Adherence to Use of a Home-Based Exercise DVD in People With Huntington Disease: Participants' Perspectives

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Background. Individualized exercise instruction on a regular basis may be desirable for people with Huntington disease (HD). Sustained interventions, however, may not be the most feasible for lifelong disease management. It is critical, therefore, for physical therapists to find ways to facilitate engagement in independent exercise programs. The capabilities of DVD technology can make the DVD a useful format to facilitate engagement for people with HD who have motivational and cognitive problems.

Objective. The purpose of this study was to explore how people with HD used a home-based exercise DVD and how it was perceived by the participants and their caregivers.

Design. An exploratory, mixed-method design was used in this study.

Methods. Fifteen participants with HD were provided with an exercise DVD, developed by the authors, to support their engagement in a home-based exercise program. Exercise diaries were used to record adherence rates. Semistructured interviews were conducted to explore what factors affected the usability of the DVD. Conversations were audio recorded and fully transcribed. Content analysis approach was used to analyze the interviews.

Results. Most of the participants (11/15, 73.3%) adhered well to the use of the DVD. Participants felt that the exercises were suitable. Commitment of the caregiver as a key to the success of the program was the main theme that emerged from the data. Participants identified barriers and facilitators that affected adherence to using the exercise DVD and described management strategies that helped promote adherence to the exercise program.

Conclusions. The DVD was perceived to be suitable and supportive. The DVD could be appropriate for use in supporting people with HD to engage in exercise at home, either outside of therapy sessions or upon completion of a therapy program.

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Huntington disease (HD) is an inherited, neurodegenerative condition resulting in clinical symptoms of progressive movement disorder, cognitive deficits, and behavioral changes and leading eventually to loss of independence in all functional activities. The disease is progressive, with no known cure, but there is some evidence to suggest that physical therapy combined with exercise is a valuable tool for maintaining and improving mobility, strength, balance, and function in this population.[1,2] Early engagement and participation in regular physical activity, outside of scheduled therapist-supervised clinic appointments, may promote achievement of physical therapy goals in this population.[3] Certainly, regular engagement in home-based exercise programs have been shown to facilitate patient self-management and empowerment in other neurological conditions such as stroke and Parkinson disease.[4,5]

There are a number of factors, including cognitive and motivational issues, that may influence the ability of people with HD to engage in unsupervised exercise programs.[3] Exercise adherence in this population is suggested to decrease after professional supervision stops and patients no longer receive external support or feedback about their progress.[1,3] There is clearly a need to develop methods that facilitate patients' engagement in and adherence to an independent exercise program. The technology capabilities of DVD/videotape (such as the use of subtitles, music and rhythm, and demonstration and structuring of content) make it a useful format to facilitate engagement in such programs, particularly for people who have motivational and cognitive problems, as is common in people with HD. Such audiovisual methods have been used in different clinical settings and disciplines, with positive outcomes[6–9] and better adherence.[10,11]

An exercise videotape has been used to successfully support a person with mid-stage HD to follow a home exercise program.[12] In this single-case study, the participant was highly motivated and adhered very well to the 14-week exercise program. This single-case study is the first to use an exercise videotape to support an independent exercise program in the HD population. More detailed information about the potential application of such methods is needed.

The aim of this study was to explore how people with HD and their caregivers used a home-based exercise DVD. Specifically, we set out to investigate whether people with HD would adhere to the home use of the

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- Demonstration Video: "Circuit Resistance Training Section of DVD"

The Bottom Line

What do we already know about this topic?

Regular involvement in an individualized exercise program may be desirable for people with Huntington disease (HD). However, barriers to exercise exist for any individual attempting to engage in an independent exercise program. Recently, DVD/video technology has been used successfully to improve outcomes and participation in self-care regimens in different clinical settings and patient populations. Very little is known about whether people with HD would use an exercise DVD at home and what factors would influence their participation.

What new information does this study offer?

This study demonstrates the usefulness of using DVD/video to help people with HD begin and adhere to a home-based exercise program. The study identifies physical, cognitive, and motivational factors as barriers to a DVD/video home exercise program. Factors that facilitate participation in a DVD/video home program are participants' self-confidence and belief that the exercise program will help them manage their disease. The study highlights the important role of the caregiver in encouraging people with HD to exercise. An exercise DVD can be a useful resource to promote sustainability of home-based exercise programs in this population.

If you're a patient or a caregiver, what might these findings mean for you?

Patients with HD and their caregivers should consider use of an exercise DVD as a means to help engage in an exercise program. Caregiver support is particularly important to such a program, particularly for people with HD, who have low motivation and more significant physical and cognitive problems.

exercise DVD and what factors would affect its usability. Quantitative and qualitative data were combined to provide multidimensional information about the participants' adherence to the use of the exercise DVD.

