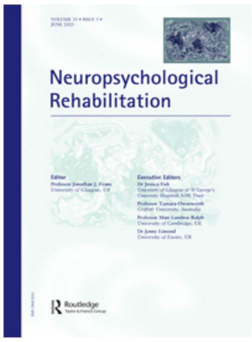

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The meaning of apathy in Huntington's disease: A qualitative study of caregiver perspectives

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ABSTRACT

Although one of the most prevalent and impactful features of Huntington's disease (HD), little is known about the impact of apathy on HD caregivers, although there is evidence it affects perceptions of distress and burden. Given the importance of the caregivers, we aimed to explore the lived experience of people supporting someone with HD and associated apathy. Semi-structured interviews were conducted with 11 caregivers and analysed using reflective thematic analysis, informed by a phenomenological framework. Five overarching themes were produced: (1) What even is apathy? (2) It makes my life harder: the practical impact of apathy, (3) They haven't forgotten me, but they have forgotten that they ever loved me, (4) I'm grieving for someone who hasn't died yet, and (5) I need a safe space to say what I really feel without fear of judgement. Inter-woven between these themes were complex narratives about the unspoken nature of HD, the invisibility of caregivers who felt trapped and unheard, and the one-sided nature of loving someone with the disease. Findings are discussed in relation to theoretical frameworks of anticipatory grief and ambiguous loss, and situated within the wider literature on caregiving for people with a neurodegenerative condition.

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Reflective thematic analysis; Huntington's disease; Caregiver; Apathy

Introduction

Huntington's disease (HD) is a rare, genetic, neurodegenerative disease, (Bates et al., 2014) which affects approximately 8.2 people per 100,000 in the United Kingdom (UK) (Furby et al., 2022). It is characterized by a triad of abnormal

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movements (Reilmann et al., 2014), cognitive impairment (Stout et al., 2023) and psychological features (McAllister et al., 2021) which progress slowly over a 10–15 year period (Furby et al., 2022).

Although heterogeneous in nature there is increasing recognition of the impact of early cognitive and psychological changes, which include impairments in executive function (Stout et al., 2023; Tabrizi et al., 2009), social cognition (Cavallo et al., 2022; Mason et al., 2021), depression, anxiety, and apathy (Brandt, 2018; Martinez-Horta et al., 2016; Stoker et al., 2022). Despite motor features being the most obvious sign of HD, it is the severity of non-motor changes that have greatest functional impact, predicting loss of independence and need for residential (Dawson et al., 2004).

Due to the progressive nature of the disease, it is inevitable that someone with HD will ultimately need support to live their life (Simpson et al., 2016). With the average onset of HD occurring during midlife (Furby et al., 2022), at a time when most people are already managing considerable work, family and financial responsibilities, caring for someone with HD can be complex (Domaradzki, 2015). In later stages of the disease, specialist care is needed, typically in institutionalized care facilities, but these are expensive (Jones et al., 2016; van Walsem et al., 2022) and few in number, often resulting in the person with HD (pwHD) being placed far from their home. Understandably, people with HD and HD caregivers prefer to manage care at home until this becomes unsustainable, with the majority of the care provided by friends and family. In addition to the financial benefit, caregivers describe this experience as rewarding and fulfilling (Roscoe et al., 2009), with evidence suggesting an association between providing care for a loved one and reduced feelings of grief later in the bereavement process (Boerner et al., 2004). Nevertheless, the increased physical, financial and emotional demands on caregivers are significant and when these accumulate, they can be perceived as a burden that is difficult to manage (Mitchell et al., 2015). It is common for caregivers to prioritize their caring responsibility over their own needs but, failing to find a balance adds to the burden of long-term caregiving (Daemen et al., 2024; Rothing et al., 2015).

In the wider literature, the extent of burden experienced by caregivers of people with long term conditions has been found to be related to caregivers' own health status, the extent and nature of behavioural difficulties demonstrated by the care recipient, the frequency and extent of care required by the care recipient, and their level of dependency (Cartaxo et al., 2023); this is similar in HD. Youssov and colleagues identified an interaction between disease stage and behavioural features of HD, where highest levels of burden are reported by caregivers supporting someone with advanced disease and therefore high levels of dependency and behaviour that challenges, or, someone with early disease and high levels of depression (Youssov et al., 2022). Recent research also reported a relationship between level of apathy exhibited by the pwHD and perceived burden in HD caregivers (Hergert & Cimino, 2021).

Once viewed under the umbrella of depression (Levy et al., 1998), apathy is now regarded by people with HD and HD caregivers as one of the most impactful features of the disease (Simpson et al., 2016). Up to 76% of people with HD report experiencing apathy (van Duijn et al., 2007) with symptom severity associated with cognitive, motor and functional decline (Connors et al., 2023; Hamilton et al., 2003; Thompson et al., 2002). As such, it is thought to be closely related to the underlying neuropathology of the disease (Nair et al., 2022).

Apathy is operationally defined as a quantitative reduction in self-initiated, goal-directed behaviour (Marin, 1991). But, far from a unitary construct, it has been suggested that apathy is dimensional, consisting of multiple subtypes. Although reported differently across studies and assessment tools, these broadly overlap to create four groups: cognitive/executive, behavioural/initiation, emotional and social apathy (Klar et al., 2022; Radakovic et al., 2018).

Research on the multidimensional nature of HD-related apathy is still in its infancy, but emerging evidence supports the delineation of different apathy subtypes (Atkins et al., 2021; De Paepe et al., 2022). Whilst previous work demonstrated an association between apathy and both executive dysfunction more generally (McLauchlan et al., 2019) and decision-making specifically (Atkins et al., 2020; Morris et al., 2022), supporting the presence of executive and initiation apathy, recent studies have shown that there is a strong association between apathy and social cognition in HD (Hellem et al., 2023) endorsing the presence of emotional and social apathy. Apathy has been linked to decreased satisfaction with social roles (Fritz et al., 2018), lower emotional awareness (Lemercier et al., 2022, january 27) and poorer emotional recognition (Kempnich et al., 2018) in people with HD.

