

ARTICLE

# Care chronicles: needing, seeking and getting self-funded social care as biographical disruptions among older people and their families

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(Accepted 18 March 2022; first published online 8 June 2022)

## Abstract

Social care to assist with the activities of daily living is a necessity for many older people; while informal care provided by family members can be a first step to meeting care needs, formal care provided by professionals is often needed or preferred by older people and their families. In England, the number of older people paying for formal care is set to rise, driven by an ageing population and the limited resources of local authorities. Little is known about how older people and their families experience the potentially disruptive processes of deciding upon, searching for and implementing such care, including the financial implications. This paper explores accounts of seeking self-funded social care in England, told by older people and their families in 39 qualitative interviews. These accounts, which we call ‘care chronicles’, include stories about the emergence of care needs and informal care-giving, the search for formal care, including interacting with new systems and agencies, and getting formal (paid) care, either as the recipient or an involved family member. Stories are analysed through the lens of biographical disruption, and analysis demonstrates that such disruptions can occur for older people and their families across the entirety of the care chronicle. Needing, seeking and getting care all have the potential to cause practical and symbolic disruptions; moreover, these disruptions can be cumulative and cyclical, as attempts to resolve or minimise one disruption can lead to new ones. While the concept of biographical disruption is a mainstay in medical sociology, it is less frequently applied to issues relating to social care, and most often takes embodiment as a key focus. This study is novel in its application of the concept to experiences of seeking self-funded care, and in its introduction of the concept of ‘care chronicles’, which invite a longer and broader view of biographical disruptions in the lives of older people with care needs and their families.

**Keywords:** social care; self-funders; older people; biographical disruption; narrative

## Introduction

Social care involves assisting with activities of daily living, helping to maintain independence and social interaction, and protecting those in vulnerable situations. In contrast, health care relates to the treatment, control or prevention of illness, injury or disability. Social care may take place in one's own home (domiciliary or home care) or in appropriate supported accommodation, such as a care home (residential care). For many, social care becomes a necessity in later life. In 2018, 27 per cent of adults in England aged 65+ and nearly half (47%) aged 80+ needed help with activities of daily living such as bathing and eating (Marcheselli and Ridout, 2019). Twenty-six per cent of adults aged 65+ needed help with activities related to living independently, such as routine domestic tasks (Marcheselli and Ridout, 2019). In the context of an ageing population, the number of older people needing social care in England is set to rise (Kingston *et al.*, 2018; Office for National Statistics, 2019).

While health care in England is provided free at the point of use through the National Health Service (NHS), social care is not. Most professional (formal) social care is provided by independent organisations, including major national companies and voluntary organisations, and smaller local businesses and charities. The cost of such care varies significantly. The Homecare Association, the United Kingdom (UK) industry body for domiciliary care providers, recommends domiciliary care fees start at £21.43 per hour (Angel, 2020), while the cost of a care home place varies from a few hundred pounds to well over a thousand pounds a week (LaingBuisson, 2017). In England, adults are entitled to have their care needs and finances assessed to determine whether they qualify to have their care costs paid by their local authority (Care Act, 2014). Currently, a person with more than £23,250 in assets (including the value of their home in certain circumstances) does not qualify and must 'self-fund' their own social care costs. Local authorities are obliged to offer information and advice on care options if requested, or self-funders may arrange their care directly with care providers, without local authority input. Estimates vary, but suggest that self-funders pay for between 36 and 46 per cent of care home places in England and around 30 per cent of domiciliary care hours (ICF Consulting, 2018; Office for National Statistics, 2021). The number of self-funders appears set to increase, as austerity measures limit the resources of local authorities and needs assessments become more stringent (Humphries *et al.*, 2016; King's Fund, 2018).

Family and friends often provide social care on an unpaid, informal basis, instead of or in addition to paid care. In 2019, around 17 per cent of adults in England provided unpaid care to another adult, mostly family members and spouses (Ashford and Hill, 2020). Alongside non-statutory organisations such as charities, friends and family are also a key source of advice and support when older people do choose to search for self-funded formal care (Heavey *et al.*, 2019). Rising demand for adult social care is likely to put increasing pressure on those who take on these informal supportive roles (Economic Affairs Committee, 2019). This paper will explore the complex and interwoven experiences of older people with care needs and the family members who support them in their search for self-funded formal care, taking a particular focus on the biographical disruptions this search can elicit.

### ***Illness, ageing and biographical disruption***

Bury (1982) argued that chronic illness disrupts the individual's normal behaviours, prompting them to rethink assumptions, self-concepts and expectations for the future, to recognise previously distant possibilities of suffering and death, and to re-examine personal relationships. To minimise such disruptions, people 'mobilise resources', e.g. rearranging their usual habits or seeking help from friends and family. Bury's (2001) later work suggested that people also use narrative resources to minimise disruption and 'normalise' illness (*cf.* Williams, 1984). In the decades since, Bury's concept has been applied to many varied conditions and illnesses, with most studies maintaining a focus on chronic illnesses. Of particular relevance to this study, ageing and familial care have emerged as themes – albeit often peripheral themes – within the literature.

In his original paper, Bury (1982: 171) suggested that rheumatoid arthritis is more disruptive for younger people because it is seen as 'a disease of the elderly'. Since then, various studies have suggested that older people may not experience illness as disruptive in the same way as younger people, especially illnesses perceived as a normal or inevitable part of ageing, such as stroke (Pound *et al.*, 1998; Faircloth *et al.*, 2004), osteoarthritis (Sanders *et al.*, 2002) and late-stage chronic kidney disease (Llewellyn *et al.*, 2014). Williams (2000: 51) argued that age (along with socio-economic hardship) could be a mediating factor which led to illness being 'biographically *anticipated* rather than ... disruptive'. Faircloth *et al.* (2004) use the term 'biographical flow' to describe this 'normalisation' of illness in the context of older age. Conversely, recent studies have found that illness and impairment in later life *can* be biographically disruptive, even if conditions are anticipated, such as frailty and mobility impairments (Korotchenko and Hurd Clarke, 2016; Lloyd *et al.*, 2020). Indeed, Larsson and Grassman (2012) suggest that growing old with a chronic condition may *exacerbate* the biographical disruption caused by that condition. Our study will explore such tensions, highlighting the relevance of both biographical disruption and flow to care needs and care associated with ageing, and considering how the two – disruption and flow – can intersect.

