

Cross-cultural adaptation and validation of the cancer survivors' unmet needs measure among gynecological cancer patients in Indonesia

Haryani Haryani¹, Yati Afiyanti², Besral Besral³, Dewi Gayatri², Kemala Rita Wahidi^{4,6}, Hana Pramiasti⁵, Ariesta Milanti^{6,7}

ABSTRACT

Background: The number of gynecological cancer survivors in Indonesia is growing, yet little is recognized about their supportive care needs due to a lack of validated assessment to measure them. This study aimed to culturally adapt the Cancer survivors' unmet needs into Indonesian language and to test its validity and reliability for Indonesian gynecological cancer patients. **Methods:** We performed the translation and adaptation of the Cancer survivors' unmet needs based on Beaton's cross-cultural adaptation process of self-report measure. We then evaluated the psychometric properties of Cancer survivors' unmet needs -Indonesian with 298 participants from three hospitals across Indonesia. **Results:** Five factors were extracted from Exploratory Factor Analysis with factor loading >0.4. Cancer survivors' unmet needs - Indonesian had negative correlations with The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30, indicating that the higher score of unmet needs resulted in the lower score of quality of life. The Cronbach's α coefficient for the Cancer survivors' unmet needs - Indonesian ranged from 0.75-0.95. **Conclusions:** The Cancer survivors' unmet needs - Indonesian version offers a valid and reliable scale for assessing supportive care needs among Indonesian gynecological cancer patients. The Cancer survivors' unmet needs-Indonesian could help clinicians to assess supportive care needs among Indonesian gynecological cancer patients. The low-resource countries such as Indonesia could use the evidence from the Cancer survivors' unmet needs assessment to develop the supportive care service in the clinical settings.

Key words: CaSUN; Survivors; Cross-cultural adaption; Indonesia; Needs, Gynecology

INTRODUCTION

Gynecological cancer is among the most common cancers in women, with cervical cancer being the leading cancer diagnosis and cause of death in Sub-Saharan Africa and South-Eastern Asia (1). The high incidence of cancer is coupled with the limited health care services and financial resources in the lower- and middle income countries (LMICs) (2). In the low resource settings services for cancer survivors, in particular, are still underdeveloped and also of low priority (3). Limitation in access for treatment and information, suboptimal treatment, and increasing problems of cost and reimbursement are the common challenges in the LMICs (4). Facing such barriers, the cancer patients are more likely to use the complementary and alternative medicine which could have minimum or even zero evidence to support its efficacy and safety (4). Moreover, for the cancer survivors these conditions may bring anxiety and low quality of life (5,6).

Supportive care to assist the patients in having a smooth transition from active treatment to post-treatment care at the community settings has been long advocated as a standard clinical cancer care (7,8). Unfortunately, this kind of service has not been implemented in most LMICs (9).

In Indonesia little is recognized about the supportive care needs of the gynecological cancer survivors despite their growing population. Only few studies had been done on Indonesian gynecological cancer survivors. They are mostly qualitative studies (10-12) or small-scale cross-sectional studies (13) focusing on the psychosocial problems. The studies indicated that the Indonesian gynecological cancer survivors experienced a high level of fear of cancer recurrence (13), altered self-concept (11), altered sexual function and intimate relationships (10,11), as well as physical discomfort (11). A phenomenology study conducted

in province in Indonesia found that one of the cervical cancer survivors' needs to survive from cancer was the support from the family and the health care providers.

The supportive care assessment as the key to provide the service was hardly implemented due to lack of a validated assessment scale in the Indonesian language. To our best knowledge, this study is the first cross-cultural adaptation and validation of a supportive care needs which was specifically developed for the cancer survivors beyond the treatment phase, *i.e.* Indonesian version of the Cancer Survivors' Unmet Needs (CaSUN) developed by Hodgkinson *et al.* (2007). This tool adaptation was a part of an attempt to develop the survivorship care service for all cancer survivors in Indonesia, starting with the gynecological cancer survivor population.

