

How do family carers assist people with dementia?

A qualitative observation study of daily tasks.

Abstract

Introduction: As people with dementia progressively experience difficulties when performing daily tasks, family carers often become the main providers of support. Little is known about the role of carer support during task performance. Therefore, Occupational Therapy interventions are often underinformed in this area. Knowledge of how carers assist people with dementia could support Occupational Therapists to promote participation in daily tasks. The objective was to explore how carers support people with dementia during the performance of daily tasks. **Methods:** A secondary analysis was conducted on observations video-recorded for the TASKed project, where people with dementia completed a task with carer support. Data were analysed using an inductive reflexive thematic analysis approach. **Findings:** Video-recordings of twenty-one dyads were included in this study. Five themes were generated depicting how carers supported people with dementia during task performance: 1) Person-enabled assistance, 2) Goal-directed assistance, 3) Carer-led assistance, 4) Partnership-oriented assistance and 5) Bystander. **Conclusion:** Our findings suggest carers employ different approaches when assisting people with dementia with daily tasks. Knowledge of these different modes of assistance could help Occupational Therapists and researchers understand what works well and what could be changed to facilitate the participation of people with dementia in daily activities.

Key Words: carer, approaches to assistance, dementia, activities of daily living.

Introduction

People with dementia (PwD) present with progressive difficulties when performing activities of daily living (ADLs) (Desai *et al.*, 2004). Consequently, the individual gradually loses their ability to remain independent and requires assistance to complete ADLs. Typically, assistance will be mostly provided by family members who become informal carers (Prince & Jackson, 2009) who usually do not receive any training to gain the skills they need to appropriately support them (Georges *et al.*, 2008).

Interventions for carers of PwD were usually developed to increase the carer's abilities to communicate with their family member (Williams *et al.*, 2018), and behavioural management (Chenoweth *et al.*, 2009). In these types of interventions, carers are trained on how best to communicate with the PwD, using specific words, tone of voice (Chenoweth *et al.*, 2009) or employing specific verbal strategies when assisting PwD (Dalpai *et al.*, 2016). Communicating effectively with the PwD is important to sustain a healthy relationship between both the carer and their family member (Ripich *et al.*, 2000) and has reduced the carer's level of distress (Done & Thomas, 2001). However, it is not clear that the communication strategies that a carer uses will lead to a successful provision of assistance when the PwD requires support to complete ADLs.

Occupational Therapists are well equipped to promote autonomous living of individuals in the community (RCOT, 2017) which coincides with PwD's main priority of living as independent a life as possible (Kelly *et al.*, 2015). There is a wealth of evidence that supports the role Occupational Therapists have in enabling PwD and their carers to engage and participate in ADLs (Burgess *et al.*, 2021; Graff *et al.*, 2006; Bennett *et al.*, 2019). Clinical practice guidelines also recommend that Occupational Therapists promote independence by training and upskilling family carers (Lever *et al.*, 2017). However, Occupational Therapy interventions tend to be multi-component which makes it difficult to

identify what works and why, with the focus on the task and the environment rather than the support provided by carers and with outcomes based on proxy report rather than observation of activity performance (Bennett *et al.*, 2019).

Observations of family carers and PwD have identified caregiving styles when carers make decisions about the PwD's care such as facilitating, balancing, and directing (Corcoran, 2011) or the type of skills they have when dealing with behavioural difficulties such as knowledge, carer qualities and approaches to caregiving (Farran *et al.*, 2009). Few studies have taken place examining assistance provided by carers during ADLs, with the emphasis on the amount of assistance carers provide (Amato *et al.*, 2021; Riffin *et al.*, 2017) rather than how carers assist a PwD to complete a task. As such, studies on the approaches carers use to provide assistance to PwD during ADLs are rare and have focused on formal carers rather than family members (Wilson *et al.*, 2013). Vikström (2005) identified the spectrum of family carer support from creating comfort to adapting spaces or activities to make tasks easier, including negative aspects such as inappropriate support. Although insightful, this study included only spouses of people with mild or moderate dementia completing one task, which limited interpretations about how support can be provided (Vikström *et al.*, 2005).