Bury (1982) noted that social networks have the potential to increase or decrease the disruptions associated with chronic illness; more recently, Bell *et al.* (2016) showed how the disrupted biographies of people living with illness were shaped by the life events of 'linked others'. Although still relatively rare, other studies have focused on how those within these networks can experience biographical disruption. Family members – and particularly family care-givers – can bear witness to another's biographical disruption and experience their own disruptions and identity losses, as their activities with and relationship to the ill person change (Karner and Bobbitt-Zeher, 2005) and their anticipated futures together are altered or cut short (Adamson and Donovan, 2005; Locock *et al.*, 2009). Spouses, in particular, may mobilise their own resources to minimise such disruptions and enable a sense of continuity, both for themselves as individuals and for the 'biographical we' of their partnership (Aasbø *et al.*, 2016). Family care-giving can also be normalised within a care-giver's biography: experienced not as a disruption but as a natural continuation of the relationship (Adamson and Donovan, 2005). Outside the biographical disruption literature, evidence on the impact of family care-giving

highlights similar themes. A review of the literature shows that family care-giving can erode the care-giver's previous identities, including the relational identity to the person being cared for, but that the care-giver identity can also be normalised as an extension of the previous familial relationship (Eifert *et al.*, 2015). Research on care-giver burden and coping strategies further suggests that, while problem-focused coping such as employing paid carers is associated with positive outcomes (Hawken *et al.*, 2018), family care-givers might avoid paid care for reasons including guilt, aversion to or mistrust of paid carers, the hassle involved and lack of knowledge about services (Winslow, 2003; Brodaty *et al.*, 2005; Carpentier *et al.*, 2008). Our study will build on this literature, addressing family members' and spouses' experiences of biographical disruption in the contexts of witnessing care needs and providing informal care, as well as their experiences of facilitating formal care. Moreover, we will demonstrate that biographical disruption and flow, as experienced by older people and their families, are deeply embedded within and impactful of one another and suggest that attempting to disentangle them might not always be possible or desirable.

Despite the number of studies deploying the lens of biographical disruption, we are aware of no studies that apply it to experiences of *seeking* social care, nor any that take a specific focus on experiences associated with self-funded care. Moreover, studies focusing on aspects of later-life illness or care usually limit their focus to a single aspect (*e.g.* a particular illness or the provision/receipt of care), and studies in general tend to emphasise embodied aspects of illness and care (Engman, 2019). In this paper, we begin to address these gaps, exploring biographical disruption within experiences of needing, seeking and getting self-funded later-life social care, from the perspective of older people and their families. In addition to building on the literature in the ways outlined above, this paper makes two key contributions. First, it highlights the specific biographical disruptions associated with seeking self-funded social care; second, it draws together the multiple interlinked 'phases' of needing, seeking and getting care, as experienced by older people and their families, demonstrating ongoing, cumulative and shared experiences of disruption. We introduce the term 'care chronicles' to capture the interrelated collections of stories that convey these complex experiences.

## Methods

Data were collected as part of a study exploring how self-funders access the information needed to arrange formal social care. The larger study included 40 interviews with members of the public who had experience of seeking such information and 24 interviews with relevant professionals. In this paper, we limit our focus to 39 interviews with members of the public; one interview was excluded because the focus was on care for young adults. Because older self-funders often rely on friends and family to help them find information about care (Baxter *et al.*, 2017; Heavey *et al.*, 2019), we interviewed people searching for information for themselves or for someone else. Participants were offered the opportunity to have someone else present in the interview; four chose to invite a co-participant (someone who had been involved in their search), making the total number of participants 43. Dyads were either an older person and a family member ( $N = 2$ ) or two

family members searching on behalf of the same older person ( $N = 2$ ). While it is beyond the scope of this paper to offer an in-depth comparison of the care chronicles told by the different groups, the sample does allow us to explore different – yet heavily intersecting – perspectives on the search for care.

Participants were recruited from different parts of England through local authorities, voluntary organisations and care providers. Purposive sampling was used to capture maximum variation in age of the person with care needs, level of support needs/type of care sought and location (urban or rural). Twelve participants (nine women and three men, aged 62–92) had sought information about care for themselves. Thirty-one (22 women and nine men, aged 49–83) had sought information on behalf of a spouse or relative (aged 77–95), usually while acting as an informal carer. Semi-structured interviews were conducted by the lead author and focused on experiences of seeking information about self-funded social care. Twenty-six interviews were conducted face-to-face in participants' preferred location (usually their homes); 13 were conducted by telephone. While there can be a moderate loss of data depth in telephone interviews (Irvine, 2011), the choice was offered to encourage participation, particularly among those with busy caring schedules. Participants were given an information sheet and the opportunity to ask questions about the study, and informed consent was obtained. Thirty-eight interviews (with 42 participants) were audio-recorded and transcribed. One participant did not consent to be audio-recorded, and notes were taken during the interview. To protect anonymity, codes were assigned to participants and later replaced with pseudonyms.

As part of the initial analysis within the larger project, interview data were analysed using the framework approach (Ritchie and Spencer, 1994) to explore the 'journey' and challenges of seeking information about self-funded care. Initial coding revealed that, in addition to detailed discussions of seeking information about care, participants told many rich stories about earlier and later 'phases' in this journey. These included stories about emergent care needs and experiences of informal and formal care-giving, whether as a recipient or an involved family member. Stories of disruption and upheaval were common throughout, leading to the decision to analyse the data through the lens of biographical disruption. Data were searched by the lead author for apparent instances of biographical disruption and/or strategies to minimise or repair it. Initial codes were 'data-driven' (Braun and Clarke, 2006), describing each segment of data in detail. Codes were organised into themes according to the nature of the disruption/repair and the phase of the process at which they occurred (*i.e.* needing care, seeking care, getting care). Coding reports were read by the other two authors, disagreements discussed and themes refined iteratively.

