Ethnocaring of Elderly with Dementia in Rural Java

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ABSTRACT
Currently, Indonesia is entering the ageing population phase. Along with increasing welfare, the life expectancy of the population is getting higher but the quality of a healthy life is low due to the cycle of recurring diseases in old age. One of the cycles of disease that requires long-term care is the elderly with dementia. In rural Java, senility as a disease is not widely known. The term senility is equivalent to dementia. The elderly that suffered from dementia are treated instinctively according to local customs. The way of caring is simple, only based on instinct when seeing symptoms without clinical medical indications. This paper discusses ethnocaring, a community knowledge perspective in the care of the elderly with dementia which describes natural care habits based on experience. The research was conducted in March-May 2023 in Bantul using a purposive sampling method and obtaining 5 caregivers in the selected villages consisting of family and community members. The results showed that senility was treated based on the status of the relationship between caregivers and elderly with dementia and the role of the philosophy of "mikul dhuwur mendhem jero" which animates behaviour and determines its role in quality and type of care.

Keywords: dementia, elderly care, ethnocaring, Javanese philosophy

How to cite:

1. Introduction
DIY (Yogyakarta) is the province with the largest number of elderly and the longest living although it has the lowest healthy life expectancy (BPS, 2022). Entering the age of 60 or retirement, elderly people begin to experience economic and social changes that affect their health, they become sick more often and increase...
health costs (Bratajaya, Triratnawati, 2023). Diseases suffered by the elderly are generally degenerative diseases such as hypertension, heart disease, diabetes, stroke and dementia which reduce their quality of life in old age. The implication is a high burden of responsibility not only for medical expenses but also for care. At this stage of life which is full of illness cycles, the indicator of care is an index of child support for parents that contributes to longevity (Niehof, 1995). One of the cycles of illness that requires long-term care due to high dependence on the help of others is dementia. Dementia is a disease that requires lifelong care due to a progressive decline in brain function (Adiningrum, 2023).

DIY and Bali are provinces that have a prevalence of dementia reaching more than 20% or higher than the world prevalence of dementia. This number will continue to grow nationally and will reach 4 million in 2050. Indonesia's economic losses due to dementia reached USD 2.2 billion in 2015 and are predicted to become a burden on the country's economy in the future. One of the factors that trigger the high cost of caring for dementia is the lack of knowledge or understanding of caregivers and health workers regarding this disease, which hinders early detection and accelerates the increase in the number of people that suffer from dementia (Suriastini, 2023). In 2019, the global economic burden due to dementia receives a contribution of 50% of care costs from informal carers, namely family members and closest people who provide an average of 5 hours of care per day, not counting other forms of care assistance.

In rural Java, the term dementia is generally unknown even though the symptoms of dementia can be understood as symptoms of memory loss. Dementia is generally not widely recognized as a serious illness and is considered normal to occur towards the elderly, so they don't think about going to the doctor. It is interesting that the contribution of informal caregivers, namely the family and community, is quite large in covering dementia care so far, even though caring for elderly people with dementia is not easy because of the lack of knowledge. Without guiding care according to adequate clinical guidelines, families are able to read, understand and respond well to the needs of people with dementia through a variety of learned behaviours. The caring process runs naturally based on its superiority. This instinct arises because there is an empathic caregiver so the caring mechanism runs normally even though it often raises conflict and psychological burnout for caregivers. Regardless of the quality of care, the contribution of family and community care practices cannot be denied, and their great role for people with dementia in living their old age.

This article discusses ethnocaring, a way of caring for elderly people with dementia in rural areas that are not guided by any clinical indications. The way of caring is only based on instinctive knowledge and experience through symptoms or behaviours that appear that caregivers can read and understand. Why does ethnocaring elderly dementia need to be studied? The first objective is to get an overview of the quality of ethnocaring in terms of its advantages and disadvantages. The results can contribute to supporting the government in covering care for the elderly who are potentially neglected in rural areas, especially the elderly with dementia who are very dependent on the help of others. According to Absor's notes (2023), formal care from the government is currently still limited in scope, only covering 0.03% or 100 thousand out of 2.9 million of the number of elderly people who need care. The second objective is to explore the extent to which the system of values and norms underlies ethnocaring through the Javanese philosophy "nikul dhuwur mendhem jero" This philosophy is Javanese ethics which is a noble speech that regulates the relationship between children and parents as a form of respect and filial piety (Tartono, 2020) or in Islam it is known as "birrul waliidain" to obey and do good to parents (Kusumawati, 2015).