Studies observing people with different abilities and doing different activities are needed to elucidate how family carers provide assistance during ADLs. This would contribute to understanding of how specific actions could be targeted in future Occupational Therapy interventions to better support PwD during ADLs and could be useful to develop carer-based interventions to sustain participation for longer.

This study's objective was to use video-recorded observations of task-based interactions to explore how family members support PwD during ADLs.

Methods

Study design

This study followed the Standards for Reporting Qualitative Research (SRQR) recommendations (O'Brien *et al.*, 2014) and used an interpretivist paradigm to conduct a secondary analysis (Heaton, 2004) of video-recorded observations to examine participants' experiences (Mertens, 2005) using data collected for the TASKed project (IRAS ID 199002). TASKed was a 4 year-long study funded by the Alzheimer's Society (between 2016 to 2020) and conducted in the United Kingdom, aiming to investigate underpinning factors of disability in PwD.

Participants, procedures, sampling and ethics

Participants included lived in the community and had a diagnosis of dementia of any stage based on the DSM-V (American Psychiatric Association, 2013). Family carers had to be fluent in English, 18 years or older and provide at least seven hours a week of unpaid support. Both participants had to be willing to be filmed and they provided written consent. If the PwD lacked capacity to consent, their carers were asked to provide consent following what the PwD's wishes to participate in the study would have been.

The TASKed sub-study we draw on comprised video-recordings of an ADL by the PwD with carer support. In total, 128 participants (64 dyads) completed the TASKed sub-study. For this study, the first author (FA) purposely sampled (van Rijnsoever, 2017) 21 observations from this dataset to include individuals with different characteristics such as dementia stage, age, living situation and relationship with the carer (Patton, 2002) to gain a wide understanding of how carers assisted during ADLs.

Ethical approval was obtained from the Health Research Authority (HRA) (IRAS ID 199002) and the National Health Service (NHS) Research Ethics Committee (REC 16/LO/0544).

Data collection

Recordings were completed in the participants' own homes. Carers completed questionnaires that included demographic information for both participants. The Frontotemporal Dementia Rating Scale (FRS) (Mioshi *et al.*, 2010), an interview-based questionnaire, was used to classify for dementia stage.

Data collection was based on a non-participant, direct observation procedure (Busetto *et al.* 2020). Interactions were video-recorded to enable revisiting of data and a thorough analysis involving more than one person. The FA stayed in the room a small distance away from the participants but with a clear view of the activity being undertaken.

All participants were given the same instruction, which was to complete an ADL; their carers were asked to assist if the PwD needed assistance completing the task. Tasks completed were making a salad (green or fruit), making a sandwich or a hot drink, serving a cold drink, or washing hands. The selection of the task was made after a discussion between the dyads and the FA, an Occupational Therapist who has extensive clinical experience working with PwD and carers. The aim was to select a task which the PwD felt comfortable to complete.

Analysis

Data were analysed using an inductive reflexive thematic analysis (Braun, 2018) approach, based on Braun & Clarke's six-phases (Braun & Clarke, 2006). Four researchers conducted a collaborative and reflexive data analysis to allow for the development of richer

understandings of the data (Braun & Clarke, 2019). Tamara Backhouse (TB), an experienced care-home worker and post-doctoral dementia care researcher. Ana Paula Trucco (APT) an Occupational Therapist with substantial clinical experience and PhD candidate. Eneida Mioshi (EM) an Occupational Therapist and Professor of Dementia Care Research, with vast clinical and research experience and the FA.

After purposively sampling 21 observations ensuring varied participant characteristics, the FA observed them to become familiar with the data and made notes. The FA, observed subsets of the interactions in phases and independently generated initial codes which were discussed and refined during several meetings. No new codes were generated from the last observations. Further engagement with observations took place and all researchers checked if the codes resonated with their understanding of the data. During this process all 21 observations were coded.

The FA then generated initial themes by critically reflecting on what the codes meant and developing broader categories and meanings. Several meetings were held between researchers (EM, TB, FA) where they reflected on the meanings, names, and scope of themes. Interpretations were revisited, discussed with themes and sub-themes further developed and refined in a final group meeting.

Findings

Video-recordings of 21 dyads were included in this study. Average recording length was eight minutes and thirty-one seconds. PwD were mostly male (61.7%), with a diagnosis of Alzheimer's disease (80.8%) and lived with their family (95.2%). Most carers were female (66.7%) and spouses of the PwD (85.7%) (Table 1).

