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research article

The role of adult social care services in improving the quality of life of older carers and the individuals they support

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We explore the quality of life of older carers (aged 65 and above) and the people they support, as well as the role of services in promoting their quality of life, both on an individual and on a dyadic level. We collected data in England and, using a framework analysis, identify three themes that were shared by 28 carers and 11 individuals with support needs: (1) experience of support within and outside of the dyad; (2) dilemmas related to receiving social care services; and (3) the impact of COVID-19. This study suggests how to potentially improve their experience of support across different areas of their lives.

Keywords care recipient • dyad • family carer • long-term care

To cite this article: Silarova, B., Collins, G., Rand, S., Milne, A. and Zhang, W. (2025) The role of adult social care services in improving the quality of life of older carers and the individuals they support, *International Journal of Care and Caring*, Early View, DOI: 23978821Y2025D000000137

Introduction

An unpaid (family) carer – commonly referred to as a ‘carer’ in the UK and Australia, a ‘family caregiver’ in Italy, China, Taiwan and India, and a ‘caregiver’ in the US ([The International Alliance of Carer Organizations, 2021](#)) – is someone ‘who provides unpaid help to a friend or family member needing support, perhaps due to illness, older age, disability, a mental health condition or addiction’ ([Strategy and Projects Team, 2018](#)). Carers offer a range of care and support, including personal care, managing

finances, providing companionship and emotional support, and arranging formal support from services ([The International Alliance of Carer Organizations, 2021](#)).

In Europe, approximately 12.7 per cent of the population are carers. The care they provide is estimated to be the equivalent of 3.6 per cent of Europe's gross domestic product ([Peña-Longobardo and Oliva-Moreno, J. 2022](#)). While being a carer can be rewarding, it is also associated with a range of negative quality-of-life outcomes, including: giving up paid work or reducing working hours; giving up hobbies and interests; experiencing isolation or difficulty sustaining social relationships ([Rand and Malley, 2014](#); [Department of Health and Social Care, 2018](#)); and adverse impacts on overall health, well-being and even mortality rates ([Chiao et al, 2015](#); [Goren et al, 2016](#); [Allen et al, 2017](#); [Dassel et al, 2017](#); [Bom et al, 2019](#); [Cohen et al, 2022](#); [Milne and Larkin, 2023](#)).

Carers and the people they support often share the same home environment – with such carers termed ‘co-resident carers’ – as well as finances and other resources ([Rand, 2020](#); [Rand et al, 2022](#)). The quality of their relationship – whether characterised by equality, positive interactions or conflict – significantly influences both parties' quality of life ([Rand, 2020](#); [Rand et al, 2022](#)). Notably, the caregiving role itself plays a crucial part in shaping the relationship ([Lyons et al, 2002](#); [Hill, 2007](#); [Braun et al, 2009](#); [Henwood et al, 2018](#); [Bielsten and Hellstrom, 2019a](#); [2019b](#)). This is particularly the case for intensive care. A recent scoping review ([Zhang et al, 2022](#)) identified three conceptual frameworks that have been applied to understand the interdependence of quality of life within the caregiving relationship: (1) the actor partner interdependence model (APIM), applied to an analysis of dyadic quality of life ([Rand et al, 2017](#)); (2) social exchange and equity theory ([Dowd, 1980](#), [Gergen and Gergen, 1986](#)); and (3) dyadic conflict and power dynamics in care relationships ([Lyons et al, 2002](#); [Hill, 2007](#), [McIntyre and Reynolds, 2012](#); [Moon et al, 2016](#)). To be more specific, the APIM consists of three key components: (A) actor effect, that is, the impact of an individual's characteristic (for example, health) on their own outcome; (P) partner effect, that is, the influence of a dyad partner's characteristic (for example, health) on the individual's outcome; and (I) interdependence, that is, the direct effect or influence of one person on another within the relationship ([Kenny et al, 2006](#)). A study applying the APIM ([Rand et al, 2017](#)) found evidence of direct interdependence in relation to control over daily life. This finding suggests that the dyad itself can serve as a meaningful target for interventions aimed at increasing perceived control over daily life.

Understanding dyadic quality of life is an emerging focus of research ([Häusler et al, 2016](#); [Moon et al, 2016](#); [Lopez-Mendez et al, 2023](#)), including in social care by exploring the interdependence of social care-related quality of life using dyadic data analytical methods ([Rand et al, 2017](#); [Rand, 2020](#)). However, more work is needed, especially regarding older carers and those they support, who have distinct needs ([Carers UK, 2015](#)). This article builds upon previous work by incorporating a qualitative approach to examine how the dynamics within caregiving dyads influence social care outcomes. This allows for a richer understanding of the lived experiences of older carers and the people they support. The aims of the study reported in this article were (1) to understand the quality of life of older carers and the people they support, both on an individual and on a dyadic level, and (2) to understand the role of services in promoting the quality of life of older carers and the people they support, both on an individual and on a dyadic level.

Methods

This article reports on an analysis of semi-structured interviews with older carers and the people they support living in England, following the 'Standards for reporting qualitative research' (O'Brien et al, 2014). The study was conducted as part of a broader research project on applying a dyadic quality-of-life lens to adult social care practice, which also included a scoping review (Zhang et al, 2022) and a qualitative study involving social care professionals in England (Rand et al, 2022).

