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# Social Life of Chronic Living (<http://somatosphere.net/2021/social-life-of-chronic-living.html/>)

By Peter van Eeuwijk (<http://somatosphere.net/author/peter-van-eeuwijk/>)

This article is part of the series: Chronic living (<http://somatosphere.net/series/chronic-living/>)

## **Chronicity, ageing, and social life**

Old-age related health conditions evolve into both a dynamic and an inert chronicity which, in the end, produces a particular quality of life when growing old: the chronification of uncertainty, insecurity, and unpredictability (Manderson, Cartwright & Hardon 2016; Eeuwijk 2020). The fragility and volatility of individual biologies cascades older persons not only into new bodily affections (Manderson & Warren 2016), but also into new social dynamics and fluidity that very often lead to experiences of multiple deteriorating transformations in the sphere of social lives (Manderson & Smith-Morris 2010). The understanding of “social life/lives” alludes to the concepts of Appadurai (1986; on value and commodities) and Kopytoff (1986; on objects and people) as well as of Whyte, Geest and Hardon (2002: 13-14; on pharmaceuticals): “Things have biographies. [...] They are lived in relation to problems and contexts.” Basically, “social life” means the activities one does with other people. In particular, the context of “chronic living” delineates the specific lives and social relations that chronic illnesses impose on people and between people. Furthermore, such an understanding of “social life/lives” has much to do with conflicting norms, rules, values, choices, meanings, expectations, imaginations, and politics by reason of varying ways of interpretation within society and of different modes of social practice and its effects.

The case of Oma Henny, a 74-year-old Protestant Minahasa better-off widow and retired state employee, who lives in her house in Manado (North Sulawesi, Indonesia) and shares the household with her son and his family, exemplifies the changing social lives of older Indonesians living with chronifying illnesses. Oma Henny suffers from severe rheumatism, gouty arthritis, hypertension, early signs of Parkinson's disease, and eye problems. This co-morbidity results primarily in massive restrictions in terms of physical movement, in spasms of despair due to violent pain, in long periods of mental unrest, and in growing loss of autonomy. The main reason for this process of increasing deprivation and suffering are her musculoskeletal impairments: "With growing age my joints and my bones give me only pain (*dengan rasa sakit*) and are getting so weak (*menjadi lemah*)", Oma Henny complains bitterly. These adverse circumstances make it difficult for Oma Henny to move about freely in her house, to leave her house, and thus maintain her formerly very active social life. This forced immobility and passivity prevents her not only from going to Sunday Mass (*ibadah Hari Minggu*) and from cooking her own daily special diet food (Eeuwijk 2007), but also from "healthy walking" (*jalan sehat*) in her neighborhood (*lingkungan*) due to the risk of falling.

### **Care in chronic living**

On account of this, care provision becomes a crucial marker for both her social life and her personal health in times of chronifying illnesses. No more and no less than the quantity and quality of her social relationships and interpersonal networks are at stake. Oma Henny frankly admits that her situation as an almost immobile and fully dependent older care-recipient is actually far from satisfactory and adequate. Just before her retirement as a state employee, she had assessed her circumstances – in view of potential need of care – as an older widow with her own house and sharing a household of her son and his family as pretty promising and safe. She tried to maintain solid and warm-hearted kin relations in this common household in the conviction that this would assure appropriate elder care. The preference for her son and his wife as main caregivers was determined by the social trust, economic safety, and spatial closeness which she had experienced whilst still working and in good health (Schröder-Butterfill & Fithry 2014). But things changed rapidly after retirement and the onset of her sufferings from rheumatism.

According to Oma Henny, the deterioration of her social relationship with her son, a high-ranked, wealthy, and committed state employee in the provincial administration of North Sulawesi, and her daughter-in-law, also a state employee, is due to two circumstances resulting from her increasing rheumatoid ailment. First, her son and his wife are too engaged in their

professional work and simply too busy in their social life to look after Oma Henny; moreover, this state got worse after she refused (following her retirement) to accept a housemaid as her main caregiver and also rejected the expected “granny duty” to babysit her two grandchildren. Secondly, her son fears that his frail, immobile, anguished, and dependent mother will become an extremely high care burden for his entire family – a manifold burden that would overstrain their capacity as full-time carers. Thus, in the case of Oma Henny, blunt rejection and denial of elder care has finally led to a de-kinning by care (Drotbohm & Alber 2015; Thelen 2015). In sum, this unfortunate situation does not meet her expectations of full-care reciprocity as dictated by normative and ideal filial piety in a mother-child relationship. Fortunately, her unmarried younger, but frail sister also lives in Manado. She provides some care – in general once per week – when Oma Henny calls her, above all with regard to more intimate care chores such as bathing and massaging.

