

博士論文

Development of the final version of the occupational
adaptation questionnaire for family caregivers
最終版「家族介護者の作業適応質問紙」の開発

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Doctoral Dissertation

Development of the final version of the occupational adaptation
questionnaire for family caregivers

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Abstract

Background: Given the growing role of family caregivers in meeting the increasing demand for ageing-related care in Japan, the occupational adaptation of family caregivers needs to be evaluated.

Methods: This study developed the Occupational Adaptation Questionnaire for family Caregivers (OAQC) and evaluated its reliability, validity, and effectiveness. To develop the OAQC item pool, the construct 'Occupation of nursing care engaged in by family caregivers' was evaluated. Using the Delphi method, 8 experts evaluated 64 items and confirmed that 41 items adequately represented the domain. The scale was then completed by 216 family caregivers of users of outpatient service establishments affiliated with hospitals in the Chubu region. The validity of the scale items was tested, and statistical analysis

was performed. The construct validity and internal consistency of the OAQC were examined using exploratory factor analysis and the ω coefficient, respectively.

Results: The discrimination ability and difficulty level were calculated using the item response theory. The findings showed that the scale's reliability and validity were satisfactory. Construct validity was acceptable for 16 items with 5 factors. The OAQC also had high internal consistency, reliability, and effectiveness. The item slope parameters and difficulty parameters revealed good item response, indicating that the scale could effectively measure family caregivers' occupational adaptation.

Conclusion: The scale was compatible with the data obtained from family caregivers. Given its overall effectiveness, data obtained using the OAQC can contribute towards implementing

personal care support programs for caregivers and enriching their lives by offering support from an occupational adaptation perspective.

Keyword: Occupational Adaptation Questionnaire for family Caregivers, family caregivers, ageing-related care, occupational adaptation, scale creation, caregiver support

Introduction

Ageing is an international phenomenon. Further, since developing countries are undergoing rapid social and economic development, their demand for social services is increasing (Silva et al., 2019; World Health Organization, 2017). A meta-analysis conducted as part of an international study found that 10.7% of older people suffered from frailty (Collard et al., 2012). Physical weakness is a predictor of negative health outcomes, such as increases in the risk of death, hospitalization rates, and social withdrawal, as well as a decrease in the activities of daily living (Carneiro et al., 2017). With the increase in the number of frail older people worldwide, the provision of nursing care will become a serious global issue.

Japan is facing problems that are associated with a 'super-ageing' society. It is estimated that one in three people will

become 65 or more years old by 2030 (Shigesato, 2012). Moreover, as a leading nation attempting to solve the problems associated with ageing, Japan has been responding to issues such as low fertility rates, an ageing population, and the growing old age burden for several decades (Parsons & Gilmour, 2018). Despite these efforts, Japan's population continues to age. In 2025, the country will introduce 'Community-based integrated care systems', a policy that enables home care recipients to live at home (Ministry of Health, Labour and Welfare, 2013). In this context, it is necessary to focus on family caregivers' caregiving ability. Japan is facing problems pertaining to the provision of adequate nursing care (Kimura et al., 2019). In order to improve the current situation, a social support system for family caregivers is necessary.

Occupational therapists (OTs) can support family caregivers

since they focus on human occupations and have the ability to provide support for occupational adaptation (O'Brien & Kielhofner, 2017). It is important for caregivers to have optimal occupational adaptation. To provide support for family caregivers, it is necessary to have an evaluation tool that clarifies the problems that they face. Therefore, the Occupational Adaptation Questionnaire for Family Caregivers (OAQC) was developed.

The OAQC was developed according to the Consensus-Based Standards for the Selection of Health Status Measurement Instruments (COSMIN) checklist, a health-related patient-reported outcome (Mokkink et al., 2010). COSMIN is an international standard for scale development proposed by experts in epidemiology, psychology, clinical medicine, and statistics (Mokkink et al., 2016).