Participants and setting

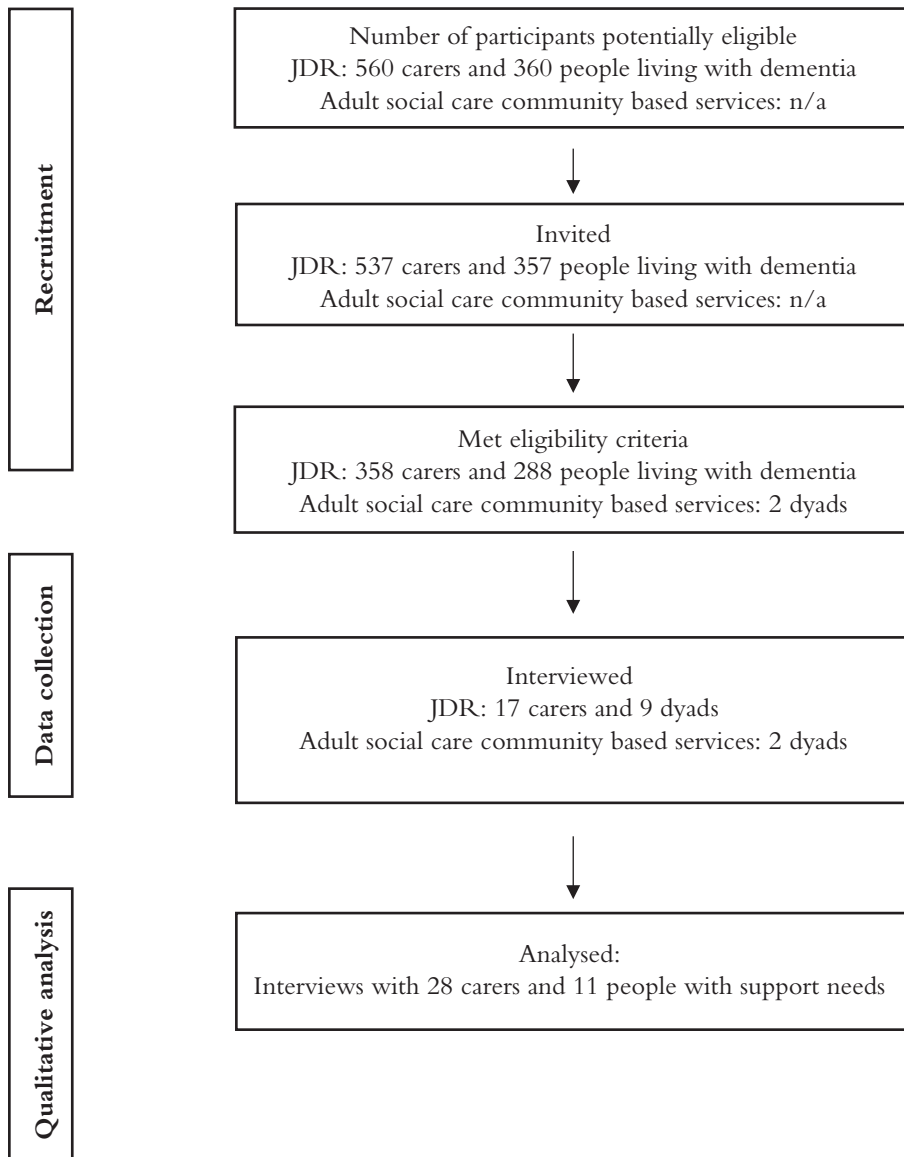
Carers and individuals with support needs (dyads) were eligible to take part if they lived together and the carer was aged 65 years or over. One or both members of the dyad also had to use at least one community-based social care service (for example, day care, home care or respite care) at the time of recruitment. This allowed us to address the study aim of understanding the role of community-based social care services in promoting the quality of life of older carers and the people they support. All the study materials were in English.

We recruited the majority of participants via Join Dementia Research (JDR), which is an online platform of volunteers interested in dementia research. Members can indicate whether they live with dementia and/or care for someone living with dementia. We invited all potentially eligible participants in alphabetical order, starting with those living closest to the University of Kent and then gradually expanding the geographical radius. Participants were first approached via either email or post (based on their preference), and if we did not hear back in three or four weeks, they were then sent one follow-up email. Despite the fact that we engaged with and secured support for recruitment from ten adult social care organisations (for example, carers' organisations), only two pairs of participants were recruited via a carers' organisation. The recruitment strategies varied across social care organisations, including promoting the study via their communication channels (for example, newsletters), sending out study invitations and inviting members of the study team to join a relevant meeting, for example, a carers' meeting, to speak about the study. In addition, the study was also promoted via the Personal Social Services Research Unit's Twitter account; none of the participants were recruited through this platform.

Data collection

Recruitment took place between April and December 2021 in England. All interviews were conducted by two members of the team (Barbora Silarova and Grace Collins; each interviewed approximately half of the participants). In total, we interviewed 17 carers on their own and 11 dyads (see Figure 1). For seven dyads, the carer and the person they supported were interviewed individually (by two researchers), while four dyads were interviewed together (joint interviews), according to participant preferences.

Figure 1: Flow of the participants through the study



Abbreviations: JDR = Join Dementia Research.

Note: n/a = information was not available.

Changes introduced to the data collection due to the COVID-19 pandemic

As we conducted interviews during the COVID-19 pandemic, we had to adapt our approach on several occasions. For example, the original plan was to conduct all interviews in person, with two interviewers working as a pair to visit people and conduct parallel interviews separately. The pandemic made this difficult; therefore, most of the interviews were conducted via phone or an online platform (for example, Zoom). Only one dyad was interviewed in person. Next, the pandemic meant that

many adult social care organisations had limited capacity to support the study or were reluctant to participate due to other pressures. As a result, we adjusted our recruitment strategy, increasing our reliance on JDR. This resulted in a higher-than-expected proportion of participants being carers of people with dementia and conducting interviews solely with carers when the person with dementia was unwilling or unable to participate. In these cases, carers were asked to reflect on their view of the quality of life of the person they support. These changes meant that we had to modify our original data analysis plan, as discussed further in the Analysis section.

The background questionnaire and the interview schedule

The background questionnaire and the interview schedule were developed by the research team and then modified based on the feedback from the Patient and Public Engagement and Involvement research advisors. A background questionnaire (only for carers) asked about their age, gender, ethnic background and any health difficulties. Carers were also asked to provide information about the person they supported, including their age, gender, any health difficulties and what their relationship is (for example, parent, partner, sibling and so on). The questionnaire also included questions about the type of support provided by the carer, as well as the length and intensity of that support. Lastly, we included questions related to community-based adult social care support and services.

We used the Adult Social Care Outcomes Toolkit (ASCOT) (Netten et al, 2012) and ASCOT for Carers (ASCOT-Carer) (Rand et al, 2015) to inform the interview schedule. ASCOT (Netten et al, 2012) is a suite of tools designed for use in social care research and evaluation, including both residential and community-based support. It is based on the capability approach and seeks to capture the effect of services on aspects of people's quality of life that are known to be important to individuals with support needs and unpaid carers and that may be improved by good-quality and effective social care support. Four of the ASCOT and ASCOT-Carer domains overlap, and three of these domains were previously used in quantitative dyadic analysis (Rand et al, 2017). The ASCOT and ASCOT-Carer have also been previously adapted and applied in qualitative studies (see, for example, Rand and Malley, 2014).

We covered the following topics as part of the interview schedule: community-based social care services and support; help from other sources, including family, friends or neighbours; and individuals' everyday experiences, such as friendships and family relationships, feeling safe, and doing things they enjoyed. For each of these, we asked participants whether and how any support they had from organisations made a difference in their daily lives. We also asked them to give a rating on whether adult social care services met their needs across different areas of their lives (areas of social-care-related quality of life). The majority of individuals with support needs struggled to provide these ratings. The interview schedule was used flexibly, depending on whether the dyad was interviewed individually or together. In the case of individuals with support needs, we adapted the interviews based on their cognitive ability on that day.

