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Research paper

Multidimensional Challenges of Informal Services for Elderly with Disabilities

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Abstract
Indonesia is predicted to start experiencing a nationwide aging population by 2035. Meanwhile, everyone has the potential to become disabled especially as they age. This research aims to explore the complexity of the challenges of elderly with disabilities and efforts to realize social inclusion. This research uses a qualitative method with a case study approach. Data collection was carried out through Focus Group Discussion (FGD) with several relevant regional apparatus organizations including the Regional Development Planning Agency and the Social Service of Yogyakarta Province. The findings of this study show that the complexity of the challenges of elderly disabilities is the result of the intersection between cultural and structural aspects. Therefore, it is necessary to explore the challenges of the elderly with disabilities in the perspective of social exclusion, especially related to the discourse of redistribution and moral underclass.

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1 Research Background

The result of population projection by the Central Statistics Agency (BPS) (2018) shows that Indonesia has now entered the era of demographic dividend. Demographic dividend is characterized by a growing proportion of the population of productive or working age that is relatively larger than the population of children and the elderly. (Adioetomo & Pardede, 2018). In 2019, the number of people of productive age (15 to 59 years old) amounted to 172.7 million, while the population aged 60 years and over amounted to 26.8 million or only 10 percent of the total population (BPS, 2018). Because of the end of the demographic dividend, Indonesia is predicted to enter the aging population phase in 2035. Ageing population occurs when the proportion of the elderly population increases progressively compared to the productive age population and children. This condition is predicted to increase until 2045 (BPS, 2018). Thus, Indonesia has a greater responsibility not only to ensure that the elderly is well served, but also to realize independent elderly including encouraging an inclusive environment.

There are several regulations that have set policies regarding the elderly, including: (1) Law Number 13 of 1998 on Elderly Welfare; (2) Law Number 40 of 2004 on the National

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Social Security System; (3) Law Number 11 of 2009 on Social Welfare; and (4) Law Number 13 of 2011 on the Poor. In 2021, the government has issued Presidential Regulation (Perpres) Number 88 of 2021 on the National Strategy for Aging. The regulation aims to realize an independent, prosperous, and dignified elderly group. In the global mission, humanity is part of the Sustainable Development Goals (SDGs). The third goal of the SDGs is to ensure a healthy life and improve the welfare of all people of all ages can be achieved. Improving the welfare and guaranteeing the rights of the elderly is in line with the SDGs motto ''No One Left Behind''. Despite having a long regulatory framework, the facts show that the implementation of policies related to the elderly still faces various challenges.

Various issues related to elderly population, one of which is related to the economic dimension. In Indonesia, the highest poverty rate is among the elderly population. Based on data from the National Team for the Acceleration of Poverty Reduction (TNP2K) (2017), around 45 percent of the elderly are in households with the lowest socioeconomic status, 67 percent of them live in very poor and neglected conditions, and 85 percent of elderly Indonesians have no income security (Kidd et al., 2017). Furthermore, the elderly are not fully protected by employment insurance and only 12 percent have social employment insurance (pension insurance) (BPS, 2019). As the 4th most populous country in the world, aging is a crucial issue and can intersect with many other challenges.

In terms of health, the elderly population is not fully protected by social health insurance. Only three out of five elderly population have health insurance (BPS, 2019). The elderly tend to experience challenges in physical and mental conditions as they age. The elderly often have to undergo multiple treatments or confirmations due to more than one disease (Cross, George, Woodward, Ames, & Elliott, 2015). In the Indonesian context, 44 percent of the elderly have more than one disease or multimorbidity (Mahmudah, Tessma, & Mahendradhata, 2022). Therefore, the elderly population is at risk of becoming disabled due to various health factors (Carnemolla, 2019; Lopes, Andrade, & Reis, 2019). More than 46 percent of the elderly (age 60 and above) have a disability, and more than 250 million seniors have moderate to severe disabilities. According to the World Health Organization (WHO), disability is the limitation of a person in participating in various activities caused by the interaction between health conditions and environmental factors. (World Health Organization, 2012).

