

Work Package Three

The role of adult social care services in individual and dyadic quality of life: perspectives from older carers and individuals they support

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A photograph of an elderly couple standing outdoors in front of a brick house. The man, on the right, has white hair and wears glasses, a blue long-sleeved shirt, and green corduroy trousers. The woman, on the left, has dark hair tied back and wears glasses, a light-colored ribbed sweater, and a necklace. They are holding hands and looking at each other. The background shows a brick house with white window frames and purple flowers climbing the wall.

Dyads study

- WP 1. Scoping literature review
- WP 2. Qualitative interviews with social care professionals
- **WP 3. Qualitative interviews with older carers, aged 65 or over, & the people they support**

A photograph of two men sitting on a light-colored sofa in a living room. The man on the left is bald and wearing a pink sweater, holding a small white and tan dog. The man on the right has grey hair and glasses, wearing a green sweater. They are both smiling and looking at each other. In the background, there is a lamp, a side table with a plant, and a colorful abstract painting on the wall.

Aims of present work package

- to understand the quality of life of older carers and the people they support – on an individual and dyadic level;
- to understand the role of services in quality of life of older carers and the people they support – on an individual and dyadic level.

Methods – Semi-structured interviews

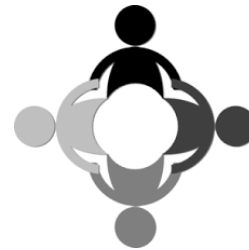
- In the interview, we asked the carer and the person they supported about their everyday experiences.
- For each of these, we also talked about whether and how community-based support made a difference in their lives.



Safety



Occupation



Social participation
and involvement



Control over daily living

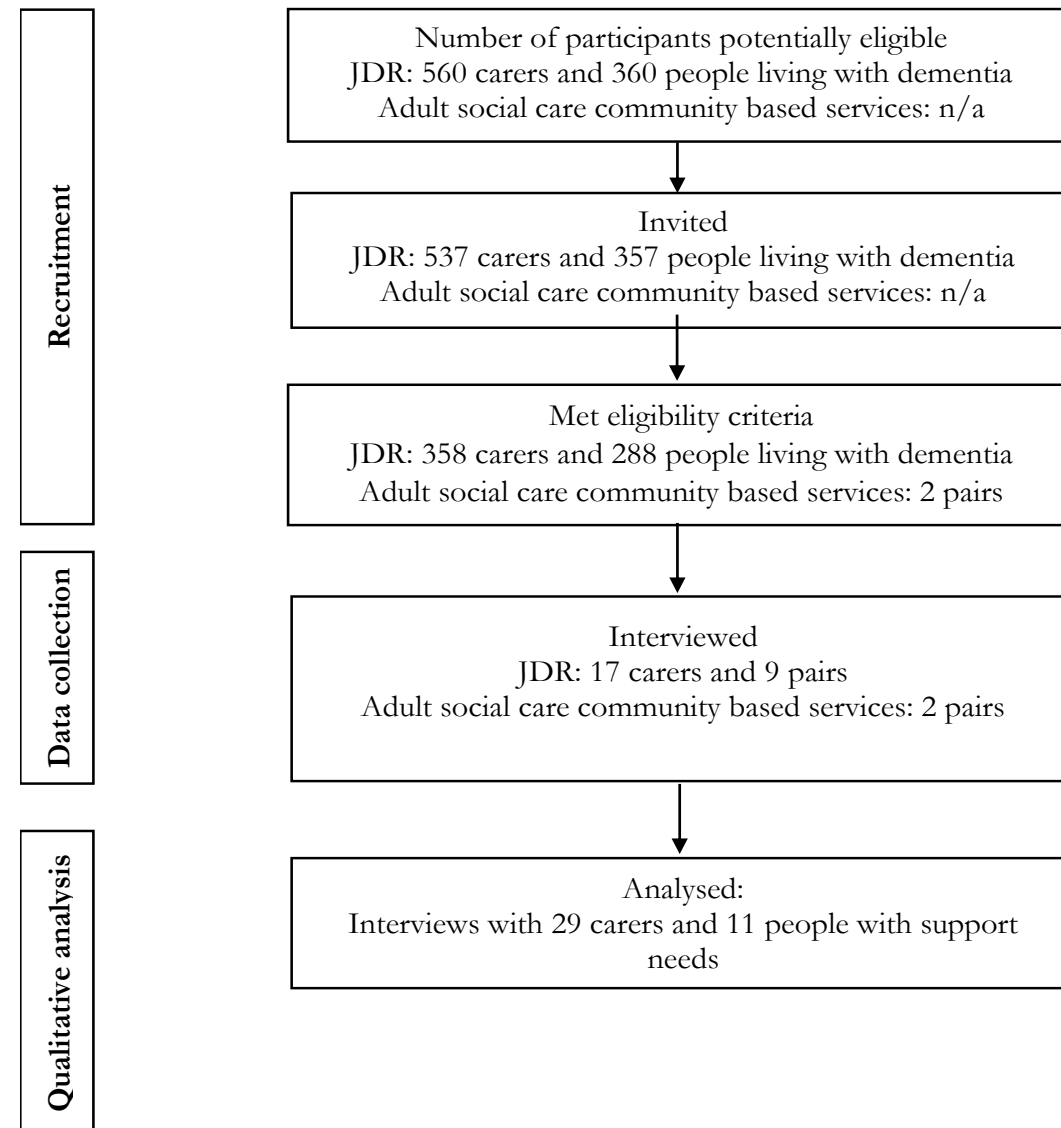
Inclusion criteria:

