A qualitative examination of apathy and physical activity in Huntington’s and Parkinson’s disease

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Aim: In Huntington’s disease (HD) and Parkinson’s disease (PD), apathy is a frequently cited barrier to participation in physical activity. Current diagnostic criteria emphasize dissociable variants of apathy that differentially affect goal-directed behavior. How these dimensions present and affect physical activity in HD and PD is unknown. Methods: Using a qualitative approach, we examined the experience of apathy and its impact on physical activity in 20 people with early-manifest HD or idiopathic PD. Results: Two major themes emerged: the multidimensionality of apathy, including initiation or goal-identification difficulties, and the interplay of apathy and fatigue; and facilitators of physical activity, including routines, safe environments and education. Conclusion: Physical activity interventions tailored to apathy phenotypes may maximize participant engagement.

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Huntington’s disease (HD) is a dominantly inherited neurodegenerative disorder that leads to motor dysfunction, cognitive impairment and neuropsychiatric changes. The disease is caused by the production of an abnormal protein that is especially toxic to the striatal cells of the basal ganglia [1]. In Western populations, HD is estimated to affect 10.6–13.7 people per 100,000. Similar to HD, Parkinson’s disease (PD) is a neurodegenerative movement disorder caused by an unexplained degeneration of the nigrostriatal dopaminergic neurons of the basal ganglia [2]. PD is more common than HD, affecting an estimated 428 per 100,000 of 60–69 year olds, with prevalence increasing steadily with age [3].

HD and PD are diseases of the basal ganglia characterized by degeneration of the cortico-striatal-thalamic circuits. In healthy people, these circuits facilitate high level cognition and voluntary motor function [4,5]. In HD and PD the degeneration of the basal ganglia leads to physical changes that detrimentally affect daily functioning [6,7]. These include changes to balance, gait and postural stability. Physical activity programs are thus especially important in the management of neurodegenerative movement disorders to promote physical, social and emotional wellbeing.

Interventions that promote physical activity in HD and PD, alongside emotional and cognitive engagement, have been trialled across inpatient, outpatient and community settings [8–11]. Most research interventions focus on short-term gains, and do not prioritize the long-term maintenance of health behaviors. Similarly, limited resources mean that clinical interventions are often targeted and time limited [12]. The long-term efficacy of physical activity interventions thus depends on the compliance and engagement of the participant, who must independently adhere...
to their program long-term to maximize the benefits. Long-term reliance on participant adherence, however, poses a challenge for people with neurological conditions in which apathy is a common symptom, such as HD and PD.

Alongside disturbances in motor function and cognition, people with HD and PD experience behavioral disturbances, of which apathy is one of the most common [13-15]. Apathy is defined as a reduction in goal directed behavior associated with reduced interest, motivation and emotional reactivity [16,17] that contributes to lower quality of life, less functional independence, cognitive decline and greater caregiver burden [18,19]. In early manifest HD, up to 63% of people report clinically relevant apathy [20], and in PD, clinically elevated apathy affects approximately 50% of people [15,21]. The high prevalence of apathy in HD and PD is attributable to altered cortico-striatal-thalamic circuits, as these pathways are important for initiating, maintaining and reinforcing motivated goal-directed behavior [22,23]. Current diagnostic criteria of apathy across psychiatric and neurological disease emphasize dissociable variants that differentially affect goal-directed behavior, including behavioral (difficulty initiating action), cognitive (difficulty identifying a goal and associated plan of action), emotional (blunted emotional responses) and social apathy (social withdrawal) [16,17,24]. How these apathy subtypes manifest and whether they relate differentially to physical activity in HD and PD is unknown.

Clinical assessment of apathy is typically based on self- or partner-rating scales, or clinician interview [25]. Self- and partner-report can enable tracking of apathy across time; however, this approach lacks information about the context in which apathy is experienced or observed and provides no account of apathy in a person’s own words. Patient-centered accounts of apathy will facilitate more accurate measurement of apathy subtypes and inform physical activity interventions targeted to HD and PD populations; these accounts may be best achieved using qualitative methods but to date have been underutilized. Only two studies have employed a qualitative framework to examine apathy in PD [26,27], but the manifestation of apathy subtypes or their impact on physical activity was not explored. Likewise, qualitative studies of physical activity in HD and PD [28] focus on the general barriers and facilitators of physical activity, without consideration to non-motor symptoms, such as apathy, that may affect participation [29].

