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

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Abstract

The number of dependent older people in England, as elsewhere, is projected to rise substantially, while the number of unpaid carers is not projected to rise by an equivalent amount. Barriers to people caring for older relatives have been theorised, however, there is a lack of understanding of attitudes to providing care in the future among people who are not currently carers. This paper presents qualitative analysis of interviews with 20 people in middle age about their willingness to care for older relatives in the future. Interviewees were asked their general views about who should provide care, then to consider future scenarios in which a close relative developed care needs. Willingness to care was influenced by beliefs about reciprocity, love and identity, beliefs about who was likely to provide the best quality and most appropriate care, and beliefs about how difficult caring would be. Older relatives' care preferences were a key consideration. While some interviewees felt the best care would always be provided by family, others considered that professional skills were needed. Interviewees saw important roles for easily accessible information and advice, sharing care, including respite care, and financial support, in making it easier to provide care. The COVID-19 pandemic and lockdown had highlighted relevant issues for interviewees, which are discussed.

Keywords: unpaid care; informal care; attitudes to caring; willingness to care; older people

Introduction

The number of dependent older people is projected to rise substantially in view of the combination of rising life expectancy, more years lived with disability, and the large cohort of baby boomers reaching late old age (R Wittenberg *et al.*, 2018; World Health Organization (WHO), 2018). The provision of care to meet needs is a key policy and societal priority in England (*e.g.* HM Government, 2008; Department of Health and Social Care, 2018), as in many other countries worldwide (WHO, 2016). In England, the number of older people needing help with

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personal care tasks is projected to increase by 69 per cent from 1.7 million in 2015 to 3.0 million in 2040 (R Wittenberg *et al.*, 2018). As in other countries, the great majority of care for dependent older people is provided by unpaid (informal) carers (Verbeek-Oudijk *et al.*, 2014). Without these carers, a huge amount of additional formal care would be required to avoid a very large increase in unmet need for care in old age. However, at the same time as care need is projected to increase substantially, numbers of unpaid carers are projected to rise by only 16 per cent between 2015 and 2035 (Brimblecombe *et al.*, 2018). While there is inevitable uncertainty around these projections, there are clear grounds for concern that there may be insufficient care for older people in the future.

These projections are based on the assumption that current propensity to provide unpaid care (ability and willingness) will continue over the forthcoming decades. However, willingness and ability to care may increase or decrease over that time. Currently, provision of care depends heavily on the ability and willingness of people, mainly in middle age, to provide care for their parents or other 'parent figures' such as parents-in-law, step-parents or aunts and uncles. It has been argued that rising rates of female labour market participation, increased geographical dispersal of families, later retirement and increased family break-up may mean that the proportion of people able to provide care for their parents will decline (Pickard, 2015; Broese van Groenou and De Boer, 2016). An alternative view, however, is that people will make sacrifices to provide care for their parents out of feelings of love and devotion and/or feelings of duty and responsibility. To plan adequately to meet care needs in the future, a better understanding of the influences on willingness and ability to care is needed. This is a key policy as well as societal question.

In considering future policies for provision of care services and supporting unpaid carers, we need to understand people's thinking about whether and how they would provide care for their older relatives in the future, and what they may have to give up to do so. With the same considerations in mind, Broese van Groenou and De Boer (2016: 271) proposed an Informal Care Model which states that *intentions* to provide care are dictated by 'general attitudes, quality of the relationship, normative beliefs, and perceived barriers'. Whether one *actually provides* care is, in addition, affected by 'the care potential of the social context, being the family, the social network, and the community'.

While research has been conducted exploring the motivations of people who are current carers (McKee *et al.*, 2006; Della Giusta *et al.*, 2011; Pillemer and Suitoer, 2014; Cash *et al.*, 2019), there is a lack of understanding of attitudes to providing care in the future among people who either are or are not current carers. This paper presents and discusses a qualitative interview study conducted in England in April 2020, during the first month of lockdown due to the COVID-19 pandemic. The interviews were part of a wider study of attitudes to the provision of unpaid care for older people. The research is a starting point for uncovering salient issues in people's considerations of willingness to care in the future.

Methods

We conducted an interview study to explore the following research question:

- What are the feelings and perceptions of people in middle age about caring for their older relatives in the future?

Sample

A participant recruitment agency was used with the aim of contacting a cross-section of people matching our criteria. The recruiters were asked to provide contact details for 22 potential interviewees aged between 40 and 65, from a range of socio-demographic strata and ethnicities, half of them with experience of providing care. Experience of providing care was ascertained by asking: ‘Do you currently, or have you previously looked after or cared for an older relative?’ We were able to make contact and conduct interviews with 20 of these individuals. Eleven gave their gender as female and nine as male; the average age was 51 with a range of 40–65. Fifteen identified their ethnicity as white British, with the remainder including Black African, Black Caribbean, Indian British and non-British European. Socio-economic status was defined by the recruitment agency based on occupation. The socio-economic group of interviewees was given by the recruitment agency, based on occupation, using the Social Grade Classification Tool. The highest grade in our sample was B (eight interviewees), with five interviewees classified as C1, three as C2, one as D and one as E (for details, see <https://www.ipsos.com/ipsos-mori/en-uk/social-grade>). Eleven interviewees had at least some previous or current experience in a caring role and nine did not. There were five interviewees from each of the following regions: North of England, Midlands, London and South of England.

