

RESEARCH ARTICLE

Cultural Adaptation and Validation of The CaSPUN (Cancer Survivors' Partners Unmet Needs) Measure Among Partners of Gynecological Cancers

Haryani Haryani¹, Yati Afiyanti², Besral³

Abstract

Purpose: The partners of cancer patients commonly provide the needs of cancer patients along cancer trajectory except for patients with gynecological cancer. In developing countries including Indonesia, who have strong family bonding, the family of cancer patients are involved more intensely in providing cancer care. This situation may bring the cancer patients' families experience the burden and decrease their quality of life. Therefore, assessing the family's supportive needs are as important as patient supportive needs. There are more gynecological cancer survivors in Indonesia; however, little is recognized about partners' supportive needs due to lack of validated assessment tools to measure it. This study aimed to translate, culturally adapted and test the validity and reliability of the CaSPUN questionnaire among partner of Indonesia gynecological cancer patients.

Design: First, the procedures of forward-backward translation and modification of the CaSPUN were conducted to ensure cultural adaptation. Second, using convenience sampling with 295 partners of gynecological cancer patients, we tested the construct validity and internal consistency of the CaSPUN-Indonesia Version (CaSPUN-I). We conducted Exploratory Factor Analysis to explore the factor structure of CaSPUN-I and Cronbach Alpha to confirm internal consistency reliability.

Results: The CaSPUN were modified to make more understandable and culturally appropriate in the Indonesian context. Five factors were extracted from EFA in the CaSPUN-I with factor loadings of items between 0.41 and 0.85. The Cronbach's alpha coefficient for the CaSPUN-I ranged from 0.96-0.97.

Conclusion: The CaSPUN Indonesia version presents acceptable validity and reliability for assessing supportive care needs among families of Indonesian gynecological cancer patients. The CaSPUN-I can be used by healthcare providers to assess and design the supportive care program for family of Indonesia gynecological cancer patients.

Keywords : *CaSPUN; Cancer survivor; Cross-cultural adaption; Indonesia; needs assessment*

Introduction

Gynecological cancer is the leading cancer among women next to breast cancer (Ferlay et al., 2015). Within Southeast Asian countries, the incidence and mortality rate of gynecological cancer in Indonesia is third in rank following Singapore and Brunei Darussalam (Ferlay et al., 2015). Gynecological cancers, including cervical, ovary and endometrium cancers, are among the top ten highest incidence of cancer among women accounting for 26%. It was predicted to increase to around 15% on 2020 in Indonesia (Ferlay et al., 2015).

The unmet needs, such as physical and psychological problems can have profound impact on the well-being of cancer patients and their partners. Patients may become dependent on their partners for managing illness-related pain and fatigue symptoms, managing additional responsibilities as a result of partner's illness, providing up-to-date information related to care, and providing emotional support (Afiyanti et al., 2019). Studies have found that partner's or caregivers' unmet needs of

¹ Department of Medical Surgical Nursing, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Yogyakarta, Indonesia. Email : haryani@ugm.ac.id

² Faculty of Nursing, Universitas Indonesia, Depok, Indonesia. Email : yatikris@ui.ac.id

³ Faculty of Public Health, Universitas Indonesia, Depok, Indonesia

adult cancer patients, including comprehensive cancer care, emotional and psychological care, impact their daily activities, relationships, information and spiritual needs (Giuliani et al., 2017; Lambert et al., 2012). In addition, studies found not only patient but also their partners have unmet needs on levels of distress (Hagedoorn, Buunk, Kuijer, Wobbles, & Sanderman, 2000; Rodenbach et al., 2019). The study reported that partners put their needs aside and neglect their own health to focus on their responsibilities in supporting patients with daily activities that have been affected by the effects of treatment (Girgis, Breen, Stacey, & Lecathelinais, 2009; Girgis, Lambert, & Lecathelinais, 2011). Social support, patients' physical and daily living needs, patients' health system and information needs, and patients' psychological needs were significant factors that burdens caregivers (Chen et al., 2009).

