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Polish adaptation and validation of a family appraisal of caregiving questionnaire for palliative care (FACQ-PC)[1,2]

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Abstract: Increasing numbers of people are taking on the role of informal caregivers of oncology patients in the advanced stages of the disease. The outcomes of such a decision are both positive (e.g. strengthening of bonds) and negative (e.g. strain). Their assessment is necessary to customise appropriate interventions for caregivers and is made possible by the *FACQ-PC (multi-dimensional Family Appraisal of Caregiving Questionnaire for Palliative Care)* – a tool used to assess the functioning of informal caregivers of patients receiving home-based palliative care. The aim of this study was to determine the psychometric properties of the Polish adaptation of the *FACQ-PC*. The study involved 150 informal caregivers of patients receiving palliative care at home, including 106 women and 44 men aged between 22 and 77 years. Study participants completed the Polish version of the *FACQ-PC* and a series of questionnaires measuring positive and negative feelings (SUPIN), stress (PSS-10) and satisfaction with family life (SOR- H). The study did not confirm the four-factor structure of the questionnaire; instead, a three-factor structure was found to be more appropriate. The following factors were determined: negative outcomes, positive caregiving appraisals and family well-being. Based on a validation review, the high reliability of the individual scales was established, and internal relevance was confirmed. *FACQ-PC-PL* was adopted as the abbreviated name of the tool. This tool can be used in scientific research and for initial assessments conducted in a clinical setting.

Keywords: cancer, care assessment, family, informal caregiver, palliative care, well-being

Introduction

As a consequence of the advancement of knowledge about the functioning and needs of patients with advanced cancer, palliative care is increasingly becoming provided at home (Friedrichsdorf et al., 2015). Home care requires the active involvement of informal caregivers in addition to medical personnel (Adejoh et al., 2021; Salifu et al., 2021). In most cases, these are immediate family members (Haan et al., 2021; Veloso, Tripodoro, 2016). Although the assumption of caregiver responsibilities usually takes place gradually, the patient's relatives are often unprepared despite having to make crucial decisions, for example, during end-of-life patient care (Harding et al., 2012; Veloso & Tripodoro, 2016). Assuming the role of an informal caregiver, regardless of the type of illness, is associated with a range of both negative and positive outcomes (Harding et al., 2015).

One example of a negative outcome is stress. Brazil et al. (2010) found that stress is primarily caused by the symptoms experienced by patients and their needs. Informal caregivers also highlight financial issues and inadequate support provided by formal caregivers. Lower levels of stress are observed in individuals with greater confidence in looking after cancer patients (Hampton & Newcomb, 2018).

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[1] Article in polish language: https://www.stowarzyszeniefidesetratio.pl/fer/59P_Pale.pdf

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Another negative outcome is informal caregiver burden, i.e. the perception of physical symptoms, psychological distress, disrupted social relationships, spiritual distress and financial crisis as a result of caregiving tasks or the demands of the role (Choi & Seo, 2019). It is, therefore, an indicator of the degree to which the functioning of a caregiver has deteriorated as a result of caring for a cancer patient (Given et al., 2012). The literature often cites the occurrence of psychiatric symptoms as a consequence of the informal caregiver burden. These symptoms may include anxiety disorders (del-Pino-Casado et al., 2021). The informal caregiver burden is also associated with symptoms of depression and fatigue (Johansen et al., 2018; Sternberg et al., 2010). While all individuals, regardless of their gender or level of education, are at risk of such burden, spending many hours on caregiving, living with the person in need of care and depression play a particularly important role (Ahmad Zubaidi et al., 2020; Adelman et al., 2014). Other noteworthy aspects include the self-assessment of the caregiver and treatment dynamics (Thana et al., 2021).

Acting as an informal caregiver can also lead to informal caregiver burnout, which is characterised by emotional exhaustion, depersonalisation of the sick person and lack of positive experiences of personal growth (Gérain & Zech, 2019). Burnout results from various factors such as loneliness, becoming burdened with caregiving responsibilities, having limited leisure time or experiencing feelings of anxiety (Proot et al., 2003). Importantly, burnout mediates the relationship between satisfaction with care and the quality of life of informal caregivers (Blom et al., 2023).