Method

Participants

This report focuses on the specific issues surrounding adherence to the use of an exercise DVD in people with HD. The data reported here were gathered as part of a larger study exploring the feasibility and potential benefits of the use of this exercise DVD. A convenience sample of 15 people with mid-stage HD were recruited from the Cardiff HD clinic at the University Hospital of Wales. Potential participants were first screened by the clinic neurologist for the following inclusion criteria: (1) a diagnosis of manifest HD confirmed by a neurologist plus a positive genetic test, (2) a Total Functional Capacity Scale (TFC) score of at least 3, (3) self-reported or physician-reported difficulties with walking or balance, and (4) maintenance of a stable medical regimen for 4 weeks prior to initiation of study and ability to maintain a stable regimen for the course of study. Participants were excluded if they had a history of coexisting neurological conditions, such as stroke, or if they had a medical condition that prevented them from completing the exercise program. Potential participants were approached by the clinic neurologist during their annual clinic appointment and were invited to participate in the study. All participants gave their consent before the start of the study.

Demographic data about participants' age, sex, and living status were collected. The TFC was used to define disease stage. This scale quantifies a participant's ability to perform both basic and instrumental activities of daily living. Scores on the TFC range from 0 to 13, with higher scores indicating higher functioning. A categorical classification of disease severity is based on these scores, which are grouped into 5 stages: stage I (TFC scores=11–13), stage II (TFC scores=7–10), stage III (TFC scores=3–6), stage IV (TFC scores=1–2), and stage V (TFC score=0).[13] Stage I corresponds to early-stage HD, stages II and III correspond to middle-stage HD, and stages IV and V correspond to late-stage HD. Cognitive status was assessed using the Unified Huntington's Disease Rating Scale (UHDRS) cognitive subscale. This subscale is a valid measure of assessing cognitive status in people with HD, in which higher scores reflect better cognitive functioning.[14]

Participants' characteristics are shown in Table 1. Data presented are coded as P1 to P15; this coding adds to the transparency of the process while protecting the anonymity of the participants and allows the reader, at the same time, to gain an understanding of the source of the information.[15] All participants were able to walk independently with or without an assistive device, and most of them (n=13) had a full-time caregiver.

Procedure

The exercise DVD that was used in this study was developed based on consultations with people with HD and physical therapists who work routinely with this population.[16] The DVD contains 5 sections of exercises (Fig. 1) (see video demonstrating one of the DVD sections available at ptjournal.apta.org). The first section is focused on warm-up and flexibility activities. The second, third, and fourth sections focus on strength, flexibility, balance, and endurance exercises specifically tailored for people with HD and on training to perform functional tasks of moving from a sitting to a standing position, stepping up onto stairs, and getting on and off the floor. The fifth section focuses on relaxation, stretching, and breathing techniques. Flexibility exercises are designed to maintain overall muscle length and potentially counteract the secondary effects of dystonia,[17] a common symptom in HD. Balance exercises focus on narrowed and altered base of support and dynamic balance during performance of upper-extremity movements.

All participants were provided with the exercise DVD, which was individually prescribed with subsections based on the participants' specific abilities. Suitable exercises from the DVD were chosen and taught to participants by a physical therapist who conducted a follow-up home visit to ensure correct execution of the exercises. During the home visit, potential benefits and risks of performing the exercises were discussed with participants, and advice about intensity of the exercises, equipment required, precautions, and postural instructions was provided. In addition, instruction and a demonstration on how to use the DVD and to perform the exercises were given by the physical therapist during this home visit. This instruction and demonstration were given in the presence of the caregiver (if applicable), who was asked if he or she would help the participant if needed.

All participants were contacted weekly via telephone by the same physical therapist to monitor their progress. During the telephone calls, participants were asked whether they had performed the exercises during the previous week, how often they performed the exercises, what exercises they performed; whether they had difficulties in performing any of the exercises; and whether they had any concerns they would like to discuss. Participants were

Section 1: Flexibility and warm-up	Section 2: Balance and coordination
1. Neck stretches 2. Shoulder rolls 3. Horizontal shoulder flexion 4. Arm circles 5. Hand stretches 6. Ankle circles 7. Calf muscle stretches 8. Hamstring muscle stretch 9. Lying supine twist 10. Quadriceps muscle stretch 11. Prone press-ups 12. Kneeling child's pose	1. Standing with feet together, eyes open 2. Standing with feet together, eyes closed 3. Standing on one leg 4. Tandem standing 5. Forward lunges 6. Side lunges
Section 3: Circuit resistance training	**Section 4: Strengthening**
1. Sit-to-stand repetitions 2. Shoulder press with weights 3. Squatting 4. Shoulder abduction with weights 5. Trunk rotations and reaching with weights 6. Step-ups	1. Bridging 2. Alternate arm and leg raises 3. Plank 4. Instruction on getting on/off floor
Section 5: Cool down and relaxation	
1. Cat/camel stretch 2. Trunk rotations 3. Breathing exercises	

Figure 1.
Sections of the exercise DVD.

encouraged to progress their exercises by gradually increasing the number of repetitions while decreasing the number and length of rest breaks and increasing the level of exercise progression. For example, standing from a sitting position was encouraged to be progressed by increasing practice repetitions, decreasing the number and length of rest breaks, and lowering the height of the chair. Participants were asked to complete the exercises at least 3 times a week for 8 weeks and to keep a record of their exercise program in an exercise diary (Appendix 1).