The CaSPUN measure was developed by Hodgkinson et al. (2007) from Westmead Centre of Gynecological Cancer, Australia to identify long-term supportive care needs of cancer survivors' partners and assist for developing supportive care services program (Hodgkinson et al., Butow, P., Hobbs, K. M., Hunt, G. E., Lo, S. K., & Wain, G. (2007). The CaSPUN consisted of 35 unmet need items, 6 positive change items and an open-ended question. It covered the following domains: existential survivorship, comprehensive care, information, Quality of Life (QOL) and relationships (Hodgkinson et al., 2007).

The CaSPUN has been used to measure the partner's unmet needs across all cancer types (Hodgkinson et al., 2007). The CaSPUN is one of the only two tools evaluated for test-retest reliability in measuring survivor caregiver needs (Prue, Santin, and Porter, S., 2015). A systematic review reported partners' unmet needs across all cancer sites (Lambert et al., 2012). Based on the 29 manuscripts found, the mean number of unmet needs experienced by partners ranged between 1.3 and 16, with 16%-68% experienced at least one unmet need (Lambert et al., 2012). In addition, a study conducted by Giuliani et al. (2017) used CaSPUN questionnaires to assess the 158 partners' unmet needs at the Princess Margaret Cancer Centre in Toronto, Canada reported that the three most commonly reported unmet partner needs were how to manage their concern about recurrence cancer, more accessible hospital parking, and how to deal with others who do not acknowledge the impact of cancer on their life. These needs were covered in relationship and partner impact domains of CaSPUN (Giuliani et al., 2017)

There are more gynecological cancer survivors in Indonesia; however, little is recognized about their supportive needs. One of the difficulty to conduct such study was due to lack of validated assessment scale in Indonesia. The CaSPUN has not been translated and validated for use in the Indonesian language

(Bahasa Indonesia). There is an urgent need to have a translated and validated scale for assessing supportive care needs in Indonesia as there is an increasing number of partners' cancer survivors in that country.

The aims of this study were to translate and culturally adapt the CaSPUN questionnaire into Indonesian context, and test the validity and reliability of the translated CaSPUN questionnaire among partners of Indonesian gynecological cancer patients.

Methods

This study was conducted in two stages: (1) the cross-cultural adaptation, and (2) the validation of the CaSPUN-I. The process of cross cultural adaptation followed the guideline as proposed by Beaton et al (Beaton, Bombardier, Guillemin, & Ferraz, 2000) to develop the CaSPUN-I. This stage was followed by a validation test with family members of gynecological cancer survivors in three hospitals in Indonesia.

Stage 1 The Process of Cross-cultural adaptation

After we got permission from Hodgkinson et al., 2007 as the original author of the CaSPUN on April, 13, 2018, then the CaSPUN was translated into Indonesian language by two translators to produce early version of the CaSPUN-I. Both translators were bilingual (English and Indonesia) native speakers of Indonesian.

The first translator was aware of the concept being examined in the CaSPUN-I to provide a more clinical and measurement perspective while the second translator was a naïve translator, less influenced by an academic goal and might reflect the language of target population. The two translators synthesized and discussed the results of translations to build consensus of translations.

Expert team including two academic nurses, two oncology nurses and obstetric gynecology physician with bilingual ability were invited to review the semantic, idiomatic, experiential equivalence and conceptual equivalence of all the versions of the questionnaire. Then, the research team compiled the feedback from the expert team and discussed with them to approve the pre-final version of the CaSPUN-I.

Two native English speakers, with no medical background and who had been living in Indonesia for more than 10 years, were asked to do backward translation for the pre-final version of CaSPUN-I.

We, then involved five family members of gynecological cancer survivors to pilot the pre-final CaSPUN-I. They were asked if they understand the meaning of the items and its responses. This process aimed to confirm that the pre-final CaSPUN-I was able to retain its equivalence in a real situation. The family members

gave feedback of content, meaning, and technical adaptation of the CaSPUN-I. The research team then synthesized the adapted version of the CaSPUN-I before the validation.

Stage 2 The Tool Validation

After process translation and adaptation, tool validation of CaSPUN-I was conducted.

Participants and Setting

The study was conducted at three hospitals including Sardjito General Hospital in Yogyakarta, the Dharmas National Cancer Centre in Jakarta, and the Dr. Soetomo General Hospital, East Java. We chose these three hospitals because these hospitals were major referral hospital for cancer patients in Indonesia. This research was conducted from February 2016 to March 2016 with the approval of the Institutional Review Board from both Faculty of Medicine of Universitas Gadjah Mada and Dr. Sardjito General Hospital (KE/FK/140/EC/2016).

