

“I never planned for it”—Exploration of expectations about caring for older parents

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Abstract

The projected increase in older dependent adults will continue straining formal care services whilst increasing the reliance on unpaid carers, in England and internationally. While motivations and willingness to care among unpaid carers have been explored, expectations around the caregiving role remain under-researched. This article delves into expectations of middle-aged individuals around providing care to an older parent in the future. Data collected through six focus groups with 35 mid-life individuals, a mix of individuals with and without caring experience, were analysed thematically, cross-sectionally, and with reference to different phases in the caregiving trajectory. Participants showed predicted, in some cases normative, expectations about taking on the role of carer for an older parent. Such expectations were rooted in emotional and socio-cultural factors and influenced how people self-identified as a carer. Expectations about what the role would entail were unformed: they were described as conditional on the uncertain and changing care needs of the older parents ('caregiving creep'). Those with caring experience highlighted that, in hindsight, their prior expectations did not match their actual experience of the role, requiring greater time commitment and impacting their life in ways they had not anticipated. When

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thinking about the future, participants envisaged stepped changes in care arrangements to meet increasing, albeit uncertain, care needs, but acknowledged their lack of awareness around the care options available to them. Policies aiming to improve general awareness about caregiving, support early identification of carers, and address their information need throughout their caregiving journey should be a priority.

KEYWORDS

caregiving creep, expectations, family care, informal care, older people, parents, unpaid care

1 | INTRODUCTION

The projected increase in the number of dependent older people, as a result of the population living for longer with multiple, long-term conditions, represents a major challenge for health and long-term care systems world-wide (Rudnicka et al., 2020).

These trends are significant in England where a large cohort of the population is now approaching older age and the growing cohort of older old (≥ 85 years) has developed high levels of dependency and complex care needs (Brimblecombe et al., 2018; Kingston et al., 2018; McKee et al., 2021; Wittenberg et al., 2018). These demographic and epidemiological changes have been unfolding alongside two policy shifts in adult social care. First, the ageing in place agenda has been increasingly promoted as a positive approach to meeting the needs of older people by supporting them to live independently, or with some assistance, in the community for as long as they wish, with the aim to postpone or avoid the use of residential care. Second, the role of family carers as a key component of the care network of older people has steadily expanded over time (Broese van Groenou & De Boer, 2016), whilst formal care services have shrunk as a result of years of austerity and shortages in the care workforce. By filling the gaps left by formal services and allowing older people to live in the community, unpaid carers are in effect enablers of the ageing in place strategy.

Research has explored, both theoretically and empirically, the concepts of motivations and willingness to provide informal care (Dombestein et al., 2020; Greenwood & Smith, 2019; Lüdecke et al., 2018; Zarzycki, Seddon, Bei, Dekel, & Morrison, 2022; Zarzycki, Seddon, Bei, & Morrison, 2022). Willingness to care has been defined as part of a carer's attitude towards providing support for an individual, whether the support required is for a current or future need (Abell, 2001), while motivation is the drive to act to achieve a goal or to fulfil a need or an expectation (Ryan & Deci, 2000). The two concepts are not unrelated: motivations can explain willingness to perform care tasks, but, since care tasks are varied, it cannot be assumed that motivations will inform willingness equally across all care tasks (Zarzycki & Morrison, 2021). Both concepts also have a temporal orientation, that is, they change as the caregiving journey unfolds (Powell Lawton et al., 2000) and intertwines with the carer's life course (Keating et al., 2019).

Implicit in the concepts of willingness and motivations in the context of family care provision seems to be the notion of *expectation*, defined as the feeling or belief that something will or should happen. Individuals may have expectations around who should and will provide care for family members in their old age, when and how care should and will be provided, and what caring should and will involve (Burns et al., 2015; Lee & Li, 2022; Pearlin & Aneshensel, 1994; Rowe, 2012). Expectations contribute to shaping and can be shaped by motivations towards caregiving and can also influence willingness towards providing care. Expectations are, by definition, prospective in

nature. Individuals currently providing care may have expectations about their role in the future. Similarly, individuals who do not have, and never had, a caring role may have expectations around what caregiving will or should look like.

In health and social care research the concept of expectation has been used and theorised with reference to user or patient satisfaction (Thompson & Sunol, 1995; Willis et al., 2016). In this context, (dis)satisfaction is the result of a comparison between prior expectations about and actual experience of a service. The greater the divergence between the two, the more apparent satisfaction or dissatisfaction becomes, depending on the direction of divergence (Thompson & Sunol, 1995). This article builds on this line of theorising around expectations and expands its application from services, which has been already established, to *roles*.

This work explores expectations of mid-life individuals, the cohort of unpaid carers for the older generations who are projected to live for longer after retirement, but not necessarily in better health (Gill & Cameron, 2022; Henchoz et al., 2019). The scale of their care needs will further strain both formal care services, already over-stretched (Idriss, 2021), and the unpaid care system, which is affected by several socio-demographic changes that will shape the future supply of unpaid carers (e.g., geographical dispersal, rising labour market participation by mid-life women, decline in co-residence of older people with their children) (Pickard, 2015). These factors, in combination, will likely have an even more noticeable impact on those shouldering caring responsibilities for both their parents or older relatives and their own children or grandchildren, whilst also still being in employment (Vlachantoni et al., 2020).

