

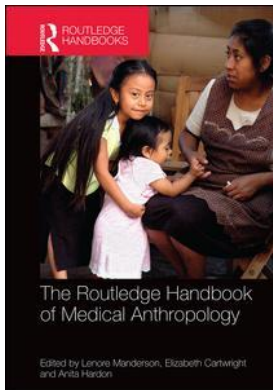
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Funeral in El Alto, 1996. El Alto, Bolivia.

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Note: Originally published in Jerome Crowder, 2007. Aymara migrants in El Alto, Bolivia, in *Ethnic Landscapes in an Urban World*, R. Hutchinson and J. Krase, eds. Pp. 181–195. Bingley, UK: Emerald Group Publishing Limited.

About the photograph

One morning I went to visit my friend Eusebio, a long-time resident and businessman in Villa 16 de julio, where I found his front door shrouded in black cloth. A traditional funeral dirge blared out across the neighborhood from a large speaker placed in the second-floor window above. Inside, the home was filled with smoke and packed wall-to-wall with family and friends. Surrounding a casket on the other side of the room were candles, large sprays of flowers, people quietly saying prayers and openly lamenting. The men sat on one side of the room, smoking and chewing coca leaves; the women congregated on the other, talking with each other and weeping. Eusebio had died the day before and I had come upon the wake in progress. Eusebio's family and friends stayed with the body for the next two days, before taking it to a cemetery on the periphery of El Alto. In the shadow of Nevado Illimani, the family recedes from the gravesite to receive condolences from friends and visitors who knew Eusebio.

—Jerome Crowder

Endings

*Lenore Manderson, Elizabeth Cartwright
and Anita Hardon*

Birth and death are wrapped in uncertainty and mystery, their timing and circumstances largely unpredictable. The two experiences are richly embellished; and where death occurs under propitious circumstances—and perhaps in an idealized setting—people honor their relationships to each other as they welcome the newborn and promise to nurture the child, or bid farewell to the departed. Many early ethnographers focused on death and its management as an example of an everyday life ritual that provides a means to comprehend local cosmologies and ontologies, life purpose and the divine. Anthropologies of death, and the responsibility of the living to ancestors, have provided insight into the relationships of humans with the physical and metaphysical; serious illnesses, dying and death sharpen the need for people to protect other individuals and the social body, and to manage the liminality of the person for whom death is imminent.

A number of early ethnographers mapped out cultural models of aging that have endured to the present. In these, characterizations of the elderly in small-scale societies often stand in sharp contrast with those of the aged in the highly industrialized global North, where social worth is more likely tied to productivity than, say, wisdom, spiritual engagement, or longevity and experience (Cohen 1998). In small-scale societies, it was suggested, older people were respected; with age, men gained power and authority with their accrued cultural and political wisdom; women enjoyed new freedoms once they ceased reproduction and were able to cast off controls over their sexuality; they too were able to take on leading cultural roles. Lawrence Cohen (1998) reminds us that these are often nostalgic and rather romanticized accounts, and not all older people fared well in such settings. Colin Turnbull (1972) makes this point in his chilling account of the Ik of Uganda, for whom forced settlement had harsh impact on frail older people who were left to die by those who were younger, fitter and more self-sufficient. Moreover, economic development, state control and capitalism have all affected the roles of the elderly, the respect conferred to them, and the care with which they are both entitled and provided.

More recent works on aging and the elderly, published in various edited collections and monographs from the last decades of the twentieth century (Counts and Counts 1985; Lynch and Danely 2013; Sokolovsky 1997; Strange and Teitelbaum 1987) and in the journal *Anthropology and Aging*, demonstrate the complexity of aging as a process, and the variable experiences of older people, under different social locations and conditions, as the consequences of class, ethnicity, social organization, gender and geography. In this chapter, we explore this diversity, first considering how older age is experienced, and then turning to the end of life and the

management of death. We begin by exploring how being old and frail merge and diverge as states of being. We highlight tensions around ideas of ‘normal aging’ and its medicalization in association with the emergence of gerontology as a unique field of medicine, and as psychiatry documented the deterioration of aging brains and minds. As Lawrence Cohen (1994; 1998) suggests, how aging and old age are understood, and how older people are cared for, are shaped by particular histories and cultural politics. Older people are sometimes, but not inevitably, infantilized as their independence, functional capacities, and capabilities are reconfigured. In the second half of this chapter, we consider different views about dying and being dead. We do not deal with infant or other early deaths here, but rather, primarily address death among adults. We look at the care of corpses, too, and so reflect on the fear of death and the stigma around dead bodies.

Aging and Its Impositions

We all age, but the meanings of aging and being old are cultural as much as biological facts. ‘Old’ is defined by a number of factors, but these are not necessarily correlated. Physical aging, cognitive ability, memory and social roles are calibrated in ways that mark who is old and who is not, and whether and how a person participates in social and economic life. Being old tends everywhere to be tied to participation in production, and the capacity to contribute economically to a household, family, community or nation. Depending on the society, lineage, inheritance laws and ownership (of land, cattle or other resources), all shape the power or powerlessness that accrue with age. Further, in all nation states, the formality of retirement from paid work provides a line by which people are measured and valued, but there is considerable variability given that in some countries there is no longer a statutory aging of retirement, while in others it can be as early as 55 years. Further, Glascock and Feinman (1981) noted that in most of the 60 societies they reviewed, people are regarded as ‘old’ well before they begin to show signs of difficulties in everyday function and independent living. The older a person is chronologically, however, the less ambiguity exists: a person who is 90 is considered to be old irrespective of their capabilities. Value judgments about how people are categorized and treated tend to have less weight as people embody the characteristics of old age.

With age, given the wear and tear on the physical body of a life long lived, people face multiple assaults on their health and strength, and they must manage conditions that cause discomfort and develop degenerative conditions and complications. They may lose mobility and sensory acuity (of hearing, vision and taste), and tend to be afflicted by and diagnosed with growing numbers of health problems, some life threatening, others regarded as an expected dimension of aging (joint pain, for instance), although no less debilitating as a result. Many conditions prevalent in older age are painful—muscle and skeletal pain from arthritis, lower back pain and sciatica, for instance; other conditions may not be painful but result in distressing dysfunctions and disorders—*incontinence, hearing and vision loss, sleep disruptions, physical instability, declining sexual function, and memory lapses, for example.* In much of the world, these are ‘normal’ dimensions to old age; they are not illnesses nor are they signs of illness.

At the same time, aged and frail people may also be caring for their spouse, a child or a grandchild, or adjusting to life after the death of their partner or children. Sjaak van der Geest (2008) reflects on the ways that ideas about reciprocity within kinship relations ensured that older people were cared for in Ghana, but while old people expected their children to take on this care, this is not always the case. In his work in Uganda undertaken prior to the introduction of antiretroviral therapy, Alun Williams (2003) similarly highlighted the isolation and everyday

difficulties of older people living in poor rural environments, who because of infirmity and weakness had reduced ability and lacked the energy to plant, harvest and prepare their own food, or to fetch water and fuel. Their children's migration from villages to urban centers, and the responsibility that they therefore had for their grandchildren and other small children, was once balanced by the sureness of remittances. However, the untimely deaths of many young adults from AIDS left these people struggling, without support. Ellen Block, in her case study in Chapter 4, similarly draws attention to the necessary renegotiation of roles of older people in Lesotho with changes in family structure due to HIV infection, the migration of young adults from rural to urban areas, and their migration overseas, all of which leave older people with far less kin-based support and extend the periods during which they are expected to provide care for younger family members (see also the case study by Tanja Ahlin, Chapter 8). Older people may be resilient in the absence of support from their children, and, with changes in life circumstances and social relationships, it is increasingly the case everywhere that older people may find themselves alone (van der Geest 1997; 2004b; 2008). Changes in function and communication, and physical and mental health problems, all cause the social worlds of many people to shrink, interfering with their capacity to maintain social and economic relations beyond close families, and so narrowing their access to networks that might provide them with support.