To face the aging population in the future, the issue of disability is an important part of looking at the issue of aging more deeply and comprehensively. The elderly with disabilities face various complex and multidimensional challenges. The main challenges for the elderly are focused on health and economic aspects. Meanwhile, persons with disabilities have a long history of discrimination in both physical and socio-cultural infrastructure aspects (Rohman, 2019). The disability paradigm itself has shifted from a medical paradigm to a social model of disability. The medical paradigm sees disability as individuals who are sick and need to be cured, while the social model of disability sees social environmental factors that need to adapt to various individual conditions (Oliver, 1996).

The intersection between elderly and disabilities issues is interesting to investigate. Efforts to realize independent, prosperous, and dignified elderly still face challenges.

Government is required to provide quality services for all including the elderly with disabilities. The intersection between elderly and disability issues presents multidimensional challenges both related to regulations at the macro level and socio-cultural aspects at the micro level. Various studies highlight that elderly with disabilities face challenges to obtain their rights, such as access to health services or other social assistance. Elderly with disabilities or living with chronic conditions have unmet care needs related to their physical and psychological health, social life, and the environment in which they live and interact (Abdi, Spann, Borilovic, Witte, & Hawley, 2019).

2 Research Method

This research uses a qualitative method with a case study approach. Data collection was carried out through Focus Group Discussion (FGD) with several relevant regional apparatus organizations including the Regional Development Planning Agency and the Social Service of Yogyakarta Province on June 22nd and 23rd, 2022. These two regional apparatus organizations were selected because they have dominant tasks and responsibilities related to elderly and disability issues in the region. Meanwhile, Yogyakarta was chosen as a case study because it is the province with the highest percentage of elderly population in Indonesia at 15.75 percent (BPS, 2023). The high level of the elderly population will illustrate the complexity of the challenges to the elderly with disabilities both structurally in terms of policy and culturally in terms of the culture of the local community. The data was processed and analysed using a social exclusion approach to identify various challenges and implications.

3 Result

3.1 Status and Service Needs of Elderly with Disabilities

Data from SUPAS 2015 showed that the elderly are starting to experience various disability conditions. In general, many elderly experience physical disabilities, namely difficulty using their fingers or hands (93 percent). Another type of disability experienced by majority of elderly are sensory disability in the form of vision (34.8 percent) and hearing (24.3 percent). However, most elderly only experience a few difficulties. Many difficulties experienced by elderly are related to walking or climbing stairs (5.3 percent) and seeing (5.2 percent). This means that the types of disabilities that many people experience with varying degrees of difficulty are physical and sensory disabilities. Meanwhile, the most common activities that elderly cannot do at all are walking or climbing stairs (2.2 percent) and taking care of themselves (1.3 per cent).

Table 3.1 Disability Status of the Elderly Based on Level of Difficulty (%)

Type of Difficulties	None	Slightly Difficult	Moderate Difficult	Severe Difficult
Vision	66.2	28	5.2	0.7
Hearing	75.7	19.4	4.5	0.4
Walking/take the stairs	77.4	15.1	5.3	2.2
Use hand/fingers	6.7	91.3	1.6	0.3
Remember/Concentrate	81.2	14.3	3.6	1
Behavioural/Emotional control disorders	92.2	6.1	1.3	0.4
Talking/Communicate	90.1	7.6	1.9	1.9
Take care him/herself	93	4.2	1.4	1.3

Source: SUPAS 2015 (analysed)

Elderly with disabilities have different level of difficulties, indicating the need to identify different types of services. The various needs of elderly with disabilities require support from both cultural and structural aspects. cultural aspects include respect for values and norms towards parents. On the other hand, support from structural aspects in the form of policies, programs and inclusive services from the government is needed as a form of government presence responding to the era of the aging population. Various programs and policies can be directed to make the elderly active and independent, for example through social activities and opening job vacancies that are suitable and friendly to the elderly. Meanwhile, social protection and alternative services to ensure the health and well-being of the elderly need to be strengthened.

A social inclusion approach to aging focuses on accommodating the diverse needs of elderly, both potential and non-potential older people. the variety and level of difficulties experienced by older people indicates the importance of special attention to older people with disabilities. The condition of disability in the elderly is often not recognized. Elderly with disabilities are more identified with elderly health problems. There is a tendency to define elderly with disabilities only as elderly and not as persons with disabilities. Thus, elderly with disabilities have the potential to not receive proper services and be excluded from activism and their rights as persons with disabilities.

