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The Limits of Old-Age Care Provision: Preferences and Practices in Three Indonesian Communities

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Abstract

In rural Indonesia, where state welfare provision remains minimal, a wide range of identities are involved in the provision of material and practical help in old age: they include close and distant kin, neighbours and community institutions. When it comes to personal care, acceptable sources of assistance are fewer, and the choices are more heavily gendered. Using longitudinal qualitative and quantitative data, this paper compares preferences and practices of care provision in situations of ill health or frailty in old age among three ethnic groups in Indonesia (matrilineal Minangkabau, bilateral Javanese and Sundanese). All three groups manifest preferences for care-provision by daughters and spouses, but to varying degrees. They also differ in the extent to which notions of shame and pollution prohibit intimate care by members of the opposite sex and 'non-blood' relatives. Actual practices of care provision are heavily constrained by circumstance: childlessness, migration, conflict or a poor reputation may force reliance on alternative arrangements (e.g. dependence on siblings, neighbours or paid carers), not all of which are compatible with well-being and a positive social identity. By probing into the norms and practices surrounding care provision in different socio-cultural settings, it is possible to arrive at a deeper understanding of notions of kinship, personhood and sociality, and the implications of these notions for vulnerability and security in old age.

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Preferences and Practices in Three Indonesian Communities

Introduction

Indonesia belongs to the world's most rapidly ageing populations (Birg *et al.* 1998; Kinsella and Taeuber 1992). Currently around eight percent of the nation's 230 million people is aged over 60, but this figure is set to increase to 24 percent by 2050 (United Nations 2002). The speed of population ageing and the huge absolute numbers involved, affecting a nation that is still firmly a developing economy, raises important questions about old-age support and care provision. What are the respective roles of family, community, civil society and state in ensuring welfare in old age, and what should they be? Which elders are most vulnerable to a lack of support or care, and what kind of targeted policies are needed to protect them without undermining future economic growth?

To date, formal old-age provision in Indonesia is minimal. There are virtually no state-run old people's homes, the few nursing homes that exist tending to be in private or religious hands. Only former civil servants and members of the armed forces receive a (generous) state pension, while formal sector workers are covered by a compulsory savings scheme which affords only minimal protection after retirement (Asher 1998; Gough 2001; Ramesh 2000; Tambunan and Purwoko 2002). Together, these account for about 10% of the elderly population. Following the economic crisis of 1997, the Indonesian government implemented a number of social assistance programmes, such as health, education and rice subsidies. Many older people have benefited from these schemes on account of being heavily concentrated among the poor, but in fact only a fraction of people's material needs are covered by these subsidies (Schröder-Butterfill 2006b). Draft versions of the new National Social Security bill, passed in 2004, anticipated the development of a comprehensive social protection packet for *all* Indonesians, including health insurance and old-age pension for formal and informal sector workers (Arifianto 2004; Lloyd-Sherlock and Schröder-Butterfill 2004; Task Force for Social Security Reform 2003). In the end critics highlighting the fiscal and administrative burdens created by such an ambitious scheme won the day, and the bill eventually passed was considerably watered down. The outlook for the future remains sobering: the vast majority of older people in Indonesia today, as well as in the foreseeable future, will have to remain reliant on their own and their informal networks' resources for old age support and care.

Research on old-age support arrangements in rural Asia is a rapidly growing field of enquiry. It has on the whole confirmed the importance and resilience of informal networks for older people's security. Once older people no longer work themselves, they tend to rely on a wide range of identities for material support. Children are often the most important sources of support (Biddlecom *et al.* 2003; Keasberry 2002; Knodel and Debavalya 1997), and contrary to widespread fears, children's migration away from their

parents' communities does not, on the whole, result in parents' abandonment and neglect (Frankenberg and Kuhn 2004; Knodel and Saengtienchai 2005; Kreager 2006). However, even where children exist, and much more so in the cases of childless and *de facto* childless elders, *material* support also stems from relatives outside of the nuclear family (such as nephews, nieces, siblings and grandchildren), and from neighbours, friends, and religious and secular community institutions (Agree *et al.* 2005; de Jong *et al.* 2005; Indrizal 2004; Marianti 2004; Schröder-Butterfill and Kreager 2005). Coresident and nearby network members, including especially spouses, children, grandchildren, siblings and neighbours, are important where *practical* help with instrumental tasks of daily living, like shopping, cooking or minor repairs, are concerned (van Eeuwijk 2006).

Much less research to date has investigated *personal care* in old age, that is, assistance to frail or ill elders with basic activities of daily living, such as dressing, feeding, washing, toileting and transferring. It is this domain of intimate, physical and very much hands-on care which is the focus of this paper. Using longitudinal in-depth qualitative and quantitative data collected over five years, we compare preferences and practices of care provision in situations of ill health or frailty among three ethnic groups in Indonesia (matrilineal Minangkabau, bilateral Javanese and Sundanese). To differing degrees the three groups manifest preferences for care-provision by daughters and spouses; they also differ in the extent to which notions of shame and pollution prohibit intimate care by members of the opposite sex and non-blood relatives. Actual practices of care provision are, of course, heavily constrained by circumstance: childlessness, migration, conflict or a poor reputation may force the negotiation of alternative arrangements (e.g. dependence on siblings, neighbours, paid carers), not all of which ensure good quality care and a positive social identity. By probing into the norms and practices surrounding care provision in different socio-cultural settings, it becomes possible to arrive at a better understanding of notions of kinship, personhood and sociality, and the implications of these notions for vulnerability and security in old age.