Recently, there has been a push to expand our understanding beyond the neurobiological explanation of its origin and its behavioural correlates, through investigating the lived experience of apathy (Massimo et al., 2018; Petty et al., 2019). Often, the person affected by apathy does not recognize or report being troubled by their apathy, in direct contrast to the experience of those around them (Massimo et al., 2009). The impact of apathy on HD caregivers is recognized but not yet well understood, however, feelings of isolation and loss of emotional connection, which are both consequences of social and emotional apathy, have been shown to negatively impact caregivers both in HD specifically (Aubeeluck et al., 2013; Rothing et al., 2015) and dementia more generally (Cheung et al., 2018; Manca et al., 2022). Furthermore, spousal apathy, as reported by the caregiver, has been shown to have a strong negative impact on marital relationships (de Vugt et al., 2006). Given the important role informal HD caregivers play in meeting the care needs of people with HD, understanding the impact apathy has on them is an important, yet understudied area of HD research.

The current study was designed to explore the subjective experience and meaning-making of HD caregivers. Secondary aims were to explore the phenomenology of HD caregivers’ experiences with regard to specific features of HD related apathy, namely proposed subtypes, with a view to consider psychological approaches to help support HD caregivers in the future.

Methods

Design

Qualitative semi-structured interviews and reflective thematic analysis (rTA) (Braun & Clarke, 2019), informed by a phenomenological framework (Larsen & Adu, 2021), was used to explore the lived experience of caregivers supporting someone who has apathy associated with HD. Motivated by the notable absence of the caregiver voice in research in this area, the study aligned with the philosophical presuppositions of a phenomenological approach (Guest et al., 2012). Particular emphasis was placed upon understanding the meaning of apathy constructed by the caregiver and the reflective process of the research team, with consideration given to the impact of different subtypes of apathy on that meaning making, through the lens of a critical realist methodology.

Quality assurance

The COREQ Consolidated criteria for reporting qualitative research (Tong et al., 2007) were used to guide reporting for this study, however, it is acknowledged that these do not fully align with the philosophical underpinnings of rTA (Braun & Clarke, 2023a). As such, the “Best practice recommendations for effectively conducting and reporting thematic analysis in health psychology” (Braun & Clarke, 2023b) were used as supplemental guidelines along with Yardley’s quality guidelines for rigour in qualitative research (Yardley, 2000).

Research team

The research team consisted of a trainee clinical psychologist (SLM), two consultant clinical neuropsychologists (CF and FG) and a consultant neurologist (RAB). The interviews were conducted by SLM, a female researcher with 17 years of HD clinical experience and 7 years of post-doctoral research experience. Expertise of qualitative research methodology was provided by FG. Reflexive analysis was used to bring the diverse experience of the multidisciplinary research team into all aspects of the study (Finlay & Gough, 2008). All authors were involved in the study design, data analysis and write up, with the first draft of the manuscript written by SLM. Recruitment was partially conducted through an HD clinic that RAB and SLM work or have worded at respectively. Four participants were known to SLM as a result of this connection. RAB only access anonymised data.

Ethical approval

The study was approved by North West Liverpool Central Research Ethics Committee, the Health Research Authority in the UK and Health and Care Research Wales (REC ref 23/NW/0026, IRAS: 319976).

Public and Patient Involvement (PPI)

Members of the HD community were approached to co-produce the language used in the recruitment tools and topic guide. A shared definition of apathy and list of common terminology used to describe apathy was created. Further details of the PPI work reported in line with the GRIPP reporting guidelines are described in supplemental data (Staniszewska et al., 2017).

Recruitment

Recruitment took place between March and September 2023. The study was advertised in three regional NHS HD clinics and online via the Huntington's disease Association (HDA) website and social media. Caregivers self-referred online or were approached in clinics and study recruitment documents were mailed to those who had previously consented to be contacted about research. Interested caregivers were invited to complete online consent followed by a brief demographic questionnaire which included details of their HD caregiving experience, the Zarit Caregiver Burden Scale (ZCBS) (Zarit et al., 1986) and the companions' versions of the Dimensional Apathy Scale (c-DAS) (Radakovic & Abrahams, 2014) and the Apathy Motivational Index (c-AMI) (Klar et al., 2022). Internal consistency and reliability of the c-DAS (Cronbach's alpha coefficient 0.86) (Radakovic et al., 2016), c-AMI (Cronbach's alpha coefficient 0.85) (Klar et al., 2022) and the ZCBS (Cronbach's alpha coefficient 0.92) (Hebert et al., 2000) have been established, with the c-DAS being used with HD caregivers previously (Atkins et al., 2021). This information was used to determine eligibility based on the study inclusion criteria (Table 1). All eligible caregivers were invited to interview.

Sample size

Purposive sampling was intended, to recruit a representative group of people with HD who experienced the full range of apathy subtypes in this research; however, none of the participants who completed the online questionnaires

Table 1. Inclusion criteria for caregiver interviews.

Inclusion criteria:	Abnormality cut-off scores for companion apathy scales
• Significant caring responsibilities for someone with clinically manifest HD	Companion Dimensional Apathy Scale[a] • Executive subscale ≥13 • Initiation subscale ≥ 16 • Emotional subscale ≥15
• Over 18 years of age • Scores for the pwHD supported exceed clinical cut-off for one or more subscale of the c-DAS or c-AMI	Companion Apathy Motivational Index[b] • Total ≥ 1.91 • Behavioural subscale ≥2.34 • Social subscale ≥3.17 • Emotional subscale ≥2.31

[a] Cut off scores based on Atkins et al. (2021).
[b] Cut off scores based on Ang et al. (2017) in the absence of HD specific values.

met criteria for the executive and social subtypes of apathy as set out in the inclusion criteria. Furthermore, barriers to participation described in the Results section below, made participating in interviews difficult for some caregivers. As such, a pragmatic approach using convenience sampling was adopted to recruit those willing and able to take part who met the criteria for any subtype. As the purpose of this research was to prompt discussion about the psychological impact of apathy on caregiver experiences and not to generalize to a wider population, and in line with a critical realist approach where experience is believed to be partially constructed by the individual, data saturation was not considered to be an appropriate nor achievable method of determining sample size (Braun & Clarke, 2021).

Interviews

Semi-structured interviews lasted for one hour and were conducted online via Microsoft Teams©. Only the caregiver joined the interviewer online for the interview although, for pragmatic reasons the pwHD was often present elsewhere in the house. Where this occurred, measures were taken to ensure interviews were conducted in a separate room where the carer would not easily be over-heard.

Care was taken to provide a safe, non-judgemental space. In the interest of establishing a good rapport, a detailed description of the interviewer's background and motivation for the research were shared before starting. At the start of every interview consent was revisited and there was a discussion about what to expect during the interview.