The CaSUN was selected because it is considered to better capture the needs of the cancer survivors compared to majority of other cancer-related needs assessment measures that tend to be more relevant for the patients in the treatment period and do not focus on the survivorship phase (15, 16). The CaSUN consists of 35 unmet needs items, six positive change items, and one open-ended question. It covers the domains of existential survivorship, comprehensive care, information, quality of life, and relationships (14).

This measure has been validated and adapted into several languages, including Chinese (17), Spanish (18, 19), Dutch (20) and showed good validity and reliability. The CaSUN has been widely used across a variety of cancer types (e.g., breast, testicular, gynecological, and other types of cancer) in various countries (3, 14, 21, 22).

The CaSUN originated from Australia whose culture and language are different from Indonesia, hence its application requires cross-cultural

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¹ Universitas Gadjah Mada, Faculty of Medicine, Public Health and Nursing, School of Nursing, Jl Farmako Sekip Utara, Yogyakarta, Indonesia

² Universitas Indonesia, Faculty of Nursing, Kampus UI Jl Prof. Bahder Djohan, Depok, Indonesia

³ Universitas Indonesia, Faculty of Public Health, Kampus UI Jl Prof. Bahder Djohan, Depok, Indonesia

⁴ Dharmas National Cancer Center, Jl Letjend S Parman No. 84-86, Jakarta, Indonesia

⁵ Dr Soetomo Hospital, Jalan Mayjen. Prof. Dr. Moestopo No. 6-8, Surabaya, Indonesia

⁶ Indonesian Oncology Nurses Association, Jl Letjend S Parman No 84-86, Jakarta, Indonesia

⁷ Chinese University of Hong Kong, Nethersole School of Nursing, Sha Tin, Hong Kong Special Administrative Region of China

Correspondence to:

Prof Dr Yati Afiyanti, Universitas Indonesia, Faculty of Nursing, Kampus UI Jl Prof. Bahder Djohan, Depok, Indonesia
yati@afiyanti@yahoo.com

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adaptation (14). In cross-cultural adaptation both languages are compared during translation process and adapted to the cultural context in which the questionnaire will be used (23). This process aims to increase the confidence that the translated instrument is equivalent to the original version and that it is valid at the conceptual level in the different culture (24). This paper presents the cross-cultural adaptation of the CaSUN made into the Indonesian version (CaSUN-I) and examines its validity and reliability. This study will inform health care practice and research professionals about the supportive care needs of the gynecological cancer survivors. The use of this measure could help to address the individualized needs of the patients after treatment and provide insights into goals for achieving better survivorship care.

MATERIAL AND METHODS

This study was conducted in two phases: (1) the cross-cultural adaptation and (2) the psychometric evaluation of the CaSUN-I. We used the cross-cultural adaptation process of self-report measure as outlined by Beaton *et al.* (2000) to develop the CaSUN-I. This phase was followed by a psychometric test with gynecological cancer survivors in three sites in Indonesia.

Phase 1

Initially, the CaSUN was translated into the Indonesian language by two translators to produce the early versions of the CaSUN-I. Both translators were bilingual (English and Indonesia) and native speakers of Indonesian. The first translator understood the concepts being examined in the questionnaire while the second one was a naïve translator who was less influenced by the academic goal but whose translation could reflect the language used by the target population. Translations from the both translators were compared and discussed between them and the research team to reconcile any discrepancies.

We then involved an expert team that consisted of two academic nurses, two clinical nurses, and one physician specializing in obstetrics and gynecology with bilingual competencies to review all the versions of the questionnaire and to develop the pre-final version of CaSUN-I. Backward translation was conducted by two native English speakers with no medical background who had been living in Indonesia for more than 10 years.

Lastly, the pre-final version of CaSUN-I was piloted to five gynecological cancer survivors. Each subject filled out the questionnaire for around 16 min and was interviewed whether the meaning of items and responses were understandable or not. This process was conducted to ensure that the adapted version was able to retain its equivalence in a real situation. The distribution of responses was examined to look for a high proportion of missing items or single responses. The cancer survivors provided valuable feedback for the content, meaning and technical adaptation of the questionnaire. The research team then synthesized the adapted version of the CaSUN-I before the psychometric testing.

