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A New Scale to Measure Family Members' Perception of Community Health Care Services for Persons with Huntington Disease

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Abstract

Rationale, Aims, and Objectives—Huntington Disease (HD) is a progressive genetic brain disease leading to disruptive cognitive, behavioral, and physical impairments. Persons with the condition and their caregivers need appropriate and accessible health care services to help them manage the disease adequately. The purpose of this study was to evaluate the psychometric properties of a new scale that measures family members' perception of community health care services (CHCS) for persons with HD.

Methods—A methodological design was used to examine the initial reliability and dimensionality of the CHCS scale among 245 family members of persons with a diagnosis of HD. Data analysis consisted of computing Cronbach's alpha coefficients, calculating the 95% confidence interval for alphas, and performing item-analysis and exploratory factor analysis.

Results—Reliability of the scale based on Cronbach's alpha (α) was .83. Factor analysis using Principal Component Analysis and Varimax Rotation suggested that three interpretable factors underlie the scale. Factor 1: HD Knowledge, had α =.82, eigenvalue of 4.67, and explained 33.42% of the variance; Factor 2: HD Community Resources, had α = .62, eigenvalue of 1.68, and explained 12.02% of the variance; and, Factor 3: Individualized HD Management, had α =.77, eigenvalue of 1.45, and explained 10.39% of the variance.

Conclusions—Findings from this study provide evidence of both construct validity and internal consistency reliability of the CHCS scale. Further psychometric testing of the scale in other samples of family caregivers of persons with HD is warranted.

Keywords

Caregivers; Factor Analysis; Huntington Disease; Psychometrics; Scale Development

Introduction

HD affects approximately three to seven per 100,000 people of western European descent.1 HD is characterized by progressive loss of motor, emotional, and cognitive functions. Although historically considered a movement disorder, it is now well accepted that psychiatric disorders, cognitive dysfunction, and psychomotor impairments often precede the clinical diagnosis based on motor exam.2,3 All cases can be confirmed with a positive genetic test of the abnormal expansion of CAG repeats in the *HD* gene (*IT 15*) on the short arm of chromosome four.4 The average age of symptom onset is in the fourth decade of life, 3 and the condition is characterized by progressive degeneration over 10-25 years.5

Family members who served as support persons during predictive testing of an at-risk person often report symptoms of HD in those with the gene mutation, between the time of a positive gene test result and clinical diagnosis.6 In addition, concerns about changes in behavioral functioning are a common theme among family members whose spouses or adult children were in the pre-manifest stage of HD.7 In addition, family caregivers for persons with HD have other concerns including practical aspects of caregiving, satisfaction with life, and feelings about living with HD as being relevant to their carers' quality of life.8 Family caregivers also may be concerned about disintegration of the caregiver's life, the loss of the relationship with the person with HD, and heritability of risk for the disease among biologically related family members.9(unpubl. Observ.) When there is a family member with a chronic illness, caregiving by family involves the caregiver, the family, and their health care environments.10 Researchers have documented distress in partners of persons receiving a positive predictive HD test,11,12 and distress may reflect not only feelings of loss and grief but also thoughts regarding the future role as a caregiver.13

Family caregivers of persons with Huntington Disease (HD) are faced with increasingly stressful situations, which reflect their loved one's needs for psychological and physical care. These stressful situations have the potential for harmful effects on caregivers' health and wellbeing.14-16 Despite extensive research in caregiving, most studies have focused on family caregivers of the elderly and have not included populations in which neurodegenerative conditions such as Huntington Disease (HD) that occur earlier in the life span. Caregivers who are depressed have a higher risk for caregiver burden and acompromised belief in his/her ability to solve problems.17 Among multiple sources of emotional distress in family caregivers is the ongoing pattern of losses of personal goals and functions in the person with HD. This pattern may influence the abilities of families to proactively prepare for changes in managing the person's care and using health care services. 9(unpubl. observ.) Challenges facing family of persons with HD and those who are their primary caregivers include the availability of adequate health care services resources.17 However, existing measures do not address community health care services resources to support these family members.

