


ARTICLE

‘When it comes to carers, you’ve got to be grateful that you’ve got a carer coming’: older people’s narratives of self-funding social care in England

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Abstract

The number of older self-funders in England is growing in the context of tight eligibility criteria and fixed financial thresholds to access statutory adult social care. Older people who self-fund their social care fall largely under the radar of statutory services and of research. Our study aimed to listen closely to the stories that older people tell about finding, managing and paying for their care. We interviewed 65 older people living in the community who were funding all or some of their social care. This paper focuses on narrative analysis of selected transcripts from these interviews. It sheds light on how older people represent their experiences of self-funding and what underpins these constructions. A key finding is that the disjunctions within older people’s accounts between the care they want and the care they receive reflect wider political and structural tensions in the funding and delivery of care. Older self-funders temper their expectations in light of their experience of shortfalls in the system. This enables them to adjust to the deficiencies but obscures and perpetuates poor care. The discussion considers the findings in relation to: the fundamental incompatibility of body labour and commodified care; the shared precarity of older people and care workers; and the individualisation of risks that makes older people and their carers responsible for making a failing care system ‘work’. Our analysis adds to the case for major reform of adult social care, including a revaluing of the status and employment conditions of front-line care workers.

Keywords: care; self-funding; older people’s experiences; narrative analysis

Introduction

Under the provisions of the Care Act 2014, local authorities in England are required to assess any individuals who appear to need social care and support, regardless of

financial means. However, their entitlement to state-funded support depends on whether they meet needs-based and financial criteria. If they fall below the prescribed needs threshold or above the financial limit, they have to pay for their own care and are known as 'self-funders'. Our definition of a self-funder, following Baxter and Glendinning (2014: 5), is: someone who pays for all of their social care or support from their own private resources (including social security benefits such as state pension or attendance allowance), or 'tops up' their local authority residential or domiciliary care funding with additional private spending. The focus of this paper is how older people construct and present their experiences of self-funding social care.

The first part of the paper outlines the policy and practice context of self-funded care and gives an overview of our research project and methods. We then describe older people's orientations to their experiences of self-funding by reference to five narrative categories: satisfied, resigned, striving, battling and fears for the future. Extracts from four older participants' interview transcripts are used to illustrate the interplay of these categories. The discussion interprets the findings in relation to the concepts of body labour, precarity, and the individualisation of risks and responsibilities.

Policy and practice context of self-funding

The pressures facing adult social care in England include demographic factors increasing the demand for care; reductions in local government funding; and increased care costs, including additional costs to providers as a result of the COVID-19 pandemic (Foster, 2020). It is estimated that central government funding to local councils has reduced by around 60 per cent (£15 billion) in real terms since the introduction of austerity measures by a Conservative-led government in 2010 (Local Government Association, 2020). One way of trying to contain spending is to restrict access to state-funded services.

Although criteria for accessing state-funded care are not new, in recent decades it has become harder to meet needs-based and financial eligibility thresholds. In relation to needs-based criteria, the Care Act 2014 implemented a revised framework based on three components: the needs must relate to an illness or impairment; the individual cannot achieve at least two from a list of defined outcomes in their daily life; and this must have a significant adverse impact on their wellbeing (Department of Health and Social Care, 2020). The Care Act 2014 also introduced revised regulations relating to charging for care. To determine the charge, local authorities carry out a financial assessment following statutory regulations. This imposes an 'upper capital limit' which represents the point up to which someone is entitled to local authority support for needs assessed as eligible. The current capital threshold is £23,250. People with capital above the upper limit can ask the local authority to arrange their care and support, but they may have to pay an administrative charge for this service in addition to the full costs of the care. Below this level, a means-test is carried out to calculate the contribution that the individual should make towards the cost of care. Any capital below the lower capital limit (currently £14,250) is disregarded for the purposes of assessing charges (Department of Health and Social Care, 2020). The value of someone's home is disregarded in the financial assessment for home care services but included in the financial

assessment for care home residency unless another eligible person resides in the property. Bottery *et al.* (2019) point out that the minimum financial threshold for eligibility for state funding has not been raised in line with inflation since 2010/11. This means that many people fall above the threshold despite a reduction in the value of their assets in real terms. There are current plans to reform charging for adult social care in England from October 2023 (Department of Health and Social Care, 2021).

It is evident that there is an increasing number of older people paying for their own care, though precise figures are lacking (Baxter and Glendinning, 2014). The National Audit Office (2021) indicates that there was a 6.6 per cent fall in the number of people aged 65 and over receiving long-term local authority support between 2015/16 and 2019/20. Older people who approach the local authority for an assessment may be identified as having assets above the financial threshold and then be 'signposted' to other sources of help, without this being recorded formally as a request for support (Bottery *et al.*, 2019). It is estimated that 45 per cent of the total number of older people in independent-sector care homes are fully self-funding while another 11 per cent contribute towards their care home fees (LaingBuisson, 2018). It is more difficult to obtain a reliable estimate of the number who are paying for care in their own homes given the fragmented domiciliary care market. Analysis by Henwood *et al.* (2019), based on data obtained between 2015 and 2016 for the UK Household Longitudinal Survey, suggests that around 6.4 per cent of people aged 65 and above living in private households (*i.e.* excluding those in residential facilities) may be paying for all or some of their care. Unsurprisingly, the percentage paying for care rises steeply by age; 10.5 per cent of people aged 80–84 and 18.2 per cent of those aged 85 and over are estimated to pay for some or all of their care (Henwood *et al.*, 2019).

