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Development of the cancer-patient social support questionnaire: reliability and validity

Opracowanie oraz analiza trafności i rzetelności Kwestionariusza Wsparcia Społecznego Pacjent–Opiekun

Abstract

Introduction: *Social support is an important mediator between disease and psychological adjustment, both for the patient, as well as for the family members. The aim of the study was to develop the self-reported Patient-Caregiver Social Support Questionnaire (KWPO) and assess the initial reliability and validity of this tool.*

Material and methods: *A total of 102 cancer-caregiver dyads completed the KWPO. The reliability and validity of the questionnaire were analyzed.*

Results: *Reliability of the KWPO can be considered satisfactory with a Cronbach's alpha ranging from 0.89 to 0.923. The mean Content Validity Ratio ranged between 0.85 to 0.92. A four-factor model with the multidimensional aspect of the construct in social support was supported. The fit indices of CFA non-hierarchical model for a flat model was eligible in the goodness of fit index (GFI) (0.943–0.982), the adjusted goodness of fit index (AGFI) (0.921–0.975), the comparative fit index (CFI) (0.703–0.968) and Tucker-Lewis Index (TLI) (0.656–0.963) for received social support, with exception of the root mean square error for caregivers demanded (RMSE) (0.112).*

Conclusions: *The KWPO can be considered as suitable for measuring social support in cancer-caregivers dyads. It can be used to help Healthcare professionals to assess the patient's need for social support and caregiver's competences to provide it.*

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Key words: *informal caregiver, cancer, social support, mental health*

Introduction

Social support plays a role as an inter-mediator factor between disease and psychological adjustment. Cancer's diagnosis, as well as the subsequent phases of the disease and its treatment are a source of extreme stress both for the patient and for the family [1]. Currently, more caregiving responsibilities have shifted from the hospital to the home situation, were social support is primary provided by close relatives or friends [2] being called informal caregivers, family caregivers, careers or caregivers [3].

Social support is a multidimensional construct of both structural and functional components [4]. The structural component includes quantitative properties of the social network, whilst the functional component refers to the types of social interactions [5]. Popularly social support is understood as comforting people in difficult situations, however, the spectrum of supportive behaviors is very broad and is classified by authors differently [6–8]. Cohen and Willis [9] named 4 types of social support: *emotional*

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conceptualized as expressing empathy, caring, reassurance and providing opportunities for emotional expression and venting; *instrumental* involving provision of material aid or help with daily tasks, *informational* referring to supplying with relevant information and *integrative* understood as spending time together. Social support is a process between two individuals [10] having their own needs and abilities to engage in this transaction. Those needs are highly individualized and may depend on sex [11] personality [12] or attachment style [13]. It seems that the match of those needs and competences may play a role in determining efficacy of social support. Cancer patients are highly distressed group due to the rapid changes following the diagnosis and the after--effects of the treatment [14–16] and as for that their needs for the support encompass all of the supportive behaviors types named by Cohen and Willis[6]. Published studies have documented that receiving social support has an important moderating role in mental and physical health outcomes [17, 18], buffering effect on stressful life events [19] as well as great impact on treatment outcomes [20]. Giving social support has also proved to have advantageous effects on the provider [21]. As cancer is affecting not only the patient but also the family [22], providing social support may have beneficial [23, 24] or disadvantageous consequences [25]. Cancer caregivers may also experience posttraumatic growth [26], have higher self-esteem or closer relations with others [27] as an effect of caregiving. However, as this population is often unprepared to performing cancer-care specific duties or taking on additional responsibilities [28], may develop depression, anxiety disorders or burden [29].

