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Family Caregiver's Quality of Life of Elderly Parent with Alzheimer's Disease

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This research explores the relationship between burden of care, health perception, and demographic as aspects that affecting the quality of life of 50 family caregivers with the mean of age is 46.68 years old and *SD* = 12.97. Each subject has been given QoL-AD, HPQ, and ZBI-22, then being analyzed with Pearson Correlational Analysis and Multiple Regression Analysis with the stepwise method. The result showed that burden of care ($r = -.454$, $p < .01$), current health ($r = .660$, $p < .01$) and history of AD ($r = .339$, $p < .05$) significantly related to quality of life, while regression analysis shows that current health and AD history as a significant contributor ($R^2 = .496$, $p < .01$) Furthermore, it is necessary to test the model with more diverse variables that significantly contributed to family caregivers' quality of life.

Keywords: elderly, AD, family caregiver, quality of life, the burden of care, health perception, current health, patient's history of AD

Jumlah penderita Alzheimer di Indonesia mengalami peningkatan, sehingga diperlukan keluarga sebagai pengasuh. Selama menjalankan perannya, muncul berbagai konflik antara peranan dan tanggung jawab yang secara sadar maupun tidak telah mempengaruhi kualitas hidup. Penelitian ini membahas hubungan antara beban pengasuhan, persepsi tentang kesehatan, demografi sebagai faktor-faktor yang mempengaruhi kualitas hidup pada 50 pengasuh keluarga. Setiap subjek diberikan instrumen berupa QoL-AD, HPQ, dan ZBI-22, kemudian dianalisis dengan analisis korelasi *Pearson* dan analisis *Multiple Regresssion* metode *stepwise*. Hasilnya beban pengasuhan ($r = -.454$), kesehatan saat ini ($r = .660$, $p < .01$), dan riwayat pasien AD ($r = .339$, $p < .05$) berhubungan signifikan dengan kualitas hidup, sedangkan analisis regresi menunjukkan kondisi kesehatan saat ini dan riwayat AD sebagai kontributor signifikan ($R^2 = .496$, $p < .01$). Dengan demikian, faktor kesehatan dan riwayat AD memiliki peranan terhadap kualitas hidup pengasuh keluarga. Selanjutnya, perlu melakukan uji model dengan variabel yang lebih beragam, misalnya kepribadian, yang berhubungan dan berkontribusi signifikan terhadap kualitas hidup pengasuh keluarga.

Kata kunci: lansia, Alzheimer, pengasuh keluarga, kualitas hidup, beban pengasuhan, persepsi sehat, kondisi kesehatan saat ini, riwayat pasien AD

AD's Disease (AD) is a neurodegenerative disease which is characterized by a decline in learning and memory function. People with an AD experience mild stage memory loss at the beginning before end up experiencing severe memory loss and disorientation. Two-third of people with AD tend to have psychiatric symptoms, including agitation, irritability, apathy, and dysphoria (Nolen-Hoeksema, 2014). Indonesia is one of the five countries with the highest population of people with AD in the world. The Alzheimer Disease International (Wortmann, Kuriahose, & Koes, 2014) estimated that the number of people with AD in Indonesia would be 1,033,000 people in 2015, 1,894,000 people in 2030 and would continue to increase as much as 3,979,000 people in 2050.

According to Kolb and Wishaw (2009), AD's patients experience seven stages, begin with the early stage (none), in which no symptom is detected, until the last stage (very severe), in which the brain loses the ability to give information verbally and psychomotor. The impacts of the disease that may be experienced by the patients are a sense of isolation, fear,

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and anxiety that make them frustrated, stressed and the possibility of depression. Such impacts indicated that there is a need for family caregivers, who are close to the patients and take care of them. The family caregivers may express love and care which build a relationship with the patients (Wallerstedt & Andershed, 2013). The person who usually becomes the family caregiver is a member of the patient's own family or people who are close to the patient.