Most social care for adults, both state-funded and self-funded, is delivered via a 'care market' that is large, complex and fragmented (Hudson, 2019), comprising a mix of large national providers, many smaller and micro providers, and individuals offering their services as sole traders (National Audit Office, 2021). It is also fragile, as evident from the significant numbers of both care home and home care providers ceasing to trade and/or handing contracts back to local authorities (Jefferson *et al.*, 2018; Association of Directors of Adult Social Services, 2019; Foster, 2020). Insecurity in the workforce is a significant factor contributing to the instability of the sector, with staff retention and turnover seen as its major challenge (LaingBuisson, 2020). Care workers have one of the highest turnover rates amongst adult social care staff and the majority of vacancies in the sector are in care worker roles (Skills for Care, 2020). Over half of care workers are on zero-hours contracts, exceeding any other social care sector (Skills for Care, 2020). Turnover is increased by care staff moving between providers to attain small pay increases (Jefferson *et al.*, 2018). Care workers receive on average lower pay than cleaners, shop workers and health-care assistants; moreover, they lack support and training, and have very limited career progression (Bottery, 2019).

Self-funders' experiences

The limited research conducted on self-funders' experiences casts doubt on the extent to which they exercise choice and control over their care arrangements,

contradicting stated policy objectives (Henwood *et al.*, 2022). A key factor is the lack of information and support for their decision-making. A report by the Competition and Markets Authority (2017) recommended wider access to supported decision-making for self-funders, including tailored advice from trusted professionals and clearer information about the workings of the care system. The research of Baxter *et al.* (2019) included 40 interviews with older self-funders and/or their families. They perceived councils as having little interest in self-funders, leaving them to find information via their own efforts or from knowledge and experience within their informal networks. Information provided by formal bodies was generalised whereas self-funders wanted personalised advice and recommendations to guide their decision-making. The study concluded that to feel empowered to make choices, people need to have access to information and be equipped to understand and manage it. In terms of financial advice, a scoping review by Heavey *et al.* (2019) found that people in England have a low level of engagement with independent or regulated financial advice about paying for current or future care, with barriers including mistrust of financial services, tendency to use family and community sources of advice, and lack of opportunity to access financial advice. The lack of advance planning for care was also noted by the Competition and Markets Authority (2017), which reinforced the findings of other research that decisions about care are often made at a time of crisis, vulnerability and distress.

It should be noted that the experiences of self-funders overlap considerably with those of older people who manage direct payments or personal budgets, who can also be viewed as individual purchasers of care, albeit with state funding (Miller *et al.*, 2013). It is beyond the scope of this paper to review this evidence, other than to note that research with older people receiving direct payments identifies difficulties such as the stress of arranging care at a time of crisis, need to have someone willing and able to take on the administrative burden, disincentives and heavy responsibility placed on families or other unpaid carers (Glasby and Littlechild, 2016; Woolham *et al.*, 2017).

Methods

The overarching aim of our three-year study was to understand older people's lived experiences of paying for social care, addressing the gap in existing knowledge. Our research was rooted in an ethics of care framework that recognises and values the need for care as a shared characteristic of being human, in contrast to individualised approaches to meeting needs for care and support enshrined in neoliberal policies (Lloyd, 2010). Care ethics views care as a relational process involving interdependence that is part of our political and collective responsibility to one another (Tronto, 2017); significantly, it highlights that 'care is always infused with power' (Tronto, 2015: 9).

Our study was carried out in three areas of the United Kingdom, each with a research team of academics and lay older co-researchers. In addition to interviewing older self-funders, we interviewed a sample of carers who were supporting older people who self-fund and key stakeholders, including local authority commissioners and practitioners, and private and voluntary-sector care providers. The analysis here focuses solely on a sample of interviews with older people.

We recruited 65 older people who were paying for some or all of their social care in their own homes to meet 'higher-level' personal care needs, such as washing, dressing, getting in/out of bed and meal preparation. We aimed to interview each older person three times over an 18-month period to explore how they negotiated changes in their care needs and arrangements over time. In total, we carried out 174 interviews with older self-funders or their consultees. Participants' ages ranged from 60 to 95, although the majority were over 85. They identified their ethnicity as White British (62), Asian (one), White Irish (one) and White European (one).

Full ethical approval was obtained from the lead university and Health Research Authority Social Care Research Ethics Committee. We included older people who lacked the capacity to consent to participate through the involvement of consultees, acknowledging the importance of understanding the self-funding experiences of people with dementia. Co-production of research with older people working as co-researchers was central to our study and most interviews were carried out jointly by older co-researchers and academic researchers. This helped to ensure that processes were responsive to the needs of participants (Ward *et al.*, 2020a).

All interviews were audio-recorded and full transcribed. Co-researchers and academics worked together to code the data and develop higher-level themes, supported by NVivo qualitative software. (Further details of this and other aspects of the study can be found in Ward *et al.*, 2020a.)

Narrative analysis

In this paper, we report on a secondary process of analysis, narrative analysis, which complemented the fragmentation and decontextualisation of experience produced from coding and enriched the understanding gained from thematic analysis (Riessman, 2008). The narrative analysis explored how older participants positioned themselves and others in relation to the process of receiving and providing self-funded care, including their constructions of their own agency in relation to others. A key focus was not just the content of what was said but the question, 'Why was the story told that way?' (Riessman, 1993: 2). Another dimension of interest was the way that 'culture "speaks itself" through an individual's story' (Riessman, 1993: 5); narrative analysis revealed not only individual constructions of identity as 'self-funders' but also perceptions of funding care as a social phenomenon.

