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The questionnaire for evaluating the quality of life of family members in neurology: Psychometric properties of the Czech version of the PNDQOL_FM

Kwestionariusz do oceny jakości życia członków rodziny w neurologii: właściwości psychometryczne czeskiej wersji PNDQOL_FM

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STRESZCZENIE

KWESTIONARIUSZ DO OCENY JAKOŚCI ŻYCIA CZŁONKÓW RODZINY W NEUROLOGII: WŁAŚCIWOŚCI PSYCHOMETRYCZNE CZESKIEJ WERSJI PNDQOL_FM

Cel pracy. Celem pracy była ocena właściwości psychometrycznych kwestionariusza do oceny jakości życia członków rodziny w neurologii (PNDQoL_FM).

Materiał i metody. Do analizy właściwości psychometrycznych kwestionariusza wykorzystano konfirmacyjną analizę czynnikową wraz z wewnętrzną spójnością skal (rzetelność), retestową rzetelność oraz analizę korelacji. Próba badana obejmowała 157 opiekunów rodzinnych pacjentów z przewlekłą chorobą neurologiczną.

Wyniki. Trafność i rzetelność kwestionariusza PNDQoL_FM uznano za zadowalające. Najlepszą zgodność modelu (TLI=0,973; CFI=0,989; GFI=0,977; SRMR=0,030; RMSEA=0,063;) stwierdzono dla modelu 2, w którym testowano cztery domeny skali funkcjonalnej (emocjonalną, społeczną, duchową), funkcjonowania i ADL. Rzetelność poszczególnych podskal również okazała się zadowalająca (α=0,735-0,923).

Wnioski. Kwestionariusz PNDQoL_FM może być stosowany zarówno w praktyce klinicznej pielęgniarek, jak i w badaniach naukowych. Ocena jakości życia opiekunów pacjentów może być wygodnym wskaźnikiem jakości świadczonej opieki.

Słowa kluczowe: jakość życia, neurologia, rzetelność, członkowie rodziny, ważność

ABSTRACT

THE QUESTIONNAIRE FOR EVALUATING THE QUALITY OF LIFE OF FAMILY MEMBERS IN NEUROLOGY: PSYCHOMETRIC PROPERTIES OF THE CZECH VERSION OF THE PNDQOL_FM

Aim. The aim of the research was to validate the Quality of Life Questionnaire for family members of patients with progressive neurological disease PNDQoL_FM.

Material and methods. To analyze the psychometric properties of the questionnaire, a confirmatory factor analysis (convergent validity of the questionnaire) was used, together with internal consistency of the scales (reliability), retest reliability, and correlation analysis. The research sample comprised of 157 family members of patients with PND.

Results. The psychometric properties of the PNDQoL_FM questionnaire were found satisfactory. The best concordance of a model and the data (CFI: 0.989; TLI: 0.973; RMSEA: 0.063; SRMR: 0.030; GFI: 0.977) was found for the model 2, where four domains of the functional scale were tested, i.e. activities of daily living, emotional functioning, social functioning, and spiritual area. The reliability of the individual subscales was also found satisfactory (Cronbach α: 0.735-0.923). The retest reliability was determined to be satisfactory for all domains as well (r>0.7).

Conclusions. The questionnaire PNDQoL_FM could be used for both research and clinical practice. The assessment of the quality of life of the PND patients' family members may be a convenient indicator of the quality of provided care.

Key words: quality of life, neurology, reliability, family members, validity

INTRODUCTION

The symptoms of the progressive neurological diseases (PND) considerably affect the mental and physical condition of the patients [1,2]. Besides the gradual reduction of physical self-sufficiency, common symptoms in advanced stage of the disease include tiredness [3], cognitive function disorders, speech disorders, or behavioral disorders [1,2]. Often the patients also suffer from depression [4,5] and anxiety. These symptoms represent a substantial burden not only for the patients themselves, but also for their family caregivers. It is the reconciliation with the loss of functional abilities related to the neurological illness (in the physical and mental areas) and the consequences of this loss, which may result in depression and reduced quality of life (QoL) of the family caregivers [6]. For the family caregivers, it is particularly difficult to reconcile with the alteration of cognitive ability of their loved ones [7].