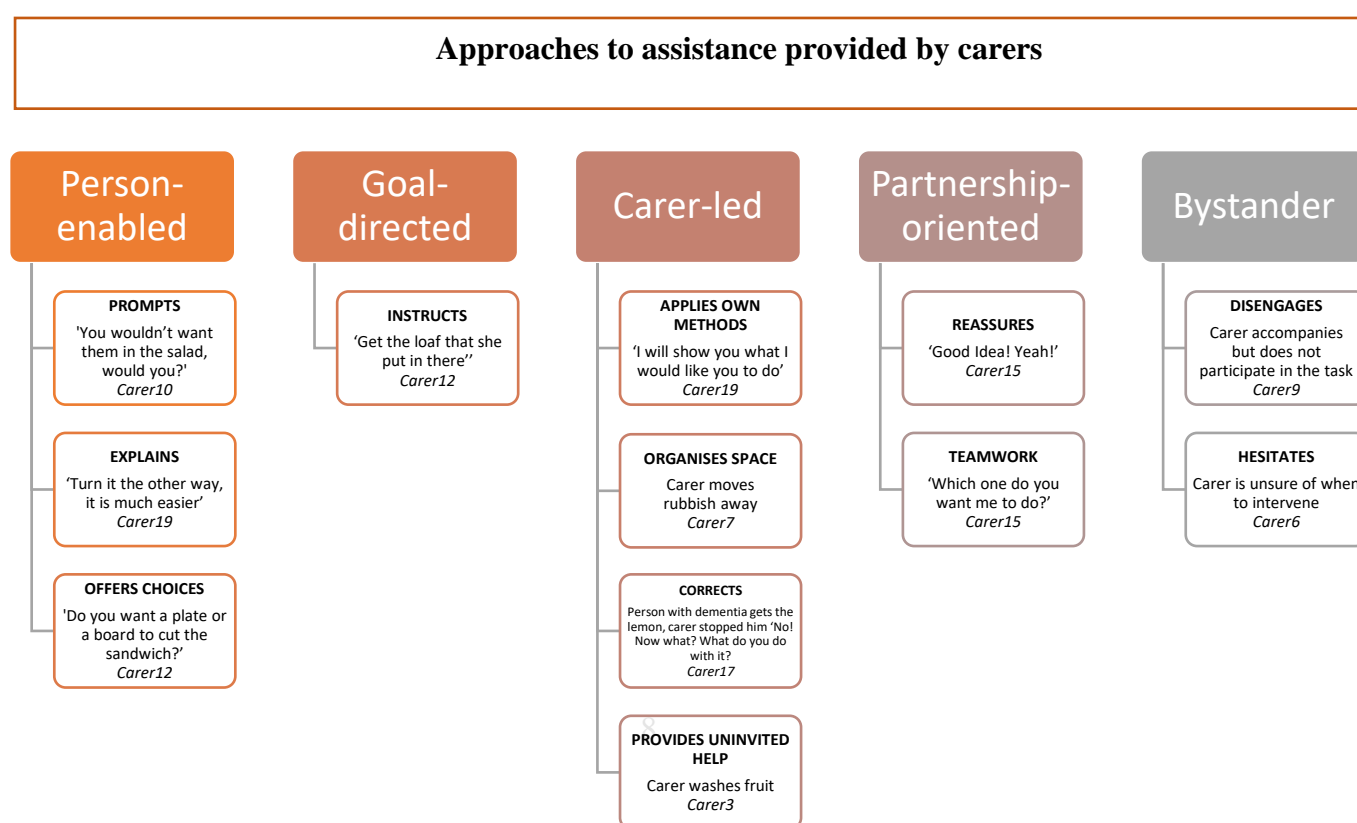
Table 1. Demographic characteristics of people with dementia and their carers (n=21).