Data Collection

Participants' self-reports about their perceptions of their involvement in the exercise program were assessed using the short form of the Intrinsic Motivation Inventory (IMI). The IMI is a multidimensional questionnaire that evaluates an individual's interest and enjoyment, perceived competence, effort, value and usefulness, and felt pressure and tension while performing a given activity.[18] The interest/enjoyment subscale is considered a self-report measure of intrinsic motivation. The perceived competence, effort, and value/usefulness subscales are regarded as positive predictors of intrinsic motivation, with higher scores indicating better motivation. The pressure/tension subscale is considered a negative predictor of intrinsic motivation, with lower scores indicating better motivation.

Semistructured interviews were used mainly to explore factors that affected the usability of the exercise DVD at home. A schedule that included both open and closed questions (Appendix 2) served as a guide to the topics covered during the interview. Each interview focused the discussion on debriefing the rate of adherence during the course of the program and exploring how people used the exercise DVD at home. The main caregiver was present at the interview in most cases (n=13); caregivers were invited to participate in the interviews and to provide clarifications where necessary. All interviews were audio recorded and lasted between 30 and 45 minutes.

The interviews were fully transcribed into text. This process of full transcription helped to strengthen the trustworthiness of the data by avoiding selective recording of the information.[19] To ensure the truth value (credibility)[20] of the study, the accuracy of the transcripts was confirmed by an independent researcher and by consultation with the participants.

Data Analysis

Quantitative analysis. Average adherence rates across the study period were calculated as the number of exercise sessions reported as a percentage of potentially expected exercise sessions prescribed for the 8 weeks. For the purpose of analysis, we used 50% of participation as a cutoff point of adherence; participants were considered to have a good adherence if they reported performance on at least 50% of the prescribed sessions. Reasons for nonadherence were documented.

Descriptive data for TFC and UHDRS cognitive scores and all IMI subscales were calculated. Additionally, the Mann-Whitney *U* test for independent samples was used to assess for any differences between those who adhered and those who did not adhere to the exercise program. Correlations among adherence rate, IMI subscale scores, TFC score, and UHDRS cognitive score were calculated using the Spearman correlation coefficient to determine the interrelationship among these factors and, in particular, to explore whether disease severity, cognitive score, and the participants' self-reported experience regarding their involvement in the program would relate to the adherence rate.

Table 1.
Participant Characteristics[a]

Participant	General Information	Caregiver Involvement	UHDRS Cognitive Subscale Score[b]	TFC Score	Stage of the Disease
P1	Female, aged 69 years at interview	Yes[c,d]	160	3	III
P2	Female, aged 41 years at interview	Yes[c,d]	197	6	III
P3	Male, aged 25 years at interview	Yes[c,d]	128	5	III
P4	Female, aged 55 years at interview	Yes[d]	76	5	III
P5	Female, aged 59 years at interview	Yes[c,d]	63	5	III
P6	Female, aged 67 years at interview	No	201	9	II
P7	Male, aged 42 years at interview	Yes[c,d]	84	5	III
P8	Male, aged 78 years at interview	Yes[c,d]	50	5	III
P9	Female, aged 51 years at interview	Yes[d]	221	11	I
P10	Male, aged 38 years at interview	No	233	9	II
P11	Female, aged 72 years at interview	Yes[c,d]	88	3	III
P12	Male, aged 41 years at interview	Yes[c,d]	198	5	III
P13	Male, aged 51 years at interview	Yes[c,d]	57	4	III
P14	Male, aged 64 years at interview	Yes[c,d]	73	5	III
P15	Male, aged 51 years at interview	Yes[c,d]	130	6	III

[a] UHDRS=Unified Huntington's Disease Rating Scale, TFC=Total Functional Capacity Scale.
[b] UHDRS cognitive subscale score >200 indicates high cognitive functioning, UHDRS cognitive subscale score ≥100 indicates moderate cognitive functioning, and UHDRS cognitive subscale score <100 indicates very low cognitive functioning.
[c] Caregiver was involved in supporting the participant during the exercise program.
[d] Caregiver was involved in the interview.

Table 2.
Characteristics of Adherence to the Use of the Exercise DVD

Participant	Reported Participation in the Program (Maximum Adherence=24 Sessions) n (%)	Reasons for Nonadherence (if Applicable)
P1	24 (100)	None
P2	21 (87.5)	3 sessions were missed due to illness
P3	22 (91.7)	None
P4	2 (8.3)	Lack of the support from the caregiver
P5	6 (25)	Caregiver-participant interpersonal relationship
P6	22 (91.7)	2 sessions were missed due to holiday
P7	22 (91.7)	2 sessions were missed due to illness
P8	10 (41.7)	Caregiver-participant interpersonal relationship
P9	23 (95.8)	1 session was missed due to being busy with a special occasion at home
P10	23 (95.8)	1 session was missed due to illness
P11	20 (83.3)	4 sessions were missed due to absence of the caregiver
P12	21 (87.5)	3 sessions were missed due to absence of the caregiver
P13	2 (8.3)	Caregiver-participant interpersonal relationship
P14	24 (100)	None
P15	20 (83.3)	4 sessions were missed due to illness