## Findings

Participants told multiple connected stories which, taken together, gave accounts of how the search for formal care came about, how it unfolded, and how and why care was eventually arranged or not. Borrowing from De Fina's (2003) study of migration narratives, we use the term 'care chronicles' to describe these accounts. De Fina (2003: 98) describes 'chronicles' as collections of stories told over the course of an

interview that relay a series of temporally and spatially ordered events. Chronicles 'do not need to have one specific point', but instead 'give an account of how a certain state of affairs was brought about' (De Fina, 2003: 98). Whether or not participants' care chronicles involved spatial moves (e.g. from the family home to a care home), all involved transformations of circumstance. They commonly portrayed these transformations as a series of interlinked biographical disruptions – and at times instances of flow – in the lives, selves and expectations of older people and their families. While the two groups offered different perspectives on events, their stories often overlapped in terms of themes and were highly intertwined.

For the sake of clarity, findings are structured into the three phases of the care chronicle. This does not imply that these phases always occurred linearly or that they are entirely discrete. Care chronicles could include phases that overlapped or repeated, some did not begin with the emergence of specific care needs and some did not conclude with the implementation of formal care. Some included anticipated, as well as realised, events. The most detailed analysis is presented in the 'seeking' phase, because this represents a new application of the concept of biographical disruption, whereas the disruptions found in the 'needing' and 'getting' phases present forms of disruption described in previous literature. However, it was important to include all three phases in our analysis to demonstrate the interlinked nature of disruptions and repair that occur over the course of care chronicles.

### **Needing care**

Care chronicles describe a shift towards (the possibility of) formal care. As such, they usually begin with the emergence or anticipation of care needs. Most of our participants had sought information in response to specific needs; these needs were linked to a variety of conditions, including dementia, falls, macular degeneration and gradually increasing frailty. Whatever the specifics of the illness or condition, participants reported various ways in which emerging care needs disrupted the older person's normal routines and behaviours. Bedtimes or mealtimes became earlier as the older person slept more; physical impairments made certain domestic tasks impossible or necessitated the relinquishment of once-loved activities and hobbies. Beyond the disruption of routine, there were knock-on effects for the older person's self-concept – or the family member's concept of the older person. When care needs began to necessitate family care-giving, older people's and family members' worlds became more interdependent and new forms of disruption emerged.

Sarah, 65, had searched for care on behalf of her mother, June, 91, who had vascular dementia and had suffered a series of strokes. Sarah's care chronicle was replete with stories about June's escalating care needs, which resulted in what Sarah referred to as her mother's 'shrinking world':

She was fairly independent; she came [to live with me] with her car which she refused to give up, but hardly drove it and it's now been sold ... increasingly over the last sort of 18 months or so, perhaps a bit more than that, she's been doing less and less, becoming more frail ... like being a great cook, loving cooking, she doesn't cook at all [now] ... She's always got up and got dressed, put her

lipstick on, her *eau de cologne*, you know, brushed her hair, looked smart ... those things don't matter to her now ... Going to the local pub, having meals out ... she was a very, very sociable woman, those things have stopped.

Sarah described a series of losses, linking June's gradually increasing care needs to the loss of various social identities that she had once cherished. Notably, family members tended to tell such stories about their older relatives' care needs much more than older people told such stories about themselves; it may be that older people put less emphasis on their own losses to save face and maintain their preferred identities. However, some older people did express frustration, embarrassment, and a sense of being limited or diminished by their own care needs. Nancy, 66, had kidney problems which left her in severe pain. She was interviewed in her home, and explained how her medical condition affected her usual domestic routine:

[Changing the bedsheets is] an absolute nightmare and it can take me three hours, and in fact my housework in here hasn't been ... let's say, not out of choice. If I had a choice and I had the health it'd be a lot smarter and better and more, it'd be more organised, but because of health ... it's knocked me sideways a bit, and that. So, in a way you've come at a good time, but in a way an embarrassing time for me.

In expressing her embarrassment and emphasising that her home's current state did not reflect how she would usually live, Nancy acknowledged a preferred identity as houseproud, perhaps with attendant implications about her personal hygiene, capability and self-sufficiency (*cf.* Williams, 1993). Her care needs interfered with her ability to maintain her home to her own standards, thus disrupting this identity.

Some participants framed emerging care needs and associated losses as a normal part of ageing. Lucy, 58, had provided extensive care for her mother Grace, 87, and her late father-in-law, Arthur. Reflecting on their lives, she said:

Realistically they've all lived good long lives but life, at the other end, is basically the reverse of what happens in the beginning. In the beginning you eat, poop and sleep, basically, as a new-born baby, and older, extreme old age is like going back into that state where everything's unwinding.

Lucy suggested that returning to a state of dependence and reduced activity – what Sarah called a 'shrinking world' – is inevitable if a person lives long enough. Such reflections on 'biographical flow' were rare and usually brief in our data, coming in the context of longer care chronicles which almost always included stories of disruption. Lucy herself told many stories of her relatives' losses, as well as her own struggles in providing care; she made multiple daily visits to their homes, until eventually both relatives moved into Lucy's home.

### ***Mobilising family resources and the emergence of new disruptions***

Like Lucy, many family members told care chronicles in which the emergence of an older person's care needs was inextricably linked to informal family care-giving, ranging from help with domestic and administrative chores to round-the-clock

assistance with eating, dressing and washing. Beyond simply ensuring their loved one was healthy and safe, family members frequently framed such care-giving as an attempt to keep things 'normal' for the older person and the family. Jessica, 54, told a care chronicle focused on her father-in-law Bobby:

My partner and his sister realised that we had to start thinking about doing something because it was getting to the extent that [Bobby] couldn't even feed himself, and we didn't know what to do, and obviously the last thing we wanted to do was put him in a [care] home, so what we decided to do was try and look after him.

Jessica went on to explain that Bobby 'would much rather we look after him than total strangers'. This reaction to emerging or worsening care needs was typical among family members, with several emphasising the normalness and naturalness of family care and contrasting it with the strangeness and unnaturalness of paid care. In addition to maintaining continuity of a familiar environment and familiar faces for the older person, family care was often described as more in keeping with the previous family dynamic. Caring for a spouse, in particular, was presented as a natural continuation of a long and mutually supportive partnership.