We recruited one member of the family of gynecological cancer patients using convenience sampling method, with the inclusion criteria: more than 18 years old and have been taking care of gynecological cancer survivor more than one month, were able to understand Indonesia language and agreed for joining this study. After we explained the research purpose and procedure, we asked them to sign the written consent forms if they agree to participate in this study

A sample size for validation was estimated based on the 35 items of the CaSPUN-I and at least five subjects or more are recommended for one item while conducting tool validation (DeVon et al., 2007). In this stage, we recruited 295 family members of gynecological cancer patients who accompany gynecological cancer patients in the follow up visit.

Instruments

Two questionnaires, demographic questionnaire and the adapted CaSPUN-I, were used in this study.

- a. Demographic questionnaire
The demographic questionnaire, developed by the research team, contained information about sex, age, marital status, income, education level, occupation, relationship with cancer patients and the duration of care of her/his family.
- b. Cancer Survivors' Unmet Needs (CaSPUN) measure
The CaSPUN Indonesia Version was used to measure unmet supportive care needs among gynecological cancer survivors' partner. CaSPUN consisted of 35 unmet need items and 6 positive change items. Those items were organized in 5 parts incorporating (a) information needs and medical care issues, (b) QOL, (c) emotional and relationship issues, (d) life perspective and (e) positive changes. A final

open-ended question was offered to identify additional needs.

The original CaSPUN is a valid and reliable instrument with the Cronbach α coefficient of 0.94, the test-retest correlation for the total CaSPUN score was 0.60, most items on the CaSPUN had intercorrelations between $r=0.2$ and 0.5 , correlations between CaSPUN needs and partner variables ranged from $r=0.20-0.29$ (Hodgkinson et al., 2007)

The CaSPUN can be scored and interpreted based on domains of need, sum of met, unmet and total needs. Positive changes items and the open-ended question were interpreted separately.

Statistical Analyses

Frequency distribution and descriptive statistics were used to summarize demographical data of participants. Exploratory Factor Analysis (EFA) with principal component analysis was conducted to examine construct validity. Acceptable standard for construct validity were factor loading >0.40 , eigenvalues >1 , Kaiser-Meyer-Olkin >0.5 , and measures of sampling adequacy >0.5 (DeVon et al., 2007). Cronbach's alpha was calculated for internal consistency reliability with acceptable coefficient ≥ 0.70 (DeVon et al., 2007)

Results

Stage 1 The process of cross-cultural adaptation

The process of adaptation of the CaSPUN was generated by reviewing the elements of semantic (the meaning of words in each culture), idiomatic (the meaning of idioms or colloquialisms), experiential (the relevance of the item measure in the daily life experience) and conceptual (the conceptual meaning between cultures) equivalence of CaSPUN items (Beaton et al., 2000).

The technical modification, as suggested by respondents in the pre-final testing also, was made, e.g. we modified the rating of unmet need from 'weak, moderate, and strong' in the original CaSPUN, into 1-3 scale (1 = less needed and 3 = strongly needed).

The sentence modification of CaSPUN included use of simple and familiar words to make it more understandable for cancer survivors' partners with low literacy condition. For example, since we have not yet established "case manager system", then we modified items asking about the need of "ongoing case manager to find out about services whenever they are needed" into "easy to reach health care provider for partners". We also explained "local health services" with "nearest health services". We also modified the terms that are more culturally fit in the Indonesian context. For instance, the term "partner" in the

original CaSPUN was translated into “wife”, to indicate the relationship that is legally and socio-culturally acceptable in Indonesia. We also translated “sex life” into “sexual/ intimate relationship”.

We added concrete examples in item 15 regarding the financial support and government benefits for supporting cancer patients in Indonesia. We put the “Family Hope Program” and “Cash transfer”, since both programs are the Indonesian government's social security programs targeting poor families.

