

Long-term care for older people in Indonesia: Unsustainable and unjust?

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Abstract

The care needs of older people in most low and middle-income countries are typically met by family members, chiefly women, or remain inadequately acknowledged and met. We know, for example, that older people's use of health services is low and that informal carers receive little support from the state. Economic pressures, exacerbated by current social distancing measures, leave families with stark choices in terms of which needs to prioritise. While local examples of small-scale programmes run by NGOs or primary health posts exist which successfully assist and empower older people and their carers, little is known yet about whether these initiatives are sustainable in the current climate, much less whether they can be scaled up. Drawing on early empirical and conceptual work on long-term care in Indonesia, this paper argues the need for taking a network approach to understanding the care provision of older people. By this we mean documenting and understanding the multiple minor and major, formal and informal actors involved in the provision of care and support to older people and the factors facilitating or impeding their successful interaction. We further argue for the need to recognise care as a cultural practice in which care needs and preferences are shaped by local values and socio-economic constraints. These values and constraints are likely to be shifting dramatically as a result of the current coronavirus pandemic, exposing fault-lines and exacerbating inequalities in access to health and social care. Uncovering these inequalities and gaps in current long-term care arrangements is a necessary step towards making care more sustainable and equitable.

Introduction

My talk addresses the question of how older people's care needs can be met in sustainable, fair and culturally acceptable ways. I lead a research project, funded by the ESRC, which aims to answer this question for Indonesia, the world's fourth largest population. The fieldwork for this project has been delayed due to the coronavirus. I'm therefore going to start with a brief case study from a different project I'm involved in, which is funded by the Australian Research Council (ARC). The ARC project looks at vulnerability across the lifecourse in Indonesia.

Case Study

Sriamah was a woman in her early 60s living on Java. She suffered from diabetes and had a stroke from which she initially made a good recovery. However, a fall, possibly due to a second stroke, left her with a badly broken leg. She was advised to have an operation, but was fearful, and her husband worried about the potential costs, despite having joined the new Indonesian health insurance system. Thus, Sriamah was taken to an alternative healthcare provider several times for nerve massages. These failed to improve her condition, and subsequently she accessed no further healthcare. Sriamah lived with her husband and a married daughter, who works in a nearby factory. Most of her care was provided by Sriamah's husband, who had to give up his work as a construction worker to look after her. He was outwardly frustrated by this and the fact that his wife

was making no progress. A nearby daughter, not in paid work, sometimes helped, but she has four children. Without help, Sriamah's husband found it difficult to move Sriamah from bed to chair, or chair to wheelchair, so she often spent hours in the same position. One of Sriamah's two sons provided monetary support, and a neighbour sometimes visited. After 18 months of being care dependent, Sriamah died. Her husband has not resumed paid work.

A typical case?

In many ways, Sriamah's case is not unusual.

- ✓ Many Indonesians experience the onset of care needs quite early, due to common risk factors like high blood pressure, diabetes and stroke (Kusuma *et al.*, 2009; Turana *et al.*, 2019).
- ✓ We repeatedly encountered a pattern of healthcare use in the early stages of an older person's health crisis, followed by disengagement from medical care. Recourse to alternative medicine is also not rare (but covered entirely by out of pocket payments).
- ✓ Commonly reported barriers to healthcare use include access (particularly the need for transport); lack of home visits; fear of doctors; dissatisfaction with the new health insurance system and related to this: concerns about affordability.
- ✓ Family care is invariably the outcome of negotiation among multiple potential family carers. Typically, this involves a narrowing over time to one or two main actors. This narrowing often results in a reduction in the quality of care (van Eeuwijk, 2020).
- ✓ Sriamah's case is slightly unusual in that the main carer is a man. Like everywhere, women are more commonly the main carers in Indonesia; however, the involvement of husbands and sons is not that rare. It depends on who else is in the network, on culture, and on negotiating power. In Sriamah's case, the husband obviously lost out to his coresident daughter.
- ✓ Sriamah's loss of status and respect, as witnessed by her husband's complaints about her, is not unusual. In previous research I found that dependence was undermining of a person's social identity and wellbeing, at least in some parts of Indonesia (Schröder-Butterfill and Fithry, 2014).
- ✓ Finally, it is well-known that caring impacts on the labour force participation, social participation and wellbeing of carers. Sriamah's husband's situation attests to this.

