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Using the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) for Predicting Institutionalization of Patients With Dementia in Taiwan

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Abstract: World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) is an assessment tool and it has been applied for disability status assessment of Taiwanese dementia patients since July 2012. The aim of this study was to investigate the predicting accuracy of WHODAS 2.0 for institutionalization of dementia patients.

Of these patients, 13,774 resided in a community and 4406 in a long-term care facility. Demographic data and WHODAS 2.0 standardized scores were analyzed using the Chi-square test and independent *t* test to compare patients with dementia in an institution with those in a community. The receiver operating characteristic (ROC) curve was applied to investigate accuracy in predicting institutionalization, and the optimal cutoff point was determined using the Youden index. Binary logistic regression was used to analyze variables to determine risk factors for the institutionalization of patients with dementia.

WHODAS 2.0 scores in all domains were higher in patients with dementia in a long-term care facility than in those in a community ($P < 0.01$). The ROC curve showed moderate accuracy for all domains of WHODAS 2.0 (area under curve 0.6~0.8). Binary logistic regression revealed that the male gender, severity of disease, and standardized WHODAS 2.0 scores surpassing the cutoff values were risk factors for the institutionalization of patients with dementia.

Editor: Samantha Martin.

Received: July 5, 2015; revised: October 30, 2015; accepted: October 12, 2015.

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The authors have no conflicts of interest to disclose.

This study was supported by the Ministry of Health and Welfare, Taiwan (no. 98M8178, 99M4080, 99M4073, 100M4145, 101M4100, 102M4018, and 103M03F4037).

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ISSN: 0025-7974

DOI: 10.1097/MD.0000000000002155

Although the accuracy of WHODAS 2.0 in predicting institutionalization is not considerably high for patients with dementia, our study found that the WHODAS 2.0 scores, the male gender, education status, urbanization level, and severity of disease were risk factors for institutionalization in long-term care facilities.

(*Medicine* 94(47):e2155)

Abbreviations: ADL = activities of daily living, DES-2012 = Disability Eligibility Determination Scale 2012, ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification, ICF = International Classification of Functioning, Disability, and Health, ROC = receiver operating characteristic, TDPD = Taiwan Data Bank of Persons with Disability, WHODAS 2.0 = World Health Organization Disability Assessment Schedule 2.0.

INTRODUCTION

Dementia is one of the leading causes of disability among elderly people and is a major cause of disability and mortality among older people.¹ The progressive course of dementia leads to functional state decline, therefore increasing restrictions in activities of daily living (ADL) and dependence on surrounding resources. The prevalence of dementia in elderly people (aged older than 65 years) is estimated to increase from 4.98% to 8.50% worldwide. As of 2010, 35.6 million people worldwide were diagnosed with dementia, and this number is estimated to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.² In Taiwan, the prevalence of dementia in the elderly population was 4.98% from 2011 to 2012, imposing a substantial economic burden.³

With the progressive loss of cognitive and functional abilities due to dementia, deficit in cognitive function can lead to disablement by restricting social participation and limiting daily activities, thus increasing the burden on caregivers and family members.^{4,5} Therefore, patients with dementia often require institutionalization when family members and caregivers can no longer cope with the demand of such patients. For effectively planning a care program for patients with dementia, predicting the time to institutionalization is crucial and helpful for the long-term care of patients with dementia and policy setting. A recent longitudinal study found that patients with dementia who had lower cognitive ability, lower functional ability, and more neuropsychiatric symptoms with the use of antipsychotic medication had shorter times to institutionalization.⁶ Another study indicated that marital status (being single or widowed), higher severity of cognitive impairment, and mobility impairment were predictors of nursing home placement among patients with dementia.⁷ However, to the best of our knowledge, no quantitative tool

for predicting institutionalization among elderly patients with dementia has been developed.

In 2001, the World Health Organization (WHO) developed an integrative biopsychosocial model of the International Classification of Functioning, Disability, and Health (ICF) for comprehensively evaluating functioning and disability in a patient. Furthermore, based on the ICF concept, the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) was developed for evaluating 6 domains of functioning, including social participation and cognition-related daily activities. WHODAS 2.0 can be applied to all disorders at parity for assessing the levels of function, and it exhibits rigorous validity, reliability, and cross-culture applicability in more than 30 languages.⁸ It has been applied for assessing disabilities caused by chronic diseases in elderly patients.⁹ Because it can evaluate patient performance in social participation and cognition-related functional activities, WHODAS 2.0 is a suitable quantitative assessment tool, particularly for patients with dementia.