The measurement of social support interactions between cancer patients and their caregivers is critical to researchers and professionals in examining the role of support in the cancer trajectory [30, 31]. Most of the social support measurements focuses on different functional or structural aspects of social support [32], however, there is still a lack of common tools available to assess social support for the cancer patients and informal caregivers population. Within this study we have tried to conceptualize the social support in terms of a transaction of emotional, instrumental, informational and integrative resources between the provider and receiver. This is in line with the Cutron's Optimal Matching Theory [33] showing that the most efficient coping with a difficult situation occurs when provided social support fits to the needs of the support beneficiary [34]. Furthermore, as shown by Merluzziego [35], cancer patients that usually do not receive an adequate level of social support may be poorly adjust to cancer in comparison to those receiving an appropriate type of support. It has already been shown that cancer patients receiving adequate social support are less likely to develop the risk of depression and anxiety disorders [36] and cope better with the treatment consequences [37]. Thus, the satisfactory level of support is required to be adjusted to the needs of the receiver [38]. Some patients may require increased general level or specific types [39] of support to better adjust, whereas others may need less support or no support of a specific type [40].

Based on the above stated conceptualization and a critical review of available literature, we have developed a tool to measure the phenomenon of receiving and giving specific types of social support. Therefore, the aim of this study was to develop and assess the reliability and validity of a self-reported questionnaire that covers an aspect of cancer patients and their informal caregivers social support in the context of measurement in receiving, providing, expecting and demanding social help.

Material and methods

Study population

The Patient-Caregiver Social Support Questionnaire and a socio demographic questionnaire were administrated to cancer patients who were undergoing chemotherapy treatment in the Department of Oncology at the Przemienienie Pańskie Clinical Hospital in Poznan. Data were collected between December 2015 and January 2017. Inclusion criteria were as follow: diagnosed with breast or lung cancer for women and colorectal and lung cancer for men, during chemotherapy treatment after first diagnosis. If the patients had cognitive disorders or refused to give informed consent, they were excluded. Patients on the ward were approached, asked for the consent and when given, asked to choose the family member who in their opinion was giving them the most support. Participants could fill the questionnaire during their stay in the hospital or at home. We disseminated 200 questionnaires, with 105 returned, giving a response rate of 52.5%. The baseline characteristics are summarized in Table 1.

The study was carried out in accordance with the regulations and approval of the Medical Ethical Board of Poznan University of Medical Sciences (NO: 859/14). With the questionnaire, participants received a letter explaining the aim of the study. As the study was anonymous, the verbal informed consent was obtained from each recruited patient before the questionnaire survey. Return of the completed questionnaire was taken as consent to participate.

Table 1. Baseline characteristic of study population

Patients (n = 102)			Caregivers (n = 102)		
Gender	Male	42.2%	Gender	Male	39.6%
	Female	57.8%		Female	60.4%
Age			Age		
Men	Mean	60.8	Men	Mean	56.6
	SD	6.2		SD	9.48
Women	Mean	54.7	Women	Mean	53.1
	SD	7.07		SD	13.83
Patient's tumor type	Breast	57.8%	Kinship	Spouse	87.2%
	Colocteral	36.3%		Child	9.5%
	Lung	5.9%		Other	3.3%
Educational level	Primary	4.8%	Educational level	Primary	4.8%
	Secondary	68.2%		Secondary	68.2%
	High	27%		High	27%
Habitancy	Countryside	27%	Habitancy	Countryside	27%
	Rural	73%		Rural	73%

SD: standard deviation

Measures

Patient-Caregiver Social Support Questionnaire (KWPO) consists of 4 main scales, two for the patients and two for the caregivers. The scales for the patients measure the received social support as well as the ideal (expected social support). The domains for the caregivers measure the provided and perceived as expected social support (demanded). The received social support was conceptualized as the amount and type of support an individual actually gets in the moment of crisis; the provided social support was conceptualized as the amount and type of the support an individual actually gives in the moment of crisis. The expected social support was conceptualized as the amount and type of an individual wish to receive, whereas the perceived as expected social support (demanded) was conceptualized as the amount and type of social support that the provider thinks is expected from him. Each of the scales consist of 20 items in a Likert 4-point scale, grouped in 4 subscales for every of the social support types named by Cohen and Willis[9]: instrumental, emotional, informational and integrative. Supplementary material includes the list of the items in both English and Polish for all of the four domains. The Patient-Caregiver Social Support Questionnaire gives an opportunity to compare the level of fit between received, expected, given and demanded aspects as well as the types of social support, independently on the direction of those transitions. The level of fit was calculated as a difference between sums on each subscale (e.g. emotional received vs emotional given) or between versions (e.g. received vs. expected) and is expressed as absolute value.