The aim of our exploratory study was to understand the subjective experience of apathy subtypes and how they influence engagement in physical activity. We included people with HD and PD because these neurodegenerative diseases share pathology of the basal ganglia and apathy is a commonly reported but poorly understood symptom in both diseases [17,30,31]. For the purpose of this study, we designed and implemented a semi-structured interview schedule and administered the Lille Apathy Rating Scale (LARS) [32], which is a clinician-administered structured interview of apathy. We then analyzed these interviews using qualitative methods, led by two overarching questions: how does the experience of apathy across its different dimensions affect engagement in physical activity behaviors? and which behavioral strategies compensate for apathy and enable physical activity?

Materials & methods
Design
We used a phenomenological qualitative research design to explore participant’s lived experience of apathy and its subtypes and how these experiences effected their engagement in physical activity. To do so, we developed a semi-structured interview schedule, which we administered alongside the LARS.

Participants
Recruitment sources included a participant registry at Teachers College, Columbia University and word-of-mouth. Four participants with HD were approached in person at the time of their clinic appointment at the Huntington’s Disease Society of America (HDSA) Center of Excellence at New York State Psychiatric Institute (NYSPI). We recruited 20 people diagnosed by a neurologist with manifest HD (n = 10) or idiopathic PD (n = 10). We included participants in the early to middle stages of disease (see Table 1 for demographic and clinical information) and excluded those with late or advanced stage disease. For HD participants, we determined disease stage using the Total Functional Capacity (TFC) score of the Unified Huntington’s Disease Rating Scale (UHDRS) [33]. For PD participants, we determined disease stage using the Hoehn and Yahr Staging criteria [34]. Late and advanced disease for HD participants was defined as a (TFC) score of less than seven [33], and in the case of people with PD, a Hoehn and Yahr stage of greater than three [34]. We obtained medical information pertaining to disease stage from the clinical recruitment site or via our internal participant registry at Teachers College.

We used a purposive sampling approach to ensure equal representation of people with HD and PD. PD participants were on average of 12.9 years older than those with HD (p = 0.009) and had more years of education.
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Table 1. Summary of participant demographics and self-report measures (means [standard deviation]).

<table>
<thead>
<tr>
<th></th>
<th>Huntington’s disease</th>
<th>Parkinson’s disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (M:F)</td>
<td>7:3</td>
<td>6:4</td>
</tr>
<tr>
<td>Age** [range]</td>
<td>53 (10.56) [41–73]</td>
<td>65.9 (9.0) [55–79]</td>
</tr>
<tr>
<td>Education** [range]</td>
<td>15.6 (2.88) [12–21]</td>
<td>19.60 (1.90) [16–21]</td>
</tr>
</tbody>
</table>

Significant difference: *p < 0.05; **p < 0.001.

LARS: Lille Apathy Rating Scale.

Table 2. Overview of Huntington’s disease participants’ disease and functional information.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age, gender and stage</th>
<th>Descriptive information</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD01</td>
<td>41-year-old male; 13 years of education; stage II</td>
<td>Single, living in rehabilitation facility; unemployed</td>
</tr>
<tr>
<td>HD02</td>
<td>59-year-old male; 14 years of education; stage I</td>
<td>Single; living independently; unemployed</td>
</tr>
<tr>
<td>HD03</td>
<td>46-year-old male; 16 years of education; stage I</td>
<td>Married; living at home with spouse; working full-time</td>
</tr>
<tr>
<td>HD04</td>
<td>43-year-old female; 14 years of education; stage I</td>
<td>Married; living at home with spouse and young child; working full-time</td>
</tr>
<tr>
<td>HD05</td>
<td>53-year-old male; 20 years of education; stage I</td>
<td>Single; living independently; working full-time</td>
</tr>
<tr>
<td>HD06</td>
<td>66-year-old male; 15 years of education; stage II</td>
<td>Single; living independently; retired</td>
</tr>
<tr>
<td>HD07</td>
<td>44-year-old female; 16 years of education; stage II</td>
<td>Married; living at home with spouse; retired</td>
</tr>
<tr>
<td>HD08</td>
<td>73-year-old male; 21 years of education; stage I</td>
<td>Married; living at home with spouse; volunteering part-time</td>
</tr>
<tr>
<td>HD09</td>
<td>49-year-old male; 12 years of education; stage I</td>
<td>Single; living independently; working full-time</td>
</tr>
<tr>
<td>HD10</td>
<td>46-year-old female; 12 years of education; stage I</td>
<td>Married; living independently with spouse; working full-time</td>
</tr>
</tbody>
</table>

Stage: Total Functional Capacity score.

