

Validation of the Polish version of the Quality of the Carer-Patient Relationship (QCPR) questionnaire in a population of seniors with dementia and their caregivers

Walidacja polskiej wersji kwestionariusza Quality of the Carer-Patient Relationship (QCPR) w populacji seniorów z demencją i ich opiekunów

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Key words

relationship quality, caregiver & care recipient, seniors with dementia, occupational therapy, well-being

Abstract

Introduction: Quality of the Carer-Patient Relationship (QCPR) questionnaire is a specific scale for testing the quality of relationship between the caregiver and the care recipient.

Aims: The aim of the study was to translate, culturally adapt and validate the Polish language version of the QCPR questionnaire.

Material and methods: The study was conducted in a group of 102 people who agreed to participate in the trial. The group included 43 seniors with early and intermediate dementia and 59 carers of people with dementia. The snowball method was used in the selection of the sample. All respondents lived in the following provinces: Małopolskie and Śląskie. Respondents completed the paper version of the QCPR questionnaire once. The research was carried out in January 2020.

Results: Cronbach's alpha reliability coefficients (α) for the Polish language version was $\alpha = 0.93$, which means that a very high level of internal consistency was noted.

Conclusions: The proposed Polish language version of the Quality of the Carer-Patient Relationship (QCPR) questionnaire enables an assessment of the quality of relationships between people forming caregiving dyads. It should be noted that the analysis concerns a single-factor variant. Although the level of reliability of the predefined scales is high (warmth: $\alpha = 0.93$; criticism: $\alpha = 0.75$), the analyses show that it is a purely arbitrary, content division and the responses of the participants do not conform to the scales defined in the original version of the questionnaire.

Słowa kluczowe

jakość relacji, opiekun i biorca opieki, seniorzy z demencją, terapia zajęciowa, dobrostan

Streszczenie

Wprowadzenie: Quality of the Carer-Patient Relationship (QCPR) to specyficzna skala służąca do badania jakości relacji między opiekunem a biorcą opieki.

Cel: Celem badania było przetłumaczenie, adaptacja kulturowa i walidacja polskiej wersji językowej kwestionariusza QCPR.

Material i metody: Badanie przeprowadzono w grupie 102 osób, które zgodziły się wziąć udział w tym badaniu. Grupa obejmowała 43 seniorów z demencją we wczesnym i pośrednim stadium zaawansowania oraz 59 opiekunów osób chorujących na demencję. W doborze próby zastosowano metodę kuli śnieżnej. Wszyscy badani zamieszkiwali na terenie województw: małopolskiego i śląskiego. Respondenci wypełniali papierową wersję kwestionariusza QCPR jednokrotnie. Badania zrealizowano w styczniu 2020 roku.

The individual division of this paper was as follows: A – research work project; B – data collection; C – statistical analysis; D – data interpretation; E – manuscript compilation; F – publication search

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Wyniki: Współczynniki rzetelności Alfa Cronbacha (α) dla polskiej wersji językowej wynosił $\alpha = 0,93\alpha$, co oznacza, że odnotowano bardzo wysoki poziom zgodności wewnętrznej.

Wnioski: Zaproponowana polska wersja językowa kwestionariusza the Quality of the Carer-Patient Relationship (QCPR) umożliwia ocenę jakości relacji między osobami tworzącymi diady. Należy zaznaczyć że analiza dotyczy wariantu jednoczynnikowego. Poziom rzetelności skal wyznaczonych odgórnie jest co prawda wysoki (serdeczność: $\alpha = 0,93$; krytycyzm: $\alpha = 0,75$), niemniej analizy wskazują, że jest to podział czysto arbitralny, treściowy, a odpowiedzi badanych osób nie łączą się w skale wyróżnione w oryginalnej wersji kwestionariusza.

INTRODUCTION

The number of people suffering from some form of dementia is steadily increasing; globally, it is estimated that this number presently ranges from 40 to 50 million¹. Care for ill people poses a challenge not only for societies and their healthcare systems, but also for the carers of those people². Close family members most often become the primary caregivers of people with dementia³. This may seem to be the obvious and natural way, since it is known that among the basic functions of the family are the protective and nursing functions^{4,5}. However, very often the responsibilities this care entails exceed the competences and strength of home-based caregivers. This particularly applies to chronic diseases that are challenging even for professional carers, as in the case of dementia.

