

## Translation and Culture Adaptation of Problems and Needs of Palliative Care Questionnaires for Use in Older People in Indonesia

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### ABSTRACT

**Introduction:** Identifying problems that affect the quality of life and the need for care generally requires using a unique screening tool with the same characteristics as those used to achieve goals. However, in a clinical setting, palliative care problems and needs are given less attention and are poorly understood. In addition, there is currently no validated instrument for measuring the problems and needs of palliative care in older people. **Objectives:** This study aimed to develop and validate a new instrument that assessed palliative care problems and needs in older people. **Methods:** Items were generated through a review of the literature and refinement by an expert. The instrument was psychometrically evaluated using construct validity with convergent and discriminant validity. At three community centers in Bandung, Indonesia, 187 older people completed the final instrument. **Results:** According to the confirmatory validity test, 35 items were found to be valid. For a problem section, the factor loading ranged from 0.17 to 0.67 and for the need section from 0.17 to 0.61. Scale reported good convergent and constructed validity A 35-item psychometric properties assessment of palliative care issues and needs of older people. **Discussion:** This instrument will be clinically useful in providing a systematic way to assess problems and needs of palliative care in older people as primary data and care management evaluation. Additional research should be conducted to examine alternative methods for establishing construct validity.

**Keywords:** problems, needs, palliative care, older people, instrument, development

### ABSTRAK

**Pendahuluan:** Mengidentifikasi masalah yang mempengaruhi kualitas hidup dan kebutuhan akan perawatan memerlukan alat skrining khusus yang memiliki karakteristik yang sama dalam mencapai tujuan. Namun, dalam pengaturan klinis, masalah dan kebutuhan perawatan paliatif kurang mendapat perhatian dan kurang dipahami. Sampai saat ini, tidak ada instrumen tervalidasi khusus untuk mengukur masalah dan kebutuhan perawatan paliatif pada lansia. **Tujuan:** Tujuan dari penelitian ini adalah untuk mengembangkan dan memvalidasi instrumen baru yang mengukur masalah dan kebutuhan perawatan paliatif pada lansia. **Metode:** Item dikembangkan melalui tinjauan pustaka dan pemurnian oleh seorang ahli. Evaluasi psikometri instrumen dilakukan dengan menggunakan validitas konstrukt dengan validitas konvergen dan diskriminan. Sebanyak 187 lansia berpartisipasi dalam penelitian ini yang dilakukan di 3 wilayah kerja puskesmas di Bandung Indonesia. **Hasil:** Sebanyak 35 item dilaporkan valid menurut uji validitas konfirmasi. Factor loading berkisar antara 0,17 hingga 0,67 untuk bagian masalah dan 0,17 hingga 0,61 untuk bagian bantuan tenaga kesehatan. Sedangkan, hasil uji validitas konvergen dan diskriminan menunjukkan hasil yang baik. Sebanyak 35 item pertanyaan untuk masalah dan kebutuhan sudah dilakukan tes psikometri pada lansia. **Diskusi:** Instrumen ini akan berguna secara klinis dalam menyediakan data

*secara sistematis untuk mengidentifikasi masalah dan kebutuhan perawatan paliatif pada lansia sebagai data primer dan evaluasi manajemen perawatan. Penelitian selanjutnya perlu dilakukan untuk mengidentifikasi validitas instrumen ini dengan alternatif untuk membangun validitas konstruk.*

**Kata kunci:** masalah, kebutuhan, perawatan paliatif, lansia, instrumen, perkembangan

## INTRODUCTION

Indonesia is the third-largest country globally, with many elderly and 80 million (United Nations, 2019). The decline in function in the elderly is closely related to the decline in quality of life. Therefore, identifying problems that affect the quality of life and the need for care requires a special screening tool with the same characteristics in achieving goals (Colón-Emeri, 2013). The instrument that can be used to identify problems and needs in geriatric is adapted from the Problem Needs Palliative Care (PNPC) instrument, where PNPC is an instrument developed in the scope of palliative care nursing. This instrument is used as an initial screening to identify Problems and Needs in palliative patients (Osse, B.H., Vernooij, M.J., Schade, E., and Grol, 2004). This is in line with the characteristics of palliative patients who focus on improving the quality of life, one of them through comprehensive nursing services based on the needs and problems found in patients (WHO, 2019).

Modifying PNPC into geriatric screening is carried out while considering the initial goal of supporting optimal care following clear identification of patient needs or requests (Osse, B.H., Vernooij, M.J., Schade, E., and Grol, 2004). This modification will be applied to the elderly population that resembles palliative patients. The characteristics of the two populations require a comprehensive assessment of the problem and its needs. In addition, it aims to determine the direction of care that must be provided by health care providers, one of which is the nurse. PNPC in Indonesian has been used in the HIV and Cancer populations, both of which are in the scope of palliative care that is not limited by age level.