Cross-cultural adaptation

The adaptation of the CaSUN was built on 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 (23). We also made technical adjustments as

suggested by the patients during our pre-testing phase. For example, we changed the rating of unmet need from „weak, moderate, and strong” in the original CaSUN, into 1-3 scale (1 = less needed and 3 = strongly needed).

We adjusted the CaSUN to be more understandable for the Indonesian women with low literacy levels by using simple and familiar words. We used the terminologies that were more culturally appropriate in the Indonesian context. For example, the term „*partner*” in the original CaSUN was translated into „*husband*”, to indicate the relationship that is legally and socio-culturally acceptable in Indonesia.

Item No. 9 („I need access to complementary and/or alternative therapy services”) was translated into „*information of the complementary and/or alternative therapy services*”. Complementary and alternative therapies pose a huge problem in Indonesia since their availability and usage were attributed to late diagnosis and treatment of cancer (25). Most patients, especially in the rural areas are most likely to access alternative therapies instead of reaching treatment in health centers. Thus, instead of access they need correct information about these therapies.

We added several concrete examples referring to the existing services for cancer patients in Indonesia. For example, in item No. 15 regarding the financial support and government benefits, we put the „Family Hope Program” and „Cash transfer”; that are both Indonesian government’s social security programs targeting poor families. On the other hand, as most hospitals in Indonesia do not use case management system (item No. 28), we referred to the „nurses/doctors” to replace the „case manager” to help patients navigate the available services.

In terms of the conceptual and experiential equivalence, the overarching concept of „unmet need” can be recognized in the Indonesian context. However, the cancer patients in our pilot test had difficulty in understanding the concepts of „quality of life (QOL)” (item No. 12) and „cancer survivor” (item No. 32). For item No. 12, „changes they experience in life” was found to be more understandable instead of the original statement of „changes in my quality of life”, hence we presented the former in CaSUN-I. Also, the term of cancer survivor did not resonate well with our cancer patients that we agreed to omit the „cancer survivor” word but framed the question in relation to the impact of having cancer.

Phase 2

Participants

We recruited gynecological cancer patients using a convenience sampling method in three major hospitals across different regions of Indonesia. The first hospital was the Dharmas National Cancer Centre which is the national referral for cancer patients located in Jakarta, the capital of Indonesia. The second hospital was the Sardjito General Hospital, in Yogyakarta, the province with the highest rate of cancer cases in Indonesia (26). Our third site was the Dr Soetomo General Hospital, in Surabaya, East Java province.

The inclusion criteria were adults (over 18 years old) who had been diagnosed with gynecological cancer including cervical, ovarian, endometrial, vulvar and vaginal cancers; had finished the primary cancer treatment for at least one month; were able to understand Indonesian language; and agreed to participate. Gynecological cancer patients with cognitive impairments and metastasis in the central nervous system were excluded.

Eligible patients were approached during their visits at the gynecological oncology and radiotherapy outpatient, or gynecology oncology wards. The research team members and research assistants who collected the data filled out the clinical data from the patients' medical records. The total sample included 298 gynecological cancer patients. Then, 52 participants were consecutively selected and asked to fill out the CaSUN-I again within 2-4 weeks, to evaluate test-retest reliability.

Informed consent was sought from the participants. The ethical approvals were obtained from two Institutional Review Boards (Universitas Gadjah Mada, Faculty of Medicine, Yogyakarta and Universitas Indonesia, Faculty of Nursing, Depok).

Questionnaires

Participants completed a demographic questionnaire, the adapted CaSUN-I, and The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ C-30) - Indonesian Version. CaSUN-I was used to measure supportive care needs among gynecological cancer survivors. After the cultural adaptation phase, we retained the 35 needs items and 6 positive changes items, with some technical and linguistic adjustments, as we described in the phase 1 section.