Data collection

Two interviewers conducted semi-structured interviews by telephone. The topic guide was loosely based around plans for a later online survey, since the interviews were designed to inform the survey. We began by asking a general question about attitudes to who should care for a parent-figure with care needs (taken from Eurobarometer, 2007) before asking about interviewees’ views about caring for their own older relatives:

Imagine an elderly father or mother who lives alone and can no longer manage to live without regular help because of her or his physical or mental health condition. In your opinion, what would be the best option for people in this situation in the first instance?

- (A) They should live with one of their children.
- (B) One of their children should regularly visit their home, in order to provide them with the necessary care.
- (C) Public or private service providers should visit their home and provide them with appropriate help and care.
- (D) They should move to a nursing home.
- (E) Other (please specify).
- (F) It depends.
- (G) None of these.
- (H) Don’t know.

After establishing which living older relatives ('parent-figures') interviewees had, we asked about their household composition and how far away they, and any siblings of the interviewee, lived. We asked about previous experience of caring for relatives, if any, and we then guided interviewees to choose a relative who would be the focus of our next set of questions. We asked interviewees to choose the older relative they thought they were most likely to be caring for in the future, who was not already living in residential care. Of the chosen relatives, nine were mothers, seven fathers, three parents-in-law, one a godmother and one an uncle.

We asked interviewees whether they had thought about, and discussed with family, how any future care needs might be met. For the chosen relative we then asked interviewees to imagine the future, suggesting 10 years hence, and how willing they would be to undertake the following care tasks:

- (A) Doing paperwork or paying bills.
- (B) Taking your relative to social engagements once or twice a week during the daytime.
- (C) Keeping your relative company, giving emotional support or keeping an eye on them during the day.
- (D) Helping your relative having a bath or shower 3 or 4 times a week.
- (E) Helping them have their meals 2 or 3 times a day? (In a situation where your parent/in-law also needed help feeding themselves, including preparing food or remembering to eat at regular times).
- (F) Helping them use the toilet when they need to.

We discussed whether and how responses might differ for different relatives. We then asked about potential future barriers to caring; what a person would, or would have to, give up in order to provide care; and what forms of support might help the interviewees to provide care. Questions on these topics were used as starting points for in-depth discussion about participants' thoughts about how they would deal with future needs for care and the trade-offs they might need to make.

The average length of interviews was 39 minutes (range 32–49).

Data analysis

All interviews were transcribed and imported to NVivo for coding. Coding proceeded mainly deductively at first. Material related to specific sections of the topic guide, *e.g.* willingness to help with paperwork, were coded into corresponding nodes, but, at the same time, themes which emerged across topic guide questions were also coded following an inductive thematic approach. For example, themes of responsibility, of the role of care-giver and recipient's gender, and of respect for, and burden on, carers emerged at different points in different accounts. When new codes were added, accounts previously coded were revisited for material to add to the new code. Codes were adjusted as the analysis proceeded, with some codes gathered together while others had sub-codes added. Once the coding scheme had reached a state that seemed logical and consistent, a second coder coded a subset of the transcriptions to test the coding scheme, the few uncertainties were discussed, and codes were adjusted or added as needed. Once all transcripts

were coded, further analysis continued across interviews by examining material related to each code. Themes were revisited and considered in light of their contribution to the overall emerging narrative (Braun and Clarke, 2006). Themes were reorganised and where needed material was 'coded on' into sub-codes, or themes which cut across existing nodes, showing where material supported the emerging theme and the identification of any counter examples. Framework matrices were used for some components of the analysis so that case summaries relevant to particular themes could be compared across interviews.

Pseudonyms are used to refer to individual respondents in the presentation of findings. The study received ethical approval under the ethics processes of the London School of Economics and Political Science.

Findings

Although we had planned our sample to be a mix of people with and without previous caring responsibilities, it was clear that caring is not a binary condition. Some people who had performed certain support tasks for relatives had identified themselves to recruiters as having caring experience, while others with similar experience had not indicated they had experience of caring. Others had seen family members provide intensive care to older relatives (*e.g.* their own parents providing care to their grandparents). Only a minority had not been exposed to a caring situation at all. Most interviewees lived fairly nearby to the older relative under discussion. The furthest away was one and a half hours, another lived an hour away and the remainder lived within half an hour's travel, with 12 living less than 15 minutes travel away. Eleven interviewees said they had thought about future care needs for their relative previously but only seven of these had discussed it with the relative. Some others responded that the subject had only been referred to in jest, *e.g.* the relative joking that they would be moving in or someone joking that the relative would be 'put in a care home as soon as possible'.