Existing research on informal caregiving in old age

There are a number of reasons why caregiving remains an under-investigated aspect of old-age support in Asia. Firstly, the numbers of elders requiring care are very low. One estimate for the USA, where life expectancy is much higher than in rural Asia, is that between five and eight percent of community-dwelling adults over age 65 require assistance with at least one basic Activity of Daily Living (ADL) (Wiener and Hanley 1989). Estimates for Asia are much less common, but suggest similarly low prevalences of disability or illness requiring physical care among the elderly population. Keasberry (2001), for example, in her study of almost four hundred elders in rural Yogyakarta (Indonesia), found merely six elders (1.5 percent) requiring help with personal care. The ASEAN ageing survey, conducted in the 1980s, found 4 percent of older Indonesians, 9 percent of Singaporeans and 3 percent of older Thais unable to get around the home without help (Chen and Jones 1989: 82). These figures are likely to exceed those for requiring intimate care tasks, such as bathing, dressing or using the toilet. A study of 170 elderly women and 179 elderly men in rural Bangladesh found slightly higher levels of disability, with 9.4 percent of women and 3.9 percent of men needing help with toileting, 5.3 percent and 1.1 percent, respectively, with dressing and undressing, 1.8% and 2.2%,

respectively, with eating (Kabir *et al.* 2001). Data from our own health survey in three rural communities in Indonesia found between 2 percent and 5.5 percent of the 204 elders surveyed unable to undertake at least some basic ADLs (eating, getting up from bed, washing one's face, bathing or using the toilet) unaided. These figures increased to 6-7 percent among the survivors re-surveyed five years later. Taking this sparse evidence together it is fair to conclude that well under one in ten elders in Asia require intimate, physical care at any given point. That said, many elders experience a period of intense care needs prior to death, with periods typically lasting between several weeks and months. The lifetime incidence of requiring physical care is therefore much higher than the prevalence at any given time.

A second, related reason for our lack of understanding of care-giving practices in old age is the heavy reliance on surveys as a methodology of research. Given the low prevalence of care needs, cross-sectional surveys are unlikely to capture many cases of physically incapacitated elders; this in turn makes it uneconomical to ask follow-up questions about care-provision. Those surveys that do enquire about care-giving at all, tend to produce fairly bland results, such as 'spouse', 'children or children-in-law', 'friend, neighbour or other' (cf. Chen and Jones 1989: 87f.). Panel surveys and surveys focusing on the very old are more likely to detect lifetime incidences of care needs, but such surveys remain rare in Asia. Thirdly, the intimate nature of care provision, and the burden often experienced by long-term carers of frail elders, make it a sensitive subject to investigate. In order to understand the complexity and changeability of care-arrangements, the norms, preferences and negotiations underlying them, and the implications of different solutions for older people's well-being, it is arguably necessary to conduct long-term, in-depth research in a community setting, where issues can be carefully probed into, and people's statements supplemented through observational data. Examples of such ethnographic approaches include Peter van Eeuwijk's (2003; 2006) study of health and long-term care in North Sulawesi (Indonesia), and Odalia Wong's (2005) work on intimate caregiving of elderly people in Hong Kong.

The European and North American literature on care-giving in old age is much more extensive and includes quantitative and qualitative studies. It is beyond the scope of this paper to provide a review, but a number of points that are salient for our Indonesian material may briefly be made here. The preference among older people to maintain independence in the fulfilment of personal care tasks is a near universal (Arber and Evandrou 1997). Even at considerable levels of disability or frailty people continue to undertake activities like bathing, going to the toilet or dressing independently, while tasks such as shopping, cooking or cleaning are more readily delegated. There are numerous reasons for this, key among them the marginalisation of the bodily in modern society and the close association of bodies with privacy, personal identity and the maintenance of boundaries (Douglas 1966). As Julia Twigg (2006: 122) has put it,

> Personal care involves nakedness, touch and the management of human wastes …. As such it transgresses normal social relations. Indeed personal care can be defined in terms of those things than an adult would normally do for himself or herself: washing, dressing and excreting. However rich we are, these are things that … we do for ourselves, typically alone or in the company of intimates. Personal care thus marks the boundary of the wholly personal and individual in modern life. Having to receive help in such areas transgresses social

> boundaries and undermines one's status as an adult. These things are normally only done for babies, and this fact underwrites the profoundly infantilising tendencies of 'care'.

The surrender of control over bodily care is generally experienced as shameful and disempowering, and the delegation of personal care where it becomes necessary therefore subject to much more tightly circumscribed notions of acceptable versus unacceptable help than is the case with other instrumental care (Wong 2005).

Contrary to widespread stereotypes, even in highly developed welfare states most of the personal care of older people is provided by informal carers (families, friends, neighbours), rather than the state and market (Grundy 2006). That said, however, informal care networks represent only a small subset of people's wider social and support networks (Keating *et al.* 2003). While it is difficult to generalise about the identity of care network members, most research points to the predominance of close kin, especially spouses and children, among them. It has been argued that as people become more heavily dependent and therefore unable to reciprocate support received, ties based on kinship are preferred over ties of friendship, which are normally characterised by balanced exchanges (Fischer *et al.* 1990; Litwak and Szelenyi 1969). Personal care provision is heavily gendered, with carers predominantly, though by no means exclusively, women (wives, daughters, daughters-in-law, nurses etc.) (Abel 1990; Stone *et al.* 1987). Men play an important role as carers where they are the most proximate network member—especially in their capacity as coresident spouse—and where the more 'normative' solution of care by a woman is difficult to achieve (e.g. where daughters are lacking or absent). Compared with care by close kin, care by more distant kin, friends and neighbours is rare (Fischer *et al.* 1990). That said, a number of studies have highlighted the importance of kin, friends and neighbours in care provision, especially among elders without close family support (Barker and Mitteness 1990; Wenger *et al.* 2000). However, the lack of formal and informal authority of non-family carers, and of normative obligation to care, usually mean that non-family caregiving is less reliable and long-term (Fischer *et al.* 1990; Wenger 1990). Elders without children and spouses are therefore significantly more vulnerable to a deficit in informal care provision and much more likely to enter a nursing home (Grundy 2006; Wenger 1997).