The original CaSUN is a valid and reliable instrument with a Cronbach α coefficient of 0.96; the average of Weighted Kappa of 0.13, and the agreement between time of measurement 1 and 2 of 66%. Items correlation in the CaSUN ranged between $r = 0.4 - 0.7$ (14). On the other hand, EORTC QLQ C-30 is a thirty-item self-reported scale which assesses multiple dimensions of QOL in patients with cancer including global QOL, functional dimensions (physical, role, cognitive, emotional, and social dimensions), common symptoms, and perceived financial impact of the disease (27). Each item in the EORTC QLQ C-30 was scored by a four-point Likert scale, from „1 = not at all” to „4 = very much” (28). A high score in a functional dimension represents a high level of function, and a high score in the global QOL represents a high level of QOL. Additionally, a high score in a symptom item represents a high level of symptomatology (28). The EORTC QLQ C-30 has been translated and validated into the Indonesian language with a Cronbach's α in each domain ranging from 0.70 to 0.83 (29).

In the current study the EORTC QLQ-C30 (Indonesian version) was given to participants to test construct validity, criterion validity, reliability using internal consistency, and test-retest reliability of the CaSUN-I.

Statistical Analyses

Frequency distribution and descriptive statistics were used to summarize demographic data and clinical characteristics of participants. Exploratory factor analysis (EFA) with principal component analysis was conducted to examine the construct validity. Acceptable standards for construct validity were eigenvalues >1 , Kaiser-Meyer-Olkin >0.5 , and measures of sampling adequacy >0.5 (30). Pearson's product moment correlation was used to test criterion validity. Correlations were expected to be found between domains of the CaSUN-I and the previously validated QOL scale. We hypothesized that the higher levels of unmet needs would be negatively correlated with QOL. Cronbach's α was calculated for internal consistency reliability with acceptable coefficient values of ≥ 0.70 (30). Test-retest reliability was evaluated using Pearson's product moment correlation. Data analysis was conducted using IBM SPSS Statistic ver.22 (SPSS Inc., Armonk, NY, USA).

RESULTS

Psychometric Evaluation

The psychometric tests involved 298 gynecological cancer patients, with no missing data. Seventy one participants filled out the open-ended section. We coded their answers and found that all of them repeated the items in the CaSUN-I (e.g. need of medical care service, financial support, and social support). The participants had the opportunity to emphasize their primary concerns at that time. As they had been represented in the CaSUN-I, we did not incorporate these findings in our analysis.

Most participants were married (88.3%), were of low economic status (48% had monthly family income of approx. \$70-140) and low educational background (35.6% finished only elementary school). The participants' mean age was 50.3 years. Of all participants, 112 (37.6%) had stage III and 86 (28.9%) had stage II gynecological cancer. The majority of the participants had no metastatic disease (80.9%) and did receive chemotherapy (50%) (Table 1).

	Mean (SD)
Age (years)	50.3 (9.6)
	N (%)
Marital status	
Single	12 (4.0)
Married	263 (88.3)
Widow	23 (7.7)
Educational background	
a. No education	20 (6.7)
b. Elementary school	106 (35.6)
c. Junior high school	54 (18.1)
d. Senior high school	90 (30.2)
e. Undergraduate	26 (8.7)
f. Postgraduate	2 (0.7)
Monthly family income (Indonesian Rupiah)	
a. < 1 million	143 (48.0)
b. 1-2 million	75 (25.2)
c. 2-3 million	28 (9.4)
d. 3-4 million	23 (7.7)
e. 4-5 million	8 (2.7)
f. > 5 million	21 (7.0)
Employment	
a. Government employee	11 (3.7)
b. Private employee	27 (9.1)
c. Retired	12 (4.0)
d. Entrepreneur	59 (19.8)
e. Laborer	44 (14.8)
f. Homemaker	145 (48.7)
Stage of Cancer	
a. I	54 (18.1)
b. II	86 (28.9)
c. III	112 (37.6)
d. IV	13 (4.4)
e. Unknown	33 (11.1)
Metastatic	
a. Yes	57 (19.2)
b. No	241 (80.9)
Treatment	
a. Chemotherapy	149 (50)
b. Radiation	38 (12.8)
c. Chemo-radiation therapy	49 (16.4)
d. Surgery	26 (8.7)
e. Other	36 (12.1)