Most of the family caregivers are in the middle adulthood. People in the middle adulthood have some duties, which include their roles in families and work. At this age, someone makes choices. They choose what they are going to do, how to invest time and resources and evaluate the aspect of life they want to change (Santrock, 2011). Therefore, events and situations that happen in life, in combination with other factors, such as physical health and family support, can affect one's development. Accordingly, the family caregivers may experience a variety of conflict and stress that are occurred in their families, such as roles division, health, financial, decision-making, routine changes, role changes, and demands (Springer & Brubaker, 1984).

Being a family caregiver is a new responsibility, a new role, as well as a new living situation which is considered as a factor that can disrupt a normal life. A role of the family caregivers may demand the person to sacrifice their time and may affect their work which influences the financial condition. Furthermore, being in such a new role may cause the conflict within themselves about the feeling of satisfaction in caring. The issue of trust, guilt, and worry over caring for a loved one is also a challenge in providing services. In addition, there is a tendency for the family caregivers to give more attention and care to the patients rather than to themselves. As a consequence, their own health is being neglected. (McCurry & Drussel, 2011; Wallerstedt & Andershed, 2013)

The study on family caregivers who deal with AD showed 31% of adults experienced stress, anxiety, depression, and 53% of them were not able to spend time with friends and families (Bedini & Gladwell, 2014). Most of the family caregivers who experienced higher loads were women than men. Family caregivers tend to spend extra efforts to look after patients who are unable to do anything in particular when they are in the final stage (Bedini & Gladwell, 2014; Hall, Wilkerson, Lovato, Sink, & Chamberlain, 2014)

In addition, one of the other factors that could affect family caregivers while taking care of people with AD is the length of time for treating the patient. Such factor has a significant correlation with the burden experienced by family caregivers. Furthermore, health becomes important matters on family caregivers. They may be susceptible to some diseases such as a decrease in the immune system, hypertension, cholesterol and other diseases. Family caregivers' views on their own health can also become a factor that affects their quality of life. The knowledge that the family caregivers have about AD and how to take care of the patients can reduce frustration, worries, and burden. The burden as a caregiver has a positive correlation with negative emotions that may occur. The negative emotion is one of the main components that may influence the family caregiver's quality of life (Yu, Wang, He, Liang & Zhou, 2015; McCurry & Drussel, 2011; Zawadzki, Mondon, Peru, Hommet & Constans, 2011).

The quality of life of the family caregiver is a personal experience of a family caregiver while treating the patients in relation to their daily life in the neighborhoods (Lawton, 1999; Jonker, Gerritsen, Bosboom & Steen, 2004). In evaluating someone's quality of life, physical aspects (e.g., age, cognitive function) and one's experience (e.g., the way of people view or interpret themselves as a caregiver, stress management strategy, emotional and social interaction) should be put into account (Glozman, 2004). The factors that affect the quality of life of a family caregiver among others are demographic factor (e.g., job, education, duration of history of disease, family situation, and economy), health (e.g., condition or health perception of family caregiver), and the burden of care (the problems which are experienced by family caregiver while treating the patient suffering from disorder or chronic disease). The burden of care is associated with disrupted health condition because family caregivers tend to pay less attention to their own health for maintaining the quality of care and the quality of relationship in social context which is becoming more limited (Serano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006; Duggleby, Swindle, Peacock & Ghosh, 2011).

The situation which may be experienced by family caregivers can put them in the vicious circle. They have the desire to treat their family members, but on the other hand, they are also struggle with several factors such as age, health, workload, economy, as well as his own family who also require attention. Moreover, family caregivers have not fully recognized the impact of factors that affect the quality of life. In addition, the research about family caregiver's quality of life is still limited in Indonesia, means it is important to study the phenomenon of the number's elderly people increasing drastically in Indonesia, especially Alzheimer's patients reaching 1.2 million people. This needs to be a concern as an effort to anticipate and maintain the family caregivers Alzheimer's quality of life.

Based on the description above, this research will examine the relationship between burden of care, health perception, and demographic as aspects that affect the quality of life of fifty family caregivers. The hypothesis of this study is the demographic, burden of care and health perceptions are significantly related to the family caregiver's quality of life of elderly with Alzheimer's disease. Further, this study wants to find out the three factors that are significantly related, which are the significant contributors.