- Carers and the person they supported (pair)* could take part if they lived together and the carer was aged 65 years or over
- Used at least one type of social care community based service
- Able to consent and able to engage in interviews in English
- Have to live in England
- *Carers could take part on their own

Recruitment period:

19th April until 31st December 2021

Figure 1. Flow of the participants through the study





Preliminary Results

Participants

Carers (n=27): 75.1 years (SD:6.8; 67-95); 48% (n=13) females; 88.9% (n=24) White/White British; 88.9% (n=24) cared for their spouse/partner; 66.7% (n=18) provided 50+hours per week of care; 22% (n=6) provided care 24/7; 29.6% (n=8) provided ≥ 10 years of care

Service users (n=27): 75.2 years (SD: 12.8; 29-99 years old); 52% (n=14) females, 92.6% living with dementia

Care services: 70.4% (n=19) of participants paid for the social care services either in full or a contribution

Community based social care and support

Figure 2. ASCOT for Carers

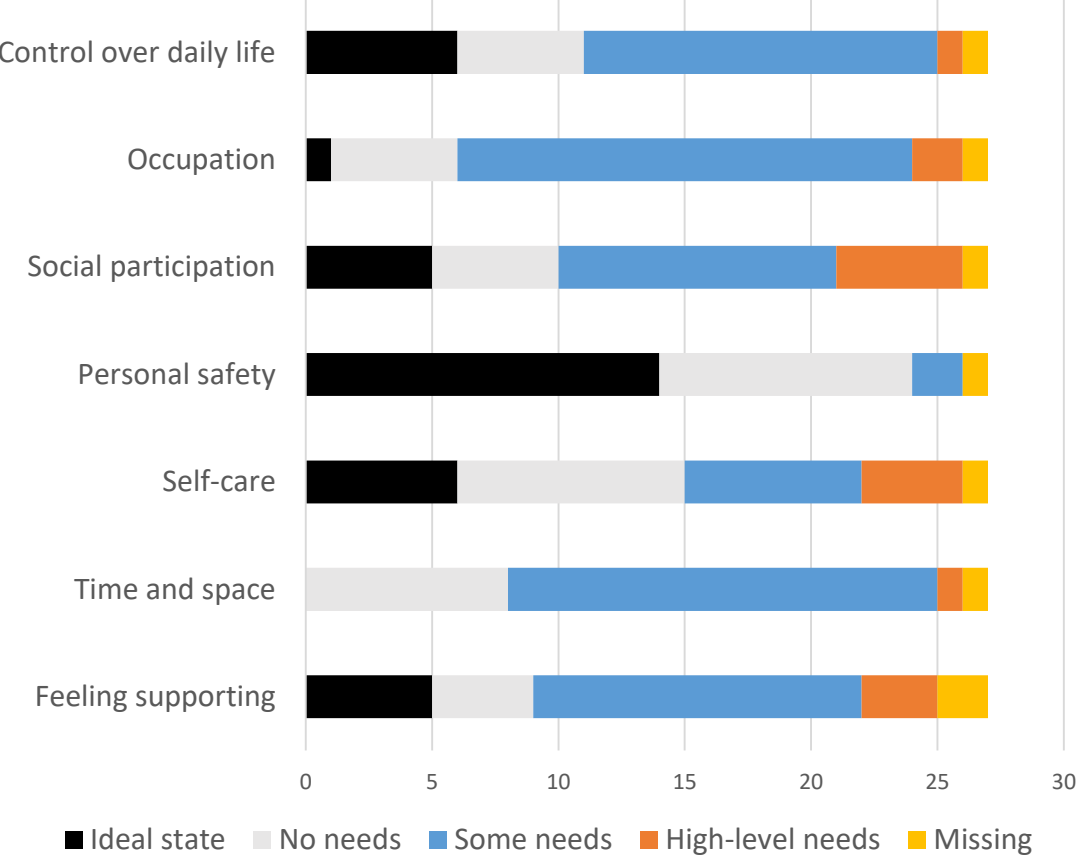


Table 1. The use of adult social care services

Variable	N (percentage)
Support or services used over the last 12 months	
Information and advice	19 (70.37%)
Support or services allowing a break from caring	17 (62.96%)
Home care/home help	14 (51.85%)
Day centre/day activities	7 (25.93%)
Lunch club	2 (7.41%)
Meals services	0 (0%)
Equipment or adaptation to the home	16 (59.2%)
Lifeline alarm	4 (14.81%)
Support from a carers organisation	19 (70.37%)

Experience of health care and adult social care services


	Recommendation
Unpaid carers	Power of attorney Memory books Emergency arrangements Sharing the routine with e.g. respite care staff
Family, friends, neighbours	Initiate social activities
Local authority (social services department)	Clear information regarding attendance allowance, a council tax reduction etc. List of available services/help to navigate the adult social care services
Community based adult social care services	Provision of the activities on the same day/time Provision of same paid carers
Assessment of needs	Provision of assessment to unpaid carers
Health care services	Awareness of dementia
Government	Adequate funding

Dilemmas related to receiving social care services

**The type and
intensity of support
needed**

**The services cater
for both carers and
individuals with
support needs**

**Whether to continue
keep their loved one
at home**

- 
- a) there is a discrepancy between the needs of a carer and an individual they support;
 - b) there is a hesitancy of allowing '*some stranger into your house to look after your husband*' (ID:006c_female, cares for husband);
 - c) the person with support needs may have an additional communication needs
