Care as crisis and care in crisis:

Older people's care networks in Indonesia before and during COVID-19

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Introduction

This paper examines a small but important node in the wider care networks of older Indonesians, namely the healthcare volunteer system and the impacts COVID-19 has had on it. The backbone of old-age care provision remains kinship based. Despite immense cultural, ethnic, religious and socio-economic diversity, the basic willingness of families to care for frail, ill or dependent members is manifest. However, there is growing evidence that the current exclusive reliance on families is unsustainable (van Eeuwijk, 2020). Multi-morbidities and mental health problems are giving rise to long-term and complex care needs. Yet the stigma associated with dementia and functional dependence, especially if it involves incontinence and intimate care, makes it difficult for informal carers – usually daughters and wives – to seek help (Schröder-Butterfill and Fithry, 2014). Moreover, the availability of family support cannot be taken for granted. Not only has aggregate fertility declined from over 5 children per woman in 1970 to 2.4 (United Nations, 2017), but significant minorities of older people (10-25%) are childless as a result of historical patterns of mortality and pathological sterility (Schröder-Butterfill and Kreager, 2005). In addition, migration, poverty conflict and disability render some older people with children *de facto* childless (*ibid*.). Demographic and social causes of a lack of children are concentrated among the poor, compounding their vulnerability to inadequate care in later life.

These trends mean that Indonesia will fail to meet the growing demand for old-age care via an exclusive reliance on families. Instead, an approach is needed which strengthens health-care delivery to older people, supports informal carers and targets specific care gaps (Jacobs *et al.*, 2016; Pot, Briggs and Beard, 2018). Recent years have seen the emergence of basic health monitoring and promotion services for older people, reliant on local health-care volunteers (*kader*) and integrated health posts for older people (*posyandu lansia*), as well as an array of NGO pilot initiatives aimed at supporting and training informal carers. This paper reports preliminary findings from research locations in Indonesia where a fragile ecology of familial and non-familial care had emerged prior to the pandemic. We examine how COVID-19 disrupted this and prompted a retreat and reconfiguration of care support from non-familial providers. We argue that the *kader* system has the potential to make an important contribution to supporting the care and healthcare of older Indonesians, but that our evidence also shows the fragility, limitations and contradictions of the system. Although these have been revealed during the pandemic, they are arguably symptomatic of broader challenges around the low prioritisation, inconsistency, and under-resourcing of long-term care in Indonesia.

Methodology

This paper reports very early findings from a project on care networks in Indonesia.[1] The project seeks to understand the nature of older people's care needs, the composition of their care networks, the impacts of caring on informal carers and the ways in which care is shaped

[1] We gratefully acknowledge the funding by the Economic and Social Research Council (ES/S013407/1) for the project 'Care networks in later life: A comparative study of five communities in Indonesia using ethnography and surveys'. The project is a collaboration between the Universities of Southampton, Oxford, Loughborough, Atma Jaya and Gadjah Mada.

by socio-economic position, gender, ethnicity and location. The project takes a comparative approach involving ethnographic fieldwork and in-depth interviews in five sites across Indonesia. Due to COVID-19, we had to first delay, then adjust our data collection. Since October 2020, anthropologists have been conducting telephone/online interviews with local healthcare providers, healthcare volunteers, NGOs and local officials in the two sites most affected by the pandemic (Jakarta, Yogyakarta). These sites also have the most well-developed system of health-care volunteers (*kader*), who are the focus of this paper. Meanwhile, socially-distanced face-to-face interviews and observations with older people and carers have been taking place in the three sites where COVID-19 has had limited impact (East Java, West Sumatra, Alor).

The community health volunteer system

Indonesia has long had a strong network of primary health care provision, centred on primary health care posts (*puskesmas*) at sub-district level (Agustina *et al.*, 2019; Aspinall, 2014). The *puskesmas* is the first port of call for medical care; it also provides preventive health measures and referral to hospitals. At village or urban-neighbourhood level (*kelurahan*), the local 'nurse' (*bidan, perawat*) has the support of community health volunteers, called *kader*. Typically, *kader* are women of all ages, including older women, who have received basic training on health monitoring, promotion and reporting. They were first used in the 1970s to support Indonesia's family planning programme and mother-and-child primary healthcare delivery (Niehof and Lubis, 2003; Reis *et al.*, 1990). For the last 20 years or so, *kader* have also begun to be recruited to service older people's 'integrated health posts' (*posyandu lansia, pos bindu lansia*) (Pratono and Maharani, 2018). These chiefly take the form of monthly health check-ups (blood pressure, weight, cholesterol, uric acid, sugar), but sometimes extend to health education (diet, exercise), assistance with access to higher-level health-services and home visits.