People with dementia's characteristics	Total sample (n=21)
Age, mean (<i>SD</i>)(range)	78.57 (8.14) (61-93)
Gender, male, %(n)	61.9 (13)
Education, years, mean (<i>SD</i>)(range)	12.57 (2.95) (6-20)
Length of symptoms, years, mean (<i>SD</i>)(range)	4.48 (3.43) (1-14)
Dementia diagnosis %(n)	
<i>Alzheimer's disease</i>	80.8 (17)
<i>Vascular dementia</i>	4.8 (1)
<i>Mixed dementia</i>	4.8 (1)
<i>Other</i>	9.6 (2)
Marital Status %(n)	
<i>Married</i>	85.7 (18)
<i>Widowed</i>	14.3 (3)
Living Situation %(n)	
<i>With family</i>	95.2 (20)
<i>Alone</i>	4.8 (1)
Dementia Stage %(n)	
<i>Moderate</i>	66.7 (14)
<i>Severe</i>	33.3 (7)
Carers' characteristics	Total sample (n=21)
Age, mean (<i>SD</i>)(range)	72.86 (8.66) (59-84)
Gender, female, %(n)	66.7 (14)
Education years, mean (<i>SD</i>)(range)	12.38 (3.42) (6-20)

Training completed, yes, %(n)	19 (4)
Relationship with the person with dementia, %(n)	
<i>Wife</i>	57.1 (12)
<i>Husband</i>	28.6 (6)
<i>Daughter</i>	9.5 (2)
<i>Son</i>	4.8 (1)

Five themes were generated showing how carers used different actions when supporting PwD during ADLs: Person-enabled assistance; Goal-directed assistance; Carer-led assistance; Partnership-oriented assistance and Bystander (Figure 1). Some carers clearly used one main approach to assistance, where others tended to use two or more different ones.

Figure 1. Themes and sub-themes, with examples, that were identified and generated from the data.



Each dyad was identified by giving them the same number. As such, Carer1 is the carer that supports Person with dementia1; Carer2 is the carer that supports Person with dementia2 and so on.

Person-enabled assistance

The Person-enabled assistance theme contained the following sub-themes: prompts, explains, and offers choices. When using this approach, carers adopted a guiding attitude when assisting the PwD and their interventions were mainly directed to promote the individual's participation:

The PwD (male, father, moderate stage) is working at the kitchen island to make a fruit salad. The carer (male, son) stands behind observing what the PwD does. The PwD gets the orange, looks at it with a confusing look:

Carer: 'How would you do the orange?' responsively using a gentle tone of voice.

PwD: 'I don't know, I don't put oranges in the fruit salad'.

Carer: 'Well, do you want to do the pear?'

PwD gets the pear and the peeler.

Carer: 'That should work!'

PwD peels the pear and starts cutting it.

(PwD13 and Carer13).

The carer used prompts to help the PwD solve a problem or overcome a barrier without making them feel like they had failed. Well-timed intervention from the carer offering stimuli or a possible solution in the form of questions enabled the PwD to maintain the pace of the task and a sense of control of the activity.

When using Person-enabled assistance, carers often provided context of what was happening:

The PwD (male, husband, moderate stage) is making a fruit salad on the kitchen table. While cutting apples, the carer (female, wife) brings a bottle of lemon:

Carer: 'If you sprinkle lemon on them, so that stops them from going brown' using a gentle voice while giving the PwD the lemon juice.

PwD pours lemon into the salad.

Carer: 'OK, if you give them a stir, so they are all coated' giving the PwD a spoon.

PwD stirs the fruit salad.

(PwD3 and Carer3).

By using explanations, the carer allowed the PwD to know what to do. They also provided rationale of why they were using different ingredients or materials. These aspects appeared to enable the PwD to complete steps and actively engage with the development of the task.

Person-enabled assistance enabled the PwD to decide how the task was completed, while the carer encouraged them in a supportive way:

The PwD (male, husband, severe stage) is sitting on a perching stool in front of the kitchen sink. They are asked to wash their hands. The carer (female, wife) is standing beside the PwD and while grabbing their arm, points at the sink:

Carer: 'Ok, where is the bowl of water for the hands? Where is your bowl of water?' using a gentle but clear tone of voice and guiding the PwD's arms to the sink, the PwD sighs.

Carer: 'Do you want to stand a little bit? Do you want to stand? supporting the PwD's back, PwD makes an unintelligible comment.

Carer: 'Or would you like to stay there?' using a casual but caring tone of voice.

The PwD stands.

(PwD18 and Carer18).

Offering choices allowed the PwD to keep their autonomy, while also being actively guided through the task.

