



The precariousness of living with, and caring for people with, dementia: Insights from the IDEAL programme

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ABSTRACT

This paper uses precarity as a framework to understand the vulnerabilities experienced by those living with or caring for someone living with dementia. Drawing on qualitative interview data from the Improving the Experience of Dementia and Enhancing Active Life (IDEAL) programme, we attend to our participants' reflections on how they manage the condition and the wider circumstances in which this occurs. To interrogate the utility of precarity, we focus on our participants' descriptions of needs and challenges and set these alongside both the wider contexts in which they seek or offer care (formal and informal) and the sets of values attributed to different ways of living with dementia. Building on the work of Portacolone, our analysis identified four interconnected themes: uncertainty; experiences of support and services; independence and personhood; and cumulative pressures and concerns. We develop this analysis by reviewing how our themes reflect, extend, or depart from previously identified markers of precarity and consider the specific ways in which these markers shape the lives of those living with dementia.

1. Background & introduction

Dementia poses challenges to people's quality of life and research shows that some people are more affected by those challenges than others (Clare et al., 2022). This paper explores how precarity can offer a framework to identify specific challenges and insecurities that some people living with and affected by dementia experience, helping to contextualise that variability. The IDEAL programme identified psychological wellbeing as a main driver of quality of life (QoL) in people with dementia (Clare et al., 2019). Social factors, such as the ability to function and manage everyday life, the experience of isolation and disadvantage relating to perceived social status and access to services also influence people's psychological state and thus shape perceptions of quality of life (Clare et al., 2022). This paper attends to these broader social factors, using the framework of precarity.

Precarity is a sociological concept that highlights life experiences characterised by risks and insecurities. The concept carries two distinct utilisations. The first is a restricted framework applied to the market and specific forms of insecure labour (Millar, 2017). The second considers a

broader application, encompassing the connections between material conditions and cultural values. For example, Standing's development of the precariat, although most associated with increasingly insecure forms of work, attends to a broader set of concerns whereby precarity constitutes a state of reduced citizenship with diminishing civil, political and economic rights (Standing and Charter, 2015). Butler considers precarity through the lens of vulnerability and suggests that although vulnerability is something universally experienced, it is unequally distributed (Butler, 2016). Consequently, precarity is actively produced in the context of dominant values, social norms and in the distribution of resources in society. Those who lack access to networks of economic and social support are disproportionately at risk from the consequences of illness or injury and are thus more exposed to vulnerability (Butler, 2004). Precarity as a framework therefore holds within it both material and existential threats to personhood, whereby people's experiences of vulnerability are set alongside increasingly entrenched values of individualism encompassed in the will to health in later life (Higgs et al., 2009).

Precarity is a theoretical construct increasingly applied to later life

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experiences and those living with or affected by dementia (Portacolone et al., 2019; Grenier et al., 2020b; Grenier et al., 2017). This reflects a recognised need by researchers to contextualise the uncertainties experienced by people living with dementia while paying attention to the increasingly powerful dual effects of a retrenchment in welfare provision (Hernandez, 2021), and the moral imperatives held within discourses of positive ageing and individual responsibility (Pack et al., 2019).

Phillipson (2020a), along with others working in critical gerontology (Estes, 2019), has suggested that precarity can be extended to think about later life more generally, rather than focusing narrowly on the specific issue of the ‘precarity trap’ (Standing, 2011) whereby there is an accumulation and entrenchment of economic inequality resulting in inequality of pension provision and secure income in later life (Lain et al., 2019). They suggest that the accumulation of precariousness throughout a person’s lifecourse can also include the differential ‘choices’ available to people in later life, particularly in instances of accessing care. In the case of those living with dementia, vulnerabilities are experienced through forms of ‘dependence’, including the need for care and the struggle to secure it (Grenier et al., 2017). Thus, experiences of precarity may be reflected in people’s everyday struggles and particularly at moments in which challenges of cognitive and physical frailty necessitate support.

Gilleard and Higgs (2019) challenge the claim that later life in general can be described as increasingly precarious, suggesting there has been a conflation of socio-economic disadvantage with specific forms of vulnerability that reflect an increasing risk of ‘corporeal’ harm. Gilleard and Higgs (2010) critique is useful to clarify our framework of precarity. Firstly, we are interested in identifying the specific vulnerabilities of those living with and affected by dementia. Secondly, precarity offers a way of contextualising people’s experiences of living with dementia both in terms of the struggles experienced in accessing care and a wider set of socio-cultural concerns. It is not necessarily reflective of increased inequality (although this may play a part), but instead attends to the experiences of navigating and securing care and the changing cultural meanings associated with forms of vulnerability and dependence. For our purposes, precarity offers a way to consider the relationships between corporeal harm and the variable resources available to people to cope with it.

