Journal of Multidisciplinary Healthcare

Dovepress
Taylor & Francis Group

Open Access Full Text Article

ORIGINAL RESEARCH

Factors Associated with Caregiver Burden in Families of Patients with Palliative and Chronic Illness: A Cross-Sectional Study

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Background: Caregivers of patients with palliative and chronic conditions often experience complex physical, emotional, and social burdens. These burdens impact not only their well-being but also the continuity and quality of care provided.

Purpose: This study aimed to identify the level of caregiver burden and factors associated with it in families caring for members with palliative conditions and chronic illnesses.

Patients and Methods: A cross-sectional study of 71 caregivers was conducted using convenience sampling. Data were collected using the FATCOD-B, knowledge toward palliative care, and Zarit Burden Interview (ZBI). Data were analyzed using the Rasch model and bivariate tests.

Results: A high burden was reported by 50.7% of caregivers, while 39.4% and 9.9% experienced moderate and low burden, respectively. The variables of marital status, length of care, the availability of health insurance, and caregiver attitude showed a significant relationship to caregiver burden ($p<0.05$). Rasch's analysis revealed that perceived loss of privacy was the statement with the lowest level of agreement. At the same time, feelings of not being optimal enough in providing care were the statement most frequently acknowledged by caregivers.

Conclusion: Psychosocial and structural factors influence caregiver burden. These findings highlight the need for integrated interventions, including psychosocial support, financial security, and caregiver education, to mitigate burden in this population.

Keywords: caregiver burden, chronic illness, family caregiver, palliative care

Introduction

The World Health Organization (WHO) defines palliative care as comprehensive support provided to patients with terminal illnesses and their families.[1] Worldwide, only about 14% of people who need palliative care currently receive it.[1] Palliative care is important in improving the quality of life for patients with chronic or terminal illness. However, providing palliative care which may demand a long and persistent care often has significant psychological, emotional, and physical impacts on family members who serve as primary caregivers.[2] The multidimensional stress arising from physical, emotional, and financial caregiving demands can be overwhelming, adding to the challenges faced by caregivers in this context.[2]

In providing care for individuals with palliative, chronic health conditions or long-term medical needs, the role of the caregiver is very crucial.[3–5] Palliative and chronic illnesses have different characteristics, and thus their caregiving challenges differ from the outset. Palliative illness typically refers to life-threatening conditions that require care focused on comfort, symptom management, and improving the quality of life of patients who may be in the final stages of their illness.[1] In contrast, chronic illness is a long-term condition that is generally not fully curable, such as diabetes or

Received: 8 April 2025
Accepted: 24 July 2025
Published: 31 July 2025

hypertension, and requires ongoing management to prevent complications and maintain daily functioning.[6] However, the ongoing responsibility of caring for patients often poses various challenges that can impact their physical, emotional, social and economic well-being.[3,7,8]

The burden experienced by caregivers, known as caregiver burden, reflects the stress that arises from the demands of complex and prolonged care.[9] This burden can increase with the complexity of the patient's condition, limited social support, and the lack of resources available to assist caregivers in carrying out their roles.[5,7] The similar results were reported in a study conducted in Indonesia, which found that several factors that cause burden on caregivers are income, marital status, and support from other family members.[10] In addition, low knowledge and inadequate skills of caregivers, limited availability of health services can be the cause of high burden for caregivers in Indonesia.[10–13] However, family caregivers ethnicity did not have significant differences.[11]

Several previous studies have reported that many caregivers of palliative patients or individuals with chronic illnesses experience a relatively high level of burden.[8,14–17] In Southeast Asia, caregiver burden is a common challenge in countries with similar healthcare systems and resources. A study in Thailand found that caregivers of patients with chronic illnesses also reported high levels of stress due to limited support and resources.[18,19] For comparison, study conducted in US reported that caregivers face additional challenges, including lack of formal training and financial difficulties, which exacerbate their caregiving roles.[20] These regional disparities highlight the importance of understanding the unique needs of caregivers in Southeast Asia, where healthcare systems are often under-resourced compared to higher-income countries.

The high burden experienced by caregivers is correlated with the poor quality of life of the patient and caregiver.[15] In addition, high burden levels also have an impact on deaths and re-hospitalizations of patients due to poor quality care.[21] Similar studies reported that the high burden on caregivers will affect the quality of care given to patients, so it will affect the recovery process both physically and psychologically.[22] As such, understanding the factors that contribute to caregiver burden is important.

