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| RESEARCH ARTICLE

Anxiety Profile of PWD and Caregiver During COVID-19 Pandemic in ALZI Surabaya Community, Indonesia

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| ABSTRACT

The consequence of COVID-19 pandemic conditions in vulnerable groups such as Patients with Dementia (PWD) and their caregivers are required to be urgently addressed. This study was conducted to collect data on PWD and caregiver characteristics, also concluding the profile of anxiety during the COVID-19 pandemic in Alzi Surabaya Community. This research is an observational descriptive cross-sectional study using the Beck Anxiety Inventory and Rating Anxiety in Dementia questionnaire to apprehend the profile of anxiety in PWD and caregivers in the Alzi Surabaya Community during the COVID-19 pandemic. PWD in this community experience significant anxiety (82.35%) with symptoms such as sleep disturbance (100%) worry over trifles (92.85%), complaints of headache and body aches or pains (92.85%) also sweating, flushes or chills, tingling or numbness of extremities (42.85%) and insignificant anxiety (17.65%) with symptoms such as fatigue and tiredness (100%), worry about physical health (66.57%), irritability (66.57%), heart racing or thumping (33.33%). Caregivers of PWD in this community all experience low anxiety with symptoms such as fear of something worst happening (80%), unable to relax (65%), indigestion and dizziness or lightheadedness (55%). Intervention, in order to reduce anxiety in PWD and caregiver during and post-pandemic, is substantial as establishing a good quality of life is important for PWD to increase fulfilment in life and also important for caregivers in order to maintain quality of care.

| KEYWORDS

Anxiety, caregiver, dementia, mental health, COVID-19, pandemic

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1. Introduction

The emergence of the COVID-19 pandemic raised awareness and questions around its effects on mental health, especially in psychological and socio-economical retrospect (Kola et al., 2021). The consequence of increased social isolation and loneliness during COVID-19 have a strong correlation with mental health; one of them is anxiety (Holmes et al., 2020). The global prevalence of anxiety disorders during the COVID-19 pandemic in 2020 was equivalent to 374 million people (Santomauro et al., 2021). Some groups are more susceptible than others to the psychosocial effects of pandemics. In particular, those at heightened risk for infection, such as the elderly, especially with pre-existing psychiatric problems, are considered as vulnerable (Pfefferbaum et al., 2020), such as dementia. Dementia is one of many psychiatric problems in the elderly. 1.2 million people in Indonesia was diagnosed with dementia in 2016 (Alzheimer's Indonesia, 2019).

Based on Coin et al. (2021), in individuals with dementia, the more severe the cognitive impairment, the higher the depression and anxiety experienced during the first wave of quarantine due to COVID-19. This evidence suggests that, despite the potential lack of awareness of the pandemic, individuals with dementia did perceive distress during the quarantine period. In particular, they showed higher scores in those items investigating psycho-somatic symptoms. These symptoms are reported to represent psychological distress expressed through physical disturbances by individuals unable to express their emotions due to genetic and

environmental factors. The complicated health needs of the patient with dementia are more likely to be neglected in the emergency phase of the pandemic; this might result in disruptive behaviour. Disruptive behaviours are more concerning because of the adverse impact on the emotional connection between the caregiver and the care recipient, in this case, a patient with dementia, thus exacerbating possible difficulties in other domains such as caring for activities of daily living (Cheng, 2017). Accordingly, caregivers might have been exposed to critical levels of stress because they had to manage PWD with little external support and complex disturbances (Canevelli et al., 2020). During this pandemic, some caregivers may become ill, they may need to isolate and be unavailable, or they may develop anxiety and other mental health issues, even exhaustion and burnout (Brown et al., 2020).

2. Literature Review

Based on precautions and suggestions published by CDC (2020), people need to stay at home to reduce exposure to COVID-19. In a precautionary measure, WHO advised restricting activities outdoors to minimize disease contraction. Isolation or imposed quarantine is an unpleasant and unfamiliar experience that involves disengagement from close relatives such as family and friends; also disconnections of daily routines as many activities are prohibited and thus creating an uncomfortable environment (Brooks et al., 2020). The prolonged effect of pandemics and quarantine could cause many stressors. Based on Brooks et al., stressors could happen during quarantine and post quarantine. Duration, fears of infection, inadequate information from public health authorities also frustration and boredom are stressors during quarantine. Financial loss and stigma to certain community groups are post-quarantine stressors. During quarantine, confinement, loss of usual routine, and reduced social and physical contact with others will cause boredom, frustration and a sense of isolation from the world and may cause psychological distress (Brooks et al., 2020). Although all stages of human life form are vulnerable to psychological damage, children, adolescent, the elderly, people with mental illness, and people with lower socioeconomic status are more prone to psychological damage (Perrin et al., 2009), and evidence of persisting psychological effect afterwards are prevalent albeit in a small percentage of studies (Brooks et al., 2020)

