Experience and Acceptability of a Guided Self-Help Intervention for Anxiety for Individuals with Huntington's Disease (GUIDE-HD Trial): A Qualitative Study

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Abstracts

People with Huntington's disease (HD) commonly experience anxiety, yet access to psychological interventions remains limited. Guided self-help is a low-cost, scalable, evidence-based approach with the potential to improve access to psychological support. This qualitative study aimed to explore participants' experience of GUIDE-HD, a remote guided self-help intervention designed to address anxiety in people with HD based on cognitive behavioural therapy and acceptance and commitment therapy, by examining: (i) the acceptability of the intervention, (ii) any perceived benefits or challenges, and (iii) ways to enhance its relevance and accessibility for people with HD (pwHD). Qualitative individual semi-structured interviews were conducted with nine pwHD and three carers and analysed using framework analysis. Three overarching themes emerged: (1) A therapeutic journey for people with and affected by HD; (2) Mechanisms of benefit; (3) Experiencing various gains. Participants valued the intervention's relevance, structure, accessibility, personalisation and facilitation. Reported gains extended beyond reduced anxiety to increased acceptance of the realities of living with and managing the condition and better relationships. While a number of limitations should be considered, such as the sample size and its predominant female representation, the GUIDE-HD intervention was acceptable and showed promise as a tailored psychological approach for pwHD.

Keywords

Feasibility, psychological intervention, guided self-help, Huntington's disease, anxiety.

Introduction

Although Huntington's disease (HD) is diagnosed on the basis of movement difficulties, individuals also often experience a range of psychological challenges (Simpson et al., 2021). While commonly described as 'neuropsychiatric', depression and anxiety, as examples, are not uniquely linked to neurodegeneration (Zarotti et al., 2022). These psychological challenges can predate movement difficulties and, when formulated from a biopsychosocial perspective, can arise from a complex series of situational and personal factors, including family dynamics, threats to identity and the stresses and stigma associated with managing with a neurodegenerative condition (Dale et al., 2022; Maffi et al., 2025; Simpson et al., 2019).

However, although psychological issues are often a major concern for people with Huntington's disease (pwHD) and openness to psychological therapy seems high (Eccles et al., 2021; Theed, 2016), access to psychological care and evidence-based therapies remains limited (Zarotti et al., 2020). Moreover, the potential for remotely delivered psychological interventions has not been explored, despite being seen in other neurodegenerative conditions (Swalwell et al., 2018). This seems a missed opportunity given that remotely delivered clinical interventions are increasingly used for pwHD to offer appointments from home and to address barriers to in-person appointments such as mobility issues, fatigue, and geographic isolation (Lee et al., 2021). A number of different types of psychological intervention can be delivered remotely, including guided self-help (GSH), a structured, evidence-based intervention where individuals work through self-help materials with support and guidance from a trained practitioner.

Guided self-help (GSH) has been successfully used in other populations with chronic illnesses and neurological conditions (Sharpe et al., 2011), though the evidence in neurological disorders still remains limited. A pilot trial in Parkinson's disease demonstrated reductions in worry following guided bibliotherapy with brief therapist contact (Lawson et al., 2013). In multiple sclerosis, several trials of computerised CBT show benefit for mood symptoms (Fischer et al., 2015; Gold et al., 2023), though these were unguided digital interventions rather than formal GSH. Together with meta-analytic support for GSH in common mental health problems (Cuijpers et al., 2011), this suggests that structured, low-intensity, facilitator-supported formats could feasibly be adapted for people in the earlier stages of HD. Compared with broader telehealth formats, GSH offers the additional advantage of written materials that can be revisited, which is an important feature when supporting individuals with cognitive or memory difficulties.

However, cognitive and motivational changes associated with HD, including executive dysfunction, difficulties in initiation, and reduced insight or anosognosia, may present barriers to engagement with written or self-directed materials. Such factors can influence awareness of difficulties, motivation to participate, and the ability to link intervention strategies with perceived benefit, underscoring the importance of evaluating the acceptability and feasibility of guided self-help in this population.

One of the most common but least researched psychological difficulty for people affected by HD is anxiety. It affects both individuals who are at the manifest (i.e., showing motor symptoms) or premanifest stages (i.e., having the gene expansion but not the motor symptoms required for clinical diagnosis). Prevalence estimates vary for pwHD who experience clinical anxiety, with approximately 40%-point prevalence and 70% cumulative prevalence (Dale & van Duijn, 2015). Anxiety among pwHD is not only distressing but can also impact other aspects of daily functioning such as cognitive skills, chorea, risk of falls, suicide risk, mood, communication, and overall quality of life (Hartelius et al., 2010; Zarotti, Simpson, et al., 2019). While the focus of this paper is on addressing the psychological factors that contribute to anxiety among pwHD, it is acknowledged that neuropathogical changes occur that have also been linked with anxiety. For example, Ahveninen et al. (2018) found that among premanifest pwHD, those with higher anxiety had smaller amygdala volumes. Addressing anxiety among pwHD presents specific challenges from a psychological perspective due to the complex and genetic nature of the condition. Anxiety can arise for various reasons including fear of the future and uncertainty around symptom onset, symptom progression, loss of functioning, and premature death (Regan et al., 2018). People at the premanifest stage may become hypervigilant to any potential symptoms (i.e., 'symptom watching', (Wieringa et al., 2022). As HD progresses to the manifest stage, people can experience anxiety around issues such as loss of independence, the social impact of having visible signs of HD (e.g., involuntary movements, reduced ambulation and oral nutrition, impaired social cognition), and fears around risks such as choking and falling (Essat et al., 2020; Hartelius et al., 2010; Zarotti, Fletcher, et al., 2019). Anxieties related to the impact on other family members are also common – not least the genetic risk of passing the disease on to children, witnessing other family members develop the disease and worries around the impact on family carers (Keenan et al., 2007). These can often be coupled with, and exacerbated by, wider societal and economic factors, such as concerns about insurance and loss of earnings (Oster et al., 2008).

