**Policy Brief**

# Older People's Care Networks in Indonesia

## Findings and Policy Recommendations

## Background and Study Context

Rising life expectancy and longer survival in old age contribute to complex chronic illnesses, functional limitations, and cognitive decline in later life. Without appropriate care, older people risk spending the last years of their lives unable to enjoy their human right to participation, dignity and autonomy. This raises an important question: How can we as a society ensure that older people receive care and support that enables wellbeing and dignity?

In 2021, Indonesia published its National Strategy on Ageing, which includes a commitment to 'comprehensive long-term care services covering health and social aspects for the elderly'. The same year, the United Nations *Decade of Healthy Aging* was launched. During this decade, countries are invited to consider how to develop integrated and appropriate health and care services that meet the needs and uphold the rights of older people. Within this context, a comparative study on older people's care in Indonesia has been conducted since 2019. The study is a collaboration between Universitas Katolik Indonesia Atma Jaya Jakarta and the University of Southampton (UK), together with Loughborough University (UK) and Oxford University (UK). The aims are to understand who is involved in older people's care, what older people's preferences and needs are, and how families can be supported by health services, governmental, and non-governmental institutions. The study involved ethnographic research in five locations across Indonesia (Jakarta, West Sumatra, Yogyakarta, East Java and East Nusa Tenggara).

## Key Findings

### Care dependence is rare but also universal

Most older people in Indonesia remain active and independent: they continue working, look after grandchildren, care for sick relatives, do housework or act as volunteers. However, a minority of older people require help with activities of daily living, like cooking, shopping, managing money; and some are entirely dependent on others due to frailty, ill health or cognitive decline. Most people will experience a period of dependence at the start and end of their lives. Giving and receiving care are part of our human identity. Having our needs for physical, emotional, and medical care met is a human right. Unfortunately, care-dependent older people are invisible in their communities, as they are confined to their homes. They are also invisible in public policies and media representations, which prioritise 'successful ageing' and 'tough older people'.

## Families are committed to providing care, but …

Despite pessimistic scenarios of declining family solidarity, our research found that family care for older people remains strong. Most care is provided by wives, daughters and daughters-in-law, raising issues of gender equity. However, sons are also active care providers, especially if there is no daughter or wife nearby. For example, Ana from Malang is bathed daily by her coresident son, while her son next door cooks for her. For married older people, a husband or wife is typically the main carer. This can be challenging if the carer also has health problems or disabilities.

Frequently care is shared among several family members. Take the example of Murni, an older woman in West Sumatra. Her five sons were on rantau, but when her health began to decline, the youngest son returned with his wife to provide care. His brothers send money for daily expenses. Sometimes family members take it in turns to bathe, provide food or accompany the older person, thereby reducing the pressure on individual family members.

However, some families struggle to provide the care that is needed. Poverty is a key factor. In our Jakarta study site, for example, a third of households with older people are below the poverty line. Poverty means families cannot afford assistive devices, like incontinence pads or wheelchairs; and it means carers must juggle care and paid work. The distribution of the government subsidy (PKH), which some older people benefit from, is not reliable, and it is not inclusive of all older people who need it. Marsinah, in West Sumatra, for example, is the sole carer for her mother, who is bed-bound, and her aunt, who has dementia: it's a full-time job! Marsinah also must work as an agricultural labourer to survive. She sleeps badly, because often she has to change soiled bedding several times a night.

## Some older people do not receive the care they need

Some older people go without much-needed care at the end of their lives, with significant impact on their quality of life. It is important to remember that not all older people have family members who can care for them. Take Paijah, from Yogyakarta: her only daughter lives abroad, her husband died many years ago. Paijah has mobility problems and moves around by pushing a chair or holding on to the walls. Without someone to care for her, she struggles on with a little help from neighbours.

Even where families are providing care, the quality of care can be imperfect. Often families are working, so they can't accompany the older person to the integrated health post for older people or health centre. In situations where the older person has dementia and shows repetitive, challenging or even violent behaviour, families often don't know how to respond. Restricting the older person's movement and autonomy, using harsh language or infantilising behaviour can then result. Similarly, carers might not know how to prevent bed-sores for people who are bed-bound. This can result in deep, dangerous and painful wounds on the older person. Ensuring an adequate diet and encouraging frail older people to eat are also common challenges. Our findings clearly show that families need support and training to provide appropriate care. There is an important role for the state in supporting older people and their caregivers.