People living with dementia have limited access to accurate information and facts about the COVID-19 pandemic. They might have difficulties in remembering safeguard procedures, such as wearing masks or understanding issued public health information. Ignoring the warnings and lacking sufficient self-quarantine measures could expose them to a higher chance of infection (Wang et al., 2020). Some with MCI or milder dementias may be unwilling or unable to comply due to apathy or depression. Those with more severe dementias will not be able to understand, appreciate, or remember most of these recommendations due to the severity of their short-term memory loss and overall cognitive impairment. Finally, behavioural and psychological symptoms of dementia (BPSD), such as motor agitation, intrusiveness, or wandering, may undermine efforts to maintain isolation (Brown et al., 2020).

3. Methodology

This research is an observational descriptive cross-sectional study. Variables researched in this study are characteristics of PWD and caregiver also the profile of anxiety of PWD and caregiver. This research was conducted online in the period of December 2020-January 2021 in Surabaya in consideration of the COVID-19 pandemic and the availability of the dementia community. ALZI Surabaya Community is part of Alzheimer's Indonesia, a non-profit organization that aims to help and improve the quality of life for a patient with dementia (PWD) and their caregivers in Indonesia, especially in Surabaya. This organization are also supported by volunteers and professionals in various fields.

The data of this research was primary data from a questionnaire. There are two sections in the questionnaire, the demography section to obtain characteristics for PWD and caregiver and the second section of the questionnaire consists of the Rating Anxiety in Dementia (RAID) questionnaire to obtain anxiety data in PWD and Beck Anxiety Inventory (BAI) for the caregivers. The population and sample of this research were caregivers that were currently taking care of PWD and mild PWD that was under the ALZI Surabaya Community. The sample gathered were 17 PWD and 20 caregivers. The data obtained were collected in Microsoft Excel 2010 and analyzed with cross-tabulation.

4. Results

4.1 Characteristics of PWD and Caregiver

Category	Frequency (%)
Sex	
Male	6 (35%)
Female	11 (65%)
Age	
50-59 years old	3 (18%)
60-69 years old	2 (12%)
70-79 years old	7 (41%)

80-89 years old	5 (29%)
Education	
Elementary School	1 (6%)
Junior High School	1 (6%)
High School	8 (47%)
Diploma	2 (12%)
Bachelor's Degree	1 (6%)
Post Graduate Degree	4 (23%)
Income	
No Income	5 (29%)
Low Income	3 (18%)
Middle Income	3 (18%)
High Income	2 (12%)
Housing	
Low Density	2 (12%)
Medium Density	11 (64%)
High Density	4 (24%)
Very High Density	0 (0%)

Table 1. Demography of PWD

Based on table 1, the demography of PWD in ALZI Surabaya Community is mostly female (80%) in the age of 70-79 (41%) with education level of high school graduate (47%). PWD in ALZI Surabaya Community mostly do not have an annual income (29%), and 64% are currently residing in a medium-density housing population area.

Category	Frequency (%)
Sex	
Male	2 (20%)
Female	18 (80%)
Age	
30- 39 years old	2 (10%)
40-49 years old	10 (50%)
50-59 years old	5 (25%)
60-69 years old	1 (5%)
70-79 years old	2 (10%)
Marriage Status	
Married	14 (70%)
Unmarried	4 (20%)
Divorced	1 (5%)
Widow	1 (5%)
Relation with PWD	
Spouse	2 (10%)
Child/In Law	15 (75%)
Grandchildren	1 (5%)
Relative	1 (5%)
Volunteer	1 (5%)
Education	
Elementary School	0 (0%)
Junior High School	0 (0%)
High School	2 (10%)
Diploma	7 (35%)
Bachelor's Degree	7 (35%)
Post Graduate Degree	4 (20%)
Income	
No Income	5 (25%)
Low Income	1 (5%)
Middle Income	2 (10%)

High Income	4 (20%)
Very High Income	8 (40%)
Housing	
Low Density	2 (10%)
Medium Density	11 (53%)
High Density	7 (37%)
Very High Density	0 (0%)

Table 2. Demography of Caregiver

The demography of caregivers in ALZI Surabaya Community mostly are female (80%) in the age range of 40-49 (50%) with mostly acquire bachelor's degree or diploma (35%) are direct children or in-laws of PWD (75%), currently married (70%), has annually very high income (40%) and living in a medium-density population housing area (64%).