Regarding the needs of the elderly, various similar studies have identified the priority needs of elderly with disabilities as economic, health and home care needs to control the activities of elderly with disabilities while at home. This means that the needs of elderly people with disabilities are concentrated on basic service support and care. Social participation support and psychological aspects were identified but tended to be less significant. Social and psychological support It is important to improve aspects of well-being for elderly with disabilities (Nareswari & Putri, 2021; Verger, 2012). Based on the type of service, various similar studies have found that the majority of elderly people, including elderly people with disabilities, receive care from home or informal services (Momtaz, Hamid, & Ibrahim, 2012; Plöthner, Schmidt, Jong, Zeidler, & Damm, 2019;

Verger, 2012). Therefore, informal services need to receive attention in developing long-term policy scenarios so that elderly people continue to receive quality services.

3.2 Institutional and Policy Challenges for the Elderly with Disabilities

Indonesia already has several policies related to the elderly, one of which is Law No.13 of 1998 concerning Elderly Welfare. Although it has had a policy framework for a long time, efforts to realize the welfare of the elderly experience various challenges, including those related to the low level of education of the elderly and limited access to social protection programs including social security. The result of the national socio-economic survey (SUSENAS) (2017) shows that only 13 percent of the elderly have access to social protection programs, such as direct cash transfers (BLT), family hope program (PKH), Social Protection Cards (KPS), Prosperous Family Cards (KKS), and people's enterprise card (KUR). The affordability of social protection programs for the elderly in Indonesia is still very limited because the program only covers the poor. Social protection programs for the elderly have a positive impact on families such as easing the economic burden (Kidd et al., 2017).

Other findings show that elderly who previously worked in the formal sector do not reach 5 percent of the total elderly population (Djamhari, Ramdlaningrum, Layyinah, Chrisnahutama, & Prasetya, 2020). The informal sector is a vulnerable sector because regulations governing the rights of workers in the informal sector are still weak and the social security system has not yet reached the informal sector, including pension security. In the future, challenges related to the elderly group, especially with disabilities, are projected to be increasingly complex with the drastic increase in the elderly population or entering the era of the aging population. The complexity of the problems of the elderly, including those with disabilities in the future, is the basis for the importance of reviewing Law No.13 of 1998 concerning Elderly Welfare which is less relevant to the dynamics of humanity today. This is evidenced, among others, by data on the welfare conditions of the elderly. Based on TNP2K data (2017), around 45 percent of the elderly are in households with the lowest 40percent socioeconomic status, as many as 67 percent of whom live in very poor and neglected conditions. Furthermore, little progress has been made in the development of more specific policies or implementation strategies to address issues related to support services and accommodation as people age. Such support is particularly important for older people with multiple difficulties or otherwise beginning to experience disabling conditions.

Elderly policies must be able to respond to the dynamics of humanity in the future and prioritize the principles of humanity through a life cycle approach. The life cycle approach sees that handling the elderly cannot be done only based on the momentum when the population begins to enter old age but is integrated since the beginning of life during the womb. Elderly is a long process that is determined by the phase of life lived before. This condition then becomes the urgency of the need for a more comprehensive approach in the Elderly Law. In 2021, the government has issued Presidential Regulation (Perpres) Number 88 of 2021 concerning the National Strategy for the Elderly. The policy regulates strategies to realize independent, prosperous, and dignified elderly. This step is the right step to respond to the complexity of the challenges of the aging population in the future. However, the National Strategy for the Elderly needs to be accompanied

by an update of the Law that has a strong foundation in which it regulates the rights of the elderly, including the elderly with disabilities.

Disability is specifically regulated in Law Number 8 of 2016 on Persons with Disabilities. The policy has been launched as a revision of Law Number 4 of 1997 concerning Persons with Disabilities as well as an effort to change the medical paradigm to the human rights paradigm and social model. Regarding welfare, the Law on Persons with Disabilities contains several affirmation policies, one of which is a special quota for persons with disabilities (3 percent of total workers in state-owned enterprises and 2 percent of total workers in the private sector). Both the elderly and disabled have been included in the target recipients of various social protection programs including direct cash transfers (BLT). However, only the elderly who are vulnerable and categorized as poor receive social assistance as part of the social protection program. In fact, the elderly are very vulnerable to disability as they age, weaken their body functions, and vulnerable to various diseases.

