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Determiners of social inclusion and exclusion in the dementia context: the perspective of family carers

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Abstract

People living with a dementia and their family carers are at high risk of being excluded from the contact, activities, information and services that help them remain resilient. Using interview data from family dementia carers, this article explores the sources of enablement and inhibition in accessing these aspects of social inclusion. Carers and those living with a dementia are found to inhibit and enable social inclusion for themselves, each other, and other carers. However, carers attribute most agency to the external environment: what is provided and how easy it is to access, along with the attitudes and beliefs of others. Poor communication surfaces as an impediment to social inclusion, with carers often left trying to bridge communicative gaps despite limited knowledge and self-confidence.

Keywords

dementia; family caregivers; social inclusion; communication; social reserve; emotional reserve

1 Introduction

The World Health Organization (2012, 47) asserts the right of people living with a dementia (henceforth PLwDs) to “live in the community and to have access to health, social and other support services that enable them to lead full and meaningful lives within society.” For at least two reasons, this right for PLwDs cannot be entirely separated from that of the family members who take on caring responsibilities for them. First, the daily experiences of carer and cared for are very intertwined, with each potentially affecting the other’s access to social activities and support. Second, in many cases, the needs of the PLwD are primarily identified, met and described by their family member.

This article explores how family dementia carers (henceforth FDCs), experience and create patterns of agency in social inclusion and exclusion – their own and that of the PLwD. Our dataset is interviews with FDCs, part of larger study about the potential transferability of a communication training initiative across communities with different geographical and social profiles. To these interviews we add, with permission, some observations made by two FDCs in personal correspondence with one of the authors.

The remainder of this section briefly sets the parameters of our account. Section 2 contextualises the study using previous research, presents a conceptual model of the issues and articulates the research questions guiding our data analysis. Section 3 uses our dataset to find indicative answers to the research questions. Section 4 draws together some conclusions about the findings.

A few preliminary observations will clarify the nature, scope and limits of our account. First, although generalising across different types and stages of dementia can be unwise, we consider it likely that many issues *consequent* on someone having dementia, such as communication breakdown and social exclusion, are rather similar across dementia types (Wray 2020, 9-10). Second, while recognising that PLwDs *without* FDCs are particularly vulnerable to social exclusion, our focus on FDCs prevents us considering the specific needs of that group. Third, our study includes first, second and third generation FDCs, both full-time and part-time, and we remain alert to the differences between them. As Murray et al. (1999, 666) point out, “A daughter who helps with domestic tasks for an hour each day is unlikely to experience caregiving in the same way as a spouse providing constant attention.” We therefore also note how FDCs relate to each other, and particularly how one FDC can have agency over the social inclusion or exclusion of another.

Finally, at its broadest, a study of social inclusion and exclusion would recognise many interfacing factors: someone living with a dementia could also be physically disabled, from an ethic minority and/or part of the LGBTQ community, for example (Innes, Archibald, and Murphy 2004, 13). Our scope is narrower. We approach *social inclusion* primarily from the perspective of access to social interaction and services, rather than the exercise of rights, even though the two are closely linked.

2 Social inclusion/exclusion and dementia care

According to an Alzheimer’s Society report (2017, 16), “more than a quarter (27%) of all carers surveyed agreed with the statement: *as a carer of someone living with dementia I feel cut-off from society*.” Of course, a simple-looking statement potentially hides a lot of important information (Galasiński and Kozłowska 2010). Some respondents may have meant that they were cut off from social contact – family, friends, work, hobbies, outings, etc. Others might have meant being overlooked by agencies they turned to for help, whether relating to dementia health care directly or the much broader range of infrastructural provision, e.g. inflexible payment systems, lack of suitable transport options, inconvenient opening hours, long waits on the telephone, inaccessible financial support. Others still might have meant that society gave them no voice in decision-making, so their needs and concerns went unrecognised. Thus, social exclusion can arise because the FDC is absent from environments that they would prefer to be in, or because systems stack the odds against them gaining free and fair access to what they need. These factors can interact. For example, studies of dementia care in rural areas (e.g. Forbes et al. 2011; Orpin et al. 2014) found that living in a small community can be either facilitatory or inhibitory in accessing support, depending on whether neighbours are a resource or are an impediment to anonymity and confidentiality.