Many persons with HD live in their homes or in a family member's home in the community until the family can no longer manage their care. Persons with HD and their family members need appropriate and accessible day-to-day health care services to help them cope with and manage the disease. However, no measures of family members' perception of health care services for persons with Huntington Disease were found. Thus, a new measure of Community Health Care Services (CHCS) for family of persons with HD was developed and fully described elsewhere.18(unpubl. observ.) This instrument was developed from a larger parent study whose purpose was to identify concerns of family members of persons with HD and strategies used to manage these concerns.19 The parent study used a mixed methods design in which common themes were identified from focus groups with 91 adult family members at six sites in the US and Canada, and a survey was constructed from the themes

and focus group statements.18(unpubl. observ.) The purpose of this component of the study is to evaluate the psychometrics of the Community Health Care Services scale of the Huntington Disease Family Concerns and Strategies Survey (HDFCSS).18(unpubl. observ.) The scale was evaluated for internal consistency, dimensionality, and construct validity. Establishing the validity and reliability of this instrument with the targeted study group is necessary for further research and for examining the utility of this measure to assess components of community health care services to support HD families.

Materials and Methods

Research Design

In accordance with suggestions made by Burns and Grove,20 a methodological design was used to examine the initial reliability and dimensionality of the CHCS scale among family members of persons with HD.

Sample and Setting

A purposive sample of 245 family members of persons with HD participated in this study. The sample was recruited through the Iowa HD Registry, the HD Lighthouse, The University of Iowa HD Center of Excellence, and the University of Connecticut Health Center. The inclusion criteria were adult family members of a person with HD who had the ability to read, write, and understand English. The sample size of 245 subjects was sufficient to examine the initial psychometric properties of the 14-item CHCS scale, based on recommendations of at least 5-10 subjects per item of an instrument.21¯23 The Kaiser-Meyer-Olkin results of .82, which exceeded the recommended value of .60 to proceed with exploratory factor analysis, also indicated that the sample size was adequate.24 The characteristics of the sample of family members and care recipients are shown in Table 1.

Instruments

A demographic questionnaire developed by the researchers was used to collect background information on family members (e.g., age, gender, ethnicity, educational level, marital status, and relationship with care recipient). The Community Health Care Services (CHCS) scale was used to measure family members' perceptions of the availability of adequate community resources to support health care of the person with HD. This instrument was developed by the research team, and its face and content validity are reported elsewhere. 18(unpubl. observ.) Briefly, focus groups, literature review, and examination of other instruments were used to compose the items of the scale. The scale has 14 items. Each item of the scale ranged from 0 (I do not know/not applicable) to 4 (strongly agree). Higher scores mean better agreement that each statement describes available and adequate community health care services. Nine clinical experts (health care providers or researchers with expertise in medicine, neuropsychology, management of HD, caregiving, and qualitative methodology) rated the content validity of a 7-item scale that was initially developed. Clinical experts used a four-point Likert-type scale ranging from “1 = Not Relevant” to “4 = Very Relevant” to assess the relevance of the items. Only 3 of 7 initial items of the CHCS scale achieved the minimum criteria of I-CVI ≥ 0.78.25 The CHCS overall scale (S-CVI/Ave) was .79, not exceeding the minimum recommendation of S-CVI/Ave of .90.26 As stated above, to address the scale content validity, focus groups, cognitive interviewing, literature review, and examination of other instruments were used to further revise and compose the items of the scale.

Research Protocol

The Institutional Review Boards at each institution approved the study. As described elsewhere18(unpubl. observ.) the researchers used the Dillman's method27 for mailing research instruments to family members of persons with HD. Briefly, the method included mailing an announcement with a reply form and postage paid envelope. Upon receipt of the reply form, a research package including a specific demographic questionnaire, the survey, and a detailed letter with information about the purpose, benefits, and risks involved in participating in the study, was mailed to the participants. If the research package was not returned in two weeks, a reminder letter was sent. If no response was received within three weeks, a second research package was mailed. Persons who returned the research package received a “Thank You Letter” and a $20.00 telephone card. Of 390 research packages mailed, 269 (70%) were returned. However, only 245 research packages were used in the data analysis because of missing data. These missing data were from blank questionnaires, and some persons indicated that they were the proband, rather than a family member. Data were collected from March to November, 2006. Data were entered into an Excel 2003 spread sheet and double-checked by two research team members. The raw data set was then imported into the Statistical Package of the Social Science (SPSS) 14.0 (Chicago, Illinois), which was used to conduct data screening, cleaning, coding, and the analysis.

Data Analysis

Descriptive statistics were used to characterize the sample of family member respondents (e.g., frequencies, percentages, mean, and standard deviation) as appropriate for the level of the data. Psychometric analysis of the CHCS scale consisted of computing Cronbach's alpha coefficient, the 95% confidence interval for alpha, and item-analysis (computing inter-item correlations and item-to-total correlations) to determine its internal consistency and homogeneity. Exploratory factor analysis was also conducted to establish the dimensionality and construct validity of the scale.