Living Uncertainly

These are all somewhat negative visions of aging and being old, reflecting lives framed by loss, lack, limitations, decline, and debility. The alternatives, as we have indicated already, have been somewhat idealized portraits of aging when reduced expectations of economic contributions provide men and women with the opportunity to spend more time as cultural advisers and arbitrators, participating in social activities and pursuing spiritual paths. Aspirations of old age framed by such shifts in focus and activity pertain, but globalization, industrialization and labor migration, and increased longevity, have everywhere troubled the processes of aging and its opportunities. In these contexts, sometimes health and illness force the choices older people have; sometimes they do not.

France, 2013. Two events contrast ways of aging. In early January, in the heart of the northern winter, a 94-year-old woman was thrown out of a retirement home near Paris, and left outside the unattended home of one of her sons, because her bills incurred at the retirement home had not been paid. Two months later, a group of older women, aged 62–85, opened a self-managed women's only social housing project in Montreuil, Paris, with 25 apartments, of which 21 were for older women, four for students.¹ The dependency of one woman, and the violence against her, and the agency and vision of the other women, suggest not ways to avoid uncaring families or undignified life in an uncaring institution, but emphasize differences in capability.

As we wrote this book, our three mothers were very much older women, and the times we spent together writing were punctuated by personal enquiries and accounts of their health, welfare, care and wellbeing. As they showed us, capacity and health are plastic: age is not a simple line from strength to weakness, acuity to confusion, autonomy to dependency. And everywhere, old age is a time of negotiation amongst kin and with others. In the following case study from coastal Tanzania, Peter van Eeuwijk and Brigit Obrist highlight the fluidity of local understandings of 'old age frailty' in relation to the physical body and mental capacity. Local understandings of 'frailty' reflect judgments and assumptions about rights and responsibilities that are embedded in kinship and dependence, so affecting care arrangements and care activities.

9.1 Becoming Old and Frail in Coastal Tanzania

Peter van Eeuwijk and Brigit Obrist

Local understandings of ‘old age frailty’ vary. Among KiSwahili speakers in coastal Tanzania, East Africa, elderly persons (60 years and older) consider their aging as both advancement and blessing, in spite of the effects of HIV/AIDS, gradually unreliable social networks and few formal welfare structures. With aging, they may face a decline in their health, and so need increased support and changes in care arrangements. Yet such frailty, with gradual loss of bodily and mental strength, and increased episodes of illness, is again part of the normal process of becoming old.

Geriatric notions of frailty in older adults include weight loss, weakness, fatigue, pain, depression, and falls as recognized symptoms of physical and mental decline, which may lead to low levels of activity, poor endurance, and slowed performance (Boockvar and Meier 2006). This professional viewpoint varies considerably from local perceptions of aging and frailty. Aged and fit Americans, for instance, adhere to understandings of healthy old bodies and active aging, characterized by good health, physical and mental fitness, energy, and the absence of illness (Steadman et al. 2013). In contrast, older Indonesians allude to getting limp, exhausted and weak, unable to resist changes in appearance and impairments; they associate the decline in their mental strength and physical robustness with the fear of losing autonomy, mobility, and activity—but not with any classification of disease (Eeuwijk 2003). Everywhere, however, frailty represents an embodied change that is constitutive and defines old age (Laz 2003).

There is no distinct linguistic term for ‘frailty’ in KiSwahili language. Old persons express becoming frail by referring to *nguvu* (strength) in reference to both physical and mental qualities. Aging persons who do not rate themselves as frail speak of *nina nguvu* (I have strength). In contrast, elderly people with a frail body and mind allude to *sina nguvu* (I don’t have strength) and refer to having ‘less fluidity’ in their bodies (e.g. in their joints). Temporary health problems of older persons associated with frailty are called *baadhi ya wakati* (in Zanzibar: some time [without strength]) or *wakati mwingine sina* (in Dar es Salaam: other time without [strength])—‘sometimes with or without strength.’ Here *nina nguvu* (having strength) dwindles for a while, but they recuperate. Older persons do not understand their ‘frailty’ as a fixed state or static illness category, nor do they see it as a sign of inevitable degeneration. Rather, an aging body and mind may fluctuate. This dynamic ‘continuum of strength’ ranges from ‘full strength’ to ‘without strength’; the boundaries of frailty, health, and illness are porous and the health of individuals is fluid. Short illness episodes such as a leg broken following a fall caused by weakness may be associated with or follow a longer period of general physical weakness or mental exhaustion, but the elderly person may recover and regain strength.

These changes in degree and outcome of bodily and mental frailty are closely monitored by the older individual and by his or her family and other household members. Their assessment of ‘performance in frailty’ may differ from that of the aged person, and may trigger debates about providing and receiving care. Local Swahili understandings of ‘frailty’ refer to judgments and assumptions about rights and responsibilities formulated in terms of kinship ties and inter- and intragenerational dependence, and thus affect care arrangements and care activities. Kinship norms and values assign eldercare obligations to children, particularly younger women. This expectation of intergenerational care for elderly parents shaped most care arrangements in the Swahili study households, due to successful negotiations between parents and their children, strong emotional ties, and feelings of reciprocity during their life course. Even so, in almost one third of the households with which we worked, an older person (60 years and more) assumed the role of major caregiver for a frail, sick, or bedridden elderly person. These aged but healthy carers contribute to daily domestic work, activities related to illness and ailment, and offer what we might, in other contexts, term psychosocial counseling. Becoming old and frailer, as a result, has an immediate impact on care arrangements: new patterns of care have to be established. Other kin may join the household of a frail elderly person, or he may leave his own household to join that of his major caregiver(s), for instance, his oldest married son. In a very few cases, too, we found major non-kin carers, such as tenants and close neighbors. Old age frailty in this sense results ultimately in the formation of (new) care regimes. Moreover, aged persons becoming frail gradually move from being caregivers to care receivers, when they cease to be able to self-care and/or contribute to the care of other family members.

This is complicated by the fact that the multiple morbidities of older people complicate reliable diagnosis and its adequate therapy. Geriatric skills are not yet widely developed in Tanzania,

and biomedical health professionals, such as those working in most urban hospitals and rural health centers, do not provide appropriate therapeutic assistance for old frail persons (e.g. palliative care, analgesia, nutriment, and restoratives). And even if this range of therapies and technologies were available, few could afford them.