Table 3.
Average (SD) Total Functional Capacity Scale (TFC), Unified Huntington's Disease Rating Scale (UHDRS) Cognitive Subscale, and Intrinsic Motivation Inventory (IMI)[a] Subscale Scores of Participants Who Adhered to the Program and Participants Who Did Not Adhere to the Program

Scale	Participants Who Adhered to the Program (n=11)	Participants Who Did Not Adhere to the Program (n=4)	*P*
TFC	6.1 (2.5)	4.7 (0.5)	.34
UHDRS cognitive subscale	155.7 (58.13)	61.5 (11)	.003
IMI subscale			
Interest/enjoyment	4.9 (1.62)	3.7 (1.3)	.85
Perceived competence	5.6 (1.13)	3.5 (1.3)	.14
Effort/importance	6.4 (0.72)	5.8 (0.8)	.23
Pressure/tension	2.4 (1.26)	5.1 (1.4)	.04
Value/usefulness	6.4 (0.71)	4.5 (0.6)	.41

[a] For each item of the IMI, a response on a scale of 7 points indicating how true the statement of the item is given (1="not true at all," 7="very true"). A lower score of the pressure/tension subscale and higher scores of all of the other subscales indicate a positive outcome.

Table 4.
Correlations Between Adherence Rate, Total Functional Capacity Scale (TFC) Score, Unified Huntington's Disease Rating Scale (UHDRS) Cognitive Subscale Score, and Intrinsic Motivation Inventory (IMI) Subscale Score

Scale (n=15)	Correlation With TFC Score	Correlation With UHDRS Cognitive Subscale Score	Correlation With Adherence Rate
TFC		.64[a]	.35[a]
UHDRS cognitive subscale	.64[a]		.57[a]
Adherence rate	.35[a]	.57[a]	
IMI subscale			
Interest/enjoyment	.44	−.01	.09
Perceived competence	.45	.37	.39
Effort/importance	.11	.16	.37
Pressure/tension	−.75[b]	−.53[a]	−.63[a]
Value/usefulness	−.12	−.32	−.24

[a] $P<.05$.
[b] $P<.01$.

Qualitative analysis. A content analysis approach[21] was used to analyze data from the interviews. Responses from closed questions were analyzed using *a priori* coding (Appendix 2), and responses from open questions were analyzed using an inductive approach in which codes emerged from the data. The qualitative data analysis package NVivo (version 8.0.163, QSR International Pty Ltd, Doncaster, Victoria, Australia) was used to aid the analysis process in which codes were placed as nodes. A procedure of coding and recoding was used[20]; the transcripts were read and re-read to do further coding and refinement. This process was continuous and entailed comparing codes from an interview with the codes from a newer interview, which helped to identify prompt questions. After open coding for the first 8 transcripts, the remaining transcripts were coded using the existing codes and by adding new codes on encountering data that did not fit into existing codes. Following identification of codes from each transcript, the modeler option in NVivo[22] was used to help with ordering the codes, linking them together and clustering them into categories and subcategories. The transcripts with their codes were made available to an independent researcher (the same researcher who checked the accuracy of the transcripts) for review, and through discussion we refined and defined the codes and their relationship to each other, as well as to the main question that was being investigated. Final codes were agreed upon within the research team and were sent to the participants for member checking to ensure they agreed that our interpretations represented their ideas. Final codes were further cross-checked and triangulated with information obtained in relevant available literature, thus confirming content and final conclusions.[23]

Results

Exercise Adherence

Characteristics of adherence to and frequency of completion of the prescribed exercises from the DVD during the 8-week period are shown in Table 2. Four participants (P4, P5, P8, and P13) did not adhere well to the use of the exercise DVD and performed fewer than 50% of the prescribed sessions (Fig. 1).

Table 3 presents the descriptive data for the TFC, the UHDRS cognitive subscale, and the IMI subscales for participants who adhered to the program (n=11) and those who did not adhere to the program (n=4). The mean score on UHDRS cognitive subscale and the IMI pressure/tension scores were significantly different between those who adhered and did

