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"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 the UK

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Key words:

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.

This 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 the 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 considers the broader significance of the analysis.

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 Coronavirus pandemic (Foster, 2020). It is estimated that central government funding to local councils 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

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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). 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.

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). National Audit Office (NAO) (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 (Laing and Buisson, 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 2015-16 for UK Household Longitudinal Survey (UKHLS), 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 (NAO), 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 (ADASS), 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 (Laing Buisson, 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*., 2020). A key factor is the lack of information and support for their decision-making. A report by Competition and Markets Authority (CMA) (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. Baxter *et al*.'s (2019) research 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 Heavy *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 CMA (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).

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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 neo-liberal 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 UK, 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 – 95, although the majority were over

85. They identified their ethnicity as White British (62), Asian (1), White Irish (1) and White European (1).

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 (Authors, 2020).

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.

Narrative analysis

As a secondary process of analysis, we used narrative analysis to complement the fragmentation and decontextualization of experience produced from coding and enrich 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: for example, whether the older person was interviewed alone or with a

  partner or family member, or anything significant about the timing of the interview

- 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

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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 described in more detail below.

Figure 1: Narrative categories

SATISFIED	RESIGNED
grateful	making the best of it
feeling fortunate	making allowances
care as friendship	being pragmatic

STRIVING	BATTLING
trying to maintain control	fighting the system
taking responsibility	sense of injustice
concern for carers	expectation of better

Fear for the future

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 carers 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'.

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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.

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) (1)[1]

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?*

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[1] The number refers to the interview (1st, 2nd or 3rd).

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 carers (Lily)

provided a significant amount of live-in care. Adele presented as being satisfied with her

care arrangements and spoke positively about the three carers and their responsiveness to

her needs:

Adele: …. 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. (1)

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. (1)

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.

The process of finding and arranging care reflected narratives of both 'striving' and

'battling'. Adele had always been risk-averse and talked of taking out insurances on

household items to remove the worry if anything went wrong. She had taken the same

approach to planning for her care.

Adele: I decided that I would like to be taken care of in my own home when I couldn't care

for myself anymore, so from the time I was 60 I paid into this insurance every month,

and then when I felt I couldn't care for myself properly anymore, I had to get in touch

with them and they came and assessed me … and agreed that I could have help, in

mornings mainly ... So I've always been one for planning ahead and trying to cover

every eventuality, so that's what I did. (2)

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:

Adele: 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.

(1)

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 carer, and the carer who did the morning call, with each complaining about the other so that Adele felt 'caught in the middle'. Adele expressed a sense of responsibility towards the carers. Despite her status as employer, she worried about telling the carer that she wanted her to leave. After the carer left of her own volition, Adele worried about the impact on the carer's income:

Adele: …she (the carer) 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 it … .so 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. (3)

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 carer space for her own life.

Adele: 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. (2)

Adele made efforts not to rely on Lily too much:

Adele: 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 and

that I feel she tends to…

Lily: I'm too protective...

Interviewer: *And how do you feel about that?*

Adele: Yes. I feel, um, don't know what the word is. I do feel overprotected. She doesn't let

me do things … she just is overprotective. (2)

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.

Adele: 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, 5 days? (3)

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:

Adele: 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

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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. (1)

Another anxiety about the future concerned the implications if her pivotal relationship with

Lily broke down:

Adele: 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. (2)

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:

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Holly: I wouldn't say I was anywhere near 100per cent, or even 70per 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 (1)

Holly found it difficult to complain about the care as the carers '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.

Holly: … 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. (1)

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 carer, she replied:

Holly: 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. (1)

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

Holly: 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.

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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' (2).

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:

Holly: 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 … they're always rushing to get away to the next place, so they are, so yeah, I have thought of changing it but when I speak to other people, they seem to say the same things as me. (2)

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.