As the disease progresses, the burden usually worsens, when the caregivers face increased worries and insecurities about the future of their family members and themselves as well. They may experience feelings of sadness, frustration, guilt, negative change of their lifestyle, limits to their social and occupational activities. These may result in a deteriorated financial situation [8], but also social isolation and chronic disease [9]. Researches also revealed that caring for one's partner or another family member with PND causes burden, psychosocial distress, and lower QoL [1,10-11]. The probability of problems with mental health is higher by approximately 20% among the informal caregivers compared to people who do not provide such care [12]. The level of the caregiver's burden is related to the duration of the care, health state of the patient, his or her increasing dependence, presence of psychiatric symptoms including behavioral disorders [13,14]. In case of cognitive functions alteration, or the development of psychiatric symptoms and behavioral disorders, the caregivers may feel like "losing" their loved one [15]. The quality of care provided to the PND patients and their family members could help both the patients as well as the family members to maintain or improve their QoL. In relation to diseases we speak about the so-called health-related quality of life (HRQL). HRQL is nowadays considered one of the most important outcome measures in many clinical studies [16]. Therefore, the World Health Organization has developed a conceptualized framework for assessing QOL as "Global concept of quality of life" that recognizes physical, emotional, social, environmental and personal domain of life [17]. Subsequently, "International Classification of Functioning, Disability and Health" (ICF model) was created to standardized the measurement of disease impacts and illness which was published in 2000. The purposes of ICF model is to provide a common language for functional and QOL data collection, which defines health as the dynamic state of complete physical, emotional and social wellbeing [18]. The ICF model covers the physical, emotional, social, environmental and personal factors. This model can be applicable for neurology patients and their family members.

In some studies, generic questionnaires were used to assess the QoL. A systematic overview of specific questionnaires evaluating the QoL of the family caregivers of patients with neurodegenerative disease was compiled by Page et al. [19]. Most questionnaires were created for the caregivers of patients with dementia [20-24], then there was a questionnaire for the family members of patients with the Huntington's disease [25,26], multiple sclerosis [27] and Parkinson's disease [28-30]. However, there is no specific questionnaire evaluating the QoL of the family caregivers caring for patients with PND in general. Monitoring the subjective view of the impact of the treatment and disease on emotional experience, ADL, social relations, and spiritual area of the family caregivers of patients with PND is highly important for the evaluation of the quality of provided care. The aim of our research is to validate the Czech version of a questionnaire for the evaluation of the QoL of family members of PND patients (validity and reliability). We also created a questionnaire to evaluate the QoL for patients with neurological diseases in the advanced stage of the disease (PNDQoL). This makes it possible to assess the QoL of patients and their families at the same time [31]. We use the ICF model, which covers the physical, emotional, social, environmental and personal factors.

METHODS

The tool was formed based on literature research, analysis of foreign tools used for the evaluation of QoL, Delphi method, and discussion of an expert group. The manual provides a description how the questionnaire for the patients was compiled [32].

The next stage of the research included the adjustment and validation of the questionnaire for the sample of family members based on the best recommendations [33]. We employed a combination of methods for the development and validation of the PNDQoL_FM. We used three phases for the development and validation the PNSQoL_FM. The first phase included the modification of the questions which was done at the expert group meeting, where two representatives of family members of PND patients were also present. The items from the PNDQoL_P questionnaire were modified for the family members (schema 1). The next stage included pilot testing of the compiled questionnaire on a sample of selected family members (n=10), and in the third phase validity and reliability of the questionnaire were evaluated.