Table 1. Demographic and clinical characteristics of participants (n=298)

CaSUN item No.	Factor loadings					Explained variance (%)
	F1	F2	F3	F4	F5	
F1: Existential Survivorship (15 items)						22.49
30. Help to strengthen my beliefs	.774					
32. Help to face expectations from others and myself	.770					
33. Help to make decisions in uncertainty of life	.746					
31. Help to face from others who don't understand the impact of cancer to me	.718					
35. Help to make my life more meaningful	.715					
34. Help to explore spiritual beliefs	.700					
29. Help to move forward in my life	.697					
26. Help to adjust my body changes	.636					
25. Help to handle how to explain cancer in social situations	.625					
24. Help to talk with other cancer patients	.601					
20. Help to get emotional support	.538					
21. Help to know how to support my partner and/or my family	.503 ^b					
16. Help to get health insurance	.470 ^a					
28. Need health care providers are available anytime I needed	.447 ^a					
14. Help to maintain my employment	.423 ^a					
F2 Medical care services (13 items)						20.31
3. Given information in a way that is easy to understand		.747 ^a				
8. My complaints are adequately addressed		.733				
4. Need better health services		.688				
1. Up-to-date information of my health		.686 ^b				
6. Feeling that my opinion is important for healthcare team		.677				
11. Help to manage the treatment side		.664 ^a				
7. To know all of healthcare providers coordinate for my care		.660				
2. My family/partner get relevant information of my disease		.642 ^b				
10. Help to relief stress		.632 ^a				
5. Availability of health care services nearby		.619				
12. Help to adjust the changes in my life as an impact of cancer		.551 ^a				
19. Help with my concerns about cancer recurrence		.522 ^a				
9. Information about alternative treatments		.499 ^a				

Table 2. Principal components factor analysis with varimax rotation of CaSUN-I

Construct Validity

Thirty-five items were included for EFA resulting in six factors with eigenvalues > 1 and explained 64.10% of cumulative variance. However, the scree plot confirmed a clear peak after the fifth component, so we then decided to use only 5 factors extracted from EFA. All of the items had factor loadings greater than 0.4. The result of the EFA is shown in the Table 2. In the original CaSUN five items had factor loadings <0.3 and researchers retained 28 items. They excluded items related to „complementary and/or alternative therapy” (item No. 9), „financial support” (item No. 15), „health insurance” (item No. 16), „legal protection” (item No. 17), „ongoing case manager” (item No. 28), „get children” (item No. 13) and „maintain employment” (item No. 14) (14). However, in the CASUN-I all 35 items had factor loadings >0.4; therefore, all of them were retained. Contrary to original CaSUN, items No. 10 and 19 in the CaSUN-I were grouped in Factor 2 (while in the original CASUN those items were grouped in Factor 1). The item No. 18 of CASUN-I was grouped in Factor 4, while in the original CASUN it was grouped in Factor 2. Also, the items No. 1-3 in the original CASUN were grouped in Factor 3 and items No. 11 and 12 were in Factor 4; while all of those items were grouped in Factor 2 in the CASUN-I. Finally, item No. 21 of original CASUN was grouped in Factor 1 and items No. 22 and 27 were grouped in Factor 3 in the CASUN-I.

We named Factor 1 of the CaSUN-I (15 items) as „existential survivorship”, Factor 2 (13 items) as „medical care services”, Factor 3 (3 items) as „relationship”, Factor 4 as the „legal protection” and Factor 5 as the „financial support”.

Then we conducted the 5-Factor model with 35 items, as suggested by the EFA using a Confirmatory Factor Analysis (CFA). This model had good fit with CFI = 0.884, RMSEA = 0.068, TLI = 0.875, as shown in the Figure 1.