In the survey mentioned earlier, "Just 17% agree with the statement *there is enough support available for those who care for people with dementia.* … Over a quarter (27%) of carers say that no one has provided them with advice or support about caring for someone with dementia" (Alzheimer's Society 2017, 22). A study for the Older People's Commissioner for Wales (2016) makes clear that primary healthcare practices must ensure adequate support in securing appointments, sending out reminders and passing on information (11). The same report acknowledges the impact of other infrastructural deficits:

> lack of access to appropriate and/or reliable methods of transport made it difficult to access services, such as appointments with healthcare professionals, attending day centres or participating in other forms of activity designed to provide social interaction and cognitive stimulation" (Older People's Commissioner for Wales 2016, 18-19).

Many initiatives for improving social inclusion (in the sense central to this article) understandably focus on offering activities suitable for PLwDs that can either free up the FDC's time or bring them into contact with support and information. However, FDCs often do not know how to find this provision (e.g. Stone and Jones 2009). Twenty-five years ago, in a study across fourteen countries, only 29% of the 280 family dementia carers interviewed belonged to a support group (Murray et al. 1999; Schneider et al. 1999). Online opportunities may since have improved the situation, but as two major factors are lack of time and guilt at prioritising self-care (Cleveland Clinic 2019), perhaps only marginally.

In practice, many socialising options may not be ideal for FDCs. One FDC, who took his wife to *Singing for the Brain*, said: "I'm not sure how long I will be able to cope with doing the Hokey-Cokey in a circle of old biddies. At one level it is profoundly depressing" (FDC A, personal communication, July 2022). *Singing for the Brain*, carer support groups, day centres, and so on, are certainly important, but the daily experience of isolation for FDCs may generate deep and conflicting feelings and perceptions about the disease, the cared for person, the situation, and the self, that require far more to unpeel and address (Wray 2013, 2014, 2016, 2020). FDC A commented: "I glimpse a possible future for us and doubt that I'm up to it." In short, as Gallagher and Rickenbach (2020, 1434) found in their study, FDCs bring to their situation "an accumulation of their life experiences". These are likely to interact with the new demands on them, since "effects of previous lived experiences are at the heart of the mediatory process of reflexivity" (Elster 2017, 281). These factors make each individual different. It is against that backdrop that we will, nevertheless, look for patterns.

2.1 Communication as a factor in social inclusion/exclusion

That communication problems shape the FDC's experience is much reported (Watson et al. 2012; Purves and Phinney 2012; McEvoy et al. 2019). Wray (2020) examines how dementia affects the general and specific dynamics of communication, and what the onward impact is on daily life. As part of this project, she makes a direct link between communication as a means to adjust one's social world through the agency of another person, and the social and emotional experiences of living with a dementia or caring for someone who does. She captures this link in the concepts *social reserve* and *emotional reserve*. These reserves mirror the neural and cognitive reserves considered protective against dementia-causing diseases and their symptoms (e.g. Stern 2012).

Social reserve is "the currency of resilience located in a person's cultural and social context… an external resource, deriving from how people living with a dementia, and those who support them, are viewed and treated in society" (Wray 2020, 76). Emotional reserve is "the internal personal (emotional) resources that individuals can draw upon to equip them to cope to a greater or lesser extent with the direct or indirect effects of dementia" (Wray 2020, 103).