COSMIN captures scale properties in terms of validity,

reliability, responsiveness, and interpretability. Therefore, this scale was developed in accordance with COSMIN.

From this construct, the study created a temporary questionnaire and verified its content validity (Nagai et al., 2020). Finally, the study verified the questionnaire's reliability and validity using the item response theory (IRT) recommended by COSMIN.

Method

Ethics statement

This study was designed in accordance with the contents of the Declaration of Helsinki. Further, the research was conducted with the approval of the Research Ethics Committee of Heisei College of Health Sciences Review Board. In this study, along with the survey form, we enclosed a letter explaining the purpose

and method and asking for informed consent. All participation was voluntary, and participants had the right to leave the study at any time without providing a reason. We regarded the return of the survey form as consent for participation. The survey form was returned anonymously in sealed submission envelopes.

Item Pool

To develop the OAQC item pool, an evaluation was performed based on the construct ‘occupation of nursing care engaged in by family caregivers’.

In order to develop such a scale, the first step is to examine the concept of composition. Although there are many evaluations of the burden of nursing care on family caregivers, no previous study has conceptualised the ‘occupation of nursing care engaged in by family caregivers’.

Therefore, the first author started by creating a concept of composition.

Unstructured interviews were conducted with 16 family caregivers who had provided at-home care for their family members for at least one month. Transcripts of the interviews were analysed using the Steps for Coding and Theorization (SCAT) method. Steps for Coding and Theorization is a method of analysis that segments word-based data, such as interview records, and devises and appends codes following the four steps described.

This analytical method describes the storyline and theory by drawing out its constitutive concepts. This method is also useful for analysing qualitative data from relatively small samples, such as a single case or a case-free description on a questionnaire (Otani, 2007). As a result, to form the constructs, 102 content

codes were identified and categorized into the following three major categories: feelings of family caregivers, caregiving life, and caregiving and environment (Nagai et al., 2020). Based on the generated concepts, we created a draft scale item.

The scale comprised 64 items. Subsequently, the Delphi method was applied to verify the scale's content validity. The Delphi method is a method in which experts judge a problem by its text. Experts are asked a number of questions individually and summarize their views until some agreement is reached. However, since the Delphi method does not have any guidelines and is performed in a variety of ways, this study was conducted by adopting Zamanzadeh's method, which clearly shows the procedures of the Delphi method (Zamanzadeh, 2015).

In this study, we selected experts who had all three of the following requirements: (1) experience in community health care,

(2) a master's degree or higher in health and welfare, and (3) experience in scale development or qualitative research. The study was conducted with the help of eight selected experts who were asked to score each item on a three-point scale of 'not necessary', 'useful but not essential', and 'not essential'. The content validity ratio varies from 1 to -1. A higher score indicates a higher level of agreement among the experts members about the need for that item.

The content validity ratio was also calculated to verify the content validity of the scale. The formula of content validity ratio is $CVR = (N_e - N/2) / (N/2)$, in which N_e is the number of experts indicating 'essential' and N is the total number of experts. All items were repeated until a CVR of 75% or more was achieved. Finally, 41 items were confirmed to appropriately represent the domain. In this study, this scale was used for field tests.

Participants

Family caregivers who had been caring for a person in need of care at home for more than one month participated in this study.

Family caregivers with significantly impaired cognitive function using medical or welfare services were removed from the sample.

The recruiting method was as follows.

Requests to research cooperation facilities

We randomly selected hospitals providing care services in the Chubu region. The hospitals that agreed to the request for participation in this study were designated as research cooperation facilities.

Selection of research participants

We requested the research cooperation facilities to distribute our questionnaire among the family caregivers of all users of the outpatient service establishments (day care service, day service, and rehabilitation) affiliated with each facility. The questionnaire was distributed in an envelope, along with a set of other documents, kept in the contact book file used by the facility's office. Family caregivers returned the completed questionnaires by post. Further, the aforementioned set of documents included a research cooperation request document, basic information (to collect age, gender, years of care, and level of care required), the OAQC, and a reply envelope.