Despite its challenges, informal caregiving may lead to positive outcomes. Li and Loke (2013) reviewed the scientific literature on the subject and found that the strongest positive aspects were: the improvement and strengthening of the quality of the informal caregiver-patient relationship, a sense of fulfilment and the perception of the role's importance in everyday life. They perceive caregiving as a method of showing affection to people considered important, which enhances the feeling of closeness. Caregivers appreciate the time spent together as they are aware that it is limited. The provision of care is also a form of expressing gratitude by the caregivers for what they received from their loved ones when they were still healthy. Caregiving reinforces a sense of personal growth and strengthens the sense of being needed. It is thanks to their role that informal caregivers often become aware of the meaning of life and change their priorities in life. Therefore, acting as a caregiver may lead to personal growth (Li et al., 2013). Leow and Chan (2017) also highlight the positive aspects of informal care. Researchers single out a sense of fulfilment, personality development and an enhanced feeling of closeness between family members.

The increasing role of home-based palliative care necessitates paying greater attention to informal carers. Research findings from around the world demonstrate that fulfilling this role is an extremely complex phenomenon that affects the lives of informal carers. On the one hand, they face challenges such as stress (Hampton & Newcomb, 2018), burden (Thana et al., 2021) or burnout (Gérain & Zech, 2019). On the other hand, this role is associated with positive outcomes, such as the deepening of bonds (Li & Loke, 2013). Few tools exist in Poland aimed at assessing the level of functioning of informal caregivers of oncology patients, especially those in palliative care (Gawlik & Kurpas, 2015). This makes the analysis of the phenomenon of informal care quite challenging and often impossible. Providing access to appropriate tools would allow screening and rapid identification of caregivers who are at risk of burnout or non-adaptive stress. This would make it possible to react to their needs in a timely manner (Molassiotis & Wang, 2022; Ochoa et al., 2020). The opportunity to analyse the positive aspects of the role would, in turn, provide a basis for identifying characteristics and conditions that can strengthen carers and facilitate the process of caregiving. Taking into account the limited number of tools necessary for the multi-dimensional assessment of the functioning of informal caregivers, this project aims to fill this gap and adapt such a questionnaire. Particularly significant is the *FACQ-PC (multi-dimensional Family Appraisal of Caregiving Questionnaire for Palliative Care; Cooper et al., 2006)*, which enables a multi-dimensional assessment of the functioning of informal caregivers of oncology patients receiving palliative care at home.

1. The original version of the questionnaire

The Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC) by Cooper et al. (2006) is a tool designed to assess the positive and negative aspects of caregiving of patients receiving home-based palliative care by informal caregivers. The researchers used Lazarus and Folkman's (1984) appraisal model and their own stress model (Kinsella et al., 2000) as the theoretical basis for the questionnaire. They explain that informal caregiving may be a source of satisfaction; however, if the caregiver perceives that the demands of caregiving outweigh their personal and social coping resources, the caregiving process may become a source of distress (Cooper et al., 2006). Therefore, they define care assessment as a primary and secondary, cognitive and affective assessment of a potential stressor and one's effectiveness in coping with it. Furthermore, researchers emphasise the increasing role of the family environment as a protective factor in the context of home-based palliative care.

Based on accepted theoretical models and taking into account research findings on the functioning of informal caregivers, Cooper et al. (2006) identified four areas that formed the basis of the scale. The caregiver strain dimension defines the perceived physical and emotional burden and the feeling of being trapped and isolated because of the responsibilities resulting from the role. The positive caregiving appraisals dimension assesses the perceived benefits or positive emotional benefits of caregiving, including commitment, confidence, development of intimacy in the caregiver-recipient relationship and satisfaction. The caregiver distress dimension comprises negative emotional reactions associated with caregiving, such as anxiety, depression and feelings of guilt. This is the average score obtained from the diagnostic questions for this subscale. The family well-being dimension includes the well-being and quality of family functioning. This is the average score obtained from the diagnostic questions for this subscale.