Various factors can influence caregiver burden, especially for those who have family members with palliative conditions or chronic illnesses. A previous systematic review concluded that caregiver variables that increase burden are increasing age, male gender, partner as care recipient, longer duration of care provision, and no assistance.[23] In addition, factors such as low education level, long duration of caregiving, unemployment, the complexity of treatment, and the number of patient comorbidities significantly correlate with increased caregiver burden.[24]

The increasing number of patients with palliative conditions due to demographic shifts and increasing life expectancy globally is one of the urgencies of this research.[1,25,26] As the elderly and chronically ill population increases, the need for palliative care also increases, which in turn increases the burden on families as primary caregivers.[3,9,27] This burden can be compounded if caregivers do not have adequate skills or resources to handle this complex situation.[22] Therefore, research on factors that influence caregiver burden is very important to identify strategies to help ease them.

Although there has been some research on caregiver burden, further exploration is still needed regarding the specific factors that influence caregivers in different cultural contexts and health systems, such as Indonesia. A previous systematic review analyzed 12 Asian studies, but none were from Indonesia.[23] This shows that limited studies still highlight this topic and population in Indonesia. In addition, Rasch analysis is rarely used in caregiver populations. Rasch is more common in morbidly obese populations,[28] CHD,[29] and spinal cord injury populations.[30] The Rasch model in Indonesia is more widely used in the student population.[31–35] In addition, Rasch analysis transforms ordinal data into interval-level measurements, enabling more precise quantification of burden levels and item difficulty.[36] Therefore, this study aims to further explore the factors that influence the burden of caregiving which is an urgent need that must be identified immediately. Understanding these factors is critical to developing targeted interventions in low-resource settings like Indonesia.

Methods

Study Design

This study used a cross-sectional design. Data collection was conducted from August to October 2024. The Rasch model was used to transform data from respondent responses.

Sample and Setting

The population in this study were families with family members experiencing palliative conditions and chronic diseases in the city of Bandung, Indonesia. The data collection technique was carried out using convenience sampling with several inclusion criteria: (1) Caregivers who have family members with palliative conditions and chronic illnesses, (2) Age >18 years, (3) Family can read. Meanwhile, the exclusion criteria were: (1) Caregivers who lives not in the same house with the patient, and (2) Caregivers who are not family members. Researchers collected data directly from caregivers in community and hospital environments.

The sample size is determined by referring to the sample size table for correlation tests.[37] Assuming a minimum correlation value (R_o) of 0.8 and an expected correlation value (R_1) of 0.9, at a confidence level of 95% ($\alpha = 0.05$) and a test power of 80%, the minimum sample size required is 59 respondents. Meanwhile, to detect a lower correlation, the sample size required can reach up to 751 respondents, depending on the strength of the expected relationship. In this study, the number of respondents included was 71 people, which is considered sufficient to detect a strong correlation with the specified level of significance and test power.

Data Collection

In this study, data collection was carried out through a door-to-door approach to identify respondents who met the inclusion criteria. Prior to the data collection process, the researchers coordinated with the nearest Primary Health Care (PHC) center to obtain an overview of the distribution of potential respondents who matched the established inclusion criteria. To meet the prospective respondents, the researchers were accompanied by a representative from the PHC. Respondents who agreed to participate in the study were provided with an informed consent form, which included an explanation of the study's purpose and benefits. Respondents who consented to participate then signed the informed consent form as confirmation of their agreement to participate in the study. All participants agreed and followed the research process.

Research Instrument

Knowledge and Attitude Scale

In this study, palliative care knowledge was assessed using a 6-item Guttman scale for the Knowledge of Palliative Care.[38] In the knowledge instrument, r count is obtained from the Pearson correlation, which ranges from 0.261 to 0.657, with r table 70 respondents being 0.235. This means that the knowledge instrument used in this study is valid. In addition, the reliability results show a Cronbach α value of 0.676, which indicates that the instrument has quite good reliability. Likewise, previous studies using the same instrument stated that the knowledge instrument has good validity and reliability.[38]

To measure attitudes, this study uses FATCOD-B Indonesia Version (30 items with a Likert scale).[39] The Frommelt Attitude Toward Care of the Dying Scale, Form B (FATCOD-B) was developed by Kristin E. Frommelt, a nurse educator and researcher specializing in palliative care and end-of-life issues. In the Indonesian context, the FATCOD-B has been translated and validated to assess nursing students' attitudes toward end-of-life care. This questionnaire aims to identify respondents' attitudes towards caring for dying patients. This instrument consists of favorable and unfavorable statements. The favorable statements consist of items 1, 2, 4, 16, 18, 20, 21, 22, 23, 24, 25, 27 and 30 which have a score of 1 (strongly disagree) and a score of 5 (strongly agree). Unfavourable statements have a score of 1 (strongly agree) and a score of 5 (strongly disagree).