The aim of this article is threefold. Firstly, it describes the expectations around caregiving for an older parent or other parent figure from the perspective of middle-aged individuals with and without experience of providing care for older family members. Secondly, for those with caring experience, it explores whether and how expectations change throughout the caring trajectory. Lastly, it compares how prospective expectations around the role of carer match the actual experience of the role.

The article presents data collected as part of six focus groups with 35 mid-life individuals, a mix of current carers and people without caring experience, living in England (UK). Focus groups were undertaken in the third and final phase of a study that aimed to explore salient issues in people's considerations of willingness to care in the future. More specifically, the study investigated middle-aged people's attitudes to the provision of care should their parents or other older family members require it at a future time.

In-depth telephone interviews with 20 people were undertaken in the first phase to explore willingness to care for older relatives in the future. This phase of the study found that willingness to care seemed to be influenced by three types of beliefs (beliefs about reciprocity, love and identity, beliefs about who was likely to provide the best quality and most appropriate care, and beliefs about the challenges of caring) combined with older relatives' care preferences (Stevens et al., 2022). Interview findings supported the design of phase 2 of the study that involved an online survey of 3600 respondents aged 40–65. The survey explored topics, such as whom the respondents expected would provide care for their parent if they developed need for help with a number of tasks (including possible formal sources of help and support), anticipated barriers, facilitators, and trade-offs to providing care, and willingness to pay for formal care. The focus groups, conducted in phase 3 and discussed in this article, allowed exploration of possible explanatory factors underpinning certain findings of the survey (such as the variation in care preparedness signalled by respondents).

2 | METHODS

This qualitative study used focus groups to collect data from two cross-sections of middle-aged individuals living in England (UK), one with experience of caring for older parents and parent figures ('carers') and one without any caring experience ('non-carers'). Carers were asked to consider their caring journey retrospectively, from when they felt they started providing care to an older parent or relative, and prospectively, envisioning how the care journey will unfold in the future. Non-carers were asked to consider prospectively their next potential caregiving phase, given their current circumstances. Data were analysed thematically, cross-sectionally, and over time.

2.1 | Sample

A recruitment agency identified and contacted potential participants aged between 40 and 65 living in England (UK), from a range of socio-demographic strata and locations. This age range was chosen since people aged over 65 are less likely to have a surviving parent and the parents of people aged under 40 are unlikely to need care until well into the future.

Experience of providing care was ascertained by the recruiters asking: 'Do you currently, or have you previously looked after or cared for an older relative?'

We held three focus groups with carers (17 participants in total) and three with non-carers (18 participants in total). Among the carers, nine identified themselves as female, eight as male, and the average age was 53. Ten identified their ethnic background as White British, one as Pakistani, and the remainder as mixed. Socio-economic status was defined by the recruitment agency using the Social Grade Classification Tool. Ten participants were from grade B, five from grade C1, and two from grade C2, the highest grade in the sample. Six lived in London, six in the West Midlands, five in the Greater Manchester area.

Among non-carers, ten identified themselves as female and eight as male. Average age of participants was 49. Thirteen participants identified their ethnic background as white British, one as Indian, and four as mixed. Six lived in the West Midlands, five in London, four in the Greater Manchester area, and the rest elsewhere. Ten participants were from grade C1, seven from grade B, one from grade C2. Details of the sample are in Tables 1 and 2.

2.2 | Data collection

The six focus groups took place online, via Zoom, in March 2022. Each lasted about 90 min. A researcher facilitated the discussion, with technical assistance from another researcher. Focus groups involving carers started with participants briefly introducing themselves and the person(s) they cared for and describing their role as carer (e.g., tasks performed, estimate of hours of care provided every week, on average). Participants were then invited to contribute to a brainstorming exercise supported by an online tool where they could type any words they would use to describe their experience of being a carer. Words were then presented as a word cloud and shared on screen. The results of the exercise were used to kick off the group discussion which covered three topics: (i) participants' experience of caring for an older parent, (ii) whether and how their experience of being a carer matched their prior expectations about caring (if any), (iii) arrangements for future care.

Focus groups with non-carers were structured in a similar way. After introducing themselves, participants were invited to take part in the brainstorming task and the resulting word cloud was used to start the discussion. The first part aimed at gathering participants' views about the role of a carer for an older parent or relative, leading to the second part when they shared what they thought would help people in that role. Lastly, we asked participants whether the discussion they had taken part in had drawn their attention to aspects of caregiving that they had not previously considered.

Focus groups were video-recorded with consent from participants and professionally transcribed verbatim.

2.3 | Data analysis

Transcripts were anonymised and imported into NVivo12. Data collected from carers were merged into a single dataset, and data collected from non-carers were treated in the same way. The two datasets were analysed separately. The analysis proceeded iteratively using a thematic approach. An initial set of codes was generated deductively from the topic guides. While the deductive analysis proceeded, additional themes started to emerge across topics and were added as new codes. The analysis zoomed in on the code *Expectations* and was organised on two dimensions. The first was temporal, to map expectations along the caring trajectory (e.g., pre-caring phase, future

TABLE 1 Socio-demographic characteristics of participants—Carers.