Three criteria were used to select interview transcripts for narrative analysis: that a set of three interviews had been completed so we could look at the development of stories over time; the interviews contained enough extended sequences of talk to allow scope for exploring the underlying narratives; and these narratives related closely to the research focus on how relationships of care are negotiated and managed by older self-funders.

In each site, the reading and analysis of transcripts was undertaken by at least one academic researcher and one older co-researcher. When reading across the transcripts for each participant selected, we completed templates for recording key observations under the following headings:

- Context: *e.g.* whether the older person was interviewed alone or with a partner or family member, or anything significant about the timing of the interview.



Figure 1. Narrative categories.

- Thematic content: key plot lines or themes within the story.
- Performance: how self and others were constructed.
- Development: a note of key points of continuity and/or change within the story.

This combined narrative techniques, allowing for different ‘jumping-off points’ for the analysis (Frost, 2009: 24). From initial reads of the transcripts, we identified recurring narratives and grouped these by category (Figure 1). We then selected a sub-sample of the sets of transcripts to analyse in more depth, ensuring that all five categories were represented in the selections.

Narrative themes

Although our analysis identified five categories of narrative, it is important to note that the categories refer to themes within narratives not to participants. Invariably transcripts reflected two or more categories, though with varying levels of prominence. Moreover, for some participants there was a shift in the dominant categories over the course of the three interviews, allowing us to explore the possible reasons for these changes.

The themes are summarised in Figure 1 and are described in more detail below:

- *Satisfied*: Participants express satisfaction and gratitude for the care they receive. They see themselves as fortunate, making positive comparisons with the experiences of other people or with other forms of care. It was common for care workers to be described as ‘like friends or family’.

- *Resigned*: Some sense of dissatisfaction with care is expressed but the response is to accept or 'make the best of it'.
- *Striving*: This may reflect a similar level of dissatisfaction to that expressed by those who are 'resigned' but the response is to make efforts to improve the experience of care, rather than accept it as it is.
- *Battling*: There is a sense of having to fight the system to get good care. Whereas 'striving' is about their own efforts to achieve change, 'battling' is more about putting pressure on others to change.
- *Fears for the future*: This co-existed with all of the other four themes. Even participants who were satisfied with their current care expressed fears about what would happen in the future if their needs increased and/or their money to pay for care depleted.

Results

For this paper, we draw on four participants' narratives, selected to illustrate the interplay of these different categories and themes.

Millicent

At the time of the first interview, Millicent, aged 92, lived with her husband, Patrick, in a privately owned bungalow in an assisted living scheme. Patrick died before the second interview. Although the care had originally been mainly for him, Millicent continued to purchase care for herself from the same agency. She considered herself to be relatively wealthy, having sold a house that had increased hugely in value. Millicent presented as very sociable and cheerful, as liking everyone and being liked by them in return. The main narrative theme across the three interviews was 'satisfied'. However, there were subtle criticisms, veiled beneath a positive comment or masked by humour.

- Millicent: And I said a categorical no to any carer. I wasn't going to have a carer. No way, no way, no way. But Sarah and Robert [daughter and son-in-law] were going [overseas]. So, 'Mum please will you have a carer just to please me because I'll be worried otherwise?' So I said yes. I wouldn't do without them now. They are wonderful. Every single one of them.
- Interviewer: Oh, that's nice.
- Millicent: All the ones that make mistakes are marvellous (laughs). (First interview)

Later in the interview, she elaborated on the 'mistakes':

- Millicent: Well, when it comes to carers you've got to be grateful that you've got a carer coming ... You really have. Because they're overworked, underpaid ... when they come, I'm grateful. Thank you for coming. Yeah, I am. And I help them, as a teacher, if they don't know what to do I put them on the straight and narrow.

Interviewer: What sorts of things do you have to help them with, in what way?

Millicent: Well, tell them, it's no good just putting that night bag piece into the leg bag [catheter] like that because it will just come out. And we've had three wet beds in a year and half or something, so I make trebly sure about it.

Interviewer: So, if you weren't happy with any aspect of the care that you're receiving would you feel able to contact them and...

Millicent: Oh yes, I can phone up Donna or Tina or Ceri. Those are the three that are in the office, oh yes.

Interviewer: And they're always helpful?

Millicent: They would all be helpful, yes. I'm lucky, aren't I?

Millicent was in a favourable position in terms of wealth, social class, professional background (her experience as a teacher) and family support. With her daughter's help, she had managed to arrange care that she was happy with, and she presented herself as being fortunate and grateful for being in this position. However, she contextualised 'being grateful' within her knowledge of the poor employment conditions of care workers and although she said they are 'wonderful', she alluded to the need to instruct them to ensure their competence. Within a predominant narrative of 'satisfied', there is evidence of 'striving' in that she initiated action to help achieve good care.

Adele

Adele, aged 91, was widowed, lived alone and had no children. She had several long-term health conditions and purchased morning and evening care from independent carers. During the study, the level of care increased to the point that one of the care workers (Lily) provided a significant amount of live-in care. Adele presented as being satisfied with her care arrangements and initially spoke positively about the three care workers and their responsiveness to her needs:

...they're very, very good and they come for two hours, well the morning carer, she comes for two hours in the morning and then the evening carers come for two hours, and they'll do anything I ask of them, it doesn't matter what it is. (Adele, first interview)

However, when asked in more detail about how well the care met her needs, it seemed that Adele had resigned herself to the calls not aligning with her preferred timings:

Adele: The time I wanted them in a morning, I mean everybody wants to get up at the same time nearly in the morning and anyway, this lady that comes in the morning, she's managed to work it in with another lady that she looks after, so she comes from nine 'til eleven and the carers at night come from half past seven to half past nine.

