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Experiences of a communication-skills course for care partners of people living with dementia, empowered conversations: A qualitative framework analysis

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Experiences of a communication-skills course for care partners of people living with dementia, Empowered Conversations: A qualitative Framework Analysis

### **Abstract**

**Objectives:** Our aims were to examine whether an experiential course for care partners of people living with dementia, Empowered Conversations (EC), was acceptable to participants, and to explore participants' perceptions of the impact of the course upon their communicative interactions. EC is based on an integrative model derived from psychological and linguistic theory and empirical evidence. EC is based on Mentalisation Theory, Perceptual Control Theory and linguistic theory (The Communicative Impact Model).

**Methods:** Qualitative data were collected via 28 semi-structured interviews.

Framework Analysis was used to analyse data.

**Results:** Three superordinate themes, "Improved communication", "Improved wellbeing" and "Support through others" were identified. Twenty-seven out of the 28 participants described feeling that they were able to better connect with the person living with dementia that they were supporting through attending EC.

**Conclusions:** The findings indicated that EC was acceptable and beneficial to care partners. Care partners developed a range of strategies and understandings that enabled them to communicate better with the person they were supporting, enhanced wellbeing and relationships, as well as developing social networks. This is the first qualitative study to examine a psychosocial intervention for care partners of people

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living with dementia using a non-CBT framework and indicates that perceived control could influence how care partners respond to stress and difficulties.

Keywords: dementia; carer; caregiver; skills training; intervention

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People living with dementia can struggle to lay down memories, think through complex plans, and produce and comprehend language due to neurological decline (Bayles & Tomoeda, 2014). Family carers provide intense practical support, whilst coming to terms with changes in their relationship (Morris, Mansell, et al., 2018).

Two systematic reviews of communication-based training-interventions for carers of people living with dementia have identified limitations to the interventions available (Eggenberger et al., 2013; Morris et al., 2017). Courses targeting communication tend to have a narrow focus on the pragmatics of communication; for example, delivering limited content information in short, simple sentences (Eggenberger et al., 2013; Morris et al., 2017). While such strategies can be helpful, they do not encompass changing relational dynamics; for example, a spouse or child may feel increasingly cast in a parent role (Pozzebon et al., 2016; Smebye & Kirkevold, 2013). A recent qualitative systematic review of the role of families in supporting communication in people with dementia, found three themes: (1) ‘identities changing’ (how interactions within the family systems impacted on identities); (2) ‘loss’ (the grief experienced by families due to changes in communication); and (3) ‘developing communication strategies’ (Braithwaite Stuart et al., 2022). The first two themes have clear relational and interactional elements that are not captured purely within specific strategies to improve communication.

Furthermore, very few courses for family care partners demonstrate improvements on specific communication outcomes and even when effects were demonstrated these were not consistent across follow-up points (Morris et al., 2017); however, several interventions demonstrate an impact on broader communication skills (Morris et al., 2017; Nguyen et al., 2018; Perkins et al., 2021). Across reviews care partner communication skills and knowledge were the outcomes that were most significantly improved by communication-based training-interventions for carers of people living with dementia (Eggenberger et al.,

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2013; Morris et al., 2017; Nguyen et al., 2018; Perkins et al., 2021). A minority of interventions demonstrated improvements in care partner anxiety and depression (e.g. Gitlin et al., 2010; Judge et al., 2010; Livingston et al., 2013). An additional recent review of communication interventions for informal care partners found that none of the studies reviewed had a significant impact on carer stress (Perkins et al., 2021). This review also identified a high quality study of a cognitive behavioural therapy communication intervention that improved care partner quality of life (Barnes & Markham, 2018). However, generally communication focused interventions have a limited effect on care partner quality of life, mood or stress (Eggenberger et al., 2013; Morris et al., 2017; Perkins et al., 2021).

[The terms ‘family carer’, ‘care partner’ and ‘informal carer’ are often used interchangeably and refer to people undertaking unpaid caring activities e.g. a spouse or friend. Based on previous consultations with people living dementia and carers, ‘care partners’ is used for informal carers and ‘people living with dementia’ for those they are supporting (Farina et al., 2017; Young et al., 2011). ‘Carers’ is used as the overall term for family and professional carers/ caregivers.]