We asked the interviewees for their general views about responsibility for providing care, before asking about their feelings towards caring for older members of their own family, to understand how their general attitudes about responsibility for caring could influence their plans to care for their older relatives. The most popular responses were that care should initially be provided by the child visiting their parent regularly (seven responses), or that the parent should live with one of their children (five responses). Four interviewees thought that initially a combination of the child(ren) visiting and public or private service provision would be most desirable. People made different considerations when answering; some thought about their own situation while others specifically thought about people in different situations from their own, and how they may or may not be able to take responsibility for caring for older relatives. Reasons motivating these initial general responses included:

- Quality of care (care is better from known people/care is better from experienced paid carers).
- Independence/self-esteem of care recipient.
- Relative's need for company.

Table 1. Summary of main themes and sub-themes derived from the analysis of interviews

Main theme	Sub-theme
Willingness to care is influenced by (a) beliefs about reciprocity, love and identity	Reciprocity and love
	Identity
	Respecting relative's wishes
Willingness to care is influenced by (b) beliefs about who will provide the best quality and most appropriate care	Considerations of ability and desirability in who should provide personal care
	Gender of the parent can be, but is not always, a factor in feelings about providing personal care
	Beliefs about the quality of professional care
Willingness to care is influenced by (c) beliefs about how difficult it will be	Willingness to help with tasks
	Considerations of time; being available every day
	What would I have to give up?
	Understanding of the burden of caring
What would make it easier to care?	Sharing care (solutions to trade-off considerations between caring, working, leisure and paying for care)
	Information and advice
	Information and communication technology (ICT)
The impact of the COVID-19 pandemic and lockdown on feelings about caring	

- One cannot be there all the time.
- Family roles/love, *e.g.* you look after your family.
- Past experience (negative experiences of trying to get suitable professional care).

Below we explore these issues in relation to interviewees' subsequent consideration of their own willingness to care for their older relatives under three headings representing three broad themes about factors influencing willingness to care: (a) beliefs about reciprocity, love and identity, including respect for relative's wishes; (b) beliefs about who will provide the best care; and (c) beliefs about how difficult it will be to care. The trade-offs people make when considering how likely they are to care in the future involve weighing up considerations in these categories. We go on to present analysis of interviewees' views about what could make it easier for them to provide care. Lastly, we consider the role of the COVID-19 pandemic and associated lockdown on participants' responses. The themes which emerged from the analysis are summarised in [Table 1](#).

Willingness to care is influenced by (a) beliefs about reciprocity, love and identity

Reciprocity and love

The feeling of wanting to help was not really conceptualised as duty, which implies obligation, but just 'what you do'. Except for Mitsy, whose mother had very difficult

behaviour, there was little sense of people feeling they might be compelled against their will by a sense of duty. Rather, people wanted to provide support because of their understanding of the meaning of ‘family’, because of reciprocity and/or because of love.

I’ll be there as long as I can for them. As long as, you know, they’re still there I’ll just – I’ll do what’s got to be done ... Not what’s expected of me – it’s what I would want to do. (Fiza)

You look after your family first, and then, you know, your own interests and your hobbies sort of go on a back burner. (Graham)

Identity

While some saw this as a universal condition (*e.g.* Pete said, ‘You step up to the plate, don’t you? I mean, that’s what families are about’), others referred to this as a specific characteristic of their family, or to their own identity as someone who would care for others:

I mean I’m the sort of person that ... if I care about someone and they need my support and I feel that that support will benefit them, I would make sacrifices to achieve that. (Dalton)

Jenny, meanwhile, reflected that being able to provide for your older relatives was an opportunity not open to all:

We would very much fit our lifestyle around our parents, if they weren’t well. End of. But not everybody can do that ... we are a very close family, my family and my husband’s family ... So, it wouldn’t be a question, it would be, you’re moving in, end of ... And that would be it. We actually bought a house with a spare room for that reason.

Mitsy, however, did not see our society as one which normalised co-living and caring for older people:

I think as a society, we’re not really geared to look after our elderly, which is why we have so much problems, I guess, now. I have a friend who lives in Singapore and she lives with her husband’s grandparents, her husband’s parents and her children. And they all look after each other, it seems much better, but we don’t do that, do we, in this society?

For both Jenny and Kate, their own conviction that they would move their older relative in to live with them turned out to be at odds with their understanding of what their relative would want; both said later in the interview that it would be difficult to persuade them. When asked whether her father would want to move in, Jenny replied:

Dad wouldn’t, not in a million years! (laughter) Sorry, he wouldn’t have a choice!