The attitude instrument (FATCOD-B) is already in Indonesian and has been tested for validity and reliability by previous studies, which reported that it is valid and reliable.[39] A Reliability test using Cronbach's alpha obtained a result of 0.68. The validity range of each question item is 0.651 to 0.713. The highest reliability result is 0.713 if item number 13 is removed from the questionnaire.[39] This means that the attitude instrument used in this study has good validity and reliability.

Caregiver Burden Scale

The ZBI was originally developed by Zarit, Reever, and Bach-Peterson (1980) to assess caregiver burden, particularly in individuals caring for those with chronic conditions.[40] The ZBI consists of 12 items, each addressing different aspects of caregiver burden, such as emotional, physical, and social strain. The scale uses a 5-point Likert scale, where respondents rate their agreement with each item on a scale from 0 (never) to 4 (nearly always), with higher scores indicating a greater level of caregiver burden.

In this study, the researcher developed an Indonesian language version of the ZBI instrument. The process of adopting ZBI instrument into Indonesian uses the back-translation technique. The back-translation technique is a process used in adopting a questionnaire into a particular language and involves two experts in the translation process.[41] In the original study, Cronbach's alpha was reported as 0.87, demonstrating strong internal consistency. For the adapted Indonesian version, Cronbach's alpha was found to be 0.84 confirming its reliability for the Indonesian population. The validity and reliability test of the ZBI-Short 12 Items Scale was also conducted in this study. The analysis results obtained a range of r count scores of 0.258 to 0.756 with r table 70 respondents of 0.235, so it can be declared valid. Meanwhile, a Cronbach α value of 0.840 was obtained for the reliability results, which stated that the caregiver burden scale instrument has good reliability. Likewise, previous studies that confirmed these results obtained a validity value of 0.28–0.78, then a reliability value of 0.83.[42]

The ZBI has been shown in different studies to have good construct validity and internal consistency, with Cronbach α ranging between 0.83 to 0.95.[43,44] The internal consistency for the short version developed by Bédard et al was 0.88, and the findings were comparable to both the 22 and 18-item formats.[44] The 12-item version has also shown good discriminatory ability in determining caregivers with low and high burdens in different contexts.[45]

Based on the reliability measurement (see Table 1), the results of the reliability test show a Cronbach alpha value of 0.84. This indicates that the interaction between person and items in the instrument is good. The reliability values for people and items are 0.82 and 0.95, respectively. The quality of the instrument, based on the item reliability value (0.95), falls into the very good category. From these results, it can be concluded that the consistency of responses from the participants is categorized as good, accompanied by a very good quality of the instrument. Furthermore, the separation values for people and items are 2.66 and 4.23, respectively.

Data Analysis

The data obtained in the form of ordinal data is transformed first into numerical data using the Rasch model (Winstep application) before being analyzed further. The data obtained in the form of ordinal data is transformed first into numerical data using the Rasch model (Winstep application) before further analysis.[36] One of the key advantages of using the Rasch model is its ability to provide interval-level measurement from ordinal data, which allows for more precise statistical analysis.[36] Unlike other methods, the Rasch model accounts for both item and person parameters, ensuring that the measurement is independent of the sample. Additionally, the Rasch model allows for the detection of misfitting items and persons, which helps improve the reliability and validity of the results.[36]

Numerical data in the form of a Log Odds Unit (logit) score is then used to categorize. The caregiver burden variable was categorized into three levels: low, moderate, and high based on the mean logit score cut-off and standard deviation (category: > 0 logit score = high burden; < 0 logit score – mean logit (−0,99) = moderate burden, and < logit score −0,99 = low burden). Additionally, for the variables of knowledge and attitude, categorization was based on the cut-off point from the mean logit score. Low and unfavourable knowledge and attitude were defined as ≤ mean logit score, while high and favourable

Table 1 Psychometric Attribute of the Instrument

Psychometric Attribute	Caregiver Burden (ZBI)
No of item	12
Raw explain variance by measure	28.4%
Unexplained Variance	<15%
Cronbach's alpha	0.84
Person reliability	0.82
Person separation	2.16
Item reliability	0.95
Item separation	4.23

knowledge and attitude were defined as > mean logit score. Then, an analysis was also carried out using the Wright map to detect and find items correctly according to the level of difficulty and ability level of the respondent.[46,47]

Analysis was conducted using the chi-square and Fisher's exact tests to identify the frequency distribution and relationship between respondent characteristics and caregiver burden. Additionally, Spearman's rank correlation test was used for numerical data. The normality of caregiver burden data was assessed using the Kolmogorov–Smirnov test, which resulted in $p<0.05$, indicating that the data were not normally distributed. All data analyses were performed using the Winsteps application version 5.4.0.0 and Jamovi version 2.3.21.

