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Title: Promoting physical activity in Huntington's disease: co-design of a care partner resource

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Abstract

Background

Clinical guidelines recommend that people with Huntington's disease (HD) should exercise to maintain/improve fitness and motor function, yet physical activity levels remain low in this group. Promotion of physical activity is often via care partners with little evidence that they are supported in this role.

Objective

The aim was to co-design a resource for care partners of people with HD to support promotion of physical activity.

Methods

A four-step co-design approach was used to develop a care partner resource. Five care partners took part in an online workshop exploring experiences and the knowledge, support and skills needed by care partners to promote physical activity. A co-design team (n=7) developed a prototype that was user tested by three people who had attended the workshop. Findings from user testing were used to develop the final resource.

Results

An easy to read, image-based prototype was developed that contained tips on planning activity, safety and activity examples. User testing identified the need for grouping of activities suitable for 10, 20, 30 minutes of available time, information on maintaining and improving activity and re-organization of information to support engagement of activity.

Conclusions

A resource for care partners that has been translated into seven languages was developed to promote physical activity. User testing indicated confidence in using the resource and appreciation of the autonomy provided to the person with HD to plan activities. Further work is needed to evaluate the impact of the resource in promotion of physical activity and the impact on care partner burden.

Key words

Co-design, physical activity, exercise, care partner, Huntington's

Introduction

Physical activity levels in people with Huntington's disease (HD) are low¹, despite evidence that exercise is beneficial.² During the pre-manifest and manifest stages of the condition it is important for people with HD to remain as physically able as possible to maintain functional independence. This is supported by clinical practice guidelines for physiotherapy in HD which recommend prescription of aerobic exercise paired with upper and lower body strengthening to improve fitness and to stabilize or improve motor function.²

A lack of opportunity to develop individualized physical activity plans was reported by people with HD and their care partners in a study in the United Kingdom.³ Although physiotherapists have been identified as key promoters of physical activity⁴, other healthcare professionals such as exercise physiologists and occupational therapists are well placed to support development of physical activity plans. In HD, with the complexity of symptoms, multidisciplinary care is essential for individualized care⁵ and therefore all healthcare professionals need to be informed about the benefits of exercise and physical activity in order to support people with HD and their care partners.

However, the role of promoter and supporter of physical activity in people with HD often falls to family members and non-healthcare professionals. Evidence suggests that care partners collaborate with people with HD to support physical activity³, despite no existing dedicated resource to them in supporting people with HD to plan and engage in physical activity. It is known in other neurodegenerative conditions, e.g. multiple sclerosis (MS), that care partners trained as exercise buddies for people with MS can improve the physical and psychological impact of the disease.⁶

The development of a resource to empower care partners in promoting and supporting physical activity in people with HD may address this gap. A co-design approach to the development of the resource,

aligning with the principles of prudent healthcare, is also necessary to ensure that the resource is usable and meets the needs of all stakeholders.⁷

The aim of this study was therefore to gather experiences of care partners in supporting promotion of physical activity to inform the development of a care partner resource.

Materials and Methods

This qualitative study used a four-step co-design approach to develop a resource for care partners of people living with HD. The focus within this design was to gather experiences of people rather than their attitudes or perceptions in order to improve healthcare provision.⁸ This study comprised four steps similar to the methodology used to create care partner resources in cancer⁹, Step 1: Resource design – gathering experiences; Step 2: Co-design of resource prototype; Step 3 User testing; Step 4 Refining the resource. The project gained approval from Cardiff University, School of Healthcare Sciences, Research Ethics Committee (REC854).

Methods

Step 1

Participants were family members of people with HD and were recruited with the support of the Huntington's Disease Association of England and Wales (HDA) via their website and social media platforms. Inclusion criteria were: Caring or have cared for a person/s living with HD and able to connect to an online workshop. The person with HD could be at any stage of the condition including having no clinical motor signs. Participants were excluded if they were unable to converse in English. No demographic data were collected from the participants.