Grenier et al. (2017) and Portacolone et al. (2019) consider both the structured and existential vulnerabilities experienced by those living with and affected by dementia. They make the case that these distinct aspects precarity can be connected through the cultural value attributed to independence, constituting dependency as a central factor in creating and sustaining the specific vulnerabilities of those living with dementia. Our study extends existing work by proposing that precarity offers a conceptual framework through which to recognise the cumulative effects of physical and cognitive vulnerability, uncertainties regarding accessing and maintaining ongoing care, and a growing cultural pre-occupation with independence - often conceptualised as individual and family responsibility (Latimer, 2018; Mansvelt and Breheny, 2018). The over-representation of successful ageing in both policy frameworks and wider public discourse is itself a mechanism through which forms of suffering may be either neglected or deemed an undesirable personal failing (Bartlett et al., 2017).

To explore these themes, we draw on the accounts of our participants whose lives are in various ways shaped by risk, uncertainty and insecurity. Through their reflections, we show how for some of our participants, resources required to live well with the effects of dementia may not be immediately available and seeking access to them can be a process characterised by uncertainty, worry and concern.

1.1. The study

The IDEAL programme is a British mixed-method, longitudinal cohort study investigating the factors that influence capability to ‘live

well’ for those living with or affected by dementia. Alongside quantitative analysis to identify factors of significance (Clare et al., 2019), the study uses qualitative interviews to explore how and why certain factors inform people’s capacity to live well with or alongside dementia. This paper is based on qualitative interviews with twenty people living with dementia and their main family carer. Participants were identified from the larger cohort study and were initially selected from those showing either a positive or negative change in their quality of life, based on their results from the quantitative data collection at Time 1 and a year later at Time 2. The change in quality of life was based on the results of a combination of standard measures of quality of life, satisfaction with life, and well-being (for a more detailed description of the quantitative measures, see Clare et al., 2019). Within this group, we selected an equal number of those showing a positive and negative change in living well and then based on maximum variation in terms of age, socio-economic background (using income and previous occupation) and urban and rural dwelling. We identified an equal number of men and women and restricted our selection to those who had the most common types of dementia (Alzheimer’s disease, vascular dementia and mixed Alzheimer’s and vascular dementia). Barbara (see Table 1) was originally thought to have Alzheimer’s disease, hence her inclusion in our sample, but was later confirmed to have Frontotemporal dementia.

Diagnoses were made by local clinicians and taken from medical records. For the main study cohort, participants were recruited through NHS memory services across the UK between July 2014 to August 2016. Recruitment was carried out by clinical researchers working as part of the UK research networks (NIHR CRC DeNDroN in England, NISCHR CRC in Wales, and SDCRN in Scotland). Only those living with dementia who had a Mini Mental State Examination (MMSE) score of 15 or above were recruited into the study and the carers were recruited via a nomination from the person living with dementia.

Our 20 dyads for the qualitative sample were made up mainly of spousal relationships, except for two mother and daughter dyads and one mother and son. The themes of the paper reflect concerns and circumstances raised by all those in our qualitative sample. However, to consider the contextual circumstances of our participants and how these frame their experiences, the paper focuses primarily on those whose accounts were most characterised by instances of insecurity and uncertainty. Below, in Table 1, we provide some demographic details of the 5 participant couples whose interview extracts are presented in the analysis.

All participants were interviewed twice, one year apart, in 2016 and 2017 and were carried out by the same qualitative researcher (author 1).

Table 1

As with much qualitative research, there are inevitably losses incurred in processes of data selection. In our case, we were less able to provide a broad representation of the ways in which uncertainty factored in the lives of all our participants. However, the detailed description provided through the stories of the participants we have selected enabled us to show how their specific circumstances framed their experiences of living with dementia, which formed an integral part of our analysis.

Participant pseudonym	Age	Diagnosis	Previous occupation	Carer kin relationship and pseudonym
Mavis	76	Mixed dementia (Alzheimer’s disease & vascular)	Barmaid	Husband (Terry)
Barbara	69	Frontotemporal dementia	Biochemist/blood tests	Husband (Jack)
Fred	77	Alzheimer’s disease	Bus driver	Wife (Margery)
Sue	66	Alzheimer’s disease	Teacher	Husband (Tom)
Sally	65	Alzheimer’s disease	Waitress	Non-resident daughter (Claire)

1.2. The approach

There are difficulties in recognising forms of precarity in the life experiences of older people (Portacolone, 2020). This is partly due to the taken-for-granted nature of certain aspects of precarity, such as the dominant ideal of independence within western cultures (Latimer, 2018; Mansvelt and Breheny, 2018). Furthermore, it is difficult for people to connect their specific circumstances to wider systemic or cultural issues (Portacolone, 2020).