Id	Age	Seg ^a	Gender	Ethnicity	Working status	Region	Relative given unpaid care to
FG1-A	55	B	Female	White British	Part-time employment	West Midlands	Mother
FG1-B	65	B	Male	White British	Retired	Greater Manchester	Mother-in-law
FG1-C	51	C1	Female	White, Black Caribbean	Full-time employment	London	Mother, father
FG1-D	57	B	Male	White British	Full-time employment	London	Mother, mother-in-law
FG1-E	44	C2	Female	White British	Full-time employment	West Midlands	Father
FG1-F	40	C1	Female	White, Black Caribbean	In full-time employment	Greater Manchester	Father
FG2-A ^b	46	C1	Female	Pakistani	Part-time employment	Greater Manchester	Mother
FG2-B	58	B	Male	White British	Retired	West Midlands	Mother
FG2-C	51	B	Female	White, Black African	Full-time employment	London	Mother, father
FG2-D	58	C2	Male	White British	Full-time employment	Greater Manchester	Mother, father
FG2-E	42	C1	Male	White British	Full-time employment	London	Mother, father
FG2-F	50	B	Female	White British	Look after the home	West Midlands	Mother, father
FG3-A	63	B	Male	Pakistani	Full-time employment	West Midlands	Father, mother-in-law, father-in-law
FG3-B	56	B	Male	White British, Black	Full-time employment	London	Mother
FG3-C	53	C1	Female	White British, non-British European	Full-time employment	London	Father, mother-in-law, father-in-law
FG3-D	47	B	Female	White British	Look after the home	West Midlands	Mother
FG3-E	56	C1	Female	White British, Black Caribbean	Part-time employment	Greater Manchester	Father, mother-in-law, father-in-law
FG3-F	63	B	Male	White British	Retired	Greater Manchester	Mother

^aBased on occupation using the social grade classification tool (for details, see <https://www.ipsos.com/en-uk/social-grade>): Grade B = Intermediate managerial, administrative, or professional; Grade C1 = Supervisory, clerical, and junior managerial, administrative or professional; Grade C2 = Skilled manual workers.

^bDropped out during the focus group.

caring phase) and to facilitate comparing expectations and actual experiences of caregiving. The second was thematic and aimed to identify inductively the different aspects of expectations that were discussed. Themes were refined until they could be applied consistently to both datasets and to different caregiving phases. As a result of this process, we developed an analytical framework organised in four themes (see also S1):

TABLE 2 Socio-demographic characteristics of participants—Non-carers.

Id	Age	Seg^a	Gender	Ethnicity	Working status	Region
FG4-A	59	B	Male	White British	Full-time employment	West Midlands
FG4-B	55	C1	Female	White British	Full-time employment	West Midlands
FG4-C	40	B	Female	White British, Asian	Full-time employment	Greater Manchester
FG4-D	49	C1	Male	White British	Full-time employment	London
FG4-E	52	C1	Male	White British	Retired	Greater Manchester
FG4-F	40	C1	Female	White British, Black African	Full-time employment	London
FG5-A	44	C1	Female	White British	Full-time employment	Greater Manchester
FG5-B	57	B	Male	White British	Full-time employment	Cheshire
FG5-C	50	C1	Male	White British, Black African	Full-time employment	Kent
FG5-D	42	B	Female	Indian	Full-time employment	West Midlands
FG5-E	57	B	Female	White British	Full-time employment	London
FG5-F	53	C2	Female	White British	Full-time employment	West Midlands
FG6-A	47	B	Female	Asian, Black	Full-time employment	London
FG6-B	48	B	Male	White British	Full-time employment	London
FG6-C	54	C1	Male	White British	Retired	Greater Manchester
FG6-D	57	C1	Male	White British	Full-time employment	West Midlands
FG6-E	42	C1	Female	White British	Full-time employment	Warrington
FG6-F	40	C1	Female	White British	Full-time employment	West Midlands

^aBased on occupation using the social grade classification tool (for details, see <https://www.ipsos.com/en-uk/social-grade>): Grade B = Intermediate managerial, administrative, or professional; Grade C1 = Supervisory, clerical, and junior managerial, administrative or professional; Grade C2 = Skilled manual workers.

1. How and when expectations around caregiving are formed
2. Care needs of older parents and caregiving tasks
3. Care arrangements
4. Impact of caregiving on the carer

3 | FINDINGS

Findings are presented by theme, separately for carers (firstly, with reference to their pre-caring phase and secondly, with reference to their future caring phase) and for non-carers.

Although participants were recruited on the basis of providing care for older parents or parent figures, at the time they were all caring or expecting to care for one or both their parents and/or their parents-in-law. For this reason, the next sections will refer to ‘older parents’ only.

3.1 | Carers

3.1.1 | How and when expectations around caregiving are formed

When prompted to think about what expectations they had before they started caring for their parents, most participants acknowledged that they did not deliberately *plan* to become a carer (“*I never planned for it*”—FG3-B, FG2-C

talked about “*just falling into it accidentally*”). For some, caring for a parent was influenced by feelings of love and reflected social and cultural norms of reciprocity and familial bonds

“You mentioned the word expectations and I sort of, not chuckled, but the expectation for me is that you look after your parents. So, there is no thought. You just do it.”

[FG3-C]

This was felt particularly by carers who were only children, had a dispersed family, or identified themselves in specific socio-cultural backgrounds (such as religion, “*There's a religious duty, we must look after the elders, and within our faith it's really up to us to do that.*” [FG3-A]). Some also acknowledged that their expectations around becoming a carer reflected the direct experience of intergenerational help they had witnessed when their parents looked after their grandparents.