Based on the scientific literature and the measurement tools available in this area, the researchers (Cooper et al., 2006) generated 35 statements, which were then evaluated by five experts. This evaluation reduced the number of statements to 26. To evaluate the psychometric properties of this tool, the authors conducted a study in which 160 informal caregivers of oncology patients receiving palliative care at home completed the *FACQ-PC*. Those participating in the study rated each item of the questionnaire on a 5-point scale ranging from 1 *(strongly disagree)* to 5 *(strongly agree)*. The higher the score, the higher the respondent's position on each dimension. In addition, 56 informal caregivers completed measures of family functioning, positive and negative affect, and subjective burden. The recruitment process of the respondents was conducted with the assistance of palliative care service institutions located in the Australian state of Victoria. The care service agencies were tasked with distributing kits containing an invitation to participate in the survey, a questionnaire and a prepaid return envelope. Statistical analyses confirmed the four-factor structure of the scale. Having assessed the caregiver distress subscale, one statement was removed due to its poor correlation with the other items. The *FACQ-PC* has good reliability parameters (Cronbach's alpha coefficient for the caregiver strain subscale consisting of 8 statements is .86; for the positive caregiving appraisals subscale consisting of 7 statements: 0.73; for the caregiver distress subscale consisting of 4 statements: 0.75; for the family well-being subscale consisting of 6 statements: 0.84 (Cooper et al., 2006). The range of scores for the positive caregiving appraisals scale varies between 7 and 35; for the caregiver distress scale: between 4 and 20; for the family well-being scale: between 6 and 30; for the caregiver strain scale: between 8 and 40. Scores of the caregiver strain and caregiver distress subscales correlated positively with measures of subjective burden and negative affect and negatively with measures of positive affect and family functioning. The score of the positive caregiving appraisals subscale correlated positively with measures of positive affect and family functioning and negatively with measures of negative affect. The family well-being dimension correlated positively with the family functioning measure and negatively with the measure of negative affect.

2. Method

2.1. Objectives and assumptions

The objective of this study was the preliminary adaptation of an Australian questionnaire developed to measure the positive and negative aspects of the role of the informal caregiver of oncology patients receiving home-based palliative care (Family Appraisal of Caregiving Questionnaire for Palliative Care; FACQ-PC) into Polish (Cooper et al., 2006). Taking into consideration the results of the validation review of the original questionnaire, the project was expected to confirm the four-factor structure. It was also expected to confirm the reliability of the tool using Cronbach's alpha coefficient and internal relevance, evaluated through a series of correlations. It was assumed that there would be a positive correlation between caregiver strain and negative feelings; between positive caregiving appraisals and positive feelings; between caregiver distress and stress; between family well-being and satisfaction with family life.

2.2. Participants

The study comprised 150 informal caregivers (44 men and 106 women) between 22 and 77 years old *(M* = 48.7; *SD* = 14.6) of oncology patients receiving palliative care at home who had been in this role for at least two weeks. Study participants cared for their mother (34 people), father (31 people), husband (27 people), wife (17 people), grandmother (9 people), grandfather (7 people), son (7 people), daughter (7 people), mother-in-law (4 people), cousin (3 people), sister (3 people) and brother (1 person). As many as 49 informal caregivers declared that they do not live with the care recipient. The voluntary assumption of the informal caregiver role was indicated by 146 people, while 4 respondents cited having no other choice. Informal caregivers were recruited with the assistance of psychologists working in home hospices in different cities (e.g. Kraków, Siedlce, Katowice, Świdnica, or Pleszew). Participation in the study was voluntary and anonymous, and each participant received an Empik store voucher worth PLN 25 as a thank-you for taking part.

Care recipients included 68 men and 82 women, who were between 5 and 96 years old (*M* = 64.5; *SD* = 18.3). All individuals were under the care of a home hospice.

2.3. Measured variables

The study used the Polish version of the *FACQ-PC (Kwestionariusz oceny opieki nad bliską opieką; FACQ-PC-PL)* and three questionnaires measuring constructs potentially related to positive and negative aspects of the role of the informal caregiver of oncology patients receiving palliative care at home. They were used to measure the following variables:

- Negative feelings: the sum of the scores obtained from the diagnostic terms for this subscale (e.g. *nervous* in *Skala Uczuć Pozytywnych i Negatywnych – SUPIN* (Brzozowski, 2010), which is the Polish adaptation of the Positive and Negative Affect Schedule – PANAS (Watson et al., 1988). Study participants responded to 10 statements on a scale from 1 (*very slightly or not at all*) to 5 (*extremely*). The range of scores for this scale is between 10 and 50. The higher the score, the stronger the negative feelings in the respondent. The reliability index for this subscale was 0.92.
- Positive feelings: the sum of the scores obtained from the diagnostic terms for this subscale (e.g. *jittery* in *Skala Uczuć Pozytywnych i Negatywnych – SUPIN* (Brzozowski, 2010), which is the Polish adaptation of the Positive and Negative Affect Schedule – PANAS (Watson et al., 1988). Study participants responded to 10 statements on a scale from 1 (*very slightly or not at all*) to 5 (*extremely*). The range of scores for this scale is between 10 and 50. The higher the score, the stronger the negative feelings of the respondent. The reliability index for this subscale was 0.9.
- Stress: the sum of the scores obtained in *Skala Odczuwalnego Stresu PSS-10* (Juczyński, Ogińska-Bulik, 2009), which is the Polish adaptation of the Perceived Stress Scale – PSS (Cohen et al., 1983). Study participants answered 10 questions (e.g. *In the last month, how often have you been able to control irritations in your life?*) on a scale

from 0 *(never)* to 4 *(very often)*. The range of scores for this scale is between 0 and 40. The higher the score, the stronger the stress of the respondent. The reliability index for this subscale was 0.85.