Such a wide range of reasons to feel anxious underscores the need for psychological interventions that are tailored for pwHD. Furthermore, given that cognitive changes can occur early in the disease trajectory (Paulsen, 2011), psychological interventions that feature adaptations for such difficulties are also required to enable pwHD to access appropriate support (Zarotti et al., 2020). Given that difficulties with anxiety can arise early in the disease (including when individuals are premanifest), talking therapies should ideally be offered at the earliest opportunity to enable pwHD to cope better as the disease progresses (British Psychological Society, 2021).

Psychological Interventions for pwHD

The current literature on psychological support and interventions for pwHD is extremely sparse, with no fully powered randomised controlled trials (RCTs) undertaken to date and none aimed at investigating approaches specifically to reduce anxiety in this population (Dale & van Duijn, 2015; Zarotti et al., 2020, 2024). However, several studies have highlighted the potential benefits of a psychological approach to reduce anxiety in pwHD. For example, the Patient Education Program for Huntington's Disease (PEP-HD; (A'Campo et al., 2012) combined elements of psychoeducation with cognitive behavioural therapy (CBT) and found significant post-intervention improvements in anxiety for individuals with manifest HD (n = 40). However, no changes were observed for premanifest participants (n = 19), and the study's lack of follow-up makes the long-term value of the benefits for manifest individuals unclear. Additionally, a 25% dropout rate among manifest participants highlighted challenges in retaining engagement. Previously, a single case (Silver, 2003) had already suggested that tailored CBT might be helpful in reducing anxiety.

Eccles et al.'s. (2020) uncontrolled feasibility study offered group mindfulness-based cognitive therapy to 12 premanifest individuals. Several outcomes, including anxiety scores, were assessed at baseline, post-intervention, and 3-month and 1-year follow-up. While the results showed no significant improvement in anxiety scores - likely due to the relatively low scores at baseline - qualitative interviews conducted after the intervention indicated that the intervention was positively appraised and acceptable (Eccles et al., 2021). More recently, a single case study reported the adoption of acceptance and commitment therapy (ACT) – a psychological approach which has shown promising results with a wide range of neurological conditions, including Parkinson's, motor neurone disease (MND), and multiple sclerosis – with an individual with manifest HD (Schriger et al., 2025). The results showed that the intervention generally yielded positive improvements for the individual (including physical function), although not for anxiety at immediate follow-up.

The GUIDE-HD Intervention

The GUIDE-HD study is the first RCT to evaluate the feasibility and acceptability of a remote GSH intervention designed specifically for anxiety among pwHD (Schriger et al., 2025). The intervention was co-designed with people affected by HD, alongside clinical psychologists with expertise in HD. Using a process-based CBT informed approach (Hayes & Hoffman, 2018), with a blend of both traditional CBT and ACT, the GUIDE-HD intervention enables participants to personalise the materials in a way that fits with their preferences. Furthermore, even though the intervention was designed primarily for those with anxiety, a process-based approach tends to be transdiagnostic, encouraging the generalisation of skills beyond anxiety difficulties to cope with other difficulties such as low mood, irritability, and overall quality of life.

Feasibility RCTs are fundamental building blocks in evaluating novel and complex interventions, enabling researchers to refine and develop their approach in order to increase the likelihood of successful outcomes at the fully powered trial stage (Skivington et al., 2021). As part of this iterative process, qualitative outcomes from participants' experiences help gain an understanding of the experiences and acceptability of an intervention (Pinto et al., 2023). This is especially important in the context of undertaking a new approach for a complex condition such as HD, where detailed feedback about the timing and pacing of the intervention, the accessibility of the materials, the support offered by facilitators, and the perceived usefulness of the intervention can all help with refining the intervention to ensure it meets the needs of pwHD.

Consequently, the overarching aims of this study were to explore: (i) the acceptability of GUIDE-HD as a psychological intervention for anxiety (including barriers to and facilitators of engagement in and delivery of the intervention); (ii) perceived benefits from receiving the intervention; and (iii) ways to enhance its relevance and accessibility for pwHD. The specific research question was: what are the experiences of individuals receiving GUIDE-HD regarding its acceptability?