3.1.2 | Care needs of older parents and caregiving tasks

Participants often could not identify the point in time when they *started* caring. They described it as a slow and gradual process

“It sounds awful, and I don't mean it that way, but it... sort of creeps in.”

[FG1-A]

In their pre-caring phase, participants had generic expectations around what type of support their parents would need and when such needs would become manifest

“There was an expectation that at some point in the future, but I don't know when that would be, that I would have to look after my parents.”

(FG1-D)

As a result, carers described how they started supporting their parents in tasks that they could not carry out independently (e.g., managing finances and bills). They did not seem to consider them as caring *responsibilities* per se. Rather, they highlighted the emotional and relational component of the practical tasks which they had started to undertake, like going shopping

“She's still fit and able to go shopping herself [...]. What she does want is me to go shopping with her, rather than just have the groceries delivered.”

(FG2-B, referring to his mother)

They also seemed to suggest that they started to support their parents in an emergent and reactive way, depending on specific circumstances

“We haven't literally just gone from like zero to... it's a gradual thing where you just say ‘Okay, well, I'll do that’.”

(FG1-A)

Several participants highlighted how the role required constant inputs, with some tasks, albeit light-touch, regularly and increasingly expected from them

“It's a very time-consuming situation... I could literally spend all day, every day, there.”

(FG2-B, referring to his mother)

3.1.3 | Care arrangements

Participants assumed that the family (i.e., themselves, with their siblings or more extended family, if they had any) would have shared the day-to-day caring responsibilities for their parents. This reflected their cultural and affective motivations, which for some were associated with the preferences and personality of their parents

“I knew my dad would be quite demanding, and reluctant to receive any form of help. (...) He refuses to let anyone walk through the door.”

(FG1-C)

Among participants who had siblings, some expected to take on the role of main carer because siblings were living afar or because of difficult family dynamics

“My brothers are kind of there, but I wouldn't rely on them in a crux to do what I needed them to do, or step up and do the things I need to do.”

(FG3-B)

Based on their understanding of the social care system, participants did not hold any expectations of receiving support from their Local Authorities

“Whenever I ever explored anything down the Local Authority route, she just doesn't qualify for it. I can't say hand on heart that I had explored it, but it's probably because I kind of knew the answer anyway.”

(FG2-B)

Participants described how the actual care needs experienced by their parents determined current care and, in some cases, living arrangements. Older people with low care needs were able to live independently in the community, often in their family house, with paid help for housework (e.g., cleaning and gardening) and family providing support with other tasks (e.g., shopping and managing finances). Depending on individual and family circumstances, unpaid care was shared among siblings or was provided solely by one adult child (either because they were only children or because of family dispersal), sometimes from a distance

“My mum is in her own home. Thankfully, she's able to buy in some cleaning care, and some gardening care, but there's still plenty of things to do.”

(FG2-B)

Other older people lived in the community after relocating (e.g., downsizing from a house to sheltered accommodation, or moving closer to the family) when they started developing increasing care needs

“It was becoming obvious that being in a semi-detached house was becoming a big strain. (...) We eventually got them to sell the house (...). Now that they're in this apartment (i.e., a warden flat) (...) I think it's made a hell of a difference.”

(FG2-D)

3.1.4 | Impact of caregiving on the carer

Several participants highlighted how this ever-expanding role brought additional responsibilities and practical challenges (for distance carers, this included the time and resources to travel to visit their parents) and had to be reconciled with other aspects of their life, for example, their own family and work

“It's in addition to everything else that's going on in your life, so it's that extra bit of responsibility that you didn't have ten years ago. (...) Part of your brain is dealing with all the other things in life, plus there's that bit about your mum. As well as the physical element of getting from A to B and doing what you've got to do when you get there, it's thinking about stuff when you're not there as well.”

(FG1-D)

Participants who had already retired or had adolescent children also underscored how the caring role impacted the expectations they had held around that stage in their personal and family life

“We can plan for retirement (...) and then suddenly it's a different ball game, you're doing something that you wasn't really expecting to do, you wasn't going to be a nanny or a carer. (...) There is a feeling there, is it frustration, is there a bit of anger that they're denying you what you want to do?”

(FG2-D)

Several acknowledged that their expectations did not match the actual demands of the role

“I remember my parents going through the process and it was very intense (...). So, it's something which I knew or was expecting, and so I didn't question myself. What I was not prepared for (...) is the element of... like it's constant.”

(FG3-C)

As a result, several noted how they had underestimated the number of hours of care older people would require

“As I was offering support to my parents, there was more things that I noticed that I needed to help with. (...) When you first start, you're like “I'll do 2–3 hours a week”, then one week turns into 5–6, one week turns into 8–10 (...). I was only starting helping out for a few hours but then I could see how much help they needed. So, I didn't anticipate the hours.”

(FG2-E)

3.2 | Carers, caring in the future

3.2.1 | Expectations around care needs and caregiving tasks

When thinking about the future, participants took stock of both their individual experiences of caring for an older parent and of the collective experiences shared by other participants, some of whom were at different points of their caring trajectory.

Except for one, all participants could envisage their parents experiencing increasing care needs

“What I can see in the future is... obviously, going to be more and more dependent on us.”