Results

Internal Consistency and Homogeneity

The overall estimate of reliability of the CHCS scale was Cronbach's alpha = .83 (.95 CI = . 80 - .86). This reliability estimate exceeded the minimum recommended criteria for determining internal consistency for new scales (Cronbach's alpha of at least .70).22 Deletion of any one of these items did not improve the overall Cronbach's alpha coefficient of the scale; the coefficient of reliability continued to be very close or equal to the reported Cronbach's alpha (α ranging from .81 to .83), which meets the minimum criteria for internal consistency.22 Inter-item correlations of the scale ranged from .04 to .82 (mean = .26). In addition, as shown in Table 2, all but two of the item-to-total score correlations for each factor were between $r = .30$ and $r = .70$, except for item 4 (factor 2) and item 6 (factor 1). These findings suggest the need for revision or deletion of these items to meet the necessary recommended criterion for scale homogeneity.28

Dimensionality and Construct Validity

A principal components factor analysis with varimax rotation was conducted on the CHCS scale items. This method was used to extract the minimum number of factors that explain the maximum variance of the items of the new scale. The Scree Plot (Figure 1) clearly suggested that three interpretable factors underlie the items of the scale. As seen in Table 2, factor 1: HD Knowledge had α =.82 (.95 CI = .78 - .85), eigenvalue of 4.67, and explained 33.42% of the items variance of the scale. Factor 2: HD Community Resources had α = .62 (.95 CI = .53 - .70), eigenvalue of 1.68, and explained 12.02% of the items variance of the

scale. In addition, factor 3: Individualized HD Management had α = .77 (.95 CI = .70 - .82), eigenvalue of 1.45, and explained 10.39% of the items variance of the scale. All factor loadings exceeded the minimum recommended criteria of .30.22,29 All communality values were above .30 as recommended by Tabachnick and Fidell24 except for item 6 and item 14, which had communalities of .13 and .23, respectively.

Discussion and consensus agreement among members of the research team defined the theme of each factor. Items in Factor 1 (HD Knowledge) reflect understanding of HD by health care providers and people in the community. Items in Factor 2 (HD Community resources) reflect services to support caregiving for persons with HD such as home health, day care, assisted living, and nursing homes. Factor 3 (Individualized HD Management) reflects the extent to which health care considers the person's holistic health care needs rather than being limited to symptoms associated with HD. Titles of each factor were developed after discussion and consensus agreement among the investigators.

Discussion

Community health care services are critical to support family who are primary caregivers of persons with HD or who participate in their care. This study conducted a psychometric evaluation of a scale that measures family members' perception of community health care services for persons with HD. The findings support the internal consistency of the scale. The Cronbach's alpha of .83 (0.95 CI= .80 - .86) for the total scale exceeded the recommended coefficient of internal consistency of Cronbach's alpha set at .70.22 Factor analysis suggested a three-factor structure scale, however, one of the subscales (factor 2), which has 3 items, had a Cronbach's alpha below .70. In addition, since not all item-to-total score correlations for each factor were between r = .30 and r = .70, a revision of the instrument would likely meet the recommended criterion for scale homogeneity.28 This should improve the internal consistency and homogeneity of the scale and subscales. We encourage clinicians and researchers who want to use the scale to do so, but we recommend further evaluation of the scale homogeneity and internal consistency based on their sample.

Family of persons with HD in the US may receive health care from specialists in HD care, such as those found in the Centers of Excellence supported by the Huntington Disease Society of America, and all will receive some health care services from community based health care providers. Community providers include those providing primary care, home health care, adult day care, assisted living facilities, and nursing homes. Factor analysis and prior validity testing establish the CHCS scale as a multidimensional and psychometrically sound community health care services assessment tool that incorporates three aspects of family member perceptions of health care services including provider knowledge of HD, community services, and individualized management of HD. Existing community based services may be a poor fit for the persons with HD and their families due to multiple symptoms in HD and the rarity of the condition. When services for persons with neurologic function loss exist, they may not fit the needs of young or middle-aged adults who need home based or community based health services. In addition to persons with HD, other examples are persons with severe traumatic brain injury30 and persons with brain tumors.31 If modified to reflect the specific diagnosis, this tool may identify those aspects of community based health care services that are most salient to other clinical populations.

Although socioeconomic status (SES) was not estimated in our sample, education is commonly used as a proxy for SES.32 It is notable that over 75% of our sample had completed post-secondary education, suggesting that this sample has the capacity to identify and evaluate adequate resources. In addition, in many chronic conditions, the majority of caregivers among family members are found to be female.33-35 This was true in the sample

responding to the survey, with a female/male ratio of approximately 2:1, and many of them, slightly fewer than 50%, lived in urban areas. Approximately half of the respondents identified themselves as primary caregivers. Thus, the sample represented greater diversity regarding location and responsibility, with less variability regarding SES and ethnicity. It will be important to consider the potential influence of demographic characteristics when the instrument is used in other populations.

