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# Measuring the Burden on Family Caregivers of People With Cancer

## Cross-cultural Translation and Psychometric Testing of the Caregiver Reaction Assessment–Indonesian Version

### KEY WORDS

Burden  
Caregiver reaction  
assessment  
CRA  
CRA-ID  
Family caregiver  
Indonesia  
Psychometric testing  
Translation instrument

**Background:** The Caregiver Reaction Assessment (CRA) is considered one of the well-developed instruments for measuring the multidimensional burden of family caregivers. To date, there is no available validated instrument to assist healthcare professionals in measuring the caregiver's burden in Indonesia. **Objective:** To translate the CRA from English into Indonesian and to conduct psychometric testing of this CRA–Indonesian version (CRA-ID) with family caregivers of patients with cancer. **Methods:** Cross-cultural translation and psychometric testing were conducted. Confirmatory factor analysis and exploratory factor analysis were performed to check, explore, and confirm the best model for the CRA-ID; internal consistency was also measured. **Results:** A total of 451 respondents participated, of whom 40 were involved in the feasibility testing. Confirmatory factor analysis with the original factors of the CRA revealed that the fit was not satisfactory, and adaptation was needed. Through exploratory factor analysis, the best model fit was developed, and confirmatory factor analysis was performed again. Five factors from the original instrument were confirmed with an explained variance of 54.89%. Almost all items in the CRA-ID appeared to have a similar structure as the original version. Cronbach's  $\alpha$ 's ranged between .64 and .81. **Conclusions:** The CRA-ID appeared to be feasible, valid, and reliable for measuring the burden of family caregivers of patients with cancer in Indonesia. **Implications for**

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**Practice:** Nurses can use the CRA-ID to measure family caregivers' burden. Its availability in the Indonesian language enhances the opportunity to conduct international comparisons of family caregiver burden using the same instrument.

Asia has the highest incidence of cancer of all continents (48% of all cases worldwide), twice as high as in Europe (24.4%) and in America (20.5%).<sup>1</sup> Cancer impacts the patients who have it and their family caregivers as well, especially in Asia where looking after a family member who is ill is part of the culture.<sup>2,3</sup> Similarly, in low-income countries, family caregivers are expected to be actively involved in the caring process, even during hospitalization.<sup>4</sup> However, the burden on family caregivers in low- and middle-income countries is ignored because of a lack of empirical data.<sup>5</sup> Having a well-developed instrument to measure family caregiver burden developed through a cross-cultural translation and adaptation process would be valuable in Asia.<sup>6</sup>

The Caregiver Reaction Assessment (CRA) is a well-developed and well-tested measure of caregiver burden.<sup>7</sup> A recent systematic review concluded that the CRA is the most frequently used instrument<sup>8</sup> and is considered to have the strongest psychometric performance for measuring family caregivers' burden.<sup>9</sup> The CRA measures the burden across multidimensional aspects, positive as well as negative. It is available in 9 languages (Appendix 1, Supplemental Digital Content 1, <http://links.lww.com/CN/A22>) and has been administered to family caregivers of patients with cancer,<sup>10–14</sup> patients with physical impairment in general,<sup>15</sup> people with dementia,<sup>16</sup> and the elderly.<sup>17</sup> Recently, it has also been tested for psychometric properties in the United States.<sup>18</sup> Translations of the CRA with its original structure in 5 subscales and 24 items were used in some studies,<sup>10,11,13–16</sup> whereas others adapted it to 4 subscales and/or deleted some items.<sup>12,17,18</sup> Internal consistencies of the CRA subscales in the different languages vary from .57 to .89 (Appendix 1, Supplemental Digital Content 1, <http://links.lww.com/CN/A22>).

Inconsistencies in the construct validity of the CRA have been reported in previous Asian studies. Six items were deleted from the CRA–Japan version because of discrepancies with the Japanese culture.<sup>12</sup> The authors of a study in Singapore used the CRA with 4 rather than 5 subscales<sup>17</sup> and recommended more studies be conducted to assess the relevance of the CRA in the Asian setting.<sup>17</sup> However, the CRA has not been tested in any Asian country for family caregivers of patients with cancer living at home, despite this being the norm in Asia. For that reason, the current study aimed to translate the CRA into the Indonesian language through a cross-cultural translation process and to conduct psychometric testing of the resulting instrument, the CRA–Indonesian version (CRA-ID).