2. Methods

The types of data collected in this study are primary and secondary data. Of the 4 basic principles of qualitative research according to Soemantri (2005) and Gubrium (1992) (in Denzin and Lincoln., 2011), this study uses two methods, involving observation and ethnographic data involving researchers in open research settings. By using a combination of the two, the researcher conducted in-depth interviews with informants and caregivers, to obtain primary data. While secondary data were obtained from village statistical data, BPS and other sources from books, journals, articles and the internet which are based on official website sources.

The research was conducted in March-May 2023 in a rural area in Bantul, DIY using a purposive sampling method in the study area with the sample criteria being family members or community members who

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1 Source: https://www.liputan6.com/health/read/3654837/kasus-alzheimer-di-yogyakarta-lebih-tinggi-dari-estimasi
2 Source: https://litbang.kemendagri.go.id/website/studi-angka-penderita-demensia-capai-4-juta-jiwa-pada-2050/
4 Source: https://alzi.or.id/statistik-tentang-demensia/
5 https://www.who.int/news-room/fact-sheets/detail/dementia
are caregivers. From these criteria, 5 informants were obtained, 4 female caregivers and one male caregiver. Of the 4 female caregivers, 2 cared for their mothers, and the remaining 2 cared for males with dementia, namely their father and one neighbour who lived alone. Of these 3 female caregivers, 2 caregivers stopped working and returned from migrating to care for them, a caregiver was a housewife, and a male caregiver who takes care of his wife. Out of 5 people with dementia, 3 people have chronic diseases namely hypertension, diabetes and heart disease.

Data collection results from interviews with selected informants were analyzed. Data analysis was carried out using a thorough framework and interpretation of the mapped data set. In interpreting it, the researcher used the informant's point of view (emic) and the researcher's point of view (ethic) based on a review of literature that is relevant to the findings in the field.

3. Result

3.1. Elderly Classification and Value

In accordance with Law No. 13/1998 concerning Elderly Welfare, the Ministry of Health has designated people over 60 years of age as elderly (Infodatin Lansia, 2022). Regarding health conditions of the elderly, table 1 below describes the condition of the elderly in today's society. There are two main segments of the elderly, namely the independent elderly and the dependent elderly. The independent elderly consists of pre-elderly and middle-aged people who are still actively working and retired elderly. The retired elderly consists of the elderly who still have the potential to work and the elderly who are at high risk for work because of illnesses and are more limited in their activities. Meanwhile, the dependent elderly consists of the elderly who have no potential and are physically unable to carry out normal activities. These are the elderly with dementia and the elderly who are bedridden due to poor health conditions are the elderly who has no potential that needs care or assistance from other people in living their old age.

<table>
<thead>
<tr>
<th>Table 1. Classification of the Elderly</th>
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<tbody>
<tr>
<td>Category</td>
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<tr>
<td>---------------------------------------</td>
</tr>
<tr>
<td>Independent</td>
</tr>
<tr>
<td>Pre-elderly</td>
</tr>
<tr>
<td>Elderly</td>
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<tr>
<td>Potential elderly</td>
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<tr>
<td>High risk elderly</td>
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<tr>
<td>Dependent</td>
</tr>
<tr>
<td>No potential elderly</td>
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</table>

The independent elderly is the potential elderly who are currently being addressed by the government to be empowered and directed to be productive and achieve successful ageing so that old age can be enjoyed in quality. The dependent elderly is a segment that has no potential and should be given special attention in care. Elderly care with dementia is an important issue to be studied because handling it is more difficult than the bedridden elderly. The elderly that suffered from dementia are generally still able to move physically but cannot carry out normal daily activities if not assisted by others, even at an early stage. If there is neglect, then the rate of memory loss will take place quickly and worsen the patient's condition.