 - d) extra support will result in spending less time together

Relationship

‘.....if **it is your wife or your partner** that is the carer, you have to realise that they see things differently. So that’s there, and I think the longer it will go on, I think **the gap between myself and my wife in relation to that will close because I’ll be more dependent on her.**’

ID:015_cr, male, supported by wife

‘I would say my time, yes. And the reason why I say that is because **he gets a bit clingy**. If I’m in the kitchen, sometimes I’ll have to come in the spare room to kind of **separate myself** that I can think.’

ID:015_c, carer, female, cares for husband

Routine

'I have my routines and I follow my routines. Every Wednesday I go for a walk with the ramblers, and I do other things as well. **There's a routine and, yeah, I'm not being told to do anything or forced** – well, she'll ask me to do some things but, yeah.'

ID:008_cr, male, supported by wife

'Yeah, how do I explain it? I mean, again, everything has been so incremental. **What I'm doing now is my new norm,** so...

....No, it's – I try to work it round so that – I mean once he's finished his phone calls he'll go and have a lie down. **While he's lying down, and resting, recovering from that, I won't do anything that makes a noise.'**

ID:008_c, carer, female, cares for husband

Impact of COVID

- Social contact with family and friends
- Feeling safe
- Death of a family member, friend
- Occupation (including voluntary work and hobbies)
- Levelling up the field
- Getting COVID
- Routine
- Assessment
- Change in delivery of services provision



Conclusions & recommendations

- Challenges with dyadic approach as a research method
- Social care needs are not fully met across different areas of people's lives
- Older carers and the people they support as experts on what works (or not) and how to improve things
- Caring as a function of relationship is very complex



Disclaimer

- This presentation reports independent research funded by the National Institute for Health and Care Research School for Social Care Research (NIHR SSCR).
- The views expressed in this presentation are those of the authors and not necessarily those of the National Institute for Health and Care Research or the Department of Health and Social Care.
- Images used from the Centre for Ageing Better's [free image library](#) showing 'positive and realistic' images of older people in a bid to challenge negative and stereotypical views of later life.
- These are preliminary findings and have not yet been published as a publicly-available report or peer-reviewed journal article.

Thanks for your attention!

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