Table 3. Overview of Parkinson’s disease participants’ disease and functional information.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age, gender and stage</th>
<th>Descriptive information</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD11</td>
<td>66-year-old male; 21 years of education; stage II</td>
<td>Married; living at home with spouse; working part-time;</td>
</tr>
<tr>
<td>PD12</td>
<td>77-year-old female; 12 years education; stage II</td>
<td>Living with partner, retired</td>
</tr>
<tr>
<td>PD13</td>
<td>73-year-old male; 21 years of education; stage I</td>
<td>Married, living at home with spouse; working part time</td>
</tr>
<tr>
<td>PD14</td>
<td>57-year-old female; 21 years of education; stage I</td>
<td>Married, living at home with spouse and adult child; working full-time</td>
</tr>
<tr>
<td>PD15</td>
<td>59-year-old male; 18 years of education; stage II</td>
<td>Single, living independently, retired</td>
</tr>
<tr>
<td>PD16</td>
<td>79-year-old female; 16 years of age; stage I</td>
<td>Married, living at home with spouse, retired</td>
</tr>
<tr>
<td>PD17</td>
<td>55-year-old female; 18 years of education; stage I</td>
<td>Married, living at home with spouse; working part-time</td>
</tr>
<tr>
<td>PD18</td>
<td>57-year-old male; 21 years of education; stage II</td>
<td>Married; living at home with spouse and adult child; working full-time</td>
</tr>
<tr>
<td>PD19</td>
<td>63-year-old female; 21 years of education; stage I</td>
<td>Married; living at home with spouse; working full-time;</td>
</tr>
<tr>
<td>PD20</td>
<td>73-year-old male; 18 years of education; stage II</td>
<td>Living alone; retired</td>
</tr>
</tbody>
</table>

Stage: Hoehn & Yahr disease staging.

(p = 0.002; Table 1). All participants ambulated independently but reported some form of cognitive or physical impairment, or mood-related changes that interrupted their ability to perform certain activities (e.g., pain, slowness in movement, reduced dexterity, delayed reaction times, balance, anxiety, problem solving). Individual characteristics of participants with HD and PD are presented in Tables 2 and 3, respectively. Technical failure in the recording of two interviews resulted in missing transcripts from the qualitative analyses for two participants, both from the HD sample. This technical failure resulted in a final HD analytic sample of eight. All participants provided informed consent in accordance with the Declaration of Helsinki. Ethical approval was obtained from NYSPI and Teachers College, Columbia University Institutional Review Boards.

Procedure

We interviewed participants in person (n = 9) or remotely via audio/video conferencing (n = 11). In person interviews were conducted at the Neurorehabilitation Research Laboratory at Teachers College, or at the HDSA.
Center of Excellence at NYSPI. All interviews were audio recorded. KJA conducted the interviews, which ranged from 60 to 90 min in duration and followed our pre-planned interview schedule, which served as a checklist and guide toward the topic area for discussion. To facilitate recall, the interview schedule was built around specific episodes of activity or sedentary behaviors. This minimized the executive load required of participants, thereby limiting the impact of possible cognitive impairment on interview responses. Broadly, the question schedule aimed to establish: the lived experience and motivation for physical activity; the lived experience of sedentary activity and the reason for sedentary behavior; and, the subjective impact of apathy on physical activity. At the completion of our interview schedule, we administered the LARS.

We then analyzed these interviews using qualitative methods, led by two overarching questions: How does apathy across its different dimensions affect engagement in physical activity behaviors; and which behavioral strategies compensate for apathy and enable physical activity?

Assessments

*Lille apathy rating scale*

The LARS [32] is a clinician-rated, semi-structured interview that assess four domains of apathy: intellectual curiosity, action initiation, emotion and self-awareness. Administration of the LARS includes 33 items read aloud to the respondent. The first three items are rated on a five-point Likert type scale, whereas the clinician evaluates the remaining 33 items on a binary yes/no scale with an not available (NA) rating option for responses that are non-classifiable. The LARS produces a total apathy score ranging from -36 to 36, with lower scores indicative of more apathy symptomatology. The developers suggest that a cutoff score of -16 or less is indicative of clinically relevant apathy [14,32].