Very few studies have qualitatively examined training and psychological interventions for family care partners. A recent systematic review of interventions for carers of people living with dementia that included a communication-focused component only identified two qualitative studies and these focused on the same intervention: carer-delivered cognitive stimulation (Orgeta et al., 2015; Yates et al., 2016). The time period searched regarding qualitative studies within this update review of training for carers with a communication element was 2010- 2017, expanding this time period to the past 20-years and searching more broadly for psychological interventions uncovered seven additional studies (Auclair et al., 2009; Brännström et al., 2000; Johannessen et al., 2015; Sommerlad et al., 2014; Sørensen et al., 2008; Goodall et al., 2021; Lauritzen et al., 2023). However, only

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three of these specifically included communication strategies or support (including a further qualitative analysis of cognitive stimulation), and these interventions did not use a group format (Auclair et al., 2009; Sommerlad et al., 2014).

The 'Empowered Conversations' (EC) course was developed for care partners of people living with dementia (Morris, Mansell, et al., 2018). EC runs weekly for 4-weeks (each session lasts 2.5 hours and includes a break) and is a community based, group-training course. It is based on the Communication Empowerment Framework (CEF), which is an integrative theoretical framework and addresses the specific psychological, relationship and communication needs of family dementia carers (Morris, Mansell, et al., 2018). It was designed to support carers with the relational stress, and other stressors, that can arise when supporting someone living with dementia. EC targets both developing communication skills and managing the stress that can arise from being a family carer.

The CEF that underlies EC draws together three theoretical accounts of how humans negotiate their world and maintain wellbeing: 1) Mentalization Theory relates to our perceptions of ourselves and others; 2) Perceptual Control Theory explains how conflicting internal and interpersonal goals can reduce control and impact on our relationships; 3) The Communicative Impact Model accounts for the complex and contradictory challenges of dementia care in terms of the intricate parameters of successful communication (Morris, Mansell, et al., 2018). The integrative CEF thus combines psychological theories that posit that both unresolved conflict regarding important goals, and difficulties within close relationships can be key causes of psychological distress. EC does not draw on a traditional CBT framework and therefore does not use traditional CBT techniques (such as cognitive restructuring).

The CEF builds on person centred principles, for example that interpersonal interactions can undermine the personhood of people living with dementia and that

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personhood can be enhanced through psychological and social interventions, to provide a detailed account of ways of improving communication and relationships. Both the CEF and EC also draw on the principles of positive psychology that wellbeing and resilience are subject to the quality of positive relationships and social contexts, and that resilience can be preserved and enhanced (Clarke et al., 2016; Morris, Mansell, et al., 2018). For example, care partners share ‘stories of change’ within the course in order to encourage them to value ways in which they have been able to improve interactions and support within their caring role.

The synthesis of the three aforementioned models informs targeted strategies and interactive exercises within the EC course that facilitate carers to consider the goals and emotions of those they are caring for, alongside their own goals and emotions, and to use this to maximize good communication. Good ‘mentalizing’ by the care partner is important in maintaining a positive relationship with the person they are caring for (Jain et al., 2014; McEvoy et al., 2019). Good mentalizing is defined as: “an accurate and effective understanding of (a) his or her personally important goals; and (b) the other person’s perspective that takes into account what is really important to them (Morris, Mansell et al., 2018, p. 7). A key goal of the training intervention is to foster the ability of care partners to reflect upon their communicative interactions, so that they can support their relatives with dementia in less reactive, more considered and responsive ways. Care partners are taught ways to increase control for the person living with dementia, such as the “invitation to respond” technique, which allows people living with dementia to respond if they want to (Morris, Mansell, et al., 2018). Details of the techniques used in EC are presented on, XXX. Another important aspect is techniques and exercises that foster empathic and engaged openness (or curiosity) regarding the perceptions and experiences of the person living with dementia (McEvoy et al., 2019). For example, this can help care partners see that the person

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they are caring for may be making communicative demands upon them that they find difficult or frustrating due to dementia-related cognitive and perceptual changes, rather than deliberately seeking to annoy them.