An interview topic guide (Supplementary data) was used which focused on creating a shared understanding about what caregivers meant when they talked about apathy, how they experienced the pwHD's apathy and the meaning they constructed of it. Particular attention was given to prompting the discussion of emotional and social apathy. Caregivers were encouraged to shape the direction of the conversation through the use of open-ended questions and prompts.

Interviews were recorded and transcribed verbatim by the interviewer (SLM). Reflective notes were made at the time of the interview and used to help with the reflective process during analysis.

Analysis

The six phase process of Braun and Clarke (2022) was used to reflexively analyse the interviews, with the research team iteratively moving through the following phases in a non-linear fashion: (1) familiarization with the data, (2) generation of initial codes, (3) generation of themes, (4) reviewing potential themes, (5) defining and naming themes, and (6) producing the report. Particular attention was paid to caregivers interpretation and understanding of their lived experience.

Transcripts and video recordings of the interviews were reviewed synchronously to achieve a deep familiarity with the data. Transcripts were read and re-read. Initial coding was completed by a single researcher, SLM, as is good practice for reflexive thematic analysis (Braun & Clarke, 2022) as it promotes depth and rigour of engagement and facilitates the meaning – making and interpretive process, before being discussed within the research team. A reflective diary was kept throughout to document the analysis process.

Coding was completed manually using Microsoft Word and Excel, as was the preference of the research team. Data were coded deductively initially and then inductively to ensure alignment with the research question. Semantic and latent coding were used, with semantic codes typically evolving into latent codes during the analysis process as they were adapted and augmented to capture the nuance of the caregiver perspective, as interpreted through the lens of the first author (SLM). Transcripts were coded three times to ensure all meaningful data was coded. Each participants transcript was coded deductively in the first pass with an a priori framework based on apathy subtype. Transcripts were then coded inductively to ensure that the phenomenology of the caregiver experience and an understanding of how caregiver's meaning-making was situated within their own social world and personal history was captured. Finally, once complete all participants were re-coded so that codes generated in the later part of the analysis could be considered for all participants. All codes were rigorously supported by rich, detailed quotes to ensure that no codes were established without meaningful data. Themes were generated based on the relationship between the codes and collaboratively reviewed within the research team to sense-check ideas and further develop the interpretation of the data and increasing the rigour of the analysis (Yardley, 2000). Consistent with a critical realist approach, caregivers were offered the opportunity to review the themes extracted from their individual interview, to check that resonance of the findings and improve the credibility of the work (Nowell et al., 2017).

Results

Participants

To characterize the sample and aid sensitivity to context (Yardley, 2000) demographic details of participants are included in Table 2. Details of the pwHD were not collected as the focus of the research was on the HD caregivers.

Twenty-three caregivers completed the online questionnaires. All eligible participants were invited to interview. Interviews were completed with 12 caregivers (49% of those invited) although only 11 interviews were included in the analysis due to technical issues with the sound on one interview preventing transcription. Caregiver commitments and difficulty finding a time location away from the pwHD were the main reasons for eligible caregivers not participating in the interviews.

Ten females and one male caregiver participated in the interviews. Of these, 10 were a spouse, and one was a parent of someone with HD. Two caregivers felt that they were able to share their caring responsibilities with someone else whilst the remaining nine where the sole carer for the pwHD. Five caregivers scored the pwHD above the clinical cut-off on the initiation apathy subscale only while six scored the pwHD above threshold on the emotional apathy subscale only. Seven caregivers scored above clinical threshold for caregiver burden based on the Zarit Caregiver Burden Scale.

Key themes

The following five key themes reflecting the caregiver experience were identified from the interviews:

Table 2. Demographic characteristics of interview participants.

	Gender	Age[a]	Relationship to pwHD	Years caring for pwHD	Cohabiting with pwHD	Knew the pwHD before diagnosis	Apathy subscale[1]	Caregiver burden score[c]
1	F	50–59	Wife	0	Yes	Yes	Initiation	18
2	F	30–39	Fiancé	2	Yes	No	Initiation	34[c]
3	F	50–59	Wife	5	Yes	Yes	Emotional	23
5	F	60–69	Wife	6	Yes	Yes	Emotional	17
6	F	50–59	Wife	9	Yes	Yes	Emotional	30[c]
7	F	50–59	Partner	4	Yes	No	Emotional	29[c]
8	F	50–59	Mother	8	Yes	No	Initiation	37[c]
9	F	50–59	Wife	7	Yes	No	Emotional	26[c]
11	F	40–49	Wife	20	Yes	Yes	Emotional	12
12	F	70–79	Wife	10	Yes	No	Initiation	26[c]
13	M	50–59	Husband	18	Yes	No	Initiation	36[c]

[1] Determined by scores on the c-DAS/c-AMI. All participants rated the pwHD above clinical threshold on the initiation subscale. Where they also scored above threshold for the emotional subscale they were classified in the emotional group.

[b] Determined by scores on the c-DAS/c-AMI. All participants rated the pwHD above clinical threshold on the initiation subscale. Where they also scored above threshold for the emotional subscale they were classified in the emotional group.

[c] Zarit Caregiver burden, clinical cut-off ≥24 (Schreiner et al., 2006).

(1) "What even is apathy?"
(2) "It makes my life harder",
(3) "They haven't forgotten me, but they have forgotten that they ever loved me",
(4) "I'm grieving for someone who hasn't died yet", and
(5) "I need a safe space to say what I really feel without fear of judgement".

The themes are detailed in Table 3 and described below.

What even is apathy?

This theme draws together complex narratives about how apathy is clinically defined, subjectively experienced and socially constructed. More than just a reflection on a lack of understanding about what apathy is and is not, it combines discussions about how HD caregiver meaning making is shaped both by their own experience, the remnants of previous relationship dynamics and the influence of gendered social discourse brought by others around them.

Table 3. Keys themes and sub-themes.