However, only 1 study has applied WHODAS 2.0 in evaluating patients with dementia, and the study population was limited to those in long-term care facilities.¹⁰ WHODAS 2.0 data on patients with dementia in a community are lacking. Therefore, we conducted this nationwide study in Taiwan to analyze the disability status of patients with dementia in a community and long-term care facility by using WHODAS 2.0. Furthermore, we investigated the accuracy of WHODAS 2.0 in predicting the risk of institutionalization among patients with dementia.

METHODS

Participants and Data Collection

In this study, data on patients with dementia were obtained from the Taiwan Data Bank of Persons with Disability (TDPD) between July 2012 and January 2015. In Taiwan, patients with long-term disability can apply for disability evaluation and social welfare support after contracting a disease. Since July 2012, we have been developing a new disability evaluation system (Disability Eligibility Determination Scale 2012 [DES-2012]) according to the biopsychosocial model and concepts of the ICF.¹¹ Disability evaluation by using the DES-2012 was performed by 2 authorized specialists. All of these authorized specialists must receive official training for qualification. Physicians (such as neurologist, neurosurgeon, and physiatrist) who were specialists in particular diseases and impairments evaluated the body function and body structure categories of the ICF and International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) disease codes. Another authorized specialist (physical therapist, occupational therapist, speech pathologist, psychologist, or social worker) evaluated the environmental categories of the ICF and WHODAS 2.0 (translated into traditional Chinese with permission) to investigate patients' daily activity limitations and social participation restrictions. Data on disability-related diseases, namely dementia (ICD-9-CM diagnostic codes: 290.0–290.1, 294.1) and Alzheimer disease (ICD-9-CM diagnostic codes: 331.7–331.9), were collected in this study. Codes for the ICF categories of body functions and body structures, demographic data such as age, gender, and area of residence (community or institution) as well as work, education, and socioeconomic status, and WHODAS 2.0 scores were obtained from the TDPD. Only patients diagnosed with dementia and disability primarily caused by cognition-related ICF body function categories (b110 consciousness functions, b117 intellectual functions, b122

global psychosocial functions, b140 attention functions, b144 memory functions, and b164 higher-level cognitive functions) were enrolled in this study. Severity of impairment caused by dementia (severity of dementia) was determined according to the highest qualifier of b codes (1 = mild: 5–24% impairment, 2 = moderate: 25–49% impairment, 3 = severe: 50–95% impairment, 4 = extreme: 96–100% impairment). The cognitive deficit related categories classification was based on the evaluation result from clinical and objective assessment tool by physician and this classification method has been performed in Taiwan for years. To protect the privacy of patients, these data were analyzed anonymously, and patient informed consent was waived for this retrospective secondary data analysis study. This study was approved by the Joint Institutional Review Board of Taipei Medical University (Approval No. 201004001 and No. 201205042).

Measurements

The WHODAS 2.0 data were obtained by administering questionnaires to both participants and their proxies (if participants were unable to answer the questions) by trained interviewers. The questionnaire for WHODAS 2.0 is composed of the 6 following domains: cognition (Domain 1: 6 items), mobility (Domain 2: 5 items), self-care (Domain 3: 4 items), getting along with people (Domain 4: 5 items), life activities (Domain 5: 4 items for household activities and 4 items for work and school activities), and participation in society (Domain 6: 8 items) (Appendix 1). Patients with dementia or their proxies were asked to rate the difficulty of performing the activities in the questionnaire by one of the trained interviewers. The items were rated using a 5-point Likert scale (1 = no difficulty, 2 = mild difficulty, 3 = moderate difficulty, 4 = severe difficulty, 5 = extreme difficulty). When participants did not experience difficulty in the items for more than 30 days, the items were recorded as unrated. All scores ranged from 0 (least difficulty) to 100 (most difficulty) for each domain, and higher scores imply more severe disability. According to the WHODAS 2.0 manual, the formula for score computation allows for up to 30% of items to be unrated in each domain, and scores for these items can be substituted by the mean of the domain for the imputation of missing data.⁸ The sum of the standardized scores in all 6 domains was calculated for each participant. Because all participants were aged older than 65 years, we assumed that they were retired and unemployed, and of the 36 items in the questionnaire, 4 related to disability in work activities were excluded. Finally, we calculated scores for 32 items of WHODAS 2.0 in this study. The internal consistency of the translated traditional Chinese version of WHODAS 2.0 was evaluated using the Cronbach α , reliability was reported to be 0.73 to 0.99, and the intraclass correlation coefficient values were 0.8 to 0.89.^{12,13}