Intentions were also motivated by feelings of reciprocity:

He would be doing the same for me ... Without a shadow of a doubt he'd be doing the same for me. (Clare)

They raised me and my sisters when we were children and you know, what goes around comes around ... I've been going through difficult times myself these last 12 months but as a family we pull together. They help out where they can and similarly that's why I'd do it for as long as I could and how I could, however, when they need it. (Rob)

There was occasionally a suggestion of social desirability bias at first; some interviewees initially said they were happy to help with everything, but then reflected that they realised it could be a big burden and some sharing would be needed. One interviewee felt the need to apologise when saying they were unwilling to carry out some tasks.

Respecting relative's wishes

Relatives' own wishes about their care was the factor which came up most in interviewees' explorations of what would decide future care arrangements:

I think if she's able to express her preference and she'd rather have me do it, or *vice versa*, a carer from outside, so as long as she's happy and comfortable, then I'm happy to take on those things. (Imogen)

Although it often came up earlier in the interview, towards the end of the discussion of tasks, there would be a point at which interviewees had to consider what would happen if their relative needed someone there all the time. The relative's wishes were a key concern:

I'd respect whether they wanted to go in a home, whether they were both together or if they wanted to stay at home, you know, I'd of course comply with their wishes. (Harry)

Many people felt they had a good idea on the whole of what their relative would want, and, while interviewees expected to be guided by their relative's wishes over things like who would help with personal care, it was often perceived that there may be a point at which some intervention that the relative did not like would need to be put in place, e.g. help with things they wanted to do by themselves, paid carers coming in or, if the need arose, moving to a care home. Often this was when it was perceived that something that was in the relative's best interest might not be the relative's preferred option.

Imogen felt her mother would want to stay at home and that Imogen would support that up until it no longer seemed best for her wellbeing:

But, you know, it all comes down to, not just her choices, but whether she's actually safe to do so.

Equally, Kate expected to do all she could to support her mother, but could see a point when it could become too difficult:

I suppose 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.

A few imagined their relative being very resistant to what may be in their best interest:

My Dad's worse than me [my] Mum in terms of his stubbornness (laughter) ... I mean, we'd fight him tooth and nail to make sure that he was looked after properly by us or whoever.

Some said their relative was adamant they would not go into a care home, but several said they would nevertheless consider it when the relative needed full-time care or supervision.

Stan felt his mother would support a pragmatic solution:

I mean, it would be down to us at the end of the day, do you know what I mean? Mum probably wouldn't like it but if there was no one to care for her then she'd understand that she'd have to go, but as we can then we will try and take up the slack and deal with it ourselves.

While relatives' own wishes, then, were a key consideration of how care decisions would be made, many interviewees imagined a time when they would have to go against their relative's preference.

Willingness to care is influenced by (b) beliefs about who will provide the best quality and most appropriate care

Interviewees considered their own abilities, and the likely quality of professional care, alongside relatives' wishes, when discussing what future care arrangements were likely to be best for their relative.

Considerations of ability and desirability in who should provide personal care

When issues around willingness to provide personal care came in to play (*e.g.* helping with bathing and going to the toilet), the types of considerations at the forefront of interviewees' minds seem to be quite different from those considered in relation to tasks such as helping with meals and company. Feelings were also complex: some interviewees were very clear about their views, others less so, with some changing their mind during the course of the interview. A couple of interviewees felt they were willing in principle to provide personal care but in practice the tasks might be better done by paid carers.

Concerns over provision of personal care were not just about intimacy but also about physicality and skills. Jenny thought about the physical difficulties when asked whether she would help her father have a bath or shower:

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. I would definitely get somebody in for the first few times to show me what to do and how to do it.

Emma felt that experienced, paid carers could sometimes be better placed to deal with difficult behaviour in an older relative:

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 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.

Some interviewees felt that care would always be better provided by a family member while others felt that professional carers had skills and attributes which meant they could provide better care.

Independence and dignity for the care recipient can be deemed more likely when the carer is family, or when the carer is professional. While in this sample it was more common for people to think that dignity was better preserved with a professional doing personal care, rather than a family member, both views were represented. Several interviewees make assumptions about their parent's preference, while some had discussed the issue with their relative. Ten interviewees specifically said either they or the relative would not be happy with a family member doing personal care and would prefer a professional carer to do this, while two interviewees said they thought the relative would prefer a family member to do it. 'Dignity' was used as a reason on both sides:

Certain care, for example personal care, in terms of washing or, you know, the loss of dignity, the loss of a sense of dignity? You don't want the children washing, or ... doing things, you know? (Annie)

Conversely, Kate said:

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

Two interviewees said they would have to see how it went, e.g. one explained that if it was a gradual development towards her doing the personal care it might 'feel ok' to both parties. Three interviewees had some prior experience of helping with personal care.

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

Of interviewees who had both a male and female parent living, five said there was no difference in their willingness to provide personal care to either parent, while nine said it would make a difference. Of these nine, seven said this was because of being a different gender; Dalton, for example, said:

If your mum's getting changed, you're not gonna walk in there ... cos morally ... I just think the fact that it's wrong, that I wouldn't feel comfortable doing that.