In contrast to previous studies, in this study, the resulting instrument is expected to be adapted in the form of language transfer to Indonesian, but the adjustment of items to identify problems and

needs in the elderly is adapted to the local culture. Cultural adjustment is motivated by the ability of individuals to perceive a problem in terms of culture. Therefore, this study aims to translate, culturally adapt and validate PNPC in the elderly population. Furthermore, the urgency of this research is to produce screening that can be used as part of a geriatric assessment so that nursing services can be provided according to the needs and problems that arise in the elderly. Therefore, this study aimed to translate and culturally adapted the PNPC for use in older people in Indonesia.

## METHODS

### Instrument Translation

This instrument is converted into Bahasa Indonesia and small-scale pilot testing for research purposes. The hearings are divided into 4 steps: forward translation, the back-translation expert group, the pre-testing, and cognitive interviews. The objective is to obtain final language versions of the English instrument for each destination country or culture and the conceptually equivalent (WHO, 2019).

### Instrument Adaptation, Validity, and Reliability

Content analysis was evaluated based on the instrument's significance, suitability, and vocabulary suitability. Experts involved in adjusting the PNPC instrument for the elderly were 5 people. Performed in two stages; the first stage consisted of one expert experienced in holding an Elderly program and two people who had expertise in geriatric science. The score criteria are 1 point if the item is unacceptable and should be deleted; 2 points are given if the items may not be suitable or relevant and significant changes are needed; 3 points are given if the items in the questionnaire are reasonable and only minor points are required.

Following the analysis by the Experts Committee, the Content Validity Index (CVI) score will be calculated by adding the converted points for each element and dividing further by the number of experts. Finally, the instrument will be adjusted based on the CVI scores and the experts' overall views (Bolarinwa, 2015).

The feasibility test is in the form of a validity test and a reliability test for the PNPC instrument modification. The test was conducted in a content validity test on experts and constructs and reliability test. The population in this study is the elderly who live in the work area of the Puskesmas Pasirkaliki. The sampling technique used is accidental for a three month period of data collection. Therefore, the inclusion criteria in this study are the elderly (aged 65 years old or older) who can communicate well, without comorbidity. Based on calculations using G-Power, the required sample of 187 elderly.

The location used as a place for collecting data is the working area of the Pasir Kaliki Puskesmas. The instrument used was the PNPC (Problems and Needs Palliative Care) -a short version questionnaire developed for the first time in 2004. The PNPC-sv instrument aims to assess the needs and problems that may arise in palliative care patients

Data analysis in this study is a statistical test in the form of content and construct validity test and reliability test using SPSS. The validity of the measuring instrument or instrument shows the accuracy of measuring an instrument. The instrument can be valid if it can measure something that should be appropriately measured (Azwar, 2014). The validity test is continued by constructing a construct validity test for 187 older adults using Pearson Product Moment correlation; if it is declared valid, it will be continued with a reliability test (Dharma, K.K., 2011). Reliability is the consistency of measurement that is the reliability and accuracy in measuring research variables. The instrument can provide the same or almost the same value if the examination takes place repeatedly (Sastroasmoro, S., Ismael, 2014). Reliability test using Cronbach Alpha.

The ethical committee has approved this study of the affiliated university. Written informed consent was obtained from the respondent before data collection. The respondent fill questionnaire in a private room and all identities were anonymous.

## RESULT

### Demographic characteristics

**Table 1. Demographic characteristics (n=187)**

Variables	n (%)
Age, mean (SD)	68.56 (3.45)
Gender	
Female	75 (40.1)
Male	112 (59.9)
Education background	
Below junior high school	100 (53.5)
Above the junior high school	87 (46.5)

Table 1 shows the demographic characteristics of studied participants. The mean was 68.56 (SD=3.45). The majority were male and having below junior high school graduated.

### Content Validity

In the initial stage, the expert provides input for the statement points no. 33 and 34. Point 33 with the statement "Difficulty in understanding the meaning of death" is recommended to be changed with the editorial "Surrender/surrender to God" and point 34 "Difficulty accepting problems experienced" in the proposed amended to "Blame God for the events in him." The second stage consisted of 2 experts, namely one from the senior science field and one from the experts experienced in the field and held the Elderly program. The results obtained, point 24 "Feeling that other people cannot be talked about the problems experienced" suggestions given that this statement is a concept of stigma is not relevant should be replaced for word editors, point 27 "Fear of problems experienced" is not relevant to healthy elderly conditions, point 31 "Surrender to the current conditions" suggested that a more appropriate editor is "resigned to the limitations

possessed." Based on the agreement of experts, points 24, 27, 31, 33, and 34 were changed. Results for I-CVI 0.782 from item level.