Methods

Participants

Participants of this research were 50 family caregivers who were members of AD Indonesia Foundation. They were based in Jakarta, Bogor, Depok, Tangerang, Bekasi, Bandung, Salatiga, and Yogyakarta. The average age of the subject was 46.68 years old (*SD* = 12.97) which ranged from 19 to 76 years old. The gender of the family caregivers consists of 36 people (72%) dominated by women and 14 people (28%) are men. In addition, the relationship between the family caregivers with the patient consist of 29 people (58%) are biological children, six people (12%) are their spouse, and the others 15 people such as grandchildren, son-in-low, and siblings.

Measures

Family caregivers were asked to provide sociodemographic information including age, gender, the level of education, marital status, the gender of the patient, relationship with the patient (partners, children, etc.), and whether he or she lived with the patient and patient's history of AD. Family caregivers were also asked to complete three instruments to assess their burden of caregiving, health perception, and the quality of life.

The Quality of Life in AD Disease (QoL-AD). An instrument of QoL-AD is used to measure the quality of life that was developed by Logsdon, Gibbons, McCurry, and Teri (1999) specifically for patient and family caregivers of AD. The researcher contacted the maker of this instrument for permission and doing face validity for translation into Indonesian by the expert who is competent in the field of quality of life, especially Alzheimer's to be tested valid during the translation process. The expert is a psychologist of Universitas Katolik Indonesia Atma Jaya and the founder of Alzheimer's Indonesia. This instrument is valid to measure construct (.88 for AD's patients and .87 for family caregivers) and reliable (.76 for AD patient and .92 for family care-givers) to be used in a context of quality of life for patients and family caregivers of AD. The dimensions in this instrument consist of physical condition, mood, interpersonal relationship, the ability to perform meaningful activities, financial situation and overall assessment of the quality of life. This tool consists of 13 items that are measured by four point-scale of Likert such as multiple choices, which scale of 1 indicates poor and scale of 4 indicates excellent. Scores are the total of all the items and the scores range from 13-52. QoL-AD can be administered by interviewing the respondent or by letting the respondents to fill it in themselves.

Health Perception Questionniare (HPQ). Health Perceptions questionnaire (HPQ) is used to measure subjective perception of health which was developed by Stewart and Ware (1992). This instrument has been adapted and carried out by the translation process of master in adult clinical professional psychology Universitas Katolik Indonesia Atma Jaya because the instrument has been a part of their assignment. Then the researcher contacted the lecturer, Magdalena S. Halim, for permission. This instrument valid to measure construct (.52) and reliable (.67) to be used in the context of health perception. The HPQ contains the 32 items and has six subscales. The six subscales include Current Health, Prior Health, Health Outlook, Resistance-Susceptibility to Illness, Health Worry and Sickness Orientation. Each item in HPQ consists of five answers by Likert's scale which are definitely true, mostly true, don't know, mostly wrong and definitely false. The five answers are a scale to measure favorable and unfavorable items on self-health perception with total scores of each subscale. The range of total score for each subscale consist of 9 to 45 for Current Health, 3 to 15 for Prior Health, 4 to 20 for Health Outlook, Resistance-Susceptibility to Illness and Health Worry, 2 to 10 for Sickness Orientation.

The Zarit Burden Interview (ZBI). The Zarit Burden Interview (ZBI), developed by Professor Steven H. Zarit of the University of Pennsylvania in 1980 (Mapi Research Trust & Zarit, 2014). The researcher contacted Mapi Research Trust for agreement to using this instrument, then translation process Indonesian was done by the expert who was competent in the field to be tested valid during the translation process. The expert was a psychologist of Universitas Katolik Indonesia Atma Jaya. This instrument is valid to measure the construct (.88) and reliable (.71) to be used in the context of family caregivers of how much burden is felt. The ZBI contains two dimensions, which are the personal strain and role strain, and consists of 22 items. Each item in ZBI consists of five answers by Likert's scale which are never, rarely, sometimes, quite frequently and nearly always. Scores are the total of all items and the scores range from 0-88.