Statistical Analysis

Participants residing in a community or long-term care institution were classified into a community group and an institution group, respectively. Demographic data such as age (65–74, 75–85, and older than 85 years), gender, education status (above collage, senior high school, junior high school, primary education, no formal education), urbanization level (urban, suburban, and rural), and severity of dementia-related impairment (mild, moderate, severe, and extreme) are represented in numbers and percentages. Chi-square analysis was used for comparing the categorical variables of dementia-related disability between community and institution groups.

TABLE 1. Sociodemographic Characteristics of Dementia Patients in Taiwan (n = 18,180)

Variables	Community Dwelling, n = 13,774		Institution, n = 4,406		P-Value
	No.	%	No.	%	
Gender					<0.001*
Male	5278	38.32	1909	43.33	
Female	8496	61.68	2497	56.67	
Age					<0.001*
<65	1245	9.04	349	7.92	
65–75	2328	16.90	679	15.41	
75–85	5866	42.59	1698	38.54	
>85	4335	31.47	1680	38.13	
Education status					0.002*
Above college	382	2.77	90	2.04	
Senior high school	878	6.37	240	5.45	
Junior high school	887	6.44	291	6.60	
Primary education	4087	29.67	1263	28.67	
No formal education	7540	54.74	2522	57.24	
Urbanization level					<0.001*
Urban	7190	52.20	2056	46.66	
Suburban	4785	34.74	1740	39.49	
Rural	1799	13.06	610	13.84	
Severity of dementia					<0.001*
Mild	3290	23.89	256	5.81	
Moderate	5291	38.41	1071	24.31	
Severe	3809	27.65	1866	42.35	
Extreme	1384	10.05	1213	27.53	

* $P < 0.05$ by Chi-square analysis.

The independent Student *t* test was used for comparing standardized WHODAS 2.0 scores in 6 domains between community and institution groups. The receiver operating characteristic (ROC) curve for the institutionalization of patients with dementia was generated using standardized WHODAS 2.0 scores in each domain and the sum of scores in 6 domains. The optimal cutoff point on the ROC curve was determined using the Youden index for the highest sensitivity and specificity in predicting residency in a long-term care institution in patients with dementia. For determining risk factors for the institutionalization of elderly patients with dementia, WHODAS 2.0 standardized scores and variables were analyzed using binary logistic regression. Analysis was performed using SAS software (SAS Institute, Inc., Cary, NC). A *P*-value < 0.05 was considered statistically significant.

RESULTS

We examined 18,180 patients with dementia who had disability (10,993 women and 7187 men) in the TDPD. Of these patients, 13,774 (8496 women) resided in a community and 4406 (2497 women) in a long-term care institution. A statistical difference was observed more percentage of male gender ($P < 0.001$), older age ($P < 0.001$), no formal education ($P = 0.002$), suburban residency ($P < 0.001$), and severe to extreme severity of dementia ($P < 0.001$) among patients with dementia residing in a long-term care institution than those residing in a community (Table 1). Higher WHODAS 2.0 scores in all domains indicated more severe disability in patients with dementia in a long-term care institution than in those in a

community ($P < 0.01$) (Table 2). The ROC curve for predicting the institutionalization of patients with dementia revealed that all domains had statistical significance ($P < 0.01$). Moreover, using the Youden index, we defined the optimal cutoff point and accuracy of WHODAS 2.0 scores for predicting the institutionalization of patients with dementia who had disability. The data of cut-off point, sensitivity, specificity, and area under curve (AUC) of WHODAS 2.0 domains are presented in Table 3. In our study, binary logistic regression analysis revealed that scores higher than 66.5 of WHODAS 2.0 standardized scores (adjusted odds ratio [aOR] = 2.086, 95% confidence interval [CI], 1.926–2.258, $P < 0.001$), the male gender (aOR = 1.277, 95% CI, 1.183–1.377, $P < 0.001$), residence in suburban (aOR = 1.183, 95% CI, 1.094–1.281, $P < 0.001$), education status and severity of dementia were independent factors predicting institutionalization among patients with dementia (Table 4).

