# Old-age vulnerability, ill-health and care support in urban areas of Indonesia

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#### ABSTRACT

The epidemiological health transition in Indonesia has lead to a substantial ageing of its population and a rapid increase in the prevalence of chronic progressive illnesses in advanced age that, in most cases, require some sort of care. This shift from 'cure' to 'care' necessitates new paradigms in both health-care delivery and research on older people in less-developed countries. Care involves both attitudes and practice, and is a dynamic interaction between giver and recipient. The vulnerability of frail older people is strongly related to the resources, capability and willingness of kin and non-kin to act as care-givers for extended periods. Normative filial piety and kinship obligations are no longer undisputed. This paper reports a study of the care and support received by chronically ill older people in urban areas of North Sulawesi, Indonesia. The majority rely on close family members, most often a wife or a daughter (or both), to provide treatment, care and support. The main care activities are support with 'activities of daily living' and therapies for specific illnesses. Care-givers experience manifold burdens when providing care for frail older people, and tend to reduce their support as the severity and duration of their relative's illness increases. It is shown that an older person's vulnerability to inadequate care provision, or its withdrawal, is associated with marital status and gender (unmarried women and widows being most at risk), poverty, weak support networks, and having caregivers who are themselves vulnerable.

**KEY WORDS** – old-age vulnerability, chronic illness, care and support, caregivers, urban areas, Indonesia.

#### Introduction

For the past two to three decades, most less-developed countries have undergone a rapid and fundamental 'health transition' (Caldwell 1993; Wilkinson 1994). In Indonesia, radical demographic changes have occurred and the population is ageing very quickly (Hugo 2000; Suryadinata, Arifin and Ananta 2003). The epidemiological transition has led to a new general

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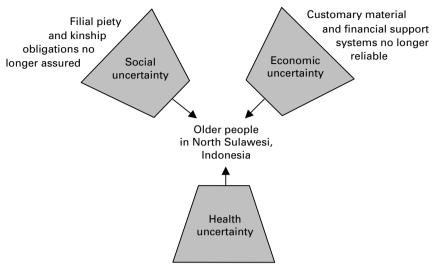
health profile, which has brought about a marked shift in the most prevalent conditions, from acute and infectious diseases to chronic, noninfectious illnesses and injuries (Departemen Kesehatan 2002; Eeuwijk 2003c; Koesoebjono and Sarwono 2003). Urbanisation, along with ruralurban migration, is in full swing and in a few years will lead to a society in which the majority of the citizens live in urban areas (World Health Organisation 1998; Eeuwijk 2003b; Kreager 2006). Moreover, these demographic processes are accompanied by changes in lifestyle and new socio-cultural forms, including altered diets, work patterns, household formations and living arrangements (Eeuwijk 2003a). In contrast to the health transition in Europe and North America during the second half of the 19th century, the dynamics of the 'health transition' in developing societies such as Indonesia manifest two distinct features: unprecedentedly rapid change, and impacts upon an extraordinarily large number of people (Eeuwijk 2004). Furthermore, in Indonesia these changes are occurring in uncertain economic and social contexts, characterised since 1997-98 by severe economic crises, especially in urban areas, and farreaching political transformations (Koesoebjono and Sarwono 2003). The pace of change and the political economic strains raise important questions about the sustainability and adequacy of the existing old-age support arrangements and about the prospects for frail and dependent older people.

# The nature of care and long-term care support

Given the dynamics of the 'health transition' in Indonesia, Hugo (2000:318) drew attention to the growing social and economic instability that faces older people in contemporary Indonesia. The author has summarised the pressures for older people in urban areas of North Sulawesi in a 'triangle of uncertainty' that has social, economic and health dimensions, as in Figure 1 (Eeuwijk 2002: 25, 2004: 124).

## Care

Both formal and informal care schemes for older people in urban areas are strongly influenced by this 'triangle of uncertainty'. In fact, the care of most older people occurs under these insecure conditions. While the resources, capabilities and resilience of older people should not be underestimated, individual resources alone are generally insufficient. Accordingly, Phillips (2000) has identified the care of older people as one of the most urgent problems arising from population ageing in the Asia-Pacific



Increasing vulnerability to chronic non-communicable diseases and degenerative disorders through increased life expectancy, changing life styles and socio-economic conditions

Figure 1. A triangle of uncertainty for older people in urban areas of North Sulawesi.

area, and has warned of 'the potential dangers of over-reliance on informal and family sources' (2000: 5). Helman (2000), a medical anthropologist, concluded that rapid ageing and the increasing number of chronically ill older people 'will require a major shift in the medical paradigm [and] a shift from "cure" to "care" (2000: 8). The main question arising from the triangle of uncertainty is, how can appropriate elder care be provided under circumstances of unreliable social networks, economic constraints, a steady increase in the number of chronically ill older people, and wholly inadequate formal welfare services?