Sample

The research sample included 157 family members who agreed on joining the project and met the following criteria: family member providing major support to the patient with PND (Parkinson's disease, multiple sclerosis, amyotrophic lateral sclerosis, atypical parkinsonism), age 18+, consent with cooperation. The selection of family members was performed under the research project of the AZV MZ ČR, no. 17-29447A. There is no shortage of recommendations regarding the appropriate sample size to use when conducting a factor analysis. Suggested minimums for sample size include from 3 to 20 times the number of variables and absolute ranges from 100 to over 1,000 [34]. Our set includes a lower criterion of 5 cases per variable.

We obtained an approval from the ethics committee of the University Hospital Ostrava (no. 486/2016). Informed consent was obtained in writing from all family members participating in the study.

The average age of the family members was 55.3 years (s=14.8; min-max: 22-85 years). The sample included more women (62%). Most often the family members were a spouse (44%), a parent (31%), and a child (12%). When analyzing the family status, most family members were married (73%), single (16%), divorced (9%), or widowed (2%). When it comes to 53%, they were employed, while 41% were retired.

Data analysis

For the analysis of the psychometric properties of the questionnaire, the confirmatory factor analysis was used, together with the evaluation of inner scale consistency (reliability), retest reliability, and correlation analysis. The confirmatory factor analysis was performed using the method of robust maximum likelihood estimation (MLR), which corrects the abnormality of item distribution. For the individual models, the following parameter values are stated: CFI – Comparative Fit Index (>0.90), TLI – Tucker-Lewis Index (>0.90), GFI – Goodness of Fit Index (≥ 90), RMSEA – Root Mean Square Error of Approximation (<0.06), and SRMR – Standardized Root Mean Square Residual (<0.05) [35-37]. The internal consistency was evaluated through Cronbach's alpha coefficient (α) (acceptable min. α > 0.70). Reliability was evaluated also via Cronbach's alpha of domains without any item, the correlation of the individual items and item-total correlation (acceptable min. r > 0.40) [16,38,39]. Stability reliability (test-retest) was determined with Spearman's correlation coefficients between the first and second responses of the scale's items (time 1 x time 2). The acceptable minimum value of the coefficient r > 0.70 [16]. The repeated measuring was performed within 5 days and a total of 40 family members took part. The correlation analysis was performed by Spearman's correlation coefficient due to the abnormal data distribution. The differences in the evaluation of individual domains between different groups (family members of patients with various types of PND) were analyzed through Kruskal-Wallis test for more than two independent samples.

RESULTS

Confirmatory factor analysis

The main aim of the confirmatory factor analysis was to test the validity of the model created together with the questionnaire. At first, we tested all domains individually, then we tested the model as a whole. All individual domains were tested as a single-factor model. Within the domains, there was confirmed a good concordance of the models and data in all domains (see Tab. 1). Despite that, the p value of the chi-square in most domains (except domains 2 and 3) is below 0.05, when we reject the hypothesis that the model accurately represents the data. This happens in case of single-factor models very often.

Through calculating in R (lavaan package), some error parts of the items were interlinked in the models. When interlinking the error items, we also based the procedure on the suggested modification table – including them would result in improved model – and on analyzing the logical links of the given items. Some item pairs have a common feature which is not measured in the basic dimension. The interconnection of their errors will make it possible to consider it.

Then, we tested the QoL model in all the domains (see Tab. 2). Model 1. includes the symptomatic scale and all 4 domains of the functional scale. In Model 2. we tested only the 4 domains of the functional scale and in model 3 we tested the domains of emotional functioning, social functioning, and spiritual functioning. The results show that the best concordance of the model and the data was found in model 2. Four domains of the functional scale were tested here – emotional functioning, social functioning, spiritual functioning, and ADL.