(FG2-D talking about his mother)

Some were already able to identify a change in care needs, shifting from requiring help mainly with practical tasks to needing assistance with personal care

“It's a huge change, I'm literally changing the bed for them, I'm doing their washing, it's becoming a lot more involved, to the point where, like my dad's toenails needed cutting, and I was like, I can't do that.”

(FG2-F)

3.2.2 | Expectations around care arrangements

Carers could foresee the impact that new or different care needs would have on caring arrangements and envisaged different scenarios, ranging from expanding the scope and intensity of their role (that some were happy to consider, alongside getting other family members more involved), to moving together or closer, to making arrangements for home care or considering residential care

“When it comes to personal care that's probably where the line would have to be drawn from my point of view, and at that point we have to have some care come into the home, if my mum still doesn't want to move into a home, or go to a nursing home where they can provide that personal care.”

(FG2-B)

Participants were aware of the role of Local Authorities in providing support for older people, in some circumstances, and some were familiar with the means-testing process. Although nobody seemed to have direct experience of it, several suspected that they would not qualify anyway

“My mum and dad have saved...I don't think they'd be entitled to any help, and I think any help they'd [need] they'd have to pay it themselves. So, I haven't looked into Local Authority help, and I don't even think there's much there.”

(FG2-F)

When discussing these options, participants anticipated three issues. First, they were aware of the cost of domiciliary and residential care and of the choices they expected to have to make in order to be able to pay for it (e.g., selling the family home) when they did not qualify for support from the Local Authority. Second, they expected to face difficulties in navigating the care system (“*It is quite a little bit of a labyrinth*” (FG3-C)), and in identifying reliable sources of information about support available or for which they could qualify. Lastly, some participants mentioned they had discussed with their parents the possibility that, in the future, care arrangements would need rethinking because care needs were increasing (and could still increase further). They described a gradual process of discussing and converging on care options suitable for the individual circumstances, rather than just a one-off conversation

“It was a bit like a drip process (referring to their discussion around moving to a warden flat). We sowed the seeds, me and my sister, because it was becoming obvious that it (the family house) was too big for them”

(FG2-D)

3.3 | Non-carers

3.3.1 | How and when expectations around caregiving are formed

Expectations for non-carers seemed to be grounded in social and cultural norms as well and were framed in terms of responsibility, love, and reciprocity

“It would be the responsibility of taking on that care after they’ve looked after you.”

(FG4-B)

The interplay between cultural norms and family caregiving was also highlighted by participants from different ethnic backgrounds, whose families held traditional views about caring roles. For example, the specific role of the son was highlighted with reference to the South-Asian culture

“My father-in-law's perception of this is that his son and I should, and will, take care of [him]. (...) His expectation was that ‘I have one son, and that son will look after me. I've done it for you, so you do it for me.’”

(FG5-D)

Participants intertwined their personal stories with comments on the current broad political and policy context around social care, the recognition of family carers in society, and the care home sector, which all seemed to have a part to play in their thinking about caring for an older parent. They also anchored their expectations in experiences they gathered from other family members, friends, and acquaintances.

3.3.2 | Expectations around care needs and caregiving tasks

Non-carers were asked to envision their parents in 5–10 years' time, to articulate tasks and activities they expected their parents to need help with, and to consider for what tasks they might be willing to help them. Several did not have fully formed expectations around the role. Some highlighted that their parents had not shown any care needs warranting support up to that moment, hence they had never considered the issue.

Others highlighted that they were expecting a progressive deterioration in the conditions of their parents, as part of ageing

“You see this frailty starting to creep in and as that happens, you're like when does it change, when does it get worse, when does the end come?”

(FG5-C)

Others could envisage the possibility of a more sudden change in their parents' health (e.g., as a consequence of a fall) which would trigger care needs that they would not otherwise have expected.

Regardless of whether they expected a progressive or sudden change, participants envisaged some uncertainty around when and how such changes would unfold and with what outcomes, in terms of care needs. They acknowledged that such uncertainty would make planning difficult

“You can't plan exactly when these things are going to happen.”

(FG5-E)

Participants discussed a broad range of tasks in which they could be involved. Some envisaged parents with low care needs, which would require occasional, low intensity support that they would willingly provide (“*the shopping and the gardening and taking them to the hairdressers*” (FG6-A), alongside helping with finances or making doctors’ appointments). This could then progress towards higher care needs, requiring regular support, for example, with cleaning and cooking. In this scenario, participants (mainly those in employment) acknowledged that they would need to make care arrangements, because they did not expect to be able to meet those needs while having work or other commitments. Participants also discussed the stage at which parents would require help with personal care, in which the vast majority was not willing to get involved. Seeking help from paid carers for personal care was also described as a way of safeguarding the dignity of their parents

“My parents would probably want us to be around and to help, but they would maybe want that someone would come to the house and help (...) with the personal side of care, get carers to do that. I don’t think they would really want to put us through that really.”

(FG6-E)

In the final remarks, some participants highlighted that the discussion not only reinforced their understanding of their role in the long-term, but also made them aware that, in fact, they may have been overlooking care needs that their parents could develop in a shorter time horizon

“I’m looking at the long-term, but actually, what it [referring to the discussion] has made me think about is, in the shorter term, the daily needs that my parents might need more help with—household type stuff—that I’m not around for.”