Interviewer: So do you feel that the way you've got it sort of organised now suits you or would you rather it were changed in some way?

Adele: The only thing is getting ready for bed at half past seven, and also in a

morning, not being finished until eleven, your morning's gone and it's dinner time, and then by the time I've had a rest and I've done various things, it's nearly time for the evening carers to come. But we can't see any other way round it and we've managed fine; it's worked out alright. (First interview)

Adele's satisfaction with the tasks and relationships of care led her to accept that her preferred timings could not be accommodated. Like Millicent, she framed this within her understanding of the broader context of there being insufficient care to meet demand at peak times.

Adele took responsibility for her care by advance planning to try to ensure that she had the resources to pay for her care. An element of 'battling' occurred when she sought statutory help with the care costs:

This original package was just for morning care and then last year ... I needed more care at night now, and there wasn't enough in the pot from this insurance company, so we got in touch with Social Services to see if they could help and they sent a letter to say, yes, they could give me so much a week, so much a month, so much a year, *etc.*, but this was before they'd done a financial assessment. Anyway ... having said this money was available, they came and assessed me, and they said no, I couldn't have this money and by then I'd organised a bank account specially for my care and I'd organised three carers to have a rota of an evening, and then they said no, I couldn't have this money and so it put me in a bit of a pickle. We're actually contesting it at the moment ... what'll happen in the end I don't know. I'll just have to go into my savings one assumes, because I don't want to sell my home or do anything like that. (Adele, first interview)

Despite her careful anticipatory planning, Adele was left uncertain about what she would be entitled to and 'what'll happen in the end'. She also had to 'strive' to make the arrangements work smoothly. One difficulty was conflict between Lily, the main care worker, and the care worker who did the morning call, with each complaining about the other so that Adele felt 'caught in the middle'. Despite her status as employer, she worried about telling the care worker that she wanted her to leave. After the care worker left of her own volition, Adele worried about the impact on the care worker's income:

...she [the care worker] said ... I'm going to have to give it up. So we're glad we didn't have to say anything because we didn't know how we were going to do itso really it all turned out for the best. But that worried me then because what was she going to do for money? Anyway ... I was talking to my old neighbour who knows her and said she's picked up quite a bit more business, so I was glad about that because I've worried about her. (Adele, third interview)

Another area of 'striving' for Adele was regulating the amount of care so that it met her perceived needs, without exceeding them, and allowed the care worker space for her own life:

Well from my point of view I mean it always worries me that Lily needs a life of her own and now she's got engaged she should be back home with her partner and also, she would like eventually to move house down to ... where her family are, and she can't. (Adele, second interview)

Adele made efforts not to rely on Lily too much:

She feels that she must be near me all the time to make sure nothing's happening to me, or I've got everything I need, and I know what I'm going to have for my lunch ... I do feel overprotected. She doesn't let me do things ... she just is over-protective. (Adele, second interview)

By the third interview, Lily was providing live-in care. When Lily's family visited her, they stayed at Adele's house as it was bigger. Lily emphasised how much her family cared about Adele and Adele referred to them as being the only family she had. Nevertheless, Adele had to grapple with the tension between her dependence on Lily's support and wish to keep her happy with her own need for autonomy and solitude:

But because [Lily] has had her family up this last week, her daughter and children. I found that a bit trying because I'm so used to being on my own and then with so many people about and talking and things going on, that's bedazzled me a little bit. But Lily's really enjoyed it and she was able to go out with the children and do things. They came for about, what, five days? (Adele, third interview)

Across the interviews, there was the recurring theme of Adele's anxieties about the future. Some of these related to her ability to pay for care:

Well it was my choice, and I suppose I'm quite happy to pay for this, as long as I've got enough money, because it does worry me now, we've taken on these night carers and Social Services at the moment won't help. I mean we really, when we've worked out all the finances, we're short of up to £200 a month, so I've got to find that from somewhere, and that is worrying. (Adele, first interview)

Another anxiety about the future concerned the implications if her pivotal relationship with Lily broke down:

I don't know what we would do if, who we would go to if say Lily and I quarrelled about anything. Where either of us would go then I don't know, sort of don't think about it I suppose. I'd go back to my family but yeah, that would be difficult knowing what to do. (Adele, second interview)

Adele's narrative across the three interviews illustrates recurring shifts between all the categories presented in [Figure 1](#): satisfaction with some aspects of care; resignation about elements experienced as unsatisfactory, but inevitable; striving to make the arrangements work for herself and her care worker; battling about financial issues; and the anxieties generated by uncertainty about the future. The relational

dimensions of care are also very apparent. Adele experiences care through the medium of reciprocal relationships rather than as a market transaction.

Jim and Holly

Jim, aged 95, had dementia. He had stayed in a care home for seven months the previous year when his partner, Holly, aged 93, became ill. When he returned home, Holly and the family arranged care four mornings a week, partly as a support for Holly, who had a heart condition. Jim also attended a day centre one day a week and they had a cleaner. The interviews were mainly with Holly (aged 93), with occasional contributions from Jim.