Person-enabled assistance seemed to involve a harmonised combination of different elements, such as timing prompts, explanations and offering options, according to PwD's abilities to complete the task. Carers' actions encouraged PwD to assume an active role during ADLs empowering them.

Goal-directed assistance

The Goal-directed assistance theme was mainly characterised by giving instructions. Some carers using this approach took the role of 'director of the scene', providing verbal instructions and directions. These carers focused on completion of the task and concentrated on the consecutive achievement of each small step:

The PwD (female, wife, severe stage) is asked to serve a glass of orange juice, which was left in the fridge of their kitchen. The carer (male, husband) walks around accompanying the

PwD:

Carer: 'Get the orange juice from there' using a neutral but direct tone of voice.

PwD: 'Uhm' looks at the carer's eyes and places their hand in the fridge's door handle.

Carer: 'Open the fridge, get the orange juice out'.

PwD: 'Yes, we'll soon find that' opening the door.

Carer: 'Can you see the orange juice?'

PwD: 'Is this, is this one?' getting one bottle of orange juice.

Carer: 'Lovely, shut the fridge door up' using a gentle tone of voice.

(PwD8 and Carer8).

This observation demonstrates how each action of the PwD was directed by the carer, and this was also shown with other carers:

The PwD (male, husband, moderate stage) is making a fruit salad in the kitchen. The carer (female, wife) is standing behind and says:

Carer: 'Add banana in there and try to cut them same size'

(PwD19 and Carer19).

Step-by step instructions were provided where the carer appeared predominantly committed to the completion of the task rather than on actively involving the PwD in deciding the next steps. The PwD could have found the directions useful for knowing what to

do, however, there was limited time or space given to the person to display their current abilities.

Carer-led assistance

The Carer-led assistance theme contained four sub-themes: applies own methods, organises space, corrects, and provides uninvited help. Most carers using this approach tended to be hands-on, which involved moving items around the task area, selecting, and getting materials and deciding how to complete steps:

The PwD (male, husband, moderate stage) is asked to make a fruit salad and is working in front of the kitchen's counter. The carer (female, wife) stands beside them leaning in towards the PwD's space. The carer gets the orange and the knife, cuts the orange in a half:

Carer: 'I will show you what I would like you to do' cuts one end of the orange.

Carer: 'You see like that' cuts the other end of the orange.

Carer: 'And then like that' cuts the peel of one side of the orange.

PwD makes an unintelligible sound.

Carer: 'Yeah please' taking rubbish away and comes back.

Carer: 'Try not to cut too much of the flesh off if you could curve it around' making a gesture with their hands running their hand down the side of the orange.

(PwD19 and Carer19).

This observation shows how carers using Carer-led assistance were deeply engaged and involved with the development of the task, adopting a central role. Here, the carer explicitly stated and demonstrated how they wanted steps to be completed. They showed the

PwD how to do things without providing space for the person to decide on the way they wanted to do things.

Carers using this approach also organised the space by bringing in materials or by removing the rubbish away. On occasion, they provided help that was not required:

The PwD (female, wife, moderate stage) is asked to make a fruit salad. All the ingredients are on the counter surface. The carer (male, husband) stays one step away from the person, following them around the kitchen. A couple of minutes later while the PwD is peeling an orange, the carer gets the berries and opens the box. Once the PwD puts them into the bowl of fruit, the carer takes the box away.

(PwD7 and Carer7).

Although their goal may have been helping the PwD, the carer repeatedly stepped in without consulting the PwD. By giving uninvited help, the carer controlled aspects of the task that may have been completed by the PwD by either organising the space, getting materials or completing steps when the PwD did not ask for help.

Other carers imposed their way by correcting the PwD:

The PwD (male, husband, moderate stage) is asked to make a fruit salad. They are working at the kitchen counter and the carer (female, wife) is standing behind them, two steps away.

The carer directs the PwD to get a dish out of the cupboard:

Carer: 'You want the chopping board, for fruit. No, in the same cupboard I said! The white one' using an authoritative tone of voice, the PwD gets the chopping board and peels and cuts an orange.

PwD: 'Right, I've done that' stepping back from the kitchen counter to face the carer, leaves the knife on the side of the chopping board and gets the lemon.