## ■ Methods

### Sample and Data Collection

In this cross-sectional study, between February and May 2017, a questionnaire was administered to family caregivers of patients with cancer in 3 outpatient clinics in Jakarta, Surabaya, and Yogyakarta.

Eight research assistants (bachelor degree nurses who had previously received a full day's training in research ethics, data collection procedures, and the study itself) were involved in the data collection process. Adult family caregivers of patients with cancer were invited to participate. Inclusion criteria were (a) the spouse, adult child, or relative looking after a patient with cancer in stages 2 to 4; (b) a family caregiver for at least 4 months; (c) living with the patient or delivering care for at least 3 hours per day; (d) 18 years or older; and (e) willing to participate.

The research assistants checked the eligibility of potential participants based on data in the medical record. If the inclusion criteria were met, the family caregivers were invited to participate and to receive the complete information about the study, including the right to withdraw from it with no consequences. Written informed consent was completed.

## STUDY INSTRUMENT

### Caregiver Reaction Assessment

The original CRA was developed to measure the burden of family caregivers of patients with chronic physical or mental impairment.<sup>19</sup> The CRA consists of 24 items with 5 subscales: self-esteem (SE), lack of family support (LFS), impact on finance (IF), impact on schedule (IS), and impact on health (IH), with Likert response format options from 1 to 5 (strongly disagree to strongly agree). Five items are reverse scored. The CRA measures the impact of providing care at the subscale level, with no overall summative score.<sup>19</sup> All subscales have negative connotations, with the exception of self-esteem (Table 1).

### Cross-cultural Translation Process of the CRA

The CRA was translated from the original English following the 5 cross-cultural translation steps as described by Beaton<sup>20</sup> (Figure). First, the CRA was translated into Indonesian by 2 professional native-speaking Indonesian English translators, neither of whom has a medical background. The second stage was the synthesis process. Two authors (M.S.K. and C.E.) compared the translations to reach consensus on a draft of the CRA-ID. In the third stage, 2 English native speakers who are also fluent in the Indonesian language both independently translated the draft CRA-ID back into English. The fourth stage was a research committee meeting in which all documents were compared and adapted. A final draft of the CRA-ID was produced. The fifth stage was a pretesting or feasibility test to check the applicability of the CRA-ID to family caregivers of patients with cancer. They were asked to complete the CRA-ID and to answer some questions to check its feasibility (Appendix 2, Supplemental Digital Content 2, <http://links.lww.com/CNA23>). During pretesting, the time taken for filling out the CRA was

**Table 1 • The Structure of the Caregiver Reaction Assessment**

Subscales	Aim	Interpretation	No. of Items	Item Number
SE	To measure how much the caregiving influences family caregiver's self esteem	A higher score means a higher self-esteem of the family caregiver	7	1, 7 (reversed), 9, 12, 17, 20, 23
LFS	To assess to which extent the family caregiver receives support from the family to complete caregiving tasks	A higher score means less support from the family	5	2, 6, 13 (reversed), 16, 22
IF	To measure to what extent the caregiving process influences financial aspects	A higher score means higher impact on financial issues	3	3 (reversed), 21, 24
IS	To measure to what extent the caregiving tasks interrupt the family caregiver's activities	A higher score means more interruptions on the family caregiver's schedule	5	4, 8, 11, 14, 18
IH	To measure the family caregiver's health and strength in providing care	A higher score means higher impact on the family caregiver's health	4	5, 10, 15 (reversed), 19 (reversed)