In order to develop the questionnaires items, we conducted open-question inquiries among 30 breast cancer patients asking them what type of support they receive and expect from their family members. The answers were then classified accordingly to social support type presented by Cohen and Willis. Next, after evaluating existing social support instruments (i.e. BSSS), items indicating those types were developed. After conducting pilot study among 30 patients and their caregivers, we then performed primary reliability tests, based on which we excluded one item from each social support type subscale (apart from given emotional social support).

Statistical approach

To determine reliability, Cronbach's coefficient alpha was used to measure internal consistency of each version of the questionnaire. To determine the validity of the tool, content and construct validity were measured. Content validity was assessed using the Lawshe method [41]. A panel of content experts was asked to review the potential scale items and confirm that they are appropriate indicators of the construct. The panel consisted of 9 people (8 women and 1 man), 7 trained psychologists and two PhD students. All of the panelists received training before the review. Content validity ratio (CVR) for nine panelists was computed (desired value > 0.78).

Construct validity was tested using confirmatory factor analyses (CFA). CFA was performed to confirm whether the data fit the model presented by Cohen and Willis [9]. The model fit indices included goodness-of-fit index (GFI) (desired value ≥ 0.90), adjusted goodness-of-fit index

(AGFI) (desired value ≥ 0.90), parsimony goodness-of-fit index (PGFI > 0.50), root mean square error of approximation (RMSEA) (desired value ≥ 0.08), comparative fit index (CFI) (desired value ≥ 0.90), Tacker-Lewis index (TLI) (desired value ≥ 0.90), and normalized chi-square (i.e., the ratio of 2/df) [42]. Statistical analyses were performed using JASP statistical program [43].

Results

Reliability

Cronbach's alpha was obtained at the level of 0.905 for received social support, 0.897 for provided social support, 0.923 for expected social support and 0.890 for demanded social support. Internal consistency was measured for the four subscales separately and has been shown in Table 2.

Validity

Content validity

Content validity was assessed by a panel of experts. We calculated CVR for each scale, mean subscales values were calculated for each tool.

All scales had a satisfying CVR value, from 0.85 for expected social support to 0.92 for demanded social support. The lowest CVR value subscale was for the expected-informational support type, the highest value was one for given and demanded-emotional support type and expected-instrumental support type. Table 3 reports the CVR values for the Cancer-Patient Support Questionnaire.

Construct validity

A Confirmatory Factor Analysis (CFA) was used to evaluate the goodness of fit to a four-factor model (informational, emotional, instrumental, integrative support) for every version of the scale. The analysis of concurrent hierarchical models (2–4 or 4–2) reached considerably lower fit indices.

The goodness of fit indexes were acceptable, the highest one for given social support (0.982), the lowest one for expected social support (0.943). The tested models posit flat, non-orthogonal structure of respective social support dimensions. Lower fit indices for given and demanded social support were probably caused by

Table 2. Internal consistency of Patient-Caregiver Support Questionnaire subscales

	Support type	Patient		Caregiver	
		α Cronbach	λ6 Gutmann	α Cronbach	λ α Gutmann
Received/Given	Informational	0.810	0.793	0.785	0.758
	Emotional	0.833	0.810	0.859	0.848
	Instrumental	0.610	0.614	0.626	0.618
	Integrative	0.777	0.752	0.743	0.752
Expected/Demanded	Informational	0.814	0.812	0.861	0.851
	Emotional	0.854	0.834	0.831	0.811
	Instrumental	0.724	0.699	0.703	0.736
	Integrative	0.814	0.813	0.750	0.739