Yet, in turn, the provision of informal care could lead to disruption for the family care-giver. Particularly when high-intensity care was needed, participants who had taken on caring responsibilities described radical changes to their own lives. Some found themselves unable to engage in their usual activities, including socialising, hobbies and running errands. Some cut down their working hours or stopped work altogether. Mirroring the disruption care needs could cause to the older person, care-giving responsibilities could represent identity blows for family members, with several describing their own lives as having been entirely subsumed by these responsibilities. Despite potential reservations, all our participants at least sought information about arranging formal care at some point, sometimes prompted by such strains. Family members were often at pains to point out that formal care was not a preferred option, explaining that the older person's escalating needs and/or the family member's own diminishing ability to cope as a care-giver forced them to seek outside help. Jacqueline, 62, had cared for her mother at home for eight years due to a variety of care needs; after 'putting it off and putting it off and putting it off', she finally started looking for residential care:

When her dementia got a lot worse and her anxieties got a lot worse and her incontinence, and her falling. Actually, all of them seemed – she suddenly seemed to deteriorate. So at that point my brother, who used to be our main respite, said 'I actually can't do this anymore' ... And my partner was ready to stop caring really, I think, because it was all getting a bit much. We couldn't get out of the house for more than half an hour at a time really. So at that point we needed to look for a care home for her.

Jacqueline's story was typical in the care chronicles of family members, in that seeking formal care was not usually framed as a 'natural next step' in response to emerging care needs (the way informal care could be). Rather, it tended to be a secondary, often long-delayed mobilisation of resources in response to the otherwise



insurmountable disruptions of the older person's needs and the knock-on disruptions of providing informal care.

### **Seeking formal care**

The search for self-funded later-life care can be complicated, involving engagement with multiple agencies and difficulty finding necessary information. Many care chronicles were dominated by stories about such difficulties. More than mere inconvenience or dissatisfaction, these stories expressed profound biographical disruptions for older people and families. Seeking care was experienced as entering a new and unfamiliar world, entailing losses of face and losses of control; as participants became familiar with how that world worked, they lost faith in a once-trusted system and questioned their own moral choices.

### **Entering an unfamiliar world**

Embarking on the search for formal care meant entering a new world: one of unfamiliar systems, language and gatekeepers. For many participants, their search was the first time they had engaged with local authorities, voluntary organisations or care providers. Their lack of prior knowledge and experience made participants 'outsiders' to adult social care, and many found it initially difficult to gain entry to that world. The only participants who did not describe such feelings and frustrations were those with prior knowledge of adult social care, based on personal or professional experience.

Older people and family members told many, often lengthy stories about the confusing nature of seeking care. Common experiences included being unsure of what steps to take or where to go for help, and being redirected from one organisation to another, often multiple times, leaving them feeling shut out of the systems they were trying to access. On a practical level, this process meant that the search could be long and tedious, interrupting participants' normal daily lives and routines. For family members, this could echo and compound the sacrifices involved in providing informal care, necessitating time away from work or other responsibilities to make telephone calls or visit different agencies. More than this, the experience was disorienting, isolating, even frightening. Layla, 60, had approached the local authority ('Social Services') for help finding a care home for her 95-year-old aunt:

You're chasing all the time with Social Services, always ringing – 'oh, you need to speak to the reablement team, you need to speak to the falls team, oh, that would be another team...' So, you're given another number, somebody else. It like there's one door called [name of local authority service] but when you go in the door it then opens up a maze and you're just trying to work your way around it.

Layla's sense of abandonment and isolation is apparent in her story and echoed that of many participants; older people and family members frequently described feeling 'lost'. While Layla used the metaphor of a maze, others described similar experiences as 'a minefield', 'a desert' and 'a great well of misunderstanding'. Although self-funders are entitled to information from local authorities, many

felt that their needs were deprioritised compared to those whom the local authority was obliged to fund, making it harder still to access the world of adult social care. As Layla put it, ‘once they know you’re a self-funder it’s almost like, “well, thank you, you’re on your own, off you go”’.

Once participants did gain access to this world, whether making an appointment for a needs assessment, or speaking to care providers or signposting organisations, the sense of isolation and confusion continued. A recurring cause was the terminology used to describe aspects of care, especially financial aspects. Mark, 72, had approached the local authority on behalf of his mother, to see if she was entitled to financial support. He described being perplexed by their letters:

It doesn’t help ordinary human beings, does it, you know? I’m not in their finance department, I don’t understand all the technicalities involved and you’d think, ‘well, what does all this mean?’, you know, I don’t know what it means; and I’m reasonably intelligent, I’ve got qualifications from several universities. If I can’t understand it, if people have got a lower reading age, how are they going to get on?

Mark made the poignant distinction between ‘ordinary human beings’ and the adult social care department multiple times in his interview, reflecting a sense of estrangement. Even as he gained access to the requested information, that information remained esoteric and out-of-reach, while Mark remained confused by the system he was trying to navigate. In highlighting his intelligence and qualifications, Mark made it clear that he was ill-at-ease with struggling in this way, and that it jarred with his preferred self-concept.

### ***Losing face and losing control***

Seeking formal care means admitting the need for professional help. Both older people and family members described their own and others’ aversions to asking for such help, even from intermediary agencies such as local authorities and voluntary organisations, suggesting that such requests were viewed as a failure to remain self-sufficient and in control. For family members, seeking professional help with care could also be experienced as a threat to their role within their loved one’s care.

Alexandra, 54, described her father Bill’s experiences seeking information about a care home for her mother, who had dementia. He had approached the local authority, who initiated an assessment of his needs as a carer:

He was embarrassed, he was ashamed, and he found it unbelievably stressful being interviewed about his personal things and things to do with the home and my mother’s care and so on ... It was just to do with him being proud and never having had help, you know, having to admit that he needed help was very hard and having strangers in the house asking him questions was very, very hard.

Alexandra perceived Bill struggling to admit he needed help, seeing the experience as a blow to his pride and sense of self-sufficiency, and an intrusion into the private dynamic between him and his wife. The experience, Alexandra believed, had consequences of the utmost severity: ‘the whole process, that’s what killed him. The extra stress gave him this bowel problem; this is my belief anyway’. While Alexandra’s

care chronicle presents a particularly extreme disruption, many participants spoke of requesting help as humiliating for themselves or their relatives, and an affront to their sense of themselves as independent and capable.