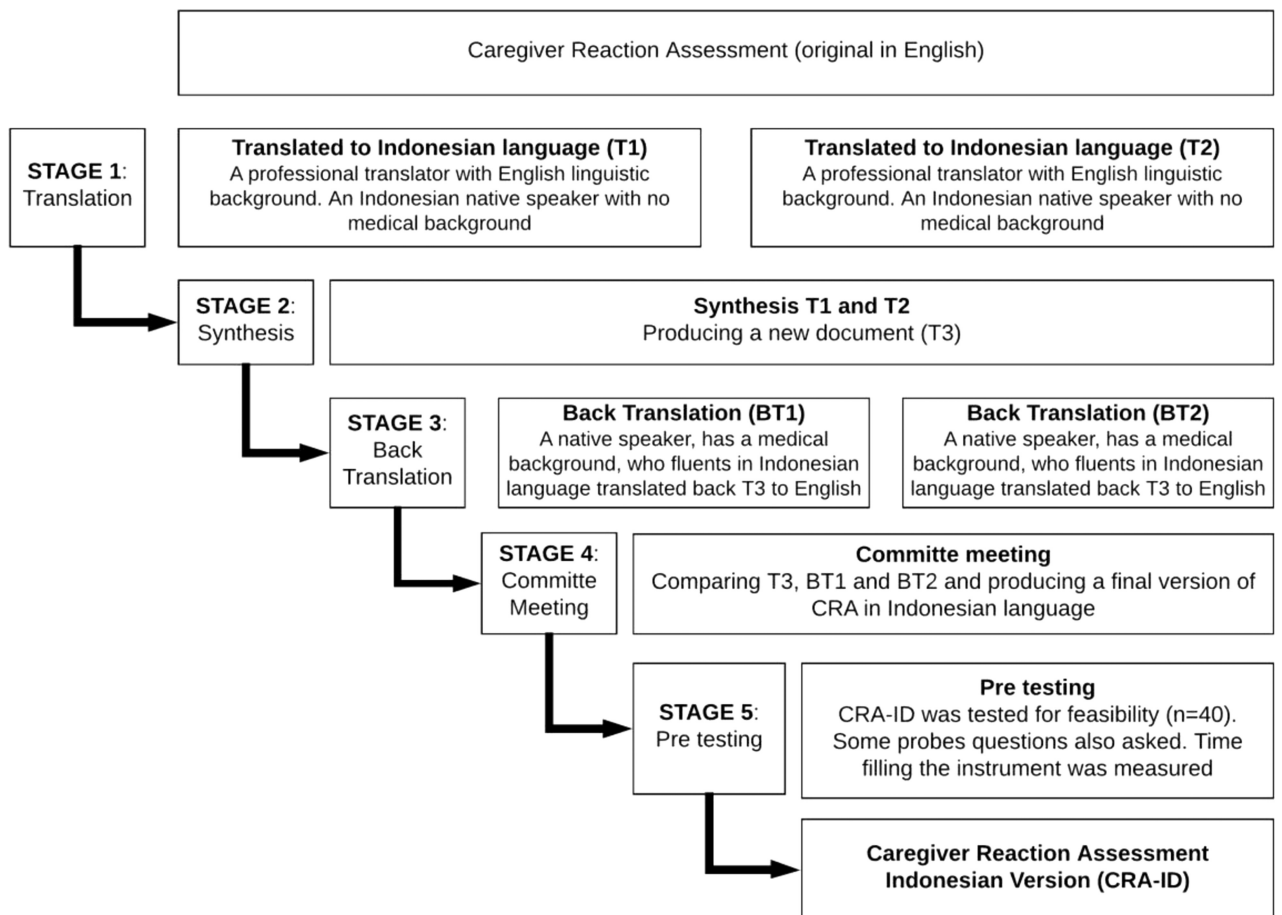
Abbreviations: IF, impact on finance; IH, Impact on Health; IS, impact on schedule; LFS, lack of family support; SE, self-esteem.

documented. Feasibility was measured by percentages of missing values, time needed, and suggestions from respondents.