Qualitative findings regarding the specific aspects of educational and support interventions that care partners experience to be beneficial to their communication, wellbeing, relationships and confidence in their caring role have been limited. This paper addresses this gap by reporting on the findings from care partners regarding their perceptions of the impact of EC upon their communicative interactions.

## **Methods**

### ***Study context***

This qualitative study was embedded within a longitudinal study to establish the impact of EC on care partner stress and communication ( $N = 169$ ); this is reported in XXX. The study was approved by the XXXX Ethics Committee prior to data collection.

### ***Participants***

Participants were recruited from across XXX a densely populated, predominantly urban geographical location in the XXX of England. Participants were eligible if they were caring for a friend or relative living with dementia, wanted to attend a training course and were able to give informed consent. They needed to have sufficient English language skills to understand the training (i.e. verbal and written language abilities required to understand verbal presentations and complete simple exercises). Twenty-eight care partners were recruited from those who took part in the longitudinal study. All participants gave informed consent. All data has been anonymised and all names are pseudonyms. See Table 1 for the characteristics of the participants.

*[Table 1 about here]*

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As this was an exploratory study, convenience sampling was used initially and purposive sampling was used after 20 interviews due to some participant characteristics being underrepresented; specifically more male and spousal care partners needed to be recruited.

### ***Interview schedule and data collection***

The first author, using a detailed semi-structured interview schedule, conducted interviews over the phone and in care partners' homes; two interviews were conducted in community locations. Generally, people living with dementia were not present during the interviews (at the choice of the care partner), sometimes people living with dementia were present for small parts of the interview if they needed support from the care partner. Given that the intervention focused on the care partner (as did the interview questions), no pressure was put on them to involve the person living with dementia they were supporting. For each interview we waited so there was at least a 4-months gap between the first intervention session and the interview (to ensure that all intervention sessions would have been accessed by the time of interview and that interviewees had some time post-intervention to try out techniques etc) and mostly 5-6 months after the first intervention session. The interview schedule was developed based on previous qualitative research with similar aims (e.g. Finucane & Mercer, 2006; Morris, Mansell, Amos, et al., 2016) and through discussions within the research team. The length of the interviews ranged between around 30 and 60 minutes, all interviews were digitally recorded and transcribed verbatim (manually by an external transcription company). In addition to the questions on the interview schedule, the interviewer asked prompt questions that were integral to the interview schedule. These were designed to encourage participants to elaborate on comments and to obtain a deeper understanding of their experience of the Empowered Conversations course and their perceptions of its impact on their ability to support the person living with dementia.

*Analytical strategy and procedure*

NVivo 12 was used to facilitate the analysis of the interview data (QSR, 2018). Following the principles of Framework Analysis (Ritchie et al., 2013) the first author familiarised herself with the data by re-reading transcripts prior to developing the initial coding scheme based on the objectives of the project. Initial coding (indexing) of 10 interviews was used to develop and refine a preliminary framework. Two members of the study team (XX and XX) then examined the framework to ensure that the codes made sense and fitted with the data. A third team member (XX) coded data to confirm that the codes were trustworthy and representative of the data (they initially coded data from 10 interviews, then the first author and XX completed and checked coding across the 28 interviews). Minor changes were made to the framework following this process and the final framework was used to index all the interviews. The first author primarily indexed the interviews but another member of the team acted as a second indexer (after detailed induction into the framework and to the data). All data was then charted and summarized. Methods of establishing reliability and validity used within quantitative research are not applicable to qualitative data (Creswell, 2013). However, measures can be taken to establish the credibility and dependability of qualitative data (Shenton, 2004). Peer verification, and regular debriefing within the research team, were used to enhance trustworthiness and confirmability.

The number of participants who reported content relevant to a particular theme is quoted throughout the results section. Although the appropriateness of such numerical specificity is debated within the qualitative literature, the authors believe that in the context of the current study it is helpful. This study was designed to capture participant experience of a training-intervention and it is useful to know how many participants reported a certain

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experience. For example, if only one participant found an aspect of the course less helpful then changes were less likely to be made than if 10 participants did.

### ***Intervention (see Table 2)***

EC is a group intervention and it was delivered in-person (face to face). It is based on an integrative framework that targets the specific psychological, relationship and communication needs of carers (Morris, Mansell et al., 2018). EC creates a space for care partners to pause, reflect and connect with peers. This approach encourages flexibility because care partners are given the space to identify and try out their own solutions using techniques from the course.