For family members, loss of their own role as care-giver was a recurring identity threat when seeking care; several explained that their family dynamics were threatened by the prospect of professionals taking over care planning. Some spoke of fears of their loved ones being ‘put into homes’ or ‘taken away’ by local authorities if they asked for help finding care. While these events did not occur, some family members did find themselves excluded from assessments and decisions in which they expected to be involved. Derek, 59, needed to find a care home that could meet his mother’s needs after a period in hospital, but felt rushed by hospital staff:

They blatantly ignored my lasting power of attorney ... I had to say that they were obliged by law to respect it, and then I got them to play ball, but they weren’t very nice. The director of operations in [hospital name] told me, ‘Well, you do realise we can put your mother where we want?’

While Derek’s awareness of his legal rights enabled him to retain control, the interaction momentarily threatened that control and undermined his familial role in his mother’s care in favour of the authority of strangers. Such interactions were particularly jarring for those who had been involved in an older family member’s care for many years. Some felt that they were treated with suspicion or contempt by professionals: seen not as concerned family members, but as interfering or, worse, as not having the older person’s best interests at heart.

### **Financial shocks and losing faith in the system**

A final prominent feature of seeking care was the shattering of participants’ assumptions about the role of the state and their rights as citizens. While often resistant to seeking care, many participants, both older people and family members, had long assumed that the state would provide financial and non-financial support if requested. Participants described feeling shocked and betrayed when they learned the limits of state support in organising formal care; they experienced even greater ‘financial shocks’ when they learned that this care would be self-funded.

The belief that the state would provide ‘cradle to grave’ care was so strongly held that some participants referred to using their own money to pay for care as theft or suggested that they were ‘pay[ing] out for basically nothing’ (Zoe, age not given). Derek (above) spoke at length about his and his parents’ lifelong ethos of hard work and described a common expectation of state support:

In England, the idea is the state will provide; I pay my taxes and my contributions, when I need something, they will help me ... when they discover that perhaps that’s not the case and perhaps they have to pay, it breaks some people’s hearts. I mean people, I think, die early because of the absolute shock of it.

Derek and many others felt that hard work and frugality practised by older people throughout their lives should be rewarded by retention of their savings. Learning that this money would be spent on care violated their sense of fairness

and led to feelings of betrayal and abandonment: a sense that their long-held beliefs about 'the way things are' – and the way things *should be* – within the English welfare system had been undermined.

This sense of betrayal was particularly strong among those who perceived other people to have worked less hard or lived profligately. Geoff, 81, had approached the local authority in relation to his own and his wife's care needs, and had assumed their care would be paid for:

It would have been so easy for us, years and years ago to say, 'Well, we're going to spend every penny we've got because we know damn well the state's gonna have to provide for us...' I think it's grossly unfair that we have to pay for this thing, because what it really amounts to, as I said to you before, is that people who've sat on their backsides, done nothing with their lives, get everything given to them. Whereas my wife and I have been prudent enough to make provision for our twilight years, for want of a better expression, [we] get nothing.

Geoff expressed a deeply held sense of unfairness, referring to the financial assessments that determined his self-funder status as a 'trap' and 'a form of discrimination'. He was left feeling that years of work and frugality had been wasted, leading him to question not only the role of the state, but his and his wife's own choices over the course of their lives.

In addition to questioning their past choices, the need to spend their savings could disrupt participants' expectations for the future. Specifically, many older people and relatives had planned for the older person to pass their savings on to the family. Lawrence, 67, had sought care for his mother after a series of falls. He reflected on his family's views about the costs of care:

My children have put it into words that I probably wouldn't use, and that is that 'Granny's spending your inheritance' (laughs). And it's true, unfortunately. My father and my mother worked all their lives to buy a house, which my father, till his dying day, said 'I do hope either you or one of the children will eventually live here, I worked to buy this house, it should benefit you and your family'. And it won't.

Lawrence's story suggested that learning about the need to 'spend the inheritance' (as many participants called it) represented more than a financial loss. It was a breach in the older person's wishes and imagined legacy, disrupting their view of themselves as a provider and their plans for their family's futures.

### ***(Re)mobilising family resources and avoiding intermediary agencies***

For some participants, this phase of the care chronicle was so disruptive that they gave up the search altogether, remobilising resources used in the earlier phase to continue with their informal care arrangements. Others continued seeking care but avoided aspects of the search that they found particularly disruptive, disempowering or distressing, such as interacting with the local authority or other intermediaries. While still time-consuming and potentially confusing, approaching care providers directly allowed participants to avoid the perceived intrusion of these

intermediary agencies. This could (re)engender at least some sense of familial control and self-sufficiency, thus helping to maintain their preferred social identities.

### **Getting formal care**

While some participants' care chronicles ended with the search phase, most did eventually arrange formal care, including occasional or regular domiciliary care, temporary care home stays and permanent residential care. Whether experiencing formal care first-hand as the recipient, or by proxy as an involved family member, most participants described disruptions that echoed those seen in earlier phases of their care chronicles. In particular, formal care could be associated with losses of face and losses of control as older people and their families entered another unfamiliar world.

Being helped by a professional care worker was a new experience for most older people, and one which could be difficult to accept. Both older people and their families described the receipt of care as a loss of independence and control for the older person; it necessitated a change to their preferred daily routines, such as timing of meals, and potentially a change of environment. The receipt of more personal forms of care such as bathing could be experienced as especially distressing. Fred (age not given) had arranged domiciliary care for himself:

For a guy who's always looked after himself, to have to ask someone for help was diabolical. You can, and you can only do that if you grit your teeth and say, 'Well, I've got to do it, so.' But it's not something I enjoyed doing. It's hard ... For example, in my case I need help with bathing, now for a guy of my sort of age to suddenly get young little girls coming in to help bathe you, it's a heck of a shock ... and I don't know how you get over that, it knocks you for six.

Fred's comments about asking for help echoed the losses of face associated with seeking care, but his shame and shock did not fade once help was in place. The receipt of this care from strangers, particularly young female strangers, continued to sit uncomfortably with his image of himself as an independent man who had always taken care of himself, and he did not foresee himself repairing or 'getting over' that disruption.