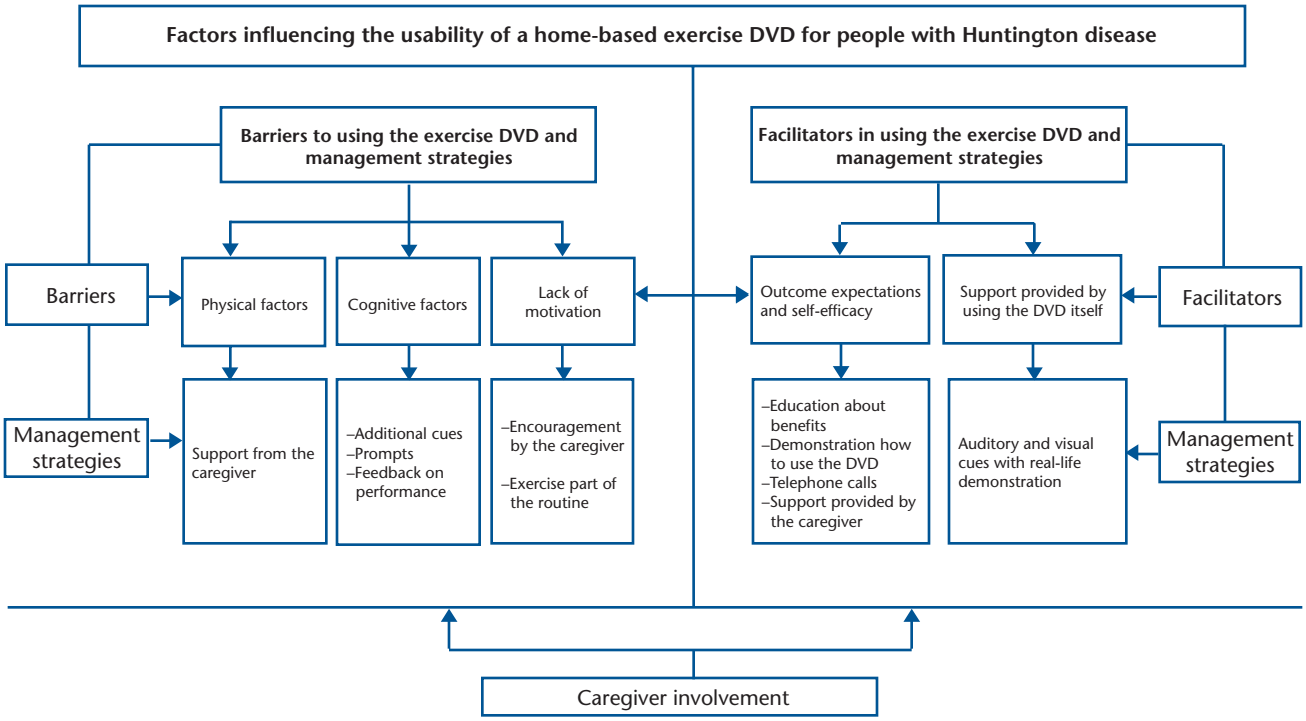

Figure 2.
Summary of main area, categories, and subcategories of interview analysis.

not adhere to the program. There were no significant differences between the TFC score and scores on the other IMI subscales.

Correlation coefficients between adherence rate, TFC score, UHDRS cognitive subscale score, and the IMI subscale scores are reported in Table 4. Adherence rate was significantly correlated with the TFC score, the UHDRS cognitive subscale score, and the IMI pressure/tension subscale score. Correlations of adherence rate with IMI interest/enjoyment, perceived competence, effort/importance, and value/usefulness subscale scores were not significant.

Semistructured Interviews

All participants who adhered to the program agreed that the DVD was simple and easy to follow and that the prescribed exercises were suitable for them. Analysis of the interviews revealed barriers and facilitators to using the exercise DVD. The DVD barriers fell mainly into 3 categories: physical factors, cognitive factors, and lack of motivation. Participants discussed strategies that they used to manage these barriers, which improved their adherence to the program. The facilitators fell into 2 subcategories: (1) cues provided by the DVD and (2) a person's self-efficacy and his or her outcome expectations. The sections below describe these barriers and facilitators and the participants' management strategies, and some illustrative quotes are provided. A summary of the categories and subcategories of interview analysis and their relationship to each other is provided in Figure 2.

Barriers in Using the Exercise DVD and Management Strategies

Physical factors. A majority of participants felt that HD-related physical problems limited to some extent their ability to perform the exercises independently. Most of the participants who completed the exercise program felt that some of the exercises were difficult to perform due to the interference of choreic movements or secondary to their perceived balance problems. Some participants at stage III needed their caregivers to assist with the exercises shown in the DVD, but participants at earlier stages were able to do the exercises independently without the caregiver being involved. Participant 3 said:

> I needed my husband actually to be with me. I do not think I would manage to do them by my own because of the choreic movement, balance problems, and. . .the power and things like that.

Cognitive factors. In addition to physical factors, cognitive problems were a main issue that potentially limited the participants' ability to independently use the exercise DVD.

Participants who were moderately to severely cognitively impaired were unable to do the exercises on their own, including the 4 participants who did not adhere to the program. The participants believed that this inability to perform the exercises was not necessarily due to their physical limitations but rather because at times they were unable to understand from the DVD what they were required to do. Participant 4 said:

> I watched the people—what they were doing on the DVD—but I could not actually see if I was doing it right.

Lack of motivation. Participants also discussed issues related to lack of motivation as another main factor that affected their use of the exercise DVD. The use of strategies such as trying to fit the program into a daily routine helped to maintain motivation and influenced adherence. Participant 6 said:

> It was just difficult to get myself into it. Obviously, people with HD do have difficulties to start new activity. However, making these exercises part of the routine would make it easier to maintain.

Facilitators in Using the Exercise DVD and Management Strategies

Cues provided by using the DVD. All participants who completed the exercise program felt that the DVD was a supportive mechanism to help them initiate and adhere to a home exercise program. Participants discussed the advantages of using the DVD to demonstrate the exercises versus using drawings of the exercises in a paper format. They commented that the main advantage of using the DVD is that it provided additional visual and verbal cues to ensure correct execution of the exercises. Participant 1 said:

> The visual thing of using the DVD makes it much easier to do it, because to do things that have to be committed to memory, particularly in my case [where] memory is a problem, is impossible. So the visual cues of the DVD make it easy to do.

