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FALLS AND FEAR OF FALLING IN NURSING HOME RESIDENTS WITH HUNTINGTON'S DISEASE

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Abstract: *Background:* Almost half of nursing home residents with Huntington's disease experience fall incidents. There is little knowledge about fear of falling in patients with Huntington's disease. *Objectives:* To explore incidence of falling and the association with fear of falling in nursing home residents with Huntington's disease compared to other nursing home residents. A secondary objective is to explore changes in incidence of falling and prevalence of fear of falling in a 24-month follow-up period in a subgroup of longitudinally followed HD-residents. *Design:* Cross-sectional multi-centre point prevalence study of relevant care problems including falls, known as the Dutch National Prevalence Measurement of Care Problems in 2012, 2013 and 2014. *Setting:* Eight Dutch nursing homes belonging to one organization. One of these nursing homes cares exclusively for Huntington residents. *Participants:* 57 Huntington residents and 404 non-Huntington residents were included over a two-year period; 30 Huntington residents participated in three consecutive measurements. *Measurements:* Residents' characteristics, fall incidence and health problems after a fall were prospectively assessed for 30 days. Fear of falling and avoiding activities were measured by a single-item question. *Results:* The percentage of fallers among the Huntington residents (30%) was significantly higher ($p<0.001$) compared to the non-Huntington residents (10%). The percentage of Huntington residents expressing fear of falling was significantly lower ($p<0.05$, 14% versus 30%). Logistic regression analysis revealed that interaction between the Huntington and non-Huntington group and age was significant (odds ratio 0.91, p-value 0.02). Fewer Huntington residents than non-Huntington residents experienced fear of falling, a difference which increased with age. The percentages of avoiding activities did not differ between the two groups. Huntington residents were more care-dependent than non-Huntington residents. Huntington versus non-Huntington residents and care dependency were significant predictors for avoiding activities, after controlling for resident characteristics. A cohort of 30 Huntington residents followed longitudinally for 24 months showed significant changes in fear of falling: an increase in the first 12 months and a decrease in the second 12 months. *Conclusions:* Although fall incidents were more common in Huntington residents than in non-Huntington residents, Huntington residents were less fearful of falling. Possible explanatory factors are age and care dependency. Future research should include cognitive functioning and insight into deficits as factors possibly contributing to fear of falling.

Key words: Nursing home, Huntington disease, accidental falls, fear of falling, avoiding activities.

Introduction

Huntington's disease (HD) is a neurodegenerative autosomal dominantly inherited disease of the central nervous system characterized by unwanted choreatic movements, behavioral and psychiatric disturbances and dementia.(1) The prevalence in the Caucasian population is estimated at 1/10,000-1/20,000. Treatment is multidisciplinary and based on symptomatic therapy with the aim of improving quality of life. The progression of the disease leads to more dependency in daily life and consequently more care.

Falls have been reported in almost half of the HD nursing home residents (2), but study of causes and contributing factors related to these falls has been limited. Considering motor signs, there is a complex interaction between chorea and bradykinesia and their impact on balance, and thus the chance of falling. In addition, disturbances in behavior and cognition, such as recklessness, lack of attention and lack of insight, have an influence, as well as other generic risk factors, such as the use of antidepressants, neuroleptics, cardiovascular medications and alcohol intake (3, 4).

Falls can lead to physical injuries, fear of falling and avoiding activities (5, 6). Anxiety can develop when thinking about or experiencing danger (7). It may be a useful emotion leading to a preventive action. However, in a retrospective study of falls in ambulant patients with HD, only a few fallers (15%) indicated being afraid of falling. There was no difference compared to the non-faller group (3).

In general, individuals who fall can often develop a fear of future falls. Conversely, fear of falling and avoiding activities due to fear of falling are predictive for future falls in both fallers and non-fallers (5, 8). In daily practice, however, we have seen residents with HD fall more often; yet fewer HD residents experienced fear of falling than non-HD residents. We assumed that if fear of falling is less common in HD residents, factors that contribute to the development of fear of falling interact differently in HD and in non-HD patients.

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The aims of this study were to evaluate the following issues with regard to HD and non-HD residents admitted to nursing homes:

- the incidence of falling and the prevalence of fear of falling and avoiding activities
- the relationship between the incidence of falling and fear of falling
- the relationship between the incidence of falling and avoiding activities

An additional aim was to explore changes in incidence of falling and both prevalence of fear of falling and avoiding activities in a 24-month follow-up in HD-residents.