Data analysis

We analyzed the verbatim responses of participants from both our interview schedule and the LARS, using the inductive thematic analysis approach described by Braun and Clarke [35]. Interviews were transcribed verbatim by KJA who subsequently re-reviewed them for accuracy. Analysis followed five stages. In the first stage, KJA carefully read all 18 transcripts to promote familiarization with the data. Throughout this stage, KJA used notes to record ideas for codes and themes, which informed the analyses. Second, transcripts were re-read in detail and coded, using an open-coding framework based on the principles of thematic analysis [35]. In the third stage, KJA and LQ sorted the generated codes into potential sub-themes. LQ is an experienced physical therapist with a research program specializing in physical therapy interventions. Charting and mind-maps were employed in the third stage to establish links between sub-themes and to visualize how each code fit within the broader theme. Fourth, KJA and LQ reviewed the codes to determine any overlap or repetition across codes, and whether any codes could be collapsed to more concisely describe the data. During this stage, we also considered whether we could improve the descriptors used to capture the content of each code or overarching sub-theme, and where relevant, we adjusted the descriptors accordingly. Finally, the sub-themes were collated into two major themes that encapsulated their overarching meaning and that related to the research questions of interest.

To ensure the accuracy of our interpretations, we employed analyst triangulation and peer debriefing. This included a sample of cross-coding, alongside multiple ongoing discussions between KJA and LQ about the generated codes and the identified themes. Through these discussions, we determined alternative interpretations and ensured data saturation was reached prior to the preparation of results. The interpretation of the major themes and the sub-themes within were discussed with all authors who together have extensive research and clinical experience in HD and PD. Discrepancies in interpretation were discussed as a group and resolved with the oversight of KJA and LQ. We used the qualitative data analysis package NVivo (QSR NVivo for Macintosh, version 2.0., QSR International Pty Ltd) to assist with summarizing and analyzing the data.

In addition to our qualitative analyses, we used the total apathy score derived from the LARS to characterize the severity of apathy in the sample.

Results

*Qualitative results*

Our qualitative analysis identified two major themes: the impact of multidimensional apathy on physical activity, and strategies to facilitate engagement in physical activity. To effectively convey their meaning, we deconstructed our major themes into six sub-themes (see Figure 1). Major theme one consisted of the following three sub-themes:
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Apathy in HD and PD

1a) apathy leads to difficulties in initiation in both PD and HD; 1b) people with HD have difficulties identifying goals for action; and 1c) fatigue influences physical activity and is not easily distinguished from apathy. Major theme two consisted of the following three subthemes: 2a) the use of prompts, routine and structure to promote physical activity; 2b) creating a safe social environment facilitates exercise engagement, however resources for people with HD appear to be lacking compared with PD; and 2c) The psychological response to a diagnosis affects engagement and psychoeducation after diagnosis may promote physical activity. We describe each sub-theme below, with examples of key quotes from participants.

Major theme two: strategies to engage physical activity

Fatigue

1) Reduced initiation

Apathy in HD and PD

2) Difficulty identifying goals

Physical activity

3) Prompts, routine & structure

Behavioural strategies

4) Safe social environment

Education

Figure 1. Visual schematic of the two major themes comprised of six subthemes. Orange shaded elements (left) refer to major theme one and subthemes within. Green shaded elements (right) refer to major theme two and subthemes within. The bidirectional arrow between apathy and fatigue indicates the overlap between these two distinct psychological constructs.

HD: Huntington’s disease; PD: Parkinson’s disease.

Major theme two: strategies to engage physical activity

Apathy leads to difficulties in the initiation of activity in both HD & PD

Both HD and PD participants described difficulty in initiating activities they believed would be positive for their physical and mental health. These descriptions were both overt, “I don’t know, if it’s just me and I’m lazy or if it’s just part of the disease, but I have difficulties sometimes getting myself off the ground and up off the couch and doing things” (HD03), and indirect descriptions of wanting to “get out” and not doing so until prompted by a friend or spouse: “I feel bad, I feel sad sometimes, because... I’ll be home, I might put on the TV... then that’s it... but as soon as she texted me, I thought ‘ooh’ this is a really good day to get out” (HD04).