### Data Analyses

The guideline from Suhr<sup>21</sup> was used for psychometric testing of the CRA-ID. The same data set was used for each step.<sup>18</sup> Step 1:

Confirmatory factor analysis (CFA) was performed for the original 5-factor model, to examine the necessity of any change. Adequacy of the sample size was measured using the ratio 5:1 between the number of parameters and participants. Model fit was confirmed if 2 or more indicators reached the criteria for model fit indices: (a)  $\chi^2/\text{degrees of freedom (df)} \leq 3.00$  was considered an acceptable fit<sup>22</sup>; (b) a root mean square error of



**Figure ■** Five steps on translation process of CRA-ID followed cross-cultural translation by Beaton.<sup>20</sup> Abbreviation: CRA-ID, Caregiver Reaction Assessment–Indonesian version.

approximation (RMSEA)  $\leq 0.06$  indicates an acceptable fit; (c) a standardized root mean square residual (SMRS)  $\leq 0.05$  was considered a good fit; (d) goodness-of-fit index (GFI) and comparative fit index (CFI)  $\geq 0.90$  indicate acceptable fit.<sup>23</sup>

Step 2: Where the CFA did not pass the criteria for a good model fit, exploratory factor analysis (EFA) was conducted. Exploratory factor analysis was used to check the instrument's constructs<sup>24</sup> and to explore the best fit for a new factor model.<sup>21,25</sup> At first, Kaiser-Meyer-Olkin and the Bartlett test were conducted to check sampling adequacy (minimum eigenvalues  $>1.00$ ). An EFA was run with a principal component analysis and varimax rotation. An item would be retained if it was unique and sufficient by loading  $>0.40$  and not cross-loading in another factor  $>0.32$ . A factor with 2 items was not deleted if those 2 were correlated with an  $r > 0.70$ .<sup>25</sup> Items were also analyzed semantically to maintain concepts based on their content.<sup>19,25</sup> Step 3: CFA was run again to confirm the new model.

Step 4: reliability estimating using Cronbach's  $\alpha$  was conducted to measure the internal consistency of the items and subscales, and  $\alpha$  scores were assessed when an item was deleted. Homogeneity was considered acceptable if a score was between 0.70 and 0.90. Statistical analyses were performed using SAS Data Management, version 9.2 (SAS Institute Inc, Cary, North Carolina), and SPSS, version 25 (IBM, SPSS Statistics, Armonk, New York).

## Ethical Considerations

Permission to translate the instrument into the Indonesian language was given by the CRA developer (given on November 15, 2016). Ethical approval for this study was received from the Medical and Health Research Ethics Committee, Faculty of Medicine, Universitas Gadjah Mada—Dr Sardjito General Hospital (KE/FK/744/EC/2015) and the Ethical Committee in Health Research of Dr Soetomo regional Hospital, Surabaya (no. 46/Panke.KKE/I/2016). Each participant received complete information about the study and signed an informed consent prior to involvement. Each was informed that they could withdraw at any point with no consequences for themselves or the patients. Participation was voluntary, and data were collected, analyzed, and stored anonymously, according to the rules of good clinical practice and the Declaration of Helsinki.

## Results

### Characteristics of Participants

A number of men and women participated, with a mean age of  $43.9 \pm 13.41$  years. More than half of the participants (53.5%)

were not the spouse but adult children, children-in-law, siblings, or parents or had another relationship to the patient.

## Feasibility Testing

For the feasibility testing, 40 participants gave their ratings on 6 short questions (Appendix 2, Supplemental Digital Content 2, <http://links.lww.com/CNA23>) on the CRA-ID. There were no missing values. The mean time to complete the CRA-ID was 3.5 minutes. Ninety-five percent of the participants reported that the instruction was simple and clear. Fifteen participants reported difficulties in understanding the term “reply” in item 12. Eighty percent found the sequence of the questions adequate, meaning that the questions' arrangement was easy to follow. Almost 90% strongly agreed that the instrument is easy to understand.

## Construct Validity

### CFA FOR THE ORIGINAL 5-FACTOR MODEL

The number of parameters was 63. With the criterion of a 5:1 ratio, 315 was the minimum required number of participants. The model fit for the original 5-factor model was as follows:  $\chi^2/df = 3.19$ , RMSEA = 0.0698, SMRS = 0.0709, GFI = 0.8713, and CFI = 0.8227 (Table 2). Only 1 of 5 indices passed the model fit criteria; therefore, the good model fit for the original model of the CRA was not confirmed. For that reason, an EFA was performed as a next step.