This question implies that care is a complex interplay of different societal dimensions, individual behaviour and structural factors. Niehof described 'care as both attitude and practice', which involves discourse, actions and intentions, and framed care as having four inter-connected phases (Niehof 2002: 181): caring about, that is, assessing the need for care and calling for attention; taking care of, assuming responsibility for meeting the need for care and assigning agency; care-giving, meeting the need for care and having competence to care; and care-receiving, assessing the appropriateness and adequacy of care and calling for responsiveness on the part of the care receiver. Geest saw these phases as 'moving from

awareness and intention to actual practice and response', and argued that care is a 'process that sustains life' and represents 'the moral quality of life' (2002: 8). A society that claims to have a moral standard has the obligation to provide adequate care for its members.

In her 'care arrangements' framework, Niehof identified five levels on which care-giving takes place: the individual, household, community, state and market domains (2002: 184). The household, as the principal locus of care provision in most societies, is the main unit of analysis in her work. Nevertheless, every society manifests its own pattern of care arrangements, which depend on the flow of resources and contributions and on the dominant levels at which care is received and provided. Phillips (2000) took a broader view of what care encompasses, referring not only to health-care needs but also to needs for social care, housing, material welfare and religious wellbeing. This broader approach to care was reflected in Keasberry's (2002) work on the care of older people in a rural area of the province of Yogyakarta, Java.

In Southeast Asia in the past, it was generally kin who took care of older people with severe ill health, physical and mental disabilities that were associated with functional impairments and the need for healthcare and emotional support (Phillips 2000). Most care and support was provided by younger household and kin members, and the majority of care-givers were women (Leung 2000). Filial piety, kinship obligation, responsibility and respect towards older family members were considered integral to and normative for informal, family- and kin-based care arrangements between the generations (Eeuwijk 2003a). The combination of the progressive 'health transition', new family structures and household forms, more women working outside the home and fewer children, means that the capacity to care for frail older people is becoming increasingly circumscribed (Leung 2000). Children's readiness and ability to provide open-ended care is undergoing change (Keasberry 2002). Commenting on the current situation in Indonesia, Kreager (2003: 12) concluded that 'we should not succumb to the cosy assumption that where there are children, they can be counted upon'. Referring to this very issue, Niehof (1995: 434) introduced the term 'negotiation' and noted that, particularly in bilateral kinship systems (i.e. where kinship is traced to relatives through both father and mother), care and support for older people were not and are not automatically assured or reliable: they have to be negotiated and re-negotiated in every case and from time to time. This applies all the more to extended intensive care, where the position, capability and power of the negotiating parties shape the vulnerability of an older person. But as Schröder-Butterfill (2004) and Marianti (2002) have shown for Java, even under bad health and socio-economic conditions, older people do

have care alternatives in the wider environment and many have ample scope as social actors for mobilising resources and capacities (see also Schröder-Butterfill and Marianti 2006). They are not well described as victims of circumstance.

## Long-term care and support

According to the formulation by Phillips and Chan (2002: 3), long-term care incorporates health-care, personal care and social services that are provided at home and in the community over a long period. They describe the recipients of long-term care as adults who lack or have lost the ability fully to care for themselves or to maintain their independence, and emphasise the heterogeneity of older people and the implication that long-term care needs differ greatly and can change abruptly and markedly. Another important point arises from the feminisation of the older population (Eeuwijk 2003a). Many more older women (most of them widows) than older men need long-term care and support (Phillips and Chan 2002). At the same time, it is women who predominate as caregivers, and indeed many older women are *primary* care-givers, many to their husbands. Clearly there is a need for a gender-sensitive approach in long-term care provision and research. As Niehof succinctly concluded (2002: 181), 'the whole [care] process is gendered'.

## The study

This paper is based upon an inter-disciplinary research project that involved four anthropologists and two medical doctors (from Sam Ratulangi University (UNSRAT), Manado, Indonesia, and the University of Basel, Switzerland). It was carried out over three years (2000–03) in three urban areas in the Province of North Sulawesi on the island of Sulawesi, Indonesia (for further details see Eeuwijk 2005).