Theme	Sub-theme	Code
What even is apathy?	I didn't know this was apathy	I thought they did less because it was harder (3) Im not really sure what apathy is (3)
	Is this really HD or is he just "being a man"?	It feels like he picks and chooses (4) People you tell think its normal but it's not (2)
It makes my life harder	It shrinks my world	It makes it hard for me to socialize (3) I have to find support elsewhere (2) I miss out on things (5)
	It feels like I have to do everything	I have to do it all and I'm exhausted (7) Everything is a battle (2)
They haven't forgotten me, but they have forgotten that they ever loved me.	It's like loving a mannequin	There's no recognition or reaction to my emotions (6) There is no emotional response (4) There is no reciprocity (1) It's like living with a stranger (3) This isn't a marriage anymore (4)
	Our relationship has gone	There is no connection (6) Im just the carer now (4) It makes me into a person I don't want to be (1)
Grieving for someone that hasn't died yet	Reminded of what has already been lost	Helplessly watching them fade (7)
	Reminded of what is left to lose	Its wasting what time we have left (2) It means we are closer to the end (3)
I need a safe space to say what I really feel without fear of judgement.	I should be able to just get on with this alone	People who understand are unavailable (3) It's hard to find space to talk (6) Nowhere to vent (2)
	It doesn't feel safe to say the truth to most people	I don't want people to think I complaining (3) Feeling judged (3)

Note: Numbers in brackets () indicate the number of participants contributing to that sub-theme.

Caregivers reflected on their perceptions of the word apathy as a clinical term, with a formal definition, that they do not know. Despite eloquently describing apathy observed in the pwHD they support, caregivers often did not feel confident in their own understanding of the term "apathy", as expressed by Participant 1:

> That's a good question: What is apathy? I don't really know now, I should have looked that up really. [Participant 1]

This was especially apparent when considering behaviour that would fall within the social and emotional subtypes of apathy. Caregivers recognized traits that would fall into these subtypes but reflected on how they had not previously considered them to have been apathy:

> I probably wouldn't have thought of that as apathy but it's very much evident in him. Yes, the emotional side of him, I think we lost in his teens. [Participant 8]

Interestingly, based on the c-DAS scores, five caregivers indicated that the pwHD they supported scored highly on initiation apathy, but not emotional apathy. However, four of these went on to discuss behaviour consistent with social and emotional apathy during their interview. Often these behaviours were made sense of as an understandable consequence of other features of HD:

> I don't think it's a lack of motivation, I think it's something … would it be cognitive? [Participant 11]

Others made sense of it as a result of the emerging symptoms of the disease impacting "confidence in [their] own abilities" (Participant 2), or as a way of avoiding the embarrassment felt from the awareness that other people may notice the emerging symptoms of the HD:

> He doesn't video call them, he just messages, so he's not having to present himself. [Participant 2]

The narrative constructed by this participant was one of withdrawal and social avoidance as an understandable coping mechanism to deal with the shame felt as conversations became harder and choreic movements became more visible. Here the lack of understanding that apathy could result in social isolation leads her to draw upon her own feelings and emotions when observing her fiancé in social situations to make sense of his behaviour:

> I think it's his appearance in public that he worries about, although as I've said, he doesn't notice people's staring at him. [Participant 2]

Often caregivers talked about their difficulty accepting that the lack of initiation was involuntary:

> It's not because he isn't capable, 'cause he is, he's not that far gone that he can't function, but I don't know, I don't know. [Participant 1]

Many discussed the internal dilemma of trying to decide whether the lack of initiation and emotional lability they saw was a part of HD or “just being a man” (Participants 1, 5, 11, 12). Even if this was not their own understanding, caregivers described how friends and family failed to see this behaviour as apathy, or even as anything abnormal, which left the caregivers feeling invalidated and unheard:

> Sometimes you feel like you don’t wanna say anything because they don’t always understand what you’re saying. A lot of them say, ‘Ohh yeah, my husband’s like that. He never knows what he wants for dinner.’ And I have to say, ‘Ohh yeah, I know a lot of men are like that.’ But this is different. [Participant 6]

By not framing this behaviour as “apathy,” caregivers and those around them, drew on social discourse about gender roles and intentionality to construct their meaning-making. The consequence of conceptualizing the behaviour on a spectrum of “normal” male behaviour was that the impact and meaning constructed by caregivers was invisible to the rest of the world. The complex interaction between their own sense-making, the gendered social construction and the belief that their experience was trivialized by others, led to feelings of anger and frustration. This was complicated further when inconsistencies in the pwHD’s behaviour fuelled the impression of choice and control on their part:

> Sometimes I just wanna scream! Sometimes I do yell, you know, just like: ‘Why can’t you do it? If you can push the garden mower you can push the hoover! [Participant 5]

During the interviews, some caregivers retrospectively reappraised their companion’s behaviour, as a result of developing a broader understanding of the multifaceted nature of apathy. Locating the problem outside of the pwHD seemed to make the experience feel less personal:

> I was more … I liked her more than she liked me, if you know what I mean. That was what I saw. I think in her mind she was like the sort of the superior one and I sort of understood that was the dynamic of the relationship and that didn’t make me feel great but I think looking back, a lot of that was to do with the very early stages of the mental side of the disease. [Participant 13]

It makes my life harder

There was a general consensus that apathy made it practically harder to be a caregiver. The pwHD’s lack of initiation to engage in daily activities meant that caregivers needed to do more to keep life going and several reflected on how exhausting they found it (Participant 2, 5, 6, 7, 9, 11, 12):

> Oh yeah, I’m the gardener, the painter, the cleaner. [Participant 12]

> He thinks he can sit there and I will do everything … He’ll say, ‘Cup of tea?’ but he means he wants me to make it! [Participant 12]

> You know, I do everything at home. I go and walk the dog and then I come back in. I do tea. I clear up, I do everything on my own. I’ve got to, I feel like I am on my own. But

> then I'm looking after somebody as well. You know what I mean? So yeah, it's sort of, yeah. I just just feel weary all the time. [Participant 6]

It wasn't just having to fit more into a day that exhausted caregivers. Many talked about the impact of being the only person doing the thinking, planning and decision-making where previously this had been shared (Participants 1, 5, 7, 11). The increased mental load left some feeling like they had no mental capacity left to think, it was literally "draining [their] brain" (Participant 1). Juggling this on top of all of normal family life that was expected to continue, felt overwhelming, and on occasion they found their frustration difficult to contain:

> I'm thinking and doing everything for him. And I did, say, I know I shouldn't, but sometimes you can't help it, I just said 'Oh my God. You know, you're just so draining'. I know you probably, you think 'ohh dear, that's a bit harsh' but some days because, I'm at work, I'm trying to support my mum, I've got my oldest, I've got my youngest son still here, I've got my daughter and we're very family orientated. God, Can someone just not drain my brain for once? Can I just please … you know? [Participant 1]