A recurring source of disruption was the curtailment of the older person's preferred activities within a care home. Mary (age not given) explained how her mother Vera's mental health problems had necessitated care homes for many years. A care home with which they were both very happy had closed, and Mary was horrified by the priorities of the new care home:

Everything to do with intellectual, emotional, spiritual, church, stuff like that, which for my mother is very important, all of that is seen as sort of not, not essential, in other words everything that makes life worth living is not part of the deal.

The care home's lack of intellectual stimulation and religious activities disrupted cherished aspects of Vera's identity. These losses echo those caused by emerging care needs in the first phase of the care chronicle; sadly, as Mary's story demonstrates, the provision of formal care did not necessarily enable a return to these aspects of self, but could compound their loss.

Formal care, whether residential or domiciliary, could entail losses for family members too, disrupting family routines and dynamics. Lucy (above) arranged domiciliary carers when her father-in-law moved in with her, and described an incident when a care worker arrived unscheduled on Easter Sunday:

And she insisted on coming into our home anyway. I'd found it very difficult to let these strangers in because, on the whole the carers are very good and they're very nice, but they're strangers, a lot of strangers coming in and sort of taking over your home, taking over your space when you're not there so I found that hard with [Arthur] in our home. And I thought, 'Oh, this is a family day.'

Beyond an inconvenience, Lucy's story reflected real distress at the interruption of their 'family day' by a stranger. She had explained previously that she wanted Arthur to live with the family because it was 'far more natural' than a care home; the intrusion undermined her attempts to keep this normal family dynamic. Indeed, she suggested that even the care workers' *scheduled* visits were difficult for her; the care workers were out of place in her home and 'take over' a space in which she would normally have had control.

One older person we interviewed did not describe the formal care she received as disruptive. Opal, 89, arranged her own move to a residential care complex in response to a minor mobility issue:

I thought I'll go and live at [care complex], because I go every week to play bridge, you see, and it's very lively there ... So that's what I – I've come quite quickly really. I mean, six months ago I never dreamt of coming. But I think, you know, as I look at it, that I'm not going to get any younger, I'm not going to get any more active than I am now and probably it's the best thing to do from everyone's point of view, and while I'm in my right mind.

In contrast to many participants, Opal's move to residential care represented not disruption and lost independence, but continuity, control and biographical flow. She emphasised that it was her choice to move to the complex, and that doing so enabled her to continue activities she enjoyed such as playing cards with friends, while curtailing nothing. She framed the move as a form of future-proofing: a normal and sensible response to the inevitability of increasing needs in older age. Another participant, Iris, 82, framed her own imagined future care in a similar way, outlining a detailed, multi-stage plan beginning with low levels of domiciliary care, gradually increasing to higher levels of care including residential care if necessary. Iris explained that through formal care, she intended to 'find a way of retaining what is important to me', such as her academic pursuits. This level of consideration for future formal care was a rarity among participants; Iris had no care needs at the time of interview, and her plans – and framing of care as biographical flow – were hypothetical.

### **(Re)mobilising family resources and managing care**

For participants who did find formal care disruptive, there were a limited number of practical strategies used to minimise disruption. Where possible, participants

chose care providers that offered some level of continuity, such as domiciliary agencies that sent the same workers at the same time each day and enabled the older person's usual routines to be followed, or care homes near pre-existing social networks and offering preferred activities. Family members also described 'managing' formal care by intervening and even providing additional care when formal care was inadequate, or simply trying to maintain aspects of normalcy for the older person. Rose, 57, left notes around the house for the domiciliary care workers who looked after her mother, reminding them of her mother's preferences:

Mum likes – she can only drink out of this cup, she likes tea without milk, she likes milky coffee, and even going to bed at night, her bedtime routine, like listening to *The Archers* [radio show], turning it off, liking a glass of lime ... even though you get carers going in you still have a lot of responsibility yourself.

Rose did her best to ensure that her mother's life remained as normal as possible, through conscientious attention to the minutia of her usual routines. Her story also demonstrates the amount of work – and worry – that this kind of (re)mobilisation of family resources could entail for family members. Indeed, like informal caregiving, 'managing' formal care in this way might be seen as a *transfer* of disruption, from the older person (back) to involved family members.

### **Losing formal care**

In a few cases, formal care arrangements became untenable, due to unsatisfactory care, escalating care needs or care provider closure. Unwillingly losing formal care was a shock, particularly when care arrangements had been working well. Mary (above) explained the experience of Vera's previous care home closing down:

There is nothing worse than you have found a solution for your mother, or whoever it may be, it works, she's happy there ... and then it's taken away and you're faced with putting her somewhere worse, it's incredibly painful to do.

Any such loss also represented a return to previous 'phases' of the care chronicle and the disruptions those phases brought. Most commonly, this involved taking on the responsibility of seeking care again. Some participants returned to family caregiving as an interim or permanent measure, potentially returning them to the disruptions they encountered at the beginning of their care chronicles.

## **Discussion**

### **Biographical disruption**

All three phases of care chronicles demonstrated biographical disruption. Findings relating to needing and getting care showed similar issues and support previous research, while empirical and theoretical novelty was demonstrated in our discussion of seeking care as biographical disruption, and in the concept of care chronicles. Echoing research on illness as biographical disruption, the emergence of care needs was shown to alter or curtail the older person's usual habits, damaging their

own concept of self and their family members' perceptions of it. This supports the idea that even 'normal' later-life illnesses and impairments can be experienced as biographical disruption (Larsson and Grassman, 2012; Lloyd *et al.*, 2020) and expands Karner and Bobbitt-Zeher's (2005: 599) finding that family care-givers experience disruptions to the 'old known self' of a person with dementia. Families' efforts to minimise disruptions through informal care-giving led to disruptions of their own lives and selves, supporting research by Adamson and Donovan (2005), as well the literature on the potentially consuming nature of care-giver identities (Eifert *et al.*, 2015). Previous research has also shown that later-life illness and informal care-giving might be normalised (Eifert *et al.*, 2015) or framed in terms of biographical flow (Sanders *et al.*, 2002; Faircloth *et al.*, 2004; Adamson and Donovan, 2005; Aasbø *et al.*, 2016). Such framings were rare and brief in our findings, and eventually superseded by discussions of ongoing disruption necessitating the search for formal care. However, this was at least partly due to our sample (people seeking information about self-funded care) and should not be interpreted as countering these earlier studies.

