

THE RELATIONSHIP OF CAREGIVING BURDEN WITH PSYCHOLOGICAL WELL-BEING OF MOTHERS OF AUTOIMMUNE SURVIVORS WITH FAMILY SUPPORT AS A MODERATOR

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ABSTRACT

This study aims to determine the relationship between caregiving burden and psychological well-being in mothers caring for children with autoimmune disease, and to determine the role of family support as a moderator in this relationship. The increasing prevalence of autoimmune conditions in Indonesia, especially after COVID-19, has significant implications for the psychological well-being of informal caregivers, especially mothers. This study used a quantitative method by conducting an online survey. Data were collected in Indonesia from 101 mothers aged 25 years and over who acted as informal caregivers for their children who had or had autoimmune diseases at the time of the study. The 18-item Ryff Psychological Well-being Scale (RPWBS) was used to measure psychological well-being, the 12-item Zarit Burden Interview (ZBI) to measure perceived caregiver burden, and the 4-item family dimension of the Multidimensional Scale of Perceived Social Support (MSPSS) to measure family support. The findings of this study were that there was a negative and significant relationship between caregiving burden and psychological well-being in mothers of children with autoimmune disease. However, family support did not play a moderating role in this relationship. Among the mothers, 48.5% were aged 25-39 years, 51.5% were aged 40-60 years. The mean score of mother's perceived caregiving burden was low (1.20 ± 0.58) and the mean score of mother's psychological well-being was high (5.46 ± 1.47). Specifically, lower caregiving burden was associated with better psychological well-being.

Keywords: autoimmune, caregiver burden, family support, mothers, psychological well-being

1. PREFACE

Autoimmune diseases represent a group of conditions in which the immune system attacks the body's own tissues, with over 100 types identified globally. The prevalence of these diseases has been increasing, particularly following the COVID-19 pandemic, which has been linked to specific autoimmune triggers such as diabetes mellitus and lupus. In Indonesia, data on the prevalence of autoimmune diseases remain limited. However, reports indicate a significant rise, especially among children (Hileman et al., 2024; Pisetsky, 2023; Syed et al., 2023).

Autoimmune diseases are complex conditions influenced by physical, environmental, and genetic factors, resulting in everyone potentially having a different type of autoimmune disease (Pisetsky, 2023). These complex conditions cause autoimmune survivors to often face psychological disorders. Several types of autoimmune diseases such as rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), ankylosing spondylitis (AS), and diabetes mellitus (DM) are often associated with psychological disorders (Besar et al., 2024). Research states that there are high levels of depression and anxiety in autoimmune survivors with brain involvement.

This condition contributes to poor psychological well-being for autoimmune survivors (Yalcin et al., 2017).

In addition, according to Retliffe, families, especially mothers who act as informal caregivers, also experience psychological disorders that lead to low psychological well-being. Mothers of children with autoimmune diseases often experience significant stress, leading to anxiety and sadness. Frustration arises from the fact that these chronic diseases can only have their symptoms managed, not completely cured, which can create a perpetual concern for mothers regarding the uncertainties in caring for their children (Uzuner et al., 2021).

The caregiving burden that mothers experience can be closely related to their psychological well-being. Changes in daily life after a child's autoimmune diagnosis can trigger difficulties in achieving psychological well-being (Singh et al., 2017). The sacrifice of personal time and resulting fatigue can limit mothers' opportunities for self-development and building relationships, both of which are crucial for psychological well-being.

To achieve psychological well-being amidst significant caregiving burdens, resources that can alleviate these burdens are necessary, one of which is family support. Family support including emotional, instrumental, esteem, and informational support has a significant impact on the psychological well-being of mothers (An et al., 2024). Strong family support can create a sense of not being alone, reducing emotional burdens, and assisting mothers in managing stress, thus maintaining their psychological stability.

2. RESEARCH METHOD

Samples

This study used non-probability sampling using purposive sampling. The selection of this sampling method aims to select participants according to predetermined criteria and ensure relevance and minimize irrelevant data. The sample of this study was 55 respondents, taken from an estimated population of 155,000 people with lupus and type 1 diabetes in Indonesia in 2023. This sample size was determined through power analysis using G*Power software with effect size=0.3, significance level=0.05, statistical power=0.95, and $p2=0.5$. Inclusion criteria for participants in this study were mothers who were 25 years of age or older and had lived with and/or cared for the child for three months or more.

Measurement

This study uses a quantitative method using three measuring instruments that are in accordance with the research variables consisting of psychological well-being, caregiving burden, and family support.