# Aims and design

The overall aim was to gain a broader and deeper understanding of the processes of 'health transition' by comparing and analysing the perceptions, experiences and individual behaviour of chronically-ill older people in the context of their social environments in urban Indonesia. A key objective was to identify and elaborate the nature of the vulnerability of frail older people, with particular reference to the forms and quality of their care. To do this, the research portrayed the complex interactions between ill elderly people's biological states and clinical requirements with their social, economic, ecological and psychological attributes. The design involved five successive steps:

- 1. Review of the Indonesian literature on older people and ageing in Indonesia, including demographic and health statistics.
- 2. A community study of seven communities in three towns in North Sulawesi.
- 3. A household survey of 50 selected households containing at least one person aged 60 or more years in each of the three towns.<sup>1</sup>
- 4. An age-cohort study of 25 chronically-ill older people in each town, selected from the above household sample.
- 5. A 'tracer illness study', with 14 case studies per town of older people suffering from specific chronic illnesses, selected from the age-cohort sample.<sup>2</sup>

A combination of quantitative research methods (such as biomedical screening and structured questionnaires), qualitative techniques (in-depth interviews, focus group discussions, direct observation, diary keeping, self-reporting, case studies and verbal autopsy inquiry), and documentary instruments (photo and film documentation) were used. More details of the design and methodology are available (Eeuwijk 2002, 2003b, 2005).

# The study area

North Sulawesi Province, one of Indonesia's 30 provinces, had a population of 2.8 million in 2000, and the three study areas have variable ethnic and religious compositions and contrasting levels of urbanism.<sup>3</sup> The first, Manado, is the provincial capital with 388,000 inhabitants who are very diverse in religious affiliation, ethnicity and socio-economic level. The second, Tahuna, is on Sangihe Besar, an island off the northern tip of North Sulawesi. Tahuna is the name of both the administrative district (*kecamatan*) and its capital, which has 29,000 inhabitants, almost all of whom are from the Sangihe and Tidore ethnic groups; the two groups live in segregated areas. The third is Tomohon, a semi-urban *kecamatan* of 74,000 inhabitants, almost all of whom are of the Minahasa ethnic group (Eeuwijk 2003b, 2005).

In 2000, the average life expectancy at birth in North Sulawesi was 68.5 years (higher than the national average of 68.0 years), and around 215,600 individuals, or 7.7 per cent of the population, were aged 60 or more years (compared with 7.6 per cent in Indonesia) (Kantor Statistik 2001; Departemen Kesehatan 2002; Koesoebjono and Sarwono 2003). Within the province, however, there is considerable diversity among the local communities (*kelurahan*). Seven *kelurahan* were selected for the study, and

Tahuna Tomohon Total Manado Need for care No. % No. No. No. % Yes ΤT 16 64 13 52 40 44 53 No 14 56 36 12 48 9 35 47 Sample size 25 25 25 75

T A B L E 1. Number and percentage of households with an elderly person currently in need of treatment, care or support, three urban areas of North Sulawesi, Indonesia

Source: Author's field data, 2000-2002.

their age structures ranged from very 'young', with 2.9 per cent of the population aged 60 or more years, to markedly 'aged', with 13.4 per cent of the population in the older age group.

Over the last decade, the number of old people's homes in North Sulawesi has changed little but there has been an appreciable increase in the number of residents (by 38 per cent in 10 years). In 1990, there were 10 homes with 385 residents, and in 2000, 11 homes with 533 residents (Kantor Statistik 1991, 2001). By 2000, private providers were running eight of the homes, and the government only three. Around 77 per cent of the residents in both 1990 and 2000 were older women. It can be assumed that the absolute number of older women is increasing faster than that of men in North Sulawesi. As in all societies, a certain number of older women can no longer fully rely on their informal care networks. That said, 73 respondents (98%) of the age-cohort survey stated that they would be very reluctant to enter an old people's home. They argued that as long as they had children and a house of their own, they would never move into such an institution of their own accord.