Criterion Validity

Table 3 shows significant correlation between total unmet needs of CASUN-I and the EORTC QLQ C-30. In addition, there were also significant correlations between the domains of CASUN-I and the EORTC QLQ C-30. The negative correlation indicated that a higher score of unmet needs resulted in lower score of QOL. These findings provide evidence that the CaSUN-I had good criterion validity among gynecological cancer survivors.

Reliability

Internal consistency was indicated by Cronbach's α values. The highest Cronbach's α value was 0.96 and across domains ranged from 0.95-0.96. Correlation between measurements 1 and 2 was $r = 0.73$ ($p = 0.001$) indicating good test-retest reliability.

DISCUSSION

Use of questionnaire that has good psychometric properties is necessary in clinical practice as well as research. Although previous instruments for the psychometric evaluation have been validated they may not be valid in a different culture, context, or time. Therefore, cross-culture adaptation and validation of such a scale is important to conduct prior to application in a different culture or context.

In general, majority of items from the CaSUN were culturally acceptable and relevant in the Indonesian context. Several additional items were included in the CaSUN-I to give clear examples that were relatable to the original CaSUN. While the linguistic translation process was relatively smooth, some concepts introduced in the CaSUN (e.g. cancer survivor and QOL) were hard to relate by the Indonesian cancer patients who mostly had lower literacy and socioeconomic status. The original CaSUN was found to be comprehensive in a way that we did not have to create additional questions. Based on our review results during the adaptation process as well as on results of our factor analyses we were able to retain all items from the questionnaire.

In the psychometric testing, five factors were identified, i.e. existential survivorship, medical care services, relationship, protection, and financial support needs. The construct dimension of CaSUN-I paralleled the sub-scale of the original CaSUN (14). The cumulative variance of our study was higher than that in the original CaSUN. The CaSUN-I study showed higher item correlations with overall factor loading of >0.4 compared to the original CaSUN (factor loading >0.3) (14). In the CaSUN-Chinese version (CaSUN-C), only four factors were extracted from EFA, yet its cumulative variance was lower than our result (17). The difference in results with the CaSUN-C might be due to different populations i.e. in our study patients with gynecological cancer were evaluated, while in Fang's study they were breast cancer patients.

The CaSUN-I also showed correlations with the Indonesian version of EORTC QLQ C-30 (29). EORTC QLQ C-30 is an established QOL scale that has been translated and validated into various languages (29,31–34). The correlations between the domains of CaSUN-I indicated low to moderate, yet significant correlations. This finding was similar with the result of the Spanish adaptation of CaSUN that examined correlation with the FACT-General QOL (19). Based on this, it can be concluded that the CaSUN-I has good criterion validity.

Furthermore, negative correlations of the CaSUN-I and EORTC QLQ C-30 scores suggested that the higher unmet needs were associated with poorer QOL, confirming our hypothesis. This finding is consistent with the findings from previous studies, for example the study among the cancer survivors in Indonesia (35), Malaysia (36), Hong Kong (37), and Asia Pacific (3).

The Cronbach's α of the CaSUN-I ranged between 0.75 and 0.95, indicating good internal consistency. These findings were comparable with the results from the original version of CaSUN (Cronbach's α = 0.78-0.93) (14), the Dutch CaSUN (0.73-0.94) (20), and the Spanish CaSUN (0.96) (19). In addition, our Cronbach's α value was higher than the CaSUN - Chinese version (0.87) (17).

The results of test-retest reliability of our study also exhibited high correlations between the first and second measurement. Our result was lower than that of the Spanish CaSUN (0.80) (19) which may resulted from the difference in time duration between the first and second measurements. In the Spanish CaSUN, the tests were conducted within two weeks, while in our study it was between two and four weeks.

Our study had some limitations as it was evaluated only in patients with gynecological cancer who were mainly receiving chemotherapy. The CaSUN-I was also not gender-neutral as the original CaSUN; but it was customized for our female population, hence limiting the applicability.

