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## Implementing physiotherapy Huntington's disease guidelines in clinical practice

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## **Abstract**

### Background

The recently published clinical practice guideline for physiotherapy practice for Huntington's disease (HD) should be integrated into practice to develop interventions that enable people with HD to achieve personalised goals. The European Huntington's Disease Network Physiotherapy Working Group aims to support and enable the use of best evidence in physiotherapy for the HD community. Successful implementation of the clinical practice guidelines requires an understanding of facilitators and barriers to therapist implementation.

### Objective

To explore facilitators and barriers to implementing recently published clinical recommendations that guide physiotherapy practice for HD.

### Methods

An online survey was distributed globally through HD networks. Data collected included demographic information and agreement/disagreement with a series of named facilitators and barriers to implementation of each of the six physiotherapy guideline recommendations. A consensus level of  $\geq 70\%$  agreement was set as indicative of agreement/disagreement.

### Results

Thirty-two physiotherapists working in a range of settings responded. Support from colleagues (81-91% agreement), an individualised physiotherapy plan (72-88% agreement) and physiotherapist's expertise in HD (81-91% agreement) were reported as facilitators. The

main barriers were behavioural (72-81% agreement) and cognitive (75-81% agreement) impairments and low motivation (72-78% agreement) in persons with HD.

## Conclusions

Physiotherapists agree that their expertise in HD and support from colleagues facilitate the development of individualised treatment plans. Further work needs to develop creative ways in which barriers specific to the cognitive and behavioural aspects of HD can be managed to enable treatment plans to be implemented.

## Keywords

Evidence-based practice, Huntington's disease, physiotherapy, guidelines

## **Introduction**

Clinical practice guidelines (CPGs) for physiotherapy management of people with Huntington's disease (HD) were first formalised in 2009(1) and updated over time with the most recent guidelines published in 2020(2). The 2020 guidelines were informed by a systematic review(3) and recommendations were developed based on Joanna Briggs Institute Grades of Recommendation(4), forming the basis of six action statements (Table 1). Action statements related to aerobic exercise and strengthening, and gait training had the strongest recommendation (level A); balance and breathing exercises were graded level B. Statements on postural control training and end stage care were not graded due to lack of sufficient evidence. Clinical recommendations need to be integrated into practice and should be used to develop interventions that can enable people with HD to achieve personalised goals(2).

Table 1

The European Huntington's Disease Network Physiotherapy Working Group (EHDN PWG) aims 'to support and enable the use of best evidence in physiotherapy for the HD community'(5). Having supported the development of the CPGs, the next step was to understand how physiotherapists can implement evidence-based practice. Therefore, this study aimed to evaluate facilitators and barriers to implementing the 2020 CPGs. This knowledge will enable development of appropriate resources to support physiotherapy for HD.

## **Materials and Methods**

A descriptive survey design and 21 item online survey developed by EHDN PWG members was used to collect data from physiotherapists working with people with HD. Participants were recruited from global HD associations: EHDN, the Huntington's Study Group, the

Huntington's Disease Society of America, the Australian Physiotherapy Association, and the Academy of Neurologic Physical Therapy of the American Physical Therapy Association. The number of physiotherapists receiving this information is unknown. Ethical approval was gained from Cardiff University, School of Healthcare Sciences Research Ethics Committee (REC746).

The first survey section gathered data in relation to the country where the respondent worked, type of healthcare setting and knowledge of the 2020 CPGs. The second section provided the six action statements from the guidelines and asked respondents their level of agreement/disagreement, on a five-point Likert scale, with a series of facilitators and barriers to implementation of the recommendations. The list of facilitators and barriers (Table 2) was developed through review of relevant literature in HD and other movement disorders(3, 6-9). Space for respondents to record other facilitators and barriers was provided. The survey was piloted by three physiotherapists before the main study; no problems were identified.

Data were analysed descriptively using frequencies and percentages. Due to low numbers of respondents, the five-point Likert scale was reduced to three categories for analysis: agree, neutral, disagree by combining agree and strongly agree and combining disagree and strongly disagree. A consensus level of  $\geq 70\%$  agreement or disagreement was chosen based on previous studies(10-11) for deciding key facilitators and barriers.