### **Results**

Three superordinate themes, “Improved communication,” “Improved wellbeing” and “Support through others,” and six subordinate themes were identified (see Table 3). These are described below. Participant quotes are used to exemplify thematic findings.

*[Table 3 about here]*

### ***Improved communication: “it underlies everything”***

Overall 27 of the 28 participants described feeling that they were able to better connect with the person living with dementia that they were supporting as a result of attending the EC course. The two main reasons for this were: improvements in the way they communicated, and greater understanding of the effects of dementia on communication.

### ***Improved communication***

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Participants described techniques learnt during the course as enhancing communication. Eighteen participants found the Invitation to respond technique helpful with the people living with dementia they were supporting. Invitation to respond involves using a comment, or an observation to initiate a conversation (rather than starting with a question). Such communication allows for a response, but does not demand one in the same way that a question does.

*And that has definitely come from the course, the invitation to respond, and to allow a conversation to take its own direction. (Rachel)*

In contrast, one participant (John) described asking more questions as a means of, “trying to keep her mind active”.

Five participants mentioned that they became more aware of the detrimental effect of background noise and distractions through attending the course. This was new learning, and very significant, for some people.

*So controlling her environment is probably a big thing. (Rachel)*

Five participants expressed that the course had taught them the importance of face-to-face interaction or touch with a person living with dementia to enhance communication.

*I now sit facing Jack. I would sit at the side of him and keep looking at him, but now do it face-to-face and I do think it's better. There's not a lot of response, but when there is it's magic. (Lauren)*

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Three participants mentioned that the course provided them with information about how music could be used to promote connections with people living with dementia.

*We know from the course as well, things like music... plays a massive part. (Amanda)*

### *Mentalization*

Twenty participants communicated that they were able to better 'mentalize' following participating in the course, that is understand how people living with dementia might feel or what they might be thinking. The majority of participants attributed this to what they had learnt on the course.

*It was very helpful for understanding how people with dementia think about things.*

*You don't realise that their thoughts aren't like yours'. (Jess)*

Four participants also stated that it was helpful to understand more clearly that people living with dementia could not help certain specific behaviours and those participants were able to reframe their understanding of such behaviours and see that the person was not acting in the way they were to irritate the care partner.

*This isn't deliberate... She's doing it because she genuinely can't. (Jane)*

Participants used this increased understanding to improve their communication and connection with the person that they were supporting:

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*I could understand so it was like when you're trying to speak in a foreign language and you're trying to do something but you just get louder instead of trying to put it another way. (Sally)*

Overall, the combination of better ways of communicating, and care partners gaining more understanding of the experience of the people living with dementia, improved the sense of connection and care partner confidence in their ability to communicate.

***Improved wellbeing: “you yourself don’t get stressed”***

Twenty-one participants described improvements in their psychological wellbeing. This included feeling more equipped to manage stress and frustrations. The majority of care partners described a positive impact on the person that they were caring for.

***Improved wellbeing of people living with dementia***

Twelve participants explicitly mention improvements in the wellbeing of the person they are supporting, or specific impact on that person’s communication as result of the course.

*Like I say the body language, the eye contact, the physical presence, the physical touch, all that just seems to have enhanced my mum’s wellbeing. (Sally)*

For 10 others, the impact on the person living with dementia is implied but not specifically stated.

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*The way that I try to get information out of him without using questions. And there's no point in carrying on repeating the same thing because it just doesn't go in so you've got to use different ways of communicating to avoid putting them under pressure. (Rebecca)*

*More easily managing being a care partner*

Care partners commonly described ways the course helped them to reduce stress or had other impact on their quality of life; for example:

*It definitely gives you the foundation blocks, and without the course, that specific course, I'd be struggling a lot more. (Ben)*

Eighteen participants described ways that they were dealing with problems differently to reduce stress, and/or described new perspectives that were helping them reduce stress:

*Sort of helped you to think about what's going on, and how you might do something differently.... it's provided you with a bit more background to sort of think about, 'Oh, maybe I should deal with it this way', or whatever. (Michael)*

Nine participants described feeling less frustrated and more patient within their caring role:

*Take time....to be more patient and understanding that she can't find the words and it's not her fault. (Suzie)*

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Twenty-four participants expressed greater confidence following the course that they could influence communication and still connect with the person they were supporting:

*Recognising that it's the still the same person, you're conversing with and making the most of what you've got really (Jack)*

In contrast, three care partners expressed feeling unable to improve things greatly even following the course:

*And I do my best to use the techniques but I have to say, unfortunately, I'm finding that... I don't think he is understanding it...so I might have to repeat myself.... Since I've been on the course, unfortunately, people, not only me, but people have seen changes with my husband's condition. (Laura)*

Although there can be an interaction between the context and the perception of self-efficacy, with relationships where communication is more challenging potentially more associated with lower self-efficacy, even when communication became really challenging some participants still expressed confidence in being able to communicate:

*Nine times out of ten she understands what I'm saying to her, but I can't get an answer... But she's aware, I can tell with her reaction, so what I do, I speak to her and I tell her jokes and funny things and keep the conversation going.... I sing to her as well. (Bill)*

Overall the quality of life and stress levels of care partners improved and the majority described improvement for the person they were supporting. In contrast, three care partners

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described limited confidence in being able to make improvements. Two of these three attributed their loss of confidence to increasing, or particularly difficult, dementia symptoms. Other participants, who also recognised this challenge, felt that the course had helped them adapt.

***Support through others: “we were all the same but we were all different”***

Support gained through attending the course with other care partners emerged as a key finding, with participants highlighting different features of being with others as the source of the support.

*Supporting each other*

Out of the 28 participants, 26 reported that an opportunity to both share and listen to other participants lived experiences of caring for someone living with dementia was of significance to them.

*That was the first time we'd spoke to other people that were in a similar situation.*

*(Claire)*

*You see that other people are in the same situation, and you get ideas from them and you can share that experience as well. (Jeff)*

Ten participants also commented that the different experiences of those at the course were valuable to them.

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*I like the fact that everybody had a different story, so different connections, different age groups, you could feed off the different stage they were at and the experiences that they've had. (Rachel)*

Findings suggested that the shared lived experience of caring for a person living with dementia promoted feelings of trust and openness within the group.

*I think there's the trust there because everybody's suffering the same ...we're not going to put each other down. (Rebecca)*

Eight participants specifically commented that the group nature of the course had helped them to address feelings of isolation.

*You don't feel quite the same isolations. (Sally)*

Participants' connections after the course had finished varied. Nine of the participants that were interviewed discussed how they had sustained connections with other members of the group. However, when participants physically met with one another this was largely due to the fact that they attended the same dementia related events and groups.

*I still see three of them... at the dementia groups we go to. (Jess)*

Connections were also continued through social media, with some participants commenting that they used Facebook to maintain contact.

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Eight participants reported that although they had not sustained any connections with fellow members of the group after the course had finished, they would have liked to.

*I've not made any contact with anybody and no one's made contact with me, so I think that's quite sad. (Amanda)*

People attributed this lack of contact to numerous reasons, including work and caring commitments, and health problems.

### *Improving relationships and support networks*

Six participants mentioned tensions within the family arising from their caring role; these ranged from disagreements regarding the best support for the person they were caring for to increasing difficulties between a family member and the person living with dementia.

*It's caused a bit of upset within the family.... I think I wanted to try and ease her into that situation... and then yet it was overtaken by another member. (Jane)*

The course does not specifically focus on family tensions, but a minority of participants described progress with these difficulties since accessing the course.

*She was going down the wrong route, (if) her daughter knows what was going on in mum's head, she could probably help her a bit more than her husband did. (Aisha)*

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Twelve participants mentioned ways in which the course, and signposting within this, had improved their social networks (beyond the direct experience of peer support within the course). For example, finding out about support services:

*She (EC facilitator) had documentation or information about another lifeline, ie the Admiral Nurse, if you wanted to ring them. (Laura)*

Overall, participants described improved social networks as a result of the course. However, one of the most significant experiences for many participants was learning from others in the group, sharing experiences and feeling less alone.