The Ryff Psychological Well-Being Scale

The Ryff Psychological Well-Being Scale (PWBS), developed by Ryff (1995) was used to assess psychological well-being. The PWBS consists of 18 items reflecting six dimensions: self-acceptance, positive relationships with others, environmental mastery, autonomy, personal growth, and purpose in life. The scale employs a 7-point Likert (1=strongly disagree to 7=strongly agree). A higher total score (maximum 126) indicates better psychological well-being. In this study, the Cronbach's α coefficient of this scale was 0.81 on 11 valid and reliable items.

The Zarit Burden Interview

The Zarit Burden Interview (ZBI) short, developed by Zarit et al. (1980), assesses caregiver burden across various dimensions, including health, social life, financial situation, emotional well-being, and interpersonal relationships. This study utilized the ZBI short, consisting of 12 items modified from Bédard et al. (2001). The ZBI-12 is divided into two dimensions: personal strain and role strain. The scale uses a 5-point Likert (0=never to 4=always). In this study, the Cronbach's α coefficient of this scale was 0.81 on 11 valid and reliable items. Researchers found that Cronbach's α coefficient of this scale was 0.82.

The Multidimensional Scale of Perceived Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS), developed by Zimet et al. (1988) and adapted by Sulistiani et al. (2022) for the Indonesian context, consists of 12 items measuring perceived social support across three dimensions: family, friends, and significant others. For this study, only the family dimension was utilized, consisting of four positive items. The scale employs a 7-point Likert (1=strongly disagree to 7=strongly agree). Researchers found that Cronbach's α coefficient of this scale was 0.94.

Data Collection and Analysis

The data collection technique used an online survey by contacting the autoimmune support community in Indonesia through social media from October to November 2024. A total of 101 participant data were collected in this survey. Each participant was informed about the survey and completed informed consent. The questionnaire included an introduction from the researcher, a brief overview of the study, participation criteria, and informed consent.

Once data collection was complete, the researcher verified, processed, and analysed the data. The received data were converted into Comma Separated Values (CSV) format for further analysis using IBM SPSS version 25. There are two data analyst techniques, namely the correlational method to identify the relationship between caregiving burden and psychological well-being of mothers of autoimmune survivors. and the second is the moderation regression method to determine the effect of family support.

3. RESULT AND DISCUSSION

Results

The total number of participants in this study was 101 participants, with an age range of 25-60 years (40.38 ± 9.18), spread across 16 provinces in Indonesia with most of their last education level being college (43.6%) and high school (42.6%). Many mothers who are busy working outside the home (41.6%) are not much different from mothers who do not have jobs (34.7%). The average mother has a monthly income of below 2 million (36.6%) and 2–6 million (36.6%), and when viewed from the financial condition during care, the majority showed a stable condition (81.2%). Almost all mothers have one autoimmune survivor child (95%), most of whom are female (86.1%), with an age range of 2-27 years. In addition, the range of duration of care carried out was 3-324 months (47.67 ± 57.61) with mothers who reported no care assistance as many as (49.5%) and those who received care assistance (50.5%). More details can be seen in table 1.

Table 1

Socio-demographic Characteristics of mothers of autoimmune survivors (N = 101).

<i>Variable</i>	<i>N/mean</i>	<i>%/SD</i>
Age	25-60 years old	40.38
Region (province)	South Sumatera	2
	West Sumatera	3
	Bengkulu	1
	Riau	1
	Jambi	1
	Lampung	4
	East Kalimantan	1
	South Kalimantan	3
	Banten	7
	D.K. Jakarta	16
	West Java	17
	D.I. Yogyakarta	9
	Central Java	26
	East Java	8
	Central Sulawesi	1
	South Sulawesi	1
Education Level	Primary education	5
	Middle education	9
	High education	43
	Higher education	44
Marital status	Married	88
	Divorce	13
Employment status	Work from office	42
	Work from home	24
	Unemployed	35
Monthly income (Rupiah)	< 2.000.000	37
	2.000.000–6.000.000	37
	> 6.000.000	27
		26.7
Length of caregiving	3-324 month	47.67
Co-Caregiver	Yes	51
	No	50
Family distance	Living together/same area	81
	Different city/province/island	19
	Different country	1
Financial condition	Stable	82
	Struggles	19
Number of children with autoimmune	1	96
	2	4
	3	1
Age of children (years)	2 – 9	25
	12 – 19	50
	20 – 27	26
Gender of children	Male	14
	Female	87
Type of autoimmune	SLE	50
	Type 1 DM	3
	HSP	8
	ITP	1
	AIHA	5
	IBD	2
	JIA	2
	MS	1
	Psoriasis	5
	RA	7
	Scleroderma	2
	Sjogren Syndrome	2
	Celiac & Dermatitis	2
	Rheumatic Fever	1
	> two types of autoimmune	10
		9.9