4.2 Anxiety in PWD

Variable	Anxiety (%)		
	Total	**Significant (≥11)**	**Insignificant (<11)**
Sex			
Male	6 (35%)	6 (100%)	0 (0%)
Female	11 (65%)	8 (83%)	3 (27%)
Age			
50-59 years old	3 (18%)	3 (100%)	0 (0%)
60-69 years old	2 (12%)	2 (100%)	0 (0%)
70-79 years old	7 (41%)	5 (72%)	2 (28%)
80-89 years old	5 (29%)	4 (80%)	1 (20%)
Education			
Elementary School	1 (6%)	0 (0%)	1 (100%)
Junior High School	1 (6%)	1 (100%)	0 (0%)
High School	8 (47%)	6 (75%)	2 (25%)
Diploma	2 (12%)	2 (100%)	0 (0%)
Bachelor's Degree	1 (6%)	1 (100%)	0 (0%)
Post Graduate Degree	4 (23%)	4 (100%)	0 (0%)
Income			
No Income	5 (29%)	4 (80%)	1 (20%)
Low Income	3 (18%)	2 (80%)	1 (20%)
Middle Income	3 (18%)	3 (100%)	0 (0%)
High Income	2 (12%)	1 (50%)	1 (50%)
Very High Income	4 (23%)	4 (100%)	0 (0%)
Housing			
Low Density	2 (12%)	1 (50%)	1 (50%)
Medium Density	11 (64%)	10 (90%)	1 (10%)
High Density	4 (24%)	3 (75%)	1 (25%)
Very High Density	0 (0%)	0 (0%)	0 (0%)

Table 3. Anxiety Evaluation of PWD

From all correspondents, six males (100%) and eight females (73%) in the age range of 70-79 years old (72%) with high school education (72%) has no income (80%) or has very high income (100%) that lives in a medium-density housing (90%) fall into the category of significant anxiety. Three females (27%), zero male in the age range of 70-79 years old (28%) with high school education (25%) has either no income (20%), low income (20%) or high income (50%) and reside in either low (50%), medium (10%) or high (25%) density housing fall into the category of insignificant anxiety.

In the significant group with a score range from 11 and above, symptoms that mostly occur in the worry category is worrying over trifles such as repeatedly calling for attention over trivial matters with 13 cases (92.85%). In the apprehension and vigilance category, symptoms that are mostly found is sleep disturbance such as troubles falling or staying asleep with 14 cases (100%). In the motor tension category, symptoms that are mostly found are motoric tension, such as complaints of headache and other body aches and pains with 13 cases (92.85%). In the autonomic hypersensitivity category, symptoms mostly found are sweating, flushes or chills, tingling or numbness of fingers and toes with 6 cases (42.85%).

Meanwhile, in the insignificant group with a score below 11, symptoms that mostly occur in the worry category is worrying about physical health with 2 cases (66.57%). In the apprehension and vigilance category, symptoms that are mostly found are irritability, such as being more easily annoyed than usual, short-tempered and angry outbursts with 2 cases (66.57%). In the motor tension category, symptoms that are mostly found is fatigue and tiredness, with 3 cases (100%). In the autonomic hypersensitivity category, symptoms that are mostly found are palpitations such as complaints of heart racing or thumping with 1 case (33.33%).