All interviews were recorded using encrypted audio-recording devices, and recordings were transcribed verbatim by a professional transcriber. On average, the interviews with carers lasted 53 minutes (ranging from 26 minutes to 2 hours 2 minutes); interviews with care recipients lasted 33 minutes on average (ranging from

11 minutes to 1 hour 8 minutes); and joint interviews lasted 1 hour 29 minutes on average (ranging from 56 minutes to 2 hours 7 minutes).

Researcher characteristics and reflexivity

All interviews were conducted by two white, female researchers, with neither of them being a carer or having a first-hand experience of using adult social care services. Barbora Silarova has a background in clinical and health psychology and works on the topics of the unmet social care needs and quality of life of people living with dementia and their carers. Grace Collins has a background in psychology and social care research. Her previous work has focused on the social-care-related quality of life of people living with dementia and innovative social care. Barbora Silarova and Grace Collins met regularly to debrief after the interviews, reflect on what worked well and what did not, and ensure the use of consistent language. They also met regularly with the principal investigator (Stacey Rand) to share their experiences and observations, and any need to adapt the interviews was decided together.

Analysis

We conducted descriptive statistics using Stata 16 (StataCorp, 2019) for demographics, health, caregiving situation (for example, relationship to a person with support needs, duration of caring and so on), social care service use and the social-care-related quality-of-life areas, as measured by the ASCOT-Carer (Rand et al, 2015). We used framework analysis to analyse the qualitative data (Parkinson et al, 2016).

We uploaded the responses to NVivo (Release 1.5) as two data sets: one for carers and one for individuals with support needs. For familiarisation, Barbora Silarova reviewed all the interviews, while Grace Collins reviewed four. We developed initial thematic frameworks (one for carers, and one for individuals with support needs) based on prior research (Rand and Malley, 2014; Rand et al, 2017) and notes from the familiarisation phase. These frameworks were refined and agreed upon with the research team. We indexed half of the data against these frameworks – Barbora Silarova for carers and Grace Collins for individuals with support needs – focusing on the relevant parts of joint interviews. Data were cross-checked by a team member not involved in indexing. After indexing, we created charts in NVivo to analyse within-case and between-case themes (Parkinson et al, 2016).

In the mapping and interpretation stage, Barbora Silarova and Grace Collins identified patterns and themes, focusing on shared and contrasting views on social care outcomes. We merged charts for a comprehensive analysis of themes across both groups.

Regarding dyadic analysis, we considered two methods (Collaço et al, 2021; Farina et al, 2021), taking into account the nature of our data, which included separate, joint and individual interviews. We determined that Farina et al's (2021) approach was more appropriate for our study, as it better captured the breadth of the data and provided insights into both unique and shared aspects of quality of life for older carers and those they support. Eisikovits and Koren's (2010) approach, adapted by Collaço et al (2021), which was the original plan for this study, was unsuitable due to the

changes introduced to this study as a result of the COVID-19 pandemic. It requires interviewing both members of the dyad, whereas 17 of our carers were interviewed without their partners. Using this method would have excluded these data.

Ultimately, we conducted dyadic analysis by focusing on shared and contrasting experiences between carers and those they support, an adaptation of [Farina et al's \(2021\)](#) approach. Unlike previous studies that have predominantly used quantitative models, our approach leverages in-depth interviews to explore how social care services impact both individuals within a caregiving dyad.

Results and findings

Participants' characteristics

The flow of the participants through the study is shown in [Figure 1](#). [Table 1](#) shows the participants' characteristics. The majority (26 out of 28) of people with support needs were individuals living with dementia. Only 10 per cent of carers did not report any mental and physical health problems.

Use of social care services

As can be seen in [Table 2](#), our participants used a range of social care services over the last 12 months. A total of 20 out of the 28 participants either paid for these in full or in part. Importantly, even though participants accessed a range of services, they reported that their needs had not been fully met across different areas of their lives (see [Figure 2](#)).

Findings from the framework analysis

We identified three key themes shared by carers and individuals with support needs regarding their daily experiences and whether community-based adult social care services met their needs: (1) experience of support within and outside of the dyad; (2) dilemmas related to receiving community-based adult social care services; and (3) the impact of COVID-19.

Theme 1: Experience of support within and outside of the dyad

This theme included three sub-themes: (1.1) experience of support within the dyad; (1.2) experience of support from health and social care services; and (1.3) experience of support from family, friends and other networks.

Theme 1.1: Experience of support within the dyad

Caring is inherently relational. Carers in this study reported that they supported their relative due to a sense of duty, mutual agreement or as 'part of life'. As support needs increase, the relationship changes too; this is associated with the loss of emotional support from the person with support needs to the carer and, especially with dementia, the loss of 'the person' themselves: 'Well, okay, that's—things change over time; it becomes more of a one-way street. Yeah, that's harder;

Table 1: Participant characteristics at the time of the interview (n = 28)

| Variable | N (%) |
|--|--------------------|
| Socio-demographic characteristics | |
| Age: carer (mean [SD]) | 75.39 (SD = 6.84) |
| Age: person with support needs (mean [SD]) | 75.22 (SD = 12.83) |
| Gender: carer | |
| Female | 13 (46.43%) |
| Male | 15 (53.57%) |
| Gender: person with support needs | |
| Female | 14 (50.00%) |
| Male | 13 (46.43%) |
| Missing | 1 (3.57%) |
| Ethnicity: carer | |
| White/White British | 25 (89.29%) |
| Multiple or mixed ethnic groups | 1 (3.57%) |
| Asian/Asian British | 0 (0%) |
| Black/African/Caribbean/Black British | 1 (3.57%) |
| Other ethnic group | 1 (3.57%) |
| Health of carer^a | |
| Physical impairment or disability | 4 (14.29%) |
| Sight or hearing loss | 10 (35.71%) |
| Mental health problems or illness | 2 (7.14%) |
| Dementia | 0 (0%) |
| Learning disability or difficulty | 0 (0%) |
| Another long-term health condition | 10 (35.71%) |
| None of the above | 10 (35.71%) |
| Health of person with support needs^a | |
| Physical impairment or disability | 11 (39.29%) |
| Sight or hearing loss | 11 (39.29%) |
| Mental health problems or illness | 2 (7.14%) |
| Dementia | 26 (92.86%) |
| Learning disability or difficulty | 3 (10.71%) |
| Another long-term health condition | 10 (35.71%) |
| None of the above | 0 (0%) |
| Caregiving situation | |
| Relationship to the person with support needs | |
| Husband/wife/partner | 24 (85.71%) |
| Child | 1 (3.57%) |
| Sibling | 1 (3.57%) |
| Parent | 1 (3.57%) |
| Missing | 1 (3.57%) |

(Continued)