Standard quantitative feasibility metrics of the GUIDE-HD RCT – such as recruitment, attrition and completion of measures – have been collected and will be reported separately elsewhere. The reporting of qualitative data separately from the main feasibility outcomes was chosen in light of its potential usefulness in developing mixed methods approaches to the refinement of psychological interventions in neurological conditions (Gould et al., 2024; Rawlinson et al., 2024).

Method

GUIDE-HD Trial Design Summary and Ethics

GUIDE-HD was a randomised controlled feasibility trial evaluating a guided self-help intervention for anxiety in individuals with premanifest or early-stage HD who met diagnostic criteria for anxiety (First et al., 2016) and had a positive genetic test. Participants were recruited through clinical, research, and charity networks. Exclusion criteria included suicidal ideation, unstable health and medications, current anxiety psychotherapy, and significant cognitive impairment. Baseline measurements included anxiety and HD-related coping, quality of life, and functioning. Participants were randomised (stratified by premanifest vs manifest HD) to either the GUIDE-HD intervention or control group. The full GUIDE-HD trial intervention protocol (trial reference: ISRCTN47330596), which was approved by the UK Health Research

Authority and NHS ethical committee, is summarised in Dale et al. (2023) (IRAS ID. 304674/REC REF. 22/EM/0092).

Recruitment took place between 2022 and 2024. For ten weeks participants received a weekly workbook, followed by an individual one-hour facilitator session, either by telephone or videocall to apply the materials. Optional text reminders supported attendance. Workbooks included reading, activities, and reflective questions, covering topics such as anxiety in pwHD, values, facing fears, acceptance, and problem solving.

Outside of sessions, carers were encouraged to assist HD participants, and facilitators offered them up to three individual sessions to support this. Where applicable, carers/partners were offered copies of the manuals to help support the participant. They were invited to help participants clarify information provided in the GUIDE workbooks, practice skills with them, provide reminders to complete tasks, and provide general support and motivation for the participants. The carers were not accessing the intervention in their own right, but only in terms of supporting their loved one. They were given options to have up to three individual sessions with the facilitators to help them in their role of supporting their loved one. Of the three carers, two undertook all three sessions with the facilitators and one had one session. Sessions were psychoeducational in nature, focusing on the needs of the individual carers and what areas they wanted to understand more, covering topics such as wanting to better understand links between HD and anxiety, hypervigilance, avoidance and specific coping techniques – e.g., ‘dropping anchor’.

Post-intervention, baseline measures were repeated at 2-week, 3-month, and 6-month follow-up. Interviews about intervention experience were offered to all intervention group participants and carer session attendees. This paper reports on this specific aspect.

Study Design

To explore participants' expectations and experiences, particularly regarding acceptability, of the GUIDE-HD intervention and carer sessions, a qualitative design using semi-structured interview data was adopted.

Sampling and Participants

All ten participants who completed the full GUIDE-HD intervention, together with their three carers, were invited by telephone, text, or email (according to preference) to participate in individual post-intervention interviews within one month of completion. One participant with HD died unexpectedly from causes unrelated to HD or the intervention during this period, leaving twelve potential participants. All remaining invitees consented to be interviewed, yielding a final qualitative sample of nine individuals with HD (five premanifest and four manifest; see Table 1 for demographic details) and three carers.

As per the trial protocol, carers' demographic data were not collected.

Table 1. Participant details (*n* = 9)

Sex	
Female, n (%)	8 (89%)
Male, n (%)	1 (11%)
Age (range)	45 (30 – 65)
Education (highest level)	
GCSE (typically taken aged 16), n (%)	3 (33%)
A Level (typically taken aged 18), n (%)	3 (33%)
Undergraduate, n (%)	2 (22%)
Postgraduate, n (%)	1 (12%)

Employment	
Full time, n (%)	3 (33%)
Part time, n (%)	2 (22%)
None, n (%)	4 (45%)
Marital status	
Single, n (%)	1 (12%)
Married/Partnership, n (%)	6 (66%)
Divorced, n (%)	2 (22%)
Ethnic group	
White British, n (%)	8 (89%)
White Jewish	1 (11%)
Age when discovered about HD, mean (range)	30 (13 – 63)
Age when received genetic testing, mean (range)	38 (19 – 67)

Materials and Interviews

The semi-structured interview schedule was designed with the aims and analysis in mind. A set of open-ended questions that aligned with the research objectives and anticipated feasibility themes, such as acceptability, implementation challenges, and experiences of the intervention, were created. Prior to beginning data collection, the schedule was discussed with a public and patient involvement (PPI) steering group consisting of individuals affected by HD to ensure clarity and relevance, and questions were consequently refined based on their feedback.

To allow participants to feel as comfortable as possible in expressing their views, all interviews were carried out by researchers not involved in the facilitation of the intervention (research associate ZK; clinical psychologists MD, KM). Interviews were conducted by telephone or videocall (according to participant choice) and lasted between 35 - 65 minutes (pwHD interview: *M* = 37 minutes; carer interview: *M* = 43 minutes). At the beginning of the interviews, participants' consent was re-established, and participants were informed that all views, positive and negative, were welcomed. Recordings were transcribed verbatim, anonymised, and securely stored on protected drives.