Tab. 1. Results of the confirmatory factor analysis of individual domains of the PNDQoL_FM questionnaire

	Symptomatic scale	**Dom 1 ADL**	**Dom 2 Ps**	**Dom 3 Soc**	**Dom 4 Dch**
Df	45	28	28	28	28
Chi-squared	656.695 p=0.007	888.303 p=0.002	827.293 p = 0.052	539.709 p=0.102	527.546 p=0.040
CFI	0.964	0.974	0.987	0.987	0.978
TLI	0.945	0.958	0.979	0.972	0.961
RMSEA (95%CI)	0.070 (0.036-0.101)	0.094 (0.055-0.133)	0.064 (0.000-0.106)	0.059 (0.000-0.108)	0.068 (0.015-0.111)
SRMR	0.044	0.037	0.041	0.053	0.045
GFI	0.938	0.938	0.952	0.968	0.958

Tab. 2. Result of the confirmatory factor analysis of the whole QoL model

	Family members		
	Model 1	**Model 2**	**Model 3**
Df	861	296	276
Chi-squared P	5187.181 p<0.001	2856.991 p<0.001	2641.537 p<0.001
CFI	0.805	0.897	0.816
TLI	0.788	0.899	0.784
RMSEA (95%CI)	0.086 (0.080-0.091)	0.067 (0.059-0.075)	0.111 (0.102-0.121)
SRMR	0.094	0.068	0.112
GFI	0.647	0.918	0.709

Reliability

The reliability of the symptomatic scale was found acceptable (α ≥ 0.7). An item which was problematic was the item of "sexual problems" (item-domain correlation r < 0.4), Tab. 3. With respect to the functional scale of the PNDQoL_FM questionnaire, the reliability was found acceptable for all domains. In the domain 4 (spiritual area),

Tab. 3. Coefficients of internal consistency of PNDQoL_FM domains

Items	p-d r	rest α	Items	p-d r	rest α	Items	p-d r	rest α
Symptoms scale			**Dom 1 – activity of daily living**			**Dom 2 – emotional functioning**		
Pain	0.547	0.851	Employment	0.523	**0.931**	Cry	0.794	0.882
Fatigue	0.636	0.842	Household care	0.826	0.905	Anger	0.582	0.901
Drowsiness	0.727	0.833	Shopping	0.697	0.916	Fear/anxiety	0.835	0.878
Palpitation	0.651	0.841	Favorite activities	0.796	0.908	Sadness	0.833	0.878
Dyspnea	0.590	0.846	Caring for oneself	0.826	0.906	Disappointment	0.764	0.886
Food intake	0.644	0.842	Health care	0.805	0.907	Helplessness	0.806	0.881
Nausea	0.731	0.839	Caring for others	0.736	0.913	Positive motions	0.320	0.918
Skin problem	0.400	0.860	Concentration	0.733	0.913	Dreams/hallucin ation	0.592	0.900
Sexual problem	**0.256**	**0.876**						
Excretion	0.625	0.844						
Domain's Cronbach α		0.861		0.923			0.904	
Dom 3 – social functioning			**Dom 4 – spiritual area**			**Dom 4 – spiritual area_rev**		
Loneliness	0.631	0.788	Worries about future	0.525	0.733	**NON-RELIGIOUS**		
Burden	0.594	0.793	Desperation	0.685	0.700	Worries about future	0.612	0.759
Worry	0.436	0.814	Meaning of life	0.685	0.715	Desperation	0.546	0.747
Relation to the patient	0.511	0.806	Control over life	0.651	0.714	Meaning of life	0.604	0.729
Physical closeness	0.587	0.794	Beauty of environment	0.603	0.724	Life goal	0.593	0.792
Emotional closeness	0.525	0.803	Composure/peace	0.710	0.705	Beauty of environment	0.531	0.751
Support	0.510	0.805	Faith/religion	**0.154**	**0.825**	Peace	0.585	0.739
Social life	0.555	0.800	Religious activities	**0.018**	**0.804**	**RELIGIOUS**		
						Faith/religion	0.684	--
						Rel. activities	0.684	--
Domain´s Cronbach α		0.821		0.768			0.813/0.735	