(FG4-C)

They also seemed to start reframing their expectations around providing care for a parent and what the future may hold for them

“Coming into this (referring to the focus group), I was thinking about almost the worst-case scenario, so the end-of-life period, or if they need to go into a home. But actually, it might be that there’s a long period of care before it gets to that point, and I don’t know if my parents or in-laws can support each other in doing it.”

(FG4-C)

3.3.3 | Expectations around care arrangements

When cultural norms did not define family roles, participants discussed what care arrangements they could envisage for their parents. Some suggested that they would expect to share the role proportionately with siblings (FG4-F), but others seemed sceptical

“I would love to share it, but equality, in this instance, is very difficult to be met. (...) So for me, it would be time and money from me and neither of those things from siblings.”

(FG4-C)

Some participants considered the options of moving their parents closer or downsizing their homes, to facilitate provision of care, while others could also anticipate circumstances requiring paid care

“[It would be] first to support and try as much practically, physically as possible, but it's whether you're able to, with other commitments, obviously work. So, it's probably a team game (referring to other family members) of who can do what, when. And if it isn't possible, because too many people have got commitments, then perhaps third parties need to be thought about.”

(FG5-B)

Related to seeking formal support, participants mentioned they would expect to require help with navigating the care system and identifying options suitable for their circumstances

“They could do with creating like a one-stop shop, an advice line....”

(FG6-C)

Overall, the participants had a limited understanding of care options. Some considered the Local Authority as their first port of call, while others were aware of the work of some charities in their area.

On making caring arrangements, participants highlighted two issues. The first was around the involvement of their parents in making arrangements that would be consistent with their wishes and preferences. Some were concerned by their parents' resistance to acknowledging their need for some support

“If you're a carer, you might see it happening before they do. (...) What I'm really going to struggle with is, are parents actually acknowledging that this is what support they need?”

(FG4-C)

Whether their parents were ready and willing to engage in such discussion seemed to be related to personalities (as in the FG6-C quote above) and to their own previous experience of caring for an older person

“They used to care for one of their parents for years, every single day, and they've already said to us: ‘We don't want you to have to do that’”

(FG6-A, referring to her parents-in-law)

Cost of formal care, depending on care needs and time over which care would be required, was the second issue raised

“The financial resource [aspect] is the big one, I think, for everybody. It's the white elephant in the room.”

(FG4-D)

3.3.4 | Expected impact of caregiving on the carer

Participants touched on the impact that their possible role as carers could have on their own health and emotional wellbeing

“It's commitment, isn't it? If you are holding down a full-time job and you've got your own family... I would imagine it's very difficult, and will take its toll on your own health.”

(FG6-E)

A point made by one participant that resonated with others was about the impact that caring, or sharing care, could have on family dynamics

“We all try to do as much as we can but, sometimes you think to yourself, ‘I could really do with a break this weekend’. But then you don’t want to say to the others ‘Could you do a second weekend on the trot’, because it’s just going to cause friction. (...) Because tensions do run high.”

(FG5-F talking about sharing care with other family members)

Participants also hinted that providing care for a parent would imply a change in roles and relationships that they should somehow navigate and, in some cases, negotiate

“It would be the change in the relationship between you and a parent to almost becoming the parent. It’s whether you’re ready for that transition.”

(FG5-A)

4 | DISCUSSION

This article explored expectations towards intergenerational family caregiving from the perspective of mid-life individuals with and without experience of providing care to an older parent.

Accounts gathered from both carers and non-carers showed that expectations are embedded in emotional, social, and cultural factors, often constructed through processes of socialisation (Zarzycki, Seddon, Bei, Dekel, & Morrison, 2022; Zarzycki, Seddon, Bei, & Morrison, 2022). Using Thompson and Suñol’s classification of expectations, this work identifies three types of expectations around caregiving. Some participants articulated *predicted* expectations around taking on the role, which were driven by feelings of love, emotional attachment, and reciprocity (Al-Janabi et al., 2021; Greenwood & Smith, 2019; Stevens et al., 2022; Zarzycki & Morrison, 2021), or framed as a common sense, a norm ‘that goes without saying’, entrenched in the individual’s moral framework (Stuifbergen & van Delden, 2010). Other participants identified *normative* expectations and obligations grounded in cultural values of filial piety, familism, and religious beliefs, often conveyed through earlier role modelling within the family. Social and cultural factors help explain carers’ perceived degree of choice or constraint when transitioning into a caring role (Al-Janabi et al., 2021; Parveen et al., 2011). Several participants seemed to have taken on (or to be considering taking on) a caring role out of a constrained choice: they underscored the emotional bonds with their older parents, whilst also acknowledging the constraints posed by social and cultural pressures (e.g., duty and obligations) and by situational circumstances (e.g., necessity or lack of alternatives).

Both groups articulated *unformed* expectations about what the role would entail, what tasks would be expected from them, and when they would need to start caring. They simply acknowledged that they did expect their parents to require some care inputs in the future and that they would support them, as and when needed. It is worth noting that, despite their expectations about taking on a caring role, participants did not describe any strategies that could help them prepare for it. This seems consistent with and expands on preliminary work on care preparedness (or lack of it) among individuals who have, or expect to take on, the role of carer for older relatives (de Jong et al., 2021).