Whilst some caregivers recognized that this was part of caring for someone with HD, others found it hard to accept and tried to motivate their companion or force them to complete at least the most routine activities, such as personal hygiene. Often this resulted in conflict which left them feeling like life had become a battle:

> Sometimes I have to shout at him to get him to respond. And I say to most people, I'm not a person that wants to control. I'm not a controlling person. But I have to be, to a certain degree, and if he was to follow my instructions life would be easy. [Participant 12]

On top of making caregivers' lives busier, some felt that the apathy contributed to their feelings of being alone and unsupported. They reflect on how the lack of interest the pwHD showed towards their feelings or emotional wellbeing, left caregivers without the normal emotional support that exists within a healthy reciprocal relationship and also made it harder to find that support elsewhere:

> I don't feel I have emotional support from him at all. Not at all. That's just all gone, [Participant 1]

Several talked about how their companion's reduced engagement in social situations meant that their own social contact was reduced as a consequence:

> He didn't want people round the house so he'd say, 'Can you put your parents off this weekend' or, you know, 'I can't cope with the kids this weekend' or then he thought he couldn't cope with their kids, my grandchildren, so I didn't have them round as often. [Participant 6]

Caregivers described finding their companion's disengagement in social situations and lack of consideration for other people's feelings rude and so avoided going to social events with friends and family through fear of offending someone. Those who did try to keep up social contact described worrying that their friends would slowly drift away:

> I mean, he's not good in many social situations. He can come across quite rude, and obviously he doesn't mean it … It's like we've got friends we used to go out with quite a lot, got another couple, and I was concerned that they were gonna stop cause I felt like they were going out with other couples instead of us. And again, that's upsetting. [Participant 9]

This left many caregivers feeling like they had missed out on things they wanted to do because of the apathy. Some shared feelings of being forced to live a life that they didn't chose nor, want which at times led to feelings of resentment:

> I'm retired, I should be, you know, I was fortunate enough I was able to take early retirement 'cause I had two decent pensions and I'm like, sitting here. I want to live, but I want, you know, I want to live with him as he was … I feel like my life's going too. [Participant 5]

For this caregiver, the social context of age and the expectations of retirement add to the nuance of their experience of apathy.

They haven't forgotten me, but they have forgotten that they ever loved me

Almost every caregiver described feeling like the relationship they had with the pwHD had diminished as a result of their apathy. The loss of the relationship was often described in a way that was consistent with the experience of a relationship breakdown:

> I did feel the fact that she wasn't as interested in doing the same things at home as well was quite, you know, upsetting in a way because you sort of feel that, like diverging. You know, we've got nothing in common sort of feeling. [Participant 13]

The discord between social narratives around dementia and HD caregivers' experience of apathy made several caregivers feel that the loss of relationship was more personal and less understandable. They described how it made sense to them that a relationship would change if one half of a couple no longer remembered a shared past but, when the memories were still there it felt more about the relationship itself:

> It's not like the memory's gone completely, but they just see you in a different way. They sort of, yeah, relate to you in a different way. [Participant 6]

One caregiver described how this left her feeling discarded:

> You feel a little unwanted because you're not wanted in in that particular way. [Participant 7]

Caregivers frequently described how the emotional cues that normally signify an intimate connection had dissipated as a result of their companions' apathy. The absence of these subtle, implicit, nuances left some caregivers feeling unloved by the pwHD, even when they were told otherwise:

> If I said to him, do you love the darling, he'll go 'course I do'. He'd say like 'yeah, absolutely'. If you asked him he'd say yeah with no doubt, I do. But he can't feel that. [Participant 5]

For one caregiver, contrasting her husband's apathy with the way he used to act towards her only highlighted what she had lost. Her experience of apathy was shaped through the lens of memories of an openly loving relationship that was no longer present:

> When we were first together he was the one that was more keen than me, shall we say, and he showed so much affection. I know when you're young and new relationships are always all loved up, but he was the one that used to share affection more. But that's completely gone now and that's why it's probably worse. [Participant 9]

For some, the lack of reciprocity or having "no one to bounce off of" (Participant 12) made them feel lonely and like they were sharing their life with a stranger:

> Normally it's a two-way thing, isn't it in relationships? And you know, maybe one has more in the relationship than the other but it's like it's not really a relationship anymore like that husband and wife, really. [Participant 9]

Whilst for others it was the lack of physical intimacy or physical demonstrations of affection that triggered feelings of rejection:

> If you said to me when did you last kiss? Ohh, he might give me a peck on the cheek if I'm going out without him but usually has to be forced. I have to go and kiss him, and quite often he'll back off. And not, you know, I'm say what's that about? And he'll be like, well I don't know? [Participant 5]

> It's very rare that we would even have a hug now, and there was lots of physical contact. There weren't just sex, but the physical contact. [Participant 7]

> It's hard as a mum to watch when your child has lost that ability to be affectionate. [Participant 8]

The loss of emotional reactivity was frequently interpreted as evidence of the pwHD's disengagement from the relationship and proof of its one-sided nature. For some caregivers this brought sadness and resignation and for others it caused anger and frustration, making them question why they continued to pour their love into an emotional void:

> When we got back to the car I had said, (so I give [her] a nice hug or something) 'this has been nice. Ohh I love when we're together on holidays', and she didn't respond. She didn't say anything … there's no interaction, you you sort of think well, why am I doing this. I'm not getting any anything back. [Participant 13]

As a result, many of the caregivers described feeling like they were no longer in a reciprocal, loving marriage but had transitioned into the role of carer or acquaintance, which were both built around functionality rather than affection:

> You know, it's so I'm only doing it in the same way as, you know, if you, I suppose if you're a nurse in a hospital looking after somebody. It's it's just a job, isn't it? [Participant 13]

This came with a sense of sadness:

> I get a bit more upset now because I feel like I'm no longer his wife anymore. I'm just this person in the house that does everything for him. [Participant 6]

but also confusion, as caregivers struggled to make sense of their own identity within the relationship and to understand what role was available to them if being a wife was no longer an option given social expectations of what constitutes "being a wife":

> Without intimacy this isn't a marriage, so what are we? [Participant 7]

Anger and resentment were commonly felt as caregivers reflected on their lack of choice in the transition. One in particular, shared a palpable sense of feeling disenfranchized and powerless in the change:

> I don't want to be his mother. I don't want to be his carer. I don't want to be. You know. I just want to be his partner. [Participant 7]