The three interview transcripts show shifts in the predominant narrative themes over time. In the first interview, Holly expressed dissatisfaction with the unreliability and discontinuity of care:

I wouldn't say I was anywhere near 100 per cent, or even 70 per cent, happy with the system or anything else. The people who come are nice people who I know are very badly paid, and so it's quite difficult. The continuity isn't there ... I wanted some kind of continuity for Jim and just for getting to know people and how the situation is ... I wanted them reasonably early in the mornings, suggesting something around about half past nine, being that time would be long enough for Jim to get up out of bed and have a shower and ... some days I had them for an hour, some days I had them for two hours. Now, today would be a two-hour day and nobody has turned up. This is the first time nobody has turned up. Usually I've had problems because they'll come along about eleven o'clock in the day and I don't want them then. It's nearly lunchtime and I've had to get Jim showered and whatever else I've had to do before then ... who wants anybody, you know, to be in their bed and trying to be showered after this time in the morning? It's just ridiculous. (Holly, first interview)

Holly found it difficult to complain about the care as the care workers 'are nice people' and she recognised that they are not paid well but, at the same time, the needs for which she was purchasing care were not being met:

...twice last week, the lady who is the Supervisor ... she was filling in and she comes and says, 'Oh, I'm really pushed today, I've got another four to do', and she's supposed to be there for an hour. Well, I'm hardly going to say to her, 'Well, I want some extra things done today', you know. I'm going to say, 'Right, just do the best you can, the bare minimum and then get off'. But I'm still having to pay for the service at the end of the day. And I don't want to make life difficult for the staff concerned. I mean, it's a management problem at the end of the day. (Holly, first interview)

Holly's perception that Jim was much happier at home than in the care home inclined her to accept the limitations of care in their own home. However, there was a limit to Holly's tolerance. When asked whether she would have to pay for the missed visit by the care worker, she replied:

Well, up to now I've just been turning a blind eye to think it'll get better. This last week, last week and this week, I'm definitely going to be saying to them I'm not paying the full bill. (Holly, first interview)

In the second interview, Holly gave a fuller account of her view of the problems facing the care sector:

That's the one thing about the caring business is that they have lots of problems, basically because of the level of staff. That doesn't mean to say that the staff aren't lovely, they are but they have to have staff who will work for very little, who work shifts, who have families that they have to take care of, they get ill themselves or they're having a baby. That kind of stuff is quite difficult because the pay is so low. In fact, I think that is one of the biggest issues in the care situation is that the people are paid inadequately and so you get a lot of fairly laid-back people or people who are doing it under some kind of situation because they need to work, whether they've got young children, or they've got other things that they have to deal with themselves. So, the level of staff is very kind of below average if you like, they have a lot of sickness ... one of the biggest things in the beginning was that ... there wasn't any continuity. (Holly)

After 'doing battle' with the care agency, Holly acknowledged that 'the continuity is better only because I'm on the phone because I had so many situations where I just thought well this is a waste of time' (second interview).

However, there were limits to her 'battling' and she would not consider changing care agencies as she had no hope that the care would be any better:

I take Jim to a little day centre ... there are people there that you meet, and you ask their experiences and everybody seemed to be suffering from the same thing. Only if you keep on ringing up and nagging, they'd say you know, that the service isn't being provided and threatening that you will go to another and all the time you feel slightly, well I feel sorry for the people who are managing it and I feel sorry for the people who work in it as well ... I have thought of changing it but when I speak to other people, they seem to say the same things as me. (Holly, second interview)

By the third interview, Holly had reached a compromise between asserting her needs with the care agency at the same time as making allowances for the shortfalls:

Somebody coming into your house the whole time, kind of changes your life ... it took a little time to get used to them. One, because they were kind of hit and miss first of all. They weren't coming at the right time. Then they would send different people and I didn't find that easy ... I was trying to hold back, not to complain ... but I found in the end that if you don't say, look this is what I need, this is the time I want it ... but then you have to understand that the number of calls that they get at the last minute, they're always short staffed ... so after I got across the initial thing, having at least some understanding of the kind of work that they have to carry out and that the difficulties they have in fulfilling the jobs ... There are nil-hour contracts ... which is, you know, for a start a really rotten situation. (Holly, third interview)

Similar to Adele's accounts, presented previously, the interviews with Holly illustrate different narrative categories. However, here there is more sense of progression of

themes over time, from one to another. Holly begins as dissatisfied with the care received and attempts to battle to seek better care before eventually becoming resigned as her understanding increases of the inherent problems in the care system.

Kitty

Kitty, aged 82, lived alone, had very limited mobility, and used a wheelchair and a stair lift. Her house was not suited to her needs, *e.g.* she could not access her kitchen because of a step. However, she had lived there for many years and did not want to move. She was not in touch with her family and had to rely on paid care for all her needs. She received care from several different sources, including some care arranged by the local authority.