A two-hour online workshop via Zoom took place on a weekday evening in March 2022 with five participants who were care partners for spouses with HD. The workshop was jointly facilitated by a member of the academic team and a visual facilitator. Participants were sent materials before the workshop including: the Physical Activity Tool for HD and associated user guide¹⁰ and blank templates for the three activities to be undertaken in the workshop. Activity 1 was an exploration of experiences of care partners supporting someone with HD to be physically active, in relation to what worked and did not work for them. Activity 2 explored where and how participants accessed support about physical activity. Activity 3 explored what knowledge, skills or resources were needed to support someone with HD to remain physically active. Participants communicated their experiences verbally based on the materials provided before the workshop and facilitation of discussion during the workshop.

Data were collected via audio recording of the workshop and a visual facilitation map drawn.

Step 2

The co-design team were purposively recruited based on their expertise in HD and/or caring for a person with a long-term condition. The team consisted of the Head of Service Development of the HDA; a representative from HDVoice, a community volunteer group within the HDA; two representatives from Carers Trust, Wales and two members of the research team (UJ and KH). A design company, Scarlet Design, with experience developing resources for HD¹⁰ joined the co-design team. The experience of this team aimed to provide a broad perspective on HD and the addition of two representatives from a non-specific care charity aimed to reduce bias within interpretation of the data and prototype development.

The co-design team met twice to discuss the data collected from Step 1 and develop content for the physical activity resource prototype. Scarlet design developed a prototype physical activity resource based on the ideas from the workshop and the co-design team.

Step 3

Three participants from Step 1 agreed to user test the prototype resource. Participants used the resource with their spouse on at least one occasion. Data on acceptability of the resource were collected via online semi-structured interviews. The interview schedule, based on the Theoretical Framework of Acceptability¹¹, included questions on affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness and self-efficacy, see Table 1. Data were audio recorded.

Table 1 User testing interview schedule mapped to Theoretical Framework of Acceptability (Sekhon et al 2017)

Step 4

The resource was refined following two further meetings of the co-design team and ongoing discussions with Scarlet Design. Additionally, the resource was reviewed by four physiotherapists from the European Huntington's Disease Network, Physiotherapy Working Group.

Data analysis

Data from the workshop and interviews were anonymized using pseudonyms chosen by the participants. Data from Step 1 and Step 3 were transcribed verbatim and analyzed deductively using a framework of consisting of a priori codes based on the triad of HD symptoms; 'cognitive', 'behavioral' and 'physical movement'¹² and the theoretical framework of acceptability¹¹, respectively. Inductive analysis using thematic analysis¹³ was also carried out for both steps. Deductive and inductive analyses were carried out independently by two researchers (UJ and KH), with themes identified through reflexive discussion between the two researchers. Double coding and awareness of the researchers' own biases enhanced the credibility of the analysis.

Results

Step 1 (Resource design – gathering experiences)

Five participants from England and Wales took part in the workshops. All were female and caring for their spouse. Five key areas related to the resource were identified from the workshop: content, tips and hints, layout, format and dissemination.

Participants expressed the need for the resource not to have too much information and that a range of activities for different amounts of time should be included.

“maybe lots of pictures and just real facts ‘cause I think if it’s too much...” (Priscilla)

“so is this, are you looking for a ten minute thing, a 20 minute or a 30 minutes thing and then a variety of things within that..” (Fleur)

They also emphasized the need for the resource to have professional authority in the advice that was provided, as this would support them in promoting activity with their spouse.

“well these exercises have been proven to really help then that would help, I would find that better [in] presenting it, ‘cause it’s not me saying it, it’s somebody else” (Val)

Participants suggested that a diary to plan activities over a week, incorporating activities that are familiar and getting agreement about the activity would be helpful.

“every Sunday evening, I’ve got him an A5 diary, week to view, and what I do is go through my diary with him and I just tell him what he needs to know really and I get him to write it down in his diary which is really good” (Priscilla)

“he [a volunteer] would just pick up my husband each week and they could go and play badminton for an hour, or half an hour, twenty minutes or ten minutes and then they’d sit and have a coffee and.....it was really beneficial to both of us” (Charlie)

“it is something he can actually do and forget about it and be, you know, himself so that is for him, it’s a massive motivation” (Luna)

Participants said that the layout should be easy to read and use plenty of pictures and that a format using activity cards would be beneficial. Dissemination of the resource should be high profile within the HDA with the suggestion of celebrity promotion. In summary, the resource should be simple and easy to read, and it should contain tips on planning activity, safety and examples of activities.