Carer: 'No! Now what?' using an authoritative tone of voice to correct the person who immediately steps forward and leaves the lemon on the counter.

PwD: 'Well, I just peeled the orange' using a hesitant tone of voice and looking at the carer.

Carer: 'What do you do with it?'

The dialogue continues and the PwD completes steps following the carer's instructions.

(PwD17 and Carer17).

Here, the carer used corrections to impose their way of doing a specific task. There was evident tension between the couple, yet the PwD did not look too uncomfortable, suggesting that these roles may have been established in their relationship, with the carer taking control over certain tasks and the PwD following. Correcting had the effect of making the PwD hesitant and unsure, and although the carer's intention may have been to stop them making mistakes, this could have a potential drawback by disempowering the PwD further.

Carer-led assistance appeared to be defined by how the carer interpreted their role in supporting the PwD and some carers may have used these actions as they usually completed tasks themselves without the PwD being involved. Regardless, the PwD seemed to have little autonomy to complete the task.

Partnership-oriented assistance

Partnership-oriented assistance comprised two sub-themes: reassures and teamwork. Some dyads worked together throughout the task as if they were working as a team:

The PwD (female, wife, moderate stage) is asked to make a fruit salad in the kitchen. The carer (male, husband) stands near the PwD. The PwD gets the chopping board from the cupboard:

PwD: 'Follow me over there' looks at the carer, nods pointing at the counter and brings the chopping board using a humorous tone of voice.

PwD: 'So, I am doing, and you are assisting'.

Carer: 'I am assisting' takes things out of the counter.

PwD: 'As necessary?'.

Carer nods.

PwD: 'Right, fruit salad' transporting the ingredients from the table to the counter.

The carer organises the space by moving objects away and the PwD gets the orange.

PwD: 'I struggle with oranges so you can start with the orange please' using a kind tone of voice.

Carer: 'Right, I'll peel the orange'.

Carer: 'It's like a silent movie, isn't it?' while peeling the orange.

PwD: 'You couldn't help yourself!' they both laugh.

(PwD11 and Carer11).

This example shows teamwork and indicates the existing trusting relationship the dyad has which facilitates task completion in constant harmony. Mutual respect and affection between pairs was noticed when they both gave space to each other to work together and they laughed at their comments. There was constant reassurance about what they were doing, which resulted in a positive encouragement that led to efficient and smooth interaction. The PwD was able to take the lead and delegate to the carer, while also having the opportunity to thrive.

In this theme, the PwD did not need physical assistance, however, when they seemed confused, Partnership-oriented assistance supported them without using instructions or prompts, while reassuring the PwD:

The PwD (female, wife, moderate stage) is asked to make a fruit salad and all ingredients are left in the kitchen's counter. The PwD gets a chopping board for the carer (male, husband) and one for themselves. They stand in front of the counter and decide what they are going to do:

PwD: 'I'm going to do the lemon'.

The carer moves away to get a knife.

PwD: 'Sorry, what are you going to do?' looking at all the different fruits displayed in front of them.

Carer: 'Should I start with the strawberries?' using a cheerful tone of voice while looking at their wife.

PwD: 'No pinches! I would do the apple then!' using a joyful and enthusiastic tone of voice she gets an apple and starts peeling it.

PwD: 'I was going to put some orange juice in there' and looks at the carer who is working on their chopping board.

Carer: 'Yes' and looks at them.

PwD: 'Or liquid?'

Carer: 'Good idea!' using a gentle and positive tone of voice.

PwD: 'Good idea?'

Carer: 'Yeah' and the PwD smiles while getting the juice out of the fridge.

(PwD15 and Carer15).

This case illustrates how the carer's initiative to work alongside the PwD pulled her back into the task when the PwD appeared confused. The proposed action as a question, empowered the PwD to focus on the activity without the need of getting direct support. The use of reassuring words provided a positive environment where the decisions made by the PwD were celebrated and welcomed.

In Partnership-oriented assistance, carers offered support and were ready to monitor and follow how the PwD wished to complete the task. This theme depicted a PwD-led approach, where the person took the initiative to ask the carer to complete certain steps and prompt them to engage. These participants showed greater abilities to solve and achieve the task indicating that this approach to support relied on the PwD having some ability to complete tasks, but also relying on carers providing the right space.

