

QUALITATIVE PAPER

Experiences and understanding of apathy in people with neurocognitive disorders and their carers: a qualitative interview study

CLARE BURGON^{1,2}, SARAH GOLDBERG¹, VERONIKA VAN DER WARDT³, ROWAN H. HARWOOD^{1,4}

¹School of Health Sciences, University of Nottingham, Nottingham, UK

²Hearing Sciences, Mental Health and Clinical Neurosciences, School of Medicine, University of Nottingham, Nottingham, UK

³Department of General Practice/Family Medicine, Philipps-Universität Marburg, Marburg, Germany

⁴Nottingham University Hospitals NHS Trust, Nottingham, UK

Address correspondence to: Clare Burgon, NIHR Nottingham Biomedical Research Centre (Hearing), Hearing Sciences, Mental Health and Clinical Neurosciences, School of Medicine, Faculty of Medicine and Health Sciences, University of Nottingham, Ropewalk House, 113 The Ropewalk, Nottingham NG1 5DU, UK. Email: Clare.Burgon@nottingham.ac.uk

Abstract

Background: apathy, defined as reduced goal-directed activity, interests and emotion, is highly prevalent in neurocognitive disorders (NCDs). Apathy has important consequences for the individuals who experience it and their carers, yet the lived experiences of apathy in this population are not well understood.

Objective: to explore how people with NCDs and their carers understand and experience apathy.

Method: in-depth semi-structured interviews were conducted in participants' homes. Sixteen people with NCDs (dementia or mild cognitive impairment) and 14 carers, living in four geographical areas of England, took part. Interviews were audio-recorded and transcribed verbatim. Transcripts were analysed using reflexive thematic analysis.

Results: four themes were generated: 'Apathy is Poorly Understood'; 'Too much trouble: Mediating Effort and Outcome'; 'Preserving Identity in the Face of Loss of Capability and Autonomy' and 'Opportunity and Exclusion'.

Conclusion: apathy is experienced as an understandable response to the everyday struggle people with NCDs face to preserve identity in the face of threats to capability and autonomy and is exacerbated by the lack of support and opportunities. Social and environmental modifications may help reduce apathy. In line with previous qualitative research, this challenges the dominant view of apathy as a neuropsychiatric symptom that excludes the social–environmental context.

Keywords: apathy, qualitative research, dementia, mild cognitive impairment, neuropsychiatric symptoms, older people

Key Points

- We emphasise the social–environmental context in our understanding of apathy.
 - Apathy is experienced as an understandable response to difficulty in the face of threats to capability and autonomy.
 - Apathy is poorly understood: it is an unfamiliar term with varied and negative interpretations.
 - Apathy is exacerbated by the lack of support and opportunities.
 - Social and environmental modifications may help reduce apathy.
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Introduction

A fundamental problem for people living with dementia is the progressive failure to undertake necessary or desired daily activities. Apathy is a potentially important contributor to this, with no currently available effective therapeutic interventions [1]. Apathy is a multidimensional construct that is broadly defined as reduced goal-directed activity in cognitive, behavioural, emotional and social domains [2, 3] and may present as reduced initiative, interest, emotion, motivation and effort [4]. It is highly prevalent across Neurocognitive Disorders (Ncds), including different types and severity of dementia [5, 6] and Mild Cognitive Impairment (MCI) [7, 8]. Apathy is associated with impaired functional ability in people with dementia; carer burden [9]; and future progression to MCI in the cognitively intact [10], dementia in people with MCI and subjective cognitive complaints [11] and severe dementia in people with early Alzheimer's Disease (AD) [12]. Furthermore, carers may not understand apathy, despite its negative impacts on their well-being and their caregiving role [13, 14].

Despite this, there are disagreements about what constitutes apathy, how it develops, how it impacts people with NCDs and their carers and how it can be managed or treated [5, 15, 16]. There is an argument to move beyond neurobiological explanations and explore the lived experience of apathy in NCDs [1, 17], which is best done using qualitative methods [18–20]. Four previous qualitative studies exploring apathy have been conducted [21–24]. However, the range of participants included in these studies has been limited: two studies investigated people living with Parkinson's disease [23, 24]; one in AD [21] and one was a study of carers [22]. Therefore, our study aimed to explore how apathy is understood and experienced and the impact of apathy on the lives of people with a variety of NCDs and their carers.

