

## Perceived burden in adult and pre-elderly informal caregiver

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### Abstract

*Purpose:* Nowadays, caregiver's role becomes increasingly important in providing care and support for old people who suffered from chronic diseases. Adult and pre-elderly informal caregiver have different growth and development tasks. It is important to identify their perceived burden. The aim of this research was to compare informal caregiver's perceived burden between adults and pre-elderly.

*Method:* This research was conducted in Sukoharjo Village between March – December 2023. Research design was cross sectional design and simple random sampling technique was used. Total respondent was 74 persons and categorized into adults and pre-elderly group. The instrument of this research was The Informal Caregiver Burden Assessment Questionnaire (QASCI-*The Questionario de Avaliacao de Sobrecarga do Cuidador Informal*) which has been tested for validity and reliability.

*Result:* Significant differences was found between adults and pre-elderly perceived burden ( $p=0.000$ ). Adults standard deviation was 25,28 higher compared to pre-elderly standard deviation. This was meant that adult perceived burden was greater than pre-elderly.

*Conclusion:* Adult informal caregiver's perceived burden was greater than pre-elderly. They have more responsibilities such as taking care of the household, earn living, and educate their children. Good coping mechanisms and family support are needed to overcome the excessive stressors due to caring process.

**Keywords:** *adult; informal caregiver; perceived burden; pre-elderly*

### INTRODUCTION

Old people is a person who has reached the age of 60 or older (Kemenkes, 2019). Every human will definitely reach the aging process where there is massive declining in both cells and body functions. Old people population in Indonesia was 10.48% from total population. The obvious body function declining is clearly visible in musculoskeletal, nervous, cardiovascular, and respiratory systems (Lilyana & Cempaka, 2023). In old people, cell function will decrease consistently with increasing age. This process can cause degenerative diseases in elderly (Fatihaturahmi, 2023). Due to this physical function declining, old people desperately need caregivers to help them meet their basic needs and providing care.

According to the Ministry of Health in 2022, caregiver is a person who has passed education or training to provide assistance for someone who is unable to take care of themselves, either partial or total due to physical or mental limitations. Informal caregiver can be spouse, parent, sibling, or close friend who provides care without being paid (Yankes, 2022). In a study conducted at Tugurejo Hospital Semarang, 55.4% of adult caregivers took care of the elderly and 44.0% of elderly caregivers (Nandha Ariska et al., 2020).

Adult informal caregiver ages is ranged between 26–45 years and 46–65 years is categorized as pre-elderly. Adult informal caregiver has several roles because they need to provide their old

people and children basic needs (Khalil & Santoso, 2022). They endure more burden and responsibility for providing care and services such as transportation, meal planning, health care, and other family affairs (Putrima Tadung & Jofial Rimate, 2023). They have several roles, as a parent, children, and informal caregivers (Fitriani Anisa dan Agustin Handayani, 2018). On the other hand, study showed that older person would be able to solve problems better than the younger one because they have more experience (Jannah et al., 2020).

This condition can lead to the increasing of caregiver's perceived burden and declining caregiver's quality of life which is need immediate attention (Fitriani Anisa dan Agustin Handayani, 2018). The aim of this research was to compare adult and pre-elderly informal caregiver's perceived burden.

## **METHOD**

This was a non-experimental research and cross-sectional design was used. This research was conducted in Sukoharjo Village, Klojen District, Malang City between March until December 2023. The population in this study was informal caregivers as much as 90 respondents. The sampling technique was simple random sampling and 74 respondents were obtained. The respondent was divided into two age categories, adult and pre-elderly, which had 37 respondents for each group.

Independent variables in this study was age (adult and pre-elderly), and dependent variable was informal caregiver's perceived burden. The data was obtained with questionnaires, which consist of two parts. The first part was identity to identify the age, and second part was The Informal Caregiver Burden Assessment Questionnaire (QASCI-*The Questionario de Avaliacao de Sobrecarga do Cuidador Informal*) to identify informal caregiver's perceived burden which has been tested for validity and reliability. It consists of 32 question items with seven sub-items, namely emotional burden, implications on personal life, economic burden, on-demand reactions, perceptions on effectiveness and control mechanisms, family support, satisfaction with roles and relatives. Validity test results for each questionnaire with a lowest value of 0.61 and a highest value of 1.0 (Anggoro, 2012). Got 32 questions, 29 valid questions. There were three questions omitted from the QASCI questionnaire component.