Data Analysis

Data were analysed using framework analysis (Gale et al., 2013). Framework analysis offers a systematic and transparent method for analysing qualitative data, with flexibility to compare themes across participant groups (i.e., pwHD and carers), making it particularly suitable for feasibility trials where diverse stakeholder perspectives might need to be synthesised (Smith & Firth, 2011), and its use is supported by guidance on intervention evaluation (O'Cathain et al., 2013). The structured approach facilitates both deductive and inductive theme identification, ensuring feasibility factors such as acceptability, implementation challenges, and context-specific barriers can be identified.

During familiarisation, the main analysts (MD, KM) reviewed all interview recordings, transcripts, and interviewer observation notes. Team members (ZK, LBJ) also familiarised themselves with the transcripts. To aid familiarisation, key ideas and themes were noted. To create a coding framework (or index) a deductive approach was initially used. The initial index was informed by the research aims and question, Sekhon et al.'s. (2017) model of intervention acceptability, and a well-used behaviour change model, COM-B (Michie et al., 2011). COM-B (which indicates the Capability, Opportunity and Motivation needed to influence Behaviour) is a theoretically driven but simple and comprehensive way of understanding and changing behaviour (Michie et al., 2011). The index comprised 11 codes: affective attitude, burden, ethically, intervention coherence, opportunity costs, perceived effectiveness, self-efficacy, facilitator relationship, opportunity, capability and motivation. This index was applied to the first three transcripts by members of the research team and by three members of the project's PPI steering group. From this process, duplication across the index was observed and the eleven codes were collapsed into six: affective attitude and value consistency, ease of engagement, perceived effectiveness, facilitator relationship, broadening from one's own experience to others, mode of intervention and intervention coherence.

Coding consistency and inter-analyst agreement were addressed through joint coding sessions and comparison of coded transcripts between analysts (MD, KM, and ZK). Discrepancies were discussed in iterative meetings until full consensus was achieved, and all refinements were documented. Agreement was therefore reached through discussion consistent with guidance for team-based framework analysis (Gale et al., 2013).

This refined index was reviewed by four members of the PPI steering group. A spreadsheet with the refined index enabled coding, charting and summarising of each transcript, enabling later comparison between the participant subgroups (i.e., premanifest, manifest, carers) (Rosen et al., 2023). Later, summaries were generated for each subgroup to identify potential typologies. During interpretation, the spectrum of views was explored, including the meaning of data and data patterns in light of the research aims, and variations between subgroup typologies were considered. This enabled the creation of three main themes (and subthemes) which provided an adequate summary and organisation of the interpretation of the data across all participants (Rawlinson et al., 2024). Mapping linkages of participant characteristics in relation to themes enabled further understanding of the nuances of intervention experiences and acceptability. The development of the theme categories was reflected upon by lead analysts (MD, KM) and the resultant themes were reviewed by four PPI members.

To ensure the rigour and trustworthiness of the qualitative analysis, strategies were employed to address credibility, transferability, dependability, confirmability, and reflexivity (Korstjens

& Moser, 2018). Credibility was supported by involving multiple researchers in the data collection and analysis. Transferability was enabled by subgroup analysis (premanifest, manifest, carers) and typology generation, allowing consideration of context and variation. The descriptions of participant characteristics in relation to the themes support relevance to similar settings. To ensure dependability, a clear, systematic process was followed that was informed by established frameworks (e.g., COM-B) and was refined collaboratively. Confirmability was addressed through team discussions, documentation of analytic decisions, and critical review of themes by PPI members. Reflexivity was maintained throughout. Both lead analysts (MD, KM) are psychologists with clinical and research experience in HD, potentially predisposing them toward valuing psychological interventions. This was acknowledged and reflected upon during analysis.

Results

The analysis resulted in three overall themes: 1. A therapeutic journey accessible for people with and affected by HD; 2. Mechanisms of benefit and 3. Experiencing a variety of gains. Individual quotes, using study-generated pseudonyms, are used to support the themes.

A Therapeutic Journey Accessible for People with and Affected by HD

This theme related to the intervention being viewed as helpful in enabling pwHD engage in HD-tailored psychological therapy. Factors that facilitated participants’ access to and engagement with the intervention included: i) containing emotions; ii) providing an accessible learning opportunity; and iii) the specific intervention format.

Containing Emotions

This subtheme related to how people felt supported with difficult feelings that arose at the start of therapy. Engaging in HD-specific psychological therapy raised mixed emotions for participants, with all mentioning some negative feelings arising before starting the intervention such as scepticism, nervousness, apprehension, and feeling daunted. These concerns were expressed regardless of whether someone was premanifest, manifest, or a carer. Several participants expressed worries about confronting HD-related content and the emotional impact this might have on themselves or their partner:

> *"I assumed I'd have some scary thoughts that things would come up. I think that I thought it was going to be worse than it was". – Frankie, premanifest HD*

For some participants with manifest HD, reading the weekly workbooks felt daunting and unfamiliar, likely due to the cognitive and energy demands exceeding their reduced capacity from disease progression. In contrast, some participants expressed positive emotions about starting the therapy including feeling keen, hopeful and motivated. Some also expressed positivity about contributing to research:

> *"…if there were opportunities to take part in trials …or exercises like this that I would definitely like to take part. And I was really pleased that I was able to do so" – David, manifest HD*

Despite initial apprehensions, participants described how these fears were alleviated soon after commencing the intervention. Features of the intervention that helped this process included: forming a routine which shifted the intervention from feeling unfamiliar to being predictable; clear communication about expectations; engaging with HD content, whereby their fears about this quickly reduced; clarification from the facilitator.