There is, however, some precedence of drawing on people's experiences over time to identify cumulative disadvantage (see Hagan et al., [2020] study into the effects of cumulative disadvantage on loneliness or Portacolone's [2020] work using participant narratives to identify specific markers of precarity at the micro, meso and macro level). Building on this approach, we identify experiences that align to previously identified markers of precarity, while using the specificity of our participants' experiences to further develop and refine them. These markers include: feelings of uncertainty regarding current and future circumstances; the fragility of care networks and the values associated with them, which we have termed 'care assemblages' drawing on the work of van Eeuwijk (2020); the predominant value attributed to independence, in opposition to the devaluing of dependence; and the nature and extent of cumulative pressures and concerns whereby different sets of needs and possible threats to personhood can accumulate to create a state of intensified vulnerability.

The interview questions were open and related to barriers and enablers to living well with dementia, what living well with dementia means to them, as well as more grounded questions relating to their everyday routines and practices. To utilise a framework like precarity, that is made up of connections between subjective experience and material conditions, it is necessary to situate our participants' accounts within their broader context. We also attend to the accounts of both the person living with dementia and the carer together, recognising that markers of precarity and striving for security are shared amongst families, albeit with distinct personal challenges (Hardgrove et al., 2015).

We approach our data with a specific purpose, to consider whether and how the wider social and cultural contexts that frame people's everyday lives can help make sense of the differences in people's experiences of living with dementia. Our analysis is therefore based on a reflexive process of meaning-making, involving a continual movement between interpretations of the data and theoretical frameworks of precarity (Srivastava and Hopwood, 2009). Our analysis categorises participants' responses into themes that reflect, refine and develop aspects of the precarity concept. This approach is best described as a theoretical thematic analysis (Braun et al., 2022), in that it addresses one aspect of the data in detail and specifically attends to the key features of precarity in our participants' talk.

The development of our interpretive themes were refined through a process of constant comparison (Boeije, 2002), checking their relevance both within individual participant stories and across the data set. Even with a theoretically informed approach, there is always a movement between theory and data. This is important to ensure that aspects of our participants' accounts that extended or diverged from previous applications or explanations of precarity could be identified.

Theoretical thematic analysis was particularly appropriate for our purposes as it aims to connect what participants say to broader social and cultural meanings or assumptions that underpin them. Analysis was undertaken by author 1 and subsequently shared with the wider research team. Early interpretations were discussed and reviewed to check for consistency of interpretations but also to support and inform the connections made between the theory and data.

1.3. Analysis and findings

Our data extracts are organised around our four themes: uncertainty; the fragility of care assemblages; independence as a personal value; and

cumulative pressures and concerns. The remainder of this section is organised according to each of our four themes. Within these themes we introduce our participants, providing a little more context on their lives and circumstances.

1.3.1. Uncertainty

This theme underscores the specific challenges that some of our participants face in maintaining a sense of security and reliability in meeting their care needs. These care needs encompass the needs of the person living with dementia that can be unpredictable, fluctuating, and uncertain. It also reflects the needs of our participants' carers, needs that are often complicated by carers' own health conditions and personal circumstances. This uncertainty was described both as a concern for now and in the context of thinking about the future. Such uncertainties are simultaneously biological and social (Manderson and Smith-Morris, 2010), arising from how our participants' experiences of dementia are shaped by their specific social circumstances, the cultural meanings attached to their condition and the broader politics of care provision.

The first extract is taken from our interviews with Mavis and Terry. Alongside dementia, Mavis has significant balance and mobility issues that are increasingly impacting upon her life. Terry, Mavis' husband, also has health problems and had started treatment for prostate cancer just before participating in a second research interview with us. An important theme that ran through both of their interviews, across both time points, was the sense in which their capacity to manage and get through each day was built on shaky ground, with Terry describing the unsustainable nature of much of the support he currently provides for Mavis. During our second interview together, he described his own feelings of uncertainty about the help he can provide and what might happen in the future:

INT: Do you still have erm someone coming to help erm Mavis get washed and up in the mornings?

Terry: No, no.

INT: No, that's stopped now, has it?

Terry: Yeah, it's stopped some while ago yeah.