item 7 (faith/religion) and item 8 (religious activities) were problematic since neither of these items correlated with the given domain (Table 3). This was revealed in the confirmatory factor analysis, when in the test of the single-factor model "spiritual area" the items 7 and 8 demonstrated low burdens in comparison to other items. For this reason, we decided to split the religious and non-religious questions into two separate scales when evaluating the domain 4. This way the reliability of the domain increased. The confirmatory factor analysis of the domain 4 showed a better concordance of the model (CFI=0.989; TLI=0.973; GFI=0.977; SRMR=0.030; RMSEA=0.063. The retest reliability was found acceptable in all domains with r > 0.7. When the measuring was repeated, there was found a high level of concordance regarding the participants' responses (see Table 4). This result showed that the PNDQoL_FM had adequate stability reliability. The correlation r=0.4 – 0.7 was found among all the domains of the PNDQoL_FM questionnaire (see Tab. 5).

Evaluation of QoL in different groups of family caregivers

The family members identified fatigue as the most burdensome feature, together with sleeplessness, pain, and sexual problems. They reported greater burden in the domain of social functioning and then in spiritual religious functioning (Tab. 6). The differences between the groups, however, were not found statistically significant.

Tab. 4. Retest reliability of PNDQoL_FM

Domains		retest	P
Sympt	Symptoms burden	0.955	<0.001
Dom 1	ADL	0.841	<0.001
Dom 2	Emotional functioning	0.968	<0.001
Dom 3	Social functioning	0.941	<0.001
Dom 4a	Spiritual (nonreligious)	0.870	<0.001
Dom 4b	Spiritual (religious)	0.973	<0.001
QoL	Global QoL	0.897	<0.001
Health	Global health	0.898	<0.001

Tab. 5. Correlation of PNDQoL_FM domains

	Sympt.	Dom1	Dom2	Dom3	Dom4a	Dom4b	Health	QoL
Symptoms	1.000							
Dom 1	0.545**	1.000						
Dom 2	0.696**	0.618**	1.000					
Dom 3	0.424**	0.609**	0.538**	1.000				
Dom 4a	0.601**	0.629**	0.671**	0.680**	1.000			
Dom 4b	0.425**	0.409**	0.405**	0.479**	0.495**	1.000		
Health	-0.590**	-0.467**	-0.525**	-0.443**	-0.554**	-0.417**	1.000	
QoL	-0.552**	-0.470**	-0.567**	-0.526**	-0.590**	-0.466**	0.697**	1.000

Tab. 6. The analysis of individual domain in all groups of studied respondents

Functioning	MS	PD	ALS	Total	Kruskal-Wallis test
	mean (s)	mean (s)	mean (s)	mean (s)	p
Symptoms burden	7.3 (5.3)	10.2 (8.3)	5.2 (4.1)	8.7 (7.1)	0.197
ADL	31.3 (20.7)	33.7 (28.2)	23.1 (26.8)	31.8 (24.4)	0.663
Emotional	29.7 (20.1)	35.7 (23.9)	37.5 (24.2)	32.9 (22.3)	0.779
Social	43.6 (16.3)	43.9 (19.6)	45.0 (12.4)	44.4 (18.1)	0.936
Spiritual (nonreligious)	28.7 (15.3)	34.0 (22.5)	25.8 (21.3)	31.3 (19.7)	0.773
Spiritual (religious)	39.8 (17.6)	39.0 (17.4)	27.5 (20.5)	38.6 (15.2)	0.195
Global health	6.5 (2.1)	6.4 (2.5)	8.2 (2.4)	6.5 (2.3)	0.203
Global QoL	6.6 (2.0)	6.4 (2.4)	7.2 (1.5)	6.5 (2.2)	0.532