Providing an Accessible Learning Opportunity

Participants identified how learning was achieved through the content being easy to digest and the programme being well-structured and clear:

> *"It was all, you know, well laid out and easy to understand" – Grace, manifest HD*

Participants appreciated being informed early about the intervention's structure and next steps. They also valued the session frequency, duration, and stepped approach, which helped them establish a routine. All participants found the workbooks helpful for accessing the content. They praised the materials for their readability, clear structure, and appealing visuals. Having physical or digital copies of the 10 workbooks for reference, along with relaxation scripts in both audio and written formats, was also valued.

While HD participants were overwhelmingly positive about the books, carers were more mixed in their appraisals. One carer mentioning a general dislike of workbook approaches, another found some of the metaphors used (in the ACT part of the therapy) confusing at times, and a third felt their loved one struggled to complete exercises in the books independently.

In terms of cognitive accessibility, facilitator sessions were also highlighted as helping people understand the materials. Participants mentioned using facilitator sessions to ask questions, adapt concepts to their personal situation, discuss materials to help them embed the ideas and techniques, and pace the intervention to their needs. The facilitators' ability to keep participants engaged and motivated was a shared theme. This included providing moral support, encouragement, and tailoring the intervention to the individual.

> *"I think by having someone there when you are stuck on questions or just help get the answer out of you, you know. Hmm… sort of having a way of digging the answer out of you, which you wouldn't get by the books themselves" – Bea, manifest HD*

Intervention Format

A further dimension of accessibility viewed as a strength by most participants was the intervention's remote delivery. Participants valued the convenience, privacy, quiet space, safety and security that being in their home offered. Preference for face-to-face contact was mentioned by one participant, but the majority of participants expressed that face-to-face would not have been as convenient. It was also recognised that online therapy enabled people from different locations to access psychological therapy more readily. Another aspect of the format of the programme considered to facilitate engagement was the flexibility of delivery. An example used was offering a choice of telephone or video conferencing.

Mechanisms of Benefit

The second theme related to the potential causal mechanisms through which participants derived benefits and what they felt helped improve their well-being. This involved feeling supported and understood and practising key techniques.

Feeling Supported and Understood

Participants expressed how during the intervention they felt supported and understood, which came from blending personalised care with the HD specific approach. They highlighted how the workbook content, facilitator sessions, and carer/partner involvement (where applicable) all worked together to enable person-centred care combined with relatable and relevant content.

The facilitator role was seen as crucial to the intervention. In addition to the facilitator's role in increasing access to the intervention (as discussed in the earlier theme around cognitive accessibility), participants also acknowledged the facilitator's personal qualities and knowledge of HD. Across all three subgroups, the facilitator's personal attributes, e.g., compassion and empathy, were highly valued, which suggested a strong emphasis on relational qualities. Participants were also impressed by the HD knowledge of the facilitator and the role this played in making them feel understood, enabling them to share their feelings:

> *"I have spoken with people about HD in the past and, you know, there's not been the same level of understanding. I felt like I could be fully and completely honest about everything I was feeling with the HD" – Josie, premanifest HD*

Participants also shared how a person-centred approach allowed them to benefit from the intervention. This was achieved through personalising content in the facilitator sessions, having the range of techniques they could draw from that suited their personal preferences, and using exercises to relate to their personal experience. They emphasised that one size did not fit all and that the different strategies on offer allowed individuals to select the ones that worked for them:

> *"I think you can hand pick the pieces that are suitable going forward to help" – Ruth, premanifest HD*
>
> *"I think it definitely still needs the therapist involvement because there's always like questions. Or how do you apply this, you know…So yeah, I know, I think it's definitely good to talk it all through and get kind of an idea of how to then apply it to everyday life" – Eleanor, premanifest HD*

Participants also emphasised the importance of having HD-specific materials. They mentioned how tailored content and relatable case examples helped improve engagement by making the intervention more relevant. For example:

> *"You know you are not the only person to have those thoughts or feelings and it's like natural that everybody thinks about things in different ways and you are not the only person, so you shouldn't feel so alone" – Liz, manifest HD*

Practising Key Techniques

All participants, regardless of their HD stage, were able to recall and use a range of the strategies offered by the GUIDE-HD intervention. Having these written down for future reference also helped, as well as opportunities to practise these in facilitator sessions and with their HD partners/carers where applicable.

Techniques that were particularly well-received by participants were relaxation and mindfulness, with strategies including breathing exercises, visualisations, sensory activities, bringing attention to the present and grounding techniques. Carer participants also highlighted how relaxation and mindfulness strategies were helpful. For some manifest participants, emphasis was given to breathing though this was not preferred by all. Imagery exercises were also practised as an alternative, indicating the benefit of having a range of relaxation and mindfulness techniques from which to choose.