Experiences of getting formal care were also largely framed as disruptive. Both older people and family members viewed it as interfering with the older person's preferred identities, whether due to care itself or the infrastructure of its provision (timings, availability of activities, and so on). Family members could also find formal care disruptive of their own roles and place in the older person's life. This supports previous research on the disruption of the 'biographical we' (Aasbø *et al.*, 2016), as well as research indicating that paid domiciliary carers can be viewed as intruders (Winslow, 2003) and formal care as eroding the comforting normalcy of the home itself (Angus *et al.*, 2005). Some disruptions could be mitigated through 'management' of care routines by family members, although this led (back) to the potential disruptions associated with the informal carer role. Two participants framed formal care as enabling biographical flow; notably, these participants had experienced minor care needs or none at all, and both had the ability and resources to choose suitable care for themselves. This supports evidence that older people can conceptualise formal care in positive, affirming ways when they feel in control of their choices (Cook *et al.*, 2015).

Participants' stories of seeking care demonstrated that, more than being a straightforward administrative process, this phase can lead to its own forms of biographical disruption. Many older people and families perceived themselves as outsiders to the world of adult social care and found the search alienating, humiliating, and entailing losses of face and threats to familial roles. While previous studies have highlighted practical challenges associated with seeking formal care (Winslow, 2003; Baxter *et al.*, 2020), we are aware of none that explore these kinds of 'symbolic losses' (*cf.* Bury, 1988). Financial shocks represented further losses of imagined futures and legacies, prompting participants to question long-held values, past choices and faith in 'the system'. Previous work has shown that economic hardship can exacerbate or outweigh the disruptions of ill health (Pound *et al.*, 1998; Wouters and De Wet, 2016), but this is the first study to suggest that financial shocks experienced by relatively affluent older people can constitute biographical disruption.

In some respects, many of the disruptions experienced when seeking care have clear parallels with previous biographical disruption scholarship. The sense of

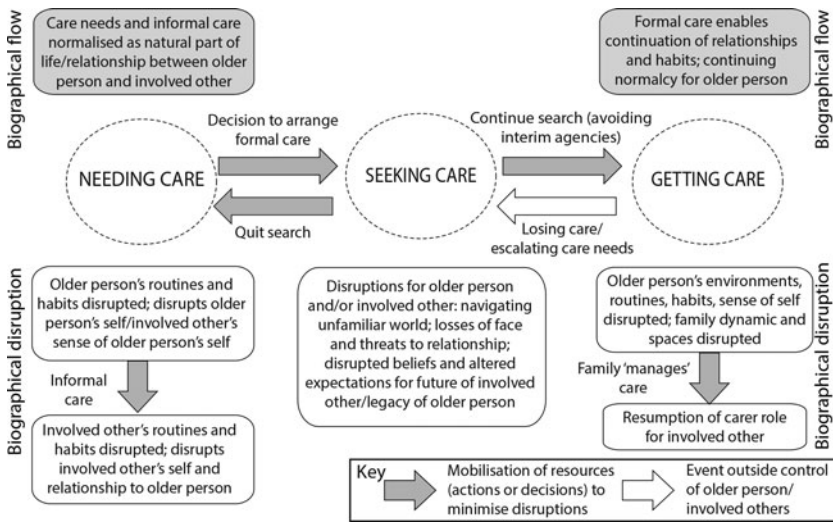


entering a strange world, losses of control and preferred self-concept, and questioning previously held beliefs have all been highlighted in work on illness experience. Both practical and symbolic losses have specifically been demonstrated in studies of later-life illness (Sanders *et al.*, 2002; Korotchenko and Hurd Clarke, 2016). Yet it is their long association with illness experience that makes these forms of disruption so novel in this context; our findings extend the concept of biographical disruption beyond specific experiences of illness and physical care, and thus beyond the usual focus on embodiment (Engman, 2019). Like illness, seeking care involves recognition of unfamiliar worlds, but these are not ‘worlds of pain and suffering’ (Bury, 1982: 169) in a physical sense. Like chronic illness, seeking care means ‘the disruption of taken-for-granted assumptions and behaviours’ (Bury, 1982: 169), not about one’s bodily states and capabilities, but about the state’s obligations towards the individual, and about what kinds of behaviours are rewarded financially. Thus, our findings extend the sociological argument that the ‘normal’ illnesses of older age can be disruptive (Larsson and Grassman, 2012), to include the disruptiveness of other (non-illness) events that occur in the course of ‘normal ageing’. Notably, while we found some evidence of participants reframing emerging care needs, informal care-giving and the implementation of formal care in terms of ‘biographical flow’, seeking care was never framed in this way. Some – not all – of its disruptions could be managed through avoidance, but the process itself was never normalised.

### Care chronicles

Previous studies on biographical disruption have tended to focus on a specific condition or aspect of care, or on the biography of *either* the person with the condition *or* those close to them. The concept of care chronicles allows us to consider the longer and broader view, incorporating the phases of needing, seeking and getting care, and the experiences of both the older person and ‘involved others’, as outlined in Figure 1.

Larsson and Grassman (2012: 1156) questioned the idea that ‘disruption is a single event that is characteristic of the early stage of a chronic illness’, highlighting cumulative embodied losses in the biographies of older people. Care chronicles support and extend this argument. They reflect the potential for accumulation, but also recurrence and cyclicity; demonstrate how disruptions can be shared or transferred; and highlight the limitations of resource mobilisation, which may lead to such cycles and transference. The framework demonstrates how resolved disruptions can give way to new forms of disruption, such as when the search gives way to the disruptions of getting formal care; attempts at resolution can also lead back to previous disruptions, such as when the search is abandoned in favour of a return to informal care. Disruption can be experienced simultaneously (albeit differently) by the older person and involved others, such as when their shared routines or environments are changed by the presence of formal care, or transferred, such as when informal care-giving or formal care management alleviates some of the older person’s biographical disruption by transferring it to the involved other. Finally, while biographical flow was rare in our data, care chronicles offer a framework which can incorporate this possibility as well.



**Figure 1.** Forms of biographical disruption and flow experienced by an older person and/or involved family members/spouses ('involved others') during the search for self-funded later-life social care.