Research settings and methods

The material presented in this paper was collected in 1999-2000 and 2004-2005 as part of a comparative, longitudinal research project into older people's support networks in three Indonesian communities.[i] Research combined qualitative and quantitative data collection. Semi-structured and in-depth interviews, life histories, kin mapping and observation served to elucidate older people's long-term contributions to, and reliance on, kin and community networks; the values and preferences governing intergenerational and community relationships; and older people's social, moral and economic standing in the community. Two randomised surveys, conducted towards the end of the two fieldwork periods, collected data on older people's health, health care use and care in illness (N=207), and on household economy and inter-household exchange (N=305).

Research locations were selected to capture some of Indonesia's rich ethnic and cultural diversity, while also focusing on regions in which population ageing is most advanced. Table 1 summarises key characteristics of the three research villages.

Table 1. Characterising the three villages

	Kidul	Citengah	Koto Kayo
District and Province	Malang, East Java	Sumedang, West Java	Tanah Datar, West Sumatra
Main ethnic group	Javanese	Sundanese	Minangkabau
Family system	nuclear and bilateral	nuclear and bilateral	extended and matrilineal
Village population (approx.) [a]	2,000 [c]	1,100	700 [c]
Population aged sixty and over [a]	10.6%	7.3%	18%
Elders' children no longer resident in the village [b]	46%	44%	75%
Households owning rice land [b]	13%	55%	66%
Work force employed in… [b]			
agriculture	15%	65%	43%
trade	25%	12%	38%
civil service	10%	5%	7%
other occupations	50%	18%	12%
Elderly households in receipt of a pension [b]	20%	31%	3%

Sources: [a] household rosters and neighbourhood censuses, 1999-2000; [b] randomised household survey, 2000. *Note*: [c] refers to hamlet we worked in, rather than entire village.

Significant cultural differences exist between the two ethnic groups on Java and that on Sumatra. The Javanese and Sundanese both have nuclear families embedded in bilateral kinship networks. Relatives are traced through male and female lines, and inheritance passed down to sons and daughters. Children are ideally expected to set up independent households sometime after marriage, although parents usually hope that some children remain nearby. The norm of intergenerational independence is less pronounced than in European nuclear family systems. Material or practical incapacity, poverty, widowhood or simple preference quite often result in several generations coresiding, although resources are not necessarily shared in such arrangements.

The Minangkabau of West Sumatra, by contrast, are possibly the world's largest matrilineal population (Sanday 2002; van Reenen 1996). Descent is traced through the female line, and property held by the women occupying a common ancestral home (*rumah gadang*). Houses have traditionally been large and accommodated married sisters and their children. Men, when in the village, divide their time between their sisters' and their spouse's home, but spend most of the year away on labour migration (*rantau*). In the case of Koto Kayo, the majority of working-age men are engaged in cloth trade,

which takes them to distant parts of Sumatra, major cities on Java (especially Jakarta and Bandung), and even as far afield as Malaysia (Indrizal 2004). In recent decades more and more women have also become engaged in labour migration. The net effect is that more than 60 percent of elderly respondents' children are living away from the community, and among the wealthy the figure is as high as 90 percent (Kreager 2006: 46). Most elderly Minangkabau parents hope that at least one adult daughter will remain living with them in the village, although the force of migration is such that for many this hope is vain. As we shall see, this is a common reason why preferred care arrangements are not achieved, and compromises have to be made.

The three communities also differ in religious terms: Citengah (West Java) and Koto Kayo (Sumatra) are both 100% Muslim, with Islam playing an especially important role in the latter. Kidul (East Java) has Hindu (10%) and Christian (2%) minorities, with Hinduism quite a major force until the late 1980s. Variants are also found among followers of Islam in Kidul, with many villagers combining Islamic and traditional Javanese mystical practices, others adhering to a 'purer', more modernist interpretation of the faith, and a small minority professing a fundamentalist reading of Islam (cf. Beatty 1999). These distinctions are also present, in less pronounced form, in Citengah.

Not surprisingly, these cultural and religious differences give rise to differences not only in people's preferences concerning care provision in old age, but also in actualised care arrangements. Let us examine preferences first, before investigating the degree to which these preferences are enacted.

Intimate care provision in Indonesia: preferences

In the little research into old-age care that exists in Indonesia, people's preferences are often glossed as a desire to rely on 'children', or more specifically, on daughters. Given the almost stereotypical emphasis in academic and public discourse on family support, and the close association of women with domestic tasks, such as cooking, cleaning and caring, such generalised statements of preference are rarely questioned or unpacked. However, familiarity with different communities and sensitivity to heterogeneity within communities quickly points to subtle but important distinctions. Our aim in this paper is therefore to question whether reliance on daughters is as universal as it is sometimes portrayed, whether several acceptable solutions might coexist, and what alternatives exist for those who don't have access to the normatively preferred solution.

A first glimpse of differences between communities is obtained by comparing the answers which middle-aged survey respondents gave to the question: *If later you are ill in old age, who do you hope will care for you?*

Table 2: Middle-aged people's expectations about future source of care in illness in old age (percentages)

	Kidul	Citengah	Koto Kayo
Self / spouse	6.0	0	0
Any child / all children	34.3	23.8	6.5
Specific child: daughter	26.9	71.4	59.7
Specific child: son	6.0	0	0
Other relative	1.5	0	3.2
Don't know	25.4	4.8	30.6
N=	68	63	62

Source: Household survey 2005. Note: Responses grouped under 'any child / all children' include those who just vaguely indicated 'child or children', those who said they hoped for help from all children, and those who said from their only child.