However, for one interviewee, it was because of the different characters of the parents, while for another it was because of the much larger size of her father, and the physical difficulty she would have.

Beliefs about the quality of professional care

Some interviewees had low expectations of being able to receive professional care for their relative, or good quality or timely care:

I would say definitely move in with family first, because I know services are stretched and it's hard to probably find somewhere suitable or get the necessary works done. (Olive)

People wanted to know they could trust professional carers:

How trustworthy it is too, 'cause you need to build that, y'know, if you were using something like that on a full-time basis and seeing the same faces you build up a little bit of a trust. (Beth)

Issues were raised over the working conditions of care workers, including low pay, and how this could affect quality of care as well as staff turnover: consistency of personnel and the ability to develop relationships were seen as important.

Attitudes were sometimes based on experience, as with Pete:

I've dealt with carers before – with my father – and it's – because it's not a particularly well-paid job, and a tough job, there's a high turnover of staff within the care system. I mean, from my own experience, a lot of the carers were different people each week.

As the above quotes indicate, there was an appreciation of the difficulty of carers' work, and appreciation for carers who were trying their best in difficult circumstances. Stan, however, had a more negative view:

I think there's too much carers doing this job for a pay cheque and not actually ... I mean, if you're going into the social care industry, you know, the second word means a lot: care!

Attitudes and beliefs about care homes could be particularly strong, as Beth shows:

They're just very anti care home they don't think that they get ... there's just a bad reputation of care homes to be honest, and they wouldn't trust the system.

A number said care homes would be considered only as a last resort. There were occasional positive comments about care homes, however. One set of parents were volunteers at a care home, and expected to go there themselves if needed, while another interviewee said they thought their father would enjoy it for the social life, although his wife would be much more resistant.

Willingness to care is influenced by (c) beliefs about how difficult it will be

Willingness to help with tasks

All interviewees said they were happy to help with paperwork, five were already doing it and three said another relative was already doing this. Interviewees frequently referred to having the right skills, or another relative having the right skills:

It's not really my thing, and I would think because of the circumstances, one of my other siblings would probably step in ... But I would be willing to do it if need be, if that makes sense. (Emma)

Interviewees were also generally willing to take their relative to social engagements in the daytime, but that this would depend on their circumstances at the time. Interviewees differed in the extent to which they thought they might rearrange their lives to accommodate provision of weekday support and began to consider the trade-offs involved:

Not during the week I couldn't, no. Not unless I took leave. So, I'd have to sacrifice my leave to take them ... I mean, you know, I'm not saying I wouldn't do that, but it would make things a bit awkward. (Graham)

Interviewees also thought about who else might provide this support, or was already doing so, including friends, other relatives or local voluntary services, e.g. the Red Cross, Royal National Institute of Blind People, British Legion or paid services such as Dial-a-Ride. Interviewees mentioned other ways they helped their older relatives, or would like to help them in the future, including gardening, taking them to appointments, shopping, cleaning and responding to household emergencies (being on call as opposed to regular visits).

Considerations of time; being available every day

As shown in the topic guide excerpts (Methods), the types of tasks asked about became progressively more time-consuming, as well as more difficult in other ways.

In relation to providing the time, people told us that it depends on what their employment, family, health and financial situations will be. Financial situation includes whether they could afford to give up work/work less and also whether they could afford to pay for care.

Rob, for example, said:

If we were in a financial position ourselves to be able to give up work to do that yes, absolutely we'd do that and we'd probably share that out between us but, if not, then it would have to be that we would look at a live-in carer for her.

When asked whether they would be willing to provide meals two or three times per day, five replied that they were very willing, though one of them pointed out he knew how stressful it could be. Interviewees spontaneously thought through how these sorts of needs could be met, with reference, for example, to pre-preparing food, giving reminder calls or using reminder devices. Five interviewees expected a paid service to provide meals, with another five expecting to share the load with paid services. Eight expected they would share meal provision with other relatives, or that other relatives would do the bulk of this. One interviewee felt that at the point visits were needed several times a day, a care home would be needed.

What would I have to give up?

We encouraged interviewees to think about what, if anything, they might have to give up in order to give more time to caring for a relative in the future. Many options and conditions were discussed in relation to having someone there all the time and how and whether this need could be met without recourse to residential care. Employment was most commonly mentioned, with half the

sample saying they would fit their work around caring, retire or reduce their work hours:

I would probably scale the work right down, to be honest, if ever that happened, that she had to move in with me. (Kate)

Two interviewees specifically stated they would not give up work in order to provide care; this was seen as something that would not be possible.

Interviewees also spoke of giving up leisure time, social life and time with their own family. Five interviewees mentioned the difficulty of taking holidays, but only one suggested giving them up. The remainder felt holidays were important and that they would plan to arrange sharing care with family or paying for respite care, to be able to take a holiday. Clare mentioned her voluntary work and that she would give up her paid work before her voluntary position.