In The Netherlands, a nursing home is an institution which provides a temporary or permanent place to live, multidisciplinary treatment, guidance and support, nursing care for mostly older patients with long-term, complex health problems, expressed primarily in functional disorders and handicaps (9). Nursing homes also offer services for younger patients with chronic diseases and considerable handicaps, requiring 24/7 care. Besides nursing staff, nursing homes employ medical, paramedical and psychosocial staff (10). In The Netherlands, there are a few nursing homes, which specialize exclusively in long-term care for residents with Huntington's disease.

Methods

For this study, data were obtained from the Dutch National Prevalence Measurement of Care Problems (LPZ) (in Dutch: Landelijke Prevalentiemeting Zorgproblemen) from 2012, 2013 and 2014 (11-13). The LPZ is a cross-sectional, multi-centre point prevalence survey and is conducted annually on one day in different healthcare sectors (hospitals, nursing homes, home care) (14). Care problems were assessed via specific modules including pressure ulcers, malnutrition, incontinence and falls. The fall incidence was prospectively assessed for a period of 30 days. The aim of the LPZ is to obtain insight into the basic quality of care (14).

In short: In the participating organizations each patient was assessed by two healthcare professionals (nurse and paramedic or physician). One of them worked in the patient's ward (14). A fall was defined as an event when the resident accidentally ends up on a lower level or on the ground (15). In the current study, the incidence represents the number of residents who have fallen at least once during the 30 days prior to the measurement day (11-13). Questions were added about the circumstances in which the fall incident took place and the possible causes and consequences of the fall. Also fear and avoidance behavior were part of the questionnaire as well as fall- and injury-preventive measures. Fear was operationalized by the question: "Has the resident a fear of falling?" and avoiding activities by: "Does the resident avoid physical activities?".

Care dependency was examined using the Care Dependency Scale (CDS) consisting of 15 items, scored on a 5-point Likert-scale (16). Based on the total score, residents were classified into 5 categories (completely dependent (score 1) to completely independent (score 5)), each indicating the level of dependency on health care support (11-13).

Study procedure

Eight out of eleven nursing homes, belonging to one large care organization called de Riethorst Stromenland, participated in 2012, 2013 and 2014. Seven institutions provide regular nursing home care; one of them exclusively provides institutional long-term care for HD residents. We first checked whether the resident characteristics (age, gender, care dependency, Body Mass Index (BMI) and dementia) of the seven regular nursing homes were representative of nursing home residents on a national level participating in the LPZ.

Secondly, within the eight nursing homes of the same organization, we compared the HD residents (HD group) with the regular residents (non-HD group), with regard to the incidence of falls and its association with fear of falling and care dependency. For this we used the last measurement of each individual participant in one of the three years. If a resident had participated more than once, we only used the data from the last measurement.

Thirdly, we looked for longitudinal changes in fall incidents, fear of falling and avoiding activities specifically in all HD residents who participated in three successive annual measurements.

Data analyses

For the statistical analyses, SPSS version 22 was used. Differences between the groups (De Riethorst Stromenland care organization versus Dutch nursing homes participating in the LPZ, HD versus non-HD and fallers versus non-fallers) were analysed using the t test for continuous variables (age, BMI, mean CDS score) and the Chi-square test for categorical variables (gender, dementia, CDS categories, fallers, fear of falling, avoiding activities). We evaluated the outcome variables, fear of falling and avoiding activities, in a multivariable logistic regression. Included in the model were group, age, gender, care dependency and fall incidence.

Finally, we applied repeated measures logistic regression by using generalized estimating equations (GEE) to evaluate the effect of year on fear of falling, avoiding activities and fall incidence, taking into account the correlation between repeated annual observations in those 30 HD residents who were followed for 24 months.

Results

Participants

On a national level, in 2012, 2013 and 2014, respectively, 11,114, 10,914 and 10,495 nursing home residents were included in the Dutch LPZ. In De Riethorst Stromenland organization, 231, 260 and 250 non-HD participants were

Table 1
Patient characteristics of the Huntington's Disease and non-Huntington's Disease residents

Participants		HD* residents (N=57†)	Non-HD residents (N=404†)	p-value
Mean age in years (SD)		55.39 (12.72)	86.8 (6.11)	<0.001
Male (%)		56.1	19.8	<0.001
Mean CDS score (SD)‡		2.14 (1.22)	3.06 (1.21)	<0.001
CDS categories (%)				<0.001
	-Completely dependent	36.8	8.1	
	-To a great extent dependent	33.3	20.9	
	-Partially dependent	17.5	29.6	
	-To a great extent independent	3.5	21.7	
	-Completely independent	8.8	19.8	
Fallers (%)§		30.4	10.1	<0.001
Fear of falling (%)**		14.3	30.1	0.01
Avoiding activities (%){		10.7	18.2	0.16