Method

Recruitment and data collection

Participants were those taking part in a randomised controlled trial (RCT), Promoting Activity Independence and Stability in Early Dementia (PrAISED; ISRCTN registration: 15320670), methods for which have been described elsewhere [25, 26]. Briefly, participants were recruited at five sites and visited at baseline and 12 months later to undergo various physical, cognitive and well-being assessments. Participants had diagnosed dementia or MCI, a Montreal Cognitive Assessment score [27] of 13–25, were able and willing to take part in an exercise-based intervention and had the mental capacity (formally assessed by a researcher) to give informed consent. For the interview study, maximal variation sampling was used to recruit a diverse sample from the pool of possible PrAISED participants with respect to diagnosis, gender, ethnicity, locality, carer relationship, cognitive abilities and scores on the Apathy Evaluation Scale [28]. Twenty-eight participant dyads were approached to

take part in this interview study about daily life, feelings, social life and interests. Participants gave written informed consent to take part.

The PrAISED studies received ethical approval from the Bradford Leeds Research Ethics Committee (Reference 18YH/0059). In-depth face-to-face semi-structured interviews were conducted by a female researcher (C.B.) with experience working with people with NCDs. Interviews were guided by an interview schedule (Appendix 1), which was revised iteratively throughout the study and initially developed from criteria for apathy, as well as feedback from a patient and public involvement (PPI) advisory group (held on 15th February 2019). The PPI group was composed of older adults, people with experience in caring, and people with dementia. The PPI group also helped inform the study design, including the decision to avoid using the term 'apathy' in the participant documents and initial stages of the interview and instead use terminology relating to its components (i.e. activities, interests, emotions and social life), to reduce stigma and ensure shared understanding. The term apathy was introduced during interviews to explore participants' understanding and thoughts on this term.

Interviews were audio-recorded and transcribed verbatim. Field notes were made after each participant interview. Recruitment and interviews occurred between September 2019 and December 2019. All interviews were conducted at participants' homes and lasted between 38 and 115 minutes.

Analysis

Reflexive thematic analysis was used to analyse the data, which involves the construction of rich meaning rather than simply summarising what participants have reported [29]. Audio-recordings were listened to numerous times, and transcripts were read and re-read (by CB) to check for accuracy and allow for data familiarisation. Notes about tentative ideas and points of interest were made throughout.

Complete coding was conducted through two main cycles, using NVivo 11 Pro. During the first cycle, initial inductive codes were generated by C.B. (all transcripts) and V.v.d.W. (two transcripts). In addition, two PPI members, self-selected from the wider PPI group, read two transcripts each, providing observations and insights, focusing on what they felt was interesting about the data, which helped generate new codes and ideas in the second coding cycle. The second cycle (by C.B.) focused on deductive coding, in which codes were produced from previously theorised mechanisms of apathy [1, 30–32]. Some deductive codes were later discarded due to lack of relevance, while others added new understandings to the transcripts, or encapsulated or subsumed existing codes, which helped further refine the initial codes. This was an iterative process of refining, grouping and organising codes into a codebook. The working codebook was frequently discussed at team meetings (with C.B., S.G., V.v.d.W. and R.H.) and was used to develop candidate themes. Candidate themes were presented (by C.B.) to the team, and subsequent discussion led to the

Table 1. Participant characteristics

Person living with NCD characteristics								Carer characteristics				
Name ^a	Gender	Age (years)	AES score	MoCA score	Highest level of education	Diagnosis	Ethnicity	Name ^a	Gender	Age (years)	Relationship to participant	Ethnicity
Mary	Female	66	51	18	College/ university	AD	White	Charles	Male	70	Spouse	White
David	Male	69	47	23	Secondary	AD	White	Patricia	Female	69	Spouse	White
John	Male	87	50	24	College/ university	VaD	White	Betty	Female	85	Spouse	White
Rahul	Male	76	24	20	College/ university	Mixed	South Asian	Ruby	Female	71	Spouse	White
Peter	Male	73	51	22	Secondary	MCI	White	Diane	Female	69	Spouse	White
Robert	Male	66	50	20	Secondary	AD	White	Sandra	Female	61	Spouse	White
Paul	Male	72	41	23	Secondary	VaD	White	Karen	Female	50	Child	White
Adrian	Male	73	42	21	Secondary	VaD	White	Susan	Female	71	Spouse	White
Chris	Male	91	41	20	College/ university	AD	White	Judith	Female	89	Spouse	White
Anne	Female	87	47	16	College/ university	AD	White	William	Male	87	Spouse	White
Stephen	Male	70	26	16	Secondary	MCI	White	—	—	—	—	—
Richard	Male	77	63	21	College/ university	AD	White	Martha	Female	73	Spouse	White
Helen	Female	66	29	24	Secondary	MCI	White	—	—	—	—	—
Nick	Male	85	59	19	Secondary	VaD	White	Cynthia	Female	76	Spouse	White
Linda	Female	67	64	17	Secondary	AD	White	Donald	Male	67	Spouse	White
Jean	Female	85	66	16	College/ university	AD	White	Joseph	Male	74	Spouse	White