# Older people and care support in urban North Sulawesi

The number of older people in the urban areas of North Sulawesi who currently need some form of care and support is quite high. Of the 75 households with at least one ill older person in our sample, 40 (53%) had at least one elderly member who needed care and support (see Table I). The ill older people in the remaining 35 households did not suffer from chronic illnesses and were not in need of support and care. The indicator of 'need for care and support' is based on the older person's responses as well the household members' accounts. Despite the religious and ethnic heterogeneity of the populations, the differences in care needs among the three urban localities were insignificant. Clearly, elder care

TABLE 2. Types of illness leading to care and support needs among ill elderly people

		Urban are	Total			
Illness	Manado	Tahuna	Tomohon	Number	Per cent	
Eye complaints, impaired vision	8	7	8	23	57	
Rheumatism	4	8	5	17	42	
Gastritis, stomach complaints	2	6	2	IO	25	
Bronchial asthma	4	3	I	8	20	
Hypertension	2	I	4	7	17	
Migraine	2	4	I	7	17	
Post-stroke paralysis	2	3	I	6	15	
Diabetes and obesity	3	3	О	6	15	
Dental problems	I	2	I	4	10	
Physical weakness	I	I	I	3	7	
Chronic cough	0	o	3	3	7	
Other health disorders	3	3	I	7	17	
Sample size	II	16	13	40	,	

*Note*: Multiple answers were possible. *Source*: Author's field data, 2000–2002.

and support is not uncommon in these urban environments. The majority of households have to bear the burden of informal care without the support of or advice from professional care-givers (Abikusno 2002). For the most part, we may conclude, elder care and support take place in the lay realm of the family or household.

# Socio-demographic characteristics of care receivers

The average age of the 40 older people in need of care and support was 69 years, and there were roughly equal numbers of men and women, but three times as many widows as widowers (Eeuwijk 2003b: 331). The respondents' religious and ethnic affiliations reflected the distributions in the respective towns. The respondents were classified into economic sub-groups on the basis of their disposable income: six respondents had no money of their own and were fully dependent on their families or other relatives; 15 had less than about 50,000 Rupiah<sup>4</sup> to spend per week, and 12 had more than 50,000 Rupiah. The seven most advantaged elderly respondents had more than 100,000 Rupiah per week.

# Health profiles

In terms of morbidity, 32 of the 40 respondents suffered from several simultaneous health disorders. The health profile of the respondents with care needs was dominated by progressive chronic illnesses, such as problems with eyesight and rheumatism (see Table 2). Loss of good

eyesight and rheumatic complaints are commonly regarded as 'disturbing', as they impede mobility, agility and autonomy as well as specific activities. They lead to a gradual loss of some key abilities required for coping in an urban environment. With diminished vision and limited mobility, as caused by painful rheumatism or post-stroke paralysis, most 'activities of daily living' (ADL) can no longer be performed properly and independently; increasingly they have to be carried out by others, resulting in dependence and passivity.<sup>5</sup>

Other degenerative illnesses, such as hypertension or diabetes, are less debilitating, but demand a strict care regime, including, for instance, a change in nutrition and drug compliance. Dental problems such as tooth decay or progressive gingivitis demand special food preparation; moreover, such apparently 'minor' impairments lead in many cases to chronic headache and indigestion and gradually to self-imposed social isolation through shame and obvious indisposition (e.g. refraining from eating, talking and singing at festivities). Chronic illnesses and infectious diseases that recur (chronification) are mainly responsible for older people becoming dependent on care support (see Table 2), and for their increasing social and economic dependency. It is important to remember that most older people in the sample had co-morbidity, that is, they were affected by more than one illness. Apart from chronic illnesses, they also regularly suffered from common acute infectious diseases, such as malaria, dengue fever and diarrhoeal diseases.<sup>6</sup>

# Care-giver arrangements

The most common care arrangement in the sample was an older man being cared for by his wife and a child (17 cases). A child alone – in most cases a daughter - took care of an ill older person in 15 households, and a wife alone provided care in 10 cases. Arrangements whereby a husband and (female) child provided care were not uncommon (q cases), but it was extremely rare for husbands to take care of their wife on their own. 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 (see Table 3). Until the present, it has been rare for carers to be non-kin housemaids or paid nurses, although this may become more common among the better-off. In six cases, an elderly sick person had no care-giver, mostly as a result of alienation or deliberate exclusion from their families or through the natural loss of all close kin. These older people in need of care had to cope alone in a situation of social exclusion and were deprived of vitally

TABLE 3. The relationship of co-resident main carer(s) to chronically ill older person

Relation to care receiver	Manado	Tahuna	Tomohon	Total
Wife+child	3	7	7	17
Child alone	7	6	2	15
Wife alone	3	2	5	IO
Husband+child	2	5	2	9
Sister alone	0	2	I	3
Child + grandchild	3	0	0	3
Husband alone	0	0	2	2
Child + daughter-in-law	I	0	I	2
Child+sister	I	0	0	I
Wife + sister	0	I	0	I
Sister-in-law alone	0	0	I	I
Housemaid alone	I	0	0	I
Child + housemaid	I	O	O	I
Grandchild + housemaid	I	0	0	I
Wife + child + grandchild	I	0	0	I
Wife + child + niece	I	0	0	I
No care-giver at all	О	2	4	6
Sample size	25	25	25	75

*Note*: The data refer to all older people interviewed who had ever experienced care and support, as opposed to the smaller subset reported on in the other tables, who are *currently* receiving care. *Source*: Author's field data, 2000–2002.

important medical support. There can be no doubt about their profound vulnerability in old age.