Procedures

A letter consisting information and a request to assist in the study were sent to Ethics Committee of the Universitas Katolik Indonesia Atma Jaya and to Alzheimer Indonesia Foundation. After the permission to conduct this study had been granted, the researcher collected the data with purposive sampling technique in Jakarta, Bogor, Depok, Tangerang, Bekasi, Bandung, Salatiga, and Yogyakarta. The family caregivers were given the informed consent for this study. Subsequently, they were asked to complete the demographic data and the three instruments.

Statistical Analysis

Pearson Product Moment calculated the relationship between burden of care, health perception, demographic data and quality of life. After the significant correlation between variables had been determined, multiple regression was used to estimate the extent to which the independent variables explained the change over time in family caregivers' quality of life.

Results

The participants consisted of 14 men and 36 women. Forty family caregivers (80%) were in the middle adulthood. Six family caregivers (12%) were the spouses of the patients and 29 family caregivers (58%) were the children of the patients. Thirty eight of fifty family caregivers were living with the patient (76%). The number of women was higher than men as a patient (60%), and the patient's history of AD ranged from two to five years (38%). The researcher categorized the quality of life, burden of care, and current health of participants into three levels (low, medium, and high). This categorized has been calculate by within-group norm and the results showed that the level of quality of life 64% (*mean* = 36.54 and *SD* = 6.27), the burden of care 66% (*mean* = 34.14 and *SD* = 15.44), and current health 64% (*mean* = 33.40 and *SD* = 6.13) which were owned by most participants were in medium level for their quality of life, burden of care as a caregivers and perception about their current health. In addition, based on the results of the normality test conducted by researchers using Kolmogorov-Smirnov, the quality of life normally distributed with a value of $Z = 0.11$ and *p-value* = .175, $\rho \geq .05$), burden of care variable is normally distributed with a value of $Z = 0.101$ and *p-value* = .20, $\rho \geq .05$), then the current health variable is normally distributed with a value of $Z = .88$ and *p-value* = .20, $\rho \geq .05$).

Table 1 shows the existence of a significant relationship between burden of care, health perception, and also demographic data on the quality of life on 50 participants (also see Figure 1). The quality of life had significant relationship with burden of care (*r*

Table 1

Intercorrelation Between Variables

Variables	Quality of Life	Burden of Care	Current Health	Resistance/ Susceptibility	Health Outlook	Patient's history of AD	Gender of AD
Quality of Life	1	-0.454**	0.660**	0.466**	0.371**	0.339**	-
Burden of Care	-0.454**	1	-0.439**	-	-	-	0.391**
Current Health	0.660**	-0.439**	1	0.595**	0.656**	-	-0.315*
Resistance/Susceptibility	0.466**	-	0.595**	1	0.641**	-	-
Health Outlook	0.371**	-	0.656**	0.641**	1	-	-
Patient's history of AD	0.339**	-	-	-	-	1	-
Gender of AD	-	0.391**	-0.315*	-	-	-	1

Note. **) $p < .01$; *) $p < .05$;

Quality of life measured by QoL-AD; Burden of Care measured by The Zarit Burden Interview (ZBI); Current Health, Resistance/Susceptibility; Health Outlook measured by Health Perception Questionnaire (HPQ); Patient's history of Alzheimer's Disease, Gender of Alzheimer's Disease measured by demography

$= - .454$, $p < .01$), current health ($r = .660$, $p < .01$) and patient's history of AD ($r = .395$, $p < .01$) The relationship between quality of life and burden of care ($r = - .454$, $p < .01$) and effect size Cohen (Gravetter & Wallnau, 2007) $d = 0.877$ showed that the higher family caregivers' quality of life, the lighter the burden they felt during the treatment of patients with AD.