High social reserve occurs when the social context in which the person lives is supportive, in terms of infrastructure (including health and welfare services, information, travel needs, finances), attitudes (in individuals, institutions and the media), social groups (places for people to meet, undertake activities, feel supported), and credibility (empowerment, voice, agency, identity) (Wray 2020, 76-78). Thus, high social reserve tends to link with social inclusion, while failures in aspects of social support will amount to, or at least feel like, exclusion, with likely onward impact on emotional resilience. Meanwhile, a person's willingness to take up opportunities for social interaction is likely to be enhanced by high emotional reserve.

Sustaining social inclusion is a significant challenge laid at the door of the whole of society, from how one votes to interacting with one's next-door neighbour. Since the support that PLwDs and FDCs need from others (individual and institutional) is necessarily brokered by effective communication in both directions, the social reserve concept helps explain how communication and social provision are interlinked.

2.2 A reference model of social inclusion and communication

To gain focus and granularity for our investigation into the social exclusion and inclusion of PLwDs and FDCs, it is useful to consider the main potential agents and how they interact (Figure 1). The PLwD and FDC's social inclusion and/or exclusion are determined through three core influences: themselves, each other, and external factors.

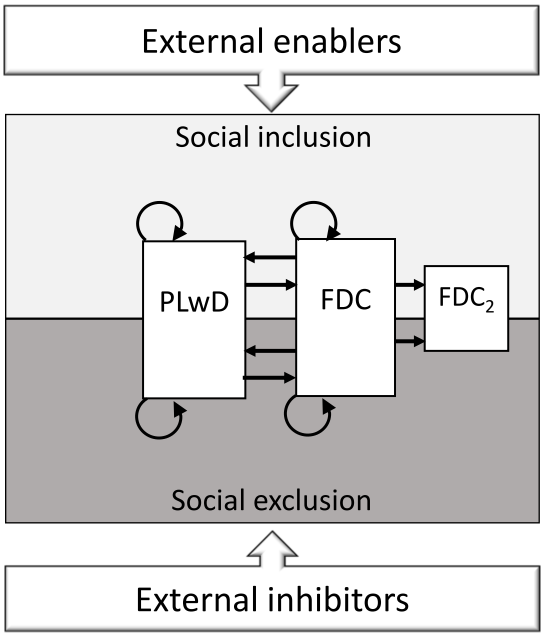

Figure 1: Enablers and inhibitors of social inclusion

The circular arrows indicate how a PLwD or FDC can facilitate or inhibit their own social inclusion. For example, a PLwD might be anxious about leaving the house or spending time with strangers (inhibitors) or be highly social and easy to please (enablers). An FDC might sacrifice a job or hobby to accommodate caring responsibilities (inhibitor) or might be motivated to seek out a group of other FDCs to gain support (enabler).

The arrows between the PLwD and FDC boxes show how each can inhibit or enhance the social inclusion of the other. For example, if the PLwD is unwilling to leave the house, or can't be left alone, the FDC's capacity for social interaction is curtailed. Conversely, if the FDC locks the door to prevent the PLwD wandering, the PLwD's ability to engage with others outside the home is limited. The link between FDC and FDC_2 indicates how one FDC can facilitate or inhibit the social inclusion of another. For example, a daughter unwilling or unable to sit with her father might prevent her full-time carer mother attending her choir practice. Alternatively, the daughter might enhance her mother's social inclusion by teaching her how to use social media or Zoom.

Figure 1 also indicates the role of external enablers and inhibitors. These include what groups and activities are available, the quality and accessibility of health and social care, general infrastructural support, such as transport, telephone and broadband, and the willingness of individuals encountering the PLwD to behave in a supportive and inclusive manner.

Jointly, these inhibitors and enablers are the key determinants of the social reserve available to the PLwD and/or FDC. It typically falls to the FDC to navigate the inhibitors of access to core social provision (Schneider et al. 1999), leaving them over-busy, over-tired and under-confident, all likely to erode their emotional reserve (Wray 2020). The integral nature of facilitation and inhibition is nicely summed up in this comment:

> looked at objectively it would seem to be a sure bet, almost axiomatic, that the lot of carers could be one of frustration, strife, anger, depression, anxiety, or even despair, such is the unworldly, intense nature of the devastation that dementia can cause. Any lack of support for carers can only exacerbate the inherent difficulties. Carers need quick access to advice and their knowledge and skill-set needs regular upgrading to match the degeneration of the dementia. Importantly, they need to feel a sense of belonging, within a backbone of proactive support" (FDC B, personal communication, August, 2022).