Many of the elderly have economic limitations and depend on their family members. It is necessary to consider developing policies to expand the benefits of universal elderly protection regardless of their economic status. If you look at the budget allocation for social protection in Indonesia, social protection programs for the elderly are only around 2 percent. Referring to the allocation of middle-income countries, on average, they allocate around 14.6 percent of GDP per capita and develop programs to provide comprehensive social pensions to all elderly people (Kidd et al., 2017). Therefore, budget allocations from both central and local governments are crucial to increase. This condition is also inseparable from various studies that find various challenges in optimizing the demographic dividend.

3.3 Informal Services for Elderly with Disabilities: an overview of social inequality

In Yogyakarta, many elderly with disabilities only receive services informally by their families. This condition is caused by at least two main factors. First, lack of access and knowledge to health facilities. Second, the belief that caring for family members, including those with disabilities with a level of difficulty is an obligation. This is inseparable from the religious construction of the values of honouring parents (Nareswari & Putri, 2021). Despite having different cultural backgrounds and social contexts, informal types of services for elderly with disabilities also dominate in various countries. The results of a previous study with a sample of Americans aged 70 years and older who lived at home and had at least one functional limitation with ADLs or IADLs, 38 percent did not receive any assistance, 48 percent received informal care, 5 percent formal care and 9 percent mixed care. In Canada, a study was conducted among individuals aged at least 65 years who lived at home and received assistance with ADLs and IADLs. Informal care was provided to 42 percent of them, formal care to 34 percent and mixed care to 24 percent. In Sweden, a sample of people aged 75 years and older living at home but receiving only ADL assistance was studied. Among them, 45 percent received informal care, 15 percent formal care and 40 percent mixed care (Verger, 2012).

Informal services have several benefits including cost and psychosocial aspects due to proximity to family. However, this research found that some people in Yogyakarta,

especially the lower middle class in villages, consider the condition of disability in the elderly as an “old disease” and a natural thing that does not require any support. This condition indicates that limited knowledge related to access to health facilities is also related to social class and social inequality. This finding is in line with several studies that the type of services for elderly with disabilities is associated with social inequality (Jönson & Taghizadeh, 2009; Muis, Agustang, & Adam, 2020; Rohman, 2019; Verger, 2012). Informal services are chosen due to limited access to formal services and the level of knowledge related to appropriate services. This is in line with similar studies which found that socioeconomic status including education level or household income level has an association with the composition and type of care chosen. Educated older people with disabilities are more likely to receive formal or mixed (formal and informal) support (Verger, 2012). Individuals who are highly educated tend to have children who are educated, at a cost and the opportunity to render higher service to them is also greater. Furthermore, educated parents may want to remain independent from their children and are therefore more comfortable requesting or paying for formal services. Less educated older adults may have more difficulty obtaining information about available formal services.

In addition, informal services face challenges in implementation. Research on older people with functional disabilities in Malaysia shows that informal services for them are inadequate. Some older adults with disabilities in the community, particularly older men and chronically ill older adults, do not receive assistance to perform basic activities of daily living, which can increase the risk to older adults with functional disabilities (Momtaz et al., 2012). Family members or caregivers are often not adequately supported in preparing for their role and most have little or no support for their role and most have little or no contact with the formal healthcare system (Plöthner et al., 2019). Nurses or family members who are able to provide professional and reliable care are hard to find.

3.4 Informal Services for Elderly with Disabilities: cultural challenges and its implications

Elderly people with disabilities face not only institutional and policy challenges, but also cultural challenges. Indonesia is known for its collective culture and high solidarity. Collectivity and solidarity are inseparable from the value of gotong royong which is inherent as the nation's identity. Collective culture, on the one hand, shows the embeddedness and attachment where norms and values become shared principles so that they can become a common social control so that society is always in a stable state. However, the positive values of collective culture are highly dependent on the social context. In the context of the elderly, collective culture can hinder the goal of empowering the elderly.