As Table 3 shows, in most households (69%), elder care was provided by a combination of inter- and intra-generational kin members, as by a spouse and a child. Many Minahasa and Sangihe older people upheld the normative *adat* customs, when remarking that until recently children, in line with the expectations of filial piety, bore their care obligations towards their parents on their own, but that today, most older people rely on both their children and an age peer when in need of care and support – some by preference, some through necessity. This means, of course, that healthy older people have increasingly become care-givers for frail people of their own age, most particularly between spouses. One should also note the strongly gendered nature of caring: the majority of the care-givers are wives, daughters or daughters-in-law. Overall, the provision of elder care in urban North Sulawesi is not only a within-household responsibility, but more specifically one that falls to women, be they old or young.

Types of support provided as part of treatment, care and support

Several of the main forms of care and support provided by the care-givers were to do with the internationally recognised Activities of Daily Living

T A B L E 4.	Main activ	ities of car	e and	! support	provided	by	care-givers	in	households
with at least of	one elderly	respondent							

	Manado	Tahuna	Tomohon	Total		
Activity	Number	Number	Number	Number	Per cent	
Washing clothes	37	37	36	110	73	
Administering drugs	39	34	33	106	71	
Preparation of food and drink	45	26	32	103	69	
Consoling and entertaining	46	29	23	98	65	
Massaging	23	26	35	84	56	
Dressing or undressing	24	14	24	62	41	
Accompanying to the toilet	25	16	18	59	39	
Bathing	22	16	20	58	38	
Preparing for bed	19	10	13	42	28	
Sample size	50	50	50	150		

Note: Respondents could give multiple answers.

Source: Author's survey data, 2000-2002.

(ADL), such as dressing, bathing and toileting, and with *Instrumental* Activities of Daily Living (IADL), for instance washing clothes and preparing food and drinks (see Table 4). For older people in need of care, these activities are of great importance because they guarantee hygiene and cleanliness, and sustain bodily vigour. Other aspects of the care and support were directly connected to the actual illness, such as managing medication or providing a massage.8 These may not become routine activities if the condition of a chronically ill elderly person is stable and does not cause concern. Administering medicines is not only crucial for the wellbeing of an ill elderly person, but also an overt manifestation of the moral responsibility of care-givers towards the care recipients. In addition, psychological support, such as consoling and providing activities to pass the time, is regarded as essential. Two-thirds (65%) of the caregivers expressed a willingness to provide emotional and mental assistance, which is of great importance for the perceived 'quality of care' and for social inclusion. Table 4 also shows that the more intimate the activity of daily living (e.g. going to the toilet or bathing), the less frequently an elderly ill person allowed care-givers to assist with the task. The Indonesian understanding of *adat* generates strong gendered precepts about appropriate behaviour, physical proximity and interactions, and these play a large role in determining which activities people prefer to undertake independently. Wherever possible, in Indonesia as elsewhere, older people try to maintain the ability to carry out highly personal activities on their own.

# Care-givers and the burden of care

The great majority of care-givers are willing to provide even intensive, stressful and arduous treatment, care and support for their older kin (Table 4). The general finding is illustrated well by a case study, of Ibu T., a 71 year-old Minahasa widow, who is a Roman Catholic and was hemiplegic at the time of the interview:

Ibu T. had suffered two heart attacks in one year. After the second attack, she was taken to a hospital by her son, but was sent home after only two weeks. After much dispute and a difficult negotiation, her three children decided that the oldest child, a son, would put her up. The right side of her body was completely paralysed, from head to foot. She was unable to speak, eat, control urination or move her body. Having led a very active and independent life, Ibu T. suddenly found herself struck down by illness and deposited on a thin mattress in a dark and stuffy corner of the kitchen in her son's house. Her daughter-in-law took care of her and became accustomed to keeping an eve on her during her daily housework. At first, Ibu T.'s two daughters, her grandchildren, sisters and also neighbours came for short visits and helped out, but after a few weeks, only the daughter-in-law provided the care. It wasn't long before Ibu T. had bedsores, water in her legs and arms, and showed signs of depression. At the same time, her daughter-in-law was physically and mentally fatigued and complained about the lack of support from Ibu T.'s three children. Family life and harmony came under severe and permanent stress. After three months, Ibu T. began to suffer from heavy leg pains and needed 'professional' medication. Her son was unable to afford this, however, because he had lost his job. Ibu T. was in a very sorry state, convulsing with pain and crying all night long, with only her daughter-in-law able to comfort her. A month later, the elderly woman had another minor heart attack. Three-quarters of her body became paralysed and she was left almost blind and dumb. Her condition had deteriorated beyond hope, and it was now merely a matter of time before she died. Her daughter-in-law remained the only person to bring water and rice gruel three times a day and to clean away her excrement in the evening. In immense agony, Ibu T. finally passed away after five months of extreme suffering. The family undeniably felt a sense of relief after this long period of continued stress and tensions.

Not every case of long-term care involves such far-reaching needs as those of the extremely frail Ibu T. Only five of the 40 elderly ill respondents (12%) were such severe long-term cases, and most required assistance with four or five of the activities listed in Table 4. Nevertheless,

many lay care-givers experienced one or more of five types of burden while carrying out elder care in their households. Physical burdens, include the tasks of dressing and undressing, washing and massaging an elderly person, are physically draining and performed alongside a pre-existing daily work routine. Not surprisingly, the fatigue of the mainly female care-givers increases with the length of time during which treatment, care and support are provided. Economic burdens are the financial costs of providing care and support (about which many care-givers complain). These costs may include food (including special foods or nutrition supplements), clothes, medications and rehabilitation tools, and older people's other special consumption needs, like cigarettes. On top of this is the loss of income if a care-giver stays at home to provide care. In some instances, available housing space has to be expanded to accommodate an additional person in the house.

Social burdens include the inter-personal tensions that arise between caregiver and care-recipient, sometimes because of divergent expectations and hopes, and the strains within the care-giver's household, family or wider set of relatives that result from the negotiated distribution of obligations and pattern of care. In some cases, the person in need of care and support may be considered by one or more household members as an 'intruder' and is not accepted, most often where affinal or distant relatives are concerned; we encountered complaints about 'quarrelsome, nit-picking mothers-in-law' and 'eccentric, solitary uncles' whose personal behaviour was not approved by all the household members. Sometimes clashes arise, as between caring and idle children and children-in-law, or between a caring wife and an indolent husband or son. In some instances, relatives exert moral pressure through accusations and rumours, producing extreme social stress for the care-givers.

Psychological burdens arise when care-givers are unable to continue to take care of an elderly relative with rapidly degenerating health, the result being one or more of hopelessness, despair, anger, and a resulting feeling of being unable to cope with the suffering of the elderly person. In addition, other kin may hold the care-giver responsible for the current health condition of the elderly person, creating pressures that make care-givers lose confidence or become mentally exhausted. Infrastructure burdens include restricted housing space, which is common in crowded city environments. When an elderly person needs treatment, care and support, a rearrangement of the housing space is often necessary to give the sick person some privacy and autonomy. Sometimes, modifications have to be made to the house, such as toilet facilities for disabled people, ropes or grab handles, or partitions to create a new room. In short, already scarce urban housing space is further constricted, which can create tensions in the household.

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The lay care-givers in the sample often questioned their *competence* and *capability* to care for a frail older person. Few had received any training on how to carry out the manifold care tasks, particularly those associated with long-term care. Moreover, many of the care needs had arisen suddenly, which allowed no time for preparation by any of those involved. Many care-givers identified their own shortcomings and lack of professional knowledge about particular therapies, nutrition and diet, physiotherapy exercises, hygiene and sanitary measures, the use of rehabilitation tools, and appropriate medication. These deficits compromised the care-givers' competence and confidence in their role. While many lay care-givers were under strong moral pressure from both relatives and health professionals to assume the responsibility for providing satisfactory care, few had the (perceived) competence to do so.