[The help Mavis was receiving previously was temporary, following a spell in hospital]

Terry: I've got people I can call on you know ... I met a couple from down the road here yesterday and she said why don't you ring us, I say well twelve o'clock at night, I said everybody will be in bed, I said I wouldn't dare wake you up and get you up here that time of the night, it wouldn't have mattered we'd have come and done it but I don't feel like doing that at twelve o'clock.

Terry: Well Grace (daughter) rang me this morning and she said she's coming up from London tomorrow to have a chat about things what we're going to do with her or how we can look after her better and me get some help you know, not being funny I can't do it forever.

INT: No, absolutely.

Terry: I'm eighty-five beginning of next month [laughter] yeah so, I'm not young am I, well I feel young but I'm not, you don't know what the future's going to bring do you?

There is a sense of insecurity in Terry's description over their capacity as a couple to meet their current and future needs. He reflects on the unsustainable nature of existing support from neighbours and friends and Terry's own health problems seem to have brought to a head the difficulties they have been living with for a while.

The second extract is taken from our interviews with Barbara and Len. Barbara is living with dementia and is particularly affected by a loss of language and verbal expression. She lives with her husband Len and they both describe the frustration Barbara experiences when struggling to find a word. Barbara talks about her worries regarding how her

dementia will progress and what this might mean for both their lives. For Barbara, the vulnerabilities related to possible increases in dependency and care needs sit alongside the uncertainties regarding the nature of dementia itself. The unknowns about how the condition will progress and what the implications might be create specific vulnerabilities for their ability to cope with the everyday and also to think about and plan for the future:

Barbara: I don't know what's going to happen when it gets worse. I mean I was told at the beginning that you'll have difficulty talking at all. I think gosh if anything happened to Len [husband], where would I be, you know.

Such uncertainties about the future may be further exacerbated if access to care and support is already characterised by the insecurities of financial difficulties or family hardships.

1.3.2. Fragility of care assemblages: experiences of support and services

Care is not simply a matter of individual needs but reflects a complex set of associations between wider socio-cultural responses to care needs and the degree to which there is a social willingness and commitment to care, resource allocation at the micro, meso and macro level, and interpersonal relationships that encompass everyday caring practices. These networks make up what van Eeuwijk (2020) describes as care assemblages. These assemblages can become fragile through the instability or unsustainability of existing informal care provision or through an unpredictability or inconsistency of formal care. Within this theme, there are different illustrations of this fragility and the implications it has for our participants.

Our first example comes from our interviews with Sally and Claire. Sally is 65 the first time we meet; she has vascular dementia as well as chronic obstructive pulmonary disease (COPD) and diabetes. Her daughter Claire is her main carer. Claire has fibromyalgia and until recently worked as a carer but, without having fixed contracted working hours, she struggled with the unpredictability of the hours and gave it up. Claire takes overall responsibility for her mother's care. Sally also has daily visits from carers to help her with medication and preparing meals and Claire is the main point of contact for the agency that sends out carers. Claire describes her struggles in managing care for her mum:

Claire: I was diagnosed with the fibromyalgia ... I could just about cope at work until they put me on forty-two hours of a weekend ... and I haven't been at work since. I was a carer, but they just had no idea. I'm still struggling ..., it's not a life. The carers [for my mum] just basically do the meds, the food, she gets a hygiene call once a week, anything else is down to me.

Precarity is in part a condition that results from a denial of our inherent interdependence (Butler 2004; 2016) whereby we all require forms of care at different intensities and at different moments throughout the lifecourse (Fine, 2020). This denial intensifies experiences of vulnerability as a form of marginalised dependence. The needs and circumstances of carers are therefore integral to understanding conditions of precarity as being experienced as *both* individual threats to personhood *and* shared experiences of insecurity that shape families and communities. Claire describes the challenges of navigating the care and income support system, as well as meeting Sally's needs appropriately, as an ongoing part of the job of caring, with variable success:

Claire: I have asked social services to actually take the calls (care visits) off me and put them into Jenna's (formal carer) but of course they can't do it until everything else [referring to other benefits assessment] is sorted.

INT: Yeah.

Claire: So, I'm still waiting.

Claire: I've got to ring social services because they're meant to be finding her a day-care, I was trying to get her into Oaktree Court, but

they never come back and, in the end, I just said I'm fed up with waiting and I put it back in the hands of social services. Because I've been trying to find a care directory to see if there's any other day-cares around, but I can't find a care directory for love nor money, I've gone round a lot of the libraries and stuff, and I can't find one.