2.3 Research questions

Turning to our data from FDCs, we explore how their comments align with the inhibitors and enablers represented in Figure 1:

- Mechanisms of social exclusion:
  - How do FDCs exclude themselves from inclusion and help?
  - How do PLwDs exclude themselves?
  - How do FDCs exclude the PLwD?
  - What are the external causes of exclusion?
- Mechanisms of social inclusion:
  - How do FDCs attempt to enhance their own inclusion and get help?
  - How do FDCs attempt to enhance the inclusion of another FDC?
  - How do FDCs attempt to enhance the PLwD’s inclusion?

3 What family dementia carers say about social inclusion and communication

3.1 Method and data

Our participants were FDCs in Greater Manchester (GM) and Cymru-Wales (CW). An FDC was someone regularly providing unpaid care for a family member with diagnosed or suspected dementia (of any kind). The English participants were previous or future attendees at a communication course for dementia carers. The Welsh participants were accessed via relevant organisations and through personal contacts of the authors.

Our analysis used data from the first 16 participants in the larger study. Three were carers of their spouse/partner, six of their mother, five of their father, two of their grandmother and one of a neighbour (one FDC cared for both mother and father). Six were full-time carers, the remainder varying from few hours per day to an hour on the phone per day along with regular visits.

Participants were interviewed one-to-one on Zoom or in person. The interviews focussed on ways of overcoming communication challenges, and were audio-recorded and transcribed verbatim. For this analysis, the authors independently coded a pool of relevant comments selected by one of the authors. The underpinning full coding was in accordance with a reflexive six-step thematic analysis framework (Braun and Clarke 2006, 2019; Byrne 2022). This approach codes explicit participant opinions (semantic codes) and potential underpinning themes relating to the research questions (latent codes).

The research had full ethical approval and all participants consented to their words being quoted anonymously.

It is important to note that the interviews did not have social inclusion and exclusion as target topics. Rather, the findings reported below emerge from the responses to questions about communication. The significance of this is discussed in the concluding comments.

3.2 Mechanisms of social exclusion

How do FDCs exclude themselves from inclusion and help? Commonly mentioned ways in which FDCs were vulnerable to self-imposed exclusion related to reorganising their life to make their new caring role possible and, once in that role, judging it too risky to step away and leave the PLwD on their own. However, most of the comments associated with FDC self-exclusion reflected social inhibition with strong links to communication. Poor previous experiences made them reticent to ask for help: “I think the trouble with… any phone line or any professional organization, the issues are getting through to somebody” (CW0201) and fearful of not being able to express their needs to others: “the communication I had with the doctor, that was the difficult bit trying to get him to make any sense of what I was saying” (CW0202). One informant commented that her mother, as the main FDC, self-excluded from family support by always moaning and being negative, which alienated them from her.

We infer from the accumulated comments that FDCs experienced a communicative barrier in relation to explaining the precise nature of their needs in a manner that could engender a helpful response. This echoes a recent study (Synergia 2022, 26) in which 46% of FDCs surveyed in New Zealand “did not feel the [needs] assessment process included their needs as a carer and they did not feel supported”.

How do PLwDs exclude themselves? When FDCs depicted PLwDs as agents of their own exclusion, underlying personality and previous patterns of behaviour could play a role, but the perceived primary culprit was the dementia. PLwDs living alone were particularly at risk of exclusion, but even those with energetic support might be reticent to access social contexts, being reluctant to spend time with (apparent) strangers, to travel by car or leave the familiarity of the house, along with unwillingness to pay for professional help.