In the following, we present examples of old people with strength and without strength. The first case is of *Bibi Asha* (60 years, Muslim, married), a woman 'with strength' (*nina nguvu*). *Bibi Asha* lives with her blind husband in an unplanned settlement area in Dar es Salaam. She and her family moved in 2008 to the city from a village in rural Rufiji, into a house owned by her brother-in-law, where 16 other people, including her brother's family, reside. She is the main caregiver of her husband, who lost his eyesight in an accident some years ago in the village. In addition, she cares for her sickly and pregnant daughter, her only living child (from another husband), and for a young boy, a child of her husband's first wife who had left him and lives elsewhere. *Bibi Asha* commutes every day between her daughter's house (in the same quarter) and her own household, with her husband and daughter fully relying on her for care. Her family relies on her brother's financial resources, and he is the main decision maker for her family—a dependency that demands that she obeys her brother and his wife. She works hard every day and follows the Swahili norm that a wife has to provide good care of her husband to secure the marriage: she cooks for him, she accompanies him to the toilet, she prepares his bath, she washes his clothes, she sweeps the floor, she guides him where he wants to go, and she shops in the market, and prays for her husband at the mosque. This daily burden of care renders her tired and sometimes exhausted, but she is physically and mentally robust, ensuring she can fulfil these many daily duties. She considers herself as 'still energized,' a blessed strength which she attributes Allah's infinite power.

Mzee Hassan (male, 89 years, Muslim, widowed), in contrast, is 'without strength' (*sina nguvu*). He lives in the small rural town of Ikwiriri close to River Rufiji. He owns a dilapidated house and lives there alone. His very weak body, his blind eye, permanent pains in his back, and numbness in his swollen legs significantly limit him physically. Thus, he stays at home, he sleeps a lot. In the morning he sits in the warm sun in front of his house, and after a while, he goes for a sleep again in his house, in the shade of the veranda, or under nearby mango tree. Sometimes an old neighbor comes by for a chat about life's difficulties. *Mzee Hassan* relies mainly on his grandchildren, who come by regularly to visit, and his daughter, who helps him every day. He ate initially in the house of his son-in-law and then his nephew. The daughter and the grandchildren now cook and bring him food (e.g. fruits, vegetables), but sometimes when his daughter is busy, he has nothing to eat and may also have no water in the house. Nevertheless, when he had to be admitted to the hospital, the daughter accompanied him, brought food, guarded his empty house, and raised money for his treatment. His frailty and mainly his partial blindness keep him from participating in social, economic, and religious activities—he feels ashamed and embarrassed when other people see him. His daughter too is sometimes unable to fulfil all his needs because she is also struggling and cannot provide permanent and adequate care. For instance, he has prescriptions of medicine for back pain, but never had the money to buy the medication; his daughter also cannot afford it. *Mzee Hassan* considers himself now an old and very frail man, because he can no longer fetch water nor ride his bicycle to go to his farm. For three years he has not cultivated corn and bananas on his farmland and no-one watches over this land. *Mzee Hassan* considers this a very distinct sign of his advanced state of frailty.

Other people fluctuate, 'sometimes with and sometimes without strength.' *Bibi Fatma* (female, 74 years, Muslim, married) lives with her husband and his second wife (and her two children) under the same roof in a remote village in Rufiji District. She married only six years ago, when her aged husband divorced one of his three wives. She does the daily housework; the two children fetch water from far away. Her husband takes care of their farm, and she makes pots from local clay soil. When *Bibi Fatma* is ill and feels weak, her husband takes over some housework such as cooking, laundry, and cleaning the house. She had recently an accident and broke her leg; she still suffers from pain. Her husband called the local healer and paid for treatment; because *Bibi Fatma* prefers local medication, she did not go to the local hospital. Due to this accident, she had to stop making clay pots because she cannot carry the clay. When she feels seriously ill and weak (e.g. due to malaria), the children of the second wife bring firewood and support her husband on the farm. At times, when the children are not around, she asks the daughter of a neighbor to fetch water and pound grain (because this is a woman's work, as *Bibi Fatma* emphasizes). Despite temporary weakness and variable health, she feels she is still strong enough to make a steady and significant contribution to her household.

Two other people are 'losing and regaining energy' (*leo sina nguvu*). *Bibi Zuhura* (female, 62 years, Muslim, married) lives with her much older husband, one of her sons, the family of another son

(including his four children), a nephew, her sister's grandson and a non-related young man (a football player), under one roof in an unplanned settlement in Dar es Salaam. She has six children (four boys and two daughters) and ten grandchildren. Bibi Zuhura worked as a government staff member at the Tanzanian Embassy in Kenya and Italy, which entitles her to a monthly pension. The family runs various businesses including a large commercial farm, which Bibi Zuhura ran after her retirement; she is the center of the family's economic undertakings and their control. Bibi Zuhura suffers from high blood pressure due to overwork, she says. One day, she collapsed during a business trip in northern Tanzania. This turned out to be a stroke. She lost her memory, speech, and bodily strength; one side of her body was paralyzed. She stayed for one month in a Christian hospital in Arusha. After she returned home, her youngest son, a football coach of a regional club, initiated a very strict physical exercise regime for her. He provided accommodation for a young football player of his club at his mother's house, and this young man supervised her daily exercise programs—using a bicycle machine, applying physiotherapy, and adhering to a strict diet. Three years later, she had recovered fully from the stroke—it was Allah who accepted her again and restored her full strength, she said. She does not feel frail any longer. She works now in the morning, and still follows the exercise program in the afternoon.

Mzee Emmanuel (male, 70 years, Christian, widowed) is a retired government employee and owns a nice apartment in a comfortable neighborhood in Dar es Salaam. Two sons, one daughter (who is a nurse and will marry soon), two grandsons (of a deceased son), and a housemaid live with him. He receives a monthly pension. His children bear his daily expenses (e.g. for food and transport) while Mzee Emmanuel supports financially his brother and one of the two grandsons. When he is at home (he often joins his church congregation), he works in his garden where he grows vegetables. Mzee Emmanuel has diabetes, but although he sometimes looks a bit frail and tired, he considers himself in good health and with strength. The health insurance, paid for by one of his children, covers his monthly diabetes treatment. The problem with his diabetes has its origins in the mode of treatment: he was prescribed oral medication, but his blood sugar level fluctuated, and he often felt very weak. At the diabetes unit in a hospital in Dar es Salaam, he then received insulin injections which he could apply at home. On the first day, however, he failed to estimate the appropriate dose to be injected due to his impaired eyesight, and he suffered from life-threatening hypoglycemia. He slowly recovered and moved back from injections to pills. After one year of increasing problems due to his diabetes, Mzee Emmanuel looks much better and stronger due to appropriate medication, traditional herbal medicine from a local healer (brought by his sister from his native village), rigid diet, and physical exercise. He walks every second morning, and this daily exercise helps control his blood sugar level. He also practices yoga every day in his bedroom by following a tutorial booklet. His voice is strong; he looks physically robust and is very confident with regard to his health.

★ ★ ★

These cases from Swahili-speaking communities in coastal Tanzania show that frailty is not about being bedridden or disabled, or to physical attributes of old age, such as grey hair and wrinkled skin. It refers rather to the limited capacity to self-care due to debility, fatigue, impaired sight and hearing, and problems in standing up, bending down, walking, and carrying weights. Elderly persons without strength or with its temporary loss can neither care for others nor themselves; they become increasingly dependent on other care providers. This transformation leads to the establishment of new care arrangements or the reconfiguration of an existing one. This entails shifts in the allocation of social, economic, physical, and emotional resources at a household level, which depends in part on the old and frail person's social agency. Bibi Zuhura and Mzee Emmanuel, who lose and regain strength, illustrate the gradual appropriation of new global gerontological concepts such as 'active aging,' 'healthy aging,' and 'successful aging,' where frailty can be mitigated and even reversible through an application of biomedical therapies and health-related regimes. This change in understandings of aging is most common in the health practices and health status of predominantly better off, middle-class urban residents. They are able to develop a degree of resilience, in face of increasing frailty, beyond the capacity of poorer, rural Tanzanians.