There was three questions omitted from the QASCI questionnaire component. The test results say reliability is when the question is obtained by Cronbach's alpha ( $<0.06$ ). Reliability test result Construction variable 1 Burden shows 0.856, Construction variable 2 Implications on personal life show 0.929, Construction variable 3 Economic load shows 0.852, Construction variable 4 On demand shows 0.868, Construction variable 5 Perceptions on effectiveness and control mechanisms denote 0.730, construction variable 6 Family support denote 0.718 and last construct variable 7 Satisfaction with roles & relatives denote 0.818 so the questionnaire is said to be reliable. The analytical technique used to test the normal distribution is Kolmogorov-smirnov, after which it is analyzed using a paired sample test.

**Table 1**  
*QASCI Indicator Question Item Validity Test*

No.	Variable Construction	Pearson Correlation
Construction 1: An Emotional Burden		
1	VAR00001	.597
2	VAR00002	.684
3	VAR00003	.643
Construction 2: Implications on personal life		
4	VAR00004	.536
5	VAR00005	.554
6	VAR00006	.548
7	VAR00007	.545
8	VAR00008	.464
9	VAR00009	.554
10	VAR00010	.484
11	VAR00011	.686
12	VAR00012	.216
13	VAR00013	.366
Construction 3: Economic burden		
14	VAR00014	.929
15	VAR00015	.892
Construction 4: Reaction on demand		
16	VAR00016	.785
17	VAR00017	.824
18	VAR00018	.825
19	VAR00019	.843
20	VAR00020	.689
Construction 5: Perception of effectiveness and control mechanisms		
21	VAR00021	.875
22	VAR00022	.338
Construction 6: Family Support		
23	VAR00025	.403
24	VAR00024	.975
Construction 7: Satisfaction with roles & relatives		
25	VAR00025	.655
26	VAR00026	.306
27	VAR00027	.381
28	VAR00028	.157
29	VAR00028	.451

## RESULT

Analysis of the research results of the two groups through group statistics found a difference of 7.52. Where in the adult group the analysis used standard deviation in the adult group of 25,281 and in the pre-elderly of 14,883 and found a difference of 1,709 greater in adults of 4,156 and in the pre-elderly of 2,447. Research findings suggest that there is a difference in burden perceived by informal caregivers in adulthood and pre-elderly ( $p=0.000$ ).

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**Table 1**  
*Sociodemographic Frequency Distribution of Respondents (n=74)*

No	Variable	Frequency	Percent (%)
<b>Gender</b>			
1	Male	15	20.2
2	Female	59	79.8
Total		74	100
<b>Marital Status</b>			
1	Married	54	72.9
2	Not Married	6	8.1
3	Not married yet	12	16.2
4	Widow/widower	2	2.8
Total		74	100
<b>Last Education</b>			
1	Elementary School	6	8.1
2	Junior High School / equivalent	5	6.7
3	Senior High School / equivalent	50	67.6
4	Higher Education (D3/D4/S1)	13	17.6
Total		74	100
<b>Occupation</b>			
1	Private sector	42	56.7
2	Civil Servant (PNS)	0	0
3	Housewife	28	37.8
4	Unemployed	4	5.5
Total		74	100
<b>Number of Children</b>			
1	1 child	20	27
2	2 children	18	24.3
3	>2 children	36	48.7
Total		74	100
<b>Living Arrangement with Elderly</b>			
1	Living together	66	89.2
2	Not living together	8	10.8
Total		74	100
<b>Age</b>			
1	Adult	37	50
2	Pre-elderly	37	50
Total		74	100
<b>Perceived Burden</b>			
1	Moderate	36	48.7
2	High	25	33.7
3	Extreme	13	17.6
Total		74	100

Table 1 showed that majority of respondents were female (79.8%), married (72.9%), and had more than two children (48.7%). Their education background were Senior High School (67.6%) and most worked as private employees (56.7%). Some respondents lived in one house with their old people (89.2%).