CaSUN item No.	Factor loadings					Explained variance (%)
	F1	F2	F3	F4	F5	
F3: Relationship (3 items)						9.3
23. Help to adapt new role in my family			.751 ^b			
27. Help to address sexual problems with my husband			.742 ^b			
22. Help to deal the cancer impact on relationship with my partner			.632 ^a			
F4: Protection (2 items)						4.4
17. Help to get legal protection (if malpractice happens)				.752 ^a		
18. Accessible hospital parking				.555 ^b		
F5: Financial support (2 items)						3.7
15. Help to get information about financial support from government					.836 ^a	
13. Help to get children					.831 ^a	

^aItems not retained in the original CaSUN
^bitems grouped in different Factors compared to the original CaSUN

Table 2. (Continued)

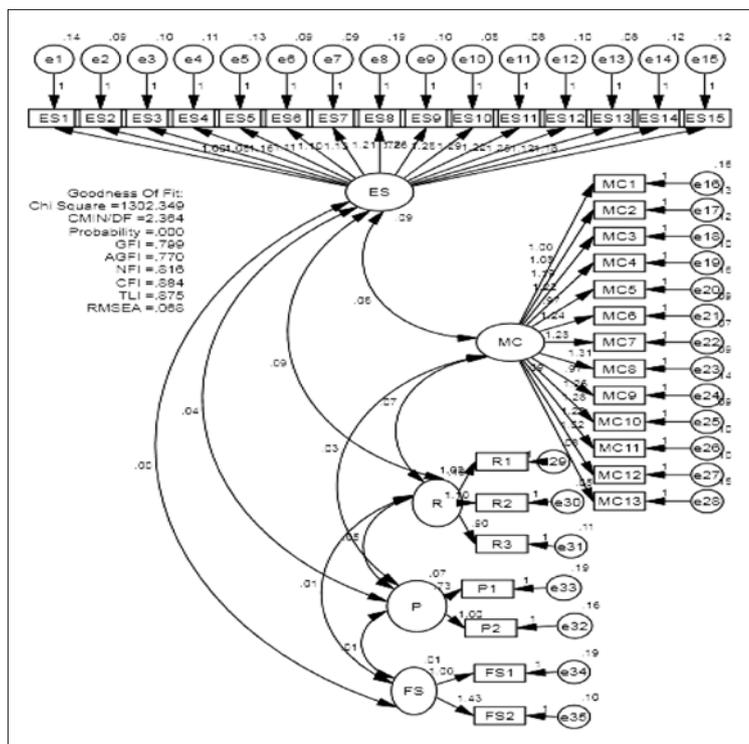


Figure 1. Confirmatory Factor Analysis

Further studies are needed to evaluate this tool in the diverse population of cancer patients in Indonesia. Apart from that, we used EORTC QLQ-C30 to evaluate the CaSUN-I validity that yielded significant but low to moderate correlations. Future studies might use different relevant tools to test criterion validity using depression-related scale such as the Hospital Anxiety and Distress Scale (HADS) and other quality of life assessment

Domain of CaSUN-I	QOL
Existential	-.318**
Medical care services	-.343**
Relationship	-.224**
Protection	-.146*
Health insurance	-.197**

*p<0.05, **p<0.01

Table 3. Correlation between scores of the CaSUN-I and the EORTC QLQ C-30

such as the Functional Assessment of Cancer Therapy- General (FACT-G) (17,19). However, given the lack of Indonesian version of validated symptom scales, our results give a valuable contribution to assess cancer-related symptoms.

CONCLUSIONS

In conclusion, the CaSUN-I offers a valid and reliable scale to assess the supportive care needs among gynecological cancer patients in Indonesia. The CaSUN-I can provide benefits to the clinicians in assessing supportive care needs among Indonesian gynecological cancer patients. The results of the assessment can build on the evidences to develop the supportive care service in Indonesia including a nurse-led consultation model or multi-professional-delivered supportive care.

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Declaration of interests

Authors declare no conflicts of interest.

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