Acknowledgments

This contribution is based on two research projects conducted in Tanzania, funded by the Swiss National Science Foundation (SNSF). The research locations were Dar es Salaam and Rufiji District, Pwani Region (2008–2011, led by Peter van Eeuwijk) and Dar es Salaam and Zanzibar City

(2012–2015, led by Brigit Obrist). Jana Gerold, Vendelin T. Simon, Andrea Grolimund, and Sandra Staudacher conducted long-term fieldwork and collected empirical data with the project heads and Tanzanian field assistants. Both studies applied a combination of qualitative techniques (in-depth interviews, focus group discussions, direct observation, case studies), quantitative research methods (e.g. statistics, structured questionnaires), and documentary tools (film and photo documentation).

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People with long-term health problems such as diabetes, chronic obstructive pulmonary disease (COPD) and heart disease, as we have already illustrated (Chapter 7), must often structure their lives and tailor their activities around the practicalities of disease, treatments and the consequences of life-saving surgery—the need to manage a stoma and bag for elimination following a colostomy or urostomy, for instance; taking immunosuppressant medication following a transplant; constant care of a stump following an amputation (Manderson 2011). Although survival from potentially fatal conditions is increasingly common, accounting for increased life expectancy globally, the division between poor and rich people, in both poor and rich settings, pertains. Illness and impairments that impact communication, cognition and function strip people of the habitual ways in which they sustain social relationships and engagement regardless of age, but as we have suggested above, increasing frailty further limits the capacity of the very old and compounds these other embodied and structural limitations.

Cognitive Impairment and Memory Loss

Increased longevity has increased the likelihood that people will develop conditions such as Alzheimer’s disease and other dementias. Changes in cognitive ability, problems with speech and vocabulary, memory loss and mood disorders all occur with aging, causing frustration and distress for the person experiencing such problems themselves, in their interactions with others, and in the ability of others to communicate with them. Anthropological research has helped us reflect on our understanding of the cognitive, personality and behavioral changes that can be associated with aging. In the same way that autism spectrum and attention deficit disorders have become increasingly common diagnostic labels of various communication, behavioral and development disorders in children (see case study from Vu Song Ha, Chapter 2; Conrad and Bergey 2014; Kaufman 2010), so a putative diagnosis of Alzheimer’s disease is often applied to older people, despite that the cognitive problem may be some other form of dementia, or may be a sign of an underlying physical problem (mental confusion in older people is sometimes the only sign of a urinary tract infection).

In *The Alzheimer Conundrum: Entanglements of Dementia and Aging*, Margaret Lock (2013) asks us to reflect on our own attitudes to aging; both she and Lawrence Cohen (1998) illustrate the ways in which attitudes to senility and frailty vary considerably, with shifts in function and capacity seen in some places as a sign that the person is moving to another world, in other cases as frightening signs of the growing loss of independence, autonomy and dignity, and impending death. How people deal with such shifts differs considerably. Ruud Hendriks (2012) trained as a

clown in order to participate in and so describe one unique approach in an aged care facility in the Netherlands. Here, clowning was introduced as a way of enriching the lives of people with dementia, by alleviating mood, helping them connect to their social surroundings, and enhancing their quality of life: the approach built on the capacity of people to retain a sense of relationality and embodiment long after they were able to communicate verbally or to interact with others in predictable and socially acceptable ways.

Changing diagnostic categories influence which people are counted as experiencing memory loss, what this means to them and others, and how they are cared for. In the case study below, Annette Leibing draws on her research in Brazil to illustrate changes in the definition, etiology and risk factors of Alzheimer's disease, and in the range of preventive actions and treatment regimens delivered to people whom she refers to as "forgetful seniors."

9.2 Alzheimer's Disease in Urban Brazil

Annette Leibing

It is a rare opportunity for an anthropologist to observe and participate in the emergence of a new diagnostic category in a given society. In my case, I studied the beginnings of Alzheimer's disease (AD) in Rio de Janeiro as an anthropologist interested in geriatric psychiatry and as the founder and director of a research center and outpatient unit that became part of the local Institute of Psychiatry (IPUB). Although in the mid-1990s dementia was starting to be discussed more intensively within the Brazilian media, this occurred in a relatively abstract way, and few people seemed to know about it. Psychogeriatrics and related fields were only just becoming popularized among neurologists, psychiatrists, and psychologists, a new field and market within a rapidly aging country where youthfulness is strongly valued. Alzheimer's disease—the most common form of dementia—was a diagnostic category still in the making. There was only a fragile understanding of the disease, and its symptoms seemed to be especially dramatic in a landscape of aging wherein only recently a strong 'third age' movement had been implanted—a movement that generally propagated youthfulness, constant activities, and consumerism of the 'not old yet'—and in which decline and decay had an especially negative connotation. However, since symptoms of dementia were often linked to madness, a modern diagnosis of dementia also meant less stigma and new forms of attention by institutions and health professionals who had discovered 'the disease of the century.'

In the early years of Alzheimer's in Brazil, from around 1979, most articles in the press referred to research and discoveries on the molecular level, and, paired with great optimism, often described recent discoveries in the United States as being one step away from the final cure. Alzheimer's disease appeared to occur in an abstract, distant world of biomedical technologies far removed from the local realities of the families caring for the old and sick (although that was changing in urban Brazil). At the same time, the great optimism and trust in biomedical technologies went hand in hand with the notion of a 'mysterious' disease—about which almost nothing was known—affecting an alarming number of elderly.

A second phase started around 1993, when Alzheimer's disease first appeared as a 'national problem' in the Rio de Janeiro newspaper, *Jornal do Brasil*. The article emphasized the former ignorance of doctors and family members in diagnosing and dealing with the 'new' condition. From this point forward, AD was regularly characterized as a disease that could affect anybody, and numerous articles asserted that 1 million Brazilians were suffering from AD, without ever citing the source of these numbers. In 1993 too, probably not coincidentally, Tacrine arrived on the international market—a medication that was both a strong carrier of hope and promptly criticized due to its serious side effects. The pressures from patient and community groups on the government became stronger and, since politicians had recently discovered the elderly as a voter population, the contested medication was imported to Brazil.

Alzheimer's had the flair of a disease of the modern world. Increasing numbers of articles began to deal with risk factors that depended on individual behavior and risk management. In the late 1990s, the regular use of the brain was especially recommended, based on the idea that a 'brain reserve' would lead to a later onset of dementia. In contrast to the preventive measures and

the strong link with cardiovascular health propagated today (see Leibling 2014), the etiology of Alzheimer's disease in the 1990s was unspecific—sometimes of genetic origins, but mostly due to bad luck and lack of education. Caregivers I interviewed often had a different idea. *Sclerose*, from the term 'arteriosclerosis,' was used to refer to two types of senility that manifest in old people's behavior. One was a gentle sliding away from the living to the dead, an in-between state where the older person was treated like a child; the other, especially when it included unpleasant, violent or anti-social behavior, was considered 'craziness' and was highly stigmatized. Very often *sclerose* was seen as the result of a person's life, stress and strain, or an especially heavy shock—something that is not specifically Brazilian.

In the first wave of research, conducted between 1997 and 2000, we asked family members whose relatives have been diagnosed with Alzheimer's disease two main questions: [1] how they understood the illness and [2] if they could tell us about the person. We found a surprising similarity when comparing these narratives to the way Harvard psychiatrist David Rothschild, and others, explained senility in the 1940s: a combination of hardship and certain personality traits that prevent an appropriate way of dealing with stress and strain.