Holly: 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

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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, if you like, because of the

staff … they're working Christmas Day, it's just – they all have to take their turn kind

of thing … they don't get extra time… they don't get extra money … There are nil

hour contracts … which is, you know, for a start a really rotten situation. (3)

The problematic issue of the carer arriving too late in the morning to give Jim his shower

had not been addressed but Holly had revised her expectations. She tried to make the care

arrangements work by assuming some responsibility for 'taking care of the carers':

Holly: By the time they come, I'm pretty well done. I don't expect any major work done,

              unless there was something really the matter … Yes, I make a point of talking to them,

              because if I need them, I need to have somebody that's good, that I can depend on – so

              if they're happy with me making them a cup of tea and whatever else, then that's what

              I'll do, yes. (3)

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; for example, 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:

Kitty: 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. And I'd say, "No I don't want to come to bed." So, they kept saying, "no we'll come later and later" but the girls kept coming and coming. 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." (1)

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

Kitty: I can't fault her (*regular carer*) 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. (2)

However, Kitty expressed understanding of why the situation arose:

Kitty: 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. (2)

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

Kitty: 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'.(2)

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:

Kitty: … 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. (3)

Discussion

Although older self-funders in our study needed care because of high level physical and sometimes cognitive needs, they were required to find and arrange this within a system that (mis)represents care as a commodity that can be chosen, purchased, consumed and rejected if unsatisfactory.   Tronto (1993) sees good care as embodying: attentiveness to the care needs of others; acceptance of responsibility for meeting them; competence in how care is given; and responsiveness to the impact of that care. In contrast, some of our participants learned that: their care needs and preferences would not be attended to; they would have to strive and/battle for agencies to meet basic responsibilities they were paid to deliver; some care would be incompetent; and care agencies would have little interest in or ability to hear or respond to their experiences. Rather than choosing from a range of options to secure the best care, they accepted weaknesses in the limited care available whilst worrying about what would happen in the future if the care arrangements broke down, their care needs increased and/or financial resources depleted. However, they themselves were relational in their orientation to individual care workers and made sense of these

encounters in the context of their understanding of deficiencies within the care sector and

the hardships endured by workers.

There were examples of participants expressing satisfaction with care and our findings

support other studies that highlight the centrality of the quality of relationships in

determining experiences of 'good' care (Lewis and West, 2014; Woolham, 2015; São José *et

al*, 2016; Leverton *et al.*, 2019; Rodrigues, 2020). Millicent's experience with her regular

carers and Adele's with her live-in carer demonstrated these qualities, at least to some

extent. However, the feelings of gratitude and 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 carer

changed.

Contradictory experiences and perceptions of 'good' and 'bad' care are discernible within

older people's accounts. Timonen and Lolich (2019) identified a key theme of 'structured

ambivalence' in the attitudes of care professionals towards care workers, defining this as

structurally created contradictions that individuals experience in their social relations. They

note:

> …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 (p.731).

A similar structured ambivalence can be seen in the narratives of older care recipients.

This ambivalence is negotiated by resignation (inaction) or efforts to change the situation (striving). 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 carer workers were underpaid and often had difficult lives themselves. When carers 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. Awareness of the problems in securing good care meant that participants were unlikely to complain or 'exit' unsatisfactory care as they were not confident of achieving better.

'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. Striving reflects a process of 'responsibilisation', whereby state responsibilities are transferred to service users who regulate their own behavior to accord with political objectives (Peeters, 2019). Older self-funders in our study assumed functions that might be expected to fall

within the remit of local authorities or care agencies. For example, Millicent referred to

having to put care workers 'on the straight and narrow' while Holly tried to look after them.

Adele also played an active role in her concern for her carers; she worried about how the

carer who had left would manage financially and she worried that her live-in carer, Lily,

'needs a life of her own'. She also had to work hard at trying to find the right balance in her

relationship with Lily. This related to both the balance between being cared for and being

overprotected and navigating the blurred line 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 acted in response to their perception of the needs of

care workers. They devoted considerable thought and effort to managing the care

relationship itself and as 'purchasers' of care, simultaneously caring about those paid to care

for them. As Rodrigues (2020: 1484) suggests, this may be 'an important way to cement

relationships that are valuable but potentially uncertain and asymmetrical'.

Although resignation and striving were strategies used to manage limitations in care

arrangements, there were situations in which participants presented themselves as battling

against these deficiencies. Battling was sometimes a stage en route to resignation if

grievances could not be resolved, or it was a crisis or tipping point when difficulties became

unmanageable.   Adele was contesting the local authority's decision that she was not

financially eligible for state support while both Holly and Kitty asserted their need to have

visits at specific times. Despite understanding the difficulties surrounding care provision,

they reached a point where the care limitations could not be tolerated. Holly had been

'turning a blind eye' but learned over the course of the study that 'continuity is better only because I'm on the phone'. 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 be left on the toilet or put to bed hours before she was ready. Her experience is a stark illustration that it is often not the mechanism of having choice of provider that matters to older people but what this delivers in terms of care outcomes (Fitzgerald and Kelly, 2019).