The strength of the relationship between variables is determined based on the accuracy of the correlation values, namely V and r. According to Akoglu (2018), the significance criteria in correlation test analysis with a 95% confidence level ($\alpha = 0.05$) for Cramer's V is as follows: >0.25 = Very strong, >0.15 = Moderate, >0.10 = Medium, >0.05 = Weak, and >0 = No or very weak correlation. Meanwhile, the correlation r values are interpreted as follows: 0.00–0.19 = Very weak (almost no relationship), 0.20–0.39 = Weak, 0.40–0.59 = Moderate, 0.60–0.79 = Strong, and 0.80–1.00 = Very strong.[48]

Ethical Consideration

This research has received ethical approval from the Padjadjaran University Ethics Commission with number No. 595/UN6.KEP/EC/2024. This approval ensures that research follows ethical principles while upholding participants' rights, safety and welfare. In line with the Declaration of Helsinki, this research adheres to the main ethical principles of medical research involving humans, including respect for individuals, concern for the welfare of participants, and fairness in treatment. Before participating, all respondents were given clear and comprehensive information regarding the aims of the research, procedures to be undertaken, potential benefits and risks that may arise. Each participant voluntarily provided written consent (informed consent) after understanding the information provided, without any pressure or coercion. The confidentiality and anonymity of participant data are guaranteed by ensuring that personal information will not be disseminated or used for other purposes outside this research. The data collected is only used for research purposes and is stored in a secure system to protect respondents' privacy.

Results

Characteristic of Participants

This study involved 71 respondents, mostly female (78.9%) (See Table 2). Most were aged 45–59 years (43.7%) and were married (83.1%). The majority had intermediate education (67.6%), were unemployed (63.4%), and were income below the minimum wage (71.8%). In addition, most had health insurance (83.1%) and had been caring for patients for less than five years (74.6%). The caregiver relationship with the patient was dominated by partner (49.3%) and children (31%).

Table 2 Sample Characteristics (n=71)

Variable	Caregiver Burden			n (%)
	Low	Moderate	High	
	n (%)	n (%)	n (%)	
Gender				
Female	5 (7)	22 (31)	29 (40,8)	56 (78,9)
Male	2 (2,8)	6 (8,5)	7 (9,9)	15 (21,1)
Age				
Adult (25–44 years old)	1 (1,4)	6 (8,5)	10 (14,1)	17 (23,9)
Middle Age (45–59 years old)	13 (18,3)	13 (18,3)	16 (22,5)	31 (43,7)
Elderly (>60 years old)	4 (5,6)	9 (12,7)	10 (14,1)	23 (32,4)

(*Continued*)

Table 2 (Continued).

Variable	Caregiver Burden			n (%)
	Low	Moderate	High	
	n (%)	n (%)	n (%)	
Marital Status				
Unmarried	1 (1,4)	0 (0)	5 (7)	6 (8,5)
Divorce	2 (2,8)	1 (1)	3 (4,2)	6 (8,5)
Married	28 (39,4)	27 (27)	28 (39,4)	59 (83,1)
Educational Background				
Elementary Education	1 (1,4)	1 (1,4)	6 (8,5)	15 (21,1)
Intermediate Education	4 (5,6)	19 (26,8)	25 (35,3)	48 (67,6)
Higher Education	2 (2,8)	2 (2,8)	5 (7)	8 (11,3)
Occupation				
Employed	3 (4,2)	12 (16,8)	11 (15,5)	26 (36,6)
Unemployed	4 (5,6)	16 (22,5)	25 (35,2)	45 (63,4)
Income				
< minimum wage	4 (5,6)	22 (31)	25 (35,2)	51 (71,8)
> minimum wage	2 (2,8)	0 (0)	4 (5,6)	6 (8,5)
No income	1 (1,4)	6 (8,5)	7 (9,9)	14 (19,7)
Health Insurance				
No	0 (0)	0 (0)	12 (16,9)	12 (16,9)
Yes	7 (9,9)	28 (39,4)	24 (33,8)	59 (83,1)
Length of Care				
<5 years	3 (4,2)	19 (26,8)	31 (43,7)	53 (74,6)
5-10 years	2 (2,8)	7 (9,9)	3 (4,2)	12 (16,9)
>10 years	2 (2,8)	2 (2,8)	2 (2,8)	6 (8,5)
Relations With Family				
Child	0 (0)	8 (11,3)	14 (19,7)	22 (31)
Distant Relatives	1 (1,4)	1 (1,4)	5 (7)	7 (9,9)
Parent	2 (2,8)	1 (1,4)	4 (5,6)	7 (9,9)
Partners	4 (5,6)	18 (25,4)	13 (18,3)	35 (49,3)

Description of Knowledge, Attitude, and Caregiver Burden

From the analysis of caregivers' knowledge and attitudes (See Table 3), it was found that 67.6% had a high level of knowledge, while 32.4% had low knowledge. Regarding attitude, 57.7% showed an unffavourable attitude, while 42.3% had a favourable attitude. Meanwhile, the level of caregiver burden is divided into three categories, with 50.7%