Step 2 (Co-design of resource prototype)

A prototype resource was developed and produced by Scarlet Design. The prototype consisted of an A4 folder with each page inside a plastic pocket to enable pages to be taken out and placed in prominent positions if needed. A small photo wallet containing individualized exercises that could be taken out and re-organized for the individual was also produced.

A background section was included in the resource to provide authority for the advice that was being given. This was followed by a page on safety first with advice on how to get up from the floor. The next section was on planning activity and included the previously developed Physical Activity Tool for HD, a diary and an image of the activity pyramid to stimulate ideas for activities. The final section was examples of activities categorized within flexibility, balance, strength and fitness. Participants quotes from the workshop were used as additional tips and hints throughout the resource, see figure 1.

Figure 1 The background page of the prototype resource

Step 3 (User testing)

Care partners found the resource attractive and liked the simple artwork showing useful views of the exercises. Although care partners reported easy navigation of the resource with clear instructions and language, the burden of developing goals for physical activity could be onerous in their busy lives.

“But for me, perfectly easy to navigate perfectly...I think that the planning thing to me seemed a bit onerous” (Luna)

“I think the hardest thing for us to do exercise at home is space” (Fleur)

Users identified that the activities in the activity pyramid were unrealistic for their spouse.

“Like what I found a bit tricky was you know the pyramid? Some of those seemed a little bit unreal, unrealistic” (Luna)

It was felt that the order of information could be changed as having the section on setting goals was long and that getting used to exercise/physical activity first and then making goals may help engagement with physical activity.

Participants felt confident in using the resource and that the small wallet of exercises fitted with their lifestyle when travelling, enabling couples to be active together.

“because you can take this one away with you and put in my handbag” (Priscilla)

“like for us, one of the reasons is because it’s something we love to do together” (Luna)

Care partners asked whether they would get support from healthcare professionals to use the resource, but they also liked that the person with HD could also be in control of planning their activities.

“We've been aware of the importance of activity for the last 10 years and what's great about this is you're not relying on a physio to tell you to come and do something. You know if this is given control to the person” (Fleur)

Suggestions for change included: advice on how much exercise to do, grouping exercises into timed sessions e.g. 10, 20, 30 minutes, information on maintenance rather than improvement of abilities.

“If you or I were doing it, we'd expect to see some progression. It's more of a maintenance or slowing down the deterioration in the thing [HD symptoms].”

Step 4 (Refining the resource)

Data from Step 2 was discussed in the co-design team meetings alongside the physiotherapists' suggestions of setting times for activities and measuring intensity could be added to the resource. The final Keeping Active with Huntington's disease resource, see figures 2 and 3, was produced based on the following changes:

- A QR code linked to a short survey was added to the first page to enable feedback to be gained on the resource.
- Additional images of doing activities together were added.
- A section on getting started was added that provided the care partner with advice on how to start with someone who had never done activity before/ were already doing activities/ were finding activities becoming harder to do.
- Amendment of the activity pyramid with more realistic activities.
- Re-organizing the order so that examples of exercise and activities were provided before goal setting information.
- An extra section on grouping activities into 10-, 20- and 30-minute bundles and categorized by level of perceived exertion (gentle, moderate and strenuous) was added.
- The format was changed to wire bound booklets for both the resource and exercise cards to ensure sustainability over time.

The resource has been designed to be printed out as a physical resource and as a digital document. A professional translation company was used to translate the resource into Dutch, Italian, Polish, Spanish, Swedish and Welsh.