## **Results**

There were 32 respondents: 18 from Europe, 7 from Australia, 5 from the USA, 1 from Africa and 1 from an unknown location due to missing data. Most respondents were aware of the 2020 guidelines (n=22), 12 were aware of other HD-related guidelines and 1 respondent reported being unable to access the 2020 guidelines. Respondents worked in hospitals (n=15), community (home care) (n=9), outpatient settings (n=9), nursing homes (n=4) and rehabilitation centres (n=4), with some respondents working across several settings. The

majority (n=24) of respondents worked with people with HD <40% of their time, 6 worked with HD between 41-80% of their time and 2 worked with HD 81-100% of their time.

Table 2

#### *Facilitators to implementation of guidelines*

From the proposed choices, support from colleagues (81-91% agreement), an individualised physiotherapy plan (72-88% agreement) and physiotherapist's expertise in HD (81-91% agreement) were reported as facilitators to implementing guidelines across all statements (Table 2). Adequate staff was a facilitator for implementing statements 2,3,5 and 6 (72-81% agreement). High motivation of the person with HD and adequate equipment were facilitators for implementing statement 2 (gait training) and 3 (balance exercises) (72-75% agreement). Adequate equipment was also a facilitator for implementing statements 5 (postural control) and 6 (end stage care) (72 and 78% agreement). Physiotherapist knowledge of facilities for exercise was a facilitator for statement 1 (aerobic exercise) (81% agreement). Additionally, respondents reported that caregiver support/understanding of the recommendations were seen as facilitators for statements 3 (balance exercises) and 6 (end stage care). No facilitators had  $\geq 70\%$  disagreement for any statement.

#### *Barriers to implementation of guidelines*

From the proposed choices, respondents agreed that the behavioural aspects of HD were a barrier to implementing statements 1-5 (72-81% agreement), low motivation was a barrier to implementing statements 1,3,4 and 5 (72-78% agreement) and cognitive aspects of HD were a barrier to statements 3, 4 and 5 (75-78% agreement) (Table 2). No barrier had  $\geq 70\%$  agreement for statement 6. No barriers had  $\geq 70\%$  disagreement for any statement. Lack of funding was reported as a barrier to implementing balance and breathing exercises, postural control training and end stage care.

## **Discussion**

This is the first study to explore facilitators and barriers to implementation of physical therapy CPGs in HD. Support from colleagues, an individualised physiotherapy plan and physiotherapist's expertise in HD were reported as being key facilitators to implementation of physiotherapy guidelines. The key barriers to implementation were reported as characteristics specific to HD, i.e., cognitive and behavioural dysfunction and low motivation. The number of respondents was low, and it is unknown as to the percentage of those receiving information about the study who completed the survey. The geographical spread of the respondents allows for some application across countries.

Major facilitators to guideline implementation across all statements were identified as support from colleagues, individualised physiotherapy plans, and physiotherapist's expertise in HD. It is important to note that these are all items that relate to the physiotherapist. Support from colleagues as a facilitator suggests a collaborative approach to physiotherapy management and this may be due to the complexity of this rare condition. It is not known if these colleagues were physiotherapists or other healthcare professionals. However, support from EHDN PWG was not reported as a key facilitator to implementing physiotherapy guidelines with only 41-65% of respondents in agreement and 28-44% neutral. It could be that physiotherapists gain sufficient support from colleagues and do not see the need to explore further, in agreement with Scurlock Evans et al(12) who suggest a preference of human sources rather than computer for seeking information.

The importance of an individualised physiotherapy plan likely stems from the need to consider each person with HD's physical, cognitive, and behavioural impairments, their lifestyles, and their living environments and resources in designing a plan of care that is feasible and acceptable to the person. The physiotherapist's expertise with HD is important



because many physiotherapists have no experience treating persons with HD due to the rarity of the disease, and therefore may not be as aware of the best available evidence for their management. Thus, clinical education and training along with on-going mentoring of physiotherapists new to the HD population by experienced clinicians may lead to greater implementation of the guidelines.