Claire describes the difficulty she has experienced in finding the right kind of care, as well as the concern over her own ability to continue supporting her mum. The difficulty of trying to find alternative care, or even just the information about what is available is a struggle. The burden of filling the current gaps in her mum's care, at least from Claire's perspective, remains with her.

One marker of precarity that can be identified through people's interview accounts is an uncertainty about being able to find and access solutions to the problems people face (Portacolone, 2020). Our study illustrates that this does not just concern the seeking and accessing of help, but also relates to the uncertain nature of the help itself. Our participants' descriptions of services that were in place to support them were sometimes characterised by unpredictability and inconsistency.

Home care services for Mavis and Terry provided physical help for Mavis but also carry risks and uncertainties. Particularly frustrating for Mavis is the unpredictability of when the carers will arrive, meaning she has a lack of control over her own bedtime. The form in which care is delivered therefore carries with it its own limitations:

Mavis: then I have help getting up in the morning and then somebody comes to put me to bed at night.

INT: How have you been finding that is that ...

Mavis: Yes, I don't really like to go to bed early but if, if I get undressed and that then I can go up on my own but when I have my lift in a couple of weeks that'll be that problem solved you know what I mean?

INT: So, they come at a certain time, do they?

Mavis: Well, that's the trouble you don't know what time, a couple, three nights ago this bloke came, he got me to the top of the stairs, didn't have a frame at the top of the stairs [laughter] and he just said you're alright now and went. Luckily, I've got a banister up there and I could reach the door handle [laughter] but I mean I never report him or anything like I should, but I did tell one of the girls so probably somebody has told them.

INT: Yeah.

Mavis: He hasn't been back since. I tell you what I don't know if I'd know if I saw him again but that really shook me up a bit, ever since then they've been very nice and the ones in the morning have been.

Mavis describes not only a lack of routine regarding when carers will come, but also the variability in confidence she has in those who come to care. Interesting in Mavis' account is the degree to which she perceives herself as lacking control or power to have a say in her care, even in instances where she feels unsafe. There is a growing recognition that women living with dementia are less likely to complain or speak up about their care needs, partly for fear of becoming a 'burden' to their family but also due to feeling less deserving of care (Savitch et al., 2015).

The next extract is taken from our interviews with Fred and Margery. Fred has Alzheimer's disease and lives with his wife Margery. Fred had experienced quite a significant deterioration in his memory, balance and vision when I visited them for our first interview. Margery was living in considerable pain and was waiting for an operation on her knee. Margery describes the challenges she faces in looking after Fred and managing her own pain, while remaining resistant to the idea of help, either from extended family or from formal services. In the extract below Margery comments on the suggestions made by her daughters when discussing the long-term care of Fred:

Margery: I've got two daughters. Now, one's got bi-polar, which doesn't exactly help, um, and she said, "Oh, I think you both ought to be in a sort of sheltered place." Now, the other one, um, she says, "I think you ought to buy a bungalow and go and live somewhere on the level." Of course, I said to her, "Well, that's okay but we won't be able to live here, not with the prices of the bungalows. We'd have to move out of the city," I said, "and if anything happened to Fred I'd be over there, ..."

Margery bemoans how her daughters do not take account of the restrictions that frame her choices when it comes to caring for Fred. Both their family circumstances that limit the capacities of her daughters to provide care and the financial and social implications of either moving to more appropriate housing or relocating to another area are ignored, according to Margery. Margery voices her frustration about framing their future security in terms of her individual choices and actions, without recognising the wider circumstances that restrict those choices. The fragility of care assemblages in Margery and Fred's case is reflected in both the difficulties they are experiencing in coping with limited external support and the accompanying restrictions on the opportunities Margery has to improve their circumstances.

Margery's frustrations reflects a lack of recognition of structural contingencies (Katz, 2013, Lamb, 2014) that shape people's everyday lives in dealing with the challenges that conditions like dementia can bring. It is reminiscent of Wright-Mills' (1959) critique of a taken-for-granted separation of private troubles from public issues. Margery goes on to express her worries about the future, particularly her fear that if Fred goes into care to enable her to have her knee operation, she may never get him back:

Margery: And, you know ... But I don't know, I mean, it's just that I'd be alright with my bad legs, but the thing is I still need to have my operations on my knees. But then that would mean Fred going into a home. That's the point. And, as things are at the moment, I've got the feeling that I won't get him back again.

INT: Yeah.

Margery: Do you know what I mean? It might not only be for the time that I'm in there, it might be not ever coming back, and I don't want that.