The application of care chronicles as a framework for analysing stories has the potential to reveal common themes, across phases and between older people and families. Two interlinked themes recurred in the care chronicles analysed here: resistance and resources. Resistance was demonstrated as participants found ways to push back at or reject disruptions and hardships. Family members turned to informal care, and in some cases continued care-giving at great costs to themselves, to avoid seeking formal care. Older people and families avoided particularly disruptive intermediary organisations when seeking care and many were fiercely resistant to spending their savings on that care. Many older people accepted formal care only reluctantly, and family members intervened in its provision where necessary. Such resistance might be experienced as empowering for older people and families; just as 'the separation of disease from self is a powerful cultural resource' (Bury, 1982: 172), so too might separation from social care systems be. However, it could also be detrimental; for example, informal care-giving might prove unsustainable, while avoiding interacting with their local authority or other intermediaries could mean missing out on useful information or non-means-tested financial support. Resistance was also often contingent on the mobilisation of unevenly distributed resources. These include the time and labour needed to provide informal care and to seek or 'manage' formal care, and the personal or professional knowledge and the financial and social capital needed to find and access appropriate formal care, particularly if avoiding intermediaries (*cf.* Baxter *et al.*, 2020).

**Limitations and future research**

Care chronicles provide a new framework for analysing stories relating to seeking care; future research could build on this framework by highlighting new forms of disruption or flow, new forms of resource mobilisation, and new interactions between

the biographies of people with care needs (including younger people with care needs) and involved others. There is broad scope for the application and expansion of this framework, including in ways which address specific limitations of this study. This study has highlighted some differences and similarities in the stories of older people and family members across the care chronicle, but a more in-depth exploration of these would be beneficial. Further research could focus on the care chronicles of dyads specifically, to understand how they relate to one another and how they differ when describing the same set of events. Such research might also compare dyads that include a spouse to those that include another family member, given the potential differences between these care-giver identities (Eifert *et al.*, 2015).

Our study focused on self-funders and their families in England. This population faces a unique set of issues, including national policy leading to greater reliance on family care-giving, low public spending on social care in England relative to other UK nations, and low levels of savings for care in the UK as a whole (Franklin and Hochlaf, 2017; Oung *et al.*, 2020). This meant that these care chronicles demonstrated rich and detailed discussions of certain disruptions, such as those related to family care-giving and financial shocks. However, the ageing population is a global issue, and reliance on one's own income in retirement is set to increase (Franklin and Hochlaf, 2017). Future research could investigate the applicability of these findings to other national contexts.

Issues relating to ethnicity were not a focus of the study; however, our participants were predominantly white. This may be because older people and carers from Black and other minority ethnic backgrounds are less likely to access the types of organisations we used for recruitment (Moriarty, 2008; Greenwood, 2018). This lack of access, and other potential differences in the experiences of needing, seeking and getting care (Moriarty, 2008; Greenwood, 2018; Harries *et al.*, 2019), means that future research on the care chronicles of different minority ethnic groups should be prioritised. The older people who participated in our study had a variety of care needs, and differing family structures and levels of financial resources, demonstrating the wide applicability of our findings. However, while we have highlighted the relevance of resources to care chronicles, it was beyond the scope of this study to explore the effects of such differences in depth. More research is needed to explore how such structural differences and inequalities affect care chronicles. Alongside ethnicity, family structure and economic status, gender differences should be explored, given gendered expectations around care-giving (Eifert *et al.*, 2015) and the fact that women are more likely than men to provide family care and to need care (Marcheselli and Ridout, 2019; Ashford and Hill, 2020).

### **Conclusion and implications**

Older people and their families can experience needing, seeking and getting later-life care as a series of biographical disruptions. Their care chronicles highlight the cumulative and sometimes cyclical nature of these challenges and demonstrate that seeking outside support does not always resolve disruptions, but can bring about new ones. Biographical flow or 'normalisation' of these events seems rare and more apparent in the stories of those with lower care needs and/or greater access

to resources. Disruption can be driven or exacerbated by lack of knowledge (e.g. about how adult social care systems work and how care is paid for) and attempts to repair disruption may lead to disengagement with potentially useful services. While it is already known that people may *initially* avoid seeking care due to lack of knowledge about services and anxieties around costs (Price *et al.*, 2014; Baxter *et al.*, 2017; Heavey *et al.*, 2019), our analysis shows that if and when they *do* decide to search, the occurrence of new disruptions risks continued disengagement.

Understanding experiences through the lens of care chronicles offers a holistic 'long view' of the nature, scope and implications of such disruptions. While it will not be possible to prevent biographical disruption entirely, these stories can be a source of information and support for older people and families, and usefully inform the approach of practitioners supporting them. Disruption might be mitigated by early information-seeking and care planning by older people and families. In light of the particular challenges associated with seeking care, local authorities, signposting organisations and policy makers should encourage and facilitate the search by using accessible language, adopting a sensitive approach to first-time users of services, and seeking to create greater public awareness of how social care is arranged and funded. Care providers might aspire to minimising biographical disruption as a marker of quality, through enabling appropriate levels of autonomy for the older person and ensuring continuity of preferred routines and activities wherever possible. Minimising disruption via statutory services and care providers is a matter of fairness, because the practical minimising strategies employed by older people and their families rely on unequally available resources.

**Acknowledgements.** The authors would like to thank all the study participants for their generosity in sharing their stories and the project advisory group for their support with this research.

**Author contributions.** EH carried out the data collection, initial data analysis and initial manuscript preparation. KB and YB developed the study and contributed to the analysis and manuscript.

**Financial support.** This paper reports on independent research funded by the National Institute for Health Research School for Social Care Research (NIHR SSCR), Project P062. The funders played no role in the design, execution, analysis and interpretation of data, or writing of the study. The views expressed are those of the authors and not necessarily those of the NIHR SSCR, the NIHR, or the Department of Health and Social Care.

**Conflict of interest.** The authors declare no conflicts of interest.

**Ethical standards.** Ethical approval was obtained from the Social Care Research Ethics Committee (reference 15/IEC08/0026).

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**Cite this article:** Heavey E, Baxter K, Birks Y (2024). Care chronicles: needing, seeking and getting self-funded social care as biographical disruptions among older people and their families. *Ageing & Society* **44**, 916–938. <https://doi.org/10.1017/S0144686X22000599>