The role of the family is very central in caring for parents as a form of reciprocal relationship that is beneficial for family health (Dwyer, 1994), so the quality of life of patients has been shown to improve when they are in family care (Susanti et al., 2023). In several studies, it was found that only families who have good mental and financial resilience are able to care for them. In Javanese rural communities, respect for parents is at least still animating in caring behaviour. According to Bern (2004), family is a source of support and takes care of each other's feelings so that the elderly feels happy, healthy and safe (Kesumaningsari, 2021: 105).

One form of strong respect in the teachings of filial piety is to place the elderly to live with their families and children. Even have married, respect towards parents can be seen in pride in continuing to prioritize them in the family. The family is the core of the social structure and respect for parents is manifested by always involving parents in family activities, and rejecting the idea of placing their parents into social institutions. In Javanese society, with a bilateral kinship system, parental status is strong and the traditional values surrounding the tradition of caring for family members can be strongly maintained.
The sacrifice of daughters who stop working to care for their parents is proof that parents' values are still strong for families in rural Java. Studies of heavy psychological, social and financial pressure on female informal caregivers (Sigilipoe, 2023), and the elderly caring for the elderly (Sare, 2023), are common phenomena in rural areas that really need attention. Cultural construction has placed girls as family caregivers. Domestic affairs are gradually becoming more complex, causing domestic activities and care activities to start interfering with each other and causing stress for both parties (Yasmin, 2023). Bad conditions can occur due to inappropriate care arrangements with low knowledge about dementia in the elderly, due to poverty or limited resources and causing the elderly in rural areas to be vulnerable to being marginalized through the stigma of stubbornness, fussing, childishness, and many prohibitions (Larastiti, 2023) and leading to neglect.

In the general condition in rural areas, the care provided is not in accordance with the standard of care because it is only based on instinct with minimal knowledge so the quality of the care arrangement applied is not the same. Even though as you get older, the physical condition of the elderly health graph decreases so it requires the right way of caring. A study in 2 districts in DIY (Bantul and Sleman) showed a significant increase in the health conditions of elderly patients after the caregivers were given the training to increase their knowledge in caring (Kurniasih, 2023).

3.2. Elderly With Dementia

Low awareness about dementia causes a tendency for families to neglect such as letting the elderly live alone without friends, families deciding to migrate or live separately, and entrusting parents to relatives or closest neighbours. This neglect, medically will result in the patient's condition getting worse and the rate of memory loss getting faster. The absence of a companion often results in chronic mental disorders and endangers such as psychiatric problems due to loneliness, feeling worthless because they are a burden to others, having illnesses that don't go away, depression and then deciding to commit suicide.

Table 2 shows some general symptoms of dementia (Adiningrum, 2023), at least 6 symptoms are found that appear most often. Most often the first is activities that are repeated, covering daily activities as a whole. Next is the disorientation of time and place so that it is difficult to find the way home, followed by not knowing the ownership of objects and money management, often losing things and emotional changes. It appears that almost all daily activities are disrupted, which includes personal, social and economic activities.

Table 2. General symptoms of dementia

<table>
<thead>
<tr>
<th>Most often (in rank)</th>
<th>General symptoms</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Decreased memory: having difficulty remembering short-term and doing repetitive activities</td>
<td>Forgot to turn off the stove, didn't recognize close relations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Asking questions, eating, taking medicine, bathing, cooking, seasoning dishes, paying instalments, and buying things, is done abnormally repeatedly</td>
</tr>
<tr>
<td>#2</td>
<td>Disorientation in time, direction and place: confusing</td>
<td>Not knowing the way home, pacing in and out of the house</td>
</tr>
<tr>
<td>#3</td>
<td>Difficulty understanding the characteristics and position of certain objects: do not know the benefits, functions, and ownership, and cannot distinguish between food and non-food and money management</td>
<td>Planting, weeding and harvesting rice belonging to neighbours, thinking soap and air freshener can be eaten because there are pictures of fruit</td>
</tr>
<tr>
<td>#4</td>
<td>Placing things out of place: often losing things</td>
<td>Goods are often lost due to forgetting to put farming tools, dentures, combs, glasses, retirement savings account books</td>
</tr>
<tr>
<td>#5</td>
<td>Changes in behaviour and personality: often angry, uttering unpleasant words, suspicious, prejudiced, jealous</td>
<td>Easy to angry, wanting to know every other person's talk</td>
</tr>
<tr>
<td>#6</td>
<td>Difficulty doing daily habits: bathing, defecating, eating, drinking, and others</td>
<td>Unmanageable, refusing to wear diapers, urinating and defecating carelessly, unable to take own food (if left will be malnourished)</td>
</tr>
<tr>
<td>Others</td>
<td>Impaired communication, difficulty focusing, making wrong decisions, anti-social</td>
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</table>