The variable of burden of care was correlated with other variables, which were gender ($r = - .328$, $p < .05$), marital status ($r = .329$, $p < .05$), gender of AD ($r = .391$, $p < .05$), and current health ($r = - .439$, $p < .01$). On variable of current health with ($r = .660$, $p < .01$) and effect size Cohen (Gravetter & Wallnau, 2007) $d = 0.700$ showed the higher quality of life on family caregiver, the more excellent of physical health of family caregiver with moderate effect size. Current health was correlated with other variables, which were resistance/susceptibility ($r = .595$, $p < .01$), health outlook ($r = .656$, $p < .01$), and gender of AD ($r = - .315$, $p < .05$). In this case, variable of resistance/ susceptibility and health outlook also significantly have a relationship with quality of life with the correlation coefficient for each of $r = .466$, $p < .01$ and $r = .371$, $p < .01$. Meanwhile, resistance/susceptibility has a significant correlation with health outlook ($r = .641$, $p < .01$) and health worry ($r = - .438$, $p < .01$). Besides correlated with current health, resistance/ susceptibility and quality of life, health outlook had a correlation with last education level ($r = - .301$, $p < .05$). In addition, the level of education correlated with employment status ($r = .281$, $p < .05$).

On the patient's history of AD showed correlation $r = .339$, $p < .05$ and effect size Cohen (Gravetter & Wallnau, 2007) $d = 0.50$, this shows the higher the quality of life of the family caregivers, the longer duration of the disease on the patient of AD with moderate scale. Patient's history of AD also had a correlation with age ($r = .395$, $p < .01$). Age of the patient had a correlation with AD ($r = .317$, $p < .05$). The relationship status between patients with AD and their caregivers had a correlation with age of participants ($r = - .483$, $p < .01$).

After the existence of a significant relationship between the burden of care, the domains of health perception and demographic data on quality of life had been confirmed, the researcher continued to the exploration of the predictions among these three factors that significantly explain the quality of life by using statistical test of Multiple Regression Analysis. This statistical test was used to find out which of those variables that had a significant relationship to the quality of life. The Multiple Regression Analysis needed to be conducted in this study due to the possibility that those variables could be significantly related to the quality of life but might not contribute significantly to it (see Figure 2).

Table 2 showed that the variable that contributes to the quality of life was the current health with $R^2 = .436$, $p < .01$, which meant that 43.6% of the quality of life could be explained by the current health. However, if the current health was combined with the patient's history of AD, the variable contribution would increase to $R^2 = .496$, $p < .0$, which meant that 49.6% of the quality of life could be explained by current health and patient's history of AD, while the rest was explained by other factors.

Furthermore, researchers want to examine the significant contributor to current health, because the current health becomes a significant contributor to quality of life (see Table 3). It was found that health outlook, the burden of care, and resistance/suscepti-

Table 2
Multiple Regression Analysis of Quality of Life

	R Square	*Beta*	*t*	*Sig.*	*Durbin-Watson*
Model 1 (Current Health)	.436	0.624	5.958	.000	1.481
Model 2 (Current Health, History of AD)	.496	0.247	2.359	.023	

Note. **) $p < .01$; *) $p < .05$

Table 3
Multiple Regression Analysis of Current Health

	R Square	*Beta*	*t*	*Sig.*	*Durbin-Watson*
Model 1 (Health Outlook)	.430	0.495	4.314	.000	2.812
Model 2 (Health Outlook, Burden of Care)	.611	-0.406	-4.587	.000	
Model 3 (Health Outlook, Burden of Care, Resistance/ Susceptibility)	.644	0.238	2.068	.044	