- Satisfaction with family life: the sum of the scores obtained from the diagnostic questions for this subscale (subscale H; e.g. *How satisfied are you with the way problems are discussed?*) in *Skala Oceny Rodziny – SOR* (Margasinski, 2013), which is a Polish adaptation of the Flexibility and Cohesion Evaluation Scales – FACES-IV (Olson, 2011). Study participants responded to 10 statements on a scale from 1 (*extremely dissatisfied*) to 5 (*extremely satisfied*). The range of scores for this scale is between 10 and 50. The higher the score, the greater the respondent's satisfaction with family life. The reliability index for this subscale was 0.9.

3. Procedure

3.1. Adaptation of the questionnaire

To begin with, consent was obtained from the author of the original FACQ-PC questionnaire to create its Polish adaptation. The first research stage was a procedure for translating the questionnaire together with establishing the equivalence of the two language versions. In the first step, all 25 items were translated from English to Polish. In the course of the next stage, a competent judge – a psychologist with experience in working with oncology patients in palliative care and their families, as well as in conducting scientific research – evaluated the translation for factual errors and clarity. Any changes put forward were introduced to the questionnaire. In the next step, the text was back translated into English and presented to the author of the original questionnaire. After several additional aspects were clarified, the final version was agreed.

3.2. The study proper

At the start, study participants signed a consent to participate in the study and a GDPR form. They then completed a form with their personal details. In the final step, they filled in the individual tools: the Family Appraisal of Caregiving Questionnaire, the Perceived Stress Scale – PSS-10, the Positive and Negative Affect Schedule – SUPIN, and Flexibility and Cohesion Evaluation Scales – SOR. The procedure was completed with the respondents receiving an Empik store voucher, having signed an appropriate form. The project was carried out between January and October 2023. The study was approved by the Ethics Committee of the Institute of Psychology at Kraków's University of the National Education Commission.

4. Results

Statistical analyses were performed using IBM SPSS Statistics (version 29) and JASP (version 0.18.1) programs.

4.1. Confirmatory factor analysis

As the first step in the analysis, a confirmatory factor analysis (CFA) was performed in JASP (version 0.18.1) to confirm the four-factor structure of the Family Appraisal of Caregiving Questionnaire.

The goodness-of-fit results obtained do not confirm the original structure of the tool. The RMSEA (root mean square error of approximation) value was RMSEA = 0.096, which is above the acceptable value of 0.08, indicating a high approximation error. An unsatisfactory fit is also indicated by a goodness-of-fit index value of CFI = 0.776 (which should be greater than 0.9). The test result was also statistically significant $\chi2(269) = 639.69$; $p < 0.001$, indicating a discrepancy between the observed covariance matrix and that implied by the model. The results are presented in the figure below (Fig. 1).

4.2. Exploratory factor analysis

As the original structure of the questionnaire could not be reproduced, an exploratory factor analysis (EFA) based on the maximum likelihood (ML) method was performed to create a new structure. Promax oblique rotation was used to isolate the factors. The JASP program (version 0.18.1) was used once again.