Table 3 Descriptive of Knowledge, Attitude, and Caregiver Burden (n=71)

Category	SE Logit	Frequency (f)	Percentage (%)
Knowledge			
Low	≤ 0.71	23	32,4
High	> 0.71	48	67,6
Attitude			
Favourable	≤ 0.41	30	42,3
Unfavourable	> 0.41	41	57,7
Caregiver Burden			
Low	< −0,99	7	9,9
Moderate	−0,99–0	28	39,4
High	≥ 0	36	50,7

Abbreviation: SE, Standard Error.

experiencing a high burden, 39.4% experiencing a moderate burden, and only 9.9% experiencing a low burden. Statistical analysis also obtained a mean logit score of knowledge of 0.71, while attitudes averaged 0.41. The average caregiver burden was −0.99 (See Table 4).

Based on Figure 1, the item in the top position, namely B7, " Do you feel that you do not have as much privacy as you would like because of your relative?" is the statement that is most difficult for respondents to agree with. In contrast, the items at the bottom, namely B11 and B12, "Do you feel that you should be doing more for your relative?" and "Do you feel that you could do a better job in caring for your relative?" were the statements with which respondents most readily agreed.

Factors Related to Caregiver Burden

In the analysis of the relationship between independent variables and caregiver burden (See Table 5), it was found that marital status (p=0.033, V=0.256) and length of care (p=0.029, r=0.259) had a significant relationship. In addition, health insurance showed a very strong relationship with caregiver burden (p<0.001, V=0.445). Meanwhile, attitude also correlated with caregiver burden, although in the weak category (p=0.026, r=−0.231). Variable duration of care and attitudes are statistically significant, but the correlation between these two variables and caregiver burden is weak. Other variables such as gender, age, education level, occupation, income, and family relationship with the patient did not significantly correlate with caregiver burden.

Table 4 Descriptive Statistic of Variable (n=71)

Category	Mean	SD	Minimum	Maximum
Age	52,2	13,1	25	75
Length of Care	5,06	5,14	0,1	27
Knowledge	0,71	1,27	−2,75	3,09
Attitude	0,41	0,33	−0,100	1,27
Caregiver Burden	−0,99	0,97	−4,66	1,98