Challenges to LTC provision

This single case study, recorded during ethnographic fieldwork in East Java in 2019, offers a lens on some of the challenges which long-term care provision in Indonesia (and other developing countries) faces.

The challenges are around:

- Sustainability: Care is not sustainable if it forces family members to choose between paid work and care, or if it results in declining health and well-being of carers. For instance, we encountered a case where a woman didn't pursue chemotherapy for her breast cancer, because she felt unable to leave her bedridden husband for whole days at a time.
- Equitability: Care is not equitable if it disproportionately falls on families rather than entailing a more collective response to what is a very common risk in ageing societies. It's also not fair if within families, it disproportionately falls on women or those with the weakest bargaining position.
- Quality: Care is not as good as it could be, if it does not include access to health care, if it does not accommodate people's cultural and personal preferences or facilitate a valued existence for the cared for person.

Indonesian context

Indonesia is at a critical juncture, because it is confronting the reality of rapid demographic ageing in a context of equally dramatic social and economic changes. Currently, there are 26 million Indonesians over the age of 60; this is set to increase to 43 million in the next 10 years. 13% of older Indonesians are classed as being poor, many more are 'near poor'. Only 10% receive a pension, while a quarter live in households that receive some form of social assistance programme. Indonesia is incredibly diverse ethnically and culturally; it also has massive disparities in health infrastructure. Into this complicated context, Indonesia is trying to develop a long-term care strategy. This is exacerbated by the fact that responsibility for the older population falls under different ministries, and that Indonesia is highly decentralised.

Local care initiatives

A central pillar of this strategy is the well-developed network of primary health centres. Yet depending on where you live, the nearest health centre may be more than an hour away (Kharisma, 2020). Communities are therefore expected to operate local-level health posts for older people (*posyandu lansia*) with the help of a community nurse and an army of volunteers (Hoogerwerf and Saludung, 2004; Pratono and Maharani, 2018). At their best, these offer fortnightly health check-ups, non-prescription medication, advice on healthy lifestyles, communal exercise and team building among older people. Many of the volunteers are elderly themselves; most are women, which arguably puts off some men from attending. Because they operate at the grass-roots level, they hold excellent local knowledge about who the vulnerable, frail or care dependent older people are. This has been a key strength during the current Corona pandemic. Despite health posts halting regular activities and health centres discouraging older people from attending, the volunteers have often continued monitoring their older clients, either via Whatsapp or visits up to the doorstep (Sare and Schröder-Butterfill, 2020).

A main disadvantage of the government mandated elderly health posts is that their curative remit is extremely limited. Any serious health needs have to be referred up to primary health centres, and upwards from there to hospitals and specialists. The case of Sriamah, earlier, noted some of the issues with these providers (access, waiting times, bureaucracy, cost, problems with health insurance system etc.) Another drawback is that in most communities, they do not offer home visits. This means care dependent people typically cease using them at the point at which they and their carers would most value external advice and encouragement. This is where charities, NGOs or private LTC organisations sometimes come in. They offer a mix of services, variously including home visits, day centres, physical care for those without family members, informal carer training, care aids (such as wheelchairs or special beds) or material support. They are pro-active, resourceful, tailored to local needs. But their coverage is minute compared to national demand, and they sometimes risk being partisan (by catering to particular religious groups or social classes).

