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Chronic Living and Delayed Death in Chinese Eldercare Institutions

Rose Kay Keimig

Author contact: rose.keimig@gmail.com

Abstract

In urban China, demographic shifts, medical interventions, and technological advancements are reshaping how, when, and where elders live and die. Within institutions, end-of-life interventions may stave off death, but have little to offer those who are saved but not cured. Meanwhile, these end-of-life encounters are unfolding within a larger caregiving landscape that is itself in transition. Increased migration, urbanization, women's employment rates, and access to medical services are radically altering caregiving arrangements. In particular, sharp declines in fertility have sapped family-based caregiving resources and put enormous pressure on medical institutions. Although China is just beginning to feel the effects of rapid population aging, demand for end-of-life institutional care has already outstripped supply. The few palliative care wards that exist routinely turn away patients, admitting only those whose end is predictably soon. In the process, dying becomes a diagnosis, complicated by insurance regulations, local bioethics, and limited resources. For those cut off from both curative and palliative care, life itself turns pathological, and they find themselves suspended in a state of "chronic living."

Keywords: *aging; caregiving; eldercare; end-of-life; dying; China; life course*

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Chronic Living and Delayed Death in Chinese Eldercare Institutions

Rose Kay Keimig

Author contact: rose.keimig@gmail.com

“How do I know that delight in life is not a confusion?
How do I know that in hating death we are not little ones who have lost our way home?”
—*Zhuangzi*

The parade of people began filing into Building 8 around 2:30pm, shortly after the Jade Hills Nursing Home staff passed around afternoon milk. I was one of five squeezed on a long couch in the small common area between the main entrance and the bedrooms. The residents were all bent over steaming metal milk bowls sipping noisily, while I, unable to refuse the insistent generosity of Ma Li on my right, nibbled a stale biscuit. At first the people walking past seemed to be on a routine visit to a bedridden patient in the dim corner room, but as young mothers carrying toddlers on their hips, businessmen on cell phones, and teenagers in bejeweled tee shirts disappeared into the room, it became clear this was not a normal visit. A man yelled. Unfazed, my fellow couch-mates fished for soaked biscuit chunks and strings of congealed milk that had sunk to the bottom of their bowls.

After a few short minutes, the visitors left, wearing expressions ranging from anger to impatience to boredom. Residents slid empty bowls onto low wooden tables. A group of care workers stretched on blue gloves and entered the corner room while others wheeled a metal table into the open space directly in front of our couch. One care worker emerged from the room carrying a large black garbage bag followed by two more care workers, each barely five feet tall, clutching opposite ends of a faded pink sheet. They shuffled out of the room and heaved their swaying bundle onto the wheeled table with a plop, rattling empty milk bowls. A few residents watched, expressionless, as the gurney bumped around tables and over the uneven floor, its unsecured cargo jouncing unceremoniously to the van waiting outside. In the quiet that followed, I expected some response to the incident, but the only utterances were the usual burps and sighs of a drowsy afternoon. When I asked a resident later how she felt about the death, she replied, “I envy her.”

Introduction

In the beginning, death and decline slithered onto the scene as punishment for wickedness and moral weakness, establishing a separation between God and humans, good and evil. The implications of this narrative have influenced Western thought on aging and dying for millennia and continue to shape contemporary bioethics, health initiatives, and global aging models. In social gerontology, there is a recognized tension between conceptions of aging as a lifelong process and old age as a separate, distinct period of life, a tension that informs and is informed by policies and eligibility criteria for age-based services (Grenier 2012). On a societal level, chronological age has an assumed significance for dividing the life course into distinct stages while, at the same time, there is a pervasive belief that the “aging self is, ideally, an ageless self” (Lamb 2014, 46; Marshall and Katz 2012). “Healthy” aging is “active” and “independent” (WHO 2016), and the body’s decline is fought, delayed, or avoided in favor of youthful immortality (Rowe and Kahn 1987; Wade 2016).