4.3 Anxiety in Caregiver

Variable	Anxiety (%)			
	Total	Low	Moderate	Severe
Sex				
Male	2 (10%)	2 (100%)	0 (0%)	0 (0%)
Female	18 (90%)	18(100%)	0 (0%)	0 (0%)
Age				
30- 39 years old	2 (10%)	2 (100%)	0 (0%)	0 (0%)
40-49 years old	10 (50%)	10 (100%)	0 (0%)	0 (0%)
50-59 years old	5 (25%)	5 (100%)	0 (0%)	0 (0%)
60-69 years old	1 (5%)	1 (100%)	0 (0%)	0 (0%)
70-79 years old	2 (10%)	2 (100%)	0 (0%)	0 (0%)
Marriage Status				
Married	14 (70%)	14 (100%)	0 (0%)	0 (0%)
Unmarried	4 (20%)	4 (100%)	0 (0%)	0 (0%)
Divorced	1 (5%)	1 (100%)	0 (0%)	0 (0%)
Widow	1 (5%)	1 (100%)	0 (0%)	0 (0%)
Relation				
Spouse	2 (10%)	2 (100%)	0 (0%)	0 (0%)
Child/In Law	15 (75%)	15 (100%)	0 (0%)	0 (0%)
Grandchildren	1 (5%)	1 (100%)	0 (0%)	0 (0%)
Relative	1(5%)	1 (100%)	0 (0%)	0 (0%)
Volunteer	1 (5%)	1 (100%)	0 (0%)	0 (0%)
Education				
Elementary School	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Junior High School	0 (0%)	0 (0%)	0 (0%)	0 (0%)
High School	2 (10%)	2 (100%)	0 (0%)	0 (0%)
Diploma	7 (35%)	7 (100%)	0 (0%)	0 (0%)
Bachelor's Degree	7 (35%)	7 (100%)	0 (0%)	0 (0%)
Post Graduate Degree	4 (20%)	4 (100%)	0 (0%)	0 (0%)
Income				
No Income	5 (25%)	5 (100%)	0 (0%)	0 (0%)

Low Income	1 (5%)	1 (100%)	0 (0%)	0 (0%)
Middle Income	2 (10%)	2 (100%)	0 (0%)	0 (0%)
High Income	4 (20%)	4 (100%)	0 (0%)	0 (0%)
Very High Income	8 (40%)	8 (100%)	0 (0%)	0 (0%)
Housing				
Low Density	2 (10%)	2 (100%)	0 (0%)	0 (0%)
Medium Density	11 (55%)	11 (100%)	0 (0%)	0 (0%)
High Density	7 (35%)	7 (100%)	0 (0%)	0 (0%)
Very High Density	0 (0%)	0 (100%)	0 (0%)	0 (0%)

Table 4. Anxiety Evaluation of Caregivers

Based on the result found in caregivers and measured with BAI (Beck Anxiety Inventory), all variables of caregivers fall into the low anxiety category. In low anxiety caregivers, symptoms that mostly occur are fear of something worst happening (80%), unable to relax (65%), indigestion and dizziness or lightheadedness (55%)

5. Discussion

5.1 PWD and Caregiver Characteristics

Psychosocial effects of the coronavirus disease 2019 (COVID-19) pandemic are indisputable and possibly could affect mental health, especially in vulnerable groups, thus increasing the urgency of matter (Holmes et al., 2020). A study from the United States about the impact of housing and living situations during COVID-19 in mental health reported Asians were 0.121 times more likely to experience mental health problems than Whites. The level of education is also reported to have significance. Compared to those who only have a high school degree or less, undergraduates and graduates were respectively 1.188 times and 1.503 times more likely to have mental problems (Ghimire et al., 2021). The findings of PWD that most high school graduates do fall in significant anxiety. On the other hand, caregivers that mostly have diplomas and bachelor's degrees experience low anxiety.

The odds of mental problems for the widowed or never married were 1.221 times higher, and the separated or divorced were 1.197 times higher than the married counterpart (Ghimire et al., 2021). In relation to this study, caregivers in Alzi that are mostly married have the possibility that they are less likely to experience a mental health problem, thus resulting in low anxiety. The odds of females having mental problems are also reported to be 1.740 higher than males (Ghimire et al., 2021). As the population of PWD in ALZI Surabaya Community with significant anxiety are mostly female, this correlates to the fact that the females do experience mental health problems, in this case, anxiety.

Being a female caregiver, initial difficult relationship with the subject, poor physical health and dealing with a severe impairment will increase the probability of anxiety (Mahoney et al., 2005). The female caregiver also reported having a higher level of strain (Yee & Shulz, 2000; Prince et al., 2012). This finding is also evident in ALZI as most of the caregivers are, in fact, females. Therefore, susceptible to experiencing anxiety, though the finding shows that the level of anxiety is low. In regards to the effects of the pandemic in a housing environment, a study shows that lower-income households have a higher probability of acquiring mental health problems (Ghimire et al., 2021). Based on the findings, PWD that has no income does have significant anxiety, but so does PWD with high income. In caregivers, most of them have very high incomes, and the level of anxiety is low.