Knowledge transfer must also take into account the barriers associated with implementing clinical practice guidelines. Major barriers to guidelines implementation were identified as disease-related behavioural and cognitive impairments and low motivation of persons with HD. Unlike the facilitators, the barriers all related to the disease process. Behavioural impairments including depression and apathy are prevalent in individuals with HD and may decrease their motivation to participate in exercise programs and activities prescribed by physiotherapists (13-14). Cognitive dysfunction in HD, such as deficits in visual attention, psychomotor speed, and visuomotor and spatial integration, can complicate the physiotherapist's evaluation and treatment of a person with HD(13). Cognitive dysfunction in HD is related to mobility impairment and difficulty performing dual tasks (i.e., simultaneous motor and cognitive tasks), that can negatively affect performance of daily life activities (15-17). Additionally, anosognosia may impact on optimal management strategies (18) but this was not identified by participants.

This study is not without its limitations. Although respondents were from USA, Europe and Australia, it is not known if the facilitators and barriers of guideline implementation are similar in other regions. The sample size is small, reflecting the rare nature of HD and limited specialist physiotherapists in the field. The use of a survey limited the findings to quantitative data of agreement/disagreement with statements and it is still unknown what problems that physiotherapists will face when they implement the guidelines. Further research is therefore needed to explore experiences of both physiotherapists and people with HD in the implementation of guidelines in practice for appropriate support resources to be developed.

## **Conclusions**

This study explored facilitators and barriers to implementation of physiotherapy clinical practice guidelines in HD. Respondents agreed that implementation of recommendations would be facilitated by the physiotherapists' expertise, developing an individualised plan and support from colleagues. However, barriers to implementation focused on cognitive and behavioural characteristics and low motivation, specific to HD. To facilitate the implementation of the recommendations, it will be necessary to explore creative ways in which physiotherapists can use their expertise to develop an individualised care plan taking into consideration the cognitive and behavioural aspects of HD.

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Tables

Table 1 Physiotherapy practice for Huntington’s disease: Action statements (8)

Number	Action statement
1	Physiotherapists should prescribe aerobic exercise (moderate intensity, 55%–90% heart rate maximum) paired with upper and lower body strengthening 3 times per week for a minimum of 12 weeks to improve fitness and to stabilize or improve motor function.
2	Physiotherapists should prescribe one-on-one supervised gait training to improve spatiotemporal measures of gait.
3	Physiotherapists may prescribe individualized exercises, including balance exercises, delivered at a moderate frequency and intensity to improve balance and balance confidence.
4	Physiotherapists may provide regular breathing exercises, including inspiratory and expiratory training, to improve respiratory muscle strength and cough effectiveness.
5	Physiotherapists may prescribe an individually tailored program to improve postural control and may use positioning devices to optimize posture.
6	Physiotherapists should ensure that care plans for individuals with HD with end-stage disease include appropriate positioning and seating, active movement, position, respiratory exercise, and education. Family and caregiver training to provide strategies for maintaining appropriate ongoing activity and participation for as long as possible is an important focus for the physical therapy team as part of end-stage care.

Table 2 Proposed facilitators and barriers to implementation of clinical guidelines

<b>Facilitators</b>	<b>Statements with <math>\geq</math> 70% agreement</b>	<b>Barriers</b>	<b>Statements with <math>\geq</math> 70% agreement</b>
Support from healthcare colleagues	Statements 1-6	HD specific issues: behavioural	Statements 1-5
Individualised physiotherapy plan for individual with HD	Statements 1-6	HD individual's low motivation	Statements 1,3,4,5
Physiotherapist's expertise in HD	Statements 1-6	HD specific issues: cognitive	Statements 3,4,5
Adequate staff	Statements 2,3,5,6		
Adequate equipment	Statements 2,3,5,6		
HD individual's high motivation	Statements 2,3		
Physiotherapist's knowledge of relevant facilities and services for exercise	Statement 1		
<b>Facilitators</b> <b>Statements with &lt; 70% agreement</b>		<b>Barriers</b> <b>Statements with &lt; 70% agreement</b>	
Support from EHDN Physiotherapy Working Group		Lack of equipment	
HD individual's self-efficacy		Not enough staff	
Physiotherapist's knowledge of relevant facilities and services for exercise*		Therapist lack of expertise in HD	
Person with HD has transportation to access exercise facilities*		Lack of knowledge of facilities/resources for exercise	
		HD specific issues – physical	
		Not enough time	
		Lack of support from family/caregivers	
		Limited transportation for person with HD to access exercise facilities*	

\* Facilitators and barriers specific to statement 1

Abbreviations: EHDN, European Huntington's Disease Network; HD, Huntington's disease