The use of PNPC reported that the majority of participants were easy to understand. The average questionnaire filling is 15 minutes.

### Validity Construction

In the problem and treatment section, the parts needs are slightly below the 0.70 limit value. Factor loading ranged from 0.17 to 0.67 for the problem section and from 0.17 to 0.61 for the health worker assistance section. Items approaching the 0.14 factor in the problem section are physical symptoms, namely item 7- "sexual dysfunction" and from spiritual problems, namely item 1- "resignation to current limitations" and item 2- "fear of death." While from the help of autonomous health workers item 1- "having difficulty continuing daily activities" and spiritual assistance items 4- "blaming God for the deterioration in health that is happening now". They considered that the items mentioned these symptoms are not answered due to theoretical and clinical confusion in the elderly. Therefore, these items were also not deleted after content testing with experts in their fields to maintain their clinical value.

**Table 2. Factors loading for each domain**

Variables	Factors loading
<b>Problems</b>	
ADL	0.34
Physical	0.54
Autonomy	0.17
Social	0.42
Psychological	0.67
Spiritual	0.61
Finance	0.35
<b>Needs</b>	
ADL	0.41
Physical	0.50
Autonomy	0.17
Social	0.37
Psychological	0.61
Spiritual	0.52
Finance	0.41

### Discriminant groups validity

Participants in the women's group reported higher scores with  $P > 0.05$  for the problem section and the need for health workers (table 3). Participants who did not have a job had higher scores on physical domain problems. In terms of primary or lower school education levels, high scores of social problems ( $P < 0.05$ ) and high social needs. Participants with marital status indicated that marriage had high social issues and social needs ( $P < 0.05$ ).

**Tabel 3. Difference in total and subscores of PNPC between female and male**

Domain	Female		Males		Z value	P-value
	n	Mean Rank	n	Mean Rank		
<b>Problems</b>						
ADL	117	94.91	70	92.47	-0.451	0.654
Physical	117	99.31	70	85.13	-1.760	0.078
Autonomy	117	94.16	70	93.73	-0.076	0.940
Social	117	92.44	70	96.61	-0.601	0.548
Psychological	117	95.53	70	91.45	-0.514	0.607
Spiritual	117	93.94	70	94.09	-0.020	0.984
Finance	117	95.42	70	91.62	-0.572	0.567
<b>Needs</b>						
ADL	117	96.01	70	90.64	-1.545	0.122
Physical	117	92.12	70	97.14	-0.641	0.521
Autonomy	117	95.09	70	92.17	-0.964	0.335
Social	117	93.84	70	94.27	-0.088	0.930
Psychological	117	91.25	70	98.60	-1.576	0.115
Spiritual	117	94.50	70	93.17	-0.492	0.622
Finance	117	93.29	70	95.18	-0.565	0.572

## Reliability

Cronbach's alpha coefficient for the scale of the real problem and need the help of health workers is 0.782 and 0.725, respectively Cronbach's alpha for all subscales in the problem

range from 0.273-0.660 while for the subscales in the health worker assistance ranges from -0.050-0.659 (table 4). The majority of average item-to-total correlations range from 0.14 to 46.

**Tabel 4. Reliability alpha Cronbach's: total scale and subscale**

PNPC	Total item	Problems		Needs	
		Range from yes to no (%)	Cronbach alpha	Range from yes to no (%)	Cronbach alpha
ADL	3	0.03-0.15	0.563	0.01-0.05	0.308
Physical	9	0.03-0.72	0.536	0.01-0.33	0.547
Autonomy	4	0.03-0.17	0.660	0.01-0.02	-0.050
Social	6	0.06-0.18	0.482	0.01-0.07	0.392
Psychological	7	0.07-0.53	0.747	0.01-0.07	0.659
Spiritual	4	0.02-0.32	0.433	0.01-0.03	0.626
Finance	2	0.10-0.27	0.273	0.03	-0.062
<b>Total</b>			<b>0.782</b>		<b>0.725</b>

## DISCUSSION

In this study, an adopted instrument was developed to measure the problems and needs of palliative care for older people. A psychometric test was used to evaluate the validity of the instrument. The analysis provided evidence of validity in this sample. Based on the analyses, the final instrument contains 35 items with seven subscales, physical and psychological, ADL, autonomy, social, spiritual, and finance, of which show acceptable. The subscales can be scored individually as follows. The instrument is scored 0 (No) and 1 (yes); it has a score range of 0-35. Further work is needed to test the new instrument in larger cohorts to evaluate normative values and assess barriers and facilitators about using this instrument in practice settings. Future research could also be conducted to determine cut-scores, such as levels on subscales at which individuals may likely be.