## Use of health services is unacceptably low among older people

Many older Indonesians who need care no longer use health services. This is worrying, because lack of medical attention means symptoms of pain are not managed and further declines in health and functioning are not prevented. Older people might see a doctor when they first experience ill health, but if symptoms persist, disengagement from health services is common. We found three inter-related reasons: ***First,*** families are concerned about the cost of medical care. Not all families have access to subsidized health insurance (BPJS). Even if covered, they worry about additional costs to access services, or to pay for medicines or assistive devices. Many families rule out using BPJS because of long waiting times in crowded conditions, unfriendly staff who don't have time to answer questions, and poor service. Instead, they rely on over-the-counter medication. One older woman we interviewed is confined to her bed due to crippling pain of arthritis. Only when her granddaughter can afford to buy pain killers does she manage to get up and move around. ***Second,*** transportation to a health centre or hospital is difficult. When an older person can no longer walk, using a moped-taxi (*ojek*) becomes impossible, and cars or taxis are expensive. One man, caring for his paralysed mother who was suffering from bed-sores asked us: *How can I get her to the health centre?!* The paradox that those older people who most need medical attention don't get it, because they cannot access it, needs to be addressed urgently. ***Third,*** a pervasive attitude that ill health is 'natural' in later life means that people think there is no point in taking older people to see a doctor: "It's old-age illness *(sakit tua)!*" In fact, stroke, diabetes, rheumatism, poor eyesight, deafness, cough, dental problems, and muscle weakness can be prevented, alleviated, or even cured, giving older people a better quality of life.

## Healthcare volunteers *(kader)* provide important support, but …

Our research found that healthcare volunteers (*kader*) play a key role in supporting older people and their caregivers. *Kader* help to run integrated community health posts (*posyandu lansia*) which provide regular health checks, preventive health messages and referrals to health centres. In our Jakarta fieldsite, *kader* were instrumental in encouraging older people to maintain safety protocols during COVID-19 and become vaccinated. *Kader* have the advantage of being locally recruited. This means they know older people well, they are trusted and approachable. However, not all communities have a functioning network of *kader*. Commitment from community leadership can be lacking, and many communities struggle to recruit and retain *kader*. Providing this voluntary service adds to the gendered burdens that Indonesian women face. The *kader* we interviewed expressed the need for training, so that they can serve older people and their families better. With the exception of a few NGO pilot programmes, *kader* do not conduct home visits to older people who can no longer leave the house. This is an important limitation, because it means that those older people who most need support are not receiving it.

# Recommendations

### 1. Barriers to healthcare use among the older population must be addressed

The barriers that older people face to realising their right to health need dismantling. For example, there's a demand for dedicated opening hours with shorter waiting periods for older people at hospitals and health centres; and provision of transport and companions for older people attending clinics. The public health provision via the BPJS system requires more investment and better communication. Universal Health Coverage (UHC) means that everyone, everywhere can access the health and care services they need without financial hardship: progress towards UHC should be part of Indonesia's efforts to meet the Sustainable Development Goals (SDGs). The ageist concept of 'sakit tua', which normalises poor health, needs to be challenged at all levels of society, starting

with healthcare professionals. A public health campaign is needed to convey the preventability and treatability of ill health and physical suffering in later life and to promote older people's use of health services.

### 2. Services must reach older people

The paradox that older people who most need medical and social care cannot access health services because of frailty, mobility issues, disability, or poverty needs to be addressed urgently! There is manifest demand for home visits to older people who are housebound by medical staff from the public health centre (*puskesmas*). This will ensure older people have access to medical examination and treatment, and can be referred to hospital if necessary. In addition, home-care visits by trained *kader* should be implemented to monitor the situation of care-dependent people, provide help with care tasks and support family carers.

### 3. Healthcare volunteers and informal carers need training

The integrated community-based health posts (*posyandu lansia, posbindu*), offering healthchecks and preventive health services, are appreciated by older people. However, the government needs to scale up this approach to all communities and to develop the capacity of *kader* and informal carers by providing training. Such training has been mandated by the Ministry of Health of the Republic of Indonesia, and good examples of caregiver training exist (e.g. by Indonesia Ramah Lansia). However, such training needs rolling out. To show recognition for the work of *kader* and successfully recruit and retain *kader* requires incentives in the form of small-scale remuneration, training, or non-monetary rewards.

### 4. Social protection for economic support is needed

Many of the challenges in providing good quality care for older people arise from a lack of resources. Older people in Indonesia need a minimum level of financial support from the government, reliably paid monthly. Those who have care needs or disabilities should be entitled to a disability and carers' allowance. This will enable families to obtain healthcare, nutrition, and assistive devices for older members, rather than having to make trade-offs between different members' needs (e.g., school fees versus health care). Currently, less than 10% of the older population receives a pension. Other countries in Southeast Asia, like Nepal, Vietnam, or Thailand, provide an important example for Indonesia in terms of implementing non-contributory pensions for older people.


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