The poor elderly, including those with disabilities, are one of the beneficiaries of government social protection programs such as Direct Cash Assistance (BLT). BLT assistance is expected to support purchasing power and fulfilment of basic needs or daily needs for the elderly group. With the fulfilment of their daily needs, they are expected to become empowered elderly. Nevertheless, the implementation and expectations of social protection programs for the elderly have not been able to run

optimally. This is partly due to the collective culture and values held firmly by the elderly group.

Elderly people in Indonesia tend to live with their children, whether they are married or not, especially elderly people with disabilities who need regular care. Collectivity is not only related to the culture of living in the same house with married children, but also to the perspective on values that need to be maintained. For example, in Java there is a slogan “eat or don't eat, the important thing is to gather”. Gathering is a priority despite living in modest conditions rather than living richly but far from each other. In this context, social protection programs targeted at the elderly are biased.

Collective culture helps reduce the burden on the government in terms of caring for and fulfilling the rights of the elderly. On the other hand, collective culture obscures the purpose of various government programs for the welfare of the elderly. This research found that elderly with disabilities in Yogyakarta often divide the social assistance money from the government for their children and grandchildren, even for the food needs of their extended family. Social assistance programs aimed at the welfare of the elderly are used collectively to meet the needs of the extended family.

This condition can occur at least for several reasons. First, elderly recipients of social protection programs live with children or extended family who also live below the poverty line. Family members who receive money are managed collectively to be able to fulfil basic needs, including social assistance for the elderly. This condition reflects the severity of poverty as well as intergenerational poverty. The collective culture of the elderly, including those with disabilities, in responding to government policies is a form of resilience to the conditions of intergenerational poverty experienced. Secondly, elderly recipients of social protection programs live with or near children or extended family with middle to upper economic conditions. The elderly distributing social assistance to their children and grandchildren can be interpreted as a ''gift''. Thus, the context of social assistance for the welfare of the elderly and the goal of social protection to encourage the elderly to be empowered failed. This can be caused by social construction of a collective culture that is not contextual or the government's socialization of the use of social assistance for the elderly that has not been optimal. Therefore, cultural challenges related to the internalization of solidarity values and collective culture need to be a concern in the context of empowering elderly groups in the future.

4 Discussion

The intersection of cultural and policy aspects in the context of informal services for elderly with disabilities is evidence of the complexity of the challenges. This finding indicates the importance of linking the issue of elderly with disabilities with the issue of social exclusion. The finding related to informal services for elderly with disabilities as an “old disease” has theoretical implication for disability issues. The public will perceive that many elderly are sick and ignore that public facilities need to be adapted to be accessible for a variety of conditions including elderly with disabilities. The implication of this stigma is that society and the government will try to make older people non-disabled. Thus, they can return to active participation in social life.

Stigmatizing disability as an old disease has implication for the absence of efforts to encourage an inclusive environment for the elderly with disabilities. This situation is a form of regression and dismisses the idea that disability occurs because of a social environment that is not friendly and provides opportunities for them to fully participate in society. The disability paradigm has moved from the medical model to the social model. The social model of disability assumes that it is the environment that makes people disabled (J.Davis, 2010). Therefore, disability only exists when the environment is not inclusive of diversity. The finding shows that elderly with disability is seen as more related to the medical paradigm than the social paradigm. This condition can encourage social exclusion. Exclusion caused by societal culture that intentionally or unintentionally implies the marginalization of certain groups is part of horizontal or cultural exclusion (Rohman, 2019).

In addition to stigma, the collective culture of elderly with disabilities in managing social assistance in informal services is linked to issues of social exclusion related to redistribution and moral underclass (Levitas, 2005). Related to the redistribution discourse, the challenges for elderly with disabilities cannot be separated from the phenomenon of poverty and socio-economic inequality. This study found a link between the quality of informal services for the elderly with disabilities and the level of social inequality in the society. The utilization of government social assistance by the elderly for the needs of extended families illustrates the depth of poverty. From the social exclusion perspective, this condition shows the failure of the state in distributing welfare to the society. The lower-class feels less impact from various government programs to alleviate poverty. As a result, they live collectively with large families with limited income, including utilizing the income of the elderly from social assistance programs to support their large families.