Numerous studies have demonstrated the negative impact upon carers of a household member suffering from dementia. The carers cite, for example, the lack of time for oneself, falling into social isolation, exhaustion, and a sense of helplessness. These personal costs are considered by the home caregivers to be more stressful than the financial challenges of caring⁶.

Home-based caregivers of people with dementia are vulnerable to problems of mental and physical health. For instance, studies show that 15-30% of home caregivers of people with dementia are diagnosed with depression, in comparison with 17% of respondents who are not caregivers^{7,8}. As far as physical health is considered, there is evidence that the stress and burden associated with caregiving may result in decreased immunity, hypertension and an increased risk of cardiac conditions⁹⁻¹¹.

Studies also show that people who look after a household member with

dementia more frequently experience conflicts in family life, problems in their professional life and are more often forced to give up their hobbies and rest^{12,13}.

Other studies have demonstrated that home caregivers experience grief at a sense of multiple losses, for both themselves (companionship, personal freedom and control over the situation), and for the dementia sufferer (loss of their past personality). Caregivers talk of emotions such as frustration, anger, a sense of guilt and uncertainty of the future in connection with their experiences¹⁴.

It should be stressed, on the other hand, that caregivers also note positive impacts of looking after a household member with dementia. Among others, they mention a sense of community and belonging to the family, increased self-awareness and resilience, personal and spiritual growth, and satisfaction derived from helping others¹⁵⁻¹⁸.

Caring for a senior with dementia is a dynamic process which requires various types of interactions. The quality of the relationship should therefore be taken into account, and an evaluation of the relationship should constitute the basis for taking measures supporting the mental well-being of both the senior with dementia and their caregiver¹⁹. An emphasis upon the importance of the client's/patient's well-being, and a focus upon the relational nature of interpersonal contacts both form part of the essence of occupational therapy. It is by taking into account, among others, these two factors that the occupational therapist, in accordance with the rules of his profession, initiates, guides and evaluates the therapeutic process. In the context of the validated questionnaire, it is worth emphasizing that occupational therapy gives equal attention to the situation of the care recipient and their

caregiver. These people are mutually conditioning elements of one system and, as such, the quality of the relationship between them is so important.

Despite addressing the importance of the caring relationship for seniors with dementia, Poland lacks culturally adapted questionnaires which may facilitate its assessment. The Quality of the Carer-Patient Relationship questionnaire (QCPR), discussed below, can be a useful tool for this purpose. The importance of the caring relationship for seniors with dementia, and the necessity to consider the well-being of both the caregiver and the person under care, suggest that QCPR may be used in various disciplines, occupational therapy among them.

The questionnaire evaluates the quality of relations between the informal caregiver and the care recipient, irrespective of the degree of kinship. It consists of 14 items, each of which is a statement regarding the carer – care recipient relationship. The respondents refer to each statement, evaluating it on 5-point Likert scale, where 1 represents “I totally disagree”, and 5 “I totally agree”. The total score ranges from 14 to 70. The questionnaire has sub-scales to assess two dimensions of the relationship: “warmth and affection” (positions: 1, 4, 5, 6, 7, 9, 12 and 14) and “lack of conflict and criticism” (position: 2, 3, 8, 10, 11 and 13). The questionnaire may be completed by a researcher recording a respondent's answers during a direct interview, or it can be completed by the respondent themselves.

AIM OF THE STUDY

The study aimed to develop and validate a Polish translation of the Quality of the Carer-Patient Relationship

questionnaire (QCPR). These activities were undertaken because the QCPR questionnaire has not been yet adapted for usage in Polish conditions. Also, the questionnaire is one of the instruments used in studies conducted within the research project HOMESIDE (home-based family caregiver-delivered music and reading interventions for people living with dementia: an international randomized controlled trial). This research is being carried out in five countries: Australia, Great Britain, Germany, Norway and Poland.