Many HD and PD participants identified activities or behaviors they wanted to engage in but described difficulty initiating the activity: “we’ve always talked about [walking] and we definitely could go out and do it after work. But for some reason you just get home and you’re just not particularly motivated” (HD03). Difficulties in initiation were especially prominent after a disruption to established routines, which ranged from relatively minor changes, such as a holiday, to major events, such as moving to a new house or losing a job.

People with HD have difficulties identifying goals for action, which may reflect cognitive apathy

Particularly for people with HD, a reduced interest or curiosity was evident, which was often associated with a difficulty identifying goals or activities of interest. Although these participants did not directly indicate a lack of interests, they responded vaguely and were unable to draw on any recent examples of self-generated, spontaneous activity. For example, when asked what they typically did after work, one HD participant reflected: “Go home... generally go home and ah...” (HD05). Subsequent prompting of his hobbies provided little further information.
and when asked whether he was interested in new things he replied: "Hmmm... doesn't faze me... don't really care." Difficulties in goal identification were also exemplified by participants who described apathy as a sense of indecision, of being "stuck and caught" and not knowing how to proceed, possibly reflecting a difficulty in mentally elaborating on a plan of action [17,36].

Fatigue influences physical activity & is not easily distinguished from apathy
People with HD and PD tended to describe apathy in a way that was conceptually similar to fatigue. One participant with PD defined apathy as "everyday activities [become] difficult, tiring, emotionally more difficult, and harder", and a participant with HD described the experience of apathy as "running out of steam". Both peripheral (difficulty maintaining physical activity at desired level of intensity) and central fatigue (subjective experience of fatigue) were prominent symptoms reported by PD participants (see Chaudhuri and Behan [37] for a review of central and peripheral fatigue). In PD, reports of fatigue were typically discussed in the context of medication in which participants reported less energy on either side of their routine dosage. Peripheral fatigue described as muscle tiredness from physical exertion was reported (e.g., arms feeling tired) as was daytime sleepiness, which was attributed to sleep difficulties. Participants also made reference to central fatigue and how this often arose at the prospect of managing their symptoms, formulating plans, initiating activities or maintaining positivity. For example, when discussing the emotional experience of a single day, PD18 reflected: "you may be feeling some fatigue because of... the effort needed to build up on motivation". Several participants described feeling mentally fatigued in the morning, which dissipated once they had commenced their daily activities. The subjective experience of fatigue was also related to the perception of the activity whereby enjoyable activities were associated with more self-reported "motivation" and subsequently less fatigue, for example, "It's funny, when I go to the gym I get bored very easily and I get tired much faster, when I go for dancing I can dance for three hours, and never get tired. It's amazing, depends on your attitude actually" (PD15).

Major theme two: strategies to engage physical activity
The use of prompts, routine & structure to promote activity
By far the most common strategy to overcome symptoms of apathy was the use of external prompts, adopted by both people with HD and PD. Prompts included reminders from family or friends, as well as electronic reminders set with smartphones: "I guess cues always help... so sometimes [it helps], if somebody else has prompted me"; (PD18). Participants also engaged cues from the environment, such as committing to an activity at a certain time of the day or agreeing to do the activity as part of a social outing. Participants who were the most physically and socially engaged described having schedules in place that provided structure to their lives and was especially prominent in PD participants. Schedules included weekly commitments to support groups, exercise classes, community groups and volunteer programs: "During the day normally I can go for classes, all sorts of classes, I've got my dancing classes, and my underwater exercise classes, yoga..." (PD15). These schedules appeared to provide the structure and routine needed to circumvent initiation deficits, whereby participants were not required to internally generate the activity. Importantly, the schedules of active participants tended to be long standing habits, adopted prior to the onset of their disease.

Creating a safe social environment facilitates exercise engagement, however resources for people with HD are lacking compared with PD
Participants with positive social supports tended to engage in more activity than those who were socially isolated or whose family members were also inactive, suggesting that community and environmental contexts may serve as a cue to overcome deficits in both initiation and goal generation. The significance of social supports was reiterated by participants who described the social setting of their activity as extremely important. For example, PD11 reflected: "there is a social aspect, which can't be ignored because it's also a part of it... I could spend part of my day with other people or I could spend the entire day sitting alone in the apartment", emphasizing community, inclusion and social acceptance as a vital component of initiating activity. This theme reflected that engagement in physical activity facilitated more than just physical health but also provided a sense of mental wellbeing: "I had to find a way to get myself motivated and Dance for PD came along and the people who I dance with are really such a remarkable group of people, community, that organisation, the dancers, they're like family there" (PD15). Whereas PD participants cited many community groups tailored to people with PD, only one HD participant discussed involvement in a HD
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LARS score