## **Discussion**

The study aims were to explore whether an experiential course for care partners of people living with dementia (EC) was acceptable and beneficial to participants, and to explore participants' perceptions of the impact of the course upon their communicative interactions. Across the three superordinate themes, the majority of participants expressed experiencing benefits from the course; for example, 27 of the 28 participants described feeling that they were able to better connect with the person living with dementia that they were supporting through attending EC, and 26 participants reported that an opportunity to both share and listen to other participants' lived experiences of caring for someone living with dementia was helpful to them. The positive comments about the group format and the benefits derived from the course indicate that the course was acceptable to the vast majority of participants (Sekhon et al., 2017). The findings provide retrospective information regarding acceptability.

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This makes a significant contribution to the literature as only two qualitative studies of interventions that specifically included communication strategies or support for care partners were identified (Auclair et al., 2009; Sommerlad et al., 2014). These two studies describe individual interventions; respectively couples counselling and a one-to-one, CBT based coping with caregiving programme (START). Further Auclair and colleagues primarily report case study material (they do not conduct detailed semi-structured interviews) and Sommerland and colleagues' data is from self-completed questionnaires. Therefore both the intervention and the type of analysis differs from the current study. Although START is CBT-based and an explicitly clinical intervention (aimed at carers accessing mental health services), there is some overlap in content covered. Similar to the current study participants valued the diverse components of the intervention.

### ***Improvements in communication, relationships and wellbeing***

One key finding was that connections and communication improved for all but one of care partners who accessed the course. These improvements were attributed to a range of different components of the course. The invitation to respond technique was mentioned as helpful by 18 participants; a number of other specific learning's regarding communication were also highlighted.

Care partners identified that their communication was improved by having a greater understanding, or ability to mentalize, the person living with dementia that they were supporting. This enabled them to be more patient and more confident in their attempts to ascertain what the person they were supported needed. For example, they mentioned that they understood more the nuances of how communication can be affected, such as impact of word finding difficulties and the importance of non-verbal communication. This understanding enabled them to respond more flexibly and put less pressure on themselves and

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the person they were supporting. For example, one care partner stated that the person they were supporting became overwhelmed and stressed by too busy an environment and used this learning in a number of ways, such as limiting the number of grandchildren who visited at one time and sometimes meeting outside so the children could play separately as well as interacting with their grandmother. These sorts of improvements, which were described by the vast majority of care partners, were linked with improved relationships. For example, the person living with dementia getting less angry and frustrated with the care partner.

Twenty-one participants described improvements in their psychological wellbeing following the course. A meta-review of interventions for carers of people living with dementia identified that the most effective interventions for supporting care partner wellbeing included an educational and therapeutic component (Dickinson et al., 2017). In the form of EC reported in this study (4-session), the skills learnt were frequently commented on by care partners; for example, learning invitation to respond. Communication skills are considered to be an educational component and were commonly described as helpful. However, specific accounts of ways of reducing stress (which could be considered ‘therapeutic component’) are slightly less prevalent in care partners’ accounts. This feedback, in addition to feedback reported in a companion paper, resulted in an additional two sessions being added to the course. As well as providing additional communication skills and relational understandings (Wray, 2020), this content focused on providing additional skills and understandings that have been found to be therapeutic in managing stress (e.g. Morris, McEvoy, et al., 2018), in accordance with the CEF (Morris, Mansell, et al., 2018).

### ***Group format and social networks***

It is notable that the relative diversity of EC attendees did not impede care partners from benefitting from peer support. Care partners attending had a range of relationships to the

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person they were supporting, including spousal, child, sibling and in-law. Another difference was that some were living with the person they were supporting, while others were supporting someone living separately in their own home or in a residential care home.