*HD=Huntington's Disease †Last measurement of each individual participant in one year during the period 2012-2014. ‡ CDS= Care Dependency Scale §Data were unavailable for 1 HD and 7 non-HD residents. **Data were unavailable for 1 HD and 5 non-HD residents. {Data were unavailable for 1 HD and 8 non-HD residents.

included in these years, respectively. The Dutch nursing home residents and the non-HD residents of De Riethorst Stromenland were found to be generally comparable to each other as far as the characteristics age, gender, care dependency, Body Mass Index and dementia were concerned, using the LPZ database. In the De Riethorst Stromenland group, a higher mean age, more female residents, a higher BMI (in 2012), and a significantly lower mean CDS score (in 2012) was found.

In total, 404 individual non-HD residents and 57 individual HD residents were assessed at least once over the three measurements. The data of these two groups was used to compare characteristics of HD versus non-HD residents.

Thirty HD residents actually participated in three consecutive measurements and their data was used to evaluate changes in HD residents over a 24-month period.

Comparison of HD versus non-HD residents

The HD group was younger, had more males, was more care-dependent, had significantly more falls and showed significantly less fear of falling compared to the non-HD group (Table 1). The rate of avoiding activities in the HD group was lower, though this was not significant.

The differences between the fallers and non-fallers for both groups over 24 months are presented in Table 2. The non-falling HD residents experienced significantly less fear of falling than the non-falling non-HD residents. For the falling HD residents, the scores for fear of falling did not differ significantly from those for the non-HD residents. Within the two groups, there were no differences regarding fear of falling between fallers and non-fallers. With regard to the difference in fear of falling between the falling and the non-falling residents (table 2), the effect of fall incidence was not statistically significantly different for HD and non-HD residents. The difference between the HD and non-HD group with respect to fear of falling did not depend on fall incidence. When evaluating the effect of HD versus non-HD group on fear of falling, the group effect turned out to be age-dependent (Table 3); the interaction of group and age was statistically significant (p=0.02): with every year of increase in age, the odds ratio (OR) of HD versus non-HD decreased by 9% In other words, controlling for the patient characteristics gender, care dependency and fall incidence, fewer HD residents experienced fear of falling than non-HD residents and this difference increased with age. Gender, care dependency and fall incidence did not significantly predict fear of falling.

There was no significant difference in avoiding activities between HD and non-HD residents in either the falling or the non-falling group (Table 2). The OR of HD residents versus non-HD residents for the outcome variable 'avoiding activities' was 0.209 (p=0.05) corrected for age, gender, care dependency and fall incidence (Table 3). Controlling for patient characteristics, HD residents were less likely to avoid activities than non-HD residents. In addition to the patient group to which a resident belongs, the stage of care dependency was also a significant predictor of avoiding activities. With increasing care dependency, there was also an increase in the avoidance of activities in both the HD and non-HD residents. Age, gender and fall incidence did not significantly predict avoiding activities.

The HD residents were significantly more care-dependent than the non-HD residents in both the falling and non-falling groups (Table 2). There was no significant difference in the distribution of severity of injuries between the HD and non-HD residents in the group with a fall status.

Table 2
Fear of falling, avoiding activities, care dependency and health problems of the falling and non-falling Huntington's Disease and non-Huntington's Disease residents

	Fallers (n=57*)			Non-fallers (n=396*)		
	HD† residents (n=17)	**non-HD residents (n=40)**	**p-value**	**HD residents (n=39)**	**non-HD residents (n=357)**	**p-value**
Fear of falling (%)‡	23.5	26.7	0.80	10.3	30.5	0.01
Avoiding activities (%)§	5.9	22.2	0.13	12.8	17.7	0.45
Mean CDS score (SD)	1.9 (1.1)	2.7 (1.1)	0.01	2.3 (1.3)	3.1 (1.2)	<0.001
CDS categories (%)	0.02		<0.001			
Completely dependent	44.4	10.6			33.3	10.1
To a great extent dependent	33.3	31.9			33.3	23.0
Partially dependent	16.7	38.3		17.9	30.3	
To a great extent independent	0.0	10.6		5.1	20.4	
Completely independent	5.6	8.5		10.3	16.2	
Health problems after fall (%)	0.25					
Minor health complaint	5.9	7.5				
Moderate health complaint	0.0	20.0				
Hip fracture	0.0	0.0				
Severe health complaint	5.9	5.0				

*Last measurement of each individual participant in one year during the period 2012-2014. †HD=Huntington's Disease. ‡Data were unavailable for 1 HD faller and 3 non-HD non-fallers. §Data were unavailable for 1 HD faller and 6 non-HD non-fallers.