When we first interviewed Kitty, she was satisfied with her care following a battle with a previous agency about the timing of calls:

I had Care Agency 02 and they went bust. So, Care Agency 03 took over and I'm very, very pleased with them. And they're far superior to the others. Because the others used to come and try and put me to bed at six o'clock at night ... I said 'I can't do it, you know. I'm not going to bed. I'm not ready to go. Get up late and go to bed early. No. I can't.' (Kitty, first interview)

At the time of the second interview, Kitty was mainly satisfied with care when this was provided by her main, regular care worker, but not with the cover provided when this care worker was not working:

I can't fault her [regular care worker] in any way, but if she is away Sunday, you are on that phone all the time asking where the carers are, it is mind blowing. You don't know what's happening, and that's one fault. When you read, 'Oh, we care about people, you just pick the phone up and we will be there for your blah, blah, blah!' You pick the phone up, you are number seven in the queue and then you hang on and hang on, you are number five in the queue. And I mean when you eventually phone and say what you want, 'Oh, she hasn't come.' They don't seem to know anything about why they haven't come. 'Oh, we will get you someone', and it could be 8:20 when they are supposed to come, by the time you ring again about 10:00, 'Is anyone coming?', 'We are getting you someone, someone will be there', you know. And I have to have help getting out of bed you see, so I am lying there until somebody comes and helps me. (Kitty, second interview)

However, Kitty expressed understanding of why the situation arose:

Sometimes she wanted to leave me sitting on the toilet one day, and I said, 'You can't.' She said, 'I have got to go now.' I said, 'What do you mean you have got to go? You can't leave me here like this.' I said, 'You have got to dress me.' 'Oh, I have got to go.' I said, 'You can't go.' Anyway, I phoned up and they said no, they are not allowed to do that; they have to wait until you finish. But she was so upset because you have got to rush, you see they are always in a rush, not their fault. I mean they have been told they have a certain length of time, and they get

everybody on the phone moaning because they are late, me included, you know. If they are late, I phone up as well. (Kitty, second interview)

The competence of some of the care workers was also a concern that Kitty raised with the agency:

I have had some, I have had girls that come to the house, and I am 83, but my goodness they don't know what they are doing. I think where they have got the sense from to have these people, you have to tell them everything ... they have to send people that they have trained for about a week or two weeks. And I phoned up and I said, 'Do you actually give them any training?' 'Oh yes, we train them.' I said, 'Well you ought to give them a bit more training then.' (Kitty, second interview)

At the time of the third interview, Kitty's main battle was with the local authority Social Services which had reduced their financial contribution towards her care, meaning that she had to fund more of the care herself. Her biggest worry was that her savings were rapidly depleting, and she did not know what would happen when she could not afford to pay for her care:

...I'm getting more money out all the while because of paying all these expenses ... I don't know what they're going to do when all my money runs out. I'm getting more out than I'm putting in. Well, I can't save anymore now. (Kitty, third interview)

Kitty faced many environmental challenges because of her lack of mobility, social and emotional difficulties linked to the absence of family support, and financial concerns as she saw her limited savings rapidly dwindling. The predominance of themes of 'battling' to get care to meet her basic needs and 'fears for the future' can be understood in this context of this vulnerability. However, despite her dissatisfaction with the practices of some care workers, she places responsibility on the wider care system that requires them to rush and operate without appropriate training.

Discussion

Some participants in our study expressed satisfaction with care and our findings support other research that highlights the centrality of the quality of relationships in determining experiences of 'good' care (Lewis and West, 2014; Woolham, 2015; O'Rourke, 2016; São José *et al.*, 2016; Leverton *et al.*, 2019; Rodrigues, 2020). Millicent's experience with her regular care workers and Adele's with her live-in carer demonstrated these qualities, at least to some extent. However, accounts of positive experiences of care were often juxtaposed with contradictory perceptions of poor care. The sense of good fortune that underpinned participants' satisfaction reveal that they did not expect good care; as Millicent says, 'you've got to be grateful that you've got a carer coming'. The feeling of gratitude arose *because* good care could not be taken for granted and, even if achieved, could easily be lost if the arrangement broke down or a preferred care worker left.

Timonen and Lolich (2019) identified a key theme of ‘structured ambivalence’ in the attitudes of care professionals towards care workers, that is, structurally created contradictions that individuals experience in their social relations. A similar structured ambivalence can be seen in the narratives of older care recipients, arising from a sense that the care they were receiving was inadequate but the deficiencies in the care system were so entrenched that they felt grateful for what they got and expressed sympathy, rather than blame, towards individual care workers. Timonen and Lolich (2019: 731) noted that the structured ambivalence of care professionals was negotiated by resignation or efforts to change the situation: ‘when individuals experience ambivalence, they have to negotiate it through the use of their agency – this can mean choosing acceptance (inaction) or attempts to alter the situation that is giving rise to ambivalence’.

These two strategies are reflected in our categories of resignation (inaction) and striving (attempts to alter the situation).

Resignation was a common response to unsatisfactory experiences, such as incompetent or untimely care. Participants were aware of inherent weaknesses in the care system, including difficulties with the recruitment and retention of care workers and their low pay and poor employment terms, factors which have been well documented (Hudson, 2019). Adele endured not having care at her preferred time because she realised that ‘everybody wants to get up at the same time’. Holly understood that the care system ‘has lots of problems’ and made allowances for poor care because she realised that care workers were underpaid and often had difficult lives themselves. When care workers told her they were ‘pushed’, she responded by adjusting her own expectations – ‘just do the best you can, the bare minimum and then get off’. She was attuned to and concerned about the difficulties faced by care workers and felt a responsibility not to ‘make life difficult for the staff concerned’, even though she was paying for the care. ‘Making the best of it’ by comparing their care with possible alternatives was another theme within the category of resignation. Thus, part of what helped Holly to resign herself to the limitations of care at home was her perception that Jim was happier at home than he had been in the care home.