Descriptive statistics

We summarised the types of participants, including gender, age,

years of caregiving, and the type of illness of those requiring care.

Using the collected data, the average and standard deviation (SD), ceiling effects (CE), and floor effects (FE) were calculated for each questionnaire item. Items outside the required range (1–7) were deleted. HAD Ver. 16.0 (Shimizu, 2016) was used for statistical analysis.

Item analysis

The items' validity were examined using exploratory categorical factor analysis. Accordingly, the polyserial correlation coefficient (PCC) estimates the relationship between the total score of the complete scale and each item. Further, the correlation coefficient was set to 0.4 or more, although 0.2 is often used as the reference value (Murakami, 2006). In the scale used by the current study, 0.4 was set as the standard to ensure that the number of items

was practical.

Evaluation of construct validity

The OAQC factor structure was determined using exploratory factor analysis (EFA) and the Maximum Likelihood Estimation method of Mplus Ver. 8.4 (Muthén & Muthén, 2012). The items that did not load on a factor (factor loading < 0.4) were deleted from the scale; subsequently, analysis was on the reduced item set. Further, the percentage of variance among the items accounted for by a factor was estimated using eigenvalues.

We used three indexes to assess model data fit. The first index was the root mean square error of approximation (RMSEA) (MacCallum, Browne, & Sugawara, 1996), whose critical values from 0.08 to 0.10 imply a mediocre fit and values below 0.08 indicate a good fit. Finally, the second and third indexes were the

comparative fit index (CFI) and Tucker–Lewis index (TLI), both with critical values above 0.95 (Kline, 2011).

Evaluation of internal consistency reliability

To evaluate internal consistency, we evaluated the ω coefficient, and a value of 0.7 or more was used as the reference value (Okada, 2011).

Item Response

The IRT was applied in the analysis using the maximum likelihood method provided by Exametrika (Bock & Aitkin, 1981; Kyougoku, Teraoka, Ooura, & Abe, 2015; Thomas et al., 2013).

The IRT was applied to calculate the discrimination ability and difficulty. Moreover, the IRT estimated the OAQC test response function (TRF) and test information function (TIF). According to

the IRT, an item's performance was judged according to its discriminating ability and difficulty. Whereas the discriminating ability ranged from 0.2 to 2.0, the difficulty was within an absolute value of 4.0.

Results

Sample characteristics

In this study, 216 family caregivers, including 51 men, 159 women, and 6 individuals who did not specify their gender, with an average age of 65.6 ± 12.6 years, responded to the survey. The average length of nursing was 5.54 ± 4.94 years. A person suffering from a stroke was the most common illness among those requiring care; that was followed by old age weakness and dementia, which was present in 80% of the total number of respondents (Table 1).

Item analysis

For five questionnaire items, the CE and FE were outside the specified range. Further, the PCC was less than 0.4 in 19 items.

Twenty-four of the 41 items were deleted, and 17 items were retained (Table 2). The points that were subject to deletion are shaded.

Construct validity

One item with a factor loading < 0.4 was deleted. Table 3 depicts the EFA results for 16 items. It is noted that five factors were generated from the EFA procedure: feeling for compassion (two items), balance of life (seven items), caring awareness (three items), my health (two items), and social existence value (two items).

Three indexes were used to evaluate the scale's fit. The CFI was

0.995 and TLI 0.988, and all values exceeded the critical value of 0.95. Further, the RMSEA value was 0.031. Critical values with $RMSEA < 0.08$ indicate a good fit (Table 3). The data are shaded for each factor.

Internal consistency and reliability

The ω coefficient was 0.929, which confirmed the scale's internal consistency and reliability (Table 3).

Item response

Table 4 depicts the results of item slope parameters (α) and item difficulty parameters (β). Overall, 16 items on the OAQC demonstrated satisfactory item response, with item slopes ranging from 1.049 to 1.696.