### EFA WITH 5-FACTOR ORIGINAL MODEL

The Kaiser-Meyer-Olkin and Bartlett score was 0.850, which reflects adequacy of the sample size. The EFA supported a 5-factor model with a principal component analysis and varimax rotation solution and accounted for 54.89% of the total variance. We found 3 conflicting items, of which 2 did not fulfill the eligibility criteria to be retained (items 12 and 10). The score of item 12 (“I will never be able to do enough caregiving to repay ...”) was not sufficient to load on any factor. Item 10 (“My health has gotten worse since I've been caring for ...”) loaded onto 2 factors: IS (0.439) and IH (0.410), which reflects that this item is not unique and measures 2 factors. Therefore, we decided to exclude items 12 and 10 from the CRA-ID. Next, item 5 (“Since caring for ..., it seems like I am tired all the time”) loaded on IS instead of on IH (Table 3). For that reason, the meaning of item 5 in Indonesian was discussed with an Indonesian linguistic expert. After that, we decided to include item 5 in the IS factor.

### CFA WITH THE NEW MODEL (CRA-ID)

The model fit indices for CRA-ID were as follows:  $\chi^2/df = 2.61$ , RMSEA = 0.0599, SMRS = 0.0637, GFI = 0.9041, and CFI = 0.8257 (Table 2). Four of 5 met the criteria for an adequate model fit.

 **Table 2 • Confirmatory Factor Analysis in 2 Models (N = 451)**

	$\chi^2$	df	$\chi^2/df$	RMSEA	SMRS	GFI	CFI
Model 1 (original) (N = 451)	773.21	242	3.19	0.0698	0.0709	0.8713	0.8227
Model 2 (CRA-ID) (N = 451)	520.69	199	2.61	0.0599	0.0637	0.9041	0.8883

Abbreviations: CFI, comparative fit index; CRA-ID, Caregiver Reaction Assessment-Indonesian version; *df*, degrees of freedom; GFI, goodness-of-fit index; RMSEA, root mean square error of approximation; SMRS, standardized root mean square residual.

**Table 3 • Exploratory Factor Analysis of the Caregiver Reaction Assessment (24 Items)**

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
9	0.783				
17	0.772				
23	0.770				
1	0.694				
20	0.564				
7	0.492				
11		0.724			
14		0.707			
4		0.641			
18		0.583			
8		0.510			
5		0.495			
10		0.439		0.410	
22			0.718		
13			0.648		
16			0.625		
2			0.572		
6			0.567		
19				0.737	
15				0.731	
3					0.773
24					0.666
21					0.586
12					

**RELIABILITY**

Table 4 depicts the internal consistencies of the CRA-ID (22 items). The subscales SE, IH, and IS had adequate internal consistencies with Cronbach’s  $\alpha$  coefficients of .810, .766, and .746, respectively. The subscales LFS ( $\alpha = .650$ ) and IF ( $\alpha = .640$ ) had low moderate internal consistency coefficients. The SE, IF, and LFS subscales would increase to .815, .687, and .676, respectively, if item 20 (“Caring for ... is important to me”), item 3 (“My financial resources are adequate to pay for things for caring”), and item 2 (“Others have dumped caring for ... onto me”) were deleted.

**Discussion**

We were able to conduct a cross-cultural translation of the CRA into the CRA-ID (Appendix 3) and tested its psychometric properties. Our study supports the use of the CRA-ID with 22 items. It has adequate psychometric properties with regard to feasibility, validity, and reliability. The CRA-ID could be applied in less than 5 minutes and has the same 5 subscales as the original version, and its internal consistency appeared to be adequate. Adapting a validated instrument is more effective and efficient than developing a new one.<sup>6,26</sup> It also provides the opportunity to conduct comparative studies between countries using the same instrument.

In our study, the results of the CFA indicated that the original model needed modification. Validity testing revealed 3 problems.