Figure 2 Advice on getting started with physical activity

Figure 3 Bundles of activity for 10, 20 and 30 minutes of time

Discussion

The Keeping Active with Huntington's disease resource was co-designed with care partners of people with HD, the Head of Service Development of the HDA, a representative from HDVoice, two representatives from Carers Trust, Wales and two members of the research team (UJ and KH). This work builds upon our earlier physical activity tools for HD¹⁰ by co-designing a resource for care partners to enable them to support a person with HD to remain physically active. The Keeping Active with HD resource aims to provide support that has professional authority and practical advice to support promotion of physical activity.

The four step co-design approach followed steps identified by Santin et al.⁹ to ensure that a person-centered approach based on care partner experience, people working with care partners and the HD community was utilized. The online workshop (Step 1) generated data that enabled a prototype to be developed around the needs of care partners. Although a deductive framework of cognitive, behavioral and movement was used to analyze the data, it became clear through inductive analysis that participants' focus was on the need for practical examples of activities that were supported and

approved by professionals. The need for tips and hints was seen as necessary content that would provide real life examples to support physical activity.

Use of the theoretical framework of acceptability¹¹ for analysis of the user testing (Step 3) data ensured that all aspects of usability were considered. Use of the prototype highlighted the burden placed upon care partners when supporting a person with HD. Care partner burden is known to be high in HD, with Aubeeluck et al.¹⁴ identifying that levels of support, dissatisfaction with the caregiving role, practical aspects of caregiving and feelings of emotional well-being as themes that compromise quality of life in caregivers. Opportunity costs may also impact on care partner burden, with participants noting the need for space to carry out the exercises, exercise taking time from other activities and the need to dress for exercise and shower afterwards. Further work is needed to explore whether this type of resource can reduce elements of care partner burden and whether a resource for care partners to care for themselves is needed.

Care partners who used the prototype highlighted that intervention coherence and perceived effectiveness may be influenced by the stage of HD and previous experience of physical activity. This aligns with themes from Hamana et al.³, where experiences of physical activity evolve over the progression of the condition and people adapt goals and activities in line with their abilities. One care partner expressed how they needed advice on supporting someone to maintain ability or slow progression of the condition rather than improving ability. This was resolved by the addition of a page that gives advice for people with different needs, see figure 2.

Studies investigating interventions to improve physical activity in people with HD have included self-management and coaching facilitated by physiotherapists^{15, 16}. These interventions were found to be feasible with indications that physical activity levels could be improved, yet the reality of people having sufficient support to develop physical activity plans³ outside of a study trial needs to be addressed. The

study interventions were based on the self-determination theory that proposes that self-determined and non-self-determined behavior is a continuum that is influenced by type of motivation (intrinsic/extrinsic/amotivation), regulation (intrinsic/extrinsic/non-regulation) and locus of causality (internal/external/impersonal).¹⁷ It could be argued that participation in research studies provides extrinsic motivation and regulation with an external locus of control, which may not be suited to sustained physical activity levels in real life.¹⁸ Additionally for people with HD, reduced initiation and difficulty in identifying goals are aspects of multidimensional apathy¹⁹ that could place them toward the amotivation, non-regulation and non-personal spectrum of self-determination theory.

Motivation and behavior change techniques associated with self-determination theory include developing a plan of action and promotion of self-monitoring, providing choice and providing a meaningful rationale for the change in behavior.²⁰ These techniques and those identified for engaging people with HD to engage in physical activity i.e. using prompts, routine and structure; a safe social environment and education¹⁹ have been integrated within the Keeping Active resource. Specifically, safety advice has been included at the beginning of the resource, planning includes generic advice using quotes from participants such as “plan activities that are familiar and enjoyable” and specific advice via the diary page. The diary page can also be used for prompting and developing a routine of activity. The opening page provides the rationale and education on why being active is beneficial for people with HD and the range of exercises and grouping of exercises provides choice. This resource has yet to be evaluated, but evidence from other neurodegenerative conditions which has explored the role of care partners in promotion of physical activity and suggests that spousal care partners of people with MS supported self-determined motivation through co-planning, problem solving and providing choice alongside empathetic understanding and competency building.²¹

This study is limited by a number of factors. Although participation was open to any care partner, only females were recruited. There is therefore bias toward the female voice, and further works needs to

explore the experiences of care partners who are male. User testing was limited by the small number of users and the fact that these participants also took part in the initial workshop that was used to develop the prototype. Participants were white, from different areas of England and Wales and well informed about HD, a more inclusive approach would be gained with a more diverse group of care partners.