The DVD was used in different ways by participants to derive the support that they needed. The more advanced participants who completed the exercise program (TFC score <9; 8/11) needed to play the DVD at each session to do the exercises. The less advanced participants (TFC score >9; 3/11 [P6, P9, and P10]) used the DVD at the beginning of the program and then were able to integrate the exercises into their daily routine and refer to the DVD or the exercise booklet only if needed.

Self-efficacy and outcomes expectations. Expectations of outcome and self-efficacy were 2 important concepts that emerged from the discussion with the participants that positively influenced their motivation and consequently facilitated their adherence to the use of the DVD. In terms of outcome expectations, most of the participants who adhered to the exercise program believed that their involvement in this program would help them to manage their condition. Participant 10 said:

> What I was just saying to myself—this is an important kind of thing, and I have to do it. I have to do it because it can be beneficial for my balance and my walking.

In terms of self-efficacy, some of the participants who adhered to the program believed that feeling confident about how to use the DVD and how to do the exercises safely helped their adherence. Participant 9 said:

> I felt that I have to do something to regain my balance, but I was not sure how to go about it, and having this program just helped because I felt that I am doing the right thing in the right way.

Participants felt the weekly telephone calls were an important component of maintaining adherence to the program and positively affected their belief in their own ability to effect meaningful change. Participant 9 said:

> The phone calls were very important to keep me on the program. We kept communicating, and you were answering my questions, so I felt I was on the right track. I do not know how well motivated I would be without them.

In addition, all participants who adhered to the program agreed that the education session provided at home at the beginning of the program was important to help them to initiate the exercise program and to promote their self-efficacy. Participant 3 said:

> The home visit was very useful because I can only see what people on the DVD are doing, so it is good that you saw how I was doing things. This gave me assurance that I was doing it right from the beginning.

Although some participants who adhered to the program thought that one session was enough to feel fully confident about how they should progress their exercises, others felt that providing more sessions during the first few weeks of the program would have been beneficial. One participant suggested that providing feedback from a distance using Web-based technology would be useful, rather than having a face-to-face session that would require either the patient or the therapist to travel.

Master Theme

All subcategories of barriers and facilitators related to a master theme that emerged from our analysis: commitment of the caregiver was a key to the success of the program. Reasons for nonadherence to the program were attributed to the lack of commitment of the caregiver or

poor caregiver-participant interpersonal relationship. Participant 5 and her caregiver discussed how the caregiver-participant interpersonal relationship would affect the participant's adherence to the program. She said: "We could not agree on how to do things." The caregiver of this participant clarified by saying:

> She did the exercises with you when you visited us at home, but she would not do them with me because mentally she has authoritarian issues, she is more likely to do things with other people who've got medical authority rather if it is someone from the family.

As noted earlier, some participants needed their caregivers to help with their performance of the exercises because of some physical limitations. In cases of cognitive impairments, the use of strategies such as prompts, verbal cues, and feedback on the participant's performance provided by the caregiver was vital to help the participant to accomplish the exercises successfully. Participant 3 said: "I always needed my nurse. . . ." The caregiver of this participant clarified by saying:

> He always needed his nurse to be there. She was providing him with occasional prompts like make sure your hand's on the chair, touch the chair, move closer, or put the chair closer.

For the majority of the participants who adhered to the program, involvement of the caregiver was necessary to manage motivation by providing continuous encouragement. Participant 11 said: "Motivation was a big issue. . . . " The caregiver of this participant added some clarification. The caregiver said:

> If I was not there, she would think "Do I need to do my exercises?" The problem is that she needed to be prompted to do it.

Support provided by the caregiver also seemed to influence self-efficacy. Participant 4, who did not adhere to the program, explained how the lack of the support from the caregiver influenced her adherence negatively. The participant said:

> I was panicking. I do not know why myself. I just felt that I would be OK if there was somebody sitting there while I was doing the exercises.

Discussion

To our knowledge, this is the first study that documents the adherence rates to unsupervised home exercise programs in people with HD. Adherence is defined as the extent to which people follow the prescribed components of their exercise program.[24] In this study, most of the participants adhered to the use of the exercise DVD; 11 participants reported adherence to at least 83.3 % of the prescribed sessions, and only 4 participants reported adherence on a maximum of 41.7% of the prescribed sessions. Interestingly, reasons for nonadherence were all attributed to the commitment of the caregiver or to the caregiver-patient relationship. It was evident that the successful involvement of the caregiver was a key to the success of the program, particularly with patients who were more advanced in the disease process. Participants did not adhere to the program if they lacked support of a caregiver or if they had a negative relationship with their caregiver about the caregiver's role in supporting them on completing the program. This finding is important and suggests that physical therapists should work cooperatively with the caregiver, supporting the caregiver's self-efficacy and building his or her confidence about the important role that he or she can play in supporting the patient with HD to engage in an independent exercise program. More research investigating the potential role of the caregiver on supporting people with HD to engage in an independent program is warranted.