Given these deficits and burdens of lay elder care and the scant contribution of formal health and social care personnel in Indonesia, it is understandable that older people 'hope for an increasing commitment on the part of biomedicine to their persistent chronic illnesses' (Eeuwijk 2003c: 15). Elderly sufferers in North Sulawesi expressed high hopes for illness recovery and amelioration of their chronic conditions through biomedicine. As Lloyd-Sherlock (2002) has shown, whilst many health planners believe that biomedical health services for older people involve predominantly expensive and complex interventions, there are affordable, effective and acceptable treatments for many chronic diseases. For example, most of the sight defects reported by the sample could be cured cheaply and efficiently, as through out-patient ophthalmic surgery or a pair of glasses. Moreover, some common chronic illnesses among older people in North Sulawesi are preventable; if biomedical services were more widespread and provided both information about appropriate treatments and early diagnosis and treatment, several conditions would be reduced, notably diabetes, obesity and hypertension. One must not succumb, however, to the simplistic assumption that biomedicine will remove either the need for informal care or its social, economic and psychological demands; it is more likely to complement the contributions of informal health and care providers and to raise the health and longevity of older people.

## Old-age vulnerability and care

The term 'old-age vulnerability' is understood to refer to the threat of negative outcomes, which include the failure to provide adequate care and support. The consequences can range from increased discomfort to hastened death. Elderly urban Indonesians are particularly vulnerable in this respect if they suffer from one or more chronic illnesses. Analyses of our research data has shown that the level of an ill older person's vulnerability to inadequate care and support in urban North Sulawesi varies by marital status, gender, wealth, social capital and the relationship between the care-giver and the care-recipient.

#### Marital status

Never-married older people (3% of the sample) were vulnerable to inadequate care because they did not have a spouse, children, children-in-law and grandchildren to provide support. They lacked the entire affinal and filial support network. Never-married women were particularly vulnerable to social exclusion and destitution, because they had not complied with the cultural norms (*adat*) of marriage and raising children. Most ill never-married women were in unreliable care situations and depended upon insecure intra-generational kin support and non-kin assistance.

#### Gender

Elderly women are more vulnerable to inadequate care than elderly men, particularly in bilateral kinship societies in which they have limited power in negotiating the arrangements for their support. They also tend to have relatively few material resources of their own and sparse human capital (e.g. education, information, knowledge). Elderly widows (29 %) were most exposed to inadequate care because of their low status in their families and among their spouse's kin. This may mean that they do not feel empowered to challenge their care-givers when they should. Older widowers (5 %) were strongly encouraged by family and kin to remarry, ideally a younger woman, with the result that they tended to have a spouse as their key care provider.

#### Wealth

Poor elderly women and men were vulnerable to inadequate care and support by having limited financial resources and material assets and by living in generally impoverished environments and social networks. Most of the poor older people did not feel in a position – morally and strategically – to ask their care-givers for good quality and expensive care. Access to professional health support, including much-needed medication, physiotherapy, check-ups or specialist diets, is denied to these older people because of their lack of financial means. Poor older people's bargaining power is weakened by their inability to participate in

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relationships of reciprocity; they tend to lack the resources and assets to compensate for the financial burdens that they place on their care-givers.

## Social capital

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Putnam (1995) described 'social capital' as the elements of social organisation, such as social networks, norms or trust, that enable co-ordination and co-operation among people for mutual benefit. Older people with social networks characterised by little trust, information exchange, reciprocation and co-operation, are more vulnerable than those with high levels of social capital, as indicated, for example, by involvement in mutual aid, social solidarity or other collective actions. Older people who have not developed bridging and bonding networks during their earlier lives are likely to be excluded or omitted from the informal vertical and horizontal social networks that provide care, as of family, wider kin, neighbourhood, community associations, or peer groups. The relation between low social capital and the resulting care vulnerabilities is evinced by the elderly people in need of care and support who have 'no care-giver at all' (see Table 3). These six elderly women and men in Tahuna and Tomohon lived alone and were isolated geographically; they hardly ever participated in church and community activities, such as weekly bible meetings (evangelisasi kolom), savings associations (arisan doi), family gatherings on festival days (kumpulan keluarga), or communal work (kerja bakti).

# Care-giver and care-recipient inter-dependency

Older people who suffer from persistent chronic illness or multiple health disorders are likely to have increasing care needs over time and to be vulnerable to either diminishing or increasingly inadequate support, including long-term care. 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. Data from our 'tracer illness study' reveal that it is the number of care-givers who are engaged in supporting and 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 of the cared-for person. 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 'construction of care' occurs as the frail care-recipients grow ever more dependent on their care-givers. As the case of Ibu T. showed, long-term care becomes more uncertain and unreliable as the obligations associated with care-giving mount.