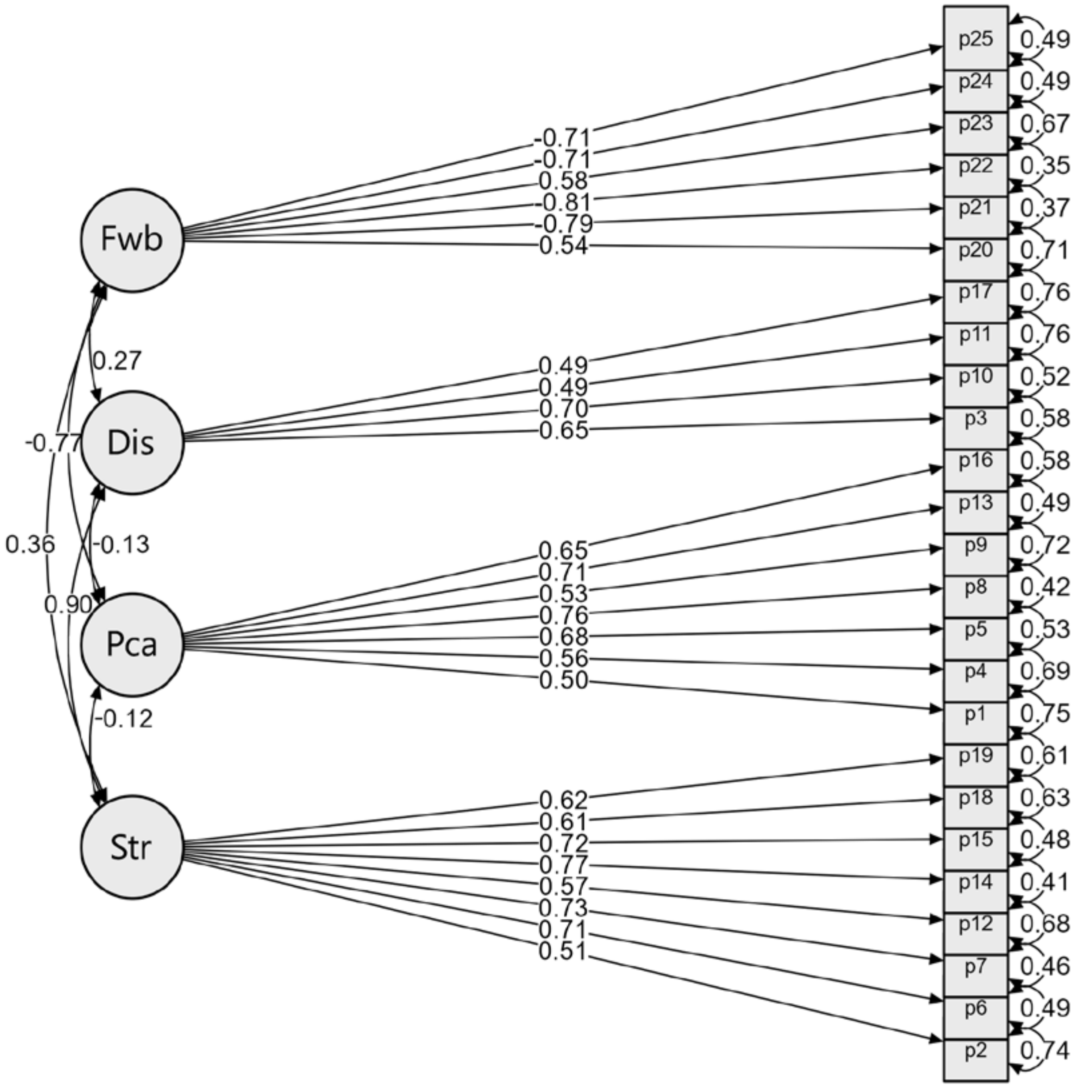

Figure 1. Results of exploratory factor analysis

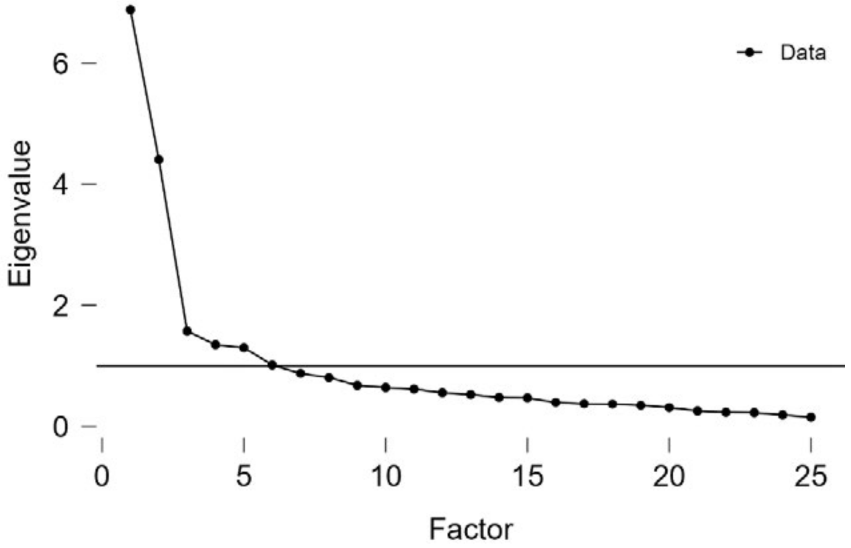

Figure 2. Screen plot showing eigenvalues for each component; based on this, it was decided to adopt a three-factor structure for the tool

To begin with, an analysis based on the criterion of an eigenvalue greater than 1 was performed. It allowed five factors to be identified, which together explained 52.3% of the variance. This structure was different from the original four-factor structure; in addition, two factors contained only one test item each (factor 4 – item 1; factor 5 – item 17). As a result, the criterion for selecting the number of factors was amended. A scree plot was analysed (Figure 1), based on which it was decided to isolate three factors.