Participant ID

-30 -20 -10 0 3 0

PD18

HD10

PD12

HD03

PD16

HD08

HD09

HD05

HD01

PD14

HD15

HD04

HD02

PD17

HD07

PD19

PD15

PD13

HD11

PD11

HD06

PD10

HD00

HD08

PD20

HD19

PD09

HD03

PD08

HD05

HD04

PD07

HD01

PD06

HD02

PD05

HD01

PD04

HD00

HD07

PD03

HD01

PD02

HD00

PD01

HD00

Figure 2. Total Lille Apathy Rating Scale scores across Huntington's and Parkinson's disease participants. Vertical dashed line indicates LARS clinical cutoff score. Scores less than -16 are indicative of symptoms meeting clinical threshold.

HD: Huntington’s disease; LARS: Lille Apathy Rating Scale; PD: Parkinson’s disease.

support group. Most HD participants were not involved in community, support or social groups specific to people with HD.

The psychological response to a diagnosis affects engagement & psychoeducation after diagnosis may promote physical activity.

This theme captured the variability in people’s responses to the onset of symptoms and prognosis. Compared with the HD group, participants with PD often reflected that their diagnosis was a 'shock' and described a period of adjustment where they sought to regain normality: “I want to do it [exercise] because it makes me feel more like a human being, you feel more normal... in spite of my limitations... it makes me feel like a real person and that is something I lost considerably” (PD15). Despite certain symptoms threatening continued engagement in activity, for example “there are certain things that are very frustrating, straining, using arms, things that reinforce the fact that you've got a disability, and things which are actively difficult to do but that in the past have been easy to do” (PD15), most PD participants expressed the importance of regaining control through physical activity. For example, almost all PD participants indicated that their physical activity was partially motivated by the belief that exercise may slow the progression of their disease: “the thing that motivates me... is I don't want to be sicker and I don't know whether there is any hope of that not happening, but I'm going to do everything possible to make it harder” (PD16). In contrast, only four participants with HD cited the importance of physical activity in relation to their disease and few cited physical activity as disease modifying.

Summary of LARS data

Across both HD and PD participants, 13 people (65%) scored in the clinical range on the LARS. Of these 13, seven (70%) had PD and 5 (50%) had HD. Individual scores are presented in Figure 2.
Discussion

In this study, we explored the experience of multidimensional apathy in people with HD and PD and how these experiences affected engagement in physical activity. We found that people described apathy in distinct ways and utilized several strategies to overcome apathy to engage in physical activity. Positively, the qualitative descriptions of apathy that we report also emerged in our quantitative LARS data, with more than half of the sample scoring in the clinical apathy range.

Our study is the first to qualitatively examine how people with HD and PD conceptualize and experience symptoms of apathy in the context of physical activity. By investigating how people experience and describe their own symptoms we provide a valuable contribution to a growing body of literature attempting to refine definitional frameworks of apathy [16,24]. Such frameworks are essential because understanding the lived experience of apathy and the context in which the syndrome occurs is needed for accurate measurement and early identification in clinical settings. Participants described examples of behavioral and cognitive apathy that are consistent with current definitional frameworks [16,17]. In both PD and HD, apathy occurred commonly as a difficulty in initiating activities. HD participants also demonstrated the difficulties in goal identification that occur in cognitive presentations of apathy [17,38]. Although emotional apathy is included in theoretical frameworks of apathy, this element did not emerge strongly from our data. The absence of emotional or social apathy however warrants further investigation to understand how these aspects of apathy affect people with HD and PD. Rather than reflecting an absence of these apathy symptoms, people with HD or PD may lack awareness into their own emotional or social blunting attributable to social cognition deficits [39–42]. Of course, this interpretation is speculative and definitive conclusions are beyond our scope.

In our study, we also observed significant overlap in the subjective experience of mental fatigue and apathy, whereby the mental energy required to commence an activity was described as inherently fatiguing. As a result people with HD and PD tended to perceive fatigue and apathy as intertwined states, rather than distinct clinical symptoms or research constructs. This tendency has been reported elsewhere [19,43], but is not sufficiently considered in current apathy consensus criteria. There have been several attempts to characterize mental fatigue in PD [44], whereas little research has addressed how fatigue affects people with HD. A more nuanced understanding of how apathy and fatigue differentially relate to physical activity and how their current definitional constructs overlap and diverge will be essential for more refined diagnostic criteria, measurement tools and the subsequent monitoring of the two states in behavioral interventions.