A frequent self-exclusion theme related to communication failure, including changes in the PLwD’s interactional behaviour, difficulty using the phone, and problems expressing their needs or understanding that they actually had needs. PLwDs would become distant from family members whom they no longer recognised and withdraw from conversations they could not keep up with: “she won’t be able to follow it and then she will withdraw into herself because she will feel vulnerable and a little bit scared about making a fool of herself" (GM1103).

How do FDCs exclude the PLwD? Unsurprisingly, FDCs did not mention deliberate actions on their part to limit the PLwD's social inclusion. Negatively oriented comments were typically about another FDC in the family. Children of PLwDs would describe their caring parent as resistant to their offers of help, or as compromising the PLwD through their own physical limitations:

> so when mum and dad go out, she walks with a stick very slowly and holds onto dad, which means that dad doesn't get a lot of exercise and he can only go out with mum or one of us because he will get lost. Otherwise, he don't remember where he is (CW0504).

Several informants mentioned a reluctance on the part of other FDCs to take the PLwD into social situations that would be socially awkward (for the FDCs): "The reason they weren't going out as much was because he was getting embarrassed about the way mum is sometimes" (GM0306).

For their own part, our informants' tendencies to limit the social freedoms of the PLwD were expressed in terms of protection, such as ensuring the PLwD wasn't vulnerable to unscrupulous or unhelpful individuals, and avoiding potentially distressing topics in the PLwD's presence: "if we're discussing… her care or trying something new or anything like that, I won't do it in front of her" (GM1101).

What are the external causes of exclusion? FDCs perceived the primary sources of social exclusion for both the PLwD and themselves as external. The Coronavirus pandemic was mentioned as a significant constraint on social inclusion. Others fell into two main categories: societal attitudes, beliefs and ignorance, and poor infrastructure and services. Ignorance was a central theme in how society excludes PLwDs and FDCs:

> If you had a plaster on your leg, they'd make sure that they didn't kick it, or if you were covered in spots they'd keep away, but because you can't physically see it and you're out and about, and you start behaving strange, no one knows what to do, no one knows how to talk to *me* (GM0303).

Ignorance led to unhelpful approaches, such as linking dementia to violent behaviour:

> [I asked] “Has the person kind of had any dementia training” and straight away the lady said, “why no is she is your nan violent or something”, something random. I was quite offended by it and I was a bit like no, absolutely not (GM1101).

Poor communication skills in outsiders could manifest in overwhelming the PLwD with chatter, bombarding them with questions, or talking down to them:

> she hates people being patronizing (.) And sort of talking quite loud as if she cannot understand anything … I know that makes mum really annoyed and she shuts down she won‘t cooperate (CW0501).

As for infrastructure and services, FDCs identified many sources of social exclusion, including weak broadband, over-complicated communication software, absence of toilets in public locations, and poor public transport. Of the many factors associated with core health and care provision, several related to aspects of communication, including absence of Welsh language care provision in Wales, health professionals failing to read the information provided about the PLwD, and difficulties getting information and/or support at or after diagnosis. Regarding the last, there were reports of both bewildering information overkill and too little information: “you can feel really quite… forgotten and ignored” (GM0203); “you have to find [support groups] yourself. No one tells you that they’re there and that they’re available, it’s word of mouth” (GM0303); “I found a generic number for independent living services and they may or may not put you through to some other people and they don’t actually tell you who they put you through to, and you never get more than the front line number” (CW0504).

3.3 Mechanisms of social inclusion

In considering facilitators, we focus on the agency of the FDC, rather than the external environment (which, in terms of core infrastructural and healthcare provision should be facilitative by definition) or the PLwD (whose capacity to sustain social engagement is likely to be viewed as a surviving capability rather than a proactive contribution). To this end, we consider how FDCs attempt to enhance their own inclusion and get help, and how they facilitate the inclusion of other FDCs and, centrally, that of the PLwD.

A notable theme was the FDC as a bridge between the PLwD and those unable or unwilling to sustain social engagement, often via communication, e.g.