The analysis was repeated, setting a preset number of three factors. The resulting structure appeared to explain 45.0% of the variance. This version of the questionnaire included 22 of the 25 test items. Items 1 and 9 from the *Positive caregiving appraisals* scale and item 11 from the *Distress* scale were excluded due to excessively low factor loadings (below 0.4).

The resulting configuration was then compared with the structure of the original version of the questionnaire. The result of this comparison, together with the factor loadings for each scale, is presented in Table 1

Table 1. Results of the exploratory factor analysis for the family appraisal of caregiving questionnaire – comparison of the structure matrix with the original scale structure

Test item	Original version of the factor	Factor 1	 2	 3
Item 6	Caregiver strain	0.756		
Item 3	Caregiver distress	0.745		
Item 7	Caregiver strain	0.685		
Item 14	Caregiver strain	0.673		
Item 15	Caregiver strain	0.651		
Item 10	Caregiver distress	0.617		
Item 2	Caregiver strain	0.611		
Item 18	Caregiver strain	0.605		
Item 19	Caregiver strain	0.546		
Item 17	Caregiver distress	0.495		
Item 12	Caregiver strain	0.409		
Item 8	Positive caregiving appraisals		0.875	
Item 5	Positive caregiving appraisals		0.831	
Item 4	Positive caregiving appraisals		0.665	
Item 13	Positive caregiving appraisals		0.570	
Item 25	Family well-being		0.567	
Item 16	Positive caregiving appraisals		0.469	
Item 24	Family well-being		0.465	
Item 21	Family well-being			0.796
Item 22	Family well-being			0.683
Item 20	Family well-being			-0.661
Item 23	Family well-being			-0.618

Annotation. Promax oblique rotation was used.

Factor 1, comprising 11 test items, comprised all eight items included in the original *Strain* scale and three of the four items originally included in the *Distress* scale. The last item of the *Distress* scale (item 11) was not included in any of the factors due to an eigenvalue of less than 0.4. These results indicate that almost all the items originally isolated as separate factors – *Strain* and *Distress* – can be treated as part of one overall factor. This is confirmed by a qualitative analysis of the content of these test items and by a similar theoretical relevance of the two constructs. Factor 1 can, therefore, be considered consistent and has been given the name *Negative outcomes (pl. Negatywne aspekty opieki)* in this version of the questionnaire.

Factor 2 comprised seven of the nine items that were part of the *Positive caregiving appraisals* scale in the original scale structure (the other two items were not part of any factor) and two of the six items of the original *Family well-being* scale. Analysing the content of these two items: item 24 *(Our family is able to talk about our feelings with each other*) and item 25 *(Because of caring for … our family is better able to cope with change*) can be considered to coincide with the theoretical meaning of the construct concerning positive caregiving appraisals. Therefore, the analysis demonstrated that they are more related to this factor than to the *family well-being* scale in the original construct. In consequence, a decision was made to retain the original name for factor 2 – *Positive caregiving appraisals*.

Factor 3 comprised four test items. All of them in the original structure of the questionnaire refer to the *Family well-being* factor. Originally, this scale contained six items, but as described above, two of these items became part of the *Positive caregiving appraisals* scale.

Table 2. Location of items in factors in the original and Polish versions of the FACQ-PC