Whilst for another, it was the contrast between her own experience of caregiving and that of her sisters who supported their husbands with different illnesses, that made her reflect on the unfairness of this aspect of HD:

> My sister's both have lost their husbands. I've got two sisters. Both have lost their one had or they both had cancers, various cancers one suffered for years and years with it. But right to the end, they went up and down in their illness. But they always cared about their wives. Always was more concerned about their wives, made sure their wives were alright. Wouldn't tell them sometimes because they would be more worried. They're concerned for them and all that and. You know that's. I know I haven't got it. I know he doesn't feel like that. [Participant 12]

I'm grieving for someone who hasn't died yet

Throughout the interviews there was a general sense of sadness expressed by the caregivers. Many found the experience of watching the pwHD slowly drift away in front of them hard. This was mixed with a sense of hopelessness at their inability to make things better meant that even those caregivers who appeared to be composed throughout, became emotional and tearful at points:

> I joined groups all across the world trying to look for a for a cure to see if there was anything anywhere anyone had tried and made a difference. And but no, I couldn't do anything for my child and I, you know, I'm still at that stage. Where I can't make it better. And I think that's the hardest thing for me to live with. [Participant 8]

> I don't always talk about it, but, yeah, quite upset. It could get upset and it does upset me now, when I talk like that, but I don't very often and I'm not an uncaring person, but I'm not a water box. [Participant 11]

For some caregivers, the loss was very much tied up with the apathy. There was a sense that the lack of initiation, emotional reactivity and social engagement was paramount to the feeling of having already lost the person they loved and being left with a shell of their former self:

> Just feel like I've lost him somewhere in there. I think that's that's the only way I can describe it. I've lost him somewhere along the way. [Participant 5]

> I thought, well, actually it's not that bad because, you know, he's still the same person. And then that was taken away. So it's sort of like a continuous grief. It's like losing somebody, you know, you lose one part of them. Then next minute you're losing something else of them. [Participant 6]

For others, apathy was interpreted as the pwHD giving into the disease and giving up the fight:

> It's hard enough that the illness takes so much from HD. It takes so much away from a person with HD. Taking the motivation as well, it's kind of like giving up. And once they do that, it's like a very slippery slope. [Participant 2]

Overall there was a shared belief that the presence of apathy acted as a reminder that the disease was progressing and with that, they are getting closer to the end of their HD journey:

> It's it's really difficult to watch. Um, because it's almost like. I felt I'd lost him when I got the diagnosis. And I'm and I feel like you start grieving for them. Before they've even gone. Because you know what's gonna come. And then watching every, you know, every time something different happens, you watch a little bit more of them go. And you just know that it's coming closer and closer to the time, when they will die. [Participant 8]

I need a safe space to say what I really feel without fear of judgement

Talking openly and honestly about their experience of supporting someone with HD was difficult for every caregiver that took part in the study and was not something they typically made space to do. The expectation was that "you just have to get on with it" (Participant 1) but caregivers describe how coping alone was difficult:

> That's hard, that is hard sometimes, cause, you know you have no way of venting. [Participant 5]

Some described feeling guilty and selfish for thinking about their own needs and worried that other people would think they were "complaining" (Participant 6):

> Sometimes what I'm saying and talking about becomes like, ohh, she's nagging again. Or she's, you know. So I try not to say certain things. [Participant 12]

> Not that I want to go on about it because I don't and I'm not a person that wants to keep bringing things up. [Participant 1]

Finding the time and space to talk openly was difficult. Caregivers were all sensitive to their companions' feelings and generally did not want to speak in front of the pwHD through fear of saying something that may upset them. This added to the expectation that they should suffer in silence:

> You can't open up because you think if he's listening, he's gonna be upset by what you're saying. Because sometimes you feel like you're complaining. [Participant 6]

There was a general consensus that people outside of the HD world, knew and understood very little about what HD was and what it was like to live with it:

> I've done my research and I kind of know what to expect. But until you're actually in the situation, I don't think you understand the level of how HD affects people. [Participant 2]

Previous experiences had left a few caregivers feeling judged after voicing their true thoughts and feelings. There was a recognition that the complexity of caring for someone with HD made it difficult to understand and empathize for anyone who hadn't lived with HD.

> Because if you say it, it's out of your head then. And the person in front of you isn't going to judge you about it. As at some point, they might have felt exactly the same. [Participant 8]

However, this was further complicated by the recognition that that whilst other HD caregivers may be the only people who truly understood their experiences, talking to them felt like burdening someone, who they knew from their own experiences, would already be dealing with so much:

> I just think, well, people have got their own crap to deal with. It's not fair to burden them with that. [Participant 1]

For many, the interview provided a safe, non-judgemental space to reflect on their experience of caregiving, that they did not have elsewhere. For some, the value of such a space only became apparent during the interview:

> I would like to meet people in similar situations and I've never ever thought that until this conversation, to be honest. [Participant 1]

Taking part required caregivers to explore their thoughts and feelings in a depth that many had not given themselves permission to do before:

> I do talk to my friends, but you don't talk like this, do you? Where you explain. [Participant 5]

The process of collecting their thoughts and formulating them in a way that could be shared, along with being given permission to approach rather than avoid difficult feelings, appeared to help caregivers process their experiences in a therapeutic way. This prompted suggestions that access to psychological therapy may be a welcome support for caregivers:

> Like talking, talking therapy, would, you know, I think would be useful. [Participant 2]

Discussion

To our knowledge, this is the first study which has sought to understand HD caregivers' experience of, and the meaning they construct regarding, apathy in HD. Reflexive thematic analysis produced five main themes concerning: uncertainty about how the clinical definition, subjective experience and socially constructed meaning of apathy fit together; the practical impact of apathy, with the expectation that caregivers do more than their share of daily tasks and hold more of the mental load; the emotional impact as apathy becomes synonymous with a gradual loss of the former relationship; grief for someone who hasn't died yet; and the need for a safe space to talk openly about the impact of caring for someone with HD, without fear of judgement. Interwoven between these themes were complex narratives about the unspoken nature of HD, the invisibility of caregivers who felt trapped and unheard, and the one-sided nature of loving someone with the disease. Caregivers described feelings of sadness, frustration and anger as they reflected openly and honestly about supporting someone with HD who had apathy, despite being often unable to voice these feelings in their everyday lives, in part through fear of judgement and in part through lack of time or opportunity. The nuance of caregivers' subjective experience was expressed as they shared deep and personally meaningful insights into their sense-making.