Whilst table 3 shows that generally, behaviour has a negative impact and is dangerous or harmful, although there is behaviour that has no impact. Therefore, an understanding of the social environment is very necessary for elderly people with dementia in order to live their old age safely.

Table 3. Impact of elderly behaviour on dementia

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Dangerous</th>
<th>Harmful</th>
<th>No impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repetitive activity</td>
<td>Overeating makes blood sugar level increase, overdose</td>
<td>Cooking, asking similar questions every few minutes, poor financial management</td>
<td>Bath</td>
</tr>
<tr>
<td>Forget</td>
<td>Turn off the stove</td>
<td>Often lose something</td>
<td>Does not recognize close relations</td>
</tr>
<tr>
<td>Disorientation</td>
<td>Don't know the way home</td>
<td>Planting, weeding and harvesting rice belonging to neighbours, raising the conflict with neighbours</td>
<td></td>
</tr>
<tr>
<td>Does not recognize the item and identify it and ownership</td>
<td>Cannot distinguish between food and non-food</td>
<td>Taking other people's things and claiming them as their own</td>
<td></td>
</tr>
<tr>
<td>Changes in behaviour and personality</td>
<td>Angry will make stress for both parties</td>
<td>Want to know every other person's talk, talk without anyone else</td>
<td></td>
</tr>
<tr>
<td>Difficulty in doing activity daily living (ADLs)</td>
<td>Urinating and defecating carelessly, slippery and slipping floors</td>
<td></td>
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</tbody>
</table>

The impact of the behaviour of the majority of dementia patients is more harmful and dangerous than those without impact. However, all of these deviant behaviours are carried out unconsciously as a result of dementia in the elderly.

3.3. Ethnocaring Perspectives in Responding to Behaviour Change

Ethnocaring

In simple terms, ethnocaring can be understood as local knowledge about how to treat naturally, based on instinct. Referring to Ahimsa-Putra (2022:14), local wisdom in ethnocaring appears in the form of a set of knowledge, views, values, and practices in a community that are obtained from daily experience to solve life problems properly and correctly. Care activities are based more on local wisdom and local cultural values that are adhered to by the community that caring for and giving attention to the elderly and respecting them is an obligation for anyone who is younger. This happens because the term dementia is not well known and understood. Rural communities only take care instinctively that senility in the elderly needs their help, especially to accompany their daily activities.

To make a diagnosis, whether a person has dementia or not must be based on a doctor's examination. In rural areas in general, people do not recognize the symptoms of dementia as a disease, so the majority do not see a doctor. Therefore, in the elements of care that are carried out, they do not follow management and guidelines or medical directions based on a diagnosis of dementia. If related to the meaning of care in general, then ethnocaring has a broader meaning than just physical care. This can be seen in how the caregiver responds to the behaviour and symptoms that appear in the elderly with dementia. It could even be said that the letting of the prohibition on the elderly with dementia could be a form of caring that has quite a positive impact so that the good intentions of the prohibitions do not mean a form of marginalization for the elderly.

In the cases of letting go, it appears that people with dementia only base their behaviour on the instinct of hunger and cannot accept logical explanations. Ethnocaring plays a role in logically accommodating behaviour and the effects of its behaviour so that it is in accordance with the caregiver's explanation by still obeying wishes but in a logical way, by serving food in small portions, and balanced with vegetables and fruits. An informant (P) said:

“If she doesn't get what she wants, she usually gets angry and emotionally utters unpleasant words which will raise stress on us. I have explained the bad effect of increasing blood sugar if multiple meals are not effective for her. I realize, a diabetic always feels hungry!”