AES, Apathy Evaluation Scale [28] (higher score indicates greater apathy, with a maximum possible score of 72); MoCA, Montreal Cognitive Assessment [27] (higher score indicates greater cognitive ability, with a maximum possible score of 30); VaD, vascular dementia. ^aNames have been changed.

review and refinement of themes over further team meetings to produce and define the final themes and sub-themes.

Results

Participant characteristics

Sixteen people living with NCD and fourteen carers participated. Two people living with NCD were interviewed alone, while the remaining 14 preferred a dyadic interview. People living with NCD resided in four different geographical areas in England: Nottinghamshire ($N = 4$), Derbyshire ($N = 5$), Lincolnshire ($N = 4$) and Bath and North East Somerset ($N = 3$). Individual participant characteristics are detailed in Table 1.

Themes

Four themes were constructed: one descriptive, 'Apathy is Poorly Understood', and three interpretive: 'Too much trouble: Mediating Effort and Outcome', 'Preserving Identity in the Face of Loss of Capability and Autonomy' 'Opportunity and Exclusion'.

Apathy is poorly understood

This theme captures participants' lack of understanding of apathy and instances where people living with NCD displayed apathy.

Participants' interpretations and understandings of apathy varied. To some, it was an unfamiliar term, while others interpreted it negatively and did not wish to be associated with it.

Charles: *[Apathy]'s a bit of a negative word really.*

Mary: *It is a bit of a negative word. [...] I think it is a bit negative. And I prefer to think about . . . what's happening rather than-*

Charles: *I think motivation is the—reasonably more accurate. Certainly in her case, rather than apathy, it's not—she's . . . < sighs > lacking in . . . well you know it's subtle isn't it.*

(Mary, 66-year old with AD, and Charles, 70-year-old carer)

Despite this, most participants experienced what is typically described as apathy, i.e. lack of or reduced: motivation, initiation, activity, interest, social engagement and emotion.

I just don't care anymore. I can sit here all day looking out of that window without even thinking about it. (Chris, 91-year-old with AD)

Some participants found it difficult to explain these experiences, describing a lack of drive or 'get up and go'. Overwhelmingly, people living with NCD and carers' explanations for these experiences were that many activities had become more difficult.

Too much trouble: Mediating effort and outcome

This theme includes the difficulties, failures and setbacks participants experienced in everyday life (subtheme 1: 'Daily

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Struggle'), and how this could make things not worth doing, unless particularly necessary or purposeful (subtheme 2: 'Impact of Consequence and Purpose').

Daily struggle

Participants' accounts of their experiences were characterised by an overarching sense of struggle and effort due to physical and cognitive impairment.

Cognitive impairment often meant that participants found daily activities difficult and made more mistakes than they expected and more than previously (i.e. prior to their cognitive difficulties). They described problems with attention, forgetting to do things, difficulty making decisions and difficulty navigating the nuances of social interaction.

[talking to her husband:] You don't think as clear do you? Things don't come so easy to you do they? (Susan, 71-year-old carer)

Many also experienced physical impairments associated with ageing or comorbidities, such as problems with mobility, fatigue and ill health, which also resulted in experiences of difficulty and struggle. Both cognitive and physical impairments meant that everyday life was more effortful or 'harder work'. People living with NCD often experienced setbacks and failure, even with previously simple tasks. This feeling of struggle and additional effort was beyond specific instances and situations but reflected a general experience.

He can't walk like he used to. And he can't think like he used to. [. . .] now everything is an effort (Martha, 73-year-old carer)

[to Adrian]: Even just little things, you struggle, don't you? Just to get it straight (Susan, 71-year-old carer)

Impact of consequence and purpose

The additional effort and struggle which participants faced meant that they were less willing to act and less engaged or interested. In particular, they tried to avoid negative consequences, and activity without perceived purpose or necessity was not worth the effort or risk.