Through interviews we had with the caregivers of older people with a dementia (who were members of the local Alzheimer's Association or attending the local specialized dementia center, the CDA), old and new models for interpreting signs and symptoms began to merge. Reminiscent of what Ian Hacking (1995) once called "semantic contagion," caregivers often referred to both the genetic and the life history of the family members they were caring for:

Other relatives in my mother's family showed similar symptoms. But not only that. My mother became a widow at the age of 27. She lived for her children, grandchildren, then her mother got sick and she took care of her until she died. I've read a lot about it, I know about chromosome 21 and everything . . . But I think that dissatisfaction, sorrow, stress and the closing of an ever-smaller world may help towards self-destruction.

(*Maria*)

I believe it is a neurological genetic problem. That's what I've learned. Until now, these diseases are very little known by medicine . . . Maybe her isolation has started the disease. I am not sure. (. . .) She was independent, a hard worker. She bought and sold clothes and took care of the house, very well and alone, she was *caprichosa* (meticulous). She had a strong temperament, was dominating, revengeful like a good 'scorpion.' Her first son only left home when he got married with a woman as authoritative as his mother. She was extremely puritan, but did not separate from my father although she knew about his lovers. I think she liked him, but the bitterness destroyed her.

(*Madalena*)

The CDA

In the late 1990s, I was lucky to receive funding from the Brazilian Ministry of Education for the construction of a center combining multidisciplinary research, and a public outpatient unit for older people with mental health problems. This center, the CDA (Center for Alzheimer's Disease and other mental health problems for the elderly), rapidly became a reference point for the study and treatment of Alzheimer's disease. The CDA was part of the Federal University of Rio de Janeiro, and the director at the time insisted that the word 'Alzheimer's' became part of the center's name because "it was the disease of the moment" and, therefore, attracted funding and public attention. The opening of the center—the only specialized public institution in Rio de Janeiro at that time—became the subject of newspaper articles and TV talk shows, and was soon unable to accept all the seniors who needed psychiatric, neurological, and other kinds of psychosocial interventions. When the *Brazilian Reader's Digest* published an article about the CDA—and it seems that this was read in even the most remote parts of the country—a huge number of letters were sent to the center from people describing their older relative's symptoms, asking whether this was that *doença de Alzheimer* they had read about, and inquiring about the treatment at the CDA. I became the director of the center (not the clinical director)—a rather peculiar and contested decision made by the director of the Institute of Psychiatry of which the CDA was part.

The CDA offered multidisciplinary treatments, including musical therapy, psychology (including psychoanalysis and counseling), physiotherapy, occupational therapy, nursing, and family therapy, and had two anthropologists on its team. However, the focus was on diagnostics and drug prescriptions made by the psychiatrists. Alternative interventions were recommended by the doctors after their initial evaluation (and after the selection of patients for their own clinical trials)—partly because not much could be done, but also because families needed help with their loved ones, who were often in an advanced stage of the disease.

Although doctors in the 1990s claimed to treat patients with dementias, and articles in the media transmitted a general optimism, doctors were only able to medicate some of the peripheral symptoms of dementia. Psychiatric medications were prescribed for sleeping problems, psychotic symptoms, and dysphoria (e.g. depression and anxiety). Concomitant diseases, especially hypertension and heart diseases, were evaluated and medicated, and vitamin B and E were sometimes added to the treatment regimen as they were thought to likely be neuroprotective. But since the central symptom, memory loss, could not be treated, doctors were generally pessimistic about their patients. As one doctor explained: “We can only make it smoother for them, the last period of time, diminish suffering, it’s the family who should make them feel good.” In this sense, the central treatment was given by other health professionals to augment the patient’s quality of life, and made them ‘feel good,’ while clinical authority remained with the doctors who could do little for those for whom they were caring.

Another psychiatrist who had just started to work at the CDA remarked that she had to rethink everything she had learned up until that point, and in essence, become a general practitioner again. “I am treating more the body than the brain,” she said, referring to the fact that little could be done to slow down the neuro-degeneration in dementia, but that she was caring for the many concurrent diseases present in the elderly.

By 2005, however, the picture had changed. All four common Alzheimer drugs on the international market were available in Brazil—Tacrine was not prescribed anymore—although the inequities of access continued. One nootropic, Exelon, could be obtained for free from the State Secretary of Health; however, this was an extremely complicated process that took several months, and one that was almost impossible for anyone who was illiterate. Doctors, however, became much more confident in their ability to cure Alzheimer’s disease. For instance, one neurologist interviewed made the following observations:

With the technological advances, magnetic resonance, for example, one can make a more truthful diagnostic, one can now give names to different pathologies and patients who before were stigmatized as suffering from sclerose. Now [these patients] have a real disease and even potentially, depending on the moment, have a treatment. With the appearance of the medications, Alzheimer’s became a treatable disease and up to a certain point, administrable.

This neurologist, who works at a public hospital and also has a private practice, considers Alzheimer’s to be *treatable*, although she later confirms in the interview that the current medications only slow down the decline. This perspective differs significantly from those found in the mid-1990s, when the diagnosis of AD automatically indicated impending death. Now that dementia was diagnosed much earlier, the neurologist, like several of her colleagues, insisted on the importance of a multidisciplinary team, which was an emphasis that did not previously exist; it became a central issue since it was a necessary corollary to drug treatment. The people in this phase of new alive-ness based on hoped-for and, in several cases, observed increased alertness of individuals taking the medications (“she even is watching her favorite soap-opera again”) needed occupational therapy or music therapy, and their families needed to know how to maximize their loved one’s capacities, thereby enhancing their quality of life and general wellbeing.

Not coincidentally, those last two concepts—quality of life and general wellbeing—were also promoted by the pharmaceutical industry. A well-known psychiatrist tells me that:

The way of understanding Alzheimer’s has changed in the last years. This is because before, the principal issue for the diagnosis was cognitive decline and people only looked at cognitive decline quantitatively. But now, pharmacology studies started to pay attention more and more to criteria which before were secondary, which have now become more important in discussing Alzheimer’s, such as activities of daily living, behavioral syndromes, costs of diseases, caregiver’s

health—all these are now considered criteria of the disease and of its severity. And, of course, medications with approved efficacy emerged in the last ten years.

This quote reiterates the descriptions of Alzheimer medication produced with the pharmaceutical industry's spin. The new generation of Alzheimer medications still target memory decline, as intended by Tacrine. However, these new drugs are also designed to address broader implications like quality of life, and activities of daily living, previously considered to be peripheral symptoms, but now central to the diagnosis and conceptualization of dementia (Leibing 2009a; 2009b). One explanation for this change is that through the growing public and medical awareness of Alzheimer's, people are now diagnosed much earlier, and are therefore much more fit than patients were ten years ago. Another reason is that the efficacy of these drugs in treating cognitive decline cannot be proven, and increasingly studies are showing that the justifications used to recommend Alzheimer medications stand on shaky foundations (Whitehouse and George 2008: 13). Compared to cognitive decline, quality of life is a fuzzy subject, but now medications can be shown to work, even if we often do not know what exactly quality of life stands for. Finally, there was increasing attention towards using behavioral and psychological symptoms in defining and treating dementia.