This instrument was tested in a community center in Indonesia to reflect generalizability. Further testing using test-retest methods should be conducted to examine the consistency of scores over time. This study was also limited by a small-to-modest sample size that precluded evaluating construct validity and another psychometric test. Further research should explore alternative methods to support construct validity.

There has not been a psychometrically assessed instrument to measure the problems and needs of palliative care for older people reliably. In this study, we adopted and initially validated a new instrument to measure problems and needs of palliative care for older people, including physical and psychological, ADL, autonomy, social, spiritual, and finance (Osse, B.H., Vernooij, M.J., Schade, E., and Grol, 2004). This information is clinically and practically meaningful. It provides a systematic way to assess problems and needs of palliative care for older people as primary data and evaluation of care management. In addition, as a new instrument is developed, feedback from this instrument may help identify ways to improve the quality of care for older people.

## Conflict of Interest

The authors declare no conflict of interest.

## CONCLUSION

This study successfully adopted the Bahasa version of PNPC to comprehensively assess the needs and problems of the elderly in Indonesia. This instrument would clinically meaningful to provide a systematic way to assess problems and needs of palliative care in older people as a primary data and evaluation of care management. Further research should explore alternative methods to support construct validity.

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## Supplementary

**Table S1. Bahasa version of PNPC**

Adakah Masalah?				Masalah anda dan Kebutuhan	Apakah Anda Membutuhkan Bantuan Tenaga Profesional?		
	Ya	Sedikit	Tidak		Ya	Sudah Cukup	Tidak
<b>AKTIVITAS SEHARI-HARI</b>							
Adl 1				Perawatan diri, mandi, berpakaian atau ke toilet			
Adl 2				Transportasi individual (berkendaraan sendiri, menyetir mobil, naik kendaraan umum dll.)			
Adl 3				Melakukan pekerjaan ringan di rumah			
<b>GEJALA FISIK</b>							
Phy 1				Nyeri			
Phy 2				Fatik/ Kelelahan			
Phy 3				Gangguan tidur			
Phy 4				Pernafasan pendek /sesak nafas			
Phy 5				Batuk			
Phy 6				Gatal -gatal			
Phy 7				Gangguan fungsi sexual			
Phy 8				Kulit terasa baal/kesemutan			
Phy 9				Badan berkeringat dan terasa panas di malam hari			
<b>OTONOMI</b>							
Aut 1				Mengalami kesulitan untuk melanjutkan kegiatan sehari-hari			
Aut 2				Kesulitan untuk memberikan bantuan pada orang lain			
Aut 3				Bergantung pada bantuan orang lain			
Aut 4				Mengalami kehilangan kontrol dalam menentukan dan menjalani kehidupan			
<b>MASALAH SOSIAL</b>							
Soc 1				Mengalami masalah dalam hubungan dengan pasangan hidup			
Soc 2				Kesulitan dalam berkomunikasi tentang penyakitnya dengan pasangan hidup			
Soc 3				Kesulitan dalam membicarakan penyakitnya dengan orang lain karena tidak mau membebani orang lain			
Soc 4				Merasakan bahwa orang lain tidak bisa diajak bicara tentang penyakit yang dialami			
Soc 5				Kesulitan menemukan seseorang untuk membicarakan penyakitnya			

**Table S1. Bahasa version of PNPC (*Lanjutan*)**

Adakah Masalah?				Masalah anda dan Kebutuhan	Apakah Anda Membutuhkan Bantuan Tenaga Profesional?		
	Ya	Sedikit	Tidak		Ya	Sudah Cukup	Tidak
<b>MASALAH PSIKOLOGIS</b>							
Psy 1				Perasaan Depresi			
Psy 2				Marah dan frustasi			
Psy 3				Takut terhadap penderitaan fisik yang dialami			
Psy 4				Takut terhadap penyebaran kanker			
Psy 5				Tidak siap dengan kondisi yang tidak terduga yang mungkin dialami di masa yang akan datang			
Psy 6				Kesulitan untuk menunjukkan emosin/perasaan yang dialami			
<b>MASALAH SPIRITAL</b>							
Spi 1				Merasakan tidak dapat melibatkan diri untuk sesuatu pekerjaan yang berguna			
Spi 2				Merasakan tidak berguna bagi orang lain			
Spi 3				Kesulitan dalam memahami makna kematian			
Spi 5				Kesulitan menerima penyakitnya			
<b>MASALAH KEUANGAN</b>							
Fin 1				Mengeluarkan banyak uang untuk penyakitnya			
				Kehilangan penghasilan karena penyakit yang dialami			
<b>Pertanyaan Tambahan</b>							
				Kesulitan untuk mendapatkan pelayanan kesehatan di puskesmas			
				Kesulitan untuk mendapatkan obat ARVs			
				Merasa sulit dalam memenuhi kebutuhan nutrisi			