Test item	Original version of the factor	Polish version of the factor
As a carer, I don't have enough time for myself.	Caregiver strain	Negative outcomes
As a carer, I feel tired and run down.	Caregiver strain	Negative outcomes
As a carer, I feel I am losing control over my life.	Caregiver strain	Negative outcomes
I feel isolated and alone in caring for X	Caregiver strain	Negative outcomes
As a carer, I feel my own health has suffered.	Caregiver strain	Negative outcomes
I have had to give up my social life to care for X	Caregiver strain	Negative outcomes
As a carer, I have not been able to do my job or study as well as I would like.	Caregiver strain	Negative outcomes
Caring for X creates financial difficulties.	Caregiver strain	Negative outcomes
I am anxious about caring for X	Caregiver distress	Negative outcomes
I feel depressed about caring for X	Caregiver distress	Negative outcomes
I feel guilty about not being able to do more for X	Caregiver distress	Removed
I worry that I won't be able to do enough to care for X	Caregiver distress	Negative outcomes
I am committed to caring for X	Positive caregiving appraisals	Removed
I am confident that I can handle most problems in caring for X	Positive caregiving appraisals	Positive caregiving appraisals
Caring for is satisfying.	Positive caregiving appraisals	Positive caregiving appraisals
It is a privilege to care for X	Positive caregiving appraisals	Positive caregiving appraisals
I am able to comfort X when he/she needs it.	Positive caregiving appraisals	Removed
I feel useful in my relationship with X	Positive caregiving appraisals	Positive caregiving appraisals
Caring for X has made me feel closer to him/her.	Positive caregiving appraisals	Positive caregiving appraisals
Our family disagrees a lot about caring for X	Family well-being	Family well-being
Our family works together to solve problems.	Family well-being	Family well-being
I feel our family is closer because of caring for X	Family well-being	Family well-being
Our family avoids discussing their fears and concerns about caring for X	Family well-being	Family well-being
Our family is able to talk about our feelings with each other.	Family well-being	Positive caregiving appraisals
Because of caring for X our family is better able to cope with change.	Family well-being	Positive caregiving appraisals

Table 3. Descriptive statistics for FACQ-PC-PLscales

Variable	*Mean*	*Median*	*Standard Deviation*	*Skewness*	*Kurtosis*	*Min.*	*Max.*
Negative outcomes	2.97	3.09	0.83	-0.31	-0.69	1.09	4.55
Positive caregiving appraisals	3.66	3.71	0.81	-0.44	-0.30	1.43	5.00
Family well-being	3.59	3.75	0.91	-0.66	0.23	1.00	5.00

This being said, the structure is close to the original one, so it was also decided to keep the original name of the scale also for factor 3 – *Family well-being*. Two items (items 20 and 23) were shown to have negative factor loadings, meaning that they are reversed items, just as in the original version of the questionnaire. The described changes are presented in Table 2.

Descriptive statistics on the results obtained for the scales of the tool FACQ-PC-PL: Negative outcomes, positive caregiving appraisals and family well-being are presented in Table 3 and intercorrelations in Table 4.

4.3. Reliability analysis

Reliability analysis was then performed for the created *FACQ-PC-PL* questionnaire using Cronbach's alpha internal consistency coefficient. Its results are shown in Table 5.

The analysis showed that all three factors have a high internal consistency. This is confirmed by Cronbach's alpha values > 0.8 for each scale.

4.4. Relevance analysis

Internal relevance analysis was then performed. The results for the factors obtained were correlated with the results of other questionnaires measuring similar constructs. It was assumed that the *Negative outcomes* scale will correlate positively with the Perceived Stress Scale – PSS-10 and the Negative Affect Schedule (SUPIN- NU), the *Positive caregiving appraisals* scale will correlate positively with the Positive Affect Schedule (SUPIN- PU), and the *Family well-being* scale will correlate positively with the Satisfaction with Family Life Scale (SOR- H). The results of the analysis are shown in Table 6.

Based on the analyses carried out, the internal relevance of all scales was confirmed. In relation to the *Negative outcomes* scale, a positive and strong correlation with PSS-10 and a positive and weaker correlation with SUPIN-NU were demonstrated. A positive, weaker correlation with SUPIN-PU was determined for the *Positive caregiving appraisals* scale. A positive and strong correlation with the SOR-H scale was shown for the *Family well-being* scale.

Table 4. Correlations between scales FACQ-PC-PL

Variable		1.	2.	3.
1. *Negative outcomes*	Pearson' *r*	—		
	p-value	—		
2. Positive caregiving appraisals	Pearson' *r*	-0.152	—	
	p-value	0.063	—	
3. Family well-being	Pearson' *r*	-0.339	0.553	—
	p-value	<0.001	<0.001	—

Table 5. Results of Cronbach's alpha reliability analysis for individual scales of the family appraisal of caregiving questionnaire

*FACQ-PC-P*L	Cronbach's alpha	Number of items
Negative outcomes	0.879	11
Positive caregiving appraisals	0.885	7
Family well-being	0.802	4

Table 6. Internal relevance analysis – correlation analysis between factors of the family appraisal of caregiving questionnaire and the scales measuring similar constructs

Family appraisal of caregiving questionnaire	PSS-10	SU-PIN-PU	SU-PIN-NU	SOR- H
Negative outcomes	0.59***		0.39***	
Positive caregiving appraisals		0.38***		
Family well-being				0.51***

Annotation. PSS-10 – perceived stress scale; SUPIN – PU – positive affect schedule; SUPIN – NU – negative affect schedule; SOR- H – satisfaction with family life scale as part of the flexibility and cohesion evaluation scales.
*** $p < 0.001$

In conclusion, the four-factor structure of the questionnaire was not confirmed based on the analyses carried out, and instead, a three-factor structure was found to be more appropriate: n*egative outcomes*, positive caregiving appraisals and family well-being. After removing three test items due to excessively low factor loadings, the *FACQ-PC-PL* comprises 22 test items. The tool has satisfactory internal consistency (Cronbach's alpha > 0.8) and internal relevance.