Margery's worry tells us something of their current difficulties but also reflect how Fred's increased dependency is marked by a fear and stigma associated with institutionalised care, something that has been shown to pervade the accounts and expectations of people's vision of a future with dementia (Swallow and Hillman, 2019). Consequently, there is resistance to formalised care, even for those like Margery who are struggling. Those providing care to their partners are shown to be particularly vulnerable to feelings of guilt or a sense of failure over a transition of their loved one into residential care and is often something actively resisted as a result (Statz et al., 2021).

1.3.3. Independence as a personal value

This theme reflects the representations in our participants' accounts of the value attached to forms of independence or a distancing from situations that could associate them or their loved one with forms of dependence. Alongside the challenges that Claire faces in both maintaining her own provision of care to her mum and in accessing care for her, Sally herself describes the difficulties she experiences in trying to do things for herself:

INT: So, what are the things that help for you to be able to keep trying, keep doing those things?

Sally: I just do keep trying.

INT: Um. So, you kind of push yourself to keep going?

Sally: Yeah, I can't help it.

INT: Uh huh, do you have a kind of um, like a typical day, a bit of a routine, do you tend to do the same things each day or what's the kind of typical day for you like?

Sally: I can't always do things, and that makes me so angry with me.

The anger she feels at not being able to do things, despite trying, becomes something of a mantra for Sally throughout her interviews and when asked about her health generally, she returns to this phrase again:

INT: Yeah, yeah, so how would you say you are in your, in your health generally?

Sally: Not alright but I do try.

INT: Uh huh.

Sally: I do really, really try, but it's just something what I've got to do.

Sally's account of what she does and what she can do is very much focused on her own will to try. The anger she feels when unable to do things is therefore also directed back on herself, as a failure of her own efforts.

For those like Margery who are caring for someone living with dementia, the sense of responsibility can be all consuming. Margery describes living with chronic pain, while also avoiding formal support for Fred. This is partly for fear of Fred being taken away from her and partly due to a sense of responsibility to do it alone, for as long as she can. She moves between expressing how difficult she is finding their current situation and describing her will to carry the burden alone:

Margery: I think, um, well probably my knee problem's getting worse and that's probably making me feel worse, do you know what I mean? And I end up being not able to cope because I can't, I can do a little job and then I've got to sit down. Because I can't, my legs ache terrible. Of course, Fred says, "Go and have them done," and I said, "No, I can't have them done," I said, you know, I can't really tell him he's the cause I can't.

Int: Would there be anyone else that you'd go to?

Margery: Well, I wouldn't, I, no, at the moment I don't, um, do, the carers, the, um, carers ... they send me their sort of information, you know, they've got all these different things that you can sort of go on and go to, and all the rest of it. But I've not really sort of like, um, felt the need for that yet. Yeah, so I thought, "Well, if I can manage on my own for as long as I possibly can then there might come a time when I do need help." But I don't want help if I can manage myself.

The resistance to asking for help, particularly formal help, depicted in Margery's interview reflects the value attributed to independence and of resisting formal care even in instances of pain and suffering. For those like Margery, this valuing of independence can not only be seen in their approach to the caring role but also in sublimating their own needs, like Margery not telling Fred why she is unable to commit to her knee operation.

The associations between dementia and senility and the subsequent connection to dependence and institutionalisation were described by Barbara as a means by which a person's value can be in some way compromised. This was explicitly reflected upon when she actively resisted using the word dementia:

Barbara: I suppose dementia sounds like you're going nuts. He [Barbara's doctor] says no, no ... it doesn't alter your intelligence, just alters your ability to speak to people.

Barbara specifically distances herself from the label dementia, something she perceives as carrying connotations of madness or, as the doctor suggests, a questioning of intelligence, both an affront to her sense of self and something that she feels cuts her off increasingly from

others, which marks her out as different:

INT: Do you think differently about yourself?

Barbara: Yes, yes I feel more, mmm, err, kind of closed off from everybody really in a way, I feel like I am in my own little erm, err, I don't know how to put this, what do I mean? Erm, I feel err, err, like everybody else is there and I am here in this little sort of, got this little thing, enclosed.

By using the term 'aphasia', Barbara purposefully avoids the term dementia. Avoiding diagnostic terms and labels, which connected people's experiences to forms of dependence or that can pose a risk to a valued personhood, is a common issue for those living with dementia (Quinn et al., 2018); in Barbara's case it carried a feeling of increased isolation.