https://doi.org/10.2147/JMDH.S533067

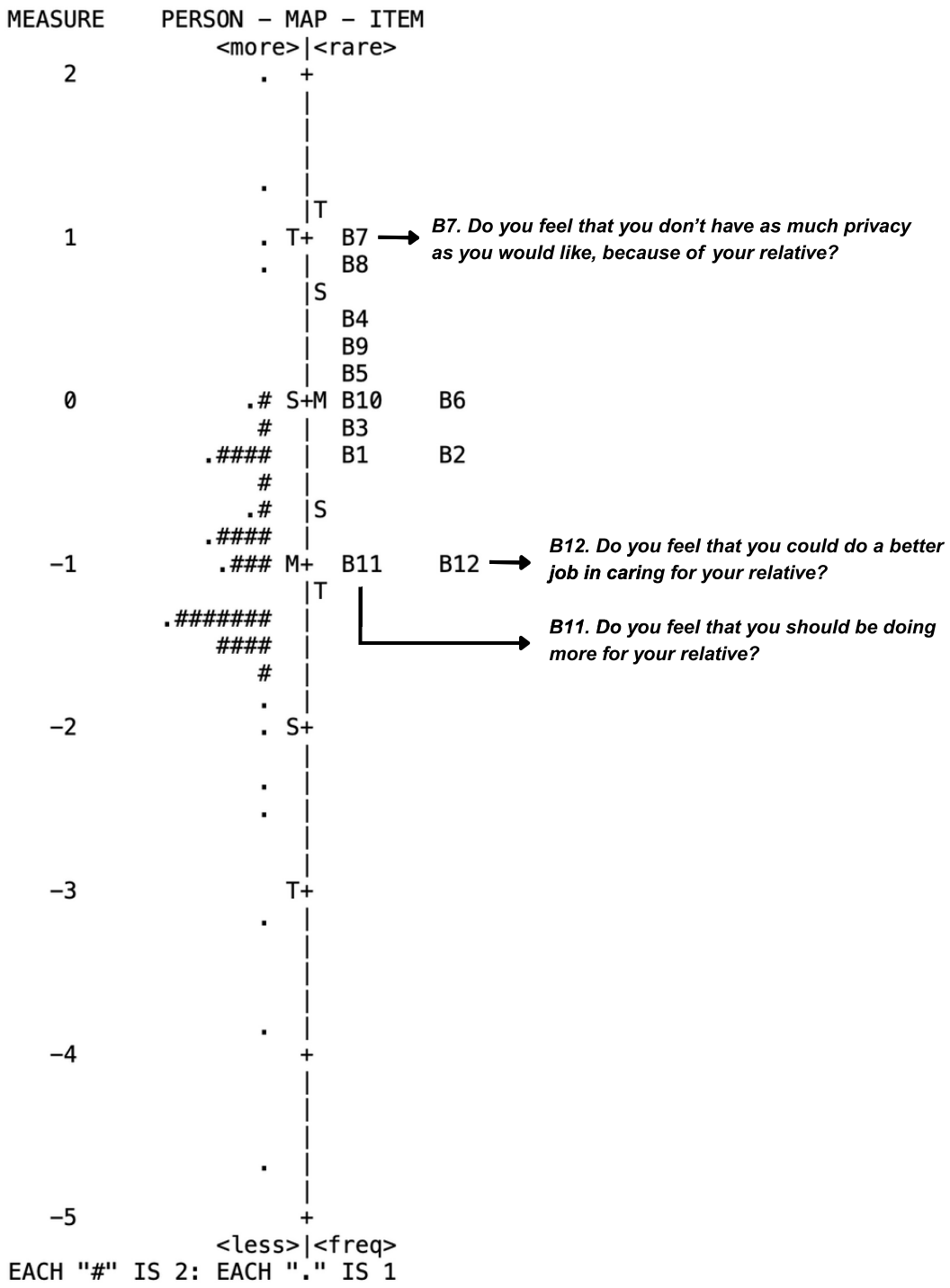

Figure 1 Wrightmap of caregiver burden.

Notes: The "person" section on the left of the Wright map describes the serial number of respondents based on caregiver burden level. The "Item" section on the right of the Wright map describes the questionnaire number from the most confident or unconfident thing respondents did. In addition, M is the mean for item and person; S means one standard deviation away from the mean value, and T means two standard deviations away from the mean value.

Table 5 Relationship Between Independent Variable and Caregiver Burden (n=71)

Variable	Caregiver Burden		
	p-value	r OR V	Interpretation
Gender	0,863[b]	0,064	NS
Age	0,076[c]	0,212	NS
Marital Status	0,033[a*]	0,256	Very strong
Educational Background	0,262[a]	0,186	NS
Occupation	0,625[b]	0,128	NS
Income	0,132[a]	0,215	NS
Health Insurance	<0,001[a**]	0,445	Very strong
Length of Care	0,029[c*]	0,259	Moderate
Relations With Family	0,053[a]	0,280	NS
Knowledge	0,321[c]	−0,056	NS
Attitude	0,026[c*]	−0,231	Weak

Notes: [a]Fisher exact test, [b]Chi Square, [c]Spearman Rank test with significance $p<0.05$, *$p<0,05$, **$p<0,001$.
Abbreviation: NS, Not Significant.

Discussion

This study identified factors associated with caregiver burden in families with family members with palliative conditions and chronic illnesses. The study's results showed that most caregivers (50.7%) experienced a high burden, while only a small portion (9.9%) experienced a low burden. These findings reflect that caring for family members with palliative conditions and chronic illnesses places significant physical, emotional, and psychological stress on caregivers. Notably, this is also the first study to examine caregiver burden using the Rasch model, providing a more nuanced and reliable understanding of the factors influencing caregiver burden, particularly in the context of palliative and chronic illnesses.

Bivariate analysis revealed several factors significantly associated with caregiver burden. Specifically, marital status and duration of care were found to have a notable impact on caregiver burden. In addition, the presence of health insurance demonstrated a strong relationship with caregiver burden. While caregivers' attitudes towards their role also showed a statistically significant association with caregiver burden. Both attitude and duration of care were found to have relatively weak correlations with caregiver burden.

The findings of this study are in line with several previous studies that reported the level of burden in caregivers with family members experiencing palliative conditions and chronic diseases. Nirmalasari and Sari (2022) found that caregivers of hemodialysis patients in Indonesia experienced a significant burden.[14] Similarly, A study conducted in China also reported that family caregivers of hospitalized patients with neurocritical illness experienced mild to moderate caregiving burdens.[49] A systematic review concluded that of the 12 studies analyzed in the context of Asian countries, caregivers consistently reported low to moderate burden.[23]

Caregiver burden is a significant problem faced by individuals who provide care to family members with chronic and palliative conditions.[23,50] The high prevalence of burden experienced by caregivers reflects the magnitude of the responsibilities and pressures they bear.[22] Especially in the context of caring for patients with chronic and palliative conditions that are progressive and require ongoing support.[2,14] This burden is not only limited to physical aspects but also includes emotional stress from witnessing the decline of a loved one's condition, as well as feelings of anxiety, fatigue, and potential role conflict in personal and professional life.