Note. **) $p < .01$; *) $p < .05$

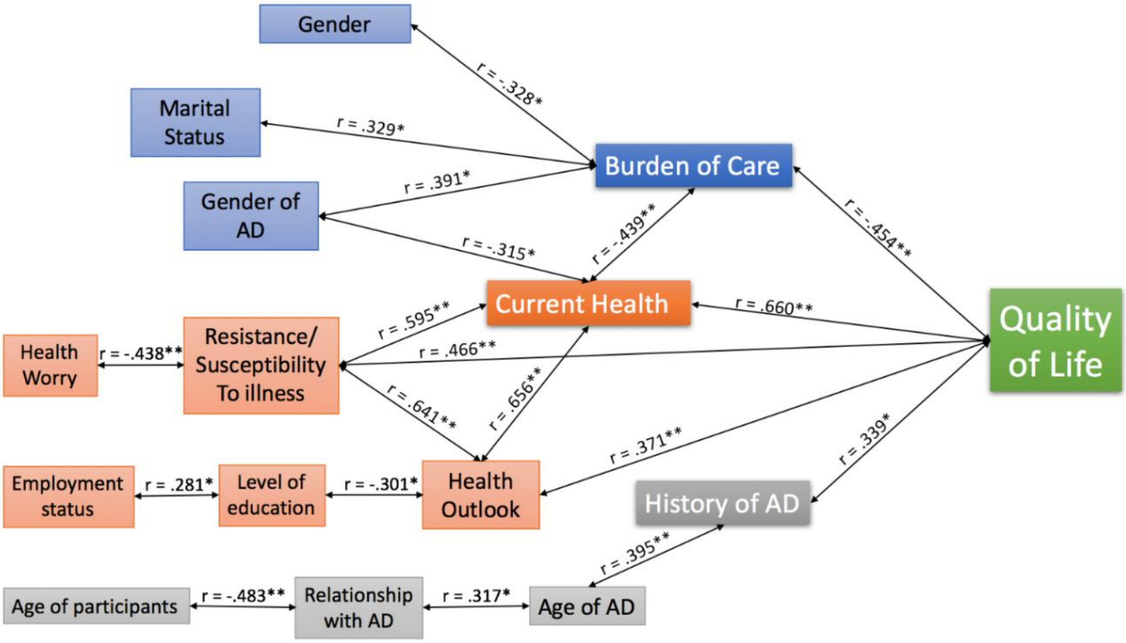

Figure 1. Intercorrelation BetweenVariables.

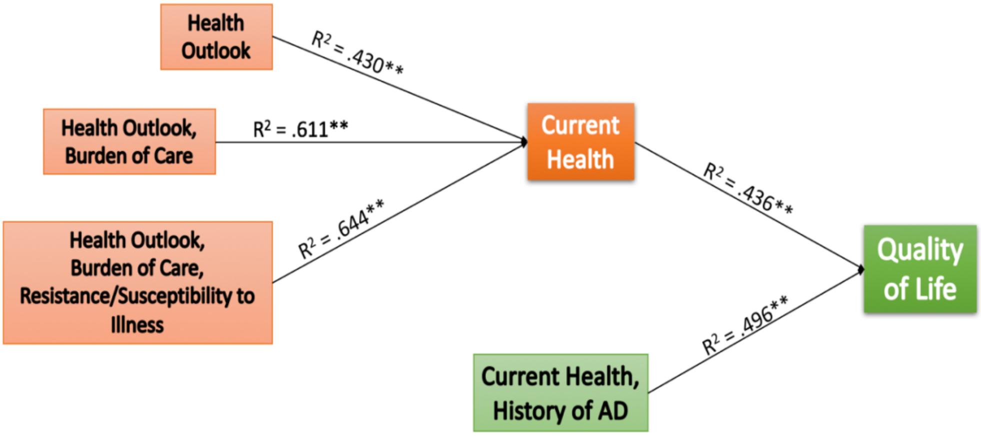

Figure 2. Multiple Regression Analysis.

bility to illness significantly contributed to the current health, where all of the three variables produced a value of $R^2 = .644$, $p < .01$. The value of R^2 meant that 64.4% of the current health could be explained by these three variables and the rest was explained by other factors.

Discussion

This study showed that current health and the patient's history of AD is a significant contributor to quality of life ($R^2 = .496$, $p < .01$). This means that the physical condition and the length of time for taking care of the patient will affect the quality of life whereas the hypothesis of this study is accepted. These results are consistent with the usual conditions experienced by family caregivers of middle age, where there was a view in themselves to ensure whether they were in a good condition or not when dealing with people with AD. It was also supported by the length of time for taking care of the patient, where the longer time showed the better process of adjustment with the behavior of the patient.

Meanwhile, the burden of care was not a contributor to quality of life, although it actually had a significant correlation of $r = -.454$, $p < .01$ compared with patient's history of AD. Such result may be caused by several things, namely based on test results obtained from stepwise multiple regression method, in which the variables that appear only current health and patient's history of AD, while the rest of the system was removed. The rest of the variables, including burden of care, might be related to the quality of life but did not contribute enough and significantly to the quality of life. Another possible reason why the burden of care was not a contributor was the burden of care might not be just purely correlated with quality of life, but also correlated with the current health ($r = -.439$, $p < .01$), while a patient's history of AD was only directly related to the quality of life ($r = .339$, $p < .05$) and not related to other variables which had a significant relationship with the quality of life. It can be concluded that when the patient be more dependent to the family caregivers, the family caregiver becomes more strenuous. This may increase frustration for the family caregivers and affect their health. In this situation, it is important for them to have sufficient time away from caregiving responsibilities to meet their own needs (Springer & Brubaker, 1984).