DISCUSSION

Dementia is the main cause of institutionalization of elderly patients.¹⁴ However, most elderly patients with dementia prefer to reside in their home as long as possible because they are more familiar with the surroundings near their home and maintain a social interaction network. Caregivers and family members may find living with patients with dementia stressful. When they can no longer cope with the burden of care for such patients at home, institutionalization is inevitable. The decision of admitting patients with dementia to a long-term care institution is complex, and the process of decision making by the

TABLE 2. Comparison of Overall Disability With Domains Among Subjects With Dementia Based on WHODAS 2.0 Scores in Taiwan (n = 18,180)

Variables	Community Dwelling, n = 13,774		Institution, n = 4406		P-Value
	Mean	SD	Mean	SD	
Domain 1	66.89	26.684	80.60	23.749	<0.001*
Domain 2	53.10	32.290	76.33	27.642	<0.001*
Domain 3	38.93	32.449	59.03	36.040	<0.001*
Domain 4	70.69	28.935	84.05	23.787	<0.001*
Domain 5	75.22	35.186	88.94	26.828	<0.001*
Domain 6	47.59	25.045	61.53	27.919	<0.001*
Total	57.78	22.700	73.87	20.779	<0.001*

Domain 1, understanding and communication; Domain 2, getting around, Domain 3, self-care, Domain 4, getting along with people, Domain 5, life activities, Domain 6, participation in society.

*Independent *t* test *P* < 0.05.

family members and caregivers is multifactorial.¹⁵ To establish an effective strategy for prolonging the duration of living at home and, thus, increasing the quality of life of patients with dementia, identifying risk factors for the institutionalization of patients with dementia is crucial. Our study found that WHODAS 2.0 standardized score, male gender, urbanization level, and severity of dementia were independent factors predicting the institutionalization of patients with dementia.

Studies have established functional impairment as a predictor of nursing home placement among patients with dementia.¹⁶ Moreover, Gaugler et al^{17,18} mentioned that ADL dependence of dementia patients can be precipitated before entry of long-term care facilities. However, the component of functional impairment is complicated, and detailed information on which part of daily activities is influenced by dementia has not been described. Hence, in this study, we used WHODAS 2.0, because it provides detailed information and is an objective quantitative tool for measuring functional impairment. Our study found that functional impairment in the mobility domain and total WHODAS 2.0 scores had better accuracy to predict the risk of institutionalization in long-term care facilities. Our study result is consistent with that of previous studies, indicating that mobility impairment can be a risk factor for nursing home placement rather than vision or hearing impairment.^{7,19}

In our study, male patients with dementia had a higher risk of institutionalization compared with female patients after adjustment for other variables. However, our study did not indicate age as an independent risk factor for the institutionalization of patients with dementia. Luppa et al reviewed the previous literature on the sociodemographic and relationship characteristics of patients with dementia and caregivers. They found advanced age and the male gender to be characteristics among patients and caregivers that were associated with a higher risk of a shorter time to nursing home placement.¹⁶ However, a recent longitudinal study found that demographic variables did not predict time to institutionalization, except that patients living alone were more likely to be institutionalized.⁶ Furthermore, another systemic review by Gaugler et al¹⁸ indicated that the male gender and age had no significant influence on institutionalization in long-term care facilities. We infer that the inconsistent findings may be attributed to differences in races and culture and other preexisting comorbidities. Furthermore, variables regarding the characteristics of caregivers and the relationship between patients and family were not recorded in our large-scale study. Further investigation is required to clarify the influence of socio-demographic variables predisposing patients with dementia to institutionalization.