Anxieties about the future pervaded all the other 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. Whereas Adele expressed her worries as, 'What'll happen in the end I don't know', I'll just have to go into my savings', according self-responsibility for the problem, Kitty phrased this as, 'I don't know what *they're* going to do when all my money runs out', perhaps because the local authority was involved in paying for some of her care. Both expressions convey uncertainty, anxiety and insecurity, seriously undermining policy aims related to facilitating people to exercise control over their lives. It highlights the need for the provision of comprehensible and trustworthy information about care eligibility and funding (Kumpunen *et al.*, 2019).

From Frank's (2012) standpoint of dialogical narrative analysis, we can view stories as being not just told but imposed on people; this then begs the question, 'How well served are people by their stories?' (p.49). The stories people tell are 'a dialogue of imaginations', but

'this dialogue is real in its consequences for how people act' (p.50). A strong story line for all

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 'resigned' story is to encourage older people to make allowances for poor quality care,

make the best of it and deter them from complaining.

Care has to be understood within a relational context (Breheny *et al.*, 2020). In common

with other studies, our research has highlighted the need to understand and evaluate care

in terms of the interpersonal dynamics within caring relationships (O'Rourke, 2016;) since

the nature and quality of these relationships is a fundamental in determining experiences of

the quality of care (Walsh and Shutes, 2013: 402). The narratives of older self-funders in

our study show that they perceived and experienced care as relational, even though the

system delivering their care was individualised and consumerist. Our participants largely

accepted the deficiencies in the care delivered to them through market mechanisms

because their orientation to care was relational and not consumerist. They were interested

in the lives of carers as people, outside of their caring roles, understood and sympathised

with the difficulties experienced by the carers, strove to mitigate or work around these and

only complained when there was no other option.

Given that all parties to care interactions have a part to play in how care is transacted and

experienced (São José, 2020), it is necessary to consider the perspectives and experiences

of front-line care workers and to recognise and value their individual identity and agency

(Fine, 2013). Miller and Barrie (2020) revealed the complexity of 'basic' care work in the

context of care homes and the tensions between what front-line carers know is good

practice and the constraints imposed by their working conditions and requirements. Baines

and van den Broek (2017) describe the actions of social workers and care workers in bleak

terms:

> In a form of indirect coercion or quiet neglect, workers act, often reluctantly, as conduits of the
>
> austere state, providing variable care to increasingly frustrated and desperate service users.
>
> (p.136-7)

Although our focus is predominantly care workers in the private sector, the state exerts

arms-length control (Baines and van den Broek, 2017) through local authority

commissioning of private agencies and, more broadly, through the underfunding of the

sector, one of the consequences of which is the higher fees paid by private clients to

subside underfunding by the state (CMA, 2017). We have argued that the ambivalent

attitudes towards care workers evident in the narratives of older self-funders is 'structured

ambivalence' (Timonen and Lolich, 2019) in that it originates in the wider structural and

organisational context. Therefore it can only be addressed by radically changing the

structures that generate the ambivalence, including the status and conditions of paid

carers.

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

Narrative analysis of interviews with older people who are self-funding their care reveals

what neoliberalism produces in practice, that is, incontrovertible tensions between values of

care and its delivery through market mechanisms governed by economics (Ward *et al*,

2020). This is unsurprising since the pursuit of efficiency and profit round directly counter to

the conditions needed to generate good care in the terms conceived by Tronto (1993),

discussed earlier.

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.

A second original contribution of our analysis is understanding of why older self-funders are

so accepting of the seemingly unacceptable. 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.

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They 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. These narratives help them to tolerate shortfalls in care and accept compromises, but also discourage withdrawal from unsatisfactory care and deter complaints, allowing poor care to continue unchallenged.

Our participants' representation of their experiences of self-funding in interview narratives help to make connections between the personal (biography) and the political (social structure) (Riessman, 2005). They manage the 'structured ambivalence' within their accounts by resigning themselves to care limitations or by making efforts to compensate for deficiencies in the care system. The latter reflects the 'responsibilisation' of individuals inherent within neoliberal policy .

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).

Alternative funding models have been proposed, based on evidence that the current system

is neither safe nor sustainable (Bottery *et al.*, 2018). It is salutary to remember that current

systems are not a given but a political choice. Duffy and Peters (2019) propose new ways of

thinking about social care and put forward strong arguments for fully funded social care. 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.

Statement of ethical approval

Approval was obtained from Health Research Authority Social Care Research Ethics

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