergstromae1@cardiff.ac.uk
School of English, Communication and Philosophy, John Percival Building, Colum Drive, Cardiff.

Thank you for considering taking part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and the consent form to keep for your records.

Participant ID no:

Appendix F – Consent form: Focus groups

CONSENT FORM

Title of research project: Perceived factors impacting on the experience of dementia communication in rural Wales

SREC reference and committee: 221129ENCAPBergstrom, Cardiff Research Ethics Committee

Name of Chief/Principal Investigator: Axel Bergstrom

Please initial box

I confirm that I have read and understood the information sheet dated 30/11-22 for the above research project and that I have had the opportunity to ask questions and that these have been answered satisfactorily.	
I understand that my participation is voluntary and I am free to withdraw any time up until analysis has begun (approximately one to two weeks after participation) without giving a reason and without any adverse consequences. I understand that if I withdraw after data analysis has started, unanonymised video data and all anonymised data about me will be retained. The video data will, however, only be used for analyses related to this research project, and not shared in any setting.	
I understand that under exceptional circumstances of research integrity auditing, individuals from Cardiff University or from regulatory authorities might have access to the consent form and/or other data and information that has been retained for that purpose.	
I consent to the processing of my personal information: Name, email address, telephone number (if collected), age, place of residence (i.e. identifying as living rurally or not), relationship to the person living with a dementia I support (e.g. spouse, child, friend, etc.), approximate numbers of hours I support a person living with a dementia per week, video recording of me talking in a focus group setting, audio recording of me containing my voice, and consent form, for the purposes explained to me. I understand that such information will be held in accordance with all applicable data protection legislation and in strict confidence, unless disclosure is required by law or professional obligation.	

Participant ID no:

I understand who will have access to personal information provided, how the data will be stored and what will happen to the data at the end of the research project.	
I understand that the audio-files containing my data may be sent to a secure automated transcription service, and that my data will exist outside of the researcher's private folders until the transcription is completed, at which point, the file automatically will be deleted, as outlined by the Microsoft Azure terms of service. For an alternative: see below	
If you would like to opt out of automated transcription and, instead, have your data manually transcribed by the researcher, please tick this box	
I consent to being audio and video recorded for the purposes of the research project and I understand how data produced from these recordings will be used in the research.	
I understand that anonymised excerpts and/or verbatim quotes from my data may be used as part of the research publication or in presentations resulting from this research.	
I agree to take part in this research project	

Name of participant (print)	Date	Signature
Axel Bergstrom		
Name of person taking consent (print)	Date	Signature

PhD Student
Role of person taking consent (print)

THANK YOU FOR PARTICIPATING IN OUR RESEARCH

YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

Participant ID:

Appendix G – Form: personal data - focus groups

Facilitators of dementia communication from the perspectives of carers to people living with a dementia in England and Wales: Focus Group Forms

How old are you?

____

Do you live in a rural or urban setting?

____

What is your relationship to the person living with a dementia that you support?

____

Approximately how many hours a week do you provide support for the person?

____

Appendix H – Focus group guide: questions

Introduction

- Researcher introduction.
- Background to research.
- Introduction to focus group rules (i.e., no wrong opinions or questions) and focus group questions.
- Addressing camera and recording device.

QUESTION 1
To start things off: As we are in North Wales, do you think that there are any particular challenges for you as carers, based on where you live, which are associated with communication?

Probes
There are many things that relates to where you live that can impact on communication. For instance, how close we are to friends and family, if we can get a GP appointment often, or if we can rely on the internet to contact people further away.

Do you think your experiences would be different if you lived in a big city like Manchester or Birmingham, say? Why?

In what ways are you glad you are dealing with your current challenges here in North Wales? In what ways do you wish you were living somewhere else?

Quite often, research about dementia and communication is conducted in bigger cities. Whilst some researchers are brought up in rural environments and have better insights to what that might be like, far from all are. Is there anything in particular you might advise them to focus on which can impact on dementia and communication in relation to living in North Wales which they might not think about?

QUESTION 2
If there was a course for people like you, focused on supporting you in communicating with people living with a dementia, what topics would you like it cover?

Probes

- Do you think that e.g. neighbours might be a bigger asset in certain settings than others, for example if the PLwD wanders?
- NHS is organised differently in Wales and England, from your experience with NHS in Wales, might this be a problem for people, living in English cities developing courses?
- Might someone who is a first language Welsh speaker encounter specific difficulties?

QUESTION 3

We all know that dementia can change the way we communicate with someone affected by the condition, and how they communicate with us. Sometimes, this can be really challenging. I would like you to have a look at the cards which you have in front of you. These contain some of the things that carers I have interviewed over the last year said were important to them.

What I'd like you to do is decide between you which of these actions are most important and put them into order. Of course, you will probably have different priorities, and that's really what I want to hear about. It'll be really helpful to me to just get you talking to each other about why *you* think that a certain action should go at the top, whilst someone else prefers something else. If you can get them in order, that's great, but if some of them tie, that's fine too.

TOPICS

- Making the person feel positive
- Creating meaningful conversations
- Accepting change by adapting to the person
- Maintaining the person's independence
- 'Reading between the lines' to figure out what they really need and want
- Providing reassurance
- Making sure you can be empathetic and patient
- Understanding how the disease impacts on communication

QUESTION 4 (IF TIME)

As a final question, I want us to think about the many different people who have to communicate with your loved one with dementia – carers, doctors and nurses, the postman, the hairdresser, shopkeepers, clergy, and so on. So I wanted to hear your views on people you have found to be particularly good or particularly bad at communicating with them, and what you think makes them so good or bad.