Furthermore, a deeper understanding of the distribution of responses to caregiver burden items was obtained through Wright Map analysis. Item B7, "Do you feel that you do not have as much privacy as you would like because of your relative?" was the most challenging statement for respondents to agree with. This suggests that the loss of privacy is viewed as a natural and acceptable consequence of caregiving. In contrast, the most manageable statements to agree with were items B11 and B12, such as "Do you feel that you should be doing more for your relative?" and "Do you feel that you could do a better job in caring for your relative?". High agreement with these two items reflects a strong sense of responsibility, accompanied by potential feelings of guilt or dissatisfaction with the quality of care provided.

These findings are particularly relevant when viewed through the lens of family duty norms. In many cultures, including Indonesian, caregiving is seen as an inherent family responsibility, driven by strong traditional values.[51,52] Caregivers often feel that their efforts are never enough, leading to feelings of guilt and a constant desire to do more, which aligns with societal expectations that family members, particularly spouses and children, provide optimal care, even at significant personal cost. These feelings are reflected in items B11 and B12, highlighting the emotional burden borne by caregivers. In Indonesia, families play a crucial role in caring for relatives with chronic illnesses, supported by norms and cultural values such as responsibility and solidarity, which encourage families to provide care with love and dedication.[51,52]

The level of burden on caregivers is an important aspect that needs to be considered. In addition, the large number of caregivers who experience depression, anxiety, and somatic symptoms indicate a high need for psychological support for caregivers.[16] Burden also greatly influences the quality of support and care provided to patients.[17,53,54] Studies have shown that caregivers who experience high levels of stress and burnout tend to have a lower capacity to provide empathetic, consistent, and effective care.[55,56] Therefore, identifying factors that influence the development of the risk of increasing excess burden is an urgent need to be done.[57]

This study's reveal several factors significantly correlated with caregiver burden in the context of palliative care and chronic illness. Marital status showed a significant relationship to caregiver burden, indicating that the presence of a spouse can act as a source of emotional and instrumental support in dealing with the complexity of caregiving. Previous studies reported similar results; marital status was positively correlated, where the percentage of caregivers who experienced low to moderate burden was higher in those with "married" status.[58] In the literature, social support, particularly from partners, is an important buffer against the chronic stress that caregivers experience.[24]

In addition, longer duration of caregiving was significantly associated with increased caregiver burden ($p= 0.029$), reinforcing previous findings that more prolonged caregiving without adequate support contributes to physical exhaustion, burnout, and decreased psychological functioning.[59,60] This prolonged duration often has implications for the caregiver's reduced adaptive capacity, especially when they have to balance their role with work demands, household responsibilities, and personal needs that are often neglected.[59]

The most striking factor is the role of finance. Although the income variable does not show a statistically significant relationship, health insurance ownership is proven to significantly affect the level of burden ($p<0.001$). This can be explained by the fact that health insurance functions as a buffer against the economic burden caused by long-term medical expenses, especially in the context of chronic and palliative diseases that require ongoing costs for treatment.[24] Without adequate health financing, caregivers often experience intense financial stress, which directly increases their psychosocial burden and worsens their mental well-being.[60] In Indonesia, where the healthcare system is still evolving, expanding health insurance coverage could significantly ease the burden on caregivers, particularly in managing long-term care for patients with palliative and chronic conditions.[61,62]

Although Indonesia currently does not have a specific program providing allowances or financial support for long-term caregivers, there is potential to develop policies that better support them, particularly in the context of palliative care. The recent law integrating palliative care into primary healthcare services presents an opportunity to introduce financing schemes that cover home care for palliative patients.[63] This initiative has the potential to include financial support for caregivers who provide home care, thus improving their quality of life and the effectiveness of care. Furthermore, while Indonesia lacks a caregiver allowance program similar to those in other countries, such policies could serve as a reference for designing similar models that could be piloted in Indonesia. The implementation of this policy is expected to enhance caregiver welfare and strengthen the sustainability of care for palliative patients in a home setting.