Without a doubt, all three communities identify daughters (as opposed to sons) as preferred sources of physical care, but the strength of that preference differs across the communities. Koto Kayo, the matrilineal village, in fact displays the most extreme degree of daughter preference, because alternatives are very largely muted. (Almost all of the one third of respondents indicating ignorance about future care do not yet have a daughter.) In the West Javanese village, Citengah, daughters are again very clearly preferred, but almost one quarter allow for the possibility that an unspecified child, or several children, may provide care. In East Java, the picture is much more diverse than in the other two communities. The expectation that it is necessarily a daughter who will care is much weaker, with one third merely indicating that they hope 'a child' or 'all children' will care. Reliance on a spouse or a son is indicated as a preference by some. Unlike in Koto Kayo, where lack of a daughter prompts uncertainty about future care, the large proportion who are unsure about future care in Kidul include many who have children (including daughters), yet don't automatically presume to rely on them.

Of course asking about future, hypothetical preferences has limitations for interpretation. We therefore now turn to older people's observations about appropriate and inappropriate caregiving in more detail.

Care preferences and practices in Koto Kayo, West Sumatra

Older people in Koto Kayo, when asked about who they wanted to care for them when ill or frail, almost universally indicate a preference for care by a daughter. This response dovetails with the Minangkabau's matrilineal kinship system, notably with the centrality of women for the continuity of the matriline and its property, and with women's traditional association with the village (as opposed to the 'beyond village', or *rantau*) and with the domestic (epitomised in their being described as the 'central pillars' of the ancestral home, or *rumah gadang*) (Indrizal 2004; van Reenen 1996). This seemingly straightforward preference only begins to change shape when intimate care arrangements

are examined in more detail, or when several competing options present themselves. These options differ for elderly men and women.

Older women's preferences and options concerning care in Koto Kayo

For elderly women care by a daughter is traditionally assured via the practice of extended family living within one *rumah gadang*, which often meant women had not one, but several daughters nearby. Nowadays with migration affecting daughters almost as much as sons, merely half of elderly women live with a daughter. Those whose daughters are all away (32%) and those who lack daughters altogether (9%) are forced to negotiate less preferred care options. The following two cases illustrate better and worse alternatives.

Case Study 1: In 2000 Darminah was living alone. All of her nine children, including her two daughters, were on labour migration. They often returned for visits, and once a year Darminah would visit her daughters in their migration sites. These visits never lasted long; soon the urge to return to the village, where she was overseeing the family's rice lands and looking after the ancestral home, would overpower her. Repeatedly Darminah pleaded with one of her daughters to return to Koto Kayo, but the daughter was unable to leave her well-paid job in Padang (three hours away). Over the next few years Darminah became senile and frail. Her daughter, aware of her obligation towards her mother, invited her to live with her in Padang, but Darminah wished to remain in Koto Kayo. A son therefore returned to the village (where his wife was already living), and together the couple provided food and practical care. When her health deteriorated to the point of needing physical care, this solution was no longer tenable, and Darminah was taken to her daughter's. There she is being cared for by her daughter and her daughter's paid help, with her son visiting regularly to keep an eye on her when the daughter is out at work.

Case Study 2: Fatimah has no daughters, only sons. In 2000 she was living in her large ancestral house together with her widowed brother, a great-niece plus family, and a more distant matrilineal relative plus family. She enjoyed a close, mutually supportive relationship with the great-niece, caring for her young children in exchange for cooked food and practical help. Her sons provided regular material support. Five years on her health is very poor, and she can no longer look after herself. Her great-niece has moved away and her brother died, leaving her only with the distant relative in the same house. For Fatimah there is now no good solution to her growing care needs. She is reluctant to depend on her relative, as the kinship link is distant, and normative obligations are therefore quite weak. Moving in with her sons is not an option: it simply never is for the matrilineal Minangkabau. She could be cared for by her daughter-in-law, but reliance on affines is considered inferior, because they belong to a different matriline. In this particular case, relations with the daughter-in-law are also very poor.

The strength of daughters' commitment to their elderly mothers in Minangkabau culture is such that we encountered no case where a daughter did not gladly provide care when the need arose. However, as the case of Darminah showed, increasingly this care is conditional on the mother moving in with a daughter away from the village. Elderly women's reluctance to do so is not trivial: leaving the village without having ensured the matriline's local continuity by passing responsibility for house and lands on to a daughter instils a sense of failure and uncertainty about the long-term future of the matriline. For Fatimah the demise of her immediate matriline is already realised, as she has no daughters. Her great-niece provided an acceptable source of care and one that, according to Minangkabau custom, is certainly preferable to reliance on a son and daughter-in-law. That great-niece's departure leaves her highly vulnerable. While it is very likely that her coresident relative will care for her, dependence on such a distant relative will entail shame and loss of status on Fatimah's part.

Older men's preferences and options concerning care in Koto Kayo

Closer examination of men's structural position within Minangkabau matrilineal society, along with consideration of local Islamic concepts of pollution, quickly reveal that elderly men's apparent preference for care by a daughter is in fact tightly circumscribed by norms and demographic contingencies. As noted above, a Minangkabau man is merely an 'honoured guest' in the house his wife and daughters live in. Primary authority in that house rests with the wife and her brothers, while the man himself occupies a position of authority in his *sisters'* house and vis-à-vis their children. Should a man's wife pre-decease him, or worse, should the couple divorce, then his foothold in his daughter's house is severely weakened; after all, she belongs to a different lineage. While daughters will generally urge their widowed father to remain living with them (unless relations are very poor), the man will often feel awkward (*sungkan*) in the presence of his son-in-law. These feelings, and the avoidance behaviour they give rise to, are so deep-seated in Minangkabau culture that they quite often result in an elderly man's return to his own ancestral home (*rumah gadang*).

Case Study 3: Isnari spent most of his life away on *rantau*, but returned to Koto Kayo in old age. He moved in with his wife and only daughter and established a good name for himself as a religious teacher. His three sons were all away on labour migration. After his wife died, Isnari developed signs of stress and ill temper, conditions often ascribed to men's ambiguous position in their wife's home after her death. He often rowed with his daughter, and soon decided to return to his ancestral home, which was occupied by a cousin and her family. This cousin henceforth cooked, cleaned and washed for Isnari, while he continued receiving visits and material support from his children. However, not long after, he experienced a severe stroke leaving him unable to walk or talk.