Although data was not specifically collected regarding dementia severity levels of the people living with dementia that carers were supporting, qualitative accounts indicated a range of severity levels were represented. For example, several carers described supporting people who had very limited verbal language production. Support groups are often organised around a shared identity and so it is interesting to note how shared the identity needs to be in order for peer support to be experienced. Despite several differences between participants and those they were supporting, 26 participants reported that an opportunity to both share and listen to others' lived experiences was helpful to them. Ten specifically commented (unprompted) that the differences in peoples' experience were beneficial. It is possible that this is because the carer role provided enough common ground for most people. In line with this, a recent evidence-based theoretical and practical account of communication, indicates that adaptations to communication changes are similar across types of diagnoses (Wray, 2020). For example, language production and comprehension may change differently across dementia types, but adaptations are more similar, such as relying on a range of communication mediums, being curious about goals and needs (Morris, Mansell, et al., 2018); in addition, role and relationship changes are not related to the specific diagnosis. Furthermore, EC encourages care partners to respond flexibly to the needs of the individuals they are supporting and uses general principles, such as maximising control and communicative impact for the person living with dementia, in order to facilitate care partners to respond to a variety of specific needs (Morris, Mansell, et al., 2018). There was no specific data to indicate that EC was more suitable for care partners of people living with the early stages of dementia. Three care partners described limited confidence in being able to

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make improvements in communication and two of these three attributed this limited confidence to increasing, or particularly difficult, symptoms of dementia; however, others described the course as facilitating adaptations to such challenges.

However, it is also important to note that two care partners did not specifically describe benefits of the group format. There was also one care partner who said that they found individual counselling sessions, which they attended separately, more beneficial than EC. This is important to recognise as the needs of different care partners and people living with dementia will vary and a range of interventions should be offered. This is especially pertinent, because a care partner can be the primary carer for someone living with dementia for a significant number of years; for example, 30% of care partners of people living with dementia had been caring for between 5 and 10 years and 22% for over 10 years (ONS, 2016-2017).

### ***Mechanisms of change***

The main agents of change described by participants in this study were: firstly a greater understanding of how the person living with dementia they were supporting was thinking or feeling (mentalization), enabling greater conversational control for the person living with dementia via the use of invitation control and other techniques (improved ability to meet valued goals), and secondly care partners gaining greater confidence that they could respond to difficulties and stress. These are the mechanisms of change suggested in the CEF (Morris, Mansell, et al., 2018). In line with Elvish and colleagues' review (2012), social support was also a key element that care partners found supportive.

As EC is not based on a Cognitive Behavioural Therapy (CBT) framework, unlike some previous accounts, cognitive reframing was not specifically mentioned by participants as contributing to change (Vernooij-Dassen et al., 2011). Although care partners identified

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helpful new perspectives, these were not focused on cognitively reframed appraisals that one would see in a CBT intervention. However, in line with CBT stress-coping models, our findings indicated that greater self-efficacy influenced how able care partners felt to respond to difficulties and stressors. The likely explanation for this is that self-efficacy has conceptual similarities with perceived control, which is directly targeted within EC (Morris, Mansell, et al., 2018). The degree of control an individual perceives they have influences what is described as the secondary appraisal in stress coping models; i.e. perceived control influences the extent to which individuals appraise themselves as able to cope (Vernooij-Dassen et al., 2011).

### ***Limitations***

A key limitation is the low representation of people living with dementia within the interviews. Persons with dementia were not the target sample because they were not course participants. Paired interviews were offered and encouraged, but they were not taken up. This research did not seek the views of people living with dementia, because it was focused on the experiences of the EC participants who are care partners. However, it would be valuable in a future study to find out whether the EC course had any direct perceived benefits for the person living with dementia. This is an important area for future research. A potential limit is that some of the interviews were conducted by phone but because the analysis did not involve analysis of Non-verbal expressions or body language, and there is no evidence that this affected the quality of responses, this does not appear to be a significant limit. Further this offers increased convenience for an over-stretched group (care partners) and therefore is likely to have made interview participation more accessible. A final limit, related to the hypothesis regarding acceptability, is that we did not recruit participants who did not access any sessions of EC. This was because we were primarily interested in participants'

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experience of the course, but it is possible we missed care partners who did not find EC acceptable and therefore did not take part.

## **Conclusion**

This is the first qualitative study to examine an intervention for care partners of people living with dementia from a non-CBT framework and indicates that perceived control could influence how care partners respond to stress and difficulties (Forgeard et al., 2011; Morris, Mansell, Amos, et al., 2016; Morris, Mansell, & McEvoy, 2016). Care partners developed a range of strategies and understandings that enabled them to communicate better with the people they were supporting, enhanced wellbeing and relationships, as well as developing social networks.

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**Declaration of interest statement**

The authors report no conflict of interest.