Table 3. Content validity ratio values of patient-caregiver support questionnaire and subscales

		Patient	Caregiver
Given/received	Informational	0.78	0.78
	Emotional	0.87	1
	Instrumental	0.96	0.96
	Integrative	0.87	0.82
	All scale	0.87	0.89
Expected/demanded	Informational	0.6	0.91
	Emotional	0.98	1
	Instrumental	1	0.91
	Integrative	0.82	0.87
	All scale	**0.85**	**0.92**

Table 4. Summary of model fit statistics from Confirmatory Factor Analysis for the Patient-Caregiver Support Questonnaire

Goodness of fit index	Criterion*	Patient		Caregiver	
		Reveived	Expected	Given	Demanded
GFI	≥ 0.90	0.964	0.943	0.982	0.959
AGFI	≥ 0.90	0.949	0.921	0.975	0.943
PGFI	> 0.50	0.687	0.673	0.713	0.684
RMSEA	≥ 0.08	0.038	0.080	0.077	0.112
RMSEA.CI.LOWER		0.000	0.057	0.058	0.094
RMSEA.CI.UPPER		0.067	0.102	0.095	0.130
CFI	≥ 0.90	0.968	0.886	0.835	0.703
TLI	≥ 0.90	0.963	0.868	0.810	0.656
CHISQ		181.228	238.461	277.527	323.472
DF		164	164	183	164
p-value		0.169	< 0.001	< 0.001	< 0.001

*based on [41]

GFI: goodness of fit index; AGFI: adjusted goodness of fit index; PGFI: farsimony Goodness of Fit/index, RMSEA: The Root Mean Square Error of Approximation; RMSEA.CI.LOWER: lower lambda for RMSEA, RMSEA.CI; UPPER: upper lambda for RMSEA; CFI: the comparative fit index; TLI: Tucker-Lewis Index; CHISQ: Chi-squared distribution; DF: degree of freedom

cross-loadings between respective items, which can be observed as high correlations between the items. The summary of the CFA for the Cancer-Patient Support Questionnaire is presented in Table 4.

Discussion

In this study, we developed a scale to measure social support among patients with cancer and their caregivers: KWPO. To the best of our knowledge, the current study was the first one to develop and validate a scale to measure social support acquisition and provison in cancer patient-caregiver dyads.

The preliminary results with the KWPO are encouraging. Our findings of the presented study provide evidence of the reliability and validity of the constructed tool for cancer patients and their caregivers. All the scales of KWPO showed good internal consistencies from 0.890 for demanded social to 0.923 for expected social support. The subscales (instrumental, emotional, informational, integrative) showed satisfactory results, with Cronbach's over 0.70, with the exception of instrumental given and received social support. The consistent findings confirmed that Cancer-Patient Social Support Questionnaire has acceptable reliability.

Content and construct validity were measured in order to determine the validity of the tool. All versions of Cancer--Patient Social Support Questionnaire had good CVR ratios from 0.85 to 0.92. The results met the criterion of 0.78 based on Lawshe method [41]. The Confirmatory Construct validity was computed by means of CFA. Our aim was to test the model fit of social support based on theoretical definitions of social support presented by Collins and Willis [9]. We expected that the scales measured a multiple dimensions of functional social support construct including instrumental, emotional, informational and integrative need. We further expected that the structure of social support measured received, given, expected and demanded social support as a subgroup of social support types. The CFA, however, non-orthogonal structure, including only the types of social support was supported by the data. The model fit indices for a flat model in four dimensions (received, expected, given, demanded) were eligible in GFI, AGFI, CFI and TLI for received social support, except for RMSE for caregivers demanded. These finding suggest that the parts of the scales can be treated separately as individual tools, assessing functional aspects of social support from providers' and receivers' perspectives.