MATERIALS AND METHOD

The first step was to obtain permission from the creators of the questionnaire to produce and validate a Polish language version. Validation was performed according to the guidelines of ISPOR (translation and cross-cultural adaptation of patient reported outcome measures)²⁰.

Preparation of a Polish version of QCPR (attachment) began with drawing up two independent translations from the original English version of the tool. On the basis of these translations, a Polish version of the questionnaire was created which, after style and linguistic revisions, was translated into English (known as *back-translation*). The back-translation was then compared with the original version of the questionnaire by a team of experts. Having found that there were no significant differences between the two versions, the prepared Polish version of the questionnaire was qualified for further research.

The research sample included 102 people, within which were 59 dyads consisting of 59 carers and 43 seniors with dementia in early or middle stages. An imbalance between seniors with dementia and their carers results from the fact that some seniors, due to their health condition, were not able to provide answers to questions included in the questionnaire. In such circumstances the questionnaire was completed only by the carers of those people.

The study employed the non-probability sampling technique of snow-

ball sampling. The selection of this technique was dictated by the difficulties in finding members of the target population – people with dementia classified as Alzheimer's disease and their carers living in one household. Difficulties in reaching and establishing communication with this group arise from the fact that people with dementia often have reduced contact with their environment due to the typical symptoms of this disease and a tendency to self-isolate. Likewise, carers of these people, as a result of the intensity and type of care provided, often have limited opportunity to participate in wider social networks.

The inclusion criteria for the study were:

- having a medical diagnosis confirming dementia (diagnosis: Alzheimer's disease),
- dementia in early, middle or late stage,
- seniors and their care-givers residing in a common household,
- living within the Małopolskie or Śląskie regions of southern Poland.

The age of seniors with dementia participating in the study ranged between 61 and 90 years, while the age of the carers ranged between 30 and 60 years. The average age of seniors with dementia was 78 years, and of carers – 50 years. Among the surveyed seniors with dementia, women constituted 75%, and men constituted 25% of the respondents. In the group of caregivers, the vast majority were again women, 82% compared with 18% men.

Consent number 186/OIL/2019 for the research was issued on 17.09.2019 by the Bioethics Committee operating at the Regional Medical Council in Kraków.

After obtaining the results, the data were prepared and subjected to statistical analysis in the IBM software package SPSS Statistics²¹⁻²³. The analysis of results included the following activities and statistical methods: factor analysis with direct oblimin rotation, Kaiser-Meier-Olkin (KMO) test for sampling adequacy, Bartlett's test for sphericity, reliability analysis, analysis with a forced

two-factor structure, matrix structural analysis, Kolmogorov-Smirnov test and Student's *t*-test for independent samples.

RESULTS

Group of people with dementia

Factor analysis was performed in order to verify the psychometric properties of the tool. It was assumed that there are two factors. Factor analysis with direct oblimin rotation was conducted as it was assumed that the created factors are correlated. The verified KMO measure of sampling adequacy (0.83) and Bartlett's test for sphericity $\chi^2(91) = 462.52; p < 0.001$ indicated the adequacy of these data for use in factor analysis. However, a scree plot clearly showed the presence of only one main factor (Figure 1). The single factor explained as much as 55.4% of the variance whereas the second factor, although obtaining a value above 1, only accounted for 8.6% of the variance. The results are compared in Table 1.

Analysis using a forced two-factor structure was continued. However, matrix structural analysis confirmed the lack of validity of this structure. Moreover, the assignment of items to the factors was not consistent with the assumed, theoretical model (Table 2). In the tables below, symbol P along with the number assigned to it, refers to the questions included in the validated questionnaire (attachment: QCPR – Quality of relationship: carer-patient).

In the case of the one-way variant there are no clear grounds to remove any items from the questionnaire since the values of factor loadings are satisfactory (Table 3).

The reliability of the measurements was analyzed using a single-factor version of the tool, after having first recoded the questions in such a way that higher results demonstrated a higher level of total score. A very high level of internal consistency was obtained, $\alpha = 0.93$. As is shown in Table 4, the discriminatory power of all items was very high. The removal of position 11 from the questionnaire may be considered, as this item

was characterized by both the lowest discriminatory power and the lowest factor loading. However, this is not an obligatory action.