Difficulties experienced by people living with NCD were frustrating and caused them anxiety and stress. At the same time, people living with NCD were less resilient, and could become more easily overwhelmed than previously.

He can't cope with stress like he used to, can't cope with any sort of stress now (Ruby, 71-year-old carer)

The combination of increased vulnerability, difficulty and effort meant that people living with NCD had to adopt a slower pace, both physically and mentally. People living with NCD described doing what they were able and opted for convenience and easier alternatives where possible.

On the whole it's because it's too much effort. It's easier not to do it. (Jean, 85-year-old with AD)

Participants considered it unsurprising and reasonable that people living with NCD sometimes gave up, were less interested in and avoided doing activities that they were unable to do, found difficult, no longer enjoyed or resulted in negative feelings of failure or frustration.

So that's why I don't do much, because I just can't do it. (Robert, 66-year old with AD)

I used to like crochet. Started once before, but then I stopped, but I wished I hadn't stopped now. [. . .] it just seemed too much trouble. I couldn't get it done quickly enough for what I wanted to do. (Jean, 85-year-old with AD)

People living with NCD frequently did not engage where they felt something was not necessary or purposeful. For example, Chris disclosed: 'Now, I avoid doing anything I don't have to do. And I say that seriously [. . .] Just the effort of doing it is difficult'. However, he later stated he did an activity 'if it's got a purpose', which for Chris was to ensure his wife, who had health problems, was not over-burdened with housework. People living with NCD's perceptions about purpose and necessity informed whether something was deemed worth the effort. Likewise, people living with NCD who felt something was not their responsibility or role were less interested in participation.

Could it be we've just got in a rut, where I do it, and he knows I will do it? (Martha, 73-year-old carer).

Carers' beliefs were influential, and they could help maintain the care recipients' involvement by setting them purposeful tasks.

I try and encourage her—I give her small shopping lists so she can go up . . . sometimes two or three times a day, don't you? (Charles, 70-year-old carer)

However, carers' encouragement was not always effective, particularly if it was at odds with the views of the person they cared for.

In summary, participants appeared to react to avoid negative consequences associated with cognitive and physical impairments by avoiding difficult activities. Cognitive impairment appeared to additionally reduce the ability of people living with NCD to cope with stress and failure, resulting in greater sensitivity to these negative outcomes. This may further increase the need for tasks to be necessary and purposeful to motivate people living with NCD.

Preserving identity in the face of loss of capability and autonomy

Loss of abilities meant that people living with NCD experienced threats to their identity as a competent and autonomous individual (subtheme 1: 'Threatened Identity'), and they made attempts to combat this, which could occur through withdrawal and avoidance (subtheme 2: 'Preserving the Capable and Autonomous Self').

Threatened identity

As a result of experiencing struggle, some people living with NCD expressed generalised feeling of incompetency and loss of confidence, for example, Robert felt *'that's regular that things go wrong for me'*. They were sometimes faced with a mismatch between their own expectations and that of others (based on previous capabilities) and their present capability.

I used to get angry with myself, because I knew I could do it, but somehow I couldn't. (Linda, 67-year old with AD)

People living with NCD frequently experienced challenges to their sense of autonomy. Declining abilities resulted in a reliance on others for support, and restrictions were sometimes imposed by carers because of concerns for safety. Furthermore, the decline in abilities was seen as unavoidable, even when this was not a result of NCD, and slowing down was seen as an inevitable part of old age. This lack of control was further seen in expressions of feelings of powerlessness and power imbalances, with carers taking on more responsibilities and new roles.

She's the one telling me off all day. I'm doing things wrong. (Adrian, 73-year-old with VaD).

People living with NCD were faced with giving up part of their self and experienced a change in their identity. However, they often did not wish to be seen as someone different and found challenges to their competent and autonomous self difficult to accept.

Annoyed. . . with myself. You know? Yeah, when I think what I used to be like and what I'm like now. (Stephen, 70-year-old with MCI)

Preserving the capable and autonomous self

This subtheme describes how people living with NCD sometimes attempted to preserve their sense of capable and autonomous self, through active avoidance and resistance, or alternatively chose to move on and focus on what they could do, leaving behind what they could no longer do.