> *"The only thing that I can't really do is the breathing exercise but everything else: the visualisation and the relaxation, the laying down and relaxing, I can do all that. So that was all very good." - Grace, manifest HD*

Another dimension of the intervention that was frequently mentioned was the educational component, with participants discussing how their knowledge of the impact of anxiety increased and that learning about vicious cycles and links between HD and anxiety was beneficial.

> *"it was quite interesting to learn about the causes and it ends up in a vicious circle and you've got to try and change your thinking" – Bea, premanifest*

Other modules of the programme explicitly mentioned as effective were learning about values, acceptance and willingness, facing fears and tackling avoidance. For example:

> *"So, I liked the, kind of, the understanding of acceptance like it's not agreeing with the things that are happening to you. It's an understanding that these things are happening to you, and then, like, the being able to sit with it. Like noticing it, observing it, and then moving on. Rather than trying to, like, squash feelings or avoid them" – Eleanor, premanifest HD*

Preferred techniques appeared to vary across both HD stages and carers. Premanifest participants mentioned using more cognitively demanding strategies, such as reducing catastrophising and addressing avoidance, as well as structured models such as choice points (a method for values-based action from ACT). Manifest participants instead mentioned more sensory and experiential strategies, such as mindfulness in nature, muscle relaxation, visualisation, and information about the brain. In addition, carers highlighted practical strategies such as breathing techniques as particularly effective in promoting relaxation and reducing stress in their partners with HD.

Although not universal across participants, some spoke of how the exercises in the workbooks helped them benefit from the intervention. Some participants enjoyed writing and reflecting, and found this useful:

> *"I took something away from every single book. The fact that it was all written down and that I could write down as well ... for me getting things down on paper and stuff it was really helpful". – Frankie, premanifest HD*

Experiencing a Variety of Gains

Gains Beyond Anxiety

The intervention was reported to provide considerable improvements in participants across premanifest, manifest, and carer groups. Participants frequently described feeling calmer, more relaxed, and less anxious, with a noticeable reduction in worry about HD. For example, participants commented:

> *"I do feel less worried about it... that it is ok to think about things, about it, erm about Huntington's" – Liz, manifest HD*
>
> *"I feel like I'm in a really good headspace ... I definitely feel like I'm not as bad as I was a year ago when I joined this. Yeah, 100%... I just thought it was amazing" – Amanda, manifest HD*

While anxiety was the target issue for the intervention, participants expressed that the intervention helped them feel less "on edge" and more able to approach life with a positive outlook. Participants spoke of reconnecting with their values and focusing on living in the moment rather than catastrophising about the future. For some, this meant feeling braver and less avoidant of HD-related challenges, enabling them to engage more fully in meaningful activities.

The intervention also helped participants develop a sense of self-acceptance and kindness, with participants learning to attend to their own needs. Many described feeling more prepared to handle life with HD and more capable of managing challenges as they arose. This change in perspective appeared to offer participants a renewed sense of empowerment and control over their circumstances:

> *"Yes, I had a lightbulb moment whilst struggling with being sociable with friends and learning it's okay to just do things that I'm comfortable doing" – Ruth, premanifest HD*

For participants living with manifest HD, these improvements often translated into changes in daily life such as improved relationships with family and friends, spending more time on fulfilling activities and reclaiming aspects of their lives they had feared losing.

A key element of the intervention was the opportunity to deepen knowledge of HD and anxiety, which helped participants better understand their difficulties and experiences. This enabled them to cope with their thoughts more effectively and to view their condition with less avoidance. For some, therapy sessions were described as profound:

> *"I ended up bringing up in the guide therapy session, well, with things that had been there for a long, long time. You know, they've been there probably since my diagnosis and say it, it was, it was really kind of like a deep, you know, healing process. Really. Yeah. And so, I think for me it really it helped me to understand it in a, in a way that I've never done before" – Josie, premanifest HD*

Carers reflected on the positive changes they observed in their loved ones with HD. They noted increased motivation, greater confidence, and reduced anxiety in their partners, which often led to improved coping with conflict and feeling more hopeful about the future.

Unexpected Gains

In addition to the benefits mentioned above, many participants also expressed surprise at noticing several unexpected gains from the intervention. For instance, some felt a sense of pride for having completed the intervention and many of those who initially felt sceptical about the programme were pleased at the progress they had made:

> *"Yeah, [I gained] definitely more than I expected and I think it helped me. It just helped me in ways that I that I'd kind of like didn't know I needed. Yeah. And I mean, I'm really, I think I'm really, I feel really proud that I finished it". – Josie, premanifest HD*

> *"Oh no, it's much better than I expected it to be. It was easier than I expected. I think I have certainly got more out of the experience that I am able to go out even for a walk or out in the garden wherever. Yes, and also being out and making sure that I have*

> *some friends over at least once, in fact two or three times, a month. Yeah yeah, and that's more important than anything -values" – David, manifest HD*

Tools for life

Another common subtheme among participants was that learning new skills and receiving reference books meant they now had tools for life to help with their ongoing journey with HD:

> *"I think it's just gonna help me now and for the rest of you know the rest of my time because, you know, I just think it's gonna be something that would be an ongoing learning with everyday really and it's, it's almost been like a turning point really for me in the journey". – Josie, premanifest HD*