First, item 12 (“I will never be able to do enough caregiving to repay ...”) appeared to be problematic because it did not load in any of the subscales, which is in line with previous studies from the Netherlands, Sweden, and the United States.<sup>10,15,18</sup> Studies in Norway and Japan found that this item is cross-loading in a different factor than in the original version.<sup>11,12</sup> Some studies choose to keep this item, although the internal consistency of the SE subscale would be higher if it was deleted.<sup>11,14,15</sup> A Dutch version modified it by reversing this item.<sup>10</sup> In Indonesia, “repay” or “membalas budi” is mostly used in relation to children paying back what they have previously received from their parents. Therefore, in particular, those family caregivers not being the child of the patient were confused by it, so this item was deleted in the CRA-ID, as in the Japanese<sup>12</sup> and the US<sup>18</sup> translations.

Second, our study showed that item 10 appeared not to be a unique factor, as it loaded into 2 subscales, IS and IH, while it should be loaded only into IH. This confirms almost all previous findings that the 2 particular subscales are related—IS and IH—and it has therefore been assumed that they might not be sufficiently distinct.<sup>10,13–18</sup> For that reason, we also excluded this item in the CRA-ID. Third, item 5 was highly loaded in IS instead of IH, which was also the case in previous studies.<sup>10–18</sup> In our case, item 5 can be interpreted as meaning that the family caregiver’s time was full with providing care, which can be seen as a schedule issue and not merely as a health problem. Therefore, we included this in the impact of schedule subscale.

All subscales in the CRA-ID had adequate internal consistencies, ranging from .640 to .810. The lowest subscale score was reported in a Norwegian study with .52 in the subscale of finances.<sup>11</sup> The highest subscales, ranging from .73 to .89, were reported in a Japanese study<sup>12</sup> with the deletion of 6 items.

**Implications for Nursing Practice**

This article provides the first translation and validation of an instrument to measure the burden of family caregivers in Indonesia. Using the CRA-ID, nurses will be assisted in exploring a family caregiver’s burden in a structured way. It also provides the opportunity to conduct comparative studies between countries using the same instrument, considering that it has been translated and validated in 9 other languages.

**Strengths and Limitations**

The CRA-ID (Appendix 3) is the first and only validated instrument in Indonesia to measure family caregiver burden. By using the steps of Beaton,<sup>20</sup> we applied a rigorous transcultural translation process. Next, we involved a larger number of participants than in previous studies. One limitation was related to the data collection process. We performed face-to-face interviews in order to reduce missing data, as the response rate for face-to-face interviews is higher than for telephone, internet-based, or postal questionnaires.<sup>27</sup> Such a face-to-face interview, however, might have influenced the family caregivers to hide their feelings or not reveal the truth.<sup>28</sup> Further, some patients were present during the session, meaning that some family caregivers might have been reluctant to reveal their feelings in front of them. Finally, we performed

**Table 4 • Factor Analysis and Internal Consistency of the Caregiver Reaction Assessment Indonesian Version (N = 451)**

Item No.	Questions	Exploratory Factor Analysis With Principal Component Analysis					$\alpha$ Subscale	$\alpha$ Subscale, if Item Deleted
		Factor <sup>a</sup> 1	Factor <sup>a</sup> 2	Factor <sup>a</sup> 3	Factor <sup>a</sup> 4	Factor <sup>a</sup> 5		
Subscale 1. SE							.810	
(9)	I really want to care for ...	0.785					.761	
(17)	Caring for ... makes me feel good	0.780					.748	
(23)	I enjoy caring for ...	0.774					.761	
(1)	I feel privileged to care for ...	0.707					.781	
(20)	Caring for ... is important to me	0.556					.815	
(7)	I resent having to take care of ... (reversed)	0.500					.806	
Subscale 2. IS							.746	
(11)	I visit family and friends less since I have been caring for ...		0.728				.682	
(14)	I have eliminated things from my schedule since caring for ...		0.715				.683	
(4)	My activities are centered around care for ...		0.695				.724	
(8)	I have to stop in the middle of work		0.585				.704	
(18)	The constant interruptions make it difficult to find time for relaxation		0.548				.704	
(5)	Since caring for ..., it seems like I'm tired all the time		0.479				.732	
Subscale 3. LFS							.650	
(22)	My family left me alone to care for ...			0.731			.540	
(13)	My family works together at caring for ... (reversed)			0.662			.581	
(16)	Since caring for ..., I feel my family has abandoned me			0.634			.601	
(6)	It is very difficult to get help from my family in taking care of ...			0.593			.599	
(2)	Others have dumped caring for ... onto me			0.559			<b>.676</b>	
Subscale 4. IF							.640	
(3)	My financial resources are adequate to pay things that are required for caregiving (reversed)				0.771		<b>.687</b>	
(24)	It's difficult to pay for ...'s health needs and services				0.704		.497	
(21)	Caring for ... has put a financial strain on the family				0.606		.427	
Subscale 4. IH							.766	
(19)	I am healthy enough to care for (reversed)					0.774	.	
(15)	I have enough physical strength to care for ... (reversed)					0.756	.	
	Eigenvalue	5.41	2.41	1.64	1.30	1.22		
	Explain variance (54.89%)	24.91%	10.99%	7.48%	5.93%	5.55%		