#### Conclusions

The correlates of a frail older person's vulnerability with failing care include not only their socio-demographic characteristics, such as marital status and gender, and their physical and material circumstances. e.g. illness severity and economic position, but also attributes of their social position like the gender of their closest relatives and social capital. Vulnerability to failure in care and support is therefore a function of a person's personal and social attributes, including their own, their family's and their community's attitudes, practices and modes of behaviour. In urban Indonesia, as elsewhere, the older people who are most vulnerable to inadequate and inappropriate care provision are unmarried women and poor widows. In the social context in which the provision of treatment, care and support for frail older people is the outcome of pragmatic and harsh negotiations (and re-negotiations) among family members and extended kin, as particularly with the Minahasa and Sangihe ethnic groups' bilateral kinship systems, older women occupy a weak bargaining position, particularly the 'adat deviant' such as unmarried women and widows. Given the 'triangle of uncertainty' surrounding old-age support systems in North Sulawesi, Minahasa and Sangihe households are not 'safe havens' for elderly women, for whom good health and access to adequate care and support decreases with increasing age (Eeuwijk 1999, 2003a).

In all but a very few cases, elder care in the urban areas of North Sulawesi is provided by family and household, that is by the lay sector. The option of professional care, through formal state-run or private institutions, is open to only a select few. Women, be they adolescents, adults or elderly, are undoubtedly the main care-givers and bearers of the care-related burdens. This social reality makes care-givers vulnerable to manifold constraints that may ultimately lead to failing care. In short, care-recipients are vulnerable partly because of the vulnerability of their care-givers. These inter-related vulnerabilities are seldom addressed in the literature on elder care. The dynamic but harsh contemporary environment of urban Indonesia shapes elder care and the forms and degrees of vulnerability of frail older people. Social and economic constraints are manifest in care-givers' burdens, in the kind of support activities that are provided, and in the bargaining power of frail older people. The social and economic changes of city life are commodifying care, with the result that poor older people are vulnerable to failing treatment, care and support. Old-age vulnerability is increasingly shaped by the monetary resources and needs of care-recipients as well as caregivers.

New forms of elder care are emerging in Indonesia's towns and cities. however, which may force a change in the vulnerability discourse towards an analysis of needs, resilience and resources, in effect a dialectic between, on the one hand, the frailty and care-needs of older people facing care, and on the other, their and their family's resources and coping capacities (Blum, McNeely and Nonnemaker 2002: 28). Until now, the resources of the elderly care-recipients have not been efficiently promoted by either informal care-givers or formal health providers. Vulnerability to failing care provision can be reduced by, for instance, supporting health maintenance and illness prevention, inspiring abilities, activating life experience, and engaging in social networks. Intra-generational support will grow in importance as older people or older people's groups support the sick and frail. The survey not only encountered such 'age-peer support' initiatives in the urban areas of North Sulawesi, but also found that elderly care by non-kin was becoming more important but had been little documented. In times of changing support arrangements and the declining availability of family support, peer networks may help to reduce old-age vulnerability by mobilising the care-giving potential of older people.

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## NOTES

- The lower age limit for inclusion in the study was 60 years. This corresponds to the official definition by the Indonesian Department of Health of *orang lansia* (a contraction of *orang lanjut usia*), meaning 'people of advanced age' (Eeuwijk 2003c).
- 2 Two elderly people died before the whole 'tracer illness study' was completed, and therefore the achieved sample size was 40 (as in Table 2).
- 3 For the location of the study areas, see the map in Kreager (2006: 43, Figure 1).
- 4 The exchange rate was 9,500 Rupiah to one US dollar in 2001–02.
- 5 The respondent older people's perceptions of other illnesses as 'disturbing', 'threatening' and 'worrying' are discussed elsewhere (Eeuwijk 2003b, 2003c).
- 6 This phenomenon is referred to as the 'double burden of disease' (Eeuwijk 2003b, 2003c). Gwatkin, Guillot and Heuveline (1999) argued that this 'double health challenge' is a distinctive characteristic of the impoverished in a population.
- 7 Adat refers to the unwritten and mostly uncodified rules, precepts, customs and rules of conduct in Indonesian society. Its broad scope includes local law as well as traditional ritual and ceremony (Eeuwijk 1999: 6). According to Minahasa adat,

- children's obligations towards the care of parents should ideally be performed on the basis of rotation (*paayoan*), starting with the eldest married child.
- 8 Although not a routine Western care activity, massage is a very popular preventive and curative practice in Indonesian households.

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