Further, Figures 1 and 2 present the OAQC's TRF and TIF

measures.

Overall, the OAQC measured an approximately equally wide range of occupational adaptation values with high precision.

Discussion

This study is novel in its development of a tool to assess the occupational adaptation of family caregivers from the professional perspective of occupational therapy. The scale has been found to be reliable and valid and can be used in clinical practice.

Psychometric properties of the OAQC

Following OAQC development, the questionnaire was evaluated from the professional viewpoint of OTs to provide caregiver support. Overall, the questionnaire's reliability and validity

were satisfactory. Several results provide evidence for the effectiveness and reliability of the OAQC (Tables 2–4). Further, construct validity, which was assessed using EFA, was acceptable for 16 items with 5 factors (Table 3). Regarding model fit information, RMSEA and CFI/TLI showed very good values. In this manner, we proved that it is compatible with the data provided by family caregivers. In addition, the value of the ω coefficient proved the questionnaire's internal consistency, and the OAQC was recognized as having high reliability.

The items' characteristics were clarified using the IRT. The OAQC score had high item slope parameters, 1.049–1.696. Moreover, difficulty parameter scores varied widely, from -1.908 to 2.353. These data strongly supported good item response of item slope parameters and difficulty parameters (Table 4). Hence, we estimated that the questionnaire can be used to measure

caregivers' occupational adaptation appropriately.

Practical implications of the study

Caregivers require help to ensure that their life is not dominated by caregiving. It is a comprehensive view of the life of one person, rather than merely the medical aspects of caring for the recipients who require care. It is very important to support caregivers from the viewpoint of occupational adaptation, as well.

The OAQC plays a significant role in supporting caregivers' occupational adaptation. Support must be provided to caregivers to overcome the problems identified by the OAQC. Aneshensel Pearlman, Mullan, Zarit, and Whitlatch (1995) clarified the importance of nursing at one's own pace through the use of social services. Based on these points, it would be preferable to provide total support for the health of family caregivers. To better

understand the situation, we used the OAQC to extract the problems of family caregivers. This assists the occupational therapist with specific support. When such support is possible, we will be closer to a society where people who need care and their family caregivers can live at home in good health for a long time.

Limitations of the study

This study has some limitations. First, we did not examine the questionnaire's retest reliability or criterion validity. Further, the study did not set any cut-off values for the OAQC. Hence, further research focusing on these limitations must be conducted in the future.

Conclusions

The OAQC is useful to evaluate the occupational adaptation of family caregivers. The study ensured construct validity and internal consistency, and item responses revealed satisfactory adaptation.

Ethics statement

The research was conducted with the approval of the Heisei Medical college Ethics Review Board (approval number H30-12).

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Declaration of Conflicting of Interests

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Table 1. Participant characteristics (n = 216).

Characteristics	Mean (SD)	Percentage
Gender		
Male	51	23.6
Female	159	73.6
Unknown	6	2.8
Age	65.6 (12.6)	
Nursing care (years)	5.54 (4.94)	
Patient age (years)	79.7 (10.01)	
Main disease		
Stroke	86	39.8
Old age weakness	47	21.7
Dementia	41	19.0
Parkinson's disease	12	5.6
Cancer	5	2.3
Orthopedic disease	5	2.3
Rheumatism	4	1.9
Spinal cord disease	3	1.4
Other	13	6.0
Family size	3.0 (1.3)	
Sleeping time (hours)	6.1 (1.3)	
Work status		
Employed		47.2
Unemployed		50.0
Other		2.8

SD, standard deviation.

Table 2. Results of analysing the 41 items of OAQC.