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Table 1. Sample characteristics

	Number [out of 28 unless specified]	
Gender, number female	19	9 male
Ethnicity (number W. British)	25	2 Asian British; 1 Italian British
Caring for:		
Parent(s)	14	
Spouse	11	
Long-term partner (never cohabited)	1	
Sister	1	
At time of interview not carer (previously had been)	1	
Communication scores on CCQ at baseline, M (SD)	3.5 (0.8)	[n = 27]
Stress scores on PSS at baseline, M (SD)	17.2 (6.6)	[n = 25]

*Note:* CCQ: Carer Communication Questionnaire; PSS: Perceived Stress Scale

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Table 2: Illustrative table of key techniques, exercises and content of each of the 4-sessions of Empowered Conversations

Week	Example technique / content	Description of technique / content
Week 1 - How do you feel speaking with somebody living with dementia? How might someone living with dementia feel talking to you?	Introducing pause for Breath	This is an opportunity to pause to facilitate responding in a more helpful way. If stressed or frustrated this affects other people (as well as ourselves) and will spill over in to the conversations we have.
	What is Dementia?	Key facts about dementia are discussed
	Dementia – The Communication Disease – Introduction (Alison Wray)	Animated video introducing key facts about dementia and communication.
	Feelings Part 1 and Part 2	Activity using post-it notes to enable participants to share how they feel talking to the person living with dementia that they support. They then consider how the person living with dementia might feel

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Week 2 - What gets in the way of our conversations?	Pause for Breath	
	Barriers - What gets in the way of having the conversations you want to have?	Discussion and exercise to illustrate some barriers to good conversations
	Complexity - Alison Wray	Outlines key points regarding communication in the context of supporting someone living with dementia. For example, that communication is already a complex process; the importance of knowing where our knowledge overlaps with other peoples' knowledge and some of the challenges that this can cause.
	Invitation to Respond	This introduces a technique called an invitation to respond - a way into a conversation that does not start with a question.
	Jack & Lillian Motorbikes - small groups, discussions and trying out Invitation to	Jack and Lillian are a person living with dementia and their care partner. These videos illustrate some of the complexities and facilitators of dialogue between a particular individual living with dementia and their long-term partner.

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	Respond	
Week 3 - Stop, Listen, Look	Pause for Breath	
	Reflections - in pairs listening exercise with feedback	An exercise to illustrate some of the barriers to listening and how it feels not to be listened to
	What gets in the way of us listening?	What are we doing that gets in the way of us being able to listen well
	Coping & Humour Alison Wray / Jack & Lillian	Humour can be used to as a way of coping with, and even 'masking', issues. However, just because someone has dementia does not mean they lose their sense of humour. The combination of these videos makes the point that it is important for care partners to be in the moment and really listen to what is being said (as much as possible). In this video the care partner misses a perfectly timed joke.
	What is Non-Verbal communication?	Interactive exercise and discussion to identify experiential elements of non-verbal communication

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Week 4 - Summing up	Pause for Breath	
- Drawing the Course to a Close	Reflections - from the previous week	
	Tony Husband Cartoon.	Using a Tony Husband cartoon to start discussion regarding some ways communication can be impaired and how each of the people are feeling
	Cartoon - draw your own conversation that didn't go quite how you'd hoped.	Care partners are asked (if they feel comfortable with this) to think of a scenario with a person they know who is living with dementia where there were barriers to communication/listening and how the conversation looked
	Revisit: Feelings exercise and capture any changes	Revisit the feelings exercise described in Session 1
	Checklist/ what can we learn - Alison Wray	Ways of supporting and enhancing communication with someone living with dementia; e.g. by taking an empathic approach
	Summing up with Stories of	Celebrate peoples' stories. These stories of change do not have to be massive; they

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Change	can be that somebody has been able to recognise when they are getting frustrated and take themselves away from the situation and do the breathing exercise!
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Table 3: Superordinate and subordinate themes

Superordinate theme	Subordinate theme
Improved communication: “it underlies everything”	Improved communication Mentalization
Improved wellbeing: “you yourself don’t get stressed”	Improved wellbeing of people living with dementia More easily managing being a care partner
Support through others: “we were all the same but we were all different”	Supporting each other

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Improving relationships and support networks
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