In describing early dementia treatment in Brazil, I want to highlight how the emergence of a diagnostic category has an impact on people; it is “making up people” (Hacking 1995). However, names can have different meanings to different people, even within the same society. Research undertaken with my colleague Daniel Groisman in a shantytown (*favela*) has shown that dementia and its synonyms had no major importance for the older people or health professionals working in that environment. This was astonishing given that people living in a *favela*—and poorer Brazilians in general—are now living longer, and therefore, are especially vulnerable if the current models of dementia are true. Most seniors in the *favela* we worked in suffered from diabetes and hypertension—conditions considered to be important risk factors for dementia today—but also with formal education levels, which are lower than in other communities. The few accounts we received from our interviewees about ‘strange old people’ described them as being crazy. Here, within the symptom pool of possible signs of dementia, the psychiatric symptoms were in the foreground, while traditionally a diagnosis of dementia highlights cognitive impairment as the core symptom. These different ways of interpreting dementia result in divergent ways of living and relating to affected individuals and their families. Diagnostic criteria are not innocent—experts defining, health professionals applying, journalists writing about, and anthropologists analyzing criterion should be aware of ‘what’s in a name.’

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Towards the End of Life

Worldwide, the care of the very old, and the care of others whose life is coming to an end as a result of disease and regardless of age, continues to be met informally largely through family-based arrangements, because of lack of alternative modes of care, because of the social value and economic advantages of enabling elderly people to remain in their own homes, and because of the wish by people and their families that they see out their days at home. Caring for people at the end of their lives is physically and emotionally challenging, and the decisions that family members must make at different points in time can be deeply distressing but also, it should be stressed, comforting (Kaufman 2005).

Everywhere spouses and adult children, women especially, are most likely to provide continuous care. But while personal relationships of carer to care-recipient—a wife, mother, sister or daughter, husband, father or son, for example—strongly influence who takes on the tasks of primary care, the capacities of families and particular individuals to give care is variable and fluid. The responsibility to do so is therefore influenced by ideas related to age and other responsibilities, gender, time, affective relationships, patterns of residence and household composition, family-based values, and ideas of obligation and responsibility, respect and duty. The socio-economic context in which families and external support services are positioned further determines who is able to take care, and with what, if any, financial and practical support from others.

A prelude to such decisions of care giving and place of care is the communication to people of diagnosis, treatment pathways, prognosis and end of life. The conventions here vary considerably not only in the arrangements that people make to provide care for the frail elderly, but also in caring for people of any age whose lives may be foreshortened by disease (Davis and Manderson 2014). Communication about cancer illustrates powerfully the challenges that health professionals face with patients and their families, for ethical reasons (the right to know) and because of requirements, increasingly worldwide, that people provide informed consent to various procedures such as surgery, radiation, chemotherapy, and resuscitation. Inherent in this, there is a growing commitment that patients and their kin understand the implications of different interventions. In hospitals everywhere, medical and surgical interventions may carry considerable risks and limited gains, depending on the general health or frailty of the patient, and patients are expected themselves to participate in decision making and to assess different treatment paths against the alternative of palliation.

The concept of the right to know, including whether one might live or die, is not a universal. In other cultural settings, families may be empowered to make these decisions for their kin, and in the event of end-of-life decisions, while senior health professionals may initiate disclosure, who receives the disclosed information and how they understand the information imparted varies considerably (Bennett 1999; Kaufert 1999). Each decision about disclosure requires that an individual patient, clinical staff, and/or family members consider the costs and benefits of knowing the outcome of the disease or particular health event, and knowing what an intervention might entail. Joe Kaufert (1999) has described how, among Aboriginal Canadians, family members may resist discussing poor prognosis, palliative care, and impending death with a patient; they see their responsibility to be both to make decisions related to care, and at the same time, to protect the emotional health of the ill person as the most appropriate strategy to ensure their possible recovery or gentle passing.

The communication of a diagnosis of any condition, therefore, can be fraught with cultural, moral, and ethical challenges—who to tell, how much information, and with what spin. People are often fearful of the end of life, and put off talking about their own death. Further, prognosis can never be certain, and no-one can predict the transition from life to death, nor the moment of

death; there is always uncertainty involved in discussions about outcome. And while there may be no known cure to a disease, no clinician or ritual healer can advise their patient of the rate of degeneration, the length of life still to be lived, the quality of that life, or its definite end. In the face of uncertainty, perhaps particularly with the increased secularization of contemporary societies in the global North, pragmatics override the optimism of cure. Increasingly, people are encouraged to complete advanced care directives on their own behalf or in relation to a family member no longer able to articulate their views, so pre-empting decisions about medical and surgical interventions, high-risk surgery, intravenous or tube feeding, and life support (Kaufman 2005).

When Death Comes

Anthropologists have long engaged in questions of how dying is managed as a social process; in the timing of death and how a person might be regarded as and known to be dead; how dead bodies are managed and disposed, and souls put to rest. Medical anthropology extends to the social lives of dead bodies and those who are presumed dead. We write ‘presumed dead’ because this is not straightforward, as Margaret Lock (2002) has explored in her research in the United States and Japan. In the United States, death is defined as brain death, the complete and irreversible loss of brain function. In Japan, death is defined as the irreversible cessation of circulatory and respiratory functions, but this latter definition is also key to lay understandings of death, wherein time of death is linked to a person’s ‘last breath’ rather than to the end of brain activity. In some settings, clinicians take control of the process of dying, determining whether to proceed with life support, for instance; in other settings, families take control over the timing if not the process of dying, and even in a hospital where the technical authority is with the clinicians, they must participate in decisions to hasten or prolong this process (Chapple 2002; Stonington 2012). This is not an easy decision, and people may spend months by the side of someone who is kept alive through intravenous feeding and other kinds of life-support, in a liminal state, neither quite alive but not yet dead.

Ideas of the proper or ideal place to die are strongly held everywhere, and home remains an ideal and common place of death, as illustrated for Ghana, the United States, and Japan (Becker 2002; Long 2004; van der Geest 2004a). Among the Pitjantjatjara of Central Australia, where people die, and the company in whose presence they do so, is framed by a deep commitment to home or ‘country,’ and in making decisions about dying, kinship relations take precedence over medical services (Willis 1999). Maureen Kirk and Lenore Manderson, in their collaborative work in Australia with regard to breast cancer, noted that Indigenous women have often chosen to reject or cease treatment, or to leave urban-based medical units to return to ‘country’ (their homes), not only because of their wish to be in country at the time of their death, but also because their commitment to kin and community overrode any personal need for pain relief, treatment, and care (Kirk et al. 2000; Manderson, Kirk, and Hoban 2001). Stonington (2012) similarly emphasizes the social values associated with dying at home in northern Thailand. Here, people may consider it unethical to withdraw life support for someone in hospital, but this does not apply at home—where life support would usually be technically impossible—because Buddhist beliefs regarding the relationship of the place of death to the quality of rebirth take precedence. Provided the family has maintained the ethical and ritual obligations associated with Buddhist and other local values, Stonington argues, home is the optimal place to die; hospitals, in contrast, are places of emergency, death, and danger.

Choosing *when* to die is an issue for people who prefer self-elected death, when their ability to function socially or physically is impaired to an extent that they feel they no longer have a good

quality of life. While in some countries people may author their own death, their right to do so is highly controversial in many cultural settings and nations. In Switzerland and the Netherlands, doctors can grant a patient's euthanasia wish, if the patient is confronted with lifelong suffering, and Robert Pool (2000) has described how in one hospital in the Netherlands, physicians facilitated end of life of lung cancer patients by administering extra doses of morphine. This form of dying is classified as palliative care. The death-hastening effects of morphine sulphate are well known among hospice workers worldwide; where pain control and respiratory suppression are intermingled, patients may retain some agency over the timing of their departure.