> 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 (GM0202).

How do FDCs attempt to enhance their own inclusion and get help? Two main determiners emerged. One was valuing what was available, including opportunities for training, and family, friends, neighbours and other FDCs acting as listeners and advisors. The other related to the FDC's internal capacity to manage situations calmly and thus be more able to engage with others. Self-awareness and reflection enabled them to accept their situation: "we've had *those* good times. Now we're having *these* good times, which are different" (CW0501), and recognise their needs, appreciate support when it was given, and give themselves space: "it's okay if she doesn't want to talk to me, that's fine, and actually it just gives me a night off." It also helped them manage challenges, such as persisting when help was slow to come and avoiding unnecessary conflict with the PLwD. One interesting observation was that communication techniques learned for use with the PLwD turned out to be valuable with other interlocutors as well.

How do FDCs attempt to enhance the inclusion of another FDC? As noted, some of the FDCs in the study were not the primary family carer, and a number of comments were made about helping their more heavily involved family member, usually their other parent, remain socially included. These interventions included assisting them to manage new communication technology, suggesting they attend training and/or engage in socialising, advising and encouraging them, and providing back-up practical support such as relief cover and coordinating contributions from family members. One FDC also recognised the importance of seeing things from others' viewpoints:

> I fell out with my mum about it because she just wouldn't even consider moving [house]… And they were so stubborn about it and, and it would have saved a lot of heartache and you know to understand from their perspective (GM0611).

How do FDCs attempt to enhance the PLwD's inclusion? FDCs mentioned practical ways of making social interaction possible: getting PLwDs into company, especially compatible friends, valuing and prioritising good communicators, recognising the communicative contexts that worked best, and prizing the emotional effects of going out: "She's never been in a supermarket the last two years or something, just basic stuff. I found- and I don't know whether it's me just imagining it or what, but I found she was more responsive" (GM0611).

Enabling social interaction also entailed managing the PLwD's anxiety about going out, experimenting with activities to see if they were feasible, and being willing to step in, to repair communication breakdowns. One FDC said: "I see my job or my dad's job is to make sure that interaction doesn't last too long (.) so that people don't feel uncomfortable" (GM0306). Another commented, "after a while I think they can obviously pick up that my mum can't follow the train of conversation so that I obviously have to step in and… sort of accommodate that" (GM0202).

Other practical interventions included making books about the PLwD's life story, so others could connect with them, teaching them to use FaceTime and Zoom, and printing out restaurant menus in advance. Responsibilities were shared around the family to ensure the PLwD got a break from the main FDC. More radical was moving house to be nearer the PLwD, though this could create significant tension. One FDC who lived at a distance felt that ideally she should move closer, even though it would impact her life:

> he's not getting that daily love and support that he needs… I just think he'd be happier knowing that somebody was just popping in… I'd maybe feel more tired if I lived around the corner… then I'd maybe feel more resentful… but it would certainly, I suppose it would set my mind at rest and make me feel like a better daughter (GM0201).

The second approach to enhancing social inclusion regarded respect for the PLwD's autonomy, and promoting a 'normal' environment. As Wray (2020) points out, 'normal' is a distorted and complex notion in the dementia context, however. As a result, some well-intentioned actions could be considered forms of unintentional malignant social psychology (Kitwood 1997). FDCs spoke of denying there were problems and simply covering for the PLwD, and of tricking them into socialising. Even setting up power of attorney, a way of protecting the PLwD's interests, had a negative side, in reducing the PLwD's autonomy.

Third, FDCs mentioned acceptance of the situation, and clearing emotional space for the PLwD to be accepted as they were: “he’s obviously telling me a tale, to him it means something, and I’m just answering something totally different to what he’s saying but as long as he is getting some form of feedback, he seems quite happy about it” (GM0303). Others spoke of managing their own emotions and of using mentalisation and empathy to remain alert to unexpressed needs.