Probes

Do you think there are any specific skills that people can have which would make it easier to communicate with someone living with a dementia more efficiently than others?

Do you think that there are specific things that are particularly important to avoid when speaking to someone living with a dementia?

- Do you think that this is something that everyone can learn to avoid doing?

Do you think you would give different answers if you lived somewhere else?

QUESTION 5 (IF TIME)

Is there anything else in relation to what we have been talking about that you want to mention? Have we missed anything?

(Sum up topics)

CLOSING THE FOCUS GROUP

- Thank participants for participating.
- Repeat procedures and contact information in the event that any participant wants to report worries or concerns, or amend any of their statements.
- In the event anyone is upset or step out, check on them.

Appendix I – Sorting task: Focus Group

This document contains the topics which participants will be asked to sort under question 3 in the focus groups (see focus group questions [Appendix 7]).

A	Making the person feel positive
B	Creating meaningful conversations
C	Accepting change by adapting to the person
D	Maintaining the person’s independence
E	‘Reading between the lines’ to figure out what they really need and want
F	Providing reassurance
G	Making sure you can be empathetic and patient
H	Understanding how the disease impacts on how you communicate

Appendix J - Gatekeeper permission form

Title of research: *Facilitators of dementia communication from the perspective of carers of people living with a dementia in England and Wales*

A 'gatekeeper' is a person who helps a researcher gain access to research participants, by virtue of a pre-existing connection that he or she has with potential participants.

This form is issued to the project manager of the Dementia Centre, Carers Trust North Wales as part of the protocol for approaching potential participants (family carers of people living with a dementia) for a research project carried out by Axel Bergstrom, Cardiff University. This document briefly outlines the core concepts of this research, and suggestions for how you may approach potential participants. This research will be carried out in the form of focus groups, i.e. between 4-8 people discussing what it is like to care for someone living with a dementia in North Wales.

This research aims to investigate the following research questions:

2.1. What factors associated with living in rural North Wales are perceived to be prominent for managing dementia communication with respect to people living with a dementia and their unpaid carers?
2.2. What aspects of communication are perceived as important to include in communication training for people living with a dementia and their unpaid carers in North Wales?
2.3. What successful communication strategies have been observed from people outside of the immediate social vicinity (e.g. GPs, nurses, hairdressers, shop assistants etc.) who successfully employ communication facilitation strategies with a person living with a dementia?

Specific formulation of questions, and procedures are outlined in the document 'Focus Group Questions' which will been sent to you.

Before the focus groups
You will be asked to help me contact family carers attending the dementia centre who might be interested in joining a focus group. Ideally, they will learn about the study one week in advance of the planned focus groups. You will be sent flyers over email which briefly outline the study. You may give these out, or email these to participants, whatever is easier for you. Should you want to print these out, I will cover the cost for this.

It is imperative that participants understand participation is voluntary, and that by reporting interest, they are by no means consenting to participate. Should potential participants be interested in participating, they will be given three choices of receiving information. These are (1) having a participant information sheet sent to them over email from me (Axel); (2) being phoned up by me, or (3) receiving a participant information sheet on the day of the study.

For participants who opt for receiving information per email or phone, I will ask you to collect their email address *or* phone number (i.e. not both, unless a potential participant explicitly asks for information over both email and phone) and check that the participant consents to having this information sent to me, before sharing this information with me over email. All participants will receive a printed consent form on the day of the study, but some might like to see it in advance. This possibility will be disclosed in the email I send to them, or over the phone.

On the day of the study

On the day of the study, I will ask you to organise a room with a closed door where the focus groups can be carried out. I will be setting up a camera and an audio recorder in this room. Each focus group (ideally two, conducted at different times) will take at least 30 minutes, but may go on for up to an hour each.

On the day of the study, I will approach the group of carers who are present, and ask them if anyone would be interested in participating, or if anyone would like more information at that time. Participant information sheets and consent forms will be available for everyone, including those who were previously sent information. They will be given at least 30 minutes to read through the participant information sheet, and will be offered an opportunity to discuss any concerns with me.

As soon as at least four participants are ready, I will conduct the first focus group immediately, allowing more time for others to read through the information. Upon concluding the first focus group, I will return to the main group, answer any questions, and hope for at least four more volunteers for the second focus group.

Depending on numbers and readiness, I may slightly vary the procedure just outlined, to address the needs and preferences of those present.

Consent-form

Statements	**Initials**
I understand the purpose and procedures of the study outlined in this, and other documents sent to me	
I have been offered a chance to ask questions which have been answered to my satisfaction	
I understand that no potential participant is under an obligation to consent, and if they choose to not participate, they will not face any negative repercussions. I will not put pressure on anyone to participate if they do not wish to.	
I understand the suggested approaches that the researcher has outlined in this document and consent to carrying them out in a manner which is best suited for the participants associated with my organisation	
I consent for this research to take place in my organisation	

SIGNATURES

Name of gatekeeper (print)	Date	Signature
Axel Bergstrom		
Name of person taking consent (print)	Date	Signature

PhD Student
Role of person taking consent (print)