Even before COVID-19, the *kader* system was implemented disparately in different communities, despite being a supposedly national programme (Pratono and Maharani, 2018). In our Jakarta fieldsite, the many, highly motivated *kader* are heavily relied upon by the local health centre and village administration for a variety of health-related tasks (see below). A similarly effective system can be observed in Yogyakarta, while in East Java the *kader* appear less well-informed, and their involvement seems confined to assisting with monthly health check-ups. On Alor, what started out as a service aimed at older people was opened up to all adults, possibly because of the island's young demographic profile. In our Sumatran site only the mother-and-child *kader* system appears to be functioning. This community relies heavily on remittances from successful migrants, and use of specialist medical services is common; this could mean that demand for primary health attention is low.

In what follows we briefly discuss the *kader* system as a part of older people's care networks and the impact which COVID-19 has had on it. The pandemic has helped to sharpen our understanding both of the (real and potential) significance of the *kader* system for older people's health and care, and its vulnerability. Key principles of the system, like local rootedness, 'translation' and 'mediation', are shared by many volunteer-based civil society organisations around the world and are worthy of emulation and extension (Krause, 2014; Kreager, 2009; Midgley, 1994). Key weaknesses arise from the lack of power, resource and training invested in the system by the Indonesian state and its vulnerability to capture by specific individuals or subgroups, which can make it partisan or ineffective.

Kader as ‘one of us’

A fundamental idea underpinning the use of healthcare volunteers (or ‘outreach workers’) is that *kader* are locally recruited: they are ‘ordinary citizens’, living in the communities they serve.[2] This local rootedness has implications: It means *kader* tend to have excellent local knowledge of ‘who is who’ and what their needs and circumstances are. This facilitates their role in identifying individuals or families in need of government, charitable or neighbourly support. For example, in our East Javanese study community the *kader* were tasked with identifying families to receive ‘basic needs’ assistance (*sembako*) and health subsidies, and during the pandemic they ensured that cooked food was provided to households having to quarantine. Of course, in communities riven by ethnic, religious or social-class cleavages, the *kader* system can reinforce these and exclude certain subgroups from receiving benefits.[3]

Being community members makes *kader* trusted and approachable. As they are *not* professional healthcare providers, they are considered peers, rather than aloof, awe-inspiring doctors. By living locally, they are encountered in daily life – out shopping, praying or attending community events. A common refrain of the *kader* women we interviewed was how often they were approached by older people or their carers for medical advice, personal issues or even economic help.[4] Particularly now during the pandemic, when the formal activities of the *kader* have ceased (see below), their local presence and knowledge enables them to play a vital part in ‘keeping an eye’ on vulnerable elders and noticing if someone has not been seen for a while.

Of course, the more sinister flipside to the *kader’s* local knowledge and presence is that it makes them ideally placed to monitor and control the people under their charge. Measuring, monitoring and regulating bodies have long been key responsibilities of *kader*, from their first deployment as assistants to Indonesia’s family planning and later ‘family welfare’ programme. Indeed, the monthly *kader*-run ‘integrated health posts’ for older people in some of our fieldsites (Malang, Alor) are so closely associated in people’s minds with ‘being measured’ (height, weight, blood pressure, even head circumference) that several older respondents have questioned their usefulness: why go there again if you’ve been measured once before, especially if you’re not feeling ill?

During the pandemic, the *kader* in our Jakarta and Yogyakarta sites have been closely involved with communicating health messages (e.g. the 3Ms – masks, washing hands and maintaining distance) and reinforcing their implementation. *Kader* spoke of their constant need to remind people they encounter to wear masks, top up the soap in the mobile hand-washing units and maintain distance. This in turn makes them the butt of jokes and teasing for their officiousness. In Yogyakarta four elderly kader were among the first to receive the Covid-vaccine, with the express expectation that they would serve as role models to encourage sceptical co-villagers to follow suit. Thus while *kader* are of the people, they are at the same time expected to police and cajole their peers.