The caregiver's attitude towards the caring role also showed a significant relationship, although in the weak negative correlation category. This negative correlation indicates that the more positive an individual's attitude towards caregiving, the lower their burden. In this context, caregivers who view their role as a form of affection, moral responsibility, or even spirituality tend to have higher resilience in dealing with stress compared to those who view caregiving as a burden or obligation alone. A positive attitude can also increase self-efficacy, strengthen intrinsic motivation, and activate adaptive coping mechanisms.[64,65] In contrast, caregivers with negative attitudes are more susceptible to feelings of being trapped, frustrated, and helpless, which, in the long term, can worsen psychological conditions and reduce the quality of care provided.[64,65]

Based on the existing findings, it is clear that caregivers of patients with palliative conditions and chronic illnesses face a complex and multidimensional burden.[23,24] Therefore, structured and needs-based interventions, whether psychosocial support, ongoing education, or facilitating access to health and financial resources, must be addressed immediately.[66,67] This comprehensive approach is expected to not only reduce the level of caregiver burden but also improve the quality of care provided and the long-term well-being of caregivers and patients.[67–70]

Implications for Practice

The findings emphasize the importance of integrating psychosocial support into nursing practice, especially for caregivers of palliative and chronic patients who demonstrate high levels of burden. Early detection of caregiver burden through routine screening needs to be implemented as part of holistic care. Furthermore, because attitudes are associated with burden, interventions should include stress-adaptation training, emotional support, and reinforcement of positive meanings of caregiving, not just increased technical knowledge. Access to health insurance has also been shown to play a significant role, so health workers need to be involved in advocacy and referral to available financing services. Finally, the long duration of caregiving requires burden redistribution strategies, such as respite care or community support, to maintain the long-term well-being of caregivers.

Additionally, the Rasch analysis provides a more nuanced understanding of caregiver burden by identifying which items resonate most with caregivers, allowing for adjustments to the Zarit Burden Interview (ZBI) that better capture the unique experiences of Asian caregivers. For example, cultural factors such as familial duty norms and caregiving expectations may require the inclusion of items that specifically address these cultural aspects, which may not be adequately reflected in the current ZBI. This adjustment could improve the tool's relevance and accuracy in measuring caregiver burden for Asian populations, ensuring that it aligns more closely with their cultural contexts and caregiving experiences.

Strengths and Limitations

One of the main strengths of this study is the use of Rasch analysis in measuring caregiver burden, which allows the conversion of ordinal data to an interval scale and provides a more accurate mapping of the burden perception of each item. Rasch analysis also allows the identification of which items are the most difficult or easiest to agree with, offering deeper insight into understanding the psychological dynamics of caregivers.

However, this study has several limitations that need to be considered. The relatively small sample size (n=71) which is smaller than the sample size required to detect a moderate correlation ($R_o = 0.5$). According to power calculations, a sample size of approximately 100 respondents would be necessary to detect a moderate effect size with sufficient statistical power. While this study maintains a higher effect size ($R_o = 0.8$), which was deemed appropriate for the given sample size, the smaller sample may limit the generalizability of the findings to broader populations. Future research with larger sample sizes is recommended to further validate the findings and explore more moderate correlations.

Additionally, the use of convenience sampling introduces potential sample bias, as it may overrepresent certain groups, such as spouses or urban caregivers. This overrepresentation could skew the perceived levels of caregiver burden and may not accurately reflect the broader caregiver population. Moreover, the cross-sectional design of this study restricts the ability to infer causality. For instance, while the study found a relationship between health insurance and caregiver burden, it is unclear whether insurance directly reduces the burden or if less-burdened caregivers are more likely to seek insurance. Furthermore, cultural attitudes, such as guilt, could influence caregiver burden in ways that are not fully captured in this study, suggesting a need for qualitative exploration of these factors.

For future research, longitudinal studies could be beneficial in tracking burden trajectories over time to identify how caregiver burden evolves and the potential long-term impacts of health insurance and other factors. Additionally, adopting a mixed-methods approach could provide a deeper understanding of the psychosocial aspects of caregiving, such as cultural influences, which are important but were not fully explored in this study.

Conclusion

The majority of family caregivers of patients with palliative and chronic conditions experience a high burden. Key factors, including marital status, caregiving duration, insurance coverage, and caregivers' attitudes, were found to significantly influence the level of burden. In Indonesia, where family-based caregiving is the predominant model but formal support systems remain limited, it is imperative that interventions capitalize on community networks. The Rasch analysis revealed that the most prevalent burden was the caregivers' perception of not providing optimal care, while the loss of privacy was comparatively less acknowledged. These findings highlight the urgent need for multifaceted interventions that incorporate psychological support, caregiver education, and enhanced financial security, alongside sustained access to social assistance.

However, it is important to acknowledge the methodological limitations of this study, particularly the use of convenience sampling and the cross-sectional design, which limit the generalizability of the findings. While our results underscore the urgent need for intervention, future studies should adopt longitudinal designs to better assess causality and the long-term effects of caregiving. Given the unique caregiving landscape in Indonesia, characterized by deeply ingrained familial duty norms and limited formal palliative infrastructure, it is essential to support initiatives that are culturally congruent and community-oriented.

Acknowledgments

All authors would like to thank Padjadjaran University, Bandung, West Java, Indonesia, for facilitating the database and funding this research.

Disclosure

The authors report no conflicts of interest in this work.

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