Analyses were also performed for the two predefined subscales. Although the level of reliability was high (warmth/affection: $\alpha = 0.93$;

criticism/conflict: $\alpha = 0.75$) and there are no grounds to remove any of the positions, the aforementioned analyses demonstrate that this is a purely arbitrary, content division, while the participants' responses do not conform to the defined subscales.

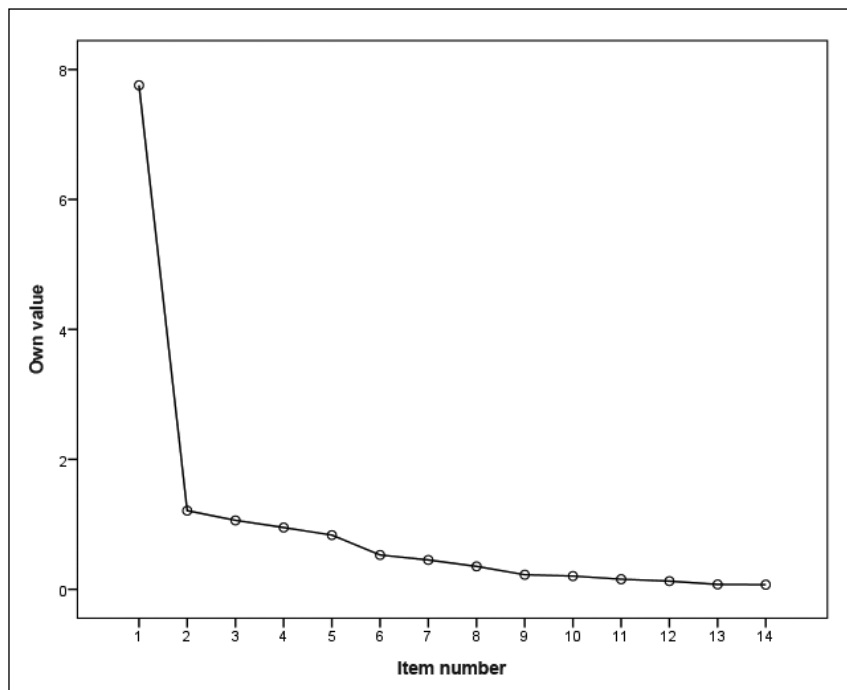


Figure 1
Scree plot

Group of caregivers

In order to verify the psychometric properties of the tool, factor analysis was performed. It was assumed that there are two factors. Factor analysis with direct oblimin rotation was conducted as it was assumed that the created factors are correlated. The verified KMO measure of sampling adequacy (0.89) and Bartlett's test for sphericity, $\chi^2(91) = 560.16$; $p < 0.001$ indicated the adequacy of the data for use in factor analysis. However, a scree plot clearly indicated the presence of only one, main factor (Figure 2). The single factor explained as much as 58.4% of the variance whereas the second factor, with a value below 1, only accounted for

Table 1

Variance explained using two factors						
	In total	% variance	% cumulative variance	In total	% variance	% cumulative variance
1	7.76	55.41	55.41	7.76	55.41	55.41
2	1.21	8.64	64.05	1.21	8.64	64.05

Table 2

Factor loadings of the two-way version of the questionnaire		
Position	Factor I	Factor II
P7	0.88	-0.63
P9	0.83	-0.47
P12	0.79	-0.60
P14	0.70	-0.66
P13	-0.69	0.57
P8	-0.68	
P11	-0.53	0.31
P2	-0.46	0.92
P4	0.59	-0.88
P3	-0.43	0.82
P1	0.70	-0.81
P5	0.73	-0.75
P6	0.71	-0.74
P10	-0.34	0.68

Table 3

Factor loadings of the one-way version of the questionnaire	
Position	Main factor
P1	0.86
P7	0.85
P5	0.84
P4	0.84
P6	0.83
P2	-0.79
P12	0.79
P14	0.77
P9	0.73
P3	-0.72
P13	-0.71
P10	-0.58
P8	-0.50
P11	-0.47