Although pre-caring expectations around the motivations for providing care were similar across carers and non-carers, participants seemed to express in different ways the socio-cultural factors and emotional drivers underpinning their caregiving identity. As part of the recruitment strategy for the study, participants were asked to self-identify as either carers or non-carers and accordingly were invited to join a focus group. However, the discussions showed that the two groups (carers and non-carers) generally seemed more similar than different in the type of tasks in which the participants said they were involved, contrary to our expectation that those self-identifying as carers would have been providing more support (e.g., more care hours). Also, the care profiles of the older people that were

described by the participants in the same groups seemed quite heterogenous, again contrary to our expectations that those cared for by carers would be described as having high care needs (and higher than the parents of the non-carers). Several participants seemed to occupy the liminal space (Beatie et al., 2021) where they were unsure about their role and identity given the low care needs of their older parents. This is aligned with existing theoretical models. For example, the caregiver stress process model frames caregiving as a career (Pearlin & Aneshensel, 1994) and conceptualises caring as a continuous trajectory, from pre-caring through caring and, eventually, into post-caring (Larkin & Milne, 2021), in which roles and identities are progressively renegotiated as care needs and caring activities change (Montgomery & Kosloski, 2013). The vagueness of expectations that participants identified in their pre-caring phase is consistent with the view that transition to the care role is an amorphous phase that is not easily distinguished from the usual mutual support that occurs within families (Kim et al., 2017).

When thinking about their pre-caring expectations, neither set of participants mentioned what role they envisaged for formal care. Through the discussion it became apparent that their lack of expectations was due to a combination of factors, for example, preferences of the parents for receiving support by family members (and, conversely, their reluctance to receive support from people outside the family, in particular their refusal to consider residential care), (future) carers' lack of awareness about what services would be available, expected cost of formal care (based on hearsay, since nobody had direct experience), no confidence in being able to access care funded by their Local Authority, their understanding of national health and social care policies (around social care funding, means-testing, workforce) and of the broader care system (e.g., the involvement of third sector organisations vis-à-vis the role of the State in service provision). This finding is consistent with previous research that underscores that carers, willingly or unwillingly, fill a gap in formal care also as a result of a lack of planning for future care needs, often driven by limited awareness about the options available to people and by their perceptions about the system (Department of Health and Social Care, 2021; Ipsos Mori, 2018; Ipsos Mori, 2022a; Ipsos Mori, 2022b; Meyer, 2018; Zarzycki, Morrison, Bei, & Seddon, 2022).

For the self-identified carers, the study allows comparison of the actual experience of caring with the same individuals' accounts of their expectations before taking on the role. Although each carer represented a different configuration of personal and family circumstances and care arrangements, their accounts brought to the surface a role which was reactive to the emerging needs of parents, who often required regular help with multiple, wide-ranging tasks. Several (in particular distant carers, i.e., those living an hour or more away from their parents) acknowledged that, in hindsight, they had underestimated the time commitment required and had a poor understanding of the pattern of caregiving, often unpredictable and associated with a feeling of being permanently on call. These findings contribute to the body of literature on temporal aspects of informal caring for older people and provide additional evidence of the limitations of using large-scale household or ageing surveys for estimating caring time (Bowes et al., 2020; Urwin et al., 2021; Urwin et al., 2022). Carers also highlighted the stress associated with caring and the impact of this role on significant aspects of their life, for example, their job, spending time with their own family, or enjoying retirement, themes which are well established in the literature (Bom et al., 2019; Larkin et al., 2019; Lindt et al., 2020; Penning & Wu, 2016).

Both sets of participants were asked to articulate their expectations about the future. Although they started from different points in their caring trajectory, three themes were common. First, participants expected older parents to develop increasing care needs over time and highlighted that such progression would be uncertain. They envisaged—and, indeed, a few had already experienced—that stepped changes in care arrangements would become necessary in the future, when higher care needs could not be met by incremental changes to current arrangements pivoted around family carers only. Depending on circumstances and preferences, this could involve the parent moving into residential care or sheltered accommodation, relocating closer to the family, or downsizing to a smaller accommodation, and arranging domiciliary care. Second, participants recognised stepped changes in care arrangements as substantial transition points in caregiving trajectories, but acknowledged their lack of awareness of the care options that would be available to them. An unmet need for advice and information was identified, and a solution, in the form of a one-stop shop, was suggested. This finding is consistent with previous work on family care which

identified 'information work' as a demanding form of hidden work for which carers require timely and adequate support (Dalmer, 2020). Third, participants anticipated some resistance from their parents to considering future care arrangements and questioned how and when the parents should be involved in such discussion.

This article makes a theoretical contribution to the scholarly literature by theorising expectations around family caregiving which was lacking. Data presented provides empirical evidence for the theoretical conceptualisation of expectations as beliefs created and sustained by affective and cognitive processes shaped by accumulated experience (Locker & Dunt, 1978). The fact that, with reference to their pre-caring phase, participants articulated only unformed expectations around the caregiving role is consistent with this conceptualisation, since individuals taking on a new role may not yet have the experience or knowledge to formulate expectations. Similarly, participants suggested that the discussions alerted them to issues they could face in the future, potentially helping their cognitive process of establishing expectations around caregiving and planning accordingly. Indeed, among the non-carers, some suggested, by the end of the discussion, that they should start seeking information and considering options.