The case of Isnari illustrates clearly that men's preference to be cared for by a daughter may be overridden by the tension, inherent in the Minangkabau kinship system, between men and their affinal relatives. Reliance on relatives from a man's own matriline may then seem more acceptable, especially if the kin bond is close. We observed several cases where elderly men lived with, and relied for instrumental support, on a sister. An alternative solution is remarriage to a younger woman, and there were several such cases in Koto Kayo. This has the advantage of securing domestic, intimate and sometimes economic support and companionship, but carries the risk of alienating children and the wider kinship group (Indrizal 2004; Indrizal *et al.* in press).

Isnari's illness, leaving him in need of intense, physical care, revealed a further limitation on daughters' ability to care for their elderly fathers, which tends to be glossed over when people talk about 'care' provision. In fact, when men talk of wanting to be cared for by a daughter, what they mean is care in terms of food preparation, housekeeping, laundry, assistance with walking and, if necessary, feeding. Any acts of intimate care involving the exposure or touching of a person's private parts by a person of the opposite sex (spouses excluded) are strictly taboo among the Minangkabau. Such acts fall under the Islamic definition of being *haram* (forbidden, polluting, sinful). (The eating of pork or drinking of alcohol are other examples of *haram* acts.) A similar taboo against transgender intimate care, related to notions of incest and sexuality, was observed by Wong (2005) in Hong Kong. In her study respondents did occasionally provide transgender care to elderly parents, but the act was experienced as deeply embarrassing and problematic (see also Barker and Mitteness (1990). In Koto Kayo the taboo means

that elderly men, even if they live with daughters or female matrilineal kin, need to look to male relatives (preferably a son, brother or nephew) for intimate care.

Case Study 3 (continued): With all of Isnari's sons living away from Koto Kayo, an alternative carer had to be found. The cousin's husband was unwilling, not only did he have to work, but he felt too awkward (*sungkan*). In the end a distant relative of Isnari's deceased wife and an unrelated man took on the task, for which they were paid. They bathed, dressed and accompanied him to the toilet, while the cousin continued to cook and feed him. The cousin's son, of school age, also sometimes helped with bathing. When his health deteriorated further, Isnari was admitted to hospital, where his intimate care was continued to be provided by his two carers. Even hospital nurses in West Sumatra feel uncomfortable at providing transgender intimate care, and gladly delegate the tasks to a family member. The fact that Isnari's family ended up paying someone for his care was kept a secret in the village: admitting to it would have brought shame (*malu*) and disgrace (*aib*) on the family for failing in its duty.

The preceding discussion has revealed that older men's preferences for care provision may in fact be made unattainable as a result of cultural avoidance prescriptions, conflict or the sheer lack of daughters. Moreover, when it comes to actual intimate care, reliance on a daughter is anything but preferred, as such care would transgress Islamic notions of proper moral conduct. Recourse to a spouse or a male relative then becomes imperative. It is likely that wealthy Minangkabau will increasingly fall back on paid help for care provision, especially where outmigration makes the preferred solution of care by a son or nephew impossible. Use of paid help for domestic and care tasks is already fairly widespread and acceptable in the cities, to which many younger people from Koto Kayo have migrated (cf. van Eeuwijk 2006). However, at present this 'solution' is still considered deeply shaming in the village context, and knowledge of it would result in a family's loss of face. Therefore the few villagers relying on paid help choose either to keep the payment a secret, or present it as 'kin care' by stressing a kin link which is either non-existent or very distant. As we shall now see, such attempts at normalising care solutions that are not considered entirely proper are also found on Java.

Care preferences and practices on Java

A striking discontinuity between Sumatra and Java to emerge in the course of our research is older people's very different attitudes to dependence. While physical incapacity and dependence are never welcome, older Minangkabau readily adjusted to material and practical reliance on others, and indeed took great pride in their ability to depend on children and other young kin for support. Such reconciliation with dependence is rarely found on Java: older people voiced strong preferences for independence in later life, be that material independence (through continued work or income from land or pensions), residential independence (living alone or just with a spouse) or practical independence (continuing to undertake domestic tasks, or contribute to the running of a shared household). The Javanese and Sundanese display keen awareness of imbalances in their social relationships, and this includes sensitivity to imbalances in status, wealth or participation in exchange (Geertz 1960; Geertz 1961; Schröder-Butterfill 2002). People quickly admit to feeling awkward (*sungkan*) in the presence of status superiors, and similarly feel uncomfortable in relationships in which at least some element of reciprocity is not maintained. Dependence is therefore always experienced as undermining of social relationships and status. Several dependent elderly people sadly summed up their social

roles as: “I can’t work, I can still eat, I only sit and keep my mouth shut (*diam saja*).” The disposition of wishing to avoid dependence and situations of imbalance has implications for elders’ preferences for care provision, for how they experience situations of physical dependence, and for their status and identity once such dependence arises.

As Table 2, above, already indicated, there appears on Java (especially in East Java) to be greater flexibility in people’s evaluation of what are suitable care providers in old age than is the case on Sumatra. For men, reliance on a wife or a daughter is clearly preferred, while women often state a preference for care by a daughter. However, for both men and women care by a daughter-in-law, granddaughter, adopted child or even son is acceptable and sometimes even preferred, especially if a daughter is not locally available or relations are not good. Affinal relatives are usually considered much more distant than blood relatives (Geertz 1961), and villagers often express feeling slightly uncomfortable vis-à-vis in-laws. One rich elderly widower, who has six sons and one daughter, explained his decision to live with his only daughter after his wife’s death with the comment: “With a daughter [as opposed to a daughter-in-law] I need not feel like a stranger (*asing*), nor reluctant (*sungkan*) to ask her to do my laundry or cook my favourite food.” However, the sense of strangeness and distance vis-à-vis an in-law is often overcome by long association and interaction, especially in situations of coresidence, and several elders emphasised the excellent relationship they have with a son or daughter-in-law. Significantly, although transgender care is not considered ideal (except between husbands and wives), it nonetheless occurs and is dealt with pragmatically when circumstances make it the best or only option available.[ii] Table 3 summarises elderly health survey respondents’ answers to the question: “Who cares for you when you are ill?”