Data from the IMI subscales indicated positive results about how participants who adhered to the program perceived the use of the exercise DVD. The IMI pressure/tension subscale resulted in a relatively low score, which indicates that overall, participants did not experience pressure during the use of the exercise DVD. The IMI effort/importance and value/usefulness subscales resulted in very high scores, which suggest that the participants felt they produced a good amount of effort to work on the exercises from the DVD; they believed that it was important for them to do the exercises, and they were satisfied with the results.

Significant differences between those who adhered and those who did not adhere to the exercise program were seen only on the pressure/tension subscale of the IMI. There was a trend toward lower scores in all of the other subscales in those who did not adhere to the program, but these scores were not significant. Further investigation is needed on a larger sample. The significant correlations between adherence rates, UHDRS cognitive scores, and IMI pressure/tension subscale scores (and the significant differences between IMI pressure/tension subscale scores and UHDRS cognitive scores) suggest that participants who were more cognitively impaired may have found it more difficult to perform the exercises and, therefore, experienced more pressure, which may have had a negative influence on their adherence to the program.

Although most participants used the exercise DVD successfully and managed to adhere to its use very well, a number of barriers that could affect the performance of the exercises

and the adherence to the use of the exercise DVD were reported. Each of these barriers was a disease-specific factor, and the barriers included physical impairments, cognitive impairments, and lack of motivation. These findings are in agreement with what has been identified about barriers to independent exercise in people with HD.[3] In terms of physical impairments, participants in this study, particularly those in more advanced stages of the disease, felt that balance deficits and choreic movements had an impact on their independent use of the exercise DVD. These participants needed their caregivers to help with the actual performance of the exercises but were still able to gain benefit from participation.

In contrast to the physical impairments, cognitive problems were reported to act as a main barrier to the independent use of the exercise DVD, particularly at the more advanced stages, which is consistent with our quantitative analysis. Cognitive symptoms are an early sign in HD in which difficulties in maintaining attention to a task, manipulating information, and planning can be recognized.[12] These symptoms may progress to include disorders of memory retrieval and eventually global dementia.[25] Given that both the number and severity of cognitive impairments increase with the progression of the disease, they have greater impact on the ability to learn new motor tasks, including the performance of new exercises, at the more advanced stages of the disease. However, participants in this study indicated that strategies such as prompts, verbal cues, and feedback on their performance provided by the caregiver helped to successfully support the accomplishment of the exercises and minimized the effect of cognitive impairment on their ability to perform the exercises from the DVD. Additional verbal cues and prompts provided by the caregiver were crucial in enhancing usability of the exercise DVD in the presence of cognitive impairment.

The DVD itself was perceived by participants as a supportive mechanism that helped in completion of the exercises, particularly in the presence of cognitive impairments. The DVD provided participants with a real-life demonstration, which was viewed by the participants as being superior to the written instructions or printed illustrations. The DVD approach augments the information provided by attention-focusing verbal and visual cues. The literature has illustrated that such cues are important to maintain correctness of performance of an imitative motor task; the visual feedback is important to guide the imitation of the performance, and the verbal description is important to assist with processing the visual information of the task.[11,26]

Lack of motivation was reported to act as another barrier to adherence to the regular use of the exercise DVD. Lack of motivation is a main feature of the disease that could act as a barrier to initiating a new life routine such as an exercise program.[1] Particularly in the realm of exercise training, people with HD may feel helpless, hopeless, and reluctant to participate in any exercise program,[27] considering the progressive and degenerative nature of the disease and the number of losses that they might experience as a result.

Because motivation is vital to adherence,[28] finding strategies to improve motivation is a key to the success of any therapy program. In this study, outcome expectations and self-efficacy were 2 main factors reported by participants that helped them to maintain their motivation and, therefore, facilitated their adherence to the use of the exercise DVD. There is a clear link in the literature among outcome expectations, self-efficacy, and adherence to an exercise program.[29,30] In a study that examined factors promoting adherence to a walking program in a group of elderly adults, participants' belief in their ability to do the exercises safely (self-efficacy) and the recognition of the benefits of the exercises (outcome expectations) were 2 key factors.[31] Outcome expectation relates to the belief that specific consequences will result from specific personal actions.[32,33] In this study, this concept seemed to be important in the initial adoption of the use of the exercise DVD; most of the participants who adhered to the use of the exercise DVD indicated that their involvement in this program was because of their belief that the use of the exercise DVD would be beneficial to manage their condition. In terms of self-efficacy, people need to believe that they have the ability to affect their own health and that they have the tools to do that. High self-efficacy implies that a person is capable of controlling his or her own behavior.[32,33] In this study, factors that contributed to participants' self-efficacy and, therefore, to their motivation to continue with the use of the exercise DVD, included the belief in their ability to use the exercise DVD appropriately and to do the exercises safely.

Caregiver involvement and home visit support and telephone calls by the physical therapist to monitor progress were factors perceived by the participants to promote self-efficacy and facilitate their engagement in the use of the exercise DVD, which, in turn, contributed to adherence. Factors that would promote self-efficacy in this population need further investigation. Behavioral motivation techniques, which have been used successfully in patients with PD to promote self-efficacy and

consequently engagement in physical activities, can be explored to engage people with HD in exercise programs.[34] In this strategy, counseling is used to promote a behavioral change through working closely with participants. The strategy includes education about the benefits of physical activity, advice about suitable activities, identifying and overcoming any perceived barriers to engage in physical activity, setting goals, and recruiting social support.