Arlie Hochschild's (1983) insights into emotion work are particularly relevant here. Many people providing such care are recent immigrants, and poorly paid; care recipients and families expect that their labor includes kindness and care as they go about the mundane tasks of intimate care. Death and dying draw deeply on the emotional resources of those who are bereaved: family members and friends, and on the resources of the palliative care staff and others involved in their care, whether a person dies in an institution or at home. Death creates a chasm in the everyday lives and emotional security of those most closely affected; grief can be overwhelming and shocking. Funerals are designed around the inevitability of death and the need to support survivors. Consider the pervasive practices of sitting with, viewing, or handling the corpse, the disposition and displays of grief by renting garments, wearing clothes of particular colors (most often black or white), veiling, shaving hair or leaving it unkempt, social withdrawal or exclusion, the employment of professional mourners, and wakes and other ritual gatherings. The care of a corpse, the timing and appropriate disposal of the remains, funerary rituals and formal aspects of mourning, are never haphazard, therefore; the adherence to such protocol is often regarded as critical to social harmony and the aversion of disaster to the community at large, and even in highly industrialized settings where this may not be perceived, the rituals of death are tightly scripted and valued. All acknowledge death's impact on those who survive, provide ways to manage grief, and—depending on local ontology—might ensure the repose of the soul of the departed or an auspicious rebirth.

Several ethnographic examples illustrate this. In his classic monograph, *The Religion of Java* (1960), Clifford Geertz describes the rituals that are conducted as soon as possible after death; these involve stripping, washing, wrapping, and burying the body according to Islamic precept. Immediately following the burial, the first of a series of *selamatan* (feasts) is held; these *selamatan* continue at intervals until 1,000 days after the death, allowing those who are bereaved a structure within which to manage their grief. The aspired demeanor of the bereaved, supported through these rituals, is *iklas*, a state of 'willing affectlessness' and detachment, intended to reinforce an understanding that any death—regardless of circumstance or the age of the person who has died—is the will of Allah. Excessive displays of suffering are condemned; the ideal is restraint and emotional control. Such managed grief is not unusual, as Marilyn Nations and Linda Rebhun (1988) argue in relation to the logic of women in their comportment at the funerals of infants and small children in northeast Brazil; since "angels with wet wings won't fly," their restraint is a way to ensure their safe passage. Their analysis contrasts with that of Nancy Scheper-Hughes (1992), who in her classic book *Death without Weeping* argues that maternal love for very young and vulnerable infants is a luxury that extremely poor women cannot afford, or at least must control, given the compromised health and poor odds of their survival.

Funerals come at a cost. Funeral societies, which collect and distribute savings to pay for funerals, are common in many societies, although these have been commercialized in contemporary industrialized societies through life insurance and funeral cover plans. The care of the corpse at a mortuary or funeral home, the announcement of death, funerary services, burial or cremation arrangements and conduct, condolences, the care of graveyards, cemeteries, and shrines,

are increasingly professionalized everywhere, and in any setting, certain people have ritual roles related to the care of the dead. In many cases, especially in industrialized settings, people's only experience of these rituals, their administration and the negotiations that shape them, may be when a close family member dies. Karen Nakamura's documentary short film *A Japanese Funeral* (2010) is an invaluable resource; she provides an intimate view of how a Japanese Christian family cares for the body of their deceased brother, accompanies his body to the crematorium and, finally, how they package and distribute his incinerated remains.

Medical anthropology therefore extends to the social lives of dead bodies, to the work of undertakers, the role of the dead in mediating commercial relationships, and how people create and recreate rituals to manage the materiality of the corpse and the bereavement of the living. In the following case study, Ruth Toulson describes how Chinese Singaporeans manage death. Deeply historical practices influence ideas of living with restless souls and evil spirits, and malevolent ghosts, capricious ancestors, and the 'undead' pervade people's homes and public spaces. In contemporary Singapore, however, living with death has led to professional transitions, and coffin carriers and gravediggers have been replaced by funeral parlors and personal shoppers for the dead.

9.3 Caring for Corpses in Singapore

Ruth E. Toulson

Singapore, June 2012

In the back room mortuary of a funeral parlor, Lavender and I worked together to prepare a corpse. The body, that of a middle-aged man who jumped to his death from the 16th floor of a public housing block, lay on the metal embalming table, naked apart from a small cloth that covered his genitalia. Tubing ran from the artery at his thigh to the pressurized embalming machine on the side table. A further tube drained his blood, which pooled in a bucket on the floor. He bore the marks of a hasty autopsy: his chest cut in a t-shape from shoulder to shoulder, then from clavicle to groin, the skin, with its inch of yellow fat, rolled back. The postmortem cuts and the fact that his neck was broken left his body opened out and flaccid on the table. Only his spine stood high: a fleshy ridge of red.

In the background, FM976 radio station played the top 40 hits and occasionally Lavender sang along. She folded fabric to pad the pulped flesh and shattered bones of the man's head, glancing occasionally at the man's driver's license, which rested on the side table, trying to match the crushed half face with the photograph. "Look, there's too much damage to wire," she showed me. "If I can just get the shape right, I can cover all this with wax, but it's going to take a while. Want to get sushi when we're done?"

In a bucket underneath the table the viscera soaked in Dodge Company cavity solution. Jade, the general manager, pushed open the door to the mortuary. "The family are back," she said. "How much longer?" Lavender was irritated. "It's always such a rush here. In New Zealand, when the funeral director rushes you, it's because he wants to get home, because his dinner's on the table. Here, it's the dead who are in a hurry." "Why's that?" I asked. "Well, supposedly, if the body isn't in the coffin before dusk, the dead will become angry. They'll come back and haunt you." Lavender smiled: "I don't really believe in ancestors or ghosts. What I do is for the comfort of the family."

Perhaps six people die each day in Singapore, a tiny city-state. Not many, but approximately the number demographers would expect for a wealthy country with an aging population. Singapore is a multi-ethnic country with an ethnic Chinese majority who constitute approximately 74 percent of the population, with the remaining Singaporeans either Malay or Indian. While their lives are integrated, death is largely segregated, dealt with on ethnic lines. And most Chinese Singaporeans

will end up in Sin Ming Drive, a dead-end street in an out-of-the-way industrial estate, each road dedicated to a different 'dirty' business: to laundry, to welding, to car repair, to death. Avenue Thirty-seven is lined with funeral companies: Hock Heng Undertaker, Charity Casket, Ang Yew Seng Funeral Services, World Casket, An Lok Funeral Services, Fairprice Funeral, One-Stop Buddhist, and Asia Casket. Each business has a small front office and one or two parlors, each parlor large enough for a casket and a circle of mourners, the parlor's front open onto the street. In that street, I worked alongside Lavender and Jade to examine transformations in how death is ritually marked and the dead are mourned.

While the depiction of Lavender at work, above, is an everyday scene in the Singaporean business of death, it is also one that would have been unthinkable a mere decade ago. Read the older literature on death in Chinese societies and one is confronted by a world in which those who work with the dead are regarded as dangerously polluted by the task that they do. Watson (1988), in an account of a Cantonese village in the 1970s, describes "those who come with the coffin" as "the ultimate form of human degradation" (126). Villagers will not speak to them, touch them, or eat with them. Such is the power of their pollution that the cups and bowls they use are broken and later buried (125). They are recognizable by the odor of garlic on their breath, as villagers believe that they keep garlic cloves in their mouths to disguise the smell of death that clings to them (125). Watson suggests that most corpse handlers are opium addicts without kin or other means of support, who lived together in squalor in the back rooms of coffin shops.