It comes as no surprise that non-kin care providers assume a great deal of caring tasks: two older female neighbors, three retired workmates from her office, and two close older members of the church congregation’s quarter unit (*kolom jemaat*) visit immobile Oma Henny on a daily basis for socializing and consoling, praying, food shopping, house cleaning, administering drugs, even doing the laundry. In alternation, the two aged neighbors bring cooked food (mostly fish and rice) or fruit to Oma Henny and keep her company over lunchtime. The three retired workmates regularly bring her things “from outside” such as drugs, the newspaper, and sweets; together they often spend the afternoon chatting, playing card, remembering the “good old times”, and helping out in housework (e.g. cleaning the floor). The two close friends from her congregation visit Oma Henny early in the morning and sometimes late in the evening for prayers and bible reading, thus providing spiritual and emotional support, along with doing some urgently needed housework (e.g. doing the laundry). Yet, Oma Henny far from enjoys this care package: when she is alone again at night, almost immobile in her room, and the pains in her joints and bones become almost unbearable, she becomes scared, especially, when in case of urgently needed help, her family members deny her any support – the “fallacies and unpredictabilities of care” expressed in the words of Leibing and Dekker (2019: 2).

Nevertheless, such vivid social arrangements of care by non-kin of the same age (and usually of the same sex) – or producing kinning by care (Carsten 2000; Howell 2006) – are increasingly and pragmatically accepted in urban areas in Indonesia, but they go against the cultural convention of intergenerational care morality (Eeuwijk 2014). After all, this particular care arrangement and its availability make Oma Henny’s life more bearable and more inclusive in her stage of physical and mental suffering (Mol 2008; Eeuwijk 2020). Even though, as a former state employee and through her

son's prosperity, she is economically more or less well protected, her social old-age resilience – represented by her tight and active social network, her aggregated social, human, and symbolic capital, and her extended social space of care – also implies her social old-age vulnerability: the high physical, psychological, social, and economic vulnerability of her already aged female kin and non-kin caregivers renders Oma Henny herself vulnerable. She attributes this susceptibility and weakness largely to her advanced rheumatism which makes her so immobile, passive, fragile, dependent, helpless and defenseless: “I can only sit in my room and wait for my good fellows – but what happens when they can no longer come?”

### **Local understandings of the chronification of rheumatism**

When we asked Oma Henny about her specific locomotor disabilities, she replied markedly: “I have *supi*” – and immediately clinched her knees with both her hands. The two local physicians of the research team nodded understandingly and whispered: “Okay, *supi* ... that's it for now.” Both Indonesian biomedical professionals explain *supi* as a widely used umbrella term for all kinds of rheumatoid arthritis or, in basic terms, rheumatism (*rematik*). The idiom *supi*, a word from the regional Manado Malay language of Northeastern Indonesia, designates in particular aching, swollen and stiff joints of the knee, elbow, foot, and hand. In general, *supi* is associated with advanced age and thus considered a typical ailment of older persons. From her own experience, Oma Henny describes the sufferings caused by *supi* in vivid words: “If you hear somebody moaning all night long – that is undoubtedly an older person suffering from *supi*!” It is hardly surprising that analgesics are the most frequent pharmaceuticals consumed by older persons in North Sulawesi (Eeuwijk 2012).