Table 1: Continued

| Variable | N (%) |
|--|-------------|
| Duration of caring | |
| Over 1 year, less than 3 years | 6 (21.43%) |
| Over 3 years, less than 5 years | 7 (25.00%) |
| Over 5 years, less than 10 years | 6 (21.43%) |
| Over 10 years, less than 15 years | 4 (14.29%) |
| Over 15 years, less than 20 years | 1 (3.57%) |
| 20 years or more | 3 (10.71%) |
| Missing | 1 (3.57%) |
| Hours of care per week | |
| 50 or more | 24 (85.72%) |
| 49 and less | 3 (10.71%) |
| Missing | 1 (3.57%) |
| Support provided by carer over the last 12 months ^a | |
| Help with personal care | 25 (89.29%) |
| Physical help | 16 (57.14%) |
| Dealing with care services and benefits | 27 (96.43%) |
| Helping with paperwork | 26 (92.86%) |
| Other practical help (for example, shopping or laundry) | 28 (100%) |
| Keeping them company | 27 (96.43%) |
| Taking them out | 25 (89.29%) |
| Giving medicines | 26 (92.86%) |
| Keeping an eye on them | 28 (100%) |
| Emotional support | 25 (89.29%) |
| Other (for example, keeping them exercised) | 4 (14.29%) |

Note: ^a Participants could select all that applied.

you realise that things have changed. It's still a very, you know, it's a very loving relationship, but it alters slightly. You know, caring, caring just changes the tenor of it' (ID:003_c, male, cares for wife). People with support needs are often aware of the changed dynamic, often experiencing guilt: 'I feel a bit guilty of taking up her time and energy because neither of us are very young anymore' (ID:006_cr, male, supported by wife).

Theme 1.2: Experience of support from health and social care services

Carers frequently get emotional support from a carers' group, alongside practical advice and a 'sense of commonality':

You know, and you realise you're all in the same boat. And you know, because sometimes when you're at home on your own, and you think you're the only person in the world, and then you get it all in perspective when you talk to other people.... So, that's nice. (ID:025_c, carer, female, cares for husband)

Table 2: The use of adult social care services (n = 28)

| Variable | N (%) |
|---|-------------|
| Support or services used over the last 12 months ^a | |
| Information and advice | 20 (71.43%) |
| Support or services allowing a break from caring | 18 (64.29%) |
| Home care/home help | 14 (50.00%) |
| Day centre/day activities | 7 (25.00%) |
| Lunch club | 2 (7.14%) |
| Meals services | 0 (0%) |
| Equipment or adaptation to the home | 16 (57.14%) |
| Lifeline alarm | 5 (17.86%) |
| Support from a carers' organisation | 19 (67.86%) |
| Financial contribution towards adult social care services | |
| Pay fully with own money | 14 (50.00%) |
| Pay contribution | 6 (21.43%) |
| Social services pay for all care and support | 2 (7.14%) |
| Other | 5 (17.86%) |
| Missing | 1 (3.57%) |

Note: ^a Participants could select all that applied.

Some carers emphasised the importance of attending groups specifically for carers rather than groups targeted at dyads: 'I've been to a carer group once, but I don't think it really suits me, what I need, because it's for both of us. And when we went, it's just as if I was at home, sort of, tending him, you know, do this or do that' (ID:015_c, carer, female, cares for husband).

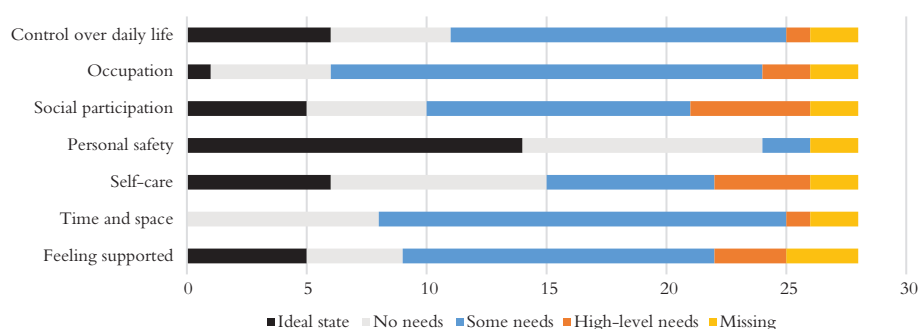
Participants also highlighted that community-based social care support, such as respite care and day centre/day activities, should provide routines and consistent care, including offering the same paid carers:

Well, I think routine is massively important with Alzheimer's. And I think familiar faces and people who treat her correctly, this is very important. (ID:002_cr, male, cares for mother)

In 12 months, I had about 11 different [paid] carers, and that is quite hard work. You know, they're strange, they don't know us, and they don't understand the patient. They've got to get to know the patient. They've got to find their way around the house. They've got to learn how we live. And I found that really, really hard work. (ID:020_c, carer, female, cares for husband)

Another challenge for services is effectively meeting the needs of people with a rare(r) type of dementia: '[The] organisation doesn't recognise young onset or is not interested in it, and there is no help. And there's not— it doesn't worry me, I don't have a problem, I am living with it. But the carers are struggling, and [they] don't get any support' (ID:008_cr, male, supported by wife).

Figure 2: Areas of social-care-related quality of life as measured by ASCOT-Carer ($n = 28$)



In addition to social care services, health services are another important source of support for dyads, especially those providing post-diagnostic support and guidance, including facilitating access to support services for carers:

And I said to him [clinician], ‘I’m not getting help from nowhere. No one is talking to me. I don’t know what to do.’ So, he was the one who said to me I need to have a break, and he said he will put my name forward and he will phone them and recommend that, you know, they phone me, which they did. And that’s how I began to get the help. (ID:015_c, carer, female, cares for husband)

Theme 1.3: Experience of support from family, friends and other networks

Family and friends played a crucial role in the daily lives of dyads. They were perceived as an essential source of both social connection and support, offering practical help as well as emotional support. For example, one participant noted, ‘But he’s [son] quite a good emotional support and occasionally gives my wife her meal or part of the meal and drink and so on. So, he’s a definite support’ (ID:001_c, male, cares for wife).

Adult children, in particular, were identified as important. The absence or loss of this support was deeply felt by a number of participants: ‘Okay, well, it started about, err, nearly three months ago, where I had to go into hospital for something. And we don’t have any children, and so I had to arrange, um, 24 care’ (ID:003_c, male, cares for wife). Other sources, such as extended family members, neighbours, social care services and the Church, also played an important role. For instance, one participant explained:

We try to talk with him [pastor] on the phone, and people have been very generous, have helped to drive me and [name] down to, if you like, the pastor’s home in [place], which is quite a way. So, you know, it’s not totally devoid, but it’s far from what I would really like. (ID:015_cr, male, supported by wife)

Theme 2: Dilemmas related to receiving community-based adult social care services

Carers and the individuals they support face various dilemmas when accessing social care services. In deciding on the type of support (for example, day centre or home

help) and intensity (for example, daily, weekly, number of hours and so on), carers must balance the preferences of the person they support, the potential benefits of the service and the affordability of the care: 'I'm weighing up whether actually I want her to go in four days a week because it's, you know, it's about her and whether she actually benefits from that, whether that's too much, whether it tires her out too much. Whether I can afford it.' (ID:002_c, male, cares for mother).