DISCUSSION

In research studies, the QoL has been analyzed not only with respect to patients with chronic disease but also their family members. The extensive emotional and physical burden of the family caregivers of patients with PND reduces their QoL [41]. Research revealed that an important predictor of the caregivers' lower QoL were the patient's ability to move and cognitive function disorders [7,13]. These symptoms are probable to emerge in the later stages of the disease in many patients with PND [1,2]. To evaluate the family members' QoL adequately, it is necessary to use validated tools which could be used both in research and clinical practice. The aim of this research was to evaluate the psychometric features of the questionnaire evaluating the QoL of the family members of patients with PND to be used in nursing clinical practice and research. The scale adopts a multi-angle perspective as its content is based on the family members' views, relevant literature, and opinions of professional experts [42]. Furthermore, the PNDQoL_FM questionnaire adopts a holistic approach to the assessment of the family members' QoL. Within the holistic approach, the burden caused by caring for a patient with PND is evaluated with respect to the physical area (symptoms burden), impact on the ADL, mental state, social life, and spiritual functioning. Various scales designed for the family members include only some of the areas. For the family members of patients with multiple sclerosis, the CAREQoL-MS questionnaire was created [27], which assesses the physical burden, social impact, and emotional state. The tool omits to include the spiritual aspect. Similarly created scale PDQ-Carer [28,29] for the family members of patients with Parkinson's disease focuses on the psychological and social area, as well as on the care for oneself. It does not include the effect on physical health and the spiritual area. The HDQoL-C scale [25,26] designed for the caregivers of patients with Huntington's disease focuses on the satisfaction with life, practical aspects of care giving, and feelings regarding one's life with HD. In the questionnaire designed by us, we focused more on the global QoL, thus the physical, emotional, social, as well as spiritual areas.

The psychometric features of the PNDQoL_FM questionnaire were found satisfactory. The validity of the suggested model was tested through the confirmatory factor analysis. The best concordance of the model and the data was found in model 2 (functional scale, four domains – emotional functioning, social functioning, spiritual functioning and ADL). The model includes a global evaluation of the QoL. The reliability of the individual subscales measured through Cronbach's coefficient alpha was found satisfactory. The questionnaire can be recommended for use in nursing practice

When analyzing the quality of care about patients with PND, the evaluation of the family members' support should be also included. The support of the family members provided by the neurologist and nurses starts with an adequate assessment of the needs of the family. The evaluation should focus both on determining their ability to provide adequate care for the patient and their personal wellbeing too [42], and the assessment of QoL. The QoL in certain time periods could be evaluated by the neurologist, general practitioner, or another member of the multidisciplinary team (social worker). The use of the PNDQoL_FM tool will enable the neurologist or the general practitioner to assess the QoL of PND patients' family members and to set the benchmark to monitor any improvements of the quality of care. Furthermore, in our research we analyzed the differences in the evaluation of QoL of the family members caring for patients with different types of disease. Regarding the domain of the ADL and spiritual functioning, the greatest burden was reported by the family members of Parkinson's disease patients. Regarding the domain of the emotional functioning and social functioning, the greatest burden was reported by the family caregivers of the amyotrophic lateral sclerosis patients. The research of Londral et al. [43] also found substantial burden in the domain of social functioning among the family members of patients with ALS. The domain score did not increase after using the assistive communication as was the case in other areas of QoL.

A certain limitation of this research may be the fact that the psychometric features were tested in a sample of family caregivers caring for patients with different types of progressive neurological disease. It is, however, a group of diseases with similar problems and symptoms [44]. Another limitation of the study may be the cross-sectional nature of the research. The subjective perception of family members may change. Therefore, for future research we recommend repeated monitoring of the family members and analyzing the changes in their QoL in connection to the various stages of the patient's disease. For future research we also recommend analyzing the impact of the provided interventions to the patients and their family members by a multidisciplinary team on the QoL and to compare any links between the QoL of the patients and their family members. To assess the QoL of PND patients, we recommend using the PNDQoL_P questionnaire [31]. The questions that are formulated in similar way may help compare the impact of the disease on the life of the ill person and their loved ones.

CONCLUSIONS

Considering the current lack of specific tools for the evaluation of the QoL of the family caregivers of neurological patients, the results are useful. The questionnaire may be used for both research and the clinical practice. An advantage of the similarly formulated questions for the patients and the family caregivers is the possibility to compare the subjective perception of the QoL of the patients and their loved ones. Thanks to that it, is possible to evaluate the quality of provided care throughout time.

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