Table 3
Factors associated with fear of falling and avoiding activities in logistic regression

	Fear of falling			Avoiding activities		
Variable	**O.R.**	**95% C.I.**	**p-value**	**O.R.**	**95% C.I.**	**p-value**
Group	0.15	0.03-0.78	0.02	0.21	0.05-0.98	0.05
Age†	1.00	0.96-1.03	0.86	0.97	0.94-1.01	0.13
Group*Age	0.91	0.83-0.98	0.02			
Gender	1.65	0.94-2.85	0.08	1.05	0.56-1.98	0.88
Fall history	0.91	0.47-1.79	0.79	1,00	0.46-2.14	0.99
CDS categories						
CDS overall test ‡			0.12			0.00
To a great extent dependent	1.61	0.76-3.43	0.22	3.04	1.17-7.89	0.02
Partially dependent	1.34	0.63-2.83	0.45	1.51	0.57-4.02	0.41
To a great extent independent	0.88	0.39-2.03	0.77	1.39	0.48-4.02	0.54
Completely independent	0.67	0.27-1.67	0.39	0.48	0.13-1.84	0.28

†Age centered around 60 for fear of falling. ‡Completely dependent = reference category

Changes in HD residents in a 24-month period

In the group of 30 HD residents who participated in two consecutive years, there was a significant increase in fear of falling (O.R. 14.71) in the first period, followed by a significant decrease (O.R. 0.30) in the second year period. There were no longitudinal changes either in the avoidance of activities or in fall incidence.

Discussion

This study focused specifically on HD residents; it also conducted a follow-up of 24 months including three measurements in a subgroup. The results of this study illustrate that the fall incidence in a 30-day period was significantly higher in residents with Huntington's disease (30%) than in non-HD residents (10%). In 1994, an international review reported an annual average incidence of falls of 1.5 per bed in nursing homes (17), and a Dutch study showed an average of almost 2 reported fall incidents per bed per year (18). In a two-year retrospective study in a HD nursing home, 55% of the residents experienced at least one fall (19). In an 18-month retrospective study of HD residents in US nursing homes, falls were documented for 48% of the residents (2). Due to different study methods, it is difficult to compare these findings with the results of the current study. Moreover, the first two studies were about nursing home residents in general without focusing on HD.

In contrast with fall incidence, fear of falling assessed with a single-item question was significantly lower in HD residents (14%) than in non-HD residents (30%). To our knowledge, fear of falling in HD nursing home residents has not been previously described in the literature. A review showed that for nursing home residents in general, rates for fear of falling ranging from 40% to 75% have been reported; however, many different constructs, underlying diseases, and measures were used (20). Differences in fear of falling between HD patients and patients with other diseases have been noticed before. Grimbergen et al. compared HD patients with patients with Parkinson's disease (3). Among ambulant HD patients, 15% of the fallers expressed a fear of falling, in contrast to the 53% in patients with Parkinson's disease. The low rates for fear of falling in HD patients are in line with the results of this study.

Although there was a lower rate of avoiding activities in the HD group (11% versus 18%), this difference was without statistical significance. As far as we are aware, avoiding activities have not been previously described in HD nursing home residents. For long-term care residents, a percentage of 37% was reported (21). There is evidence for an association between avoidance of feared activities on the one hand and physical performance or performance in (instrumental) activities of daily living on the other. Avoidance of activities may have negative effects on physical ability and may also be a predictor of future falls (22, 23).