The next extract is taken from an interview with Tom, husband of Sue who lives with Alzheimer's disease. During the interview with Sue, she describes her approach to living with her condition as getting on with things and relying on daily routines, particularly daily walks, and spending time with family. Tom describes a shrinking world in which Sue is increasingly reliant on him, less able to walk very far and spending less time alone or with friends outside of immediate family. The relationship Butler (2016) sets out between dependence and value, was reflected in Tom's account. He describes how Sue is increasingly anxious and agitated if left alone. I ask if he would consider a day centre or having carers come to the house and he sets out why this is not something he has considered:

Tom: I didn't want to gallop into invalidating her ... before that needed to happen and I still feel that really, I still feel that.

Tom's reluctance to use formal carers to visit and sit with his wife is based on the perception that this would invalidate her or in some way diminish her as a person. Lamb's (2014) concept of 'permanent personhood' is a useful way of characterising the cultural value placed on independence as part of the overall project of successful ageing and one that runs counter to the increased vulnerabilities and care needs that accompany the lives of those living dementia. It is based on a specific cultural ideal that requires independence, autonomy and an active commitment to deny and resist dependence and decline. Butler's (2016) argument is that this constitution of personhood denies the existence of an inherent inter-dependence and subsequently intensifies experiences of vulnerability for those affected, creating a precarity of personhood.

1.3.4. Cumulative pressures

This theme speaks to the ways in which experiences of uncertainty can multiply across different aspects of people's lives in a way that intensifies feelings of insecurity and can exacerbate the specific difficulties that can come from living with dementia. For some of our participants it was the accumulation of uncertainty itself that contributed to increased feelings of precarity. For example, if current care arrangements were unreliable or inconsistent and future care needs were deemed both unpredictable and worrying, this created a situation of increased pressure. This may be further exacerbated by connected uncertainties that intersect with those care needs, like, for example, financial insecurity. As van Eeuwijk (2020) states, 'when insecure conditions constantly recur or initial instability persists, we may speak of a chronification of uncertainty' (p. 41). Our work develops this concept as a useful marker of precarity, while also illustrating how cumulative uncertainties are intensified when there is an accompanying threat to personhood.

If we return to Sally and Claire's situation, Claire describes receiving social security benefits that support her own needs and enable her to care for her mum: employment and support allowance (ESA) and personal independence payments (PIP), benefits provided to those whose disability or health condition poses difficulties for their daily living and incur increased costs to manage. She is unsure if these benefits will continue, as she has been placed in the 'work-related activity group'.

This means that the government Department of Work and Pensions (DWP) that oversees the allocation of these benefits considers her to be capable of working in the future and expects her to be taking immediate steps towards this:

Claire: I used to take her out to a lot of places and what have you but erm I've now got ESA and PIP, erm they've put me in the working related group but at the minute the pain is just, don't even go there. Erm it's hard but mum has actually got a lot more understanding, she understands when I have to sleep, erm because when I go to sleep that is a case of just sleep but I can't do half of what I used to and it's even hard for me to comprehend that I can't do the head says yes, the body says no.

In Sally and Claire's case, vulnerabilities in relation to care needs may accumulate not just over an individual's life course, affecting their access to care choices, resources and services, but also accumulate across support networks where insecurity in accessing care may affect both those living with dementia and those caring for them. The uncertainties of managing Sally's care needs are exacerbated by financial insecurity resulting from the uncertainty over the continuation of Claire's social security benefits.

Cumulative pressures may also occur when difficulties experienced as part of living with dementia and the struggles incurred in seeking access to relevant care and support result in frustration and anger being directed back on oneself, reflecting entrenched values of independence. The pressures experienced because of cumulative uncertainty are more intensely felt when those pressures are perceived through the lens of individual responsibility. Mavis' account of the difficulties she faces is presented as a consequence of her own failings. When exploring why she lacks motivation to do things, she initially talks about a lack of confidence and a feeling of safety but then rests on laziness as the best explanation:

Mavis: I would love to go out walking, but I never feel safe without (gestures to her walking frame), I've got another one out there what I bought, but I don't think I push myself enough to do it.

INT: Mm. Yeah, do you have an idea why you think that is? Is it just a lack of, kind of, q motivation?

Mavis: A lack of confidence, I think.

INT: Or a lack of confidence. Yeah.

Mavis: Yeah, mm. I won't push myself to do anything, you see.

INT: Yeah.

Mavis: I think the best word would be "lazy", no, really. Mm. Because I've always been able to do everything for myself, I think just somebody's knocking on my door, you know, no, not that's not quite the phrase I should have said, but, em, I mean everybody would help me. I feel useless when they say, "Well, we'll help you do it." And I really want to do it on my own.

Mavis suggests that doing things with the help of others feels like a failing or perhaps a reminder that she is more dependent on others, so much so that she tends not to do things at all. Cumulative pressures are therefore the result of both the 'chronification of uncertainty' regarding care needs (van Eeuwijk, 2020) and a feeling of personal responsibility to manage them.