Items of OAQC	Mean	SD	CE	FE	PCC
1 I can feel a sense of fulfillment through nursing care.	4.2	1.5	5.70	2.72	.339
2 I am making an effort to provide better care.	3.1	1.2	4.32	1.85	.108
3 Caring for compassionate acts	3.2	1.2	4.45	1.99	.294
4 I am taking care of the care patient with a feeling of gratitude towards him or her.	3.5	1.3	4.74	2.17	.433
5 It is not a life centred on the care recipient.	4.4	3.2	7.58	1.25	.092
6 The relationship between the care recipient and family caregiver remains the same as that before nursing.	3.7	1.6	5.29	2.04	.317
7 Taking care of a recipient allows me to spend more time with my family.	3.5	1.5	5.02	1.93	.348
8 There is no complaint (anger or irritability) regarding the care recipient.	4.3	1.7	6.00	2.51	.337
9 There is no concern that the amount of care required by the care recipient will increase in the future.	4.5	1.8	6.39	2.69	.313
10 The personality of the care recipient has changed; however, there is no confusion.	4.2	1.6	5.87	2.58	.280
11 I feel the gratitude of the care recipient.	3.6	1.8	5.43	1.83	.449
12 It is normal even if there are no words of labour from the care recipient.	3.8	1.4	5.24	2.34	.447
13 I am not anxious about my future life.	4.4	1.8	6.23	2.58	.337
14 Care does not make your life lonely.	3.7	1.7	5.43	2.06	.457
15 I can walk my life even though I have been nursing care.	3.6	1.6	5.21	1.95	.627
16 It is natural for me to take care of others.	3.4	1.7	5.06	1.69	.479
17 Balance care activities and your own life (work, play, food, etc.).	4.0	1.6	5.61	2.38	.640
18 Care is done without difficulty.	3.7	1.7	5.37	2.04	.661
19 I perform activities (e.g. hobbies) that are important to me.	4.0	1.7	5.61	2.30	.524
20 I am healthy (physical, mental, and economic).	3.9	1.7	5.63	2.20	.492
21 I have not fallen ill since I began to take care of a recipient.	4.1	1.9	5.98	2.14	.452
22 I am full of energy now.	4.2	1.8	5.95	2.45	.547
23 I have sufficient sleep.	4.2	1.6	5.74	2.58	.559
24 I can manage myself, and my mind and body are in good condition.	3.9	1.6	5.52	2.32	.658
25 I maintain my motivation for activities that I consider fun.	4.2	4.6	8.83	-0.40	.562
26 I try not to provide care by myself.	3.4	1.7	5.10	1.74	.389
27 There is an environment where the mind and body can rest.	3.5	1.6	5.08	1.90	.589
28 Social roles (paid and unpaid) are fulfilled.	4.0	1.7	5.62	2.28	.422
29 I am aware of my existence value as a member of society.	3.8	1.6	5.41	2.21	.431
30 Interacting with nearby residents.	3.2	1.5	4.72	1.68	.302
31 I often leave the house.	3.4	1.6	5.02	1.78	.339
32 One option is for the care recipient to use the facility service.	2.1	1.3	3.38	0.87	-.085
33 I can emotionally support my family even from a distance.	3.1	1.6	4.74	1.47	.306
34 There are people who have similar nursing experience and can listen to my story.	3.8	1.9	5.72	1.83	.258
35 Obtain useful information from people with similar care experience	3.9	1.8	5.78	2.09	.197
36 I do not feel jealous of a person who has nothing to do with care.	4.0	1.8	5.83	2.19	.368
37 There is consideration from local resident	3.8	1.6	5.37	2.26	.298
38 I look forward to nursing and welfare services.	2.3	1.3	3.57	1.05	.102
39 The care recipient is physically and mentally supported by care and welfare services	2.0	1.1	3.05	0.93	.112
40 I am convinced about the contents and use of the care and welfare services.	2.3	1.2	3.55	1.13	.201
41 It have a good relationship with the care manager and the counselor at the facility.	2.0	1.1	3.11	0.93	.211

SD, standard deviation; CE, ceiling effect; FE, floor effect; PCC, polyserial correlation coefficient.