Caregivers described in great detail and with intense emotion, how they saw apathy as synonymous with the parts of the pwHD that they had lost as a result of the disease process. Apathy was viewed as both the mechanism through which this loss occurred and a reminder that they no longer had access to the person they once knew, the companion they once shared their lives with and the future they had expected to have. These feelings were constructed as part of an early and prolonged grieving process, consistent with the concept of anticipatory grief (Chan et al., 2013).

Anticipatory grief is well understood within the field of dementia research but has only recently started to receive attention in the world of HD (Leidl et al., 2023). Between 47% and 71% of caregivers of someone with dementia report experiencing pre-death grief as a result of the "compound serial of losses" endured through the disease process (Blandin & Pepin, 2017; Large & Slinger, 2015). Lindauer and Harvath (2014) identified four components of the grief: the psychological death of the care recipient or loss of the person they used to be, the protracted and uncertain journey of dementia, difficulties communicating with the person with dementia and changes in the relationship. In the current study, all four components were discussed or alluded to as a consequence of the pwHD's apathy, not just the caregiving experience as a whole. It is unclear whether this is a distinct feature of anticipatory grief in the context of HD, but further understanding this relationship may provide an opportunity to both identify HD caregivers at risk of experiencing a more protracted grieving process and to utilize therapeutic strategies to reduce the emotional impact of apathy. Therapeutic interventions for anticipatory grief in dementia caregivers are receiving increasing attention in the empirical literature and implementation research is planned (Rupp et al., 2023). Work with HD caregivers could meaningfully contribute to this work.

The correlates of anticipatory grief in HD need to be understood. Pre-death grief has been reported at any stage of dementia, but it is typically found to be greatest in those supporting someone with moderate to severe disease (Adams & Sanders, 2004; Blandin & Pepin, 2017; Chan et al., 2013) where it has been shown to relate to caregiver burden (Gilsenan et al., 2023; Perez-Gonzalez et al., 2023). In the current study, caregivers were typically supporting people in the early stages of HD. There is significant evidence showing that apathy is an early feature of HD, sometimes occurring in the premanifest stages of the disease (Matmati et al., 2022) however, this is the first study to identify the importance if experiences in keeping with the concept of anticipatory grief in the context of HD related apathy. Furthermore, given that research on this issue is very limited, it is not possible to make any conclusions about the relationship between anticipatory grief and disease stage or the role of apathy, but it is perhaps an interesting observation that could be explored further.

Caregivers interpretation of the social and emotional apathy shown by the person they supported, led them to feel unloved and rejected. The absence of any emotional response or empathy for the caregiver's feelings, and lack of unprovoked signs of affection, both physical and verbal, were interpreted as disinterest and ambivalence on the part of the pwHD. Similarly, although not discussed in the context of apathy, reduced spousal intimacy is common in people who have sustained an acquired brain injury (Ponsford et al., 2012, october 12) where it is understood to be associated with the physical (Ponsford et al., 2012, october 12), cognitive and emotional consequences of the brain injury (Bowen et al., 2010). Breakdown of the loving pre-injury relationship has been associated with reduced emotional warmth and difficulties maintaining conversations (Yasmin & Riley, 2022); factors which overlap with our understanding of emotional apathy. Furthermore, the reconstruction of spousal reciprocity, partially linked to the ability to establish good patterns of communication, has been identified as a key contributing factor in marriage satisfaction following a stroke (Anderson et al., 2017).

Importantly, many caregivers described how the pwHD, when asked, still reported loving them as much as they always had. Understanding this disparity, and what leads caregivers to feel unloved, may help to identify ways to reduce the distress experienced by caregivers as a result of HD-related apathy. Frith and Frith (2023) suggest that "meaning" in a social context is "created through mutual adaptation and is a product of joint action". They propose that to successfully communicate meaning, both parties need to be reciprocally aligned in their verbal and non-verbal communication. Copying and responding to non-verbal actions such as eye gaze, gesture, speech sound, grammar and choice of words in a complementary way are fundamental parts of this process. People with HD typically experience difficulties understanding the actions and intentions of other people in the social world, even in the early stages of disease (Bora et al., 2016). Deficits in social cognition have been shown to relate to the social and emotional quality of life (Eddy & Rickards, 2022) and HD-related apathy (Fritz et al., 2018; Hendel et al., 2023; Kempnich et al., 2018). However, little is known, about how a pwHD expresses themselves in a social situation, or how this impacts their social relationships. In other disorders where emotional expressiveness is reduced, such as Parkinson's disease (PD) where the stoic masked face is a characteristic feature, and schizophrenia where negative symptoms are commonplace, similar feelings are reported by caregivers. A qualitative study of impaired non-verbal expressivity in people with PD found that facial masking led caregivers to think that the person with PD was emotionally unaffected by things, and unfeeling towards them. This led to reduced social connection and emotional distancing (Wootton et al., 2019). Similarly, people reported feeling less willing to engage in future interactions with someone with schizophrenia if they have reduced facial expressiveness, vocal prosody, gesturing and quality of spoken language (Riehle & Lincoln, 2017). In the neuropsychological rehabilitation literature, strategies to remediate the impact of deficits in social cognition have been described (McDonald & Cassel, 2017; Spikman et al., 2022). Although this work has not yet been applied in HD, future research is needed to determine whether similar approaches could also be effective here.

Caregivers talked about not knowing what behaviours were included in the definition of apathy and what were not. Many didn't include behaviours that would fall under the umbrella of social and emotional apathy, in their understanding of apathy. This is consistent with findings from a recent qualitative study which reported that people living with a neurocognitive disorder and their caregivers, were unfamiliar with the term "apathy" and also found it difficult to explain apathetic behaviour despite it being a significant feature of their condition (Burgon et al., 2023).

Regardless of which subtypes of apathy were endorsed by caregivers on the c-DAS, the impact of social and emotional apathy was discussed by every HD companion, at some level, during the interview. Here, in the absence of understanding the behaviour as apathy and/or part of the disease process, social rules and norms were used to interpret the social avoidance and lack of emotional reactivity in the same way that it would be understood in someone without HD, as a product of free will and choice. This was amplified by the incongruence between the lack of physical signs of HD and high levels of apathy seen by caregivers, which were taken as evidence that these behaviours were independent from the disease process. Situating the locus of control for social and emotional apathy, within the pwHD coupled with perceptions of conscious control, understandably led to feelings of anger and frustration.