Understanding of the burden of caring

About half the sample referred to the likely strains on the carer of providing care intensively for a relative, in their considerations about willingness to care. Several of these spoke from experience, including seeing the pressure put on a relative caring for another relative (such as a spouse):

It puts a tremendous, you know, strain on the actual mental health and wellbeing of the family carers I think. (Pete)

They've always refused to ever put him into care even though he was living with the grandmother who was great, but it was all the responsibility was really on her shoulders even though the children helped out. (Beth)

But some without personal experience, or minimal past connection with someone with care needs, also considered the potential burden:

I'd also like to share the care as well, because I can't imagine how hard it must be ... you know, to have to look after someone who's elderly, particularly if they don't want your help because they don't understand what's going on. (Jenny)

You know, all the time doing it, it takes a toll on you doesn't it, and then it's hard work, but at the same time I don't really want them going to sit in a home where they're ignored. (Uma)

What would make it easier to care?

We discussed with interviewees what might make it easier, or encourage them, to provide care in the future. Some prompting was needed on this, *e.g.* everyone agreed when asked that there should be flexible work policies, but nobody raised this spontaneously, which seemed to be either because they already had flexible working arrangements, thought their employer was likely to be sympathetic or did not have the sort of work that could easily be flexible. Equally, when prompted, and occasionally unprompted, support groups for carers were seen as important if they could be

sources of advice, professional counselling and/or to share experiences with other carers. Several interviewees mentioned this being useful for those without their own support network and three specifically said they did not think they would use peer support groups themselves, despite thinking they were a good idea in principle. Nine interviewees mentioned that having suitable adaptations and gadgets had helped, or could help, older people remain independent longer, and could make it easier for them to deal with personal care, and for family to help them. Some concern was raised about the ability to have adaptations installed in a timely fashion.

A major theme arising from this segment of the interview was around the need for information, while another theme, arising both in response to questions about what would make it easier to care and throughout interview discussions, was the importance of being able to share caring responsibilities with others, whether with other unpaid carers or with paid services.

Sharing care (solutions to trade-off considerations between caring, working, leisure and paying for care)

As indicated throughout this Findings section, there was much discussion on the trade-offs between paid professional care and family care; these included cost and quality considerations, but also trade-offs for time, one's own aspirations and activities, and the effort and emotional impact, as well as beliefs around who would provide better care and the degree to which relatives' preferences can be taken into account. Interviewees considered the trade-offs they would need to make between working (and other aspects of their lives as shown above), caring and paying for care. In trying to balance these concerns they often spoke about the desirability of being able to share caring responsibilities. Sharing care came up frequently, both sharing between family members and with paid services.

Seven interviewees said it would be useful to have professional carers to share the care work, some specifically saying this should be government funded. Types of care mentioned as useful to support and complement one's own caring role included respite care, befrienders or people to make check-in calls, trips for the relative, help with cleaning and meals services.

Sharing care responsibilities came up in response to how the government might be able to support people to care for their relatives. One interviewee felt that all formal care services should be funded by the government and taken out of private hands. Another said they would rather pay themselves than claim government support, if they could afford it. Another described being surprised to find they qualified for financial support, but that the application process was onerous. Two interviewees referred specifically to raising taxes, and being reluctant to pay more: while one suggested this might be necessary, another thought redistribution of current government spending should be feasible. Three-quarters of interviewees felt financial support for the care recipient or to fund care services would be helpful, and one suggested an insurance scheme.

Information and advice

We asked whether there was anything government could do to make it easier for people to provide care for their older relatives. The strongest theme here was about having an easy route to information and advice, mentioned in some form by 13 interviewees. Several interviewees felt they had little idea of what might be

involved in caring for a vulnerable relative or how to prepare for caring. Some who had been carers felt, on looking back following their caring experience, that dealing with care issues had been made more stressful by difficulty getting information, or the lack of pre-knowledge. Graham spoke about how he felt about his mother having to sell her house to pay for her care, when friends who had taken the step of moving property between family members earlier were receiving funding:

Nobody prepares you for that and nobody teaches you that, cos when you're younger you don't even think about it, do you, really.

Interviewees suggested ideas about how information could be usefully provided (some of which already exists to some degree). The suggestions can be broadly grouped into the following categories:

- Information on available services: ideas here included easily accessible information about available services, including council, voluntary, support groups, transport and respite all in one place (*e.g.* council website, general practitioners, a government portal).
- Assessments of carers and care homes: reviews, recommendations and background checks on carers; information on quality of care homes.
- 'How-to' advice: drop-in, phone or Web-based advice services specific to older people's care; how to best provide physical and emotional help and support; tailored signposting; products and adaptations; courses to build up relevant knowledge and skills; links to other carers.
- Education to the general population about older age and caring, *e.g.* automatic information provided by government to everyone of a certain age about entitlements and sources of support and services; and inclusion of issues around caring and old age in young people's education.