5. Discussion of the results

Fulfilling the role of an informal caregiver for oncology patients receiving home-based palliative care is a complex experience with both positive and negative outcomes. Suitable tools are necessary to quickly detect the suffering of the caregiver and the benefits stemming from the role undertaken. The aim of this study was the verification of the psychometric properties of the Polish adaptation of the *FACQ-PC: FACQ-PC-PL*. The questionnaire was first translated into Polish and then back translated into English. The resulting version was approved by the creator of the original scale. The questionnaire and three others were then filled in by 150 informal caregivers. The confirmatory factor analysis performed did not confirm the original four-factor structure of the family appraisal of caregiving questionnaire. The results of the exploratory factor analysis demonstrated that a three-factor structure was more appropriate, with most items included in the Caregiver strain and Caregiver distress scales in the original version of the questionnaire forming one overall factor, which was named *Negative outcomes*. This means that the scale measures the negative consequences of the informal caregiver role, such as perceived strain and negative emotional reactions associated with caregiving. The structure of the remaining two factors – Positive caregiving appraisals and Family well-being – also differs from the original, but the discrepancies are not significant; therefore, it was decided to retain the original naming of the scales. Ultimately, the *FACQ-PC-PL* tool comprises 22 test items. Of the initial 25 items, three were rejected because of excessively low factor loadings. The created version of the questionnaire has satisfactory internal consistency (Cronbach's alpha > 0.8) and internal relevance. The intensity of the caregivers' negative outcomes was demonstrated to be positively correlated with the intensity of negative feelings and stress, in line with the study's assumptions. A positive relationship between family well-being and satisfaction with family life and between positive caregiving appraisals and positive feelings was also confirmed. These results are consistent with those obtained by the authors of the original questionnaire (Cooper et al., 2006). The *FACQ-PC-PL* tool is designed to assess the functioning of adult informal caregivers. As the study did not involve children and adolescents, its use in this age group is not recommended.

As regards the functioning of Polish informal caregivers of palliative care patients, researchers most frequently focus their research on the caregivers' quality of life (Masternak et al., 2020). This trend coincides with that occurring internationally (Del Río Lozano et al., 2017; Duimering et al., 2020). The *FACQ-PC-PL* provides additional, complex information on the functioning of informal caregivers of palliative care patients. This tool not only allows an assessment of the positive and negative aspects of the role, but it also enables a preliminary analysis of the family system's functioning.

Limitations of the study and further directions for research

The vast majority of study participants were women. Although this is in line with previous observations on the numerical predominance of women in informal caregiving (Dahlberg et al., 2007) and similar proportions demonstrated in other studies (do Nascimento et al., 2021; Leow and Chan, 2017), the participation of men should not be underestimated (Dahlberg et al., 2007). The results would more accurately reflect the factual state of affairs if the proportion of men and women was maintained. Secondly, the number of people participating in the study was not considerable. It should be emphasised, however, that this paper-and-pencil study was conducted on an individual basis, and the participation criteria were very specific. Furthermore, a large number of informal caregivers refused to participate in the study, citing their low mood as the reason for this decision. This may mean that most study participants had a better frame of mind, which also reduces the variability of those surveyed. Another limitation of the project is that no information was collected on how long the care recipients had been receiving palliative care. Such information could provide a broader context for the study group to be described.

Further research should aim to standardise the tool. The availability of standards would considerably facilitate the screening and determination of informal caregivers who require psychological support and those who have been successful in adapting to their new role.

Conclusion

Taking into account the psychometric parameters obtained, it is reasonable to use the FACQ-PC-PL in scientific research addressing the functioning of informal caregivers of patients receiving home-based palliative care. This tool significantly broadens the range of possible analyses and, as a result, enables a more accurate characterisation of the caregivers taking on this role and focusing the attention on those who require support. The tool, therefore, is a solution that can be used to address the increasing need for researchers and clinicians to focus on informal caregivers. However, it is important to remember that this tool has a different structure from the original one.

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