Participants also frequently spoke of the applicability of the intervention to others, to their past selves, and to carers as well as other pwHD, highlighting "there's not many like out there that are HD specific" (Eleanor, premanifest HD). Many said they would recommend GUIDE to other HD family members and would encourage those just been diagnosed or have little knowledge of HD:

> *"And I think it would really, really help and those that have just been diagnosed because I think for me, if I'd have had this like 10-11 years ago now, it would have changed my life." – Josie, premanifest HD*

> *"I can say this has helped me. It's stopped me stressing about the future and things to come. It's made me live more in the moment… I would recommend doing it; how useful it is, the techniques I've learned. You get to sort of speak to somebody as well… I know for me just talking about it, or like I say now writing it down, is a massive help" – Frankie, premanifest HD*

Carers also spoke of the benefits to them:

> *"Yeah as I said from the start I was there to support [Participant name] and you know in the long term it benefitted me. You know I get my partner back to normal if you like" – Martin, HD carer*

All participants, while highlighting different aspects, all felt they had experienced positive change as part of the intervention.

Discussion

The present study aimed to understand the acceptability, experiences, benefits, and challenges of pwHD who attended a novel psychological intervention for anxiety in pwHD (GUIDE-HD). From this, three overarching themes were constructed across pwHD and carers: 1. A therapeutic journey accessible for people with HD; 2. Mechanisms of benefit and 3. Experiencing a variety of gains. Participants generally expressed positive attitudes towards the intervention, particularly noting its potential to improve psychological outcomes (anxiety specifically, but also more broadly) and provide tailored support. Additionally, while many participants acknowledged the intervention's innovative aspects, they also emphasised the necessity of context-specific modifications to enhance practical applicability.

This nuanced insight into both the strengths and challenges provides a detailed overview of the intervention's acceptability and lived world experience, mirroring the complexity often encountered in real-world health service implementations (O'Cathain et al., 2013). In line with UK guidance on developing and evaluating complex interventions (Skivington et al., 2021), this study underscores the value of qualitative insights in shaping both the design and future implementation strategies of health interventions.

The findings from this aspect of the GUIDE-HD study largely converge with existing literature on psychological interventions for HD while also extending our understanding in several important ways. Similar to previous studies, GUIDE-HD demonstrated that tailored interventions are perceived to reduce anxiety and improve overall well-being by addressing HD-specific emotional and cognitive challenges. For instance, research by A'Campo et al. (2012) and Eccles et al. (Eccles et al., 2021) has shown that interventions adapted to the HD context, particularly those that address the unique emotional turmoil and cognitive changes in HD, can yield positive and valuable outcomes. This aligns with our incorporation of structured, HD-specific materials, such as the accessible workbooks and flexible facilitator sessions used in GUIDE-HD, as essential in helping participants manage difficult emotions and engage more fully in therapy.

A further key point of convergence with prior work is the critical role of the therapeutic relationship. Our study underscored that the facilitator's empathy, expertise in HD, and ability to personalise intervention content were central to establishing a strong therapeutic alliance. Such strong alliances between therapist and client have repeatedly been associated with improved outcomes in other populations (see Noyce & Simpson, 2018,for a review) and have been replicated in HD research specifically (Eccles et al., 2021). In this study, due to the nature of the intervention (GSH), there was a facilitator, rather than a therapist per se, and the importance of this facilitator role in remotely delivered self-help interventions generally is being increasingly recognised (Akdemir et al., 2024; Traviss et al., 2013). While psychological intervention research also involving carers is rare in HD, the value of carer input also resonates with Schriger, Nurse and O'Hayer's (2025) case report on acceptance and commitment therapy (ACT) with an individual with HD. Here caregiver involvement further underscored the potential importance of broader relational dynamics in treatment acceptability.

Another important aspect where GUIDE-HD aligns with prior research is in the broader gains reported by participants. As with Eccles et al. (2021) and Schriger et al. (2025), our findings reveal that psychological interventions can yield benefits that extend well beyond the primary target of anxiety reduction. Participants described enhanced self-acceptance, empowerment, and improvements in interpersonal relationships. Unlike A'Campo et al's. (2012) study, the positive experiences were not limited to just symptomatic pwHD, instead being represented across both premanifest and manifest individuals.

Differences between the preferred techniques of premanifest and manifest participants may reflect underlying neuropsychological and motivational factors linked to disease stage. Premanifest individuals, who generally retain stronger executive functioning and metacognitive insight, may find structured and cognitively focused approaches such as reframing or values-based decision-making more accessible and consistent with their wish to maintain control. In contrast, manifest participants, who often experience greater executive and processing difficulties, may benefit more from experiential or sensory-based strategies such as mindfulness, relaxation, and visualisation, which support emotional regulation without high cognitive demand. These distinctions align with evidence of progressive changes in executive skills, social cognition, and self-reflective capacity in HD (Hendel et al., 2023; Tranel et al., 2010; You et al., 2014; Zarotti et al., 2025) and highlight the value of adapting psychological materials to disease stage.