This decision making is particularly challenging in certain circumstances, for example: (1) when there is a mismatch between the needs of a carer and the preferences of the person they support (for example, when a carer needs a weekly break but the person with dementia refuses to go to a day centre); (2) when there is a discomfort with allowing a stranger into a home (for example, letting 'some stranger into your house to look after your husband' (ID:006_c, female, cares for husband)); (3) when the person with support needs has additional communication needs (for example, '[Name] doesn't provide me any feedback whatsoever. He doesn't show any emotion. He doesn't express his feelings. We don't know what he thinks' (ID:016_c, male, cares for brother)); and/or (4) when extra support will result in spending less time together.

One way in which carers and the people they support address these challenges is by having the person with support needs agree to the service, understanding that it is necessary for the carer's well-being:

It makes a positive difference to me. But there are still some adjustment issues because [name] feels very guilty about the fact that she can't do these things anymore, even though we're both getting old. And so, in some ways, the fact that I've got a heart condition actually helps because the [paid] carers are helping both of us. (ID:003_c, male, cares for wife)

Some carers gradually increase the amount of support they get from a service, allowing both the individual with support needs and themselves to adapt to the new arrangements:

At first, it's often the way that the person with the condition is not happy to have somebody else in the house. And my wife certainly felt that way, so the first time we just met with her [paid carer]. We met with [paid carer] and spent an hour with her just talking, just us, the three of us. The second time I was on a meeting on Zoom and [paid carer] spent the time with my wife – indeed, part of the time, they was in the garden because it was an early-start meeting – and they seemed to get on okay. We've just had the third time, and she will be coming next Monday to be with my wife while, again, I have a Zoom meeting, and I'm building it up so that I'm hoping to be able to get back to the occasional meeting from mid-October. (ID:013_c, male, cares for wife)

Sometimes, carers choose not to disclose that they are receiving help ('but he won't accept it at the moment. He doesn't even know I have a cleaner [laughs]' (ID:008_c, female, cares for husband)). This finding highlights a coping mechanism used by carers, particularly as discussions about needed care can be contentious:

[Wife] is sometimes resistant to the idea of having a carer. It's frustrating to have to go over the reasons we need carers, but it's easier from the viewpoint of a lack of control and easier to deal with by pointing out that [wife] does have some control over what they do and when. (ID:003_c, male, cares for wife)

Other emotions associated with these dilemmas are guilt and worry about the person's well-being:

But the holiday itself was not an easy thing to actually do because you're constantly thinking of your loved one and their needs, and how are they getting on with that person or not? Or that group or not? And they're constantly ringing you too, making the contact, and that was the hardest thing for me. I had to try and make a decision: 'Do I contact her or not? Do I let her text me or not?' (ID:010_c, female, cares for daughter)

Finally, carers often face difficult decisions about whether they feel able to continue caring for their relative at home:

I suppose one has to admit the time has probably nearly come when he should go into care. That's probably the only answer, actually. And one hesitates to do that because we've lived in this house 50 years. This is his only memory, literally his only memory. He doesn't necessarily know his children. He certainly doesn't know the grandchildren. But he does love the garden and just enjoys looking at it or, in fine weather, sitting out in it. (ID:020_c, female, cares for husband)

Theme 3: The impact of COVID-19

While we did not ask participants directly about the impact of COVID-19 on their daily lives, the pandemic's effects emerged organically. It impacted many areas of participants' lives, including social interactions with family and friends, their sense of safety, their engagement in such activities as voluntary work and hobbies, and their daily routines (for full details, see [Table 3](#)).

A key challenge was the complete suspension of most adult social care services for both carers and the people with support needs. Some services transitioned to online formats, such as carers' support groups, but participants felt increasingly isolated and abandoned. Many also found that online services were not suitable for (most) people living with dementia or for those without suitable technology, such as smartphones or computers with a camera. Participants noted that the enforced isolation during the pandemic led to a noticeable deterioration in the social and communication skills of individuals living with dementia. These changes were often permanent: 'We did go to that [carers' support group] a couple of times, and then lockdown came around. And I've got to say that without those contacts, things have deteriorated a lot from a patient's point of view. We've had no contact with anyone' (020_c female, cares for husband). While life during COVID-19 was very different for everyone, many carers found that the pandemic's restrictions somewhat 'levelled the playing field':

It's a terrible thing to say in a way, but, you know, nobody else can go out either, we can't go out, we can't go out, and there's nowhere to go out to because it was all closed. So, we weren't any better or any worse off or much worse off than anybody else. (ID:014_c, carer, male, cares for wife)

Table 3: Examples of the impact of COVID-19 on older carers and people they support, with illustrative quotes

| Areas of impact | Type of participant | Illustrative quote |
|---|--|---|
| Social contact with family and friends | ID:008_c, carer, female, cares for husband | 'You know, we've not been able to see people because, you know, you weren't allowed to. And I think that part of life has now gone more because of the lockdown thing than 'cos of Alzheimer's itself.' |
| Feeling safe | ID:018_c, carer, male, cares for wife | 'We were— prior to her admission to hospital after the accident, I was looking into care because it was becoming a bit too much to manage personally and then, of course, the pandemic erupted on us and everything went haywire, so I just really held off because it was difficult to see how we could have help coming in and knowing that they weren't infected and one thing and the other. So, I held off doing anything on it until we had to, really, because the pandemic was still prevailing back in April.' |
| Death of a family member, friend | ID:002_c, carer, male, cares for mother | 'Who was a sort of, you know, someone [best friend] who could help died in March last year of COVID.' |
| Occupation (including voluntary work and hobbies) | ID:003_cr, female, supported by husband | 'Right, well, we— I like playing golf, for example. We both do it, play golf. So, at the moment, we're not playing it; it's not happening at the moment. But we've always been regular golf players, so that's something.' |
| Levelling up the field | ID:002_c, carer, male, cares for mother | 'Which I've managed to anaesthetise myself to for the last year because everyone else is going through the same sort of thing. But as soon as everybody else is piling down to the [name] to see [name] play [name] again, um, I'm going to feel a bit left out.' |
| Getting COVID-19 | ID:012_c, carer, male, cares for wife | 'It was in January, I was— I had COVID, and my young son who lives with me, who's co-carer, he had— we both had it together. We were both hospitalised, and my wife had nobody to look after her. So, my elder son, who doesn't live with us, he organised live-in care, emergency live-in care, which was funded by the social services for a short period of time.' |
| Routine | ID:005_c, carer, female, cares for husband | 'Yeah, you know, there was the old routine, but now we've got the new routine. And as things have slowly come out of COVID, there's newer routines, and it's really hard for the diagnosed to savvy the next stage on.' |
| Assessment | ID:001_c, carer, male, cares for wife | 'So, I would guess it's something to do with COVID: they don't want people coming into houses; they don't want the assessors coming into houses, I would guess. But it's due to be reviewed.' |