In the context of redistribution discourse, social exclusion needs to be reviewed not only from the horizontal dimension (based on social division), but also the vertical dimension (based on social stratification) (Seda, 2023). The redistribution discourse tends to show the intersection between the challenges of elderly with disabilities and other social issues. Thus, informal services for elderly with disabilities will be difficult to optimize if other inherent challenges such as poverty have not been successfully resolved. The multidimensional challenges of elderly with disabilities are part of non-inclusive development policies in the past. Therefore, there is a need for in-depth studies that review aspects of elderly with disabilities and structural poverty.

The issue of social exclusion of elderly with disabilities is not only related to the redistribution discourse, but also to the moral underclass. Elderly with disabilities' decision to utilize various social assistance programs for extended family can be seen as a form of dependency. The program does not make beneficiaries empowered but increasingly socially excluded. Social assistance should be used to maintain consumption levels for the elderly including those with disabilities and still be able to actively participate in society. In fact, some elderly people and their extended families prefer to be categorized as poor to continue receiving government assistance. Moral underclass is integral to the issue of informal services for elderly people with disabilities. The morality of wanting to always be given can make elderly with disabilities appear even more powerless. Moral underclass can be seen as deviant behaviour

caused by the welfare state system. The policy implications of the welfare state have led to deviant behavioural responses by choosing to live in dependence rather than independence (Levitas, 2007).

The morality may obscure that elderly with disabilities have different levels of difficulty, indicating the need to identify different types of services. Thus, informal services for elderly with disabilities need to be geared towards keeping older people active and productive, especially those with slight difficulty. The role of extended family in informal services for elderly with disabilities needs to be restored as cultural support rather than exacerbating their social exclusion. Cultural support for the elderly in informal services is crucial as it recognizes and addresses the unique needs, values, and beliefs of older adults within their cultural context. This support ensures that care is not just about practical needs but also about respecting individual preferences and promoting well-being (Dong, Cheng, & Cao, 2024).

The finding of this research confirms that informal services for elderly with disabilities are not only related to cultural challenges but also policy challenges. Government policies have not captured the intersection of poverty with the types of services for elderly with disabilities. It is necessary to synchronize social assistance policies with various community empowerment programs, including to lead to independent elderly. The issue of moral underclass does not focus on how appropriate the policy is to target excluded groups, but to change the perspective of dependence by minimizing instant assistance and providing a stimulus towards sustainable independence, for example in the form of training. However, realizing independent elderly is still a big challenge in its implementation. Various elderly empowerment programs including job training have not been accompanied by affirmative policies on expanding employment opportunities for productive elderly groups.

5 Conclusion

This research found that the complexity of the challenges of older people with disabilities is the result of the intersection between cultural and structural aspects. The stigmatization of disability in the elderly as an old disease returns the disability paradigm to a medical rather than social paradigm. The implication is that informal services for the elderly with disabilities are considered more of a family responsibility to care and treat so that they are able to return to active participation in the community. Thus, the social construction that is formed can obscure the government's efforts to create a friendly and accessible social environment for all including the elderly with disabilities. In addition, the collective culture adversely affects the informal care of the elderly with disabilities, especially for the elderly from low-income families. The utilization of social assistance by the elderly to support extended families shows the depth of poverty and social inequality as well as the moral underclass issues. Otherwise, various policies on the elderly and disabilities have not been able to fully respond to the challenges of the elderly with disabilities to be active and independent, including due to cultural aspects and their relationship with issues of poverty and socio-economic inequality. Therefore, informal services for older people with disabilities still face multidimensional challenges that need to be addressed.

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Data Availability

The datasets generated and analysed during the current study are not publicly available due to ethical restrictions concerning the privacy and confidentiality of the participants

Declarations

The manuscript is the original work of the authors and has not been previously published in any media.

Competing interests

The authors declare no competing financial or non-financial interests that influenced the results reported in this manuscript.

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Myranda Zahra Putri is a Researcher with a dedicated focus on public health issues, particularly concerning vulnerable populations. Her primary research interests include elderly health, health inequalities, and the well-being of minority groups. Her work aims to translate research findings into actionable public health policies and interventions.

Author contributions

The authors confirm contribution to the paper as follows:

Yani Fathur Rohman: Conceptualization, Methodology, Formal Analysis, Writing – Original Draft Preparation.

Utin Kiswanti: Data Curation, Investigation, Project Administration, Writing – Review & Editing.

Myranda Zahra Putri: Resources, Supervision, Funding Acquisition

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