Table 4

Discriminatory power of the items for the one-way version of the questionnaire	
	Discriminatory power
P1	0.81
P2	0.75
P3	0.66
P4	0.78
P5	0.81
P6	0.79
P7	0.82
P8	0.45
P9	0.69
P10	0.52
P11	0.42
P12	0.74
P13	0.65
P14	0.73

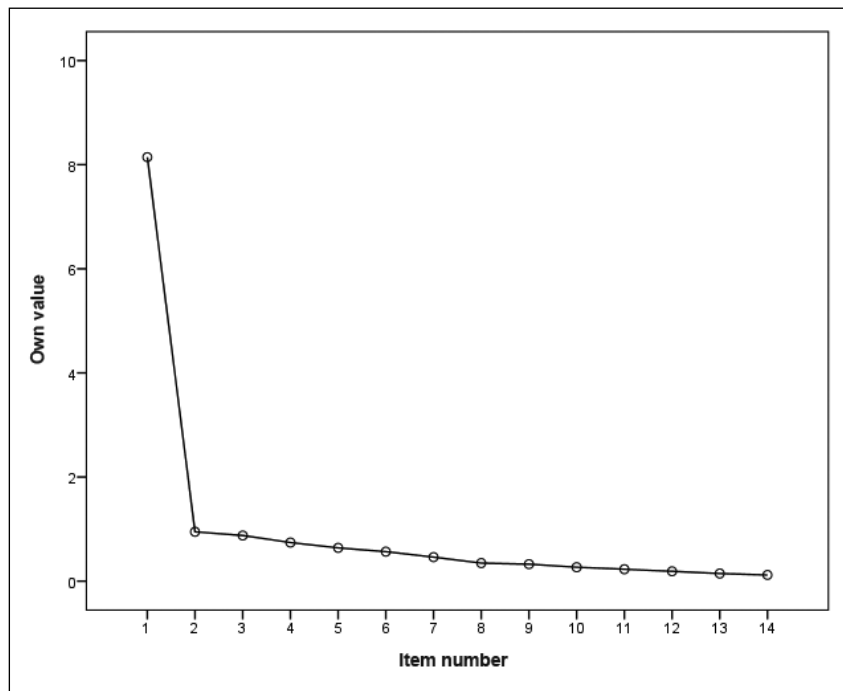


Figure 2
Scree plot

6.8% of the variance. The results are compared in Table 5.

Analysis with a forced two-factor structure was continued, however matrix structural analysis confirmed the lack of validity of this structure. Moreover, the assignment of the items to the factors was not consistent with the assumed, theoretical model (Table 6).

In the case of the one-factor variant, there are no clear grounds to remove any positions from the questionnaire since the values of factor loadings are satisfactory (Table 7).

The reliability of the measurements was analyzed using a single-factor version of the tool, after having first recoded the questions in such a way that higher result demonstrat-

ed a higher level of total score. A very high level of internal consistency was obtained, $\alpha = 0.94$. As is shown in Table 8, the discriminatory power of all items was very high.

Analyses were also performed for the two predefined scales. Although the level of reliability was high (warmth: $\alpha = 0.90$; criticism: $\alpha = 0.88$) and there are no grounds to remove any position from the questionnaire, the analyses presented earlier show this to be a purely arbitrary, content division, while the participants' responses do not conform specifically to the defined scales.