(Continued)

Table 3: Continued

| Areas of impact | Type of participant | Illustrative quote |
|--|--|---|
| Change in the delivery of adult social care services provision | ID:003_c, carer, male, cares for wife | 'The things that my wife tells me about the meetings that are important are really the side conversations, which a Zoom meeting will never provide you with. You know, it's talking to the person who's sitting next to you, and sharing little experiences and things like that.' |
| | ID:023_c, carer, female, cares for husband | 'But they continued on Zoom, so we were sort of doing it online, but unfortunately [name] doesn't seem to interact with anything, a picture online, he doesn't even look at it, and he certainly didn't show any interest in it at all. It was more me really sounding interesting and helpful, just to have somebody to talk to, and something happening, and just seeing some other faces.' |
| | ID:025_c, carer, female, cares for husband | 'It is difficult. And I particularly think that the government didn't do— they didn't even mention throughout that pandemic, people who are caring 24/7 at home on their own. And had all their support cut off. For 18 months, the whole of the support was just totally cut off for 18 months, totally cut off, and they didn't even mention that.' |

Discussion and conclusion

This article offers a new perspective that complements earlier quantitative research on dyadic quality of life (Rand et al, 2017), as well as previous qualitative or mixed-methods studies focused on individual quality of life (Rand and Malley, 2014; Rand et al, 2020). Given the vital role that older carers play in sustaining many people with care and support needs, it is imperative to understand how community-based services can best support them. In particular, this article suggests that there is a need to understand their quality-of-life support needs in the context of their relationship and the quality of life of the person they support.

This article illustrates that tensions and dilemmas frequently emerge when carers and care recipients have differing needs, preferences or capacities regarding the use of social care. These tensions can result in emotional strain, compromise or covert behaviour, such as carers arranging support without disclosing it to the person they care for. As illustrated in our results (see Theme 2), carers often find themselves needing respite, support or time for other commitments (for example, work or medical appointments), while the individual they care for may resist services due to discomfort with unfamiliar people, reluctance to acknowledge their changing needs or communication barriers that prevent them from expressing how they feel about the proposed support.

This dynamic can create a subtle but significant conflict of interest: the carer's well-being and ability to sustain care often depend on the very services that the person being supported may resist or actively reject. Our findings show how carers navigate this conflict through various strategies, including the gradual introduction of services, framing service use in terms of mutual benefit or concealing the use of external help. These strategies reflect the complexity of relational decision making within caregiving dyads and underscore the emotional labour involved in negotiating care arrangements that work for both parties.

This article indicates that recognising and addressing these potential conflicts of interest is crucial in the assessment and care-planning process. The article highlights the importance of a relational, dyad-focused approach, one that acknowledges not only individual needs but also how these needs interact, compete with or align within the caregiving relationship. A consistent and trusted professional (for example, a social worker) can play a key role in supporting both members of the dyad to navigate these tensions in a way that respects autonomy, sustains relationships and promotes the quality of life for both (Ingersoll-Dayton et al, 2019; Rand et al, 2022, Tanner et al, 2023).

To strengthen our findings, we examined how the presence or absence of adult children affects caregiving relationships. Carers with adult children often rely on periodic assistance, whereas those without children report experiencing heightened social isolation, financial strain and emotional distress. The lack of such support frequently leads to greater dependence on formal care services, which are not always equipped to meet their nuanced needs (Pickard, 2015; Swinkels et al, 2017; Zygouri et al, 2021; Pacheco Barzallo et al, 2024).

The article also provides evidence about the impact of the COVID-19 pandemic on older carers and the people they support (Caprioli et al, 2023; Lancashire et al, 2023; Rosenberg and Eckstrom, 2023), both individually and dyadically. Specific impacts include a lack of access to social care services and a lack of social contact with family and friends. Carers (especially those providing 24/7 care) felt invisible to and forgotten about by welfare agencies and the government.

The study has a number of limitations. First, our sample was a convenience sample. Our participants were predominantly white, and those looking after their partner were all in heterosexual relationships. Second, at times during the dyadic interviews, the carer's voice was more dominant; this may reflect the fact that the carer has become a 'spokesperson' for the pair. Even though we adapted the interviews to the needs of the participants with dementia or cognitive difficulties, drawing on our previous interviewing experience, the study was not originally planned to be conducted with people experiencing more advanced dementia.

Recommendations for policy makers and practitioners

Our findings provide important recommendations for commissioners and policy makers in England concerning older carers, based on the experiences of both the carers and those they support (see Table 4). To ensure that community-based social care services meet the needs of older carers, we recommend the following:

- Design and implement carers' support services that are relationship-aware, recognising and responding to the interdependent nature of caregiving relationships. Rather than focusing solely on the individual needs of carers in isolation, services should be developed with an understanding that carers' well-being is deeply connected to the experiences, preferences and needs of the person they support. This means acknowledging that support offered to carers may only be effective or acceptable if it aligns with, or at least does not undermine, the needs, preferences and well-being of the care recipient. Such services should aim to promote shared well-being across the caregiving dyad by:

Table 4: Recommendations to potentially improve the experience of adult social care services by older carers and those they support

| For whom | Recommendation | Type of participant | Illustrative quote |
|---|---|--|--|
| Carers and individuals with support needs | Power of attorney | ID:023_c, carer, female, cares for husband | 'So, my advice to everybody is to get power of attorney as soon as you can [laughs], whether you need it or not, I really– I go around sort of telling everybody, "Just do it" [laughs].' |
| | Memory books | ID:011_c, carer, female, cares for husband | 'But because we do memory books for people, so if they go into hospital or if they're in a nursing home, people say they don't see this individual in the bed that looks totally incompetent and doesn't seem to understand anything. You point to the book next to them and say, "This is the person you're looking at; they were a nurse themselves once", or "They were a teacher once", or "They were in construction", you know, "They are not what you see in front of you now, there's some more of these other things, and they have to be treated with dignity and respect."' |
| | Emergency arrangements | ID:021_c, carer, male, cares for wife | 'I've put in place– do you know the [organisation], who can do– they're ready to come and help for 48 hours if I have to go into hospital or anything like that. So, I put that in place, and I've got myself a key safe with all the keys in there and various people knowing the combination, and I've got a message in a bottle in the fridge in case people have to come round and help, and I'm not there to help.' |
| | Share the routine with, for example, respite care staff | ID:017_c, carer, female, cares for husband | 'Yeah, I've got to– I've got to give them a clearer picture of his routine during the day when he sleeps here so that they've got a better grip on when he needs to go to the loo and will need some help. So, I'm going to write it all out.' |
| | Join the carers' group | ID:025_c, carer, female, cares for husband | 'You know, and you realise you're all in the same boat. And you know, because sometimes when you're at home on your own, and you think you're the only person in the world, and then you get it all in perspective when you talk to other people, you know. So, that's nice.' |
| | Keep records of services provided | ID:009_c, carer, male, cares for wife | 'And I kept a note of what the carers were missing from what they should have been doing, when they were late, when they left early or whatever. These are the sort of things that the social services are not aware of, and yet they go by the records that they supposedly have, and then they just charge people irrespective of checking whether carers have been or not.' |
| | Push, push and push | ID:009_cr, female, supported by husband | 'I know it can be– sometimes it can be quite a smooth process, but a lot of the time it can be quite– you have to really push, don't you? It all depends on where you live as well sometimes.' |