Psychoeducation is a tool widely used in neuropsychological rehabilitation to help families understand and anticipate the specific implications of a brain injury by creating a sense of empowerment and shape realistic expectations which has been shown to improve quality of life for the family as a whole (Kitter & Sharman, 2015). Using psychoeducation to help caregivers understand apathy as a normal part of the HD disease process, including an understanding of social and emotional apathy, may help caregivers to feel more validated and develop more adaptive attributions, locating the problem firmly with the disease process.

The experience of apathy expressed in this study appeared to mirror caregivers' experience of HD in general – never discussed, hidden from view and dealt with alone. When discussing apathy with family, friends or even healthcare professionals, HD caregivers reported feeling unheard and unsupported. The lack of understanding shown about their experience, left them believing that it was not "socially unacceptable" to struggle in response to the apathy. Similar themes have been described by HD caregivers following the genetic testing process (Decruyenaere et al., 2005; Sobel & Cowan, 2000, 2003) where the invisibility of the disease contributed to caregivers experience of disenfranchized grief (Doka, 1989). Furthermore, apathy was not even discussed between the caregiver and the pwHD with many caregivers going to great lengths to conceal their participation in the research. Although intended to shield the pwHD from the potential distress of feeling blamed for the impact of their apathy, this reluctance to talk openly about apathy within the family removes the possibility of using neuropsychological rehabilitation strategies for both the pwHD and the family to develop more adaptive patterns of behaviour to counteract the impact of apathy for the caregiver.

Talking openly about the presence and impact of apathy with people with HD and their families is a simple way of starting to breakdown this stigma. Modelling and normalizing the discussion of apathy would both empower people with knowledge about what they may need to deal with in the future and help to dispel the narrative that caregivers should be expected to cope with this distressing aspect of HD alone. Exploring what the barriers are that currently prevent people from talking about apathy could facilitate this work. In particular, understanding the social discourse around apathy and whether there is a taboo or shame around judging someone to have apathy, may inform our understanding of why clinicians do not routinely discuss apathy and why friends and family try to minimalize the caregiver's experience of apathy in the pwHD.

Implications for practice

It is clear from this work, and that of others, that more could be done to support HD caregivers. Some of this could be achieved within the current framework for routine clinical practice, namely,

- Taking a more systemic view of HD, including the caregiver experience alongside the impact for the pwHD.
- Including conversations about apathy which are normalizing and informative. Not assuming that there is a shared understanding of the word apathy but working to ensure that the language we are using aligns with the caregivers experiences.
- Upskilling existing staff in active listening and creating space within clinics for this to happen whilst also being aware of how difficult it is for caregivers to prioritize themselves. Encouraging staff to open those discussions and take the lead where necessary to create a safe space for caregivers to share their experiences.

With the availability of additional resources, more formalized psychological interventions may be helpful for caregivers, such as Acceptance and Commitment Therapy (ACT), Compassion Focused Therapy (CFT) or narrative therapy, in either a group or individual format. Combining this with neurorehabilitation strategies for the pwHD would support both the practical and emotional needs of caregivers dealing with HD-related apathy.

Strengths and limitations

The quality assurance for this work was guided by Yardley's four principles of sensitivity to context; commitment and rigour; transparency and coherence; impact and importance (Yardley, 2000). Sensitivity to the caregiver experience was integral to the design and conduct of the study, with adaptations made to facilitate participation and particular attention given to establishing an authentic rapport between caregivers and the researcher. Reflexivity, reflection and detailed record keeping were used throughout to attest to the rigour and transparency of the work, while the richness of the quotes included is testament to the impact and importance of the work.

Limitations of this study include the challenges of recruitment and the impact of the COVID-19 pandemic. The study was conducted following the COVID-19 pandemic, when restrictions had been eased in the UK. The impact of restrictions on social contact, on the emotional well-being of caregivers of people with dementia has been widely reported (Hanna et al., 2022; Manca et al., 2022) and should be mindfully considered when interpreting the results of this study. Wider restrictions on the social contact available to HD caregivers over an extended period of time may have changed caregivers' awareness and response to the pwHD's reduced emotional responsiveness, empathy and social behaviour. Furthermore, as a piece of qualitative research the intention was not to assume that HD caregivers are a homogeneous population nor that the findings of our study could be generalized to the wider population; however, having a larger sample, or a similar size study in a different country or socio-economic context, may have generated alternative themes that could be relevant to a wider group of HD caregivers. Specifically, due to practical constrains recruitment was limited to three UK sites, interviews were only held online and despite our best efforts, caregivers of all apathy subtypes were not represented in the sample, though it is recognized this may be a reporting artifact on the part of the caregivers rather than a true reflection of the apathy subtypes represented. It should also be acknowledged that only approximately 50% of caregivers who expressed an interest in the study were able to participate, therefore the voice of those who could not commit for practical or psychological reasons are not represented. These limitations were unavoidable in the current study but a future replication with a recruitment strategy that addresses these points would meaningfully contribute to our understanding of the impact of apathy for HD caregivers.

Finally, focusing on "apathy" in the recruitment material may have inadvertently excluded those caregivers who do not label the behaviour of the pwHD they support in this way. Taking a more exploratory approach and recruiting for a study into the challenges of caregiving in HD in general may have yielded a more diverse understanding of the experience of supporting someone with HD related apathy.

Conclusion

Our study indicates that apathy makes life harder for HD caregivers. The distress they experienced was linked to an early grieving process and in particular the ambiguous loss of the relationship between caregiver and the pwHD. This was further compounded by caregivers tendency to draw upon wider social discourses about the pwHD's behaviour, and not understanding it as apathy which led to feelings of anger and frustration, as reduced social and emotional behaviour was attributed to the pwHD, rather than the disease process. Currently, apathy is an understudied area of HD research that warrants further investigation. Future research should focus on determining whether existing strategies from the wider neuropsychological rehabilitation literature would help reduce the psychological impact of apathy on HD caregivers, including the use of couples and family therapy approaches. Co-producing this work with HD caregivers would help ensure it meets needs of this unheard and under-represented community and support services to better recognize the existential challenges experienced by caregivers.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Data availability statement

Anonymised data relating to this research and additional information regarding the analysis and methodology are available by request to the corresponding author.

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