Although the co-design team included a range of expertise, inclusion of people with HD as participants would have provided a broader perspective. Specifically, people with HD could provide evidence as to whether the advice resonated with their needs. The resource was linguistically translated into seven languages, but not user tested in different countries. Further work is therefore needed to explore cultural acceptability of the resource. For example, healthcare provision in The Netherlands is coordinated nationally and compared to other countries, the needs of people with HD may be different in relation to accessing support and services.

The Keeping Active resource is freely available via the HDA of England and Wales website

<https://www.hda.org.uk/get-involved/studies-and-research/research-we-fund/physical-activity-in-huntingtons-disease/> and future work includes active dissemination, monitoring and evaluation of the

uptake and use of the resource. Further research is needed to explore the validation and use of Keeping Active within different settings e.g. residential care homes and community settings within different socio-economic areas across different countries. Key outcomes for future research include care partner burden, physical activity levels of people with HD and quality of life of people with HD and their care partner/s.

In conclusion, the four-step approach to co-design⁹ was successfully used to develop a resource for care partners of people with HD to support promotion of physical activity, that is available in seven languages. User testing indicated confidence in using the resource and appreciation of the autonomy provided to the person with HD to plan activities. Further work is needed to evaluate the impact of the resource in

promotion of physical activity, the impact on care partner burden and cultural acceptability outside of England and Wales.

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Conflict of Interest

The authors have no conflict of interest to report.

The data supporting the findings of this study are available on request from the corresponding author.

The data are not publicly available due to privacy or ethical restrictions.

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Tables

Table 1 User testing interview schedule mapped to Theoretical Framework of acceptability (Sekhon et al 2017)

Theoretical Framework of Acceptability Domain	Questions
Affective attitude	<p>What are your thoughts and experiences of using the carer's resource?</p> <p>What is your overall, general experience?</p> <p>What have you learnt?</p>
Burden	<p>How easy/difficult was it to navigate the resource?</p> <p>Were the instructions to set physical activity goals clear?</p> <p>How easy or difficult was it to understand the information in the resource?</p> <p>Was the language suitable?</p> <p>Was the level of information appropriate?</p>
Ethicality	<p>Did the resource fit in with your lifestyle?</p>
Intervention coherence	<p>Were you able to develop a plan for physical activity?</p> <p>Were you able to use the cards to plan physical activity?</p> <p>Did you use each section of the resource?</p> <p>Was one section more useful than others?</p> <p>Was one section used more often than others?</p>
Opportunity costs	<p>Did you experience any inconvenience using the resource?</p>
Perceived effectiveness	<p>Do you think this resource could be valuable for carers to help support someone with HD to be physically active?</p>

	Do you think that people with HD could become more active if carers used this resource?
Self Efficacy	How confident are you in using the resource?

Figures

Figure 1 The background page of the prototype resource

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE
EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

"THE SOONER YOU START THE BETTER"

This resource provides information and tips and hints on how to make a physical activity plan that is unique for a person with Huntington's disease. The resource was developed by researchers at Cardiff University, the Huntington's Disease Association of England and Wales, Carer's Trust Wales and carers and people with Huntington's disease. The exercises are based on the Move to Exercise resource that was developed by specialist physiotherapists and occupational therapists specifically for people with movement problems. You can find the 'Move to Exercise' video here <https://www.hda.org.uk/professionals/resources-for-professionals/resources-from-other-organisations>

Carers have told us that it helps if a professional provides advice, so here is what the World Health Organisation says about physical activity:

"PHYSICAL ACTIVITY HAS GENERAL HEALTH BENEFITS SUCH AS IMPROVED SLEEP, IMPROVED QUALITY OF LIFE AND HELPS IN MANAGING ANXIETY AND DEPRESSION"


Physiotherapy research shows that for people with Huntington's disease, **exercise can improve balance confidence, mobility, independence, posture and breathing.**





So, keeping flexible and strong helps with ordinary things like getting dressed, climbing stairs and getting out and about.