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[2] Often they have extensive social and kinship networks in the community and ties to village leaders which help to bring them to the attention of the healthcare professional tasked with recruiting *kader*. The expectation of giving up time for free (or in exchange for a small monthly stipend) means that mothers without paid work and retired people predominate.

[3] In previous research, we observed allegiance to the then dominant Golkar party shaping the distribution of benefits in one community. In the present study, the fact that the main hamlet in the Sumatran site is well-supported by remittances may have contributed to the neglect of the kader-run elderly health-care services; these would benefit the poorer hamlet, occupied by newcomers, which relies on agriculture rather than remittances.

[4] One *kader* woman recounted repeatedly being asked to buy government-donated rice from elderly beneficiaries of the ‘basic needs subsidy’, because they needed cash more than rice.

Kader as mediators and translators

The *kader* – where they work well – occupy a key position within Indonesia's state healthcare and welfare ecology. They act as mediators, translators and brokers (Jakimow, 2018). On one hand, they facilitate communication between the state and local people and help to direct state efforts towards those who need it. On the other hand, by conducting basic health monitoring, they can identify health problems and encourage people's engagement with professional health-services. Older Indonesians often hesitate to approach medical services, especially if they don't have a family member to take them. By sometimes accompanying older people to the *puskesmas* or helping with arranging their health insurance (BPJS), *kader* play an important part in making healthcare accessible to older people (Berenschot, Hanani and Sambodho, 2018).

The mediation and translation role of *kader* has been thrown into sharp relief over the course of the pandemic. Indonesians have been bombarded by health messages, warnings and ever-changing regulations. The vulnerability of older people to COVID-19 has been emphasised in cartoons, posters and broadcasts (Insriani and Porath, 2020), prompting some adult children to restrict their elderly parents' movements. Yet the invisibility of 'the enemy' and the relative rarity with which it has struck have made it difficult for people to relate to the threat, especially over a long period of time (Fithry and Schröder-Butterfill, 2020). One *kader* stressed the importance of repeatedly explaining health protocols and recounted how she vividly describes the practical implications of catching COVID – having to go to a special isolation centre, being separated from family – in order to encourage compliance.

Some of the top-down instructions have been frankly unrealistic, notably the insistence on social distancing in what is one of Southeast Asia's most densely populated neighbourhoods (Sare and Schröder-Butterfill, 2020), the wearing of masks before these were freely available or, most recently, the expectation that people register online for vaccinations. It has thus fallen on village leaders and *kader* to translate the messages into workable, understandable and acceptable solutions. Reliance on social media has been a boon and widely used by *kader* to keep in touch among themselves and to check up on elderly clients. But they recognise that many older people don't have mobile phones, and that face to face contact is therefore necessary. Some *kader* have therefore made doorstep visits to older clients to check on them or convey a message, others stop and talk when they meet older people or their carers in the street. One kader recalled performing some exercise moves in front of a group of older people to encourage them to keep fit, jokingly reminding an older person to keep wearing a mask to cover up her crooked teeth and prompting the carer of a person with dementia to check for her mask when she goes outside. It is likely that many of these initiatives are taken by *kader* informally, rather than this being part of their formal remit.

In the process of adapting and putting into practice poorly considered government instructions, the *kader* place themselves at considerable risk of infection. As they occupy the lowest rung in Indonesia's healthcare system, are unpaid and don't have access to any protective measures, such as PPE or priority vaccinations, the government's reliance on *kader* appears callous. For example, early in the pandemic, when realisation struck that many Indonesians don't have access to masks, it was the *kader* who helped with their distribution, even showing elderly clients how to put them on properly. Despite the emphasis on older people's vulnerability, elderly *kader* were not necessarily exempted from such activities. As one elderly *kader* recounted, it was only after she was diagnosed with a heart problem that she was told by the head of neighbourhood to desist from meeting elderly clients face to face.

The 'toxic optimism', as Sandeep Nanwani (2020) has called it, of assuming near-universal internet connectivity is another example where mediation by *kader* is necessary. It is coupled with an assumption that all older people have access to family support: even if they themselves can't access information or register online, their families can surely do it for

them! Thanks to their local knowledge and presence, the *kader* understand which older people need help with the registration and assist them in the process. In Jakarta, even though enrolment is done electronically, the invitations to vaccination events are still paper-based. It is the *kader* who are tasked with delivering these to the elderly people. A similar inconsistency was observed in our East Javanese site, where elderly health check-ups were reinstated in November 2020, but with strict limits on numbers and good health a requirement for attendance. The effect of these precautions was reduced by the fact that they had to be communicated through face to face *kader* visits to the homes of more than 60 older people, and by the fact that the event coincided with the mother-and-child clinic.