Another logical response can be found in the case of retirees who can no longer manage their finances but still remember the routine of taking a pension. Generally, the caregiver will let him use the pension money at will. However, when usage cannot be controlled and runs out before the time for the next collection,
caregivers usually find out the cause and look for ways to make the pension money safe in use until the next month’s withdrawal. An informant (L) said:

“I always ask the bank cashier to give small change. The goal is to make it easier to give exact money when buying something because some sellers aren’t honest about giving change. Losses can be minimized and we feel that nothing ever happened”

As in the previous case, ethnocaring plays a logical role in accommodating behaviour and the availability of facilities so that the elderly with dementia continue to do according to their preferred habits but can minimize the loss of experience.

Caring management is an important part, especially in elderly people with chronic diseases. Schedules and types of medicine that are missed often occur because not only one type of medicine must be given. Caregivers who faced cases of forgetting to give medicine managed to overcome them with simple tips. Apart from having to be logical, the caregiver must also have a way to secure medicine administration so that adherence to taking medication is good. An informant (D) said:

“I make a sachet containing each prescription 3 times a day, then post it on the calendar. It will increase compliance to take medication. It is easier for us with strategic and tricky tips”.

Etnocaring sometimes requires the instinct to lie so that the elderly with dementia doesn’t argue too long over unnecessary things. Lying that avoids psychological burnout is needed because honesty often causes psychological fatigue for caregivers. Lies are done for the good of both parties. Caregivers can answer as they please and not have to be honest with often meaningless questions which can save caregivers from psychological exhaustion. Caregivers need to cater to their own emotional needs so they don’t get stressed out by giving whatever answers they want. There seems to be no ethics but it is necessary in ethnocaring. An informant (T) said:

“If she refuses to take a bath or is not cooperative enough to go to the doctor, I persuade her with the lure of going to a place they really like. Just instinctive and finally she will follow my order with pleasure”

Getting rid of dangerous objects is very important in ethnocaring. That is the easiest way is to store objects that have the potential to attract the attention of people with dementia. Caregivers seem to face more dangerous problems with activities mostly performed by females that suffered from dementia who do a lot of domestic activities. Etnocaring is needed to prevent the elderly with dementia from having bad and dangerous impacts. An informant (P) said:

“Even though it has been explained, it will still be repeated again. It is a logical action. Removing gas lines, or hiding pans for cooking. Remove dangerous objects that attract attention and store them safely in cupboards or locked rooms This will stop it. Safer for the elderly with dementia and peace of mind for us”

In relation to daily activities, caregivers are not only required to be able to respond instinctively, naturally, and logically but also expect that with limited knowledge about dementia, the social environment can understand the patient’s condition so as not to cause social tension. But this is not easy because almost all daily activities cause problems, but not all people can understand. An informant (S) said:

“ I hope that other people and the community can understand what people with dementia do and not give a negative stigma, because we can maintain harmonious relations!”

Disorientation of time and place causes the elderly with dementia to have irregular sleep times and cannot be sure when to wake up and go back to sleep. It is very hard for caregivers because have no quality sleep time. Not infrequently in the middle of the night, they will walk out of the house and can fall unnoticed if the caregiver is resting. The way to deal with this is ethnocaring which helps caregivers stay alert all night. It is important to prioritize the interests of both parties equally. An informant (L) said:

“ I usually will start to tell stories about the past even though I myself am bored because I tell the same thing, when tired he usually falls asleep. Naturally, people are generally happy to be invited to tell stories”.

Ethnocaring is a way of emotional adaptation by carrying out natural, instinctive, logical and ethical responses to behaviour change which is a form of caregiver tolerance for their illogical thinking ability due to memory loss. The goal is to save the caregiver's psychological burnout and comfort the elderly with dementia. Dishonesty under certain conditions is also necessary and does not always have a negative meaning, but must be a logical, natural strategy based on instinct in caring as a form of respect, affection and genuine concern for the elderly. Etnocaring is a caregiver care system that is sensitive to work and can be very dynamic depending on the caregiver's goals that direct the result of the behaviour of the person with dementia to get a good feeling. When should the elderly with dementia be cared for continuously and when can they be left for some time?
Caregivers have that sensitivity even without perfect communication with the person with dementia and limited knowledge about what stage the person with dementia is in, whether in the early, middle or late stages.