In relation to the qualitative findings from ACT-based interventions with people with other neurological conditions, these findings support the acceptability of ACT (Rawlinson et al., 2024; Storey et al., 2025), also showing that despite some initial hesitancy, participants found ACT valuable in managing anxiety, increasing psychological flexibility, and fostering acceptance. However, participants' accounts here placed more emphasis on cognitive accessibility, long-term applicability, and disease-specific materials, perhaps reflecting the particular, long-term challenges of HD compared to other conditions such as MND, which has a much shorter illness duration. Some of the specific components of the intervention – e.g., the emphasis in ACT on values – were specifically referenced by participants, providing further evidence of the appropriateness of ACT as a third wave intervention for individuals with neurodegenerative conditions (Bowers et al., 2021; Foote et al., 2023) .

Limitations and Future Directions

While the study provides valuable insights into the acceptability of the intervention, several limitations should be acknowledged. First, the sample size and focus on premanifest and early manifest individuals may limit the applicability of the findings to those at later stages of the condition. As HD is associated with difficulties in initiation, planning, and other executive functions, such cognitive impairments in manifest participants may hinder the ability to engage independently with self-help materials, follow structured exercises, or maintain motivation between sessions, even with facilitator support.

Secondly, although qualitative research is not designed for statistical generalisation, those who agreed to take part and completed the intervention might have had a predisposition towards innovation or change. Thirdly, the sample comprised mostly female participants, which may also limit its applicability. Fourthly, participants gave largely positive accounts, despite being prompted to provide a full range of views. While this might well have reflected their views, it is not possible to rule out the influence of issues such as social desirability or general gratitude for receiving any psychological support. The adoption of multi-arm RCT designs in future studies may help address these by providing a way of comparing feedback on GUIDE-HD to other approaches. The exploration of the views of a larger sample of carers should also be prioritised, particularly in light of the finding that carers in this study expressed more mixed opinions about the intervention materials, potentially highlighting the need to improve the workbook as well as the support provided to them when helping pwHD between session.

Finally, the dynamic nature of the health intervention context means that some identified barriers and facilitators could evolve over time, potentially altering the intervention's acceptability in the long term. Future studies should consider longitudinal qualitative designs with repeated follow-up to capture these temporal dynamics (e.g., Murray et al., 2024). Additionally, further understanding of mechanisms of benefit could be gained by comparing differences between psychological interventions across neurodegenerative conditions. This may help to identify elements particularly effective for HD, as well as those applicable to other conditions, and could form a valuable focus for future research.

With regards to GUIDE-HD specifically, a further study could focus on the longitudinal impact of the intervention, as investigating the evolution of participant perceptions over time could yield insights into the processes of adaptation and resistance, which are critical for the successful implementation of complex interventions (Plsek & Greenhalgh, 2001). A key further development would be to extend the scope of the study, involving additional facilitators and primarily targeting other common psychological difficulties such as depression.

Clinical Implications

Clinically, the findings of this study have important implications for the development and implementation of new psychological interventions in pwHD. Materials should be explicitly tailored to the cognitive, emotional, and functional complexities of HD, ensuring that content and examples are relevant and formats are accessible. Participants valued HD-specific content, relatable examples, and flexible formats that supported cognitive accessibility. This tailoring should become standard practice in service design, consistent with wider reports from HD families regarding the importance of practitioners having condition-specific knowledge and providing coordinated specialist care (Etchegary, 2011; Røthing et al., 2015; Skirton et al., 2010).

Facilitator or therapist involvement appears critical, even within guided self-help frameworks. The GUIDE-HD data highlight that facilitator input through personalised pacing, clarification, and motivational support was crucial for participation and benefit. This finding supports evidence from broader guided self-help research emphasising the guide's role in maintaining fidelity and motivation(Shafran et al., 2024). Clinically, low-intensity interventions for pwHD should therefore incorporate facilitator training and supervision in not only HD, but in the relevant models such as COM-B and in the case of GUIDE, CBT and ACT principles and neuropsychological communication strategies suited to executive dysfunction.

Beyond immediate anxiety reduction, the reported gains in self-acceptance, agency, and relationship quality indicate that interventions of this kind may serve rehabilitative and growth-oriented functions. Recognising these wider outcomes suggests the need for psychologically informed care pathways embedded within multidisciplinary HD services, potentially using stepped-care models and ensuring sustainability and scalability through flexible methods including digital or hybrid delivery formats.

Embedding such approaches within clinical services internationally will require alignment with both specialist HD networks and general mental health infrastructures. In well-resourced settings, guided self-help could represent a first-line, low-intensity tier integrated into specialist HD clinics, while in regions with limited access to neuropsychological care, remote and hybrid formats may provide a feasible and scalable alternative. GUIDE-HD illustrates how evidence-based psychological models can be adapted to meet the complex needs of a neurodegenerative population. Its integration within stepped-care or multidisciplinary frameworks offers a clinically relevant model for extending equitable psychological support across HD services internationally.

Declarations

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Disclosure Statement

The authors have no conflict of interest to declare.

Data Availability Statement

The data that support the findings of this study are not publicly available due to ethical and legal restrictions. Specifically, the data contain sensitive information about potentially easily identifiable individuals and sharing them would violate the approved participant confidentiality agreements.

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