As a lay health concept, *supi* is deeply embedded in the social dimensions and societal scopes which the affected person shares and reproduces. The popular aetiology of this rheumatoid arthritis is shaped by both (A) a life course perspective and (B) a bodily transformation. The chronology of this illness (A) follows the time trajectory of particular health practices in younger years; they cause certain health disturbances when growing old and finally break out in advanced age when the body is not as strong as before and thus less resistant (Eeuwijk 2003). Such detrimental habits and adverse events in previous life stages are attributed to qualities of a person's social life such as food and nutrition, life style, and times of deprivation. Oma Henny's retrospective narratives mention the fatty, oily, very spicy, and extraordinary foods (for instance, dog [*erwe*], bat [*paniki*], rat [*tikus*], lizard [*soa-soa*] or python [*ular sawa*]) that are served on the occasion of religious celebrations, formal social gatherings, and family feasts, her preference for bitter water spinach (*kangkung*) and fresh sweet-sour palm wine (*saguer*) when

socializing with peers and workmates – and by this food as social representation –, and the hard times during periods of societal unrest and public violence in her younger years that went on for almost 20 years (between the 1950s and 1970s) which led to exposure to famine and malnutrition. The process of somatic alteration in older age (B) hinges on the “drying out” of joints due to a continuous loss of fluids and fluidity and thus of viscosity in the ageing body. This chronification of bodily desiccation in old age shapes local understandings of why and how the body of older persons transforms. The “dry old body” that increasingly causes ailments of the joints and bones also constitutes a prominent part of Oma Henny’s reflection on her locomotor disabilities. In particular, her regular intake of too much fatty and hot meat, water spinach, and palm wine in younger years results in an elevated level of uric acid (*asam urat*) in her blood, which dries out the joints and may cause gouty arthritis (*penyakit asam urat*) – an ailment condition and course (“I have too much uric acid and therefore suffer gradually from uric acid illness”) which she mentions several times when describing her increasing frailty and reduced physical mobility.

### **The social life of chronic living when growing old with rheumatism**

Oma Henny considers her musculoskeletal infirmities (in particularly gouty arthritis) and her ageing ailment (visually impaired) as the most disturbing and hampering impairments in everyday life. Both health disorders severely hamper her mobility and agility to carry out important daily household chores as well as most social, religious, and economic activities of outside her domicile (Eeuwijk 2003). Her particular social and emotional circumstances as both an aged widow and an older mother neglected by her own son and her daughter-in-law are exacerbated by her failing health condition. Oma Henny addresses quite frankly a certain mutuality, or even mutual influence, between her bad health condition and the socio-psychological distress she experiences with her family. In this sense, she deeply regrets that exactly now, in this hard time of social destitution and need of daily care, her body does not “work well” anymore. On top of all this, she suffers from hypertension (*darah tinggi*) and mild Parkinson’s disease. Whereas Oma Henny perceives her Parkinson’s disease as a non-ascribable result of a previous biomedical diagnosis, her hypertension has become for her a real-life companion: “living the hypertension” – or in her own words “a guest in my body who was never invited.” She experiences her high blood pressure as a threatening illness which she associates with additional bodily and mental complications, progressive health deterioration, and uncertain living circumstances in the near future. In sum, it leads to strong feelings of uncertainty and insecurity, but she tries to cope with the situation.

Yet, Oma Henny finds it much more difficult to deal with her rheumatism,

which severely intrudes on her very extensive social, economic, and religious life and makes it increasingly impossible to lead a life as normal social human being in her role as mother, grandmother, sister, widow, government retiree, neighbor, and church member. Every day, she experiences swollen feet, stiff fingers, painful joints, and aching spasms in her legs. This explicit “living the rheumatism,” represented in corporeal terms as pain, discomfort, stiffness, turgidity, and flushes gradually leads to physical immobility, inactivity, dependency, exclusion, and mental stress – adverse values which prevent a balanced social life in the harsh environment of an Indonesian city (Eeuwijk 2006).

“In sum, health and wellbeing must be understood within the contexts in which they unfold as lived realities,” reason Kehr, Dilger and Eeuwijk (2018: 4). Considering the case of Oma Henny, we may conclude: the implicit social life of (chronic) living with rheumatism shapes aspects of embodied social experiences faced by older persons such as exclusion, loss of autonomy and freedom, dependency, marginalization, as well as uncertainty and precarity. In reply to our question, what she would do if she did not suffer from rheumatism, Oma Henny says: “You know, I could leave my house, go shopping to the market, and meet my friends; I could cook for myself, clean the house, and invite my peers. And I could carry out all my church activities, including Sunday Mass and the weekly congregational gatherings.” She incidentally remarks that she would love to enjoy just one full day without pain in her joints and bones. And in a low voice she adds: “Without my rheumatism I am sure that my relationship with my son and his family would be much better than it is now.”

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