Table 3. Construct validity of OAQC.

OAQC 16 items $\omega = 0.929$		Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
4	Item 1 I am taking care of the care patient with a feeling of gratitude towards him or her.	0.668*	0.040	0.021	0.039	0.146
11	Item 2 I feel the gratitude of the care recipient.	0.426*	0.011	0.384*	0.076	-0.038
19	Item 3 I perform activities (e.g. hobbies) that are important to me.	-0.021	0.825*	-0.012	0.090	-0.172
17	Item 4 Balance care activities and your own life (work, play, food, etc.).	0.088	0.800*	0.119	0.020	-0.067
18	Item 5 Care is done without difficulty.	0.106	0.720*	0.181	-0.157	0.082
24	Item 6 I can manage myself, and my mind and body are in good condition.	0.085	0.683*	-0.033	0.024	0.295
23	Item 7 I have sufficient sleep.	-0.053	0.623*	-0.181	-0.029	0.322
15	Item 8 I can walk my life even though I have been nursing care.	-0.174	0.589*	0.495*	0.058	0.007
27	Item 9 There is an environment where the mind and body can rest.	-0.027	0.521*	0.008	0.211*	0.190
12	Item 10 It is normal even if there are no words of labour from the care recipient.	0.074	-0.004	0.595*	-0.071	0.142
14	Item 11 Care does not make your life lonely.	-0.011	0.014	0.587*	0.073	0.059
16	Item 12 It is natural for me to take care of others.	0.150	0.260*	0.515*	-0.105	-0.021
29	Item 13 I am aware of my existence value as a member of society.	0.003	0.027	0.051	0.871*	-0.013
28	Item 14 Social roles (paid and unpaid) are fulfilled.	0.037	0.012	-0.036	0.781*	0.105
21	Item 15 I have not fallen ill since I began to take care of a recipient.	-0.048	-0.003	0.270*	0.035	0.612*
22	Item 16 I am full of energy now.	0.064	0.212	0.042	0.308*	0.558
Geomin Factor correlation						
	Factor 1	1.000				
	Factor 2	0.461*	1.000			
	Factor 3	0.470*	0.480*	1.000		
	Factor 4	0.197*	0.574*	0.235*	1.000	
	Factor 5	0.215	0.521*	0.276	0.350*	1.000
Model fit information						
	RMSEA	0.031 [90%CI = 0.000–0.056]				
	CFI	0.995				
	TLI	0.988				

OAQC, Occupational Adaptation Questionnaire for Family Caregivers; Factor 1, feeling compassion; Factor 2, balance of life; Factor 3, caring awareness; Factor 4, my health; Factor 5, social existence value; RMSEA, root mean square error of approximation; CFI, comparative fit index; TLI, Tucker–Lewis index

*Significant at 5% level.

Table 4. Item response of OAQC.

OAQC Items	α	$\beta 1$	$\beta 2$	$\beta 3$	$\beta 4$	$\beta 5$	$\beta 6$
Factor 1							
Item 1	1.131	-1.680	-0.628	-0.052	1.022	1.411	2.353
Item 2	1.159	-1.215	-0.500	0.000	0.682	0.907	1.191
Factor 2							
Item3	1.392	-1.475	-0.805	-0.249	0.334	0.872	1.409
Item4	1.639	-1.549	-0.907	-0.224	0.309	0.838	1.475
Item5	1.616	-1.444	-0.614	0.017	0.491	0.910	1.551
Item6	1.696	-1.634	-0.761	-0.241	0.388	0.858	1.591
Item7	1.251	-1.908	-0.904	-0.367	0.148	0.818	1.406
Item8	1.645	-1.470	-0.492	-0.012	0.704	1.053	1.470
Item9	1.475	-1.373	-0.492	0.083	0.720	1.074	1.723
Factor 3							
Item 10	1.049	-1.671	-0.747	-0.345	0.612	1.207	1.671
Item 11	1.090	-1.378	-0.527	-0.224	0.514	1.019	1.409
Item 12	1.245	-1.188	-0.329	0.148	0.770	1.077	1.546
Factor 4							
Item 13	1.234	-1.582	-0.747	-0.185	0.656	0.897	1.434
Item 14	1.197	-1.661	-0.814	-0.201	0.526	0.749	1.273
Factor 5							
Item 15	1.225	-1.411	-0.491	-0.241	0.158	0.572	1.125
Item 16	1.636	-1.586	-0.852	-0.380	0.219	0.678	1.077
Information criteria							
AIC	-2014.636						
BIC	-8171.144						