‘Striving’ highlights the effort involved to make the care arrangements proceed smoothly, both practically but also in terms of the attention given to the care relationship. For example, Millicent referred to having to put care workers ‘on the straight and narrow’, while Holly tried to look after them. Adele worked hard at trying to manage the boundaries in her relationship with Lily. This related to both the balance between being cared for and being overprotected, and navigating the blurred line between employer and friend. Being a care ‘recipient’ involves negotiating tensions between the needs and preferences of self and those of others. Rabiee’s (2013) research found that for older and disabled people, choices were not rational decisions made based on self-interest, but closely implicated with evaluation of the likely effect on others. Participants often acted in response to their perception of the needs of care workers rather than their own self-interest.

Whilst resignation and striving were strategies used to manage ambivalent attitudes towards care, battling represented a refusal to accept care deficiencies. Battling was sometimes a crisis response or tipping point when the problems presented by poor care could no longer be tolerated. Kitty was totally reliant on care to carry out

basic physical functions so, despite recognising that ‘it’s not their fault’, insisted ‘You can’t leave me here like this’ and refused to be left on the toilet or put to bed hours before she was ready. In other situations, battling was a stage en route to resignation. Thus, by the third interview, Holly’s emphasis had shifted from her dissatisfaction with the poor timing of calls and lack of continuity of staff to ‘having at least some understanding of the kind of work that they have to carry out’ and ‘the really rotten situation’ care workers faced.

The many tensions between care of the body and market-based systems of care provision are highlighted by the concept of ‘body work’ (Twigg *et al.*, 2011). Cohen (2011: 191) defines body work as involving ‘the manipulation or touch of another’s intact body’, further distinguishing ‘body labour’ as ‘body work that is sold for a wage or commodified’. The nub of Cohen’s (2011: 201) argument in respect of body labour is that there is ‘a set of labour process constraints that occur when work takes the human body as its object. These constraints arise out of the intersection between the dynamics of capitalist employment relations and the properties of the body worked-upon’.

The ‘labour process constraints’ Cohen (2011) identifies include the inability to increase efficiency by reducing the ratio of labour to bodies without the body receiving less attention or being made to wait. Cohen (2011: 195) uses the example of care home residents having to wear incontinence pads instead of receiving prompt assistance to go to the toilet: ‘Lacking socio-economic power, residents are unable to characterise their bodily needs as important. Instead, in the context of labour shortages, residents are forced to “learn” to cope with a situation most adults would find intolerable, effectively recalibrating bodily need.’

Cohen (2011) highlights the ‘temporal unpredictability’ of body work, which is also aptly described by Cottam (2021: 26): ‘Care belongs in the world of *kairos* time (measured by flow and connection) as opposed to *chronos* time (the industrial time measured by minutes and deadlines).’

Other issues raised by Cohen (2011) are the need for co-presence of the worker at the times of bodily need and the power differentials between the bodies being cared for and those caring for them. As the body being worked on becomes more dependent, greater temporal control is assumed by the care worker or their employer. There was pressure for Kitty to ‘recalibrate bodily need’ when she faced being left sitting on the toilet to free the care worker to leave for her next call. Despite her status as a paying customer, her numerous telephone calls to the care agency objecting to care workers turning up late or not at all had little impact. Cohen’s final point is that the complexity and temporality of body work is diametrically opposed to the need to the capitalist imperative to standardise tasks. This tension is exemplified in many of our participants’ experiences of care agencies seeking to reconcile their care objectives with the need to survive financially and achieve profit. However, whilst market pressures impel them to standardise, ‘standardisation is inherently dehumanising, because human beings are not standard, not temporally and not physically’ (Cohen, 2011: 201).

Significantly, body labour is also not just ‘body’ labour; it also involves the emotional work of caring ‘about’ (as distinct from ‘for’) people. England and Dyck’s (2011) Canadian study of long-term publicly funded home care noted the interweaving of care workers’ and care recipients’ concerns about ‘care for’ the body

with 'care about' the self. The human interaction between older people and care workers, including sharing interests and concerns, was central in our participants' descriptions of 'good' care. From the opposite perspective, it is possible that lack of continuity of care workers, as described by Holly, for example, leads to more efficient commodified care if it encourages care workers to adopt standardised approaches to caring for the body and distances them from care about the self.

Recent work on precarity, defined as 'the insecurities, unwanted risks and hazards of contemporary life, typically associated with globalization and neoliberal economic and social policies' (Grenier *et al.*, 2020: 2), offers another lens to assist understanding of the impact of a failing care system on older people's lives. Older self-funders in our study led precarious lives both in the structural sense of having to navigate the fault-lines in a fragile care system, and culturally through processes of ageism, including the devaluing of older people and, by association, those who care for them. Older people are rendered frail by social, economic and political conditions which in turn devalue frailty (Grenier, 2020). As well as worrying about certain aspects of current care arrangements, anxieties about the future pervaded all four narrative categories. Many of our participants worried about how they would manage in the future if their care needs increased, their current care arrangements broke down and/or their money ran out. Equally, their awareness of the problems in securing good care meant that they were unlikely to complain or 'exit' unsatisfactory care as they were not confident of achieving anything better.

This level of uncertainty and insecurity seriously undermines the policy aim of enabling people to exercise control over their lives. It is compounded by the precarity of care workers themselves. Holly shows that she is well aware of the precarious situations of care workers in terms of their very poor conditions of employment and the impossible demands placed on them, but also their structural positions as (usually) women juggling family and other responsibilities. Participants devoted considerable thought and effort to managing the care relationship itself and, as 'purchasers' of care, simultaneously cared about those paid to care for them. Adele worried about how the care worker who had left would manage financially and was concerned that her live-in carer, Lily, 'needs a life of her own'. As Rodrigues (2020: 1484) suggests, this may be 'an important way to cement relationships that are valuable but potentially uncertain and asymmetrical'. The concept of precarity illuminates the mutual vulnerabilities of older people, family carers and paid carers (Fine, 2013). Further research is needed on whether and how this shared precarity can form the basis for new forms of intergenerational solidarity (Phillipson, 2015).