Bystander

This theme was characterised by two sub-themes: hesitates and disengages. In very few occasions, the carer did not respond to the situation and did not intervene even when it was clearly needed:

The PwD (male, husband, severe stage) is asked to serve a glass of a cold drink. The bottle sits on the kitchen's counter where they are standing. The carer (female, wife) is behind them.

The PwD opens the cupboard, gets a glass and puts it on the counter:

PwD: 'It's all your fault, isn't it?' points in a direction where there is no one present, then closes the cupboard.

PwD: 'Do I have to put this in there?' grabs the bottle and points at the glass and looks away in the direction where there is no one. The carer does not intervene and stays standing in their initial position.

PwD: 'Eh?' opens the bottle and looks at the researcher.

PwD: 'That's what I have to do?' the carer looks at the researcher.

FA: 'Your wife is going to help you if you need help' the carer approaches the PwD but stays away from them, holding their hands, and leaning forward as trying to observe what the PwD was doing.

Carer: 'You are going to pour a glass of tonic, or just half a glass' using a low tone of voice. (PwD6 and Carer6).

This observation depicts a carer who does not respond to the situation and even when the PwD clearly asks for support. The carer is distanced and appeared confused, and no assistance is given until the carer is prompted. This approach left the PwD uncertain about what they were doing as there was no confirmation or response. The carer may have interpreted the researcher's instructions incorrectly particularly since the carer assisted the PwD after she was prompted to do so. However, it shows the PwD faltering with the task due to receiving no support.

Another carer became disengaged from the task:

The PwD (female, wife, moderate stage) is asked to make a fruit salad. The carer (male, husband) is standing behind the person. While the PwD makes the salad, the carer looks around for approximately twelve seconds, then looks at the person, and finally moves to the kitchen sink where they look through the window and start washing the dishes.

(PwD9 and Carer9).

Here, the carer was not engaged with what the PwD was doing.

Bystander was the least observed approach to assistance. Carers using this approach appeared unsure of how and when support was needed, and even though they may have attempted to allow the PwD to apply and use all their skills to perform the task, there was a sense of disconnection between the carer and the PwD that sometimes resulted in difficulties completing the activity.

Discussion and Implications

This study examined video-recorded observations to explore how family carers supported PwD during ADLs. Five themes were generated during the analysis: Person-enabled assistance; Goal-directed assistance; Carer-led assistance; Partnership-oriented assistance, and Bystander.

These themes provide understanding of the different ways in which carers assist PwD with ADLs. They included subtle carer actions which were generally targeted to the PwD's response to the task. Future research could examine the impact each approach has on the task performance of the PwD to enable an understanding of what works well and what could be changed to facilitate the person's participation in ADLs.

Our findings suggest that the approach adopted by carers could have been shaped by their perception of the PwD's abilities to complete the task. This was seen when carers were attuned to the person, adjusting their actions and the setting to provide prompts, explanations, or options to the person, despite the stage of dementia and the activity completed. Most carers in this study had not completed any formal carer training which means that they have

intuitively and progressively learnt from their own experiences how to assist their family member in ADLs.

Previous roles and mechanisms that formed the relationship between the dyad seemed to define the approach to assistance. Some carers were strong on suggesting and even imposing their own ideas for the task while the PwD accepted them, following what seemed like a pre-established dynamic in the relationship of these dyads. This has been noted before, where Occupational Therapist delivering a pilot intervention found that previous and established mechanisms in the relationship between the PwD and their family carer positively or negatively affected the intervention being delivered (Burgess *et al.*, 2021). Similarly, gender has been found to be associated with the amount of assistance provided in ADLs (Spector & Fleishman, 1998) showing that male older adults received more support than women. The fact that the carers using Partnership-oriented assistance were all husbands (males) highlights the specific role that gender may have when providing assistance to the PwD. How carers support PwD may depend on the nature of the relationship between them and how the person is presenting at that time.

Previous studies have measured the amount of assistance carers provide and showed that specific ADLs required the highest level of support, such as showering, dressing and home maintenance (Amato *et al.*, 2021) or have observed spouses supporting family members with mild to moderate dementia (Vikström *et al.*, 2005). However, after many years of disease progression, the strategies used by carers may be directed to compensate for missing abilities, rather than to improve participation, which can reveal new and different approaches taken.