Information and communication technology (ICT)

We asked whether interviewees could think of any way in which ICT could be helpful in supporting care for older relatives. Several interviewees mentioned the positives of being able to use video calls; for some this had been used with their relative for the first time as a result of the pandemic. Although some relatives were mentioned as not being able to, or not being willing to, engage with the technology, others seem to have benefited. Video calls could be more rewarding than phone calls, particularly when there were hearing issues, allowing easier, and more relaxed and varied, types of communication. Relatives being able to use the internet and mobile phones independently was seen as very helpful. Interviewees suggested that support for this, and the development and provision of easier-to-use devices, could promote independence and be used for shopping, keeping in touch, socialising and keeping up with news. It was suggested that FaceTime could lift relatives' spirits and could also let one see how one's relative seemed, as well as enabling remote helping with tasks such as interpreting letters or advising on fixing or using things.

Alarms, *e.g.* for falls, were mentioned as potentially useful although problems were also highlighted such as alarms going off incorrectly (*e.g.* an alarm to remind

the person not to go out when he goes near the door at night going off too frequently), and the relative forgetting how to use the alarm. Three people also referred to the possible benefits of video surveillance, although both Harry and Imogen also felt that this sounded 'a bit Big Brother'.

The impact of the COVID-19 pandemic and lockdown on feelings about caring

These interviews were conducted in the third and fourth weeks of the spring 2020 lockdown in the United Kingdom (UK) and we asked interviewees whether they felt this had influenced their answers in any way. Most did not feel their answers would have been different before the pandemic, but some individual comments showed some ways in which there may have been an effect. Care homes had been in the news and had caused one interviewee to think about possible future need for a care home for their relative, another had gained an appreciation of the risks of isolation, and a third felt he had addressed his answers with more empathy and a stronger feeling of loyalty to his relatives. One realised that there is help available, e.g. from friends and neighbours of the relative, that he had not been aware of; and another noted that the situation had marked a turning point in the parent-offspring relationship as she and her brother had been trying to tell their parents what to do to keep safe, when the parents had been reluctant to comply. One interviewee said that her own regular activities, now stopped because of lockdown, no longer seemed as important as they had, and so the idea of giving them up to provide more care did not seem as daunting; another, however, noted that, for her father with dementia, the changes needed to his routines had caused distress. It was also noted that the vast costs associated with the pandemic and the government's response might mean that future funding for social care might be even more limited than it would have been anyway.

Discussion

This is, to the best of our knowledge, the first study including middle-aged people in England not currently providing care, as well as current carers, that examines attitudes to providing care in the future for parents or other older relatives.

We found that people's willingness to care was influenced by feelings about love and reciprocity, *i.e.* that they wanted to be able to care for their relatives as they themselves had been cared for. The wishes and wellbeing of the relative were usually high up in people's considerations, and willingness to care was therefore strongly influenced by interviewees' beliefs about who would provide the best care. This was sometimes thought to be family, but sometimes paid carers, when it was felt that certain skills and temperament were needed. Equally, views differed about whether the relative's dignity was best preserved when personal care was provided by a family member or by a professional; interviewees generally seemed to feel that they could anticipate relatives' preferences on this matter. Beliefs about the quality of care services were important. However, interviewees' own needs were also a consideration, and their willingness to care was influenced by beliefs about how difficult it would be. Potential difficulties included personal feelings about appropriateness of providing personal care (for some, but not all, the relative's

gender was a consideration here); time, including what would need to be given up to care; and the potential physical and mental burden of caring.

We noted in our analysis that some feelings about willingness to care seemed strongly linked to interviewees' sense of identity, *e.g.* relating to understandings of 'family'. In previous research exploring what motivated *current* carers to provide care, familial, cultural, gender and/or social norms were found to be motivators (Della Giusta *et al.*, 2011; Parveen *et al.*, 2011; Pillemer and Suito, 2014; Cash *et al.*, 2019). Reciprocity has been identified as a significant factor in motivation to provide care in spousal relationships (Cash *et al.*, 2019). In the current study feelings of reciprocity were shown to be important also in relation to care for parents. Our findings raise the question of what happens when family experiences do *not* lead to feelings of reciprocity.

Broese van Groenou and De Boer's (2016) Informal Care Model concerns care provided to people living in the community, rather than in residential care, and that is also the main focus of the current study. Their Informal Care Model distinguishes general attitudes to providing care rooted in socialisation, educational experiences and family backgrounds (dispositional – do I want to?), quality of the relationship (affectional and associational solidarity), normative beliefs of reciprocity and solidarity (do I have to?) and perceived barriers to care provision (can I?). Yet these are inevitably intertwined, and discussion around family roles and love in our study seemed to combine aspects of all three. We found that when people contemplated in depth the idea of providing care for their relative in the future, they considered their *ability* to provide care, in terms of their own health and skills; their *willingness* to provide care, despite potential costs such as reduced employment opportunities; and the *likelihood* of them providing care, *e.g.* alone or shared with relatives or paid carers. In other words, people might be willing in principle to provide care, and may answer this way in a survey, but may not actually consider it likely that they would do so, because someone else may be better placed to do so, or because the trade-offs they were likely to need to make would lead to a different course of action.