Stage 2 The Tool Validation

The tool validation involved 295 family members of gynecological cancer patients. As shown in Table 1, majority of participants were married (84.4 %), with a mean age of 43.69 years old, passed senior high school (43.1%), had income less than 1 million IDR (35.1%), and were labor workers (26.4%). The families have been taking care of patients for an average of 10.92 months, and majority who takes care of gynecological cancer patients were the husbands (51.5%).

Construct Validity

Exploratory Factor Analysis (EFA) with principal component analysis and varimax rotation produced a five-factor structure to the CaSPUN-I. The five factors accounted for 66.12% of cumulative variance. All of the items have factor loadings greater than 0.40. The factors were comprehensive cancer care (15 items), partners' impact (10 items), emotional support (5 items), protection (3 items) and relationship. The result of the EFA is shown in the Table 2.

Reliability

Internal consistency was indicated by Cronbach's Alpha values. The total of Cronbach's α values is 0.97. The Cronbach's Alpha values of each items were above the threshold of 0.70 and ranged between 0.968 and 0.969

Discussion

Assessing cancer survivors' partners unmet needs, including gynecological cancer patients, allow health care providers to develop individualized care plans for them. The current study provided details of cross-cultural adaptation and validation of the CaSPUN-I.

Generally, the items of the CaSPUN were culturally acceptable and relevant in the Indonesia context as well as comprehensive. Currently, the CaSPUN only validated in

Table 1. Demographic and clinical characteristics of participants (n=295)

Characteristics	
Age (years)	Mean (SD) 43.69 (13.75)
Duration of care (months)	10.92 (12.54)
Sex	f (%)
Female	93 (31.5)
Male	202 (68.5)
Marital status	
Single	42 (14.2)
Married	249 (84.4)
Widow/widower	4 (1.4)
Last Education	
Not go to school	6 (2.0)
Elementary school	50 (16.9)
Junior high school	59 (20.0)
Senior high school	127(43.1)
Undergraduate	49(16.6)
Postgraduate	4(1.4)
Income (IDR)	
< 1 million	106 (35.9)
1-2 million	95 (32.2)
2-3 million	35 (11.9)
3-4 million	23 (7.8)
4-5 million	19 (6.4)
> 5 million	17 (5.8)
Employment	
Government employee	14(4.7)
Private employee	76(25.8)
Retired	17 (5.8)
Entrepreneur	68 (23.1)
Labor	78 (26.4)
Jobless	42 (14.2)
Relationship with cancer patients	
Husband	152 (51.5)
Parents	10 (3.4)
Children	88 (29.8)
Neighbor	1 (0.3)
Relatives	38 (12.9)
Other	6 (2.0)

Table 2. Principal components factor analysis with varimax rotation of CaSPUN-I⁴

CaSPUN item number	Factor loadings					Explained variance (%)
	F1	F2	F3	F4	F5	
F1: Comprehensive Cancer Care (15 items)						21.54
3. Need understandable information	0.77					
2. Need information as a partner	0.73					
6. Need to know that the health care team works together for his partner	0.72					
5. Manage partner's health with health care provider team	0.72					
9. Need help to manage treatment side effect of partner	0.71					
7. Need that complaint be addressed	0.68					
1. Need update information about my partners condition	0.65					
4. Need information about local health service	0.64					
8. Need help to reduce stress in partners life	0.62					
20. Need help to communicate with others	0.56					
18. Need help on concerns of cancer recurrence	0.55					
19. Need emotional support	0.52					
10. Help with own health	0.51					
21. Help how to support partner	0.47					
11. Easy to reach health care provider for partners	0.41					
F2: Partner impact (10 items)						19.07
32. Need help to deal with other that not understand my life is changed		0.75				
33. Need help to deal with uncertainty		0.74				
27. Need help to cope with the impact on relationship		0.69				
35. Need help to make my life count		0.68				
34. Need help on spiritual belief		0.67				
28. Need help to adapt with physical changes of my partner		0.67				
26. Need help to deal with the changes of my life		0.64				
25. Need help with additional responsibilities		0.62				
31. Need help so my partners can move on		0.58				
23. Need help to talk with other who have same situation		0.50				
F3: Emotional support (5 items)						11.83
13. Need help to deal with changes of partners life			0.71			
14. Need help to deal with the impact on my working life			0.67			
12. Need accessible hospital parking area			0.60			
24. Need help to explain partners condition to others			0.57			
22. Need support for loved ones			0.47			
F4: Protection (3 items)						8.56
15. Need information how to get financial support				0.70		
17. Need help to get legal protection				0.66		
16. Need information how to get health insurance				0.63		
F5: Relationship (2 items)						5.12
30. Help to get children					0.85	
29. Help to deal with intimacy					0.68	

⁴ Indonesian version of the tool available upon request.