The suggestion of utilizing Web-based technology rather than face-to-face sessions merits some consideration. Telemedicine has been successfully applied in other populations such as people with stroke, cerebral palsy, and obstructive sleep apnea syndrome to monitor the delivery of therapeutic interventions.[35–38] Although further investigation in this area is needed, the use of telemedicine technology could be beneficial to people with HD to support their engagement in the independent use of the exercise DVD or in any other unsupervised exercise programs.

In conclusion, this study demonstrated that the exercise DVD was perceived to be suitable to facilitate people with HD to engage in an independent, home-based exercise program. Although the settings of home-based programs do not allow social interaction, their advantage is the convenience of doing the exercises when a person is able, not having to travel to an exercise facility, and reduced direct cost to the patient.[3] In addition, there is support for the home approach in that delivering training programs in the home in people with neurodegenerative disease have been shown to promote efficient transferability of skill acquisition.[39,40] It seems, therefore, that innovations such as a DVD can play a supporting role in the provision of physical therapy, offering choice in the way that exercises can be delivered outside therapy sessions or between consultations. Given that a number of factors affect the usability of the exercise DVD in this population, this study suggests that therapists should work in collaboration with patients in evaluating their specific considerations on delivering the exercise DVD to ensure its acceptability.

Study Limitations

The rate of adherence of people with HD to the home use of the exercise DVD in this study was very good, although there is a possibility that participants might have potentially overreported their participation. Every effort was made by the researchers to cross-check the reported participation, and reported adherence was confirmed with the caregivers (if applicable) and with participants during the weekly telephone calls and at the time of the interviews. Therefore, we assume that overreporting was unlikely to be a factor in this study.

Given the cognitive issues and communication difficulties in this population, we considered structured interviews to be the most appropriate method to ensure meaningful responses. Although the highly structured format of the interview schedule provided mostly survey-type data, the interviews included some open questions to which qualitative analysis was applied.

In qualitative research, there is the possibility that the researchers' views may influence interpretation of the data. However, when we asked the participants in this study to comment on the categories that we developed, they provided positive feedback, thus contributing to the credibility of the results. Findings from this study might not be transferable to the general HD population because of the small sample that was used and considering that the majority of the participants were moderately to severely cognitively impaired, with minimal representation of people with HD who were mildly cognitively impaired. The sample also was a convenience sample of people who were recruited from a clinic that was actively involved in physical therapy research and in which patients were committed to research in general, which might have influenced our findings. Future studies should include a larger number of participants with a wider range of impairments recruited from different sites and go beyond our content analysis aiming to develop theory or seek understanding of the lived experience about adherence in this population.

All authors provided concept/idea/research design and project management. Ms Khalil, Dr Quinn, and Dr Busse provided writing and data analysis. Ms Khalil provided data collection. Professor Rosser, Dr Busse, Dr Quinn, and Ms Khalil provided fund procurement. Professor Rosser provided participants. Dr van Deursen and Professor Rosser provided facilities/equipment. Dr van Deursen, Professor Rosser, and Dr Busse provided institutional liaisons. Dr Quinn, Dr van Deursen, Mr Martin, Professor Rosser, and Dr Busse provided consultation (including review of manuscript before submission).

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Local research ethical approval was obtained from the South East Wales Research Ethics Committee for all aspects of this study. All research was undertaken in accordance with Research Governance regulations.

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For more information about the DVD, contact the corresponding author at: busseme@cardiff.ac.uk.

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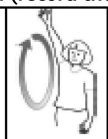
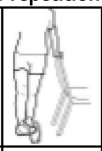
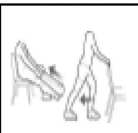
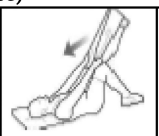
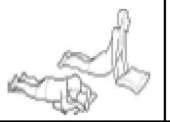
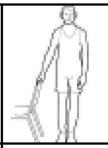
Appendix 1.
Exercise Diary

Exercise Diary (week 1) **Week start date:** **Week end date:**

1-Please check when exercise is completed (record the number of repetition for each exercise)

												
Session 1												
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									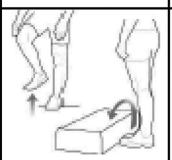			
Session 1												
Session 2												
Session 3												

Appendix 2.

Interview Schedule of Evaluating the Home Use of the Exercise DVD

Closed Questions	*A Priori* Codes
Was the training program suitable for you? What do you think about the overall structure of the DVD? Was it easy to navigate and follow?	Suitability of the exercise DVD
Did you have difficulty in performing the exercises? Can you explain?	Barriers
Was the home visit useful? Were the telephone calls useful?	Facilitators

Open questions:

Please state if you were using the exercise DVD.

Prompts: If yes,

- How often were you using the exercise DVD?
- What exercises have you performed, and how long was each session?
- Can you explain how you were performing the exercises?

Prompts: If never,

- Can you explain why you think you have not performed the exercises?

Please describe what you have liked most and least about the program.