TABLE 3. Predictive Accuracy of WHODAS 2.0 for Institutionalization Among Dementia Patients

Variables	Cutoff Point	Sensitivity	Specificity	AUC	95% CI		P-Value
Domain 1	77.50	0.657	0.584	0.659	0.649	0.668	<0.001*
Domain 2	78.00	0.599	0.721	0.712	0.704	0.721	<0.001*
Domain 3	55.00	0.546	0.714	0.659	0.649	0.668	<0.001*
Domain 4	96.00	0.519	0.730	0.652	0.643	0.661	<0.001*
Domain 5	95.00	0.754	0.477	0.623	0.614	0.632	<0.001*
Domain 6	60.50	0.521	0.703	0.647	0.638	0.657	<0.001*
Total	66.50	0.669	0.630	0.704	0.695	0.713	<0.001*

Domain 1, understanding and communication, Domain 2, getting around, Domain 3, self-care, Domain 4, getting along with people, Domain 5, life activities, Domain 6, participation in society, cutoff point determined by Youden Index, AUC, area under curve.

*Receiver operating characteristic (ROC) curve *P* < 0.05.

TABLE 4. Logistic Regression of WHODAS 2.0 Scores for Residence Degree of Disability and Basic Characteristics

Variables	Effect	OR (Adjusted)	95% CI		P-Value
WHODAS Score	Low (≤ 66.5) (Reference)				
	High (> 66.5)	2.086	1.926	2.258	$< 0.001^*$
Gender	Female (Reference)				
	Male	1.277	1.183	1.377	$< 0.001^*$
Age	< 65 (Reference)				
	65–75	1.040	0.885	1.221	0.636
	75–85	0.918	0.791	1.067	0.267
	> 85	1.006	0.864	1.172	0.939
Education status	Above college (Reference)				
	Senior high school	1.222	0.917	1.627	0.171
	Junior high school	1.508	1.136	2.001	0.005*
	Primary education	1.417	1.099	1.828	0.007*
	No formal education	1.415	1.100	1.820	0.007*
Urbanization level	Urban (Reference)				
	Suburban	1.183	1.094	1.281	$< 0.001^*$
	Rural	1.082	0.968	1.210	0.167
Severity of dementia	Mild (Reference)				
	Moderate	2.242	1.939	2.592	$< 0.001^*$
	Severe	4.441	3.841	5.133	$< 0.001^*$
	Extreme	7.044	6.017	8.247	$< 0.001^*$

Residence: Community Dwelling = 0, Institution = 1.

WHODAS Score Group Separate by ROC curve best cut point.

CI = confidence interval, OR = odds ratio, WHODAS = World Health Organization Disability Assessment Schedule.

* $P < 0.05$.

Severity of dementia was found to be a strong independent predictor of institutionalization in our study. Gaugler et al reviewed predictors of nursing home admission among patients with dementia. They analyzed indicators of dementia severity and consistently found that these variables had a positive predictive effect among all and high-quality studies.⁸ Our study provided evidence of an association between severity of dementia and the risk of institutionalization. When concerning the accuracy of predicting institutionalization in long-term care facilities, the WHODAS 2.0 scores of domains related to understanding and communication (Domain 1), getting along with people (Domain 4), and participation in society (Domain 6) were less accurate than mobility domain (Domain 2) and summary WHODAS 2.0 score.

It can be explained by a recent study which investigated the WHODAS 2.0 scores of institutionalized Portuguese patients with dementia, they found that despite high cognitive impairment, the participation domain (Domain 6) was the least affected.¹⁰ They hypothesized that formal caregivers mostly focus on the domains related to instrumental activities, such as mobility, self-care, and daily activities, because caregivers mainly manage the disability experienced during ADL rather than social participation among patients with dementia.¹⁰

The strength of our study is the large sample size of patients with dementia from a population-based database, who were evaluated using a well-recognized assessment tool for predicting the risk of institutionalization. Nevertheless, this