English Version (Gordon and Chen, 2017), therefore we only compare our study with original of CaSPUN. We included 35 items suggested in the original version of CaSPUN, however we did some modifications. Similar with the original CaSPUN, most respondents suggested no items to be excluded or inclusion and minor typographical alterations were made (Hodgkinson et al., 2007).

We modified the format of the CaSPUN in rating the unmet need from “weak, moderate, and “strong” in the original CaSPUN into 1-3 scale (from less needed to strongly needed) in the CaSPUN-I. This format made our participants relate easy to reflect and rank their needs. In item 15 we added concrete examples e.g. 'Family Hope Program' and 'Cash transfer' as financial support and government benefits for supporting cancer patients in Indonesia for our participants to easily understand the question. To make it more culturally-fit and take note the linguistic differences in the Indonesian context, we change the word “partner” into “wife” in all items that state the word “partner”. In item 29, we changed “sex life” into “sexual/intimate relationship” since talking about sex is still taboo in Indonesia culture. Therefore, we changed it to make our participants more comfortable when they answer the questions.

In this study, we identified five factors namely comprehensive cancer care, partners' impact, emotional support, protection and relationship, with the cumulative variance of 66.12%. That cumulative variance indicated that items in the five factors are highly correlated and provided the most interpretable and theoretically-coherent solution. The construct of the CaSPUN-I paralleled with the original CaSPUN (Hodgkinson et al., 2007); however the cumulative of variance in our study was higher compared with the original CaSPUN. In the original version of CaSPUN a five factor solution accounted for over 51% of variance. In addition, all items of the CaSPUN-I showed higher item correlations with overall factor loading >0.4 compared with the original CaSPUN (factor loading >0.3), five items in the original CaSPUN have factor loading <0.03.

Reliability using an internal consistency in this study demonstrated stronger at 0.97 as well as the Cronbach Alpha of each CaSPUN-I items, ranging from 0.968 to 0.969. Internal consistency indicated how well the items on a tool fit together conceptually. The Cronbach Alpha ≥ 0.90 is acceptable standard for clinical tools while ≥ 0.70 is accepted standard for research tools (DeVon et al., 2007). Therefore, we can conclude that CaSPUN-I is reliable as a tool to measure the needs of family of cancer patients for clinical practice as well as for research. Our findings are comparable with the Cronbach's alpha of original CaSPUN which is 0.94.

Study limitation

Since our study only involved the family of gynecological cancer patients and mostly received chemotherapy treatments, therefore future studies are needed to test the CaSPUN-I across cancer and treatment. However, due to the absence of validated measure for assessing the partners' supportive care needs as well as the increasing number of gynecological cancer cases, this research has greatly contributed for identifying the supportive care needs among partners or family members of gynecological cancer patients.

Conclusion

The CaSPUN-I was a valid and reliable scale for assessing the needs of supportive care among partners or family of gynecological cancer patients. The assessment of supportive care needs may allow to develop supportive care programs that are not well established in Indonesia.

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ABOUT THE AUTHORS



Assistant Professor Haryani, BSN, MSc, Ph.D. She is a faculty member of Department of Medical Surgical Nursing, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Indonesia. Currently, she is the Director of Undergraduate Nursing Program, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Indonesia. Her research interests include oncology nursing, evidence-based practice and nursing education.



Professor Dr. Yati Afiyanti, BSN, MSN. She is a professor and senior researcher on Faculty of Nursing, Universitas Indonesia. Currently, she works as a faculty member of Maternity and Women's Health Department, University of Indonesia. Her research interests include women health, sexuality and oncology nursing.



Dr. Besral, SKM, MSc. He is a senior lecturer in Faculty of Public Health, Universitas Indonesia. His research interests include data modelling, HIV/AIDS, Surveillance, Reproduction Health.

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