Table 3: Identity of care provider to elder in illness, by gender of elder (Kidul only)[iii]

	Men	Female
Self	0	17.1
Spouse	61.5	0
Daughter	26.9	36.6
Son (and daughter-in-law)	0	12.2
Just daughter-in-law	0	9.8
Child (unspecified)	0	4.9
Granddaughter	0	9.8
Other	11.5	9.8
N=	26	41

Source: Health Survey 2005. *Notes*: ‘Son’ occasionally referred to only the son (e.g. where the caregiving son was unmarried), but more often included the son and his wife. ‘Other’ includes siblings, neighbours or distant kin. Care in the context of this table might include quite light caring tasks during an elder’s illness, as many of the respondents had not experienced serious illness.

For elderly men, where there is a wife (and often there is), she is by default the predominant carer. Indeed, in Citengah, our West Javanese village, a wife's role for ensuring men's domestic comfort and care in illness is recognised as so important that remarriage, even in old age, is not uncommon. Only if there is no wife do daughters emerge as caregivers. (In a small number of cases, coresident daughters assist their mothers in caring for their sick fathers.) The one-in-ten older men and women indicating reliance on 'others' are spouseless and childless.[iv] Some of their care arrangements will be discussed below. Women's carer profile is much more varied. Many are still able (or forced) to look after themselves in illness. Care by a daughter is most common, but granddaughters, sons, and daughters-in-law also feature prominently.

It is important to note that the picture emerging from Table 3 significantly understates older people's supportive networks in Java. The range of identities providing material (food, money, medication), practical and emotional help to elders is typically broad, and includes sons *and* daughters, grandchildren, siblings, nephews and nieces, neighbours and community institutions. Thus, as has been observed for Europe and North America, care-provision in illness or frailty is the outcome of a narrowing of elders' supportive networks as care needs arise or intensify (Keating *et al.* 2003). The following case study illustrates this.

Case Study 4: When we first met Pipah she was living with her married son, daughter-in-law and two grandchildren. Her two married daughters lived close by, and a further married son lived in a village not far from Kidul. Pipah suffered from bad rheumatism and was no longer able to work or undertake significant housework. However, she still managed to get about and often visited her sister and daughters in the same neighbourhood. In 2001 her son and his family decided to move to his wife's natal village, and Pipah was left living alone. Her two daughters, who had provided minimal help until then, took it in turns to take her a plateful of cooked food twice a day. Both sons visited, and especially the son who had previously coresided regularly gave Pipah money. By 2004 Pipah's rheumatism had deteriorated to the point that she was no longer able to walk any distance. An earlier experiment of having her live with one of her daughters had failed, as she couldn't get on with the young grandchildren. The four children therefore got together and built a one-room extension to her elder daughter's house. This allowed Pipah to see her daughters and sister, but gave her some privacy and independence. The two daughters continued to take it in turn to provide food, while her son paid for her medical care. Her sister and sister's children often visited and kept her company. On our return to the village in 2005 to conduct the follow-up health survey, we were prevented from meeting Pipah. Her daughter was adamant that we would be unable to stand the smell in Pipah's room and she was clearly ashamed at the thought of our seeing her in her present state, even just to say hello. In conversation with Pipah's daughter it emerged that Pipah had been bed-bound for the past few months. Both daughters shared preparing special, easily digestible food for her and fed her whenever she was too weak to eat herself. A special commode had been built for Pipah, but often she simply peed in bed. Every two days the two daughters together carried her to the bathroom and bathed her. The sons continued to visit, but their role was now much diminished.

Pipah's case portrays fairly typical support network dynamics as more intensive physical care needs arise. The circle of active kin narrows, becomes more heavily gendered and more strongly biased towards proximate and close kin (cf. Szinovacz and Davey 2007; Wenger 1990). Pipah's family's response to her changing needs is exemplary in that all children continue to play at least some part in looking after her.[v] In many other cases of frail elders the division of labour became extremely uneven once intensive care needs arose. Caring then fell almost exclusively on the shoulders of a coresident female relative, typically a daughter, with other children and relatives fading into the background

(cf. Schröder-Butterfill 2006a; Silverman and Huelsman 1990; van Eeuwijk 2006). One daughter complained that since her coresident mother had become bed-bound, her siblings hardly even visited, let alone offered to help. They apparently found the smell emanating from the elderly woman too offensive, and were frustrated if she didn't recognise them. As a result of the extreme burden of caring single-handedly for her mother, the daughter had become quite depressed and apathetic. The mother's quality of care had also become very low. Her clothes were dirty, she had no access to health care, she apparently often missed meals ("if I forget to feed her, she never complains") and was locked into her room whenever the daughter had to go out. These observations of declining care quality and caregiver burden echo the findings by van Eeuwijk in North Sulawesi:

> "Older people who suffer from persistent chronic illness or multiple health disorders are likely … to be vulnerable to either diminishing or increasingly inadequate support … This is because there is a tendency for care-givers to reduce their care effort with the increasing deterioration of the health of the elderly sufferer, which in turn is often a function of the duration of the illness and the growing physical, economic, social and psychological burdens. [Our data] reveal that it is the number of care-givers who are engaged in … taking care of an ill elderly person, rather than the quantity or quality of the care that individuals provide, which diminishes with the increasing severity and duration of chronic illness … The fewer the support givers, the less comprehensive is the care provided, and the heavier are the burdens for the remaining care-giver(s). This 'constriction of care' occurs as the frail care-recipients grow ever more dependent on their care-givers" (van Eeuwijk 2006: 76).