Availability of adequate resources to support the care of persons with HD is distinct from the construct of Quality of Life (QOL). Quality of life can refer to a person's subjective experience of life and may include biological function, symptoms, functional status, and general health perception.36 For a persons with HD, QOL can be distinct from severity of illness,37 QOL for caregivers has been found to address a wider range of concepts as measured by the Quality of Life Battery for Carers (HDQoL-C) developed by Aubeeluck and Buchanan.8 Both types of scales are needed for this population.

Conclusion

Findings from this study provide evidence of the validity and reliability of the data collected from this sample using the CHCS scale to measure HD family members' perception of community health care services in the US. Although for most part, the scale has met for the most part the recommended criteria for construct validity, internal consistency, and homogeneity, further psychometric testing of the scale in other samples of family caregivers of person with HD is warranted. We believe the psychometric properties of the CHCS scale are supportive of its use in current research. However, we realize it could be improved with the addition of new items and the revision of two of the items. The scale can be useful in research and clinical practice to determine adequacy of community health care services to support family and family caregivers of persons with HD.

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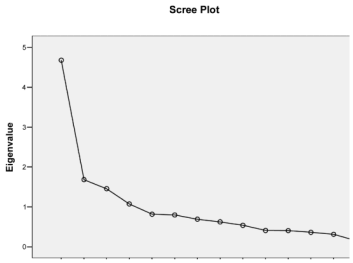

Figure 1.
CHCS's Factor Analysis Scree Plot

Table 1

Sample Characteristics (N =245)

Variable	*N*	%	*M*	*SD*
Age			45.0	14.1
Country of Residence				
United States	242	98.8		
Other	3	1.2		
Ethnicity				
Non-Hispanic White	228	93.2		
Native American	5	2.0		
Hispanic	6	2.4		
No response	6	2.4		
Gender				
Male	74	30.2		
Female	171	69.8		
Education				
Less than High School	10	4.1		
High School	47	19.2		
Associate Degree	77	31.4		
Baccalaureate Degree or Above	110	45.0		
No response	01	0.3		
Marital Status				
Single	40	16.3		
Married	159	64.9		
Widowed	06	2.6		
Divorced	18	7.3		
No response	22	8.9		
Relationship with Care Recipients				
Spouse (or Significant Other)	78	31.8		
Child	65	26.5		
Parent	31	12.7		
Sibling	34	13.9		
Other family relationship	37	15.3		
Community Area				
Metropolitan	81	34.7		
Urban	111	46.1		
Rural	39	15.9		
No response	08	3.3		
Primary caregiver				
Yes	121	49.4		
No	121	49.4		
No Response	3	1.2		

Variable	*N*	%	*M*	*SD*
Age of Care Recipients			50.8	13.3
Place Care Recipient Lives				
Caregivers' Home	93	38.0		
Care recipients' home	87	35.5		
Nursing Home	32	13.1		
Assisted Living Facility	10	4.1		
No response	20	8.1		
Health Care Services Access				
Huntington Disease Center	41	16.7		
Family Physician	46	18.8		
Neurologist	31	12.7		
Psychologist	02	.8		
Multiple Providers	114	46.3		
No response	11	4.6		

Table 2

CHCS's Item Analysis and Factor Analysis (N = 245)

Item	Factor 1	Factor 2	Factor 3	Item-to-Total Score Correlation	h^2
01. Education		.46		.35	.44
02. Health Problems			.62	.51	.72
03. Treatment Preferences			.64	.46	.69
04. Knowledge		.78		.22	.71
05. Resources	.62			.52	.39
06. Financial Benefits	.34			.28	.13
07. National Attention		.71		.31	.73
08. Quality Care	.61			.52	.39
09. Activities	.76			.65	.64
10. Available Facilities	.76			.63	.78
11. Prepared Facilities	.78			.64	.79
12. Prepared Staff	.72			.59	.67
13. Appropriate Care	.52			.43	.45
14. Discrimination	.47			.39	.23
Eigenvalue	4.67	1.68	1.45		
% Variance Explained	33.42	12.02	10.39		
Factor Cronbach's Alpha	.82	.62	.77		
Cronbach's Alpha .95 CI	.78 - .85	.53 - .70	.70 - .82		