4. Discussion

In rural communities, the term dementia is not very familiar even though its symptoms are known. Most of them know it as senility, senile or some others call it "nagebleng" (blank). Ethnocaring does not use a medical basis whose results can be proven clinically both in terms of success and benefits, even though the result and goal to be achieved are the same, which is to improve the quality of life of elderly people with dementia so that they can live a quality old age.

Quality care is very important, so it is necessary to build public awareness and knowledge about dementia and how the pattern of care is appropriate to the family situation, case by case, concern, sensitivity, instinct and logic as well as medical ethics that can be compromised with the knowledge and situation of the local community. The "sense of crisis" will awaken by itself, but the community must have good knowledge and awareness of dementia in the elderly. The goal is to maintain the psychological or emotional state of the caregiver because the elderly with dementia is no longer even concerned with a statement or answer and the caregiver's response is right or wrong.

4.1. Javanese philosophy “mikul duwur mendhem jero”

In families in rural Java, there is no tradition of sending parents to be cared for in a nursing home for cultural reasons, although there are some nursing homes whose rates are very affordable or don't even pay a penny. The Javanese philosophy of “mikul duwur mendhem jero” is still firmly adhered to, so that even though it is hard, the mission of caring for parents is carried out so that it does not cross the mind of the child to send his parents to a nursing home. The responsibility for care in Javanese society is in the hands of the daughter or female relative, and if the child or relative cannot afford it, then it will be handed over to local residents or close neighbours. By adhering to this philosophy, families do not neglect the fate of their parents by taking care of them themselves.

Differences in who the caregivers are determine the quality of care. Caregivers here are daughters, husbands, and neighbours (community members). With regard to health culture, the anthropological study of care continues to grow today and its insights are broadening as more and more anthropologists explore the care culture that was previously dominated by sociologists and psychologists (Foster, Anderson, 1986). Schulman (1958) (in Foster, Anderson, 1986: 230) universally describes the ideal role of a nurse as helping the sick and managing, like a "surrogate mother" who is feminine, full of compassion, and caring for and protecting children. According to Fakih (2013), the inherent characteristics of women have been socially and culturally constructed so that women are considered more suitable to provide care and are manifested in kinship patterns. In bilateral societies such as in Java, the primary family nurse is the daughter, although boys are equally likely to help care for their parents in other forms such as financial or emotional support.

<table>
<thead>
<tr>
<th>The caregiver from a family member (informal/habitual care)</th>
<th>Caregiver non-family member (community care)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter</td>
<td>Partner (Husband)</td>
</tr>
<tr>
<td>Primary caregiver and sufficient for all care needs (physical, emotional, financial, spiritual)</td>
<td>Routinely take medication without missing (high compliance)</td>
</tr>
<tr>
<td>Meet all care needs (except emotional and spiritual needs)</td>
<td>Give medicine regularly</td>
</tr>
<tr>
<td>More often alone</td>
<td>More often alone</td>
</tr>
</tbody>
</table>

In responding to dementia elderly behaviour, differences in ethnocaring caregivers were found between family members, in this case, girls, and non-family members (neighbours) who were entrusted with the responsibility of caring for them. The elderly that suffered from dementia are generally not involved in outdoor activities because of hassle, activities are slow, ask lots of questions, and often ask to urinate but are reluctant to use diapers. However, this condition can be tolerated by the daughter's caregivers. Emotionally, female caregivers have more bonding with their parents to make them happy according to their abilities.

5. Conclusion

Ethnocaring has been applied by village communities in DIY in providing assistance and support for elderly people who are experiencing senility. Families and local residents treat senility based on natural instincts and habits prevailing in their area. They give full attention to the senile elderly because it is based on the Javanese philosophy "mikul duwur mendhem jero" and Islamic religious values "birrul walidain". These two values become guidelines for them in helping and supporting the elderly to stay healthy and qualified.
Based on this research, the advantages and benefits of ethnocaring in helping to overcome dementia in the community are that it is easy, inexpensive, and appropriate to local culture. Diverse ethnocaring research in many communities will enrich local knowledge and can become a body of knowledge for assistance materials for caregivers in the community. The possibility of success in treatment will be greater because of its suitability to the conditions of the local community. The nature of this very local knowledge will be very relevant for various assistance programs for the elderly with dementia.

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