The study found that 87.1% of mothers of autoimmune survivors had a high level of psychological well-being (Mean=5.16, SD=0.96), low perceived caregiving burden (Mean=1.20, SD=0.58) for 88.1%, and high perceived family support (Mean=5.46, SD=1.47) for 80.2%. More details can be seen in tables 2 and 3.

Table 2

Variable description

<i>Variable/ Dimension</i>	<i>Min</i>	<i>Max</i>	<i>Empirical Mean</i>	<i>Hypothetical Mean</i>	<i>SD</i>
Caregiving burden	0.08	3.33	1.20	2.00	0.58
Psychological Well-Being	2.64	6.64	5.16	4.00	0.96
Family Support	1.00	7.00	5.46	4.00	1.47

Table 3

Distribution of participants by variables categories

	<i>Low (N/%)</i>	<i>Moderate (N/%)</i>	<i>High (N/%)</i>
Caregiving burden	89 (88.1)	3 (3)	9 (8.9)
Psychological Well-Being	11 (10.9)	2 (2)	88 (87.1)
Family Support	13 (12.9)	7 (6.9)	81 (80.2)

According to the results of the correlation test, the burden of caregiving has a negative and significant effect on psychological well-being by obtaining a value of $r_{xy} = -0.26$, $p = 0.01 < 0.05$, thus H_{a1} is accepted. Next is the moderation test of the family support variable. The researcher obtained a value of $R^2 = 0.309$. So thus, 30.9% of the variation in psychological well-being can be explained by the interaction between the burden of caregiving and social support. While the rest is explained by other unknown factors. In the simultaneous test, the calculated F value was obtained = 14.455, $p = 0.00 < 0.05$. Thus, the regression model of this study can be used to predict psychological well-being variables. $\beta = 0.89$, $p = 0.76 > 0.05$. Thus, the interaction of the burden of caregiving with family support is not significant, H_{a2} is rejected. This means that family support does not show a moderating effect on the relationship between the burden of caregiving and psychological well-being. More details can be seen in tables 4 and 5.

Table 4

Simultaneous F test and determination coefficient of regression model

<i>Model</i>	<i>R²</i>	<i>F</i>	<i>df1</i>	<i>df2</i>	<i>p</i>	<i>Model</i>
1	0.309	14.455	3	97	0.00	1

Table 5

Multiple regression models

<i>Model</i>	<i>B</i>	<i>β</i>	<i>t</i>	<i>p</i>
Caregiving Burden	-0.366	-0.243	-0.92	0.36
Family Support	0.801	0.448	2.33	0.02
FS x CB → PWB	0.006	0.089	0.32	0.76

Researchers conducted a difference test on the variables of caregiving burden and psychological well-being reviewed from sociodemographic using independent sample T-Test and Oneway Anova. The results of the difference test obtained were that there were significant differences in psychological well-being reviewed from the level of education ($p = 0.03$, mean SD = 4.38; SMP

= 5.84; SMA = 5.05; college = 5.21) and duration of care ($p = 0.03$, mean 13-24 months = 5.39; 25-36 months = 5.22; 37-48 months = 4.47; 49-107 months = 5.01; > 108 months = 5.64). Furthermore, there were significant differences in caregiving burden reviewed from the age of the participants ($p = 0.002$, mean 25-39 years = 1.38; 40-60 years = 1.03) and financial conditions ($p = 0.02$, mean stable = 1.14; difficulty = 1.46).

Discussion

This study shows a significant negative relationship between the burden of caregiving and the psychological well-being of mothers of children with autoimmune survivors. This means that when mothers do not feel the burden of caregiving while caring for their children with autoimmune, the level of psychological well-being of mothers is higher, and vice versa. This finding is in line with previous studies showing that high levels of caregiving burden in parents caring for children with systemic lupus erythematosus (SLE) are strongly associated with low psychological well-being in informal caregivers (Bongelli et al., 2024; Uzuner et al., 2021).