Considering the limited literature in this area, our findings provide much needed insights into daily task interactions between carers and PwD. Findings could inform future studies to examine these approaches to assistance, the factors that accompany the use of

these, and how they promote or hinder ADL participation in PwD. In due course informing Occupational Therapists or dementia services educating carers on what approaches they may implement to support participation in ADLs. For example, to maintain ADL functioning by promoting autonomy through person-enabled assistance.

The identification of the five approaches to assistance provides some indication of possible motives and goals for which the carers adopted different ways to support ADLs, such as promoting active participation, completion of the task and teaching own methods. Some carers used one or more approaches to assistance while the task was completed which also suggests that they tend to adapt to the PwD's needs. More research would be needed to explore why carers provide support during ADLs to understand the approaches to assistance further.

An important finding was that carers appeared to have a key role in facilitating the PwD to either thrive or become hesitant and unsure during ADLs. When carers gave space for the PwD to execute the task and make their own decisions, a door was open for them to succeed. Conversely, when carers corrected the PwD, imposed steps or disengaged, a sense of disconnection from the task seemed to arise. Our findings suggest, carers had a crucial and meaningful role in maintaining or enabling the PwD's sense of autonomy that allowed them to feel more confident when doing a task.

Observing how carers provide support during ADLs is a useful tool for Occupational Therapists to understand their clients' family dynamics. This knowledge could be drawn on to promote collaborative approaches between the PwD and their carers, which can increase involvement during Occupational Therapy interventions promoting better outcomes (Banerjee *et al.*, 2003; Burgess *et al.*, 2021). Monitoring and supervising interactions during task performance could also inform clinicians advising carers about when support may be needed, which aligns with clinical guidelines for Occupational Therapists working with PwD

(Lever *et al.*, 2017). For carers in our study, finding a balance between the assistance provided and the assistance needed appeared to be a constant challenge, with some carers over-assisting the PwD, providing support when it was not clearly needed. Future research could focus on the PwD's perspectives of receiving support when doing a task to help carers identify the right moment to assist the PwD during ADLs.

Strengths and limitations

This was a secondary analysis, so we had limited control over the data collection processes. Information about the number of years that carers had supported the PwD with ADLs and on the ethnicity of the participants was not collected, therefore the sample used in the study may lack the heterogeneity needed to get a richer and wider understanding of how relationships and/or culture shape carers' actions. This information may have helped to understand how the experience these carers had may have contributed to the development of the different approaches to assistance identified by this study. Additionally, we had no control over the tasks which were observed, with the variety of tasks in the sample making direct comparisons non-viable. Another limitation arises from analysing inductively from the video-recorded observations, therefore, our findings only include the range of support our participants provided so other approaches may have been missed.

Strengths of the study included its credibility and trustworthiness, which was demonstrated by conducting a consistent analysis, that included multi-analyst interpretations, providing a deep engagement and reflexivity about data from multiple perspectives (Braun & Clarke, 2019). This has enhanced the quality of the analysis by reducing selective perception and blind interpretive bias (Patton, 1999). During the data collection debriefing sessions and

peer scrutiny were also implemented, which increased the credibility of the study (Shenton, 2004).

Another strength of this study was the use of direct observation of real tasks which reduced informant-bias (Hammer *et al.*, 2009); however, this also poses a limitation since carers and the PwD may have acted differently due to being observed. Multiple observations for each dyad could have enhanced our understanding and added reliability. We also cannot know the underlying motivations for, or emotional aspects of, participants' actions. Complimenting observations with interviews would have been one way of examining this.

Conclusion

This study analysed observations of family carers supporting PwD during ADLs. Findings suggest that carers employ different approaches to assist a PwD and these appeared to affect PwD's confidence and participation. Knowledge of different approaches and their impact could be used by Occupational Therapists to inform carers how and when best to support a PwD with ADLs.

Key findings

- Carers employ different approaches when supporting people with dementia performing ADLs.
- Carer approaches appear to have a role in supporting people with dementia to thrive or become more hesitant.

What the study has added

Observing people with dementia's task performance with carer support provides key understandings of dyad relationships, which could be utilised by Occupational Therapists supporting carers to promote participation of PwD in daily tasks.

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