**Table 2**
*Analysis of Data Using Paired Samples Test (n:74)*

Age	n	Mean	Std. Deviation	Std. Error mean	p value
Adult	37	64.38	25.281	4.156	0.000
Pre-elderly	37	56.86	14.883	2.447	

Table 2 showed that there was a significant difference ( $p=0.000$ ) in burden perceived by informal caregivers. The adult informal caregiver's perceived burden was higher compare to pre-elderly group.

## DISCUSSION

Sociodemography is the study of the characteristics of individuals that involve four demographic factors, namely age, sex, level of education and work experience (I Putu Sastra Dinata, 2023). The results of the sociodemographic analysis according to table 1, the first factor (gender) shows that the number of informal female caregivers is greater than that of males. The second factor (Marital Status) shows that married informal caregivers have the most percentages compared to not married yet, not married, or widow/widower. The third factor (Last Education) shows the highest level of high school/equity education among others with a frequency of 50 people. The fourth factor (age) shows the equation between adult and pre-elderly with 50% percentage each. And the last additional factor is employment, from the four types of jobs, namely private sector, civil servants (PNS), housewife, and unemployed, the private sector has a maximum frequency of 42 people.

Based on the results of the study, there was a difference in the burden felt by informal nurses in adulthood and pre-elderly, indicating that the burden felt by informal nurses in adulthood is greater than that of pre-elderly nurses. The burden felt by nurses has several dimensions, one of which is emotional burden. Emotional burdens have an important role that affects the quality of care. In adulthood, the emotional burden felt is greater than the emotional burden felt in pre-elderly times. In one study it was explained that adult individuals chronologically made it possible to have a low level of emotional maturity. The increase in age and level of emotional maturity go hand in hand, but individuals who are mature and physically not necessarily emotionally mature (Adila & Kurniawan, 2020). The statement could reinforce that adult informal caregivers may not yet have a stable emotional maturity due to the amount of burden they bear, moreover if they have to become informal caregivers.

Physical burden is a burden factor because the informal role of caregiver is to meet or help all elderly needs from physical, mental, social or spiritual needs. Weak physique can make caregivers even more burdened if they have to do all the work accompanied by personal work. Physical work on informal caregivers of adult age is certainly more than that of pre-elderly, which can be an excessive physical burden on informal caregivers and affect their health. There are studies that have found physical burden effects that can affect caregiver's health, such as fatigue, sleep disorders, non-food, headaches, high blood pressure, boils. Adults have busier lives, thus risking health problems because adults are still in the productive age category, compared to pre-elderly age who have passed their productive years (Nandha Ariska et al., 2020).

Economics is one of the factors affecting the burden felt by informal caregivers. The economic burden is related to the income and expenditure of a caregiver, the adult age expenditure is more because they have to meet the needs of their children if they have children, the needs of themselves because at this age they still want to meet tertiary needs such as vacations, clothing, clothing, and clothing. buy self-decorated equipment and others. Meanwhile, in pre-elderly, they have passed through those times so that at their current age they are not as ambitious as in adulthood. Hence, in adulthood, people have to be more productive and work even harder in earning extra money for their needs. In one study, it was also mentioned that economic burdens occur if the administrator has financial responsibilities for the elderly, who are associated with higher burdens (Hadi Widiastuti et al., 2019).

As an individual who lives cannot be separated from responsibility, but excessive responsibility can also be a burden and if not mechanized properly it will lead to stress that can even lead to depression. In addition to the above factors, there are several other factors that can also affect the burden on informal caregivers. As in the research conducted by (Putri et al., 2023). In his research, he found the relationship of burden to quality of life, but it also had something to do with the level of caregiver education. Caregiver's highly educated quality of life is not too bad and burdened because they can manage his time well which makes his burden light, In low-educated caregivers, in contrast, they are lacking in time management, resulting in a buildup of burdens that should be lightweight.

## CONCLUSION

From this study, it can be concluded that adult and pre-elderly group encounter different perceived burden. The adult caregiver perceived burden was higher than pre-elderly. Perceived burden consist of several factors, but in this research the dominant factors were emotional, physical, economic, and family support.

From this study, we suggest informal caregivers to manage some aspect of their life, such as implementing good time management, creating a regular daily schedule, provide personal space and time, and have a better income and expense planning. Family support also play important role to maintain informal caregiver mental health.

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