While curative, life-promoting ideals promote positive visions of lifelong potentiality, they also generate dissonance in the face of actual experiences with incurable conditions and failing minds and bodies. In her research in U.S. medical institutions, Sharon Kaufman (2005) described the “zone of

indistinction” characteristic of end-of-life medical encounters where diverse understandings and expectations about aging and dying converge with institutional practices that are themselves in constant flux. A “good” death is often at odds with the curative goals of medicine or stymied by limited physical, economic, or human resources. Bioethics, medical interventions, and technological advancements work together to defeat aging and delay death, but they offer little guidance for those who are saved but not cured and suddenly thrust into a “gray zone” between life and death (Kaufman 2005, 2015).

In contemporary urban China, these end-of-life encounters are unfolding within a larger caregiving landscape that is itself in transition. Increased migration, urbanization, women’s employment rates, and access to medical services are radically altering caregiving arrangements (Broad *et al.* 2013). Sharp declines in fertility have sapped family-based caregiving resources and put enormous pressure on medical institutions (Yeoh and Huang 2014). Although many countries, including China, are just beginning to feel the effects of rapid population aging, demand for end-of-life institutional care has already outstripped supply. The few palliative care wards that exist routinely turn away patients, admitting only those whose end is predictably, certainly, soon. In the process, dying becomes a diagnosis, complicated by insurance regulations, local bioethics, and limited resources. For those cut off from both curative and palliative care, life itself turns pathological, and they find themselves suspended in a state of “chronic living.”

As with other chronic illnesses, “chronic living” describes the excess of an otherwise benign condition that becomes pathological only when it crosses the subjective boundary of too much or, more often, too long. Life lingers, intractable and incurable. While this condition is not unique to contemporary China, the speed and magnitude of medical advancements and caregiving shifts have made it increasingly visible there. In this article, I examine the ways these end-of-life interventions complicate and compromise both living and dying for today’s institutionalized elders.

Methodology

In order to understand China’s evolving eldercare situation, I conducted ethnographic fieldwork in Kunming, China between 2013 and 2015. Yale University’s Institutional Review Board approved the research and a local hospital director supervised the project. Kunming, with a population of 6.7 million, is the capital of Yunnan Province in southwestern China. Despite its distance from the political and economic centers of the country, Yunnan’s temperate climate and rich natural resources make it a top eldercare destination (Zhang 2013).

During the first phase of the research, from October 2013 through May 2014, I collected data primarily in geriatric and palliative care hospital wards. I lived onsite at a busy city-level hospital and spent nearly every day in the palliative care unit. Observations were collected while shadowing doctors and nurses on rounds, during staff meetings, and at palliative care conferences in Shanghai and Beijing.

In the second phase of research, from May to November 2014, I continued to visit the palliative care ward regularly, but shifted my focus from hospitals to residential care facilities. I visited a range of eldercare institutions in the region—high-end and low-end, public and private, urban and rural—for a total of over seventy-five visits to six different facilities. I visited on both weekends and weekdays during visiting hours, which were usually 8AM to 8PM. As with the first phase of research, this phase relied heavily on participant observation and open-ended interviews. I conducted formal interviews with thirty-three elders: fifteen men and eighteen women. Interviews were recorded with permission. The average age of institutionalized elders was seventy-four years old, and all informants had at least one child. A local

research assistant helped translate written materials and transcribe interviews. Pseudonyms were assigned to participants and institutions.

While recorded interviews are the sources of all direct quotes in this article, an estimated 250 hours of participant observation in eldercare facilities provided the foundational data for the research. Many Chinese elders are wary of signing documents, and some of my closest informants would not or could not participate in formal interviews. Nonetheless, through the insights they shared during countless informal interactions, they were still able to contribute to understandings of the everyday experience of living and dying in Chinese eldercare institutions.