People living with NCD could be embarrassed or 'proud' and did not wish to be seen as incompetent, or assume a lower status, particularly if this contrasted to their previous sense of self. This sometimes resulted in avoiding and even resisting encouragement, in particular situations that were new or unfamiliar, outside their comfort zone, and would expose them to these challenges, such as situations where they had to assume a lower status or risk experiencing failure.

It sounds awfully big headed but I don't really like that, after being top dog and sort of organising everything, I might find it a bit difficult not to. I would want to interfere, and I can't do that. To be honest, I know it sounds big headed but [. . .] I would want to take control [. . .] even if I haven't got the capacity or capability to do it, I'd still feel I would want to if I was there. (Jean, 85-year-old with AD)

Others did not outwardly resist requests from others, but frequently deferred activities until 'tomorrow', but these did not occur despite encouragement. People living with NCD enjoyed and engaged with activities of their own choice, and those in which they could take on a role with higher status and feel in control, supporting their feelings of competency and autonomy.

[when discussing gardening in their retirement village:] *Ninety percent of the people that are here couldn't do anything anyway. If they bent down they wouldn't be able to get up again. Um, so I'd jump in for that [doing their gardening], without a doubt.* (Peter, 73-year-old with MCI)

Though autonomy was under threat, it was important to people living with NCD and carers that they retained their independence where possible, and this was seen as key to engagement and interest. However, carers sometimes found it difficult to balance people living with NCD's need for independence with their need for support and supervision.

I'm trying not to be controlling and it's hard to get that balance, because sometimes you just have to step in and sort something out [. . .] You don't want to take over all the roles either. I don't wanna sort of say right every night I'm gonna do that then we're gonna do this cause it just devalues Mary's contribution and makes her more dependent still. So it's trying to get that . . . happy balance. Which doesn't always work but we try to make it work. We try and share it out. So there's still a fair bit of responsibility still with Mary, but within safe limits. (Charles, 70-year-old carer)

In contrast to avoidance and resistance, some participants felt they had to accept the changes they experienced, which enabled them to let go of what they could no longer do, and focus on their present capabilities. However, this acceptance sometimes meant giving up activities and losing interest in previously enjoyed activities.

Well, it's one of those things. If you can't do it you can't, can you? And um, I don't rail against things that I can't do, I just get on and do the things I can do, which isn't very much. (Anne, 87-year-old with AD)

Opportunity and exclusion

People living with NCD required supportive contexts and the help of others to remain engaged and participate in a meaningful way. However, they sometimes faced exclusion, and others were not always able to meet their additional needs.

Opportunities in the environment encouraged participation and engagement. Carers that were able to take on an organiser role could help people living with NCD remain engaged. However, some participants who struggled to navigate civic society and services were not sure what was available and were not provided with the same opportunities for engagement. Some people living with NCD felt there were no options for meaningful activity.

I don't worry about it, just. . . sit here. That's all you can do. She says I don't do nothing, I'm sat here all day. But what else can I do? (Nick, 85-year old with VaD)

Socialising was seen as inherently positive, although sometimes not enjoyed by the people living with NCD who could find this difficult. Support networks, particularly familiar friends, provided an important sense of security and confidence, which in turn supported engagement and mood. Social networks, and carers in particular, were important providers of opportunities and facilitators of engagement. Some participants experienced a loss of social support, due to others having their own problems, but sometimes people avoided people living with NCD, due to their condition.

My mates used to come, but since the Alzheimer's, they haven't bothered [. . .] I think they feel embarrassed, or they're frightened, or what have you, so they don't come. (Robert, 66-year-old with AD).

Reducing the difficulty and effort of everyday life was an important need that had to be met to support participation. Without supportive contexts, such as accessible and familiar environments, prompting, routines and set scheduled activity, people living with NCD experienced difficulty and could find it difficult to be active and interested.

If I haven't got anything arranged I'm terrible. Like I say, I'll just stay in bed in the morning, instead of getting up and doing something. (Helen, 66-year old with MCI)

People living with NCD found that their environment was not always inclusive of someone with cognitive or physical impairment. Others sometimes lacked understanding and failed to provide extra support or cater for dementia symptoms, resulting in exclusion.

I said I'm finding it difficult to follow you, can you give me notes? He said no, I won't give you notes. That's what he said. [. . .] and he gave notes at the end but then, the notes didn't make any sense to me. (Rahul, 76-year-old with MD)

Carers frequently facilitated and adapted people living with NCD's activities to make them more manageable, and they tried to prompt, engage and motivate the person they cared for.