The fragility of the *kader* system

The previous paragraphs attested to the myriad ways in which *kader* have communicated and translated health messages and supported older people during the pandemic. This should not distract from the fact that their core business of running regular health monitoring clinics for older people (*posyandu lansia*), was halted during much or all of the pandemic so far.[5] What is more, the *posyandu lansia* is the only health-service which was discontinued across our fieldsites. Primary health centres (*puskesmas*) and hospitals continued receiving, assessing and treating patients, even for preventive medicine, and the 'mother-and-child' equivalent service (*posyandu balita*) resumed much sooner. It could of course be argued that halting the clinics was done to protect older people, given their greater vulnerability to serious health problems in the face of COVID-19, and that given the minimal curative remit of local health monitoring clinics, their loss was outweighed by the safety gains. However, our evidence points to significant direct and indirect detriments to older people from the *posyandu* closures.

By pointing people for routine check-ups to higher-level healthcare providers (*puskesmas* or hospitals), which are further away and more crowded, risks from COVID-19 are still encountered. Moreover, by eliminating the health monitoring layer of health-service provision, it is likely that preventable deaths among older people occurred.[6] The *kaders'* narratives repeatedly centre on their need to encourage older people to seek medical care, even to the point of accompanying them to the *puskesmas* or hospital. Reluctance to engage with government health-service providers has expanded dramatically during the pandemic thanks to rumours that ordinary health problems are being classified as COVID-19, with all the protocols and restrictions this then entails.[7] By removing the regular meetings for health-checks, older people lack the vital encouragement for health-seeking which the *kader* normally provide and risk foregoing treatment which in reality they urgently need.

Outlook

Our emerging evidence suggests that the *kader* and *posyandu* system in Indonesia is a potentially important node in older people's care networks. It provides health monitoring and communication of health-relevant information, as well as assistance with referral to medical

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[5] In Jakarta and Yogyakarta, the sites most affected by COVID-19, the posyandu lansia have still not resumed, despite the fact that much of social and economic life is back to normal (e.g. weddings, factory work, traditional markets, restaurants). In East Java, the mother-and-child clinics resumed before the clinics aimed at older people and have been halted again since. In the Sumatran site, only mother-and-child clinics are operational, and as noted in the text, on Alor the clinics went age-integrated even before the pandemic.

[6] Anecdotally, the kader in Jakarta commented on a large number of deaths among older clients attributable to problems like heart disease and stroke. They also observed a rise in over-the-counter medication, including for severe headaches, which they cautioned carers against as it may mask serious underlying health problems, like high blood pressure.

[7] In some of our sites, this phenomenon has given rise to a new expression – *dicovidkan* – roughly meaning: made into COVID.

services. Where it is well-embedded, it can extend to broader monitoring of older people's needs and improve the targeting of welfare interventions. The fact that *kader* are recruited and organised in a highly localised way (usually at neighbourhood level) means that they have excellent knowledge of the conditions and needs of their target population. It was striking, for example, that *kader* we interviewed seemed well-informed about who older people's main carers were and which older people live alone.

The weaknesses of the *kader* approach which emerged during the pandemic point to systemic issues in need of addressing if healthcare volunteers are to become a universal and sustainable part of Indonesia's long-term care. Financial resources need allocating to allow *kader* to be better equipped and safer, but also to provide them with recognition and ensure adequate future recruitment of volunteers. This would also signal stronger political commitment to prioritising long-term care. Training of *kader* needs expanding, given their bridging role between older people and informal carers, and the wider Indonesian health and welfare system. It is clear from our evidence that *kader* are regarded as important sources of advice and information, thus developing their knowledge and understanding will have strong multiplier effects. An obvious way to expand their role would be by formally incorporating home-visits and home-care into their remit. At present, those older people who would most benefit from contact with health services are excluded because they are too ill, frail or cognitively impaired to access the integrated health posts. Their informal carers are likewise the ones who would most appreciate guidance and support from trained volunteers.

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