Abbreviations: IF, impact on finance; IH, impact on health; IS, impact on schedule; LFS, lack of family support; SE, self-esteem.

<sup>a</sup>Factor loading > 0.4.

a cross-sectional study, which did not include confirmation of longitudinal stability of the CRA-ID factor structure.

## Conclusion

Our study suggests that the CRA-ID is a feasible, valid, and reliable instrument to measure the burden on the family caregivers

of patients with cancer but needs to be confirmed in a next study. The CRA-ID can be applied in less than 5 minutes; hence, healthcare providers may consider using it during their regular consultation sessions. Some cautions need to be considered. In Indonesia, family caregivers may find it inappropriate to show resentment about caregiving tasks; it is better therefore to apply such an instrument without the presence of the patient. Based on our results, there is no need to modify the number of factors.

We suggest renaming the “self-esteem” subscale to “belief in caregiving” in order to better represent its content. And finally, having a validated instrument with the same construct raises the chances of conducting comparison studies with other countries.

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I. Pengkajian Reaksi Keluarga (CRA-ID)

Petunjuk:

- Isi \_\_\_\_ dengan nama anggota keluarga yang anda rawat.
- Pilihlah jawaban yang menurut anda sesuai dengan yang anda rasakan dengan tanda centang (√)

No.	Pernyataan	Respon				
		Sangat tdk setuju	Tidak setuju	Ragu-ragu	Setuju	Sangat setuju
1.	Saya merasa beruntung bisa merawat ____.					
2.	Anggota keluarga lain telah melemparkan tanggungjawab merawat ____ kepada saya.					
3.	Sumber keuangan saya memadai untuk membiayai hal-hal yang dibutuhkan dalam perawatan.					
4.	Kegiatan saya terpusat untuk merawat ____.					
5.	Semenjak merawat ____, saya seperti selalu merasa kelelahan.					
6.	Sulit mendapatkan bantuan dari keluarga saya untuk merawat ____.					
7.	Saya sangat tidak suka merawat ____.					
8.	Saya harus berhenti bekerja untuk merawat ____.					
9.	Saya sangat ingin merawat ____.					
10.	Saya menjadi jarang mengunjungi saudara dan teman-teman sejak merawat ____.					
11.	Keluarga saya bekerjasama dalam merawat ____.					
12.	Kegiatan-kegiatan pribadi telah saya hilangkan dari jadwal sejak saya merawat ____.					
13.	Saya memiliki cukup kekuatan fisik untuk merawat ____.					
14.	Semenjak merawat ____, keluarga telah mengabaikan saya.					
15.	Merawat ____ membuat saya merasa senang.					
16.	Gangguan yang terus menerus membuat saya sulit untuk menemukan waktu bersantai.					
17.	Saya cukup sehat untuk merawat ____					
18.	Merawat ____ penting untuk saya					
19.	Merawat ____ telah membebani keuangan keluarga.					
20.	Anggota keluarga lain meninggalkan saya sendiri untuk merawat ____.					
21.	Saya menikmati merawat ____.					
22.	Sangat sulit membayar biaya dan pelayanan kesehatan untuk kebutuhan ____.					