We've left [the Christmas cards] on the table, to remind him [. . .] But he kept forgetting. [. . .] My sister's written a list of what he needs and then, to encourage him a bit further, I've been writing little [. . .] notes [. . .] for the spelling because you forget don't you? And he's been doing them. (Karen, 50-year old carer)

However, carers' involvement could lead to them missing out on their own interests and when carers took on more responsibilities, this could result in less freedom for both people living with NCD and carers. Moreover, carers were limited in their abilities to encourage motivation, and sometimes had to prioritise their own well-being. This could mean taking over completely or giving up altogether, rather than try the difficult task of involving and encouraging the person they cared for.

[To Jean:] I mean in the end I just gave up quite frankly. [. . .] it's just a waste to have a row with you to get you physically wound up enough to make you do something. You can't go on doing it, it's not good for my blood pressure apart from anything else. (Joseph, 74-year-old carer)

Discussion

This study explored how apathy is understood and experienced and the impact of apathy on the lives of people living with NCD and their carers. Apathy was not well understood or recognised as part of the NCD, and instead participants experienced apathy as a natural reaction to changes in cognitive and physical ability and associated threats to their identity, which were aggravated by exclusion and lack of social support.

The finding of varied interpretations, lack of understanding and dislike of the term apathy was in contrast to a previous qualitative study of apathy in people with AD, where understandings of apathy were found to be consistent with current definitions [21]. This could reflect the difference in approach, as we invited potential participants to talk about activity, interests, and emotions instead of using the term apathy (which was only introduced later to ascertain participants' views of the term), enabling the inclusion of participants who were less aware of the concept of apathy in NCDs. This is consistent with another qualitative study with carers (about general experiences of caring rather than apathy *per se*), which reported that carers found apathy difficult to understand [33].

It has been proposed that apathy is the result of an impairment in the reward-based decision-making process, in which effort and consequences are inaccurately estimated, reducing the likelihood of exerting effort for potential reward [30, 32]. While the participants in this study did seem to be making judgements about potential effort and consequences, these often appeared to be reasonable conclusions based on previous experience of struggle, failure and negative emotional consequences. This is supported by other qualitative studies that have found people with AD disengage due to experiencing a struggle and stigma [21] and to avoid negative consequences such as failure and stress [34, 35]. Similarly, it has been concluded that people with Parkinson's disease and apathy make realistic changes to activities and interests in response to their impairment [24]. However, it has been argued that this could be explained by people living with NCD holding pessimistic views, which are only sometimes based on actual experience [21]. It is therefore possible that experiences of struggle, effort and failure in NCDs may result in a hypersensitivity to negative consequences, so that in addition to avoiding expected negative consequences, consequences are more likely to be predicted to be negative, and a more risk-averse approach is adopted.

We found that people living with NCD experienced threats to their feelings of capability and autonomy, which could result in feeling permanently changed or lead to withdrawal, avoidance, resistance and sometimes acceptance. Loss of self in the context of illness has long been reported [36] and may be exacerbated in dementia where people living with NCD are aware of inevitable decline [37]. Meta-syntheses of qualitative studies have demonstrated that changes experienced in dementia, in particular memory problems, and the diagnostic label itself threaten individuals'

overall identity and sense of competency and autonomy, which in turn further threatens identity [35, 38, 39].

Autonomy and competency are inherent universal basic psychological needs within self-determination theory, a motivational theory which posits that their fulfilment enables individuals to seek interesting and enjoyable activities and engagement with others [40]. Self-determination theory proposes that when these needs are thwarted, individuals can develop maladaptive strategies to cope, such as withdrawal, resulting in negative outcomes such as loss of motivation and psychological distress [41]. Previous qualitative studies have found people living with NCD experience threats to their autonomy and competency, sometimes reacting with withdrawal, resistance, disengagement, distraction and redirection to protect themselves and their identity [24, 33, 35, 38, 39]. While people living with NCD in our study often used these avoidance strategies, they also sometimes accepted their impairments and the changes they brought. This acceptance has previously been characterised as a more 'adaptive' [33] coping strategy to preserve identity, in which, as in the present study, people with dementia adjusted to the changes they experienced through reluctant acceptance or making active decisions to move forward, focusing on what they could still do rather than what they were no longer able to do [35, 38, 39]. This apparently 'adaptive' coping strategy could still mean less engagement and narrowed interests and activities, both in the present study and others [38, 39]. Therefore, withdrawal, avoidance and reduced interests and activities seen in apathy may be at least partly understood as responses to threats to basic psychological needs of autonomy and competency to retain identity.