(Continued)

Table 4: Continued

| For whom | Recommendation | Type of participant | Illustrative quote |
|--|---|--|--|
| Family, friends and neighbours | Initiate social activities | ID:004_c, carer, female, cares for husband | 'But if people had any idea what it's like, they would perhaps be more, more likely to say– instead of saying, "Let me know if there's anything I can do." "Get the diary out and tell me whether you can have a drink with me in a week's time." |
| | Feedback and praise | ID:012_c, carer, male, cares for wife | 'But you never, you never think you're doing very well, but everybody that comes in says we are.' |
| Local authority (adult social care departments) | Clear information regarding Attendance Allowance, a council tax reduction and so on | ID:013_c, carer, male, cares for wife | 'So, continuing from that, we decided with [name] that we wouldn't apply for– correct me if I'm using the wrong terms, but I think it's Attendance Allowance and a council tax reduction. I was a little concerned about what we were signing because my wife is still driving.... Why I didn't do it then was– I can't remember exactly what we were signing, the wording, but it made me worry that the signing to say that she was at a certain condition could have an effect on her driving.' |
| | List of available services/help to navigate adult social care services | ID:014_c, carer, male, cares for wife | 'And matters relating to me are not dealt with by social services; they're dealt with by a myriad of charities, which constantly merge, change their name, rebrand themselves, reorganise, and it can be a bit difficult to follow. I imagine that's not something which is new to you.' |
| | Provision of courses | ID:004_c, carer, female, cares for husband | 'A really– telling you what it's going to be like to look after somebody with dementia. And that [course] was the single most useful thing that I had; I did it with four or five other women whose husbands had– people, men and women, whose partners, or had somebody, the person they cared for, had just been diagnosed with dementia.' |
| | Provision of 'non-traditional' social care services | ID:013_c, male, cares for wife | 'The grass cutting, next year I might employ the local guy to cut the grass. And I might get the local guy to make the grass even so my wife can actually walk outside with more ease.' |
| | Involvement of people drawing on adult social care services | ID:009_c, carer, male, cares for wife | 'I would like to see as well some regional panel set up, or area panels everywhere, because you can never have, like, a forum where you can have somebody from the, say, social services, carers, people that are being cared for if they're physically able, well enough to attend, and people like yourselves [researchers]. There's nothing like that, so that these managers that are managing things, you know, that they don't know what they're managing, they can have actual feedback from people that are actually experiencing what they are or are not doing.' |

(Continued)

Table 4: Continued

| For whom | Recommendation | Type of participant | Illustrative quote |
|--|--|---|---|
| | Inclusive environments | ID:010_c, carer, female, cares for daughter | 'And because she's in a wheelchair, it's a difficult thing anyway because it's not always disabled friendly in the places that we go to.' |
| | Management's understanding of the context of adult social care | ID:009_c, carer, male, cares for wife | 'They [social workers] see the situations with the clients, and they go back and report back, but they can't pass the managers.... It's the management higher up, as you said earlier on, they're not at the coal face, they're not actually in the situation.' |
| Community-based adult social care services | Provision of the activities on the same day/time | ID:005_c, carer, female, cares for husband | 'They're not open on the day that he used to go and only wants to go on that particular day, which is fair enough, it was a day that he was used to.... Things are specific days, specific times, so that [name] knows.' |
| | Provision of support to people with a 'rare type of dementia' | ID:008_cr, male, supported by wife | 'Organisation doesn't recognise young onset or is not interested in it, and there is no help. And there's not-- it doesn't worry me, I don't have a problem, I am living with it. But the carers are struggling and don't get any support.' |
| | Enable carers to have their own time | ID:015_c, carer, female, cares for husband | 'I've been to a carer group once, but I don't think it really suits me, what I need, because it's for both of us. And when we went, it's just as if I was at home, sort of tending him, you know, do this or do that.' |
| | Provision of pastoral care | ID:026_c, carer, male, cares for wife | 'We do get-- one of our local vicars calls in ... every week, um, not to preach religion but just to be there for support, once a week, and that is quite useful for both of us, 'cos we can chat about anything we want, and that is, as I say, another back-up, which, again, we don't have to pay for; it's provided by our local church pastoral team.' |
| | Organise events for community-based healthcare services | ID:019_c, carer, female, cares for husband | 'So, we're trying to get people to find out more about it [dementia], and the GPs [general practitioners], they don't really give information out, you know. So, that GP I spoke to yesterday, he wanted me to give him as much information as possible.' |
| | Provision of training to paid carers | ID:020_c, carer, female, cares for husband | 'We have found, finally, another carer, and this was not easy because although they claim to be carers, most of them felt they couldn't handle an Alzheimer's case. And eventually I did find someone who comes for five hours once a week while [name] is off to do her own thing. So, that's virtually the time she has off, actually.' |
| | Provision of the same paid carers | ID:020_c, carer, female, cares for husband | 'In 12 months, I had about 11 different carers, and that is quite hard work. You know, they're strange, they don't know us, and they don't understand the patient. They've got to get to know the patient. They've got to find their way around the house. They've got to learn how we live. And I found that really, really hard work.' |

(Continued)