Caregiving arrangements where preferred carers are lacking

We found in Koto Kayo that elders sometimes failed to achieve their preferred care arrangements, either as a result of demographic forces (outmigration, lacking a daughter, divorce), or due to tensions inherent in the local kinship system. Similar constraints operate on Java and can make the negotiation of care in old age highly uncertain. Childlessness and very small family sizes are a particular problem in Kidul, where one quarter of elderly people have no surviving children (although some have adopted children instead).[vi] The comparative figure for Citengah is seven percent. Outmigration further diminishes people's pool of local kin. Among elders with children, 20 percent had no daughter locally in Citengah, and in Kidul it was as many as 47 percent. Elders lacking children altogether, and those without children nearby, are forced to seek alternative sources of care in illness, not all of which are equally good.

Case Study 5: Haji Lina's three marriages remained childless, but with her third husband she succeeded in adopting two sons and a daughter. However, by the time she was old and going blind, one son had died and her daughter had established a successful career in a nearby town, leaving only a married son close by. Unwilling to rely on a daughter-in-law, she used her wealth to extend her house and offered the extension to her granddaughter in exchange for looking after her. She normalised what was essentially a contractual relationship by henceforth referring to her granddaughter as adopted daughter. That way less attention was drawn to the fact that Lina, a woman of immense standing, was not being cared for by her daughter, as ought to happen. The granddaughter spent the following few years caring for her increasingly frail grandmother. The last few months, following a stroke, she had to be fed, washed, bathed and turned. The granddaughter was her primary carer, although Lina's son spent hours with her, especially at night when she couldn't sleep, and her daughter-in-law and nephew's wife helped with the

bathing. Lina's daughter occasionally visited, but on account of the smell merely talked to her mother from the doorway.

According to the Javanese and Sundanese bilateral kinship systems, there are fairly minimal obligations for support and care among kin beyond the immediate family (spouses, children, siblings). In this they differ from the Minangkabau, where the logic of matrilineal extended kinship is such that people may, at least in theory, legitimately look to ever more distant circles of matrilineal kin for assistance (Indrizal 2004). On Java, nephews, nieces, grandchildren etc. will not automatically step in if closer kin are lacking. Instead, close, supportive relations with a particular relative have to be built up over time, with kinship merely providing the 'raw material' from which such bonds may be forged. This is clear in Lina's case, as it is neither *all* of her grandchildren, nor '*any old'* grandchild who cares for her, but instead a particular granddaughter with whom Lina has established reciprocal relations.[vii]

Lina is fortunate in that she has wealth, status and an adoptive family to compensate for the poor cards demography dealt her. For elderly people without any children or spouse, there are very few options for acceptable, reliable and dignified care. Not surprisingly, those of our respondents who lacked an obvious source of care often vehemently refused even to discuss the eventuality of ill health. As one woman put it, "It's best not to even think about it! I pray that I will die quickly!" The severe vulnerability of 'familyless' elders is in part due to the fact that kin and neighbours, who are often happy to provide the odd bit of money or plateful of food, as a rule draw the line at providing intimate care. Siblings are typically the exception, but of course sibling ties are biologically close and culturally highly valued throughout much of Southeast Asia (Banks 1983; Carsten 1997; Jay 1969). We found several cases of elderly siblings living together, and encountered an extremely moving example in which a stroke-paralysed elderly childless widower was cared for over several years by his sister, who undertook even the most intimate care tasks on her brother.

The final case study provides a sobering illustration of the limits of informal caregiving where close family members are lacking and where there is no alternative, formal safety net in place.

Case Study 6: Lubis, in his early 80s in 1999, had no children of his own, but his first wife had two children whom he helped raise. He later married a divorcée with two daughters, and with his wife helped bring up two boys belonging to a neighbour. None of the step- and 'raised' children lived locally nor provided much support. The elderly couple lived on their own in considerable poverty. In 2002, Lubis's wife decided to leave him and go and live with her daughter, several hours away. Lubis subsequently lived on his own, relying for daily food on a neighbour and a local affinal nephew (Lubis's first wife's sister's son) called Rusmin. Not long after, Lubis fell and became bed-bound. A step-daughter (via the first wife) once visited and sent money to compensate Rusmin and the neighbour for their troubles, but soon the money dried up. Rusmin quickly tired of caring for the old man, who often needed cleaning up after soiling himself. He also claimed Lubis made inappropriate sexual advances towards the neighbour when she bathed him. Rusmin decided that it was the turn of Lubis's only remaining blood relatives to do their bit. Under a pretext he lured Lubis into a car and took him to the nearby town, where a great-nephew was living. He was the heir to Lubis's house, and as Rusmin bluntly put it: "He who has the right to inherit also has the right to care!" When Lubis realised what was happening he put up a tearful protest but to no avail. He only survived a few months on the floor of his great-nephew's house. His wish of being buried in Kidul was not respected.

Intimate caregiving is rarely a pleasant task. Close family members will nonetheless usually provide it, be it out of obligation, affection, reciprocity or guilt. More distant kin and neighbours are typically not bound by a strong sense of duty or necessarily even fondness, and once an exchange relationship becomes heavily imbalanced by the overdependence of one party on the other, the commitment to care can quickly dissolve. The result can be sequential shifts in the identity of carers, as the 'caring capacity' (to use Keating *et al*'s term) of network members is quickly exhausted, and can ultimately lead to the breakdown of a person's care arrangement and their untimely, degrading death. Lubis's case is dramatic, but it is not unique. We encountered several cases where affinal kin or neighbours refused to provide intimate care and instead forcibly delegated responsibility to the person they considered the more 'appropriate' carer—typically the closest blood relative—even if that person had no history of a positive or meaningful relationship with the elder (cf. Marianti 2004). In other cases affines or 'created kin' were quite happy to care on account of enjoying a close relationship with the elder, but more influential blood relatives stepped in to take over, supposedly out of concern for the relative, but more likely out of concern for their reputations.