2. Discussion

This paper contributes to a growing body of research using precarity to make sense of the lives of older people, and particularly those living with or caring for someone living with dementia. Our analysis highlights the contextual circumstances of our participants' and their vulnerabilities across multiple domains, including relationships and support networks and a striving for security, as well as socio-cultural norms of

value.

Our study extends and refines previously identified markers of precarity in several ways. Firstly, we have drawn on work from medical anthropology that utilises precarity as a framework for understanding illness experiences, as it attends to the connections between those experiences and their associated care needs and a striving for greater security (see [van Eeuwijk, 2020](#)). This provides a useful mechanism through which to connect the uncertainties that our participants' experience in navigating and securing care, with social and cultural meanings associated with dementia and related forms of dependence. It is the development of this connection that is central to the utility of precarity as a framework for understanding the variability in the experiences of those living with dementia, whereby threats to personhood may be more intensely felt for those whose lives may be characterised by other forms of insecurity.

Our work extends a recognition of 'situated biologies' ([Niewöhner and Lock, 2018](#)) whereby disease is shown to be manifest through its subjective experience and shaped by social circumstances, including the ways in which it is perceived by the person themselves and represented by others. Research shows that older people draw on the social and cultural representations available to them to make sense of their experiences ([Cluley et al., 2021](#)) and therefore the stigma of institutionalised care and other markers of the fourth age ([HiggsLeontowitsch et al., 2009](#)) play an important role in the disproportionate experience of vulnerability felt by some of our participants living with dementia. Indeed, an increasingly central component of dementia care involves the resistance to or substitute for apparent absences in conventional constructions of personhood ([Gjodsbol et al., 2017](#)). Our study utilises these anthropological concepts related to cultural framing of illness experiences to identify and further develop markers of precarity.

Secondly, our analysis strengthens the previously identified marker of precarity, that of cumulative pressures ([Portacolone, 2020](#)). We have shown the multiple challenges and uncertainties that some of our participants experience in meeting care needs and how these can sit alongside worries about uncertain futures and a devaluing of lives characterised by increased dependence. We contribute further to the development of this marker, by illustrating how forms insecurity can extend not just into an individual's later life, but also through networks of support. This development calls for a recognition of our inherent inter-dependence ([Butler, 2016](#)) but also demonstrates how forms of precarity can affect individuals, families and communities.

Thirdly, we have shown how uncertainties regarding the meeting of care needs must also consider the unpredictability and inconsistencies of care itself. This creates further insecurities, particularly in the context of the uncertainties that dementia itself creates, whereby the nature of a person's dementia symptoms, when they develop and the specific ways individuals and families experience them, are uncertain, creating new and unpredictable care needs.

As our data illustrates, these uncertainties regarding dementia's progression can also often sit alongside multiple chronic conditions, which can impact on the quality of life of those living with dementia ([Nelis et al., 2019](#); [Fox et al., 2014](#)). Our paper illustrates that the uncertainties related to dementia itself further intensify the challenges and insecurities that arise from accompanying physical vulnerabilities and the capacities and resources available to individuals and families to manage them.

Finally, we have illustrated how the value attributed to forms of independence position our participants as free to choose the best course of action, support and care while also being ultimately responsible for the consequences of those choices. The circumstances shaping and restricting choices become subsumed within the discourse of independence so that uncertainties over how to cope and manage fall increasingly to individuals and families, rather than identifying systemic sources of support or the systemic failings that may be contributing to the challenging circumstances they face. An illustration of this responsibility could be seen during the pandemic, where there was an

intensification of feelings of responsibility to cope alone for those living with or supporting someone living with dementia ([Pentecost et al., 2022](#)). Such feelings of responsibility in the face of global challenges are particularly pertinent in the contemporary context, with war and climate change playing a substantial role in current cost of living crises.

The resultant feelings of worry as a consequence of challenging circumstances are more likely to be interpreted by our participants as personal dispositions rather than social problems ([Beck et al., 2003](#)), or – as in the case of Sally or Mavis – as personal failings. Precarity, if understood in this way, represents a vicious circle whereby the effects of the circumstances people find themselves in are increasingly directed inwards, intensifying feelings of vulnerability and undermining more collective responses.

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Author contributions

All authors contributed to the critical revision of the article and approved the version to be published.

Data availability

IDEAL data were deposited with the UK data archive in April 2020. Details of how to access the data can be found here: <https://reshare.ukdataservice.ac.uk/854317/>.

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