OAQC, Occupational Adaptation Questionnaire for Family Caregivers; α , item slope parameters; β , Difficulty parameters; AIC, Akaike's information criterion; BIC, Bayesian information criterion.

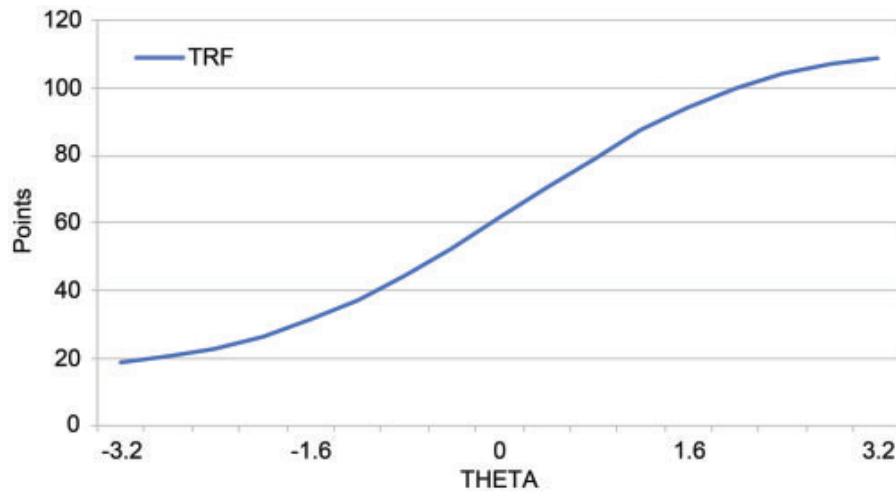


Figure 1. Test response function (TRF) of the Occupational Adaptation Questionnaire for Family Caregivers.

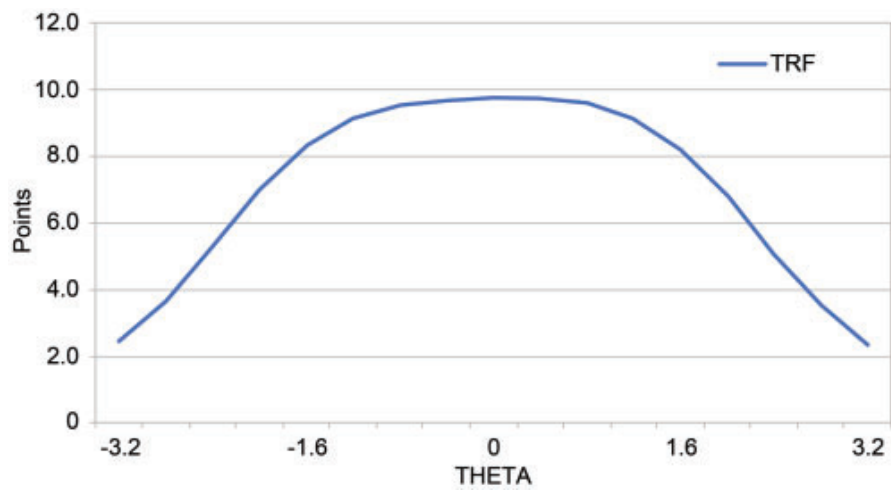


Figure 2. Variation in the test information function (TIF).