The impairments and increased needs of people living with NCD meant that they required additional support to remain engaged and participate in a meaningful way, yet others with whom they interacted were not always able to meet these additional needs and people living with NCD sometimes faced exclusion. This is consistent with Kitwood's notion that increased 'work' was required of carers to enable people living with dementia to be included, occupied and related to [42]. The finding of exclusion is consistent with the findings from a qualitative study of people with Parkinson's disease, in which participants were said to experience 'psycho-emotional disablism' [24]. Our findings suggest that apathy can be managed at least in part by environmental alterations, including carers' directed efforts to encourage engagement [22, 23, 43], yet carers and people living with NCD show varied and sometimes limited understanding of 'apathy' [13, 14, 33]. This highlights the need for sufficient information, education and support for carers, as well as accessible services, and dementia-friendly communities to effectively support people with NCDs experiencing apathy [19, 33]. Education could include providing information on the occurrence and possible causes of apathy in NCDs. Recommendations to manage apathy could include the promotion of routines, familiarity, adaptations to reduce the effort of activity, engaging people living with NCD with

established interests and social support groups and providing opportunity for purposeful or necessary activity. However, it is important to recognise that purposeful activity becomes increasingly challenging to achieve as dementia progresses, as identified by a meta-synthesis of qualitative studies with people with dementia at various stages [38]. Meaningful engagement may need to be reconsidered towards the later stages, where more passive activity, such as observing others, may suffice [44]. Pool et al. have emphasised the importance of matching abilities ('activity levels') with what is offered at all severity levels in dementia [45]. Furthermore, while it is suggested that the provision of social support groups could reduce apathy, it is also recognised that reduced engagement and interest in socialising may form a part of apathy itself [3], highlighting the challenges of this type of intervention in practice.

Definitions and proposed 'diagnostic criteria' for apathy in NCD have consistently excluded behaviours that are exclusively the direct result of cognitive or physical impairment and environmental context [2, 3, 46]. However, our study indicates that problems due to cognitive and physical impairment, lack of opportunity or social support, and exclusion may not be separable from apathy. While the role of neurobiological changes in apathy is not contested here, the role of the environment, in particular, social support and opportunities must not be underplayed [42]. The process appears to be more complex and nuanced than diagnostic criteria allow for. Conceptual biopsychosocial models of apathy have attempted to recognise the role of caregiver and environmental factors in apathy [1]; future research may benefit from redirecting efforts away from categories and criteria based on neurobiological models towards management and understanding of individuals' experiences. In the absence of interventions that substantially change the neurobiology of apathy, this would allow a focus on elements that may be easier to alter in practice, such as opportunities and practical support, and is consistent with recommendations for the use of personalization in non-pharmacological treatments for apathy [47].

Strengths and limitations

Culture influences how NCDs are experienced [48], so it is important to recognise that our findings should be understood within their context. Participants were mostly of white ethnicity. All people living with NCD in this study were aged 65 or over, which may explain the focus on comorbidities and physical impairment in the second theme.

A major strength was that we interviewed people living with NCDs rather than relying solely on the proxy views of carers. All but two people living with NCD chose to be interviewed with a carer in this study, and no carers took part in an interview on their own. This may have restricted how open and honest people living with NCD and carers felt they could be in front of one another. Carers tended to express the experience of the people living with NCD and spoke little of the impact on themselves. However, it also may

have allowed people living with NCD to be more supported in expressing themselves, and the back-and-forth discussion between participants enabled useful insights that may not otherwise have been realised.

Conclusion

Though apathy may occur due to neurobiological changes, it should not be considered in isolation from cognitive and physical impairment and the wider context. Apathy is experienced as an understandable response to the everyday difficulties people with NCDs face and could be understood, at least in part, to be a coping mechanism to preserve identity in the face of waning abilities and threats to competence and autonomy. This is exacerbated by a lack of support and opportunities and highlights that improvements in the environment, including social support, may help reduce apathy. Our findings echo and expand upon qualitative research regarding apathy in people with Parkinson's disease [23, 24], AD [21] and carers of people with AD [22].

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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