As well as understanding the subjective experience of apathy, our study also highlighted several strategies that may promote engagement in physical activity. Participants who described being highly physically active tended to be those who had structured schedules that served as external prompts for activity. These prompts served to circumvent initiation deficits, as participants were not required to internally generate their activity. External prompts are likely to facilitate behavior in most people, independent of disease, however external prompts appear especially important for people with neurodegenerative diseases in which apathy is prominent [45,46]. Importantly, the schedules of active participants tended to be long standing habits, adopted prior to the onset of symptoms. These findings suggest that to reduce the impact of apathy, care providers may seek to engage participants early in the disease course, or in the case of HD, the pre-manifest period, before apathy becomes a prominent feature.

Implementing a structured routine early in the disease course may assist people in maintaining engagement later in the disease, when generating ideas or selecting goals becomes more difficult and the initiation of new behaviors becomes increasingly cognitively demanding [47–49]. Our study also suggested that educating people about the importance of physical activity is a critical first step of any community-based intervention to foster continued engagement and that this may be especially important for people with HD who, in our study, were not as engaged with services or as health literate, as people with PD [12,29]. Although it was not the focus of this study, improved service provision for people affected by HD may be necessary to help this community of people engage socially and physically.

The role of executive dysfunction in the manifestation of cognitive apathy must be acknowledged as a limitation of this study, given the evidence that cognitive apathy and cognition share aspects of their neuropathology [5,17]. Although a comparison of apathy and cognition is beyond the scope of the present study, there is likely to be a complex interplay between the cognitive aspects of apathy and the progressive cognitive impairment characteristic of neurodegenerative diseases, particularly in HD [45–47,49]. Our study sought to focus on the lived experience of apathy and as a result we did not include caregivers. We nonetheless acknowledge that some participants may not
A qualitative examination of apathy & physical activity in Huntington's & Parkinson's disease

Conclusion
In this study, we have examined the subjective experience and context in which apathy, across its variable expressions, occurs in people with HD and PD, and how these expressions affect engagement with physical activity. These results provide qualitative support for recently published apathy diagnostic criteria, with the exception that emotional apathy did not strongly emerge from our data. The findings from this study are intended to assist clinicians and researchers in engaging HD and PD participants in physical activity interventions, acknowledging that an improved understanding of the subjective experience of apathy variants will lead to more targeted interventions with more meaningful participant engagement.

Summary points
- We examined the subjective experience of apathy in people with Huntington's disease (HD) and Parkinson's disease (PD), and how these expressions affect engagement with physical activity.
- Our results provide qualitative support for recently published apathy diagnostic criteria citing distinct subtypes of apathy.
- Participants with apathy tended to have difficulty initiating behavior or thinking of activities to engage in.
- The experience of fatigue was difficult to disentangle from the experience of apathy.
- Emotional subtypes of apathy did not strongly emerge from our qualitative data.
- The findings from this study are intended to assist clinicians and researchers in engaging HD and PD participants in physical activity interventions.
- An improved understanding of the subjective experience of apathy will lead to more targeted interventions with more meaningful participant engagement.

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Ethical conduct of research
The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

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References
Papers of special note have been highlighted as: of interest; of considerable interest

- A manuscript that highlights the importance of community-based exercise programs for people with HD, alongside the difficulties in maintaining long-term engagement.


- A manuscript that highlights the importance of physical activity in HD.


- A seminal paper in advancing our understanding of the multidimensionality of apathy. A theoretical paper rather than a clinical applied paper.

- A thorough overview of apathy in Parkinson’s disease highlighting the most important issues in our current conceptual understanding and how this dictates the quality of care/intervention.

- One of the very few qualitative papers exploring apathy in neurodegenerative disease with a qualitative approach. The conceptualization of apathy in this manuscript differs from current neurobiological conceptualizations such as the one adopted in our paper.

- A very relevant paper describing the importance of identifying and acknowledging apathy in PD and the utility of qualitative research to better understand the subjective experience of apathy.


- An important paper documenting the experience of physical activity in HD and neurodegenerative disease more broadly.