This work also described how the caregiving role is rooted in emotional and socio-cultural factors and emerges and evolves as a response to the increasing, often uncertain, care needs of older parents. This echoes the sociological concept of creep used to denote processes of unintended transformation and expansion of systems (e.g., ethics creep to characterise the expansion of the scope of the research ethics and governance regulation (Haggerty, 2004), mission creep as the tendency of organisations to expand their mission or remit (Einhorn, 2001)). Adapting this concept to the context of family care, we can start theorising about caregiving creep, that is, the process whereby a role that stems from predicted expectations (either on normative or affective grounds) undergoes a process of unanticipated and, sometimes, unwanted transformation and gradual expansion, to accommodate changes in care needs and preferences, or personal or family circumstances.

Policy implications raised by this work are manifold. Opportunities to improve awareness about the carer role, to facilitate carer identification and to seek timely support should remain a policy priority (Carers UK, 2022). Care needs are uncertain: it is often not possible to anticipate what needs an older person will develop, when needs will become apparent, what care arrangements will be required, and what provision will then be available, in the context of the changing landscape of adult social care. Uncertainty affects planning and limits the scope of interventions to support care preparedness. However, when needs do arise, the 'information work' of carers should be a focal point of policy, as also acknowledged by the Adult Social Care Reform White Paper (Department of Health and Social Care, 2021). Moreover, services should not expect carers to be more knowledgeable than they actually are, since they may not know or may struggle to articulate what information they would need (Meyer, 2018; Stevens et al., 2022). The suggested one-stop shop could deliver both public awareness initiatives, provide carers with timely and reliable information, offer targeted interventions and training opportunities (e.g., on managing medications, as mentioned by the participants). Carer's assessments could provide the context for discussing individual expectations in a socially and culturally acceptable way and providing or signposting information.

It is important to recognise strengths and weaknesses of this work. The heterogeneity of the sample, both in terms of the socio-demographic profiles and of the caring experiences of participants, is a strength of this work. We did not, however, collect systematically any information about the individuals the participants were caring for or, for non-carers, were expecting to care for. The size of the sample is consistent with empirical guidance on effective sample sizes for qualitative research (Hennink & Kaiser, 2022). Moreover, it can be considered adequate given the exploratory nature of the study, the methods used, and the relatively narrowly defined study population (i.e., individuals living in England aged 40–65). The age criteria used for sampling purposes helped targeting the discussion to a group who was likely to find the topics salient and relatable, in contrast to people aged over 65 (who are less likely to have a surviving parent) and under 40, for whom thinking about older parents with care needs may be too distant a scenario.

While the analytical process showed that the sample was sufficient to reach data saturation, the transferability of the study findings beyond the English setting and/or across different age groups (e.g., younger than 40 or older than 65) could be further explored.

The cross-sectional design may represent a further study limitation: carers were asked retrospectively about their expectations of caring for an older parent and their accounts may be affected by recall bias (Scott & Alwin, 2014; Thompson & Sunol, 1995). Nonetheless, we believe that our approach has yielded valuable insights, given the nature of the caregiving role and the difficulty in situating the starting point of the caregiving trajectory.

The inclusion of both carers and non-carers is a strength of this work. However, the finding that the two groups were not as different as anticipated has methodological implications that a future longitudinal qualitative study, with data collected over time (e.g., every six months) from those study participants who consented to be contacted for follow up, could address.

5 | CONCLUSIONS

The study explored expectations about providing care to a parent among mid-life people in England, who are expected to take on or to continue undertaking caring roles for the growing cohort of older people.

The design of the study allowed exploring expectations about the initial phase of the caring journey, so far under-researched. It highlighted how becoming a carer for an older parent is an emergent process, with people gradually entering the role because of normative expectations, grounded in social and cultural norms and obligations, or preformed expectations driven by emotional factors. Future work could explore in depth how families construct their expectations around who will be taking on the role of main carer for older parents.

This work provided a thorough description of expectations of carers around tasks, intensity, and impact of caregiving over time which allowed comparing prior expectations and the actual experience of providing care to an older parent. The discrepancy between prospective expectations and the actual experience of the role, perceived as more demanding and time-consuming than envisaged, may open up three lines for further research. The first could explore the consequences of the discrepancy and understand whether it matters if there is a mismatch between expectations and reality, and if so why. The second could investigate interventions to help address this mismatch, by supporting carers to re-assess their expectations or to access timely and meaningful support. Lastly, a longitudinal study would allow comparing expectations with reality, track change and continuity in expectations while caregiving adjusts to changes in care needs, and explore how participants interpret and respond to such changes.

AUTHOR CONTRIBUTIONS

Chiara De Poli, Raphael Wittenberg, Amritpal Rehill, Nicola Brimblecombe, and Madeleine Stevens, designed the study. Chiara De Poli facilitated the focus groups, with support from Raphael Wittenberg and Amritpal Rehill. Chiara De Poli led the data analysis and interpretation and wrote the first draft of the article. Raphael Wittenberg, Amritpal Rehill, Nicola Brimblecombe, and Madeleine Stevens contributed to the data analysis and interpretation, and to the drafting of the article. All authors agreed the final version.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

This study was approved under the research ethics procedures of the London School of Economics and Political Science. All participants gave written informed consent to participate in the study and for their anonymised interview to be used to write articles and reports.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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