Our analysis illustrates some of the trade-offs that interviewees considered when thinking about how willing they are to provide care for their older relatives or whether they might prefer to use paid services. Previous research on current carers' motivations also showed the importance of financial considerations and other commitments including paid employment (White-Means, 1992; Carmichael *et al.*, 2010) and availability of formal care (Oudijk *et al.*, 2011; Millenaar *et al.*, 2018). Quality, as well as cost, of formal care was raised by our sample in relation to considering these trade-offs. Many said they would give up or reduce employment in order to care. For some, the need to give up work may be temporary, but many current unpaid carers, who have had to give up work to care, face practical and emotional barriers when they try to return to paid employment (Centre for Ageing Better, 2020). Interviewees, including non-carers, also highlighted that respite care and financial support could play an important role in enabling them to continue to participate in current activities. Respite care was particularly mentioned in relation to taking a holiday.

In thinking through likely future scenarios and approaches, sharing care was a major theme. Sharing care, either with other relatives or with paid carers, was seen as a desirable way to manage caring responsibilities without becoming overburdened,

which was anticipated by several interviewees as a risk, not in anybody's interest. Sharing care can bring its own difficulties, however. In their review of informal caregivers' views on the division of responsibilities between themselves and paid carers, Wittenberg *et al.* (2018) concluded that unpaid carers did not feel their views were taken into account and that sometimes roles were not clear. Where the role and expertise of the unpaid carers were acknowledged and appreciated, collaboration was easier. The structures within which paid carers work need to be flexible and paid carers need to be supported to be proactive in forging collaboration.

In studies of current carers, barriers to caring were found to include inadequate access to support, financial issues and need for more information about services (*e.g.* Ferrell *et al.*, 2019). These issues were raised by our interviewees when thinking through possible problems and solutions in the future. Some interviewees were alerted by the interview to how little they knew about possible arrangements for care, while others had already experienced difficulties trying to access information. Information they wanted included advice on how to look after relatives and meaningful reviews of care providers, including individual professional carers.

Speaking to people about intentions to care in the future introduces the possibility of choice, and gives people the opportunity to imagine choices and the decisions they might make when faced with choices. While research with current carers has in some cases suggested that few considered they had a choice in taking on their caring role (*e.g.* Parveen *et al.*, 2011), other research has shown that perception of choice is correlated with satisfaction as a carer and other positive carer outcomes (Al-Janabi *et al.*, 2018; Cash *et al.*, 2019). Policy responses might consider how perceptions of choice may be supported.

Strengths of this study are that it included 20 middle-aged people with a living parent or other older relative from a range of backgrounds and that it asked detailed questions about attitudes to providing future unpaid care with a number of specific tasks. The study also has some limitations, including that we explore intentions without knowing how people's intentions will be related to their actual decisions about caring if and when the need arises. While the interviewees were from a range of backgrounds, they were all people who expressed willingness to be interviewed about their attitudes to providing care in the future, and they had generally positive feelings towards their older relatives. Moreover, nearly all interviewees in our small sample lived near their parents, whereas one of the reasons contributing to concerns about the future availability of unpaid care is that many people do not live near their parents (Petrie and Kirkup, 2018). People may have been more likely to take part if they had positive feelings towards their older relatives, and there is also a risk of social desirability bias in people's answers, although we feel that this risk was countered somewhat by the in-depth nature of the discussions. There can be no certainty that interviewees' views are typical of, or cover the range of views of, middle-aged people in England.

In recent years there has been increased public discourse about our ageing population and the potential crisis in care funding; yet among the general public there remains a lack of understanding of care needs in old age and of the publicly funded social care system (National Audit Office, 2018). The COVID-19 pandemic has raised the profile of social care, especially residential care in care homes, but there has also been recognition in the UK of the increasing numbers of people providing care during the pandemic and associated lockdown due to the closure of some support services.

Conclusions

The topics raised in the interviews were challenging. It was not easy for interviewees to consider what care they would be able and willing to provide, or what arrangements their families would be likely to make, in 10 years' time. Nevertheless, the interviewees were happy to consider these issues and explain what they felt they would provide if their parents or other older relatives should require care in the future. The findings suggest that a large-scale survey taking account of the types of considerations revealed here can help inform policy development. We found high levels of willingness to provide care, affected by beliefs about reciprocity and love, including the importance of respecting relatives' wishes, beliefs about who will provide the best quality care, and beliefs about how difficult caring will be. Interviewees' willingness to care was expressed in a context of choice. The implications for policy makers, faced with a projected future care gap, may be that potential carers need to feel choices are available. Interviewees suggested what would make it easier for them to choose to provide care, and policy could address the desire for information about how to care and how to assess quality of services, as well as supporting the sharing of caring responsibilities.

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