The Cancer-Patient Social Support Questionnaire offers promising possibilities for intervention and research and the implications of this work are important for patient-caregiver dyads as well as for Health Service specialists. Firstly, the differentiation of social support types in accordance with the source and side of social support (e.g. receiver vs. provider, close family relative vs. distant relative, friend) may be useful in characterizing individual social support needs on the receiver's side and competences on the providers side. Other available questionnaires concerning patient and caregivers care perspective are generally administered separately which

prevents to observe the transactions between care giver and receiver [44–46].

Futhermore, KWPO gives an opportunity to assess the fit between the received and expected social support together with the given and demanded social support. As the Cutron's Optimal Matching Theory [33] states the fit between the required support and given, plays a beneficiary role in the trajectory of social support. The tool gives a possibility for Health Care specialists to analyze those transactions and modulate the direction accordingly to whom the intervention is addressed or who is object of research inquiry. The level of fit can be of great importance for the receiver's health, however, as the social support is a process between two people, the tool can be also used to analyze the effects of the level of this fit from the providers' perspective. Differences in the dimensions identified in The Cancer-Patient Social Support Questionnaire may have implications in assessing where social support needs to be mobilized or what type of interventions need to be delivered to individuals to improve their social support skills.

There were some limitations of the presented study. Firstly, the study had a cross-sectional design. Secondly, the sample size was small, even though the statistical power of this research was enough to test the model with CFA. Thirdly, the research was based in one country, Poland, specifically in Wielkopolska region with only 3 types of cancer diagnosis at a specific stage of the disease and treatment regimen, which limited the generalization of the results to all cancer patients and their caregivers. Finally, almost ½ of participants refused to participate in the study due to other obligations or poor health. There is a need for further research, in bigger and more heterogenic groups and implementing longitudinal studies to develop a clearer understanding of change over time.

Conclusions

In conclusions, the constructed KWPO can be considered as suitable for measuring social support in cancer-caregivers dyads. It can be used to help Healthcare professionals to assess the patient's need for social support and caregivers competences to provide it. This questionnaire is easy to use tool with promising propriety for further development in specific cancer-side patients that will help to improve the quality of life cancer patients.

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Streszczenie

Wstęp: *Wsparcie społeczne jest istotnym mediatorem pomiędzy chorobą nowotworową a psychologicznym dostosowaniem się do niej, zarówno wśród pacjentów, jak i ich członków rodzin. Celem tego badania było stworzenie Kwestionariusza Wsparcia Społecznego Pacjent-Opiekun (KWPO) oraz wstępna ocena jego rzetelności oraz trafności.*

Materiał i metody: *102 pary pacjentów i ich opiekunów wypełniło KWPO. Następnie przeanalizowano rzetelność oraz trafność badanego narzędzia.*

Wnioski: *Alfa Cronbacha narzędzia znajdowała się w zakresie od 0,89 do 0,92, trafność narzędzi znajdowała się w zakresie od 0,85 do 0,92. Potwierdzono czteroczynnikowy model wsparcia społecznego. Testowany model wskazuje na płaską, nieortogonalną strukturę poszczególnych wymiarów wsparcia społecznego z następującymi współczynnikami dopasowania: GFI (0.943–0.982), AGFI (0.921–0.975), CFI (0.703–0.968) TLI (0.656–0.963).*

Podsumowanie: *KWPO jest odpowiednim narzędziem do pomiaru wsparcia społecznego wśród pacjentów chorujących z powodu nowotworu oraz ich opiekunów. Można z niego korzystać w celu oceny zapotrzebowania na wsparcie u chorego oraz możliwości jego udzielenia u członka rodziny.*

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Słowa kluczowe: *nieformalny opiekun, choroba nowotworowa, wsparcie społeczne, zdrowie psychiczne*

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