The unravelling of care arrangements of poor, childless elderly people illustrates two important points. The first concerns Javanese people's perceptions of the boundaries of kinship and therefore belonging. Although much emphasis is placed on the potential of creating kin through adoption or marriage (Carsten 1991), when it comes to the bodily domains of caring and feeding, blood relations matter more. This is mirrored both in elderly parents' preference for care by a daughter, rather than daughter-in-law, and in people's assignment of care duties on behalf of a frail elder to blood kin, rather than neighbours, friends or created kin. The second point concerns the social identity and status of physically dependent elders. Lubis's forcible removal from Kidul is merely an extreme manifestation of the profound disempowerment, infantilisation and exclusion which frail elders experience. Just as Julia Twigg observed for elderly Britons requiring care, in Java, too, a person's need for help with simple bodily functions undermines their status as a complete social being. Less overtly violent examples of the stripping away of frail persons' social integrity and respect are gossiping about their smell, their bodily functions or their senility; talking on their behalf, rather than allowing them a voice; and excluding them, for example by keeping them hidden away, ceasing to consult them or to consider them worthy of a visit.

Conclusions

This paper has examined the care preferences and practices of older men and women in three different rural communities in Indonesia. The aims were to analyse people's preferences concerning appropriate sources of care in the light of their own understandings of kinship, morality and personhood, to identify the range of acceptable care arrangements around the general norm of 'daughter preference', to examine the constraints operating on people's attainment of preferred practices, and the implications for their quality of care and social identity of failures to remain within the local norms.

Our research confirmed the strongly gendered nature of care provision found by other researchers in Asia, Europe and North America, and the general preference for care by a daughter or a spouse. However, the extent of daughter preference differed between

different communities and kinship systems, and in all three communities socially acceptable alternatives to care by a daughter existed and were enacted. Moreover, we showed that the norm of 'daughter preference' glosses over important contexts in which care by a daughter is in fact prohibited by religious norms or made difficult by cultural constraints. Indeed, the force of gender-specific cultural and religious taboos in Minangkabau culture is such that elderly men are much more vulnerable to care failures or unacceptable care arrangements than are elderly women.

On Java, prohibitions against transgender care are much more muted and the kinship system more flexible in its range of acceptable care-givers. However, this flexibility masks a lack of social obligations to support and care provision beyond the immediate family, which means elders without close family have to invest in social relationships early on if they are to enjoy a secure and respected end of life. This is because especially in the domain of intimate care provision the range of identities willing to take on and sustain such care is narrow and tends to constrict further over time. Outside of the more neutral arena of material support provision, where actors include distant and close kin, friends and neighbours, community institutions and the state, we found a much greater emphasis on kinship in the drawing of boundaries between acceptable and unacceptable care. Distinctions are then made not only between kin and non-kin, but also between blood kin and affines.

Concepts of shame, reputation, and morality guide intimate care provision much more than other forms of old-age support. Notions of pollution, sexual propriety, shame and avoidance shape who can and can't provide care to a particular person. Likewise, the fear of disgrace befalling families for failing to provide appropriate care motivates the negotiation of (outwardly) socially acceptable solutions, even if this negotiation involves dissimulation and the concealment of neglect. Care provision to frail elders may therefore be interpreted as an important mark of a family's reputation and solidarity. Reputations are threatened when the 'right sort' of carer cannot be found, while families gain in respect when members appear to cooperate harmoniously in the division of labour at the end of a person's life. In reality, the quality of care provision often declines steeply with the length of an elderly person's dependence and the increasing concentration of the burden of care on one or two carers.

The loss of social identity, autonomy and respect which we found to accompany physical decline on Java is striking and confirms the centrality of independence and mutuality in people's understanding of social personhood. The extent to which the apparent lack of ostracism and social exclusion of frail elders in Minangkabau culture is genuine and related to a greater tolerance in general of dependence and imbalance in kinship relationships in that culture, will require further investigation.

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[i] The research project, *Ageing in Indonesia 1999-2007*, was directed by Philip Kreager at Oxford University and was a collaboration with *Universitas Indonesia* and *Universitas Andalas* in Indonesia. The authors are grateful to the Wellcome Trust and the British Academy for the generous support of this research, and to Philip Kreager, Edi Indrizal and Haryono for their contributions to the discussions resulting in this paper.

[ii] A small minority of families in the East Javanese community belong to a fundamentalist Islamic stream (LDII). Members of this group forbid persons of the opposite sex to touch each other—even to shake hands—on account of this being *haram* (forbidden, polluting). Among this group transgender caregiving is of course unimaginable, but other families reported no such prohibition.

[iii] The breakdown of carers by gender has not yet been undertaken for Citengah and Koto Kayo, therefore these data are confined to Kidul.

[iv] Compare van Eeuwijk's (2006: 69) observation: "Other care-giver arrangements included other kin, such as sisters, grandchildren or daughters-in-law, but these were much less frequent, possibly because care support is a very intimate process, and a certain social affinity is a prerequisite for effective and acceptable care."

[v] In similar, positive cases of shared care-giving distant daughters returned to the village to help with the caring, or coresident and non-coresident children took it in turns to help with the bathing of an elderly parent.

[vi] For a detailed account of childlessness and its causes in East Java see Schröder-Butterfill and Kreager (2005).

[vii] A similar case presented itself in Citengah, where a man with four sons and two daughters, one of whom had moved far away, ended up raising a granddaughter in his daughter's stead. In the end it was this granddaughter, rather than the local daughter or daughters-in-law, who cared for the elderly man prior to his death.

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