The findings of this study showed that most mothers (87.1%) showed high psychological well-being and 88.1% of mothers showed low caregiving burden. This shows that mothers as informal caregivers of children with autoimmune survivors have a better level of psychological well-being compared to previous studies (Ehsan et al., 2018). Both statistically and descriptively show a low burden. This means that most mothers of autoimmune survivors almost do not feel the burden of caregiving, while most previous studies stated that being an informal caregiver and living with a patient with a chronic illness experiences a high burden of caregiving, especially when they do not get social support (Stathopoulou & Fragkiadakis, 2023).

The selection of social support from the family as a moderator variable in the relationship between caregiving burden and psychological well-being is based on previous research showing that family support provides the highest contribution compared to other social support (Haya et al., 2019). The results of this study indicate that mothers of children with autoimmune disease feel high family support ($5.46 > 4.00$), with 80.2% of respondents reporting high family support. This family support is associated with increased psychological well-being (Hizbullah & Mulyati, 2022). However, the results of this study did not show a moderating effect of family support in the relationship between caregiving burden and psychological well-being. This finding is in line with previous research (Thongthammarat & Yamarat, 2022), which stated that family support was not effective as a moderator in the relationship. Thus, the low perceived caregiving burden and high psychological well-being of mothers of children with autoimmune survivors were not influenced by the role of family support in this study. It can be assumed that mothers as informal caregivers of children with autoimmune survivors do not feel their caregiving as a burden. Furthermore, there are other possible factors that influence the burden of caregiving and maternal well-being. Sociodemographic factors such as education, duration of care, age, and financial conditions influence the burden of caregiving and psychological well-being.

The results of the difference test showed that mothers with higher education and longer duration of care had better psychological well-being. The highest psychological well-being was found in mothers with a junior high school/equivalent education, followed by mothers with a college education. The higher the education obtained by mothers and informal caregivers, the better their ability to manage their own health, access health information, and obtain the necessary formal support, which ultimately had a positive impact on their psychological well-being (Tough et al., 2020). Based on the duration of care, the highest psychological well-being was shown by mothers who had been caring for more than 108 months (9 years). However, this finding is

different from previous research which stated that the duration of care for more than six years is associated with significant stress in personal, social, and family life (Kaerts et al., 2023).

Furthermore, differences in caregiving burden were found based on participant age and financial condition. Mothers with middle-aged (40-60 years) and stable financial conditions showed lower perceived caregiving burden compared to other factors. Previous researchers found that caregiving burden decreases with increasing age of caregivers (Dikmen et al., 2023). Older informal caregivers tend to show lower potential for psychological stress despite similar caregiving burden, supported by experience and emotional resilience (Sezgin et al., 2022). Then, stable financial conditions are also associated with lower caregiving burden and higher psychological well-being (Gabriel et al., 2019; Liu et al., 2020).

In addition, other factors that can influence these conditions include spirituality, where higher levels of spirituality in caregivers can contribute to better psychological well-being (Anum & Dasti, 2016). In addition, psychological attitudes, and positive emotions such as optimism, happiness, and hope are often associated with higher well-being and help in coping with caregiving burden (Maguire et al., 2019; Wang et al., 2024). Personal competence in caregiving, religiosity, personality, and socioeconomic status can also reduce the negative impact of caregiving burden (Asmarani & Sugiasih, 2020; Desiningrum et al., 2019). The results of this study emphasize the importance of considering sociodemographic and other factors in the analysis of caregiving burden, psychological well-being, and family support of mothers of autoimmune survivors.

The limitations of this study are 1) the researcher cannot fully explain the findings due to the lack of literature to support the findings, which results in the weak validity of this study; 2) the number of samples is still inadequate to be generalized more widely; and 3) the measuring instrument in the form of a questionnaire can produce bias that may be influenced by factors that are not measured in this study. Therefore, it is necessary to re-examine the participants' perceptions of the questionnaire questions given.

4. CONCLUSIONS AND RECOMMENDATIONS

This study found a significant negative relationship between caregiving burden and psychological well-being of mothers of informal caregivers of children with autoimmune disease. The lower the perceived caregiving burden, the higher the mother's psychological well-being. This finding supports Ha1 but rejects Ha2 which states that family support moderates this relationship. This means that family support does not moderate the relationship between caregiving burden and maternal psychological well-being. This study is expected to be a useful reference for further researchers who study similar topics, such as identifying factors that influence low caregiving burden and high psychological well-being of mothers of children with autoimmune disease, such as positive emotions, gratitude, spirituality, mother-child relationships, personality, and social and cultural factors. The use of more complete psychological well-being and caregiving burden measurement tools and increasing the number of samples will provide a broader picture and higher validity.

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