Descriptive statistics of the studied variables

In the next step, basic descriptive statistics of the tested quantitative variables were calculated, together with a Kolmogorov-Smirnov test to check the normality of distribution of those variables. As can be seen in Table 9, in the case of the warmth scale and total score in the group of people with dementia and the criticism/conflict scale in the group of carers, distributions similar to a Gaussian distribution were noted. In the case of the other variables, statistically significant results from the Kolmogorov-

Table 5

Variance explained using two factors						
	In total	% variance	% cumulative variance	In total	% variance	% cumulative variance
1	8.14	58.17	58.17	8.14	58.17	58.17
2	0.95	6.77	64.94	0.95	6.77	64.94

Table 6

Factor loadings of the two-way version of the questionnaire		
Position	Factor I	Factor II
P6	0.88	-0.54
P12	0.85	-0.75
P5	0.84	-0.60
P3	-0.83	0.48
P14	0.82	-0.69
P7	0.82	-0.73
P2	-0.77	0.52
P10	-0.68	0.65
P1	0.64	-0.56
P8	-0.62	0.87
P13	-0.55	0.86
P9	0.60	-0.86
P11	-0.67	0.76
P4	0.48	-0.49

Table 7

Factor loadings of the one-way version of the questionnaire	
Position	Main factor
P12	0.88
P7	0.85
P14	0.84
P5	0.81
P6	0.80
P8	-0.78
P9	0.77
P11	-0.77
P3	-0.75
P13	-0.74
P2	-0.73
P10	-0.73
P1	0.66
P4	0.53

Table 8

Discriminatory power of the items using the one-way version of the questionnaire	
	Discriminatory power
P1	0.60
P2	0.68
P3	0.71
P4	0.47
P5	0.76
P6	0.77
P7	0.81
P8	0.75
P9	0.73
P10	0.67
P11	0.72
P12	0.85
P13	0.69
P14	0.80

ov-Smirnov test were recorded. For these variables it is advisable to verify the level of skewness. If this value falls within the range of -2 to +2, it can be assumed that these distributions are not significantly asymmetrical against the mean. This was

found to be the case for all the variables tested. For this reason, it can be assumed that the tested distributions are not significantly different from a symmetrical distribution and it is therefore recommended to use parametric tests.

Comparing the results of people with dementia with the results of carers

Last, the results of the people with dementia were compared with the results of the carers. Student's *t*-tests

Table 9

Basic descriptive statistics of the studied quantitative variables									
	<i>M</i>	<i>Me</i>	<i>SD</i>	<i>Sk.</i>	<i>Kurt.</i>	<i>Min.</i>	<i>Maks.</i>	<i>K-S</i>	<i>P</i>
People with dementia									
Warmth	26.49	25	6.03	0.26	-0.79	16	38	0.12	0.115
Criticism (reversed)	20.00	20	3.85	-0.07	-1.40	14	27	0.15	0.012
Total score	46.49	47	9.55	0.09	-1.24	32	62	0.10	0.200
Carers									
Warmth	28.92	31	6.17	-0.30	-1.14	17	39	0.14	0.005
Criticism (reversed)	20.64	22	5.37	-0.24	-1.05	10	30	0.11	0.072
Total score	49.56	53	11.02	-0.28	-1.18	27	68	0.15	0.003

M – mean; *Me* – mediana; *SD* – standard deviation; *Sk.* – skewness; *Kurt.* – kurtosis; *Min* and *Max.* – lowest and highest value of distribution; *K-S* – result in Kolmogorov-Smirnov test; *p* – significance

Table 10

Comparison of the results of people with dementia and their carers									
	Person with dementia (n = 43)		Carer (n = 59)		<i>T</i>	<i>P</i>	95% <i>CI</i>		<i>d</i> Cohena
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			<i>LL</i>	<i>UL</i>	
Warmth	26.49	6.03	28.92	6.17	-1.98	0.050	-4.86	0.00	0.40
Criticism (reversed)	20.00	3.85	20.64	5.37	-0.71	0.482	-2.46	1.17	0.13
Total score	46.49	9.55	49.56	11.02	-1.47	0.145	-7.22	1.08	0.29

M – mean; *SD* – standard deviation; *t* – result of Student's *t*-test; *p* – statistical significance; *CI* – confidence interval; *LL* – lower limit; *UL* upper limit

for independent samples were performed. As can be seen in Table 10, one result at the level of statistical significance was recorded; in the warmth dimension, significantly higher results were recorded among the group of carers. However, the strength of recorded effect, measured with *d* Cohen coefficient, was low. In respect of the other tested variables, there were no differences recorded even at the level of a statistical trend.