In this study, there was no significant relationship between incidence of falling and either fear of falling or avoiding activities. The difference between the HD and the non-HD group with respect to fear of falling and avoiding activities did not depend on fall incidence. In residential long-term care, an association has been described between fear of falling and incidence of falls (20, 24, 25). Fear of falling was predicted by an interaction between group and age. Fewer HD residents experienced fear of falling than non-HD residents and this difference increased with age. Both group and care dependency predicted avoiding activities. Due to the mean age of onset of HD (1) it is plausible that there is an age difference between HD and non-HD residents. Age did not, however, predict fear of falling and avoiding activities. Although several studies have reported gender as a risk factor in community-dwelling elderly (6), gender did not predict fear of falling and avoiding activities in the current study. In HD residents, neither age nor gender predicted fear of falling or avoiding activities. Predictors generally considered important (e.g. age and gender) were retained in the model irrespective of their statistical significance. Possible explanations for the differences in experiencing fear of falling and consequently avoiding activities between HD and non-HD residents have been mentioned by several authors (3, 26, 27). Eddy et al. reported altered fear responses in Huntington's disease. These patients had lower fear ratings than controls for pictures and scenarios selected to elicit this emotion. They also had higher anger ratings in response to fear pictures (26). Sprengelmeyer et al. (27) found that two HD patients' self-assessment of their emotional experience, indicated a reduced fear experience. The reduced fear responses exhibited by patients with HD, possibly reflecting dysfunction of the amygdala, may result in increased risk-taking due to inadequate emotional feedback (26). Grimbergen (3) suggested that one possible explanation for the small proportion of fallers who experienced fear is the low incidence of severe injuries (low "penalty" for falling). In the present study, there was no significant difference in the distribution of severity of injury after a fall between the two groups. Previous studies in HD patients found physical injury in 20% after a fall in a nursing home and minor injuries in up to 72.5% in an ambulatory setting (3, 19, 28).

In addition, a general indifference to serious consequences, perhaps related to cognitive decline, may also underlie this absence of fear in Huntington's disease. Cognitive impairments were associated with more falls and reduced levels of fear of falling in older adults (29-31). HD patients also lack insight into several deficits, such as motor dysfunction (32, 33), which may also be a reason for reduced anxiety. Although there was a significant change in fear of falling in HD residents over 3 measurements, this change consisted of an increase followed by a decline. Cognitive decline and the severity of the decline is a possible explanation for these findings. Uemura (29, 30) and de Melo Borges (31) described an association between a lower prevalence of self-reported fear of falling with cognitive dysfunction in older adults. Participants with global cognitive impairment or dementia had the lowest prevalence of fear of falling, compared to cognitively healthy older adults and elderly with mild cognitive impairment. The latter group had the highest prevalence of fear of falling. The present study does not, however, present data on cognitive functioning in general and more specifically on insight into deficits and judgement ability to confirm this association in HD residents.

This study was an initial exploration into fear of falling

and avoiding activities in Dutch HD nursing home residents. The study had some limitations regarding type or content of the questions used. Firstly, two single-item questions were used to measure fear of falling and avoiding activities. Single-item questions have previously been used to measure fear of falling (34), but this limited the ability to discover the depth and varying levels of the construct across different situations (20). Secondly, the LPZ question about avoiding behavior was: 'Does the resident avoid physical activities?'. This question may not be directly linked to fear of falling. Avoiding activities may, therefore, have other causes, such as apathy, a common neuropsychiatric feature of HD (35). Thirdly, all questions were answered by the nursing staff and based on observations. Measures for these constructs, posing questions directly to the residents themselves, do exist, but questioning the residents may be too complex and difficult (36). Within the HD population, many subjects suffer from cognitive decline(37). Literature has demonstrated that in subjects with dementia, reporting of their actions is inaccurate when self-reporting questionnaires were used, due to cognitive decline like memory loss or impaired judgement. Cox and Vassallo, therefore, advised seeking the assistance of proxies (38). Furthermore, some items such as cooking or shopping of current fear of falling questionnaires are no longer performed by nursing home residents (39). Another limitation was the limited number of cases. Multivariable regression models showed no effect, possibly due to the subsequent lack of power. Nevertheless, this study clearly indicates that HD residents showed less fear of falling and less avoidance of activities than non-HD residents.

In future research it is important to examine whether there is an association between both cognitive decline and a low prevalence of fear of falling and avoiding activities. Also, altered fear experiences in HD patients or consequences related to a fall may be a topic for future studies. For the HD population, additional and more specific questionnaires are needed to assess fear of falling and avoiding activities. The validity of the hetero-questionnaire related to fear of falling should be further addressed in future research, because we cannot exclude completely that sometimes incorrect assessment of fear of falling has been performed, when a carer may have interpreted inappropriate or excessive risk taking by the HD resident as being a low fear of falling. However, we tried to minimize this risk by using two assessors per patient. The usefulness of fear of falling as a protective response to a realistic fall risk, and the relationship between concerns of resident and caregiver about the patient falling, are interesting additional topics.

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Ethical Standard: The LPZ study in the Netherlands has been approved by the ethical committee of the Maastricht University Medical Center.

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