Gaps in knowledge

Policy planners in Indonesia are trying to identify best-practice examples from this huge variety of initiatives and to assess what might be scaled up or applied elsewhere. The difficulty is that they are trying to do this in the absence of detailed information about what older people's care needs are, how common these needs are and how they change over time. (For instance, estimates of dementia prevalence range from 6% to 35% (Hogervorst *et al.*, 2011; Suriastini *et al.*, 2020).) Similarly, not enough is known about what support family carers need to help them in their care provision. If we think back to Sriamah, some home visits by a physiotherapist might have been welcome; or an allowance to bring in some paid care to permit her husband to continue working. If a key aim of formal care initiatives is to make care more equitable, we need to know how care is negotiated within family networks, what tangible and intangible assets matter in the bargaining of care, and how care dependent older people are valued. Lastly, we need to understand which older people are

most vulnerable to not having their care needs met due to a lack of family, poverty, reputation or where they live.

The project

My team of Indonesian and British researchers and I hope to answer these questions and contribute to an empirical base for policy planning. As part of a comparative project on care networks in Indonesia, funded by the Economic and Social Research Council (ESRC), we will conduct in-depth ethnographic research in six communities across Indonesia. This will be followed by randomised household surveys in the same locations. The different locations capture important cultural variation, as well as different health and social care infrastructures. Some are urban, others rural. Some of the sites have been studied before as part of research funded by the Wellcome Trust and the Australian Research Council.

Three ideas

Three ideas are central to the research and its methodology.

First, we consider care a cultural practice: culture shapes preferences for care providers, what counts as acceptable care, and what being dependent does to a person's identity. This is why we use ethnography and compare ethnic groups across Indonesia. Second, care – in its widest sense – is often provided by a mix of close and distant family members, neighbours, health-care providers and volunteers. This is why we collect data on complete care networks and how they evolve over time. Third, we understand that older people are very diverse, and this shapes their experiences of care. This is why we collect information on economic, demographic and social status and compare care among economic strata and other sub-groups.

The start of fieldwork has unfortunately been delayed due to the COVID crisis. But when finally we can start, we hope the research will be even more policy relevant than before.

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How can the care needs of older people be met in sustainable, fair and culturally acceptable ways?

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2



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Case study

3

3

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A typical case?

- ✓ Early onset of care needs
- ✓ Discontinuation of healthcare use
- ✓ Common barriers to healthcare use
- ✓ Negotiation of family care → narrowing to a few carers
- ✓ (Gender of carer)
- ✓ Loss of status
- ✓ Detrimental impacts of long-term caring

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Challenges to long-term care provision

- Sustainability
- Equitability
- Quality of care

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Indonesian context

- Rapid demographic ageing (60+ grown from 11m in 1990 to 23m today, 43m in 2030);
- Significant minorities are poor or near poor;
- Limited state support: Very low pension coverage; social assistance programmes; problematic new health insurance;
- Huge diversity.

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Towards an Indonesian LTC strategy

- Long-term care strategy in process of development; different ministries + decentralisation.
- Network of primary health centres (*puskesmas*)
- Local level older people's health posts (*posyandu lansia*), reliant on volunteers
- NGOs, charities, private care providers, etc. ...



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Gaps in knowledge

1. What is the nature and extent of older people's care needs? How do care needs fluctuate over time?
2. What support do family carers need to provide sustainable, acceptable care?
3. How is care negotiated among care network members?
4. What are the impacts of care dependence on older people's status, wellbeing and 'value'?
5. Who is vulnerable to a lack of care?

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Research project

Care Networks in Indonesia: A Comparative Study of Six Communities using Ethnography and Surveys



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Three central ideas

1. Care is a cultural practice (therefore: comparative, ethnographic approach).
2. Care is provided by a network of family members, neighbours, community institutions, healthcare providers, NGOs, charities... (therefore: complete networks, over time).
3. Diversity matters: care is shaped by socio-economic status, gender, local conditions... (therefore: household survey data).

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