study has several limitations that must be addressed. First, variables related to the burden and stress of caregivers were not included in this study. The burden, life satisfaction, and quality of life of caregivers are associated with the risk of institutionalization in a long-term care facility. However, the burden and stress of caregivers is a multifactorial component including physical, psychological, financial, and social aspects. Thus, it is difficult to thoroughly evaluate these parameters through interviews. They should be included in our future studies. Second, our study design is cross-sectional, and longitudinal follow-up of the WHODAS 2.0 scores of patients with dementia is lacking. We can only analyze the relationship but not the causal effect. Third, this nationwide database study is limited to Taiwan. Differences in culture, race, and medical care systems among countries may influence the risk of institutionalization of patients with dementia. Finally, the bias of WHODAS 2.0 evaluation by questionnaire should be noticed. For mild severity of dementia patients, the WHODAS 2.0 scores could be underestimate if poor insight of these patients. And most patients with dementia who had cognitive impairment could not communicate with interviewers for WHODAS 2.0 evaluation. Hence, the assessment of such patients was dependent on their caregivers. As mentioned, caregivers may pay considerable attention to the domains of mobility, self-care, and daily activities rather than cognitive aspects. However, WHODAS 2.0 was used to evaluate the disability condition in the past 30 days, and this

evaluation was dependent on caregivers of patients with dementia who were unable to communicate, because only caregivers could observe their daily performance.

CONCLUSIONS

For patients with dementia, the male gender, education status, severity of disease, and WHODAS 2.0 summary score were risk factors for institutionalization in long-term care facilities. The mobility domain and summary WHODAS 2.0 scores had better accuracy for predicting institutionalization of dementia patients than those domains related to communication, social interaction, and participation. Our study used a quantitative assessment tool to determine which patients with dementia were at a high risk of institutionalization. Furthermore, our study findings can facilitate establishing an effective intervention strategy and health care service for delaying institutionalization. Longitudinal assessment of WHODAS 2.0 scores and the control variables of caregivers of patients with dementia should be performed in future studies.

ACKNOWLEDGMENT

We thank Guan-Yu Chen, Pei-Hsin Chen, and Kai-Hsiang Chuang for helping us prepare this manuscript.

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APPENDIX 1: CONTENT OF WHODAS 2.0 QUESTIONNAIRE

Domain 1: cognition

-
- D1.1 Concentrating on doing something for ten minutes?
 - D1.2 Remembering to do important things?
 - D1.3 Analyzing and finding solutions to problems in day-to-day life?
 - D1.4 Learning a new task, for example, learning how to get to a new place?
 - D1.5 Generally understanding what people say?
 - D1.6 Starting and maintaining a conversation?
-

Domain 2: mobility

-
- D2.1 Standing for long periods such as 30 minutes?
 - D2.2 Standing up from sitting down?
 - D2.3 Moving around inside their home?
 - D2.4 Getting out of their home?
 - D2.5 Walking a long distance such as a kilometer [or equivalent]?
-

Domain 3: self-care

-
- D3.1 Washing your/his or her whole body?
 - D3.2 Getting dressed?
 - D3.3 Eating?
 - D3.4 Staying by yourself/himself or herself for a few days?
-

Domain 4: getting along with people

-
- D4.1 Dealing with people you/he or she does not know?
 - D4.2 Maintaining a friendship?
 - D4.3 Getting along with people who are close to you/him or her?
 - D4.4 Making new friends?
 - D4.5 Sexual activities?
-

Domain 5: life activities

- D5.1 Taking care of your/his or her household responsibilities?
 - D5.2 Doing your/ his or her most important household tasks well?
 - D5.3 Getting all the household work done that is needed?
 - D5.4 Getting the household work done as quickly as needed?
 - D5.5 Your/his or her day-to-day work/school?
 - D5.6 Doing your/his or her most important work/school tasks well?
 - D5.7 Getting all the work done that is needed?
 - D5.8 Getting the work done as quickly as needed?
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Domain 6: participation in society

- D6.1 How much of a problem did you/your relative have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?

- D6.2 How much of a problem did you/your relative have because of barriers or hindrances in the world around him or her?
- D6.3 How much of a problem did you/your relative have living with dignity because of the attitudes and actions of others?
- D6.4 How much time did you/your relative spend on your/his or her health condition, or its consequences?
- D6.5 How much has you/your relative been emotionally affected by your/his or her health condition?
- D6.6 How much has you/his or her health been a drain on your/his or her financial resources or on the financial resources of other relatives?
- D6.7 How much of a problem did you or the rest of your/his or her family have because of your/his or her health problems?
- D6.8 How much of a problem did you/your relative have in doing things by yourself/himself or herself for relaxation or pleasure?