Participants in this study had an average age of 46.68 years old (*SD* = 12.97), which showed that most family caregivers were at the age of middle age. Santrock (2011) explains that within this age, individuals have the time to evaluate, assess, and reflect the work and activities they want to do. They use their time to determine future career paths, divide roles between family and work, as well as plan their future life (Santrock, 2011). Besides, they also spend the time to do fun activities, such as hobbies, sports, reading, or traveling. Such activities can make them keep functioning optimally in daily life.

Data showed that 52% of participants, who were in middle age, had a work status and 68% lived together with patients. In this case, the majority of family caregivers were active workers. It means that they consciously or unconsciously divided their time and energy between work and family, especially for taking care of people with AD's. Dealing with such circumstance, it was found out that as many as 16% of family caregivers were experiencing heavy burdens, especially when they had just been entering the new role as a caregiver for 0-2 years (32%). In addition, 18% of middle-aged participants rated the state of their health and quality of life as poor.

In addition, this study also showed that the role of the family caregivers is dominated by women. Therefore, it may be concluded that the Indonesian society tends to view women as the primary family caregiver. This may be happened due to several reasons, such as the role of women that should be caring and nurturing the family, as well as the woman nature that tends to have a higher standard for treating rather than men. However, amongst the participants who were involved in this current study, there were 28% of male family caregiver. Consequently, it may be concluded that there are still some people who think that men can also take care of people they love in a different way from women. The men refer to discuss instrumental support instead of affection aspect and they would work hard at giving care (Bengston, Gans, Putney, & Silverstein, 2009).

Furthermore, the result of this research showed that AD affected more women (60%) than men (40%). It is consistent with previous study that the 168 AD patients, 52.4% were females (Yu, Wang, He, Liang, & Zhou, 2015). Therefore, it is suggested for women to give more attention in taking care of their health properly. The result also showed that the age of participants who were affected by AD was mostly 75-85 years (50%) and did not eliminate the possibility of age under 65 years (6%) can also suffer from AD.

The awareness of emergence of AD needs to be addressed by all people, regardless of their age, gender, economic status, and so on. The importance of AD awareness is because AD can occur in any individual regardless of background, age or gender if there is an absence of early prevention. Moreover, the adverse effects on patients accompanied with various stages of the disease make the quality of life of the patient and the family caregiver tend to decline. Some precautions as part of the early prevention of AD, such as a regular diet, regular exercise, and healthy lifestyle, and so on should be encouraged. (Kuhn, 2003; Kolb & Wishaw, 2009).

Suggestions for the family caregivers, relaxation techniques can be given as one of coping when experiencing stress or negative feelings and experienced learning how to communicate with AD in order to understand the needs of sufferers (Hersen & Sledge, 2002). In addition, education sessions and support systems are also needed for the family caregivers to increase knowledge related to AD and maximize the resources around them to help improve quality of life.

Limitation of the Study

There were limitations in this study. First, the researcher did not consider other factors that may affect the quality of life, such as personality. Personality is seen from various aspects, such as intellectual capacity, affection and social relations with the surrounding environment (Feist & Feist, 2009; Bond & Corner, 2004). If there is a dysfunction of these three things while caring for people with Alzheimer's disease, it tends to affect a person's condition in low of quality of life and current health, then has a relatively high level of burden of care. Second, the sample size was too small for creating a model that can explain the factors which affect the family caregiver’s quality of life. Therefore, the future research should consider other factors that have not been studied in addition to incorporating a bigger sample size.

Conclusion

The conclusion of this research is that the quality of life in AD family caregiver was influenced by current health and patient’s history of AD. The higher the health conditions experienced and the longer the time spent on caring for the patient may indicate the higher perceived quality of life.

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