One of the consequences of neoliberal social policies is the individualising of risks associated with later life (Phillipson, 2020) and it seems from our study and other research (Kemp and Denton, 2003) that older people have largely accepted responsibility for what were once seen as risks to be managed collectively via the welfare state. It is recognised that agency in 'later later life', or the fourth age, may take different forms to earlier in the lifecourse (Grenier and Phillipson, 2013). Our participants did not perceive themselves or act as empowered consumers exercising choice from a range of options to secure the best care. However, they demonstrated their agency in enacting their own sense of responsibility in relation to care, including in 'training' staff and making compromises and sacrifices to make problematic care 'work'. Particularly notable in the 'striving' category, older people took

responsibility not only for adjusting their needs and expectations to accommodate the care available but also for the wellbeing of the care workers. In this way, older self-funders in our study assumed functions that might be expected to fall within the remit of local authorities or care agencies, reflecting a process of 'responsibilisation', whereby state responsibilities are transferred to service users who regulate their own behaviour to accord with political objectives (Peeters, 2019). In the domestic space of the home, it is the individual care worker who has to manage time and tasks (Twigg *et al.*, 2011) and the older person directly engaging with the care worker who feels responsible for their wellbeing and workload. This is even to the extent of compromising their own needs which they may be paying the care agency high costs to meet.

Limitations

The narrative excerpts presented here are all from interviews with White women so differences by gender and ethnicity have not been considered. A limited number of transcripts were selected for detailed narrative analysis due to time constraints and further selection has been necessary for this paper. Our aim is not to re-present all the experiences relayed to us but to identify transferable messages from analysis of selected transcripts. We acknowledge that an important missing dimension in the analysis presented here is the influence of co-researchers' involvement in the co-production of knowledge (Littlechild *et al.*, 2015). This has been beyond the scope of this paper but merits examination.

Conclusion

This paper offers new understanding of how older people who are paying for care construct and present their experiences. A key finding is the level of acquiescence about receiving care that falls far short of meeting their needs. This is particularly striking in the context of the sometimes very large sums of money they are paying for it. This can be understood in the context of incontrovertible tensions between values of care and its delivery through market mechanisms governed by economics (Ward *et al.*, 2020b). The pursuit of efficiency and profit run directly counter to the conditions needed to generate good care (Tronto, 2013), not least because the nature of body labour is itself incompatible with a commodified care system (Cohen, 2011). Older people whose lives are vulnerable to loss and change anyway because of processes such as age-related impairment, bereavement and loss of social support, become more so because of the in-built precarity within the care system. In this context, it is older self-funders and their carers who are accorded the risks and responsibilities associated with finding and managing care in a care system that is failing and unsustainable (Glasby *et al.*, 2021).

A second original contribution of our analysis is understanding of why older self-funders are so accepting of the seemingly unacceptable. Their narratives connect the personal (biography) and the political (social structure) (Riessman, 2005); it seems that their own experiences of purchasing and managing care equip them with a realistic understanding of the tensions, limitations and contradictions in the current system of funding and providing social care. Older self-

fundors orient themselves to these ambiguities and deficiencies when making sense of and managing their experiences. Although the system itself is based on market principles of individual consumerism, older care-receivers are relational in their own care interactions, making allowances for care deficits and showing sympathy and concern for care workers. They demonstrate agency in taking on responsibilities to help make the system ‘work’ for them and their care workers. Frank (2012: 49) suggests that stories are not just told but also imposed on people, and poses the question: ‘How well served are people by their stories?’ A strong storyline for our participants was, ‘the care system care is in crisis so you can’t expect good care’. At a personal level, this helped them to tolerate unsatisfactory care, but the social function of this story is to encourage older people to make allowances for poor quality care, accept compromises and deter them from complaining, thus allowing poor care to continue unchallenged.

A key implication from older people’s narratives of self-funding is the need for greater investment in the care sector to ensure the recruitment and retention of a trained, competent and compassionate workforce with time to care (*see also* Lewis and West, 2014; Beech *et al.*, 2019). It is difficult to see how this can be achieved in a market-based system with its in-built tension between quality and cost. If the only feasible means of increasing the profitability of care work is by making the work more routinised and intensifying its pace, this presents inevitable risks for its quality, effectiveness and humanity (Lolich, 2017).

An analysis of adult social care policy and practice since 2010 highlights ‘a lost decade’ in terms of the potential for reform and highlights the disproportionately adverse impact on older people, including in the level of unmet need, increase in self-funding and poor quality of care (Glasby *et al.*, 2021: 427). Alternative funding models have been proposed, based on evidence that the current system is neither safe nor sustainable (Bottery *et al.*, 2018). A White Paper on the reform of adult social care (Department of Health and Social Care, 2021) (now the Health and Care Act 2022) has been critiqued for failing to dedicate sufficient funding to address core issues such as the level of unmet need, instability in the care market and inadequate pay for care workers (Local Government Association, 2021). These are political choices. If the central component in quality care is the nature of relationships between all parties in the caring network, attention is needed to the funding, structures and processes that support the exchange of care that is attentive, responsible, competent and responsive (Tronto, 2013).

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