DISCUSSION

The QCPR questionnaire has already been validated in many countries of the world. One such example is the validation performed by a group of Malaysian researchers²⁴. These authors stressed the importance of the relationship between the home based care-giver and the patient with dementia for the quality of informal care. Validation was completed with a conclusion that the QCPR questionnaire constitutes an important and reliable tool which enables an assessment of the quality of the relationship in dyad: carer – care-recipient.

It is worth drawing attention to the diligence with which the authors approached, among others, the matter of translation: bilingual professional linguist and blinded students of clinical psychology took part in the translation. Additionally, they consulted a multidisciplinary group of professionals that included geriatric psychiatrists, gerontologists, clinical psychologists and linguistic experts. This diligence suggests that the researchers have high hopes for the QCPR tool in the practice of informal care of seniors and see the sense and usefulness of validating the questionnaire.

Another example of the adaptation and validation of the QCPR questionnaire is the work of a Portuguese research group²⁵. In this case also, they consulted with a group of experts and completed their validation on the basis of their consensus. The hope with which the researchers view a validated and adapted QCPR tool is again evident.

In undertaking QCPR questionnaire validation the Polish researchers too were motivated by the belief that the tool will prove useful in the

Polish senior care setting, particularly when taking into consideration the currently existing shortcomings of this type of instrument for evaluating the quality of the relationship between home-based caregiver and senior with dementia.

An additional requirement which the authors of the validation of the Polish questionnaire were driven by was the intention to adapt to Polish conditions a tool which can be used in occupational therapy, a discipline currently undergoing a process of deep professionalization and rapid academisation in Poland. One of the fundamental aims of occupational therapy is the pursuit of the client's/patient's well-being. However, it should be remembered that a factor directly related with their well-being is the care relationship. Rogers, to whose concept of focusing on the client/patient occupational therapy is so strongly committed, sees the therapeutic relationship as the most significant factor in achieving changes in the process of therapy²⁶. The addressee of an occupational therapist's actions should always be not only the client/patient themselves, but also their

family system - the closest social network. Therefore, an occupational therapist needs adequate, effective tools for evaluating the relationships between people within the environment in which he works. The authors of the presented validation express their hope that the QCPR questionnaire will prove to be such a tool.

Furthermore, as previously mentioned, after completing validation the questionnaire will also be used as a tool in the HOMESIDE project.

The Polish translation was adapted for cultural specificity and verified by a group of experts. The psychometric properties of the tool were also verified by way of factor analysis. Owing to the satisfactory values of factors loadings, there were no reasons to question or remove any of the items from the questionnaire. At the same time, it should be stressed that a very high level of internal consistency was achieved. Position 11 seemed to be relatively problematic (having the lowest value of discriminatory power and the lowest factor loading), however, after an in-depth study, the authors decided to keep it (removing it does not seem necessary). Another problem to highlight is that the answers of the respondents do not conform specifically to the defined scales. Rather, the division is purely arbitrary. Nevertheless, considering the high level of reliability, the authors one more decided to keep all the positions.

CONCLUSIONS

The proposed Polish language version of the Quality of the Carer-Patient Relationship (QCPR) questionnaire enables us to assess the quality of the relationship between the people forming the care dyads. It should be noted that the analysis concerns the one factor variant. Although the reliability levels of the predefined scales are high, the analyses indicate that it is purely arbitrary, content division, and the answers of the respondents do not correspond with the scales described in the original version of the questionnaire.

Nevertheless, the Polish version of the questionnaire enables the evaluation of the quality of the relationship between a senior with dementia and their informal carer.

Thanks to this validation, it will be possible to use the Polish language version of the Quality of the Carer-Patient Relationship (QCPR) questionnaire among people struggling with dementia - both the patients themselves and their carers. The insights the tool provides may assist in identifying adequate supporting actions aimed at increasing the mental well-being of both parties and encourage in caregivers more positive emotions towards their duties. This is all the more important in the light of studies cited at the beginning, which show that home caring for people with dementia can be interpreted also in terms of the caregiver's empowerment, and not only as a crisis.

Conflict of interest

The authors declare no conflicts of interest

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