4. Conclusion: Social inclusion and the opportunity for communication

Despite being interviewed about communication, all of our informants made many observations that reflected aspects of social inclusion and exclusion. This link can be explained as follows. Social connection is vital for many things central to our well-being, including information, reassurance, entertainment and physical help. Meanwhile, communication is a significant means by which we sustain our well-being, insofar as we use it to get others to act as agents in changing our experiential world (Wray 2020). Thus, when people are deprived of the opportunity to communicate with others, it will likely be immediately and fundamentally detrimental to their well-being. This connection between communication and social inclusion frames some final observations based on our findings.

First, a huge responsibility seems to fall on FDCs to bridge communication gaps, which poses a challenge even for those with relevant training. These gaps extend beyond the primary miscommunication between the FDC and PLwD to encompass also interaction between the PLwD and third parties, where the FDC may feel the need to ‘mop up’ miscommunication in order to rescue meaning and save face. Another gap is between themselves and health and social care professionals. It seems to fall to FDCs to convey their needs comprehensibly and convincingly, and to navigate biomedical, psychological and infrastructural jargon. All these responsibilities require pragmatic skills and self-confidence, which FDCs may not have.

A second notable topic, no doubt arising in part from the first, was the adoption of avoidance strategies, that is, social exclusion (of themselves and the PLwD), due to anxiety about being able to effectively cope with communicative demands arising in relatively uncontrolled social contexts.

Future research might explore the extent to which improved communication can enhance social inclusion. But what would that mean exactly? One indication comes from a study by Dooley and Barnes (2022). They found that doctors doing out-of-hours home visits to PLwDs had greater success in gaining compliance for an examination or treatment when they explained to the PLwD why they were there. Their finding illustrates a more general point of key importance to our study, namely that, insofar as shared contextual knowledge plays a central role in effective communication (Wray 2020, 149), it will also play a role in social inclusion. If the interlocutors in a conversation make different assumptions about what is known and unknown, interaction is likely to engender misunderstandings. However, that is only the tip of the iceberg, because each interaction creates the context for the next. Thus, where information is appropriately and effectively shared, a greater and more beneficial contextual space is created for future interaction.

This rule of thumb can be applied to how health professionals do or don't offer adequate contextual information to the PLwD, as in Dooley & Barnes' (2022) study, but also how they explain biomedical and other information to FDCs, and how they receive the contextual information that FDCs attempt to share with them when they seek advice. Training in better communication is not, then, simply about guidance in what to say and how, but about developing alertness to the needs of the interlocutor. This requires empathy and mentalisation (McEvoy et al. 2019), that is, training in new ways to think about oneself and others.

Finally, our participants' depictions of the enablers and inhibitors of inclusion indicated a complex conceptual space, full of contradictions and tensions. Although there was evidence that FDCs did inhibit social inclusion (for themselves, the PLwD and other FDCs), it was far outstripped by ways in which they attempted to enable it. It would be interesting in a future study to ask FDCs specifically about this topic. However, we value our sideways look at it, drawn from their comments on communication, since this minimised any risk of them becoming defensive or of imposing their own assumptions about what might be most interesting to mention.

We close with two comments from FDC B, who looks after his wife full-time. His observations capture the practicalities of enabling social inclusion, and its importance:

> Carers have a big job to do helping those they care for to maintain links, particularly with family and friends. Often small things help to maintain contact, e.g. using loudspeaker for all incoming and outgoing phone calls and reading out aloud e-mails or letters. Keeping family and friends aware of developments, particularly in terms of communication, would also be most helpful, allowing them to better anticipate how they might relate to those living with dementia, so helping to avoid unnecessary frustrations (Family Carer B, personal communication, August 2022).

> When we help others we can receive in return an enormous amount of satisfaction, a sort of thank-you to ourselves. Helping can become a win-win situation, a virtuous circle, helping ourselves whilst we help others, which can sustain us when difficulties inevitably occur (Family Carer B, personal communication, August 2022).

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