A Good Death

Death is one of the few certainties in life. Its finality gives existence meaning and form, and shapes the contours of the human experience. It is an inescapable fate yet “irrevocably interwoven” with freedom in life (Mbembe 2003). Historians, such as Philippe Aries (1981), have traced past societies’ reactions to death and dying, and psychologists like Elisabeth Kubler-Ross (1969), who developed the “Five Stages of Dying,” continue to influence contemporary experiences and clinical encounters with death. Whether feared, tamed, denied, or named, across Western sources, death is treated as something deeply meaningful and potentially redemptive (Green 2012). In his anthropological study of death and dying, James Green attributes this to an “enduring salvational ethos” (2012, 25), which Marshall Sahlins (1996) observed in Christianized cultures sharing the same “peculiar Adamic inheritance” (Sahlins 1996, 403 quoted in Green 2012, 24). Despite anthropological accounts demonstrating the relativity of death, there is also an enduring belief that death and life, the body and the spirit, and the dead and the living are separate (Lock 2002).

However, these epistemological models are not easily applied to the Chinese context. Classical Chinese thought on death and dying, drawn primarily from early Confucian and Daoist texts, does not emphasize individual salvation or redemptive themes. “Based neither on God nor the death of God” (Perkins 2015), death is often meaningless, abrupt, and absurd, guided by the same disinterested forces of fate as the weather. Chinese philosophies on death also lack the radical life-death dualism found in many Western traditions. Instead, they stress relationality, reciprocity, equilibrium, and harmony with natural rhythms. Death is life’s complement—the states are differentiated, but “a difference is not yet a conflict” (Sahlins 1996, 402). Rather, death is one half of an unending circle, and the fertile soil from which life emerges. (Li 2013; Perkins 2015; Qin and Xia 2015; Watson 1988).

While complexly interwoven and mutually transformative, Daoist, Confucian, and Buddhist approaches each speak to different facets of death and dying. In line with yin-yang understandings, Daoism portrays death and life as the shaded and sunny sides of a mountain, which are not in opposition and cannot be separated. In the *Zhuangzi*, a central Daoist text, the sage claims, “Whoever knows that life and death, existence and annihilation are all a single body, I will be his friend” (6.4). Confucius also saw death and life as intimately connected, but prioritized the practical here-and-now concerns of right living: “If you don’t understand what life is, how will you understand death?” (*Analects*, 11.12). The centrality of Confucian thought in Chinese social life contributes to the observation that Chinese people rarely discuss the afterlife or other metaphysical mysteries (Guang 2013). However, even within Confucianism, death is a concern, but it is approached from the perspective of those still alive, who are expected to maintain proper relationships and continued reciprocity even after death (Perkins 2015). Buddhism, which has been highly influential in China since the third century, does attend to metaphysical concerns through its teaching of karma and rebirth (Desjarlais 2016; Guang 2013; Li 2013).

While only 10% of Chinese openly affiliate with a religion, and regional, local, and individual religious practices show great diversity (Li 2013), the widespread similarity of funeral rites across China in the nineteenth and early twentieth centuries indicate that these shared philosophies have contributed to a standardized Chinese “way of death” (Watson 1988). Prior to 1949, most Chinese died and performed funeral rituals at home in order to help ease spirits out of their bodies and into the afterlife (Cohen 1988; Whyte 1988). After funeral rites were completed, ghosts, ancestral tablets, and tombs continued to have a place in the daily lives of the living since death did not sever bonds of kinship, reciprocity, community, or exchange (Cohen 1988). More recently, pressures of urbanization and bureaucratization have encouraged cremation over burial, imbued elaborate funerals with meeting-like efficiency, and moved death out of the home and into institutions, but a “good death” still adheres to the aforementioned values of balance, harmony, and reciprocity (Ikels 2004). For the living, this means attending to the proper rites and ceremonies to ensure continuous kinship bonds and exchanges between the living and the dead (Watson 1988; Whyte 1988). For the dead and dying, a good death is a timely one, in which a person has reached their pinnacle of self-cultivation and, surrounded by family, leaves behind a web of social relationships spun so carefully that even death does disrupt its balance (Hsu, O’Conner and Lee 2009).