Certainly, Lavender and Jade don't fit the stereotype of those "who come with the coffin," and not only because both are female. Jade is Mrs. Ang's eldest daughter, just turned 30, dark hair to her waist, undeniably beautiful. She is a mortician who loves to roller-blade and salsa dance, a relative newcomer to the world of death. After her father died, with her mother worn down by the burden of the business, Jade decided to leave her job in finance and work at Ang Yew Seng full time. At first there was resistance to a woman running the firm, particularly a young woman with new ideas. Some of the older men refused to work for her, telling her: "I've eaten more salt than you've eaten rice."

Lavender is just 23 years old, her hair tied up in a ponytail, black eyeliner perfectly applied. She sleeps in her make-up, she tells me, so as to not go out bare-faced if a call comes in the middle of that night. Today, she wears lilac scrubs, a macabre Hello Kitty appliqué stitched on the chest pocket, a bow-adorned skull and cross-bone kitten with heart-shaped hollows for eyes. She tells me she is Hokkien—Singapore's most common Chinese dialect group, who trace their descent from Fujian and Guang Dong Provinces—but she speaks little Hokkien dialect, only enough to make her friends laugh, and is more comfortable if we speak in English than in Mandarin. Her English is tinged with a New Zealand accent; she had just returned from embalming school there, where she gained a four-year degree in mortuary science. She had known at high school that she wanted to do this; she tells me, "It's a way to operate on people without being a doctor, and here, well, wanting to be a doctor is just too cliché."

Despite her professional qualification, Lavender's introduction to the world of death came from a very different time. Her first knowledge of embalming was when, as a child, she caught a glimpse of the preparations for a funeral, in the open public area underneath the high-rise apartment block where she lived. Seeing the dead body, lying under a sheet, while the embalmer worked with an embalming machine fashioned from a bicycle pump, she'd asked her mother why a doctor's clinic had set up on the deck. Then embalmers worked in the open air, preserving bodies while families watched. Lavender recalls, at her grandfather's funeral, chasing away cats that had gathered to lap his blood as it pooled into the storm-drain.

Now, Singaporean corpses are treated in sterile mortuaries, with Australian and American embalming technologies, and licensed professionals trained overseas. But that is not to say the world of death is entirely transformed nor that Singapore is an easy place to work in the funeral business. While highly trained young men and women have now largely replaced illiterate coffin-carriers, they have largely failed in their attempts to rebrand the business as a service industry like any other. Their necessary work is still treated with disdain and they continue to face discrimination. Jade's mother, for example, had begged her to reconsider her choice of occupation, telling her that "no good Chinese boy will ever love you if you work with the dead." No matter how many times she washed, Lavender's parents asked that she did not touch her infant sibling with her "filthy" hands. She often remarked that Singapore was no place for a highly trained professional with a four-year degree in mortuary science. She wanted to go back to New Zealand; she had a boyfriend there. They had fallen in love at mortuary school, exchanged glances across the corpses, their hands first touching

as he passed her a trocar, the implement used to pierce the organs so that the powerful cavity solution can solidify the stomach contents, and guided her to pierce it through the abdomen to pump embalming fluid into the body's cavities. They dreamed of opening a funeral parlor together one day.

While Lavender was adamant that her work was for the benefit of the family, she had not entirely discarded notions of symbolic pollution. When we discussed her future plans, she shared her worries about becoming a mother. "Imagine," she said, "can you really picture a bump in the mortuary?" Pregnant women avoid the dead at all cost, in case proximity to the corpse causes miscarriage. The dead are a danger to the unborn as they share a state of vulnerable liminality. Following death, in the days before burial or cremation, the soul is pulled apart from the body. In pregnancy, over time, the soul becomes attached to the body of the fetus. The corpse may envy the fetus as it gains what the corpse loses. "What would you do?" I asked. "Tie a red ribbon around my middle, I suppose," said Lavender. The red thread is a common element of funeral ritual. It acts as form of protection, channeling pollution away from the body of the wearer.

If the body is symbolically polluted, one might wonder why embalm at all? The vast majority of Singaporean Chinese bodies are embalmed. This is in contrast to funeral trends in the US, for example, where embalming is falling out of fashion with the decline of open-casket funerals and wakes held in the home, increasing concern regarding the long-term impact of formaldehyde-based embalming solutions on the environment, and rising demand for funerals that are inexpensive and 'green.' Even more puzzling is the fact that the vast majority of Singaporean Chinese bodies are cremated, generally within a week of death, so embalming is not necessary for preservation. The choice to embalm is often motivated by the decision to have an open casket for much of the three- to five-day funeral. Funeral directors stress the importance of embalming in creating a 'memory picture,' of seeing the dead for one last time but now in peaceful repose. They suggest that, particularly in the case of an unexpected violent death, if family members do not see the body, their imaginings of it are often far worse than the reality. Embalming solution, because it plumps skin and lifts out bruises, can hide the signs of a long illness. Reconstructive embalming, where body parts are rebuilt, can erase injuries, hiding the traumatic nature of a death. This is particularly important in the case of death by suicide, which is considered shameful. A skillful embalmer may be able to hide the cause of the death and protect the family's reputation. Practically too, if bodies are not embalmed, by the third day, the body becomes less pleasant to view; the features begin to collapse inwards and the body may purge, the decaying stomach contents bubbling from the nose or mouth.

Family members often provide alternative narratives to explain their choice to embalm. An open casket is necessary so that the dead can take part in the funeral. The dead are not considered entirely dead, but exist in a liminal state, where the soul, often in a state of distress, hovers near the body until burial or cremation. Funeral rituals are not for the cathartic release of grief or to bring emotional closure, but for the good of the dead themselves. By ritual actions, the living transform a corpse into an ancestor. If they fail to perform rituals correctly, the dead risks becoming a wandering hungry ghost. Further, the purchase of the services of a skilled, overseas-trained embalmer is seen as a sign of the family's cosmopolitan tastes, a further element of conspicuous consumption. Through expenditure, families make visible the degree to which they loved the dead. Further, relatives often described elements of the encoffining process—washing the body, applying make-up, dressing in clean clothes—as final acts of love and care. The family members themselves once performed these acts. Now, funeral professionals take on this work but they are regarded as polluted by it.

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We have written of the pain and grief associated with ailment and infirmity, frailty and loss of independence, dying and death. Elaine Scarry (1985), in *The Body in Pain*, wrote of the

inexpressibility of physical pain: pain dominates the perceptivity of the sufferer, yet it is beyond others' apprehension. Her insistence of pain beyond language applies equally to emotional pain. We struggle to find proximate experiences by which to empathize and so minister care to others. We do not know, until we too are in that place, what it is like to lose control over bodily functions, or for confusion to reign—for memories, vocabulary, volition, and logic to recede and muddle. We capture poorly the anguish of the decisions that must be made about someone with a disease for which there are no more interventions, or of caring for someone who can no longer dress or feed themselves; we have few accounts of how these play out in families and communities where resources are few and the options especially limited. Without further accounts, we will continue to struggle to advise on and provide care and support for people at the end of life, and for those professionals and families who are part of this process.

Note

1. "French retirement home throws out 94-year-old woman on winter weekend," <http://www.english.rfi.fr/economy/20130107-french-retirement-home-throws-out-94-year-old-woman-winter-weekend>; "The Babayagas' house, a feminist alternative to old people's homes, opens in Paris," <http://www.english.rfi.fr/france/20130305-babayagas-house>.

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