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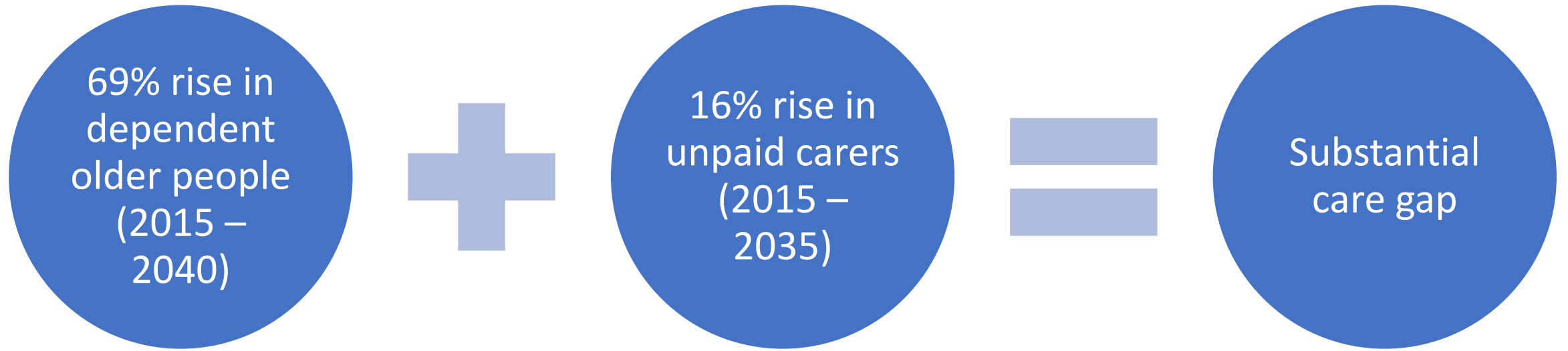
CARE POLICY AND EVALUATION CENTRE

Thinking about caring for older relatives in the future: A qualitative exploration

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Funded by the National Institute for Health Research (NIHR) and
conducted by the Adult Social Care Research Unit (ASCRU).

Background



- based on maintenance of current willingness and ability to care
- but this may change e.g. increased female labour market participation, geographic dispersal, later retirement

Research questions

- What are people's feelings and perceptions about providing unpaid care for their older relatives in the future?
- How do they envisage providing care?
- What might they give up to do so?
- What factors do people consider in willingness to care?

Study also aims to inform forthcoming large survey of attitudes to providing future unpaid care for older relatives

Methods

Semi-structured phone interviews with 20 people aged 40-65 with an older living 'parent figure', with/without caring experience, April 2020

General attitudes



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graph TD; A[General attitudes] --> B[Scenarios with own relative]; B --> C[Implications of caring and what might help]
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Scenarios with own relative

Implications of caring and what
might help

Findings

General attitudes

- if relative can no longer live alone without regular help

- A. Live with one of their children
(n=5)
- B. Child(ren) visit to provide care
(n=7)
- C. Public or private service providers visit to provide care **(n=4, in combination with children visiting)**
- D. Move to a nursing home

Considerations affecting answers:

- Quality of care (better from: known people/experienced paid carers)
- Independence/self-esteem of care recipient
- Relative's need for company
- One cannot be there all the time
- Duty/love e.g. you look after your family
- Past experience (negative experiences of trying to get suitable paid care)

Scenarios with own relative

- A. Doing paperwork or paying bills
- B. Taking to social engagements once or twice a week
- C. Keeping company, emotional support, keeping an eye on
- D. Helping with bathing 3 or 4 times a week
- E. Helping with meals 2 or 3 times a day
- F. Helping them use the toilet

Willingness to care is influenced by:

...beliefs about reciprocity, love and identity

- Not duty, just 'what you do'; Reciprocity: caring for relatives, as they had been cared for themselves

Pete: you step up to the plate, don't you? I mean, that's what families are about

Or related to personal feelings or identity:

Rob: I love my Mum and Dad immensely and I would always do whatever I could for them, that goes without question. Same with my sisters – they'd do it as well

Dalton: I mean I'm the sort of person that, I would make sacrifices, you know.

...beliefs about reciprocity, love and identity

- Relative's wellbeing, and their wishes, are prime considerations, but...

Kate: if it really took over my life completely and I had no life, or if my mum was very, very difficult, you know, sometimes ... or even with dementia, they sort of don't know you and ... Yeah, if it got too much

Two had plans for their parent to move in with them, but later admitted their relative had other ideas:

Jenny: Dad wouldn't, not in a million years! Sorry. He wouldn't have a choice!

... beliefs about who is likely to provide the best quality and most appropriate care

- intimacy, skills, physicality

Jenny: Do you know what, of course I would do it, but I would rather a professional did it. I think I'd be too scared. You know, if my dad's old and frail, you know, I wouldn't necessarily know how

Emma: When you have got carers in they kind of tend to just, it's like, no nonsense, they come in, they do it and they [care recipient] take more notice almost, sometimes, and they don't – it sounds awful to say 'play up' but it is kind of almost that kind of thing

- Gender of the parent can be, but is not always, a factor in feelings about providing personal care

... beliefs about who is likely to provide the best quality and most appropriate care

- More independence and dignity when carer is family/ when carer is professional

Annie: Say for example personal care, in terms of washing or, you know, the loss of dignity, you know? You don't want the children washing, or, doing things, you know?

Kate: It's personal so I think she'd rather I do that

- Beliefs about the quality of professional care
 - Services are overstretched, staff underpaid
 - Trustworthiness of carers

... beliefs about how difficult caring would be

Other than personal care tasks, main considerations were time

- Willingness to give time would depend on: employment, family, health, financial situation
- Interviewees thought up ways of organising provision of care e.g. of regular meals
- Awareness of the potential burden of caring
- Half would reduce or give up work to care
- Interviewees would spend less time on leisure & social time, time with family

What would make it easier to provide care

- Information and advice
 - to help provide unpaid care
 - to assess quality of care/carers/homes
- Sharing care (solutions to trade-off considerations between caring, working, leisure and paying for care)
 - including respite care, befrienders, people to make check-in calls, trips for relative, help with cleaning, meals services
 - Friends & family, paid and charitable services
- ICT – video calls, alarms, surveillance, enabling relatives to use the internet independently e.g. for shopping, socialising

The impact of C-19 pandemic and lockdown on responses

- More exposure to issues around care homes
- Appreciation of the risks of isolation
- Realisation that help is available (e.g. from neighbours)
- More feelings of empathy and loyalty to relatives
- Some changes in parent/child relationships (who sets the rules)
- Own leisure activities seem less important

Summary of findings

- People are interested in talking about these issues
- Willingness to care is influenced by:
 - Beliefs about reciprocity, love and identity
 - Beliefs about who was likely to provide the best quality and most appropriate care
 - Beliefs about how difficult caring would be
- Interviewees can suggest what may help them provide care:
 - Information (how to help; quality of care)
 - Sharing of care
- Pandemic/lockdown highlighted some relevant issues
- Survey should explore people's willingness, ability and perceived likelihood of providing care

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