This resource includes information on safety, advice on how to plan physical activity and exercises that can be done to help someone with Huntington's disease stay physically active.

Thank you to all the carers and people with Huntington's disease who helped create and test this resource. You can see what they have said in the quote boxes throughout.

Please scan this QR code when you use this resource. If you have any feedback, please contact Una Jones jonesuf@cardiff.ac.uk



2

PHOTOGRAPH BY SHUTTERSTOCK.COM/ANDREW LEE JONES

Figure 2

Advice on getting started with physical activity

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

GETTING STARTED

It is often difficult to start being active or to increase activity. Here is some advice on how to start a chat about being active with someone who isn't usually active, someone who does some activity and someone who is now finding it difficult to stay active.

BE REALISTIC AND FLEXIBLE IN THE PLAN

ALLOW TIME FOR THE ACTIVITY - OR FIT THE ACTIVITY TO THE TIME THAT YOU HAVE.

THINK OF SHORT AND FREQUENT ACTIVITIES.

SOMEONE WHO HAS NEVER DONE ANY SPORT/EXERCISE/ACTIVITY

That's OK!

- Find something that the person with HD would like to do or enjoys.
- Have a look together at the activities in this book and chat about what they'd like to do.
- Then think together of how the activity could be linked with the thing they'd like to do.

Start gently and build up, for example:

- They would like to buy something new
- Park the car a short distance away from the shop, walk around the shop/shopping centre before buying the item.
- Check steps on a phone.
- Have a treat to something special as a reward.
- This is increasing their physical activity. They can then start to increase the distance they walk or doing some of the exercises in the book.

SOMEONE ALREADY DOING SOME SPORT/EXERCISE/ACTIVITY

Well done!

- Think of what else they would like to do.
- Increase the activity gradually.
- The aim can be to do exercise that makes you breath hard, 3 times per week and do strengthening exercises 3 times per week.

You can use the exercises in this book to help you to make an activity plan.

IT'S GETTING HARDER TO DO SPORT/EXERCISE/ACTIVITY

That's OK!

- Find something that the person with HD likes doing.
- Think of how they could make the activities a little easier to do e.g. chair exercises rather than standing.
- Plan how to get the balance between keeping active, keeping safe, enjoying activities and having enough energy for other things.

'Little and often' may be better than long activities.

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Figure 3

Bundles of activity for 10, 20 and 30 minutes of time

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

CHOOSING ACTIVITIES THAT SUIT THE ABILITIES AND LIKES OF THE PERSON WITH HD.

Here are some ideas for exercises/activities. Gentle, moderate and strenuous will be different for each person, so choose activities that suit the person's abilities.

As a guide, you can think of a scale of 0 -10, with 0 being no exertion and 10 being maximum exertion. On the scale:


- Gentle activity would be 2-3,
- Moderate activity would be 4-5,
- Strenuous activity would be 6-8.

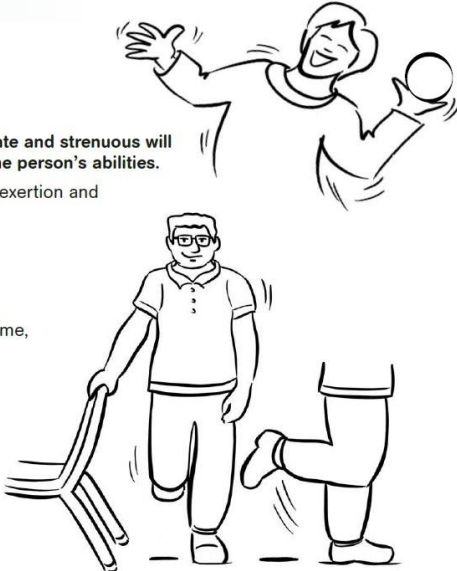
Remember you can increase or decrease your activity over time, depending on how you feel and your symptoms.

Choose things that the person may like to do and you can mix and match across the examples.

Take a rest between activities if needed.

We have grouped some of the exercises and activities explained in this book into 10, 20 and 30 minute sessions.





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