A dense living environment will also decrease housing satisfaction, thus contributing to the rise of mental health problems. But, on the contrary, some study shows close-knitted residence may share herd resilience to face challenges and may lift the burden in deprivation (Ghimire et al., 2021; McNamara et al., 2013). Findings in ALZI shows that most population of PWD that has significant anxiety live in medium-density housing and for the caregiver as well, though the level of anxiety in caregivers is low. However, employment status, relationship with spouse and siblings and having dependent children didn't associate with caregiver anxiety (Ghimire et al., 2021).

5.2 Anxiety in PWD

Based on the people with dementia findings measured with RAID questionnaire (Shankar et al., 1999) in ALZI Surabaya Community from December 2020 to January 2021 during the COVID-19 pandemic in order to measure the severity of anxiety acquired during the pandemic, six samples of male PWD (100%) and eight samples of female PWD (72.73%) have significant anxiety with score ranges from 12-35. People with dementia that fall into the significant anxiety category mainly experience sleep disturbance (100%), calling for attention over trivial matters (92.85%), body aches and headache (92.85%) and other complaints such as sweating, flushes or chills and tingling or numbness in the extremities (42.85%). In the category of insignificant anxiety, no sample of male PWD and three samples of female PWD (27.27%) have fallen into this category with score ranges from 5-10. PWD that fall into the

insignificant anxiety category usually experiences fatigue and tiredness (100%), worrying about physical health (66.57%), easily annoyed, short-tempered and frequent angry outbursts (66.57%), also complaints of racing and thumping of the heart (33.33%). Immediate withdrawal from social contact was reported to exude anxiety-related trauma experiences, which accelerate cognitive decline and worsen prognosis. Anxiety caused by isolation is present in the most clinical presentation of a woman diagnosed with dementia (Simonetti et al., 2020). RAID questionnaire diagnoses general anxiety disorder (Goodarzi et al., 2019), which contain mainly symptoms such as restlessness, muscle tension, irritability, respiration distress and excessive fear (Starkstein et al., 2007). A study from Porter et al. (2003) suggested that muscle tension and fatigue complaints are specific in PWD. This correlates with findings in ALZI Surabaya Community as both PWD with significant or insignificant anxiety have common complaints of body aches and fatigue.

5.3 Anxiety in Caregiver

Based on the evaluation of self-assessments from caregivers with BAI (Beck Anxiety Inventory) in ALZI Surabaya Community from December 2020 - January 2021 during the COVID-19 pandemic, all samples have low anxiety with the range of score from 0-21 with symptoms such as fear of something worst happening (80%), unable to relax (65%) also indigestion and dizziness or lightheadedness (55%). No caregiver have moderate anxiety or severe anxiety.

The phenomenon of low anxiety might be explained by multiple factors such as culture, personality and environment. In Asian countries, caregiving is universally believed not just as a duty but also as an expression of devotion and love by a family member. This factor depicts the importance and reliance on the role of the family as a support system (Chaudhuri & Das, 2006). Other than said initial beliefs, personal traits such as resilience or the ability to recover quickly from difficulty may also contribute as a protective factor against caregiver burden and increase positive perspective (Dias et al., 2016; Altieri & Santangelo, 2020). Another positive factor that might contribute to lower anxiety is belonging to a part of the community; therefore would encourage the ability to share support, also reinforcing a sense of common fate and identity (Ntotis et al., 2018). The role of the community is crucial during a disaster as being in one motivates a cohesive prosocial outlook towards a sense of reinforcement and solidarity. The feeling of shared fate and solidarity depicted in coordinated action and community-based support has risen in the COVID-19 pandemic (Drury & Tekin Guven, 2020).

6. Conclusion

PWD and caregivers in ALZI Surabaya Community experience anxiety during the COVID-19 pandemic. PWD in ALZI Surabaya Community during the COVID-19 pandemic fall into two categories of anxiety in dementia, which are significant and insignificant. PWD that experience significant anxiety has symptoms such as experiencing sleep disturbance, calling for attention over trivial matters, body aches and headache, as well as complaints about instance sweating, flushes or chills and tingling or numbness in the extremities. Meanwhile, PWD that has insignificant anxiety has symptoms such as fatigue and tiredness, worrying about physical health, easily annoyed, short-tempered and frequent angry outburst, also complaints of racing and thumping of the heart. Caregivers in the ALZI Surabaya Community during the COVID-19 pandemic all experience low anxiety with symptoms such as fear of something worst happening, inability to relax, indigestion and dizziness or lightheadedness.

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