Table 4: Continued

| For whom | Recommendation | Type of participant | Illustrative quote |
|------------------------------------|--|---|--|
| | Provision of information through different media | ID:011_c, carer, female, cares for husband | 'That's why we use a telephone to contact people regularly; that's why we send out a newsletter people can read, as well as Twitter and Facebook. Twitter and Facebook are really not for our core members. Twitter and Facebook are to tell everyone around what we're doing.... That's it. And the Zoom and things like that are only, as I said, for small groups of people who can, who can just access it.' |
| Social care needs assessors | Provision of assessment | ID:012_c, carer, male, cares for wife | 'It was focused mostly on the needs of my wife, and they kept saying to me I should get a carer's assessment ... but the second social worker that came recommended, she put forward that I would have a carer's assessment, but I've never had one.' |
| | Provision of training to assessors | ID:019_c, carer, female, cares for husband | 'I'm not satisfied because it appears– and this is talking to other people as well in the [organisation], it all depends who does your assessment. Because we know one person has got hours and doesn't really need any hours at all. So, whoever's helped her to do her assessment or whatever, there's different things.... I don't know what goes on, basically.' |
| | Follow-ups | ID:010_c, carer, female, cares for daughter | 'So, the actual length of time in between an assessment and nothing happening, and you get these things put down on the paper, but actually nothing moves on from that point. That's very, very stressful and worrying.' |
| | Co-production of assessment procedures/forms | ID:025_c, carer, female, cares for husband | 'Well, they didn't seem as if they listened to me. That's the thing, I wasn't being listened to. This young woman was– I reckon she was sitting on the other end of the phone, ticking boxes. And she wasn't listening at all to what I was saying we needed. She thought it was okay for her to ring me up and say, "I've decided what you need is...."' |
| Healthcare services | Awareness of dementia | ID:017_c, carer, female, cares for husband | 'I think then I was very desperate, and I'd changed GPs because the first GP we were allocated when we moved here didn't understand or recognise my husband's problems. And I had to pay £1,000 to go to a private hospital to get the actual diagnosis of frontotemporal dementia for him, but I knew that he was ill; I could tell. But she wouldn't acknowledge this, so I had to change GPs.' |
| | Awareness of a person being an unpaid carer | ID:025_c, carer, female, cares for husband | 'So, you know, and like I said to you, the consultant, when he says to me about having my knees done, you've got to let me do them and all that, he doesn't say a thing about what you're going to do with the person you care for.' |

(Continued)

Table 4: Continued

| For whom | Recommendation | Type of participant | Illustrative quote |
|-------------------|---|--|--|
| | Support and guidance post-dementia diagnosis | ID:024_c, carer, male, cares for wife | 'Um, I felt – talking right back at the beginning – quite disappointed that after the diagnosis, there was no obvious guidance or support from anywhere. I'm not going to say anywhere; I'm not quite sure where it should come from anyway.' |
| | Facilitate support for unpaid carers and the people they support | ID:015_c, carer, female, cares for husband | 'And I said to him [clinician], "I'm not getting help from nowhere. No one is talking to me. I don't know what to do." So, he was the one who said to me I need to have a break, and he said he will put my name forward and he will phone them and recommend that, you know, they phone me, which they did. And that's how I began to get the help.' |
| | Flexibility of appointments for unpaid carers (for example, mode of delivery, provision of times and so on) | ID:019_c, carer, female, cares for husband | 'I'm thinking now about going to my hospital appointment. [Paid carer] can't come to cover me for that time because she has to go somewhere else. So, I've got to think, "Now, do I change that appointment again?"' |
| Government | Adequate funding | ID:017_c, carer, female, cares for husband | 'So, the support I have is very good, but there's not nearly enough of it; I need much more. And also, it's very expensive; I'm paying for it all privately. So, I'm just waiting for the local authority to make that telephone call and arrange the care needs assessment because I'm led to believe there will be some support. I'll have to pay for it all, I don't know how, but there will apparently be some more support. But we have to have the assessment.' |

- facilitating communication and decision making between carers and those they support;
- providing flexible options that can be gradually introduced and adapted over time to accommodate relational dynamics;
- involving both parties, where possible, in assessment and care-planning processes to identify mutually acceptable forms of support; and
- ensuring staff understand the emotional, practical and ethical complexities of caregiving relationships, particularly where needs diverge or where there is resistance to formal support, while, at the same time, services focused on the person being supported should similarly acknowledge the role, needs and well-being of carers, recognising that person-centred care often requires a nuanced understanding of the broader relational and social context in which care takes place.
- Develop policies that account for the growing number of older adults without children – a common term now used is 'ageing without children' – ensuring they have access to tailored social care services.
- Strengthen the role of social workers as consistent points of contact for dyadic assessments and support planning, facilitating more personalised and responsive care interventions over time.

- Invest in community-based peer support initiatives (for example, current and former dementia carers acting as peer supporters/mentors to other carers) to improve carers' well-being and improve the quality of life among caregiving dyads (Greenwood et al, 2013).

To conclude, this article has explored the experiences of older carers and their relatives in England related to social care services. While some feedback was positive, there is a considerable need to improve both the quality and the availability of services to better support carers and those they care for. Family and friends, especially adult children, play a vital role in providing care, and without this support, reliance on formal services would increase. However, policies often assume the universal availability of familial support, overlooking the growing number of older adults without children (Pickard, 2015; Freeman, 2023). More research is needed to address the needs of this increasing demographic. The lasting impact of COVID-19 on service delivery has further constrained access to social care, compounding existing challenges. Experiences also differ widely by socio-economic status (Giebel and Heath, 2023), and the uneven quality of care exacerbates these challenges. Addressing these disparities is essential to improving the lives of those reliant on social care.

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Funding

This work was supported by the National Institute for Health and Care Research School for Social Care Research (NIHR SSCR) under Grant Number 23063.

Acknowledgements

Recruitment to this study was supported through Join Dementia Research, which is funded by the Department of Health and Social Care (DHSC) and delivered by the NIHR in partnership with Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society. We would also like to thank participating sites across the adult social care sector for their support. Next, we would like to acknowledge help with the delivery of the study from the following teams based at the University of Kent: the LSSJ Finance Team and Estates Post Room Team. We would also like to thank Alan Dargan from the Personal Social Services Research Unit for promoting the study on social media. In addition, we would like to acknowledge the contribution of the Patient and Public Engagement and Involvement (PPIE) research advisors, Helen Ramsbottom, Christina Reading and Della Ogunleye. They provided their feedback to the background questionnaire and the interview schedule, as well as the summary of the results. Lastly, we are very grateful to all the carers and people who draw on adult social care services who took part in our study and enhanced our understanding of the role of adult social care services in their lives.

Research ethics statement

Ethical approval for the study was obtained from the North West Liverpool Central Research Ethics Committee in England in January 2021 (Ref: 20/NW/0473/281639). Research governance was obtained from the Association of Directors of Adult Social Services in England in March 2021 (Ref: 17 March 2021), as well as from participating local authorities. Informed written consent was obtained from each participant prior to the interview; they signed either a paper or an electronic consent form. Prior to beginning the interview, the researcher double-checked that the participant was happy to take part and to have the interview recorded.

Conflict of interest

The authors declare that there is no conflict of interest.

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