Evidence from my thirteen months of ethnographic fieldwork indicated that these ideas about a good death continue to hold true for many contemporary elders and their families today. In formal interviews and casual conversations, participants expressed a deep and enduring need for familial connection and balance regardless of their end-of-life care setting. However, evidence from palliative care wards, nursing homes, and other eldercare settings also revealed that obstacles to achieving a good death, including family disharmony, economic concerns, and disease and disability, are increasing as dying moves out of the home and into institutions.

Modern Dying in Urban China

The most common popular understanding of ‘the dying process’ is that there will be a relatively long period of stability followed by a short period of physical decline. While this trajectory often characterizes cancers, it does not, in fact, characterize most disease that precedes death. A more common situation is one of long-term disability, with periods of acute symptom exacerbation that may or may not be accompanied by obvious decline. Patients, families, and sometimes physicians expect that, given the right medical treatment, patients will survive each exacerbation, and the patient frequently does survive many flare-ups or acute episodes. Thus, when death finally occurs, it seems ‘sudden.’

— Sharon Kaufman
...And a Time to Die

Sitting in his modest single room at Singing Meadows Nursing Home, Zhang Wei describes the incident six years ago that triggered his health decline and inspired a recent discussion with nursing home staff about end-of-life directives:

Just after dinner I was helping [my wife] use the commode when she suddenly collapsed on the bed. I yelled for help and the nurses and doctors rushed in to revive her. The doctor doing CPR asked me, “Should I save her?” At that time my mind moved very quickly. What I thought was this: It is useless to try to save her in this situation. But how did I answer the doctor? I said, “Save her!” Immediately he sent her down to the ICU where she was hooked up to a ventilator and other machines. Why did I think “Don’t save her” and yet tell the doctor “Save her!”? I knew trying to save her was futile, but if I didn’t save her,

if I didn't say, "Save her!" she would have died. My children, my sons and daughters, would not have understood my decision. They could not have possibly understood. They would only demand: "Why didn't you save my mom?!" Right? How could I explain myself to them?

Although Zhang Wei's wife survived the incident, she never recovered consciousness and passed away a few days later. Now institutionalized and nearing ninety, Zhang Wei has made clear to family and staff that he does not wish to be "saved" from death: "I have discussed it with my daughter, as well as with the nursing home staff and the doctor. If I fall ill again, it would be best that they don't say, 'Quick! Get him to the hospital!' If I am admitted to the hospital, I simply cannot afford to pay 10,000RMB (\$1660 USD) for 15 days...I am 90 years old. This life is basically finished."

In China, institutions are playing an increasingly larger role in the urban experience of aging and dying. Although national surveys show considerable discrepancies in rates of home and institutional deaths, they agree that education level, urban residence, and social position are all strongly correlated with higher rates of institutional death (Jing and Yuan 2016). In wealthier nations an opposite trend is observed, but the same principle is at work—those with better resources die wherever they can receive the best care (Gu *et al.* 2007). In the Chinese context, the demand for institutional care is also being fueled by rising rates of insurance coverage, access to specialized medical services, and bureaucratic pressures (Jing and Yuan 2016). For example, in 2014 the Ministry of Public Safety issued new end-of-life protocols that mandate signed death certificates for in-home deaths, encouraging some families to transport their imminently dying relatives to hospitals in order to avoid the hassle of paperwork (*ibid.*).

While demand is clearly increasing for institutional end-of-life care services, it is unclear who should or can provide and receive it. China's official hospice and palliative care institutions are in a comparably early stage of development. The first hospice care institution opened in 1988, and by 2011, there were approximately 200 palliative and hospice care facilities serving an estimated 1% of individuals in need of palliative care in mainland China (Li, Davis and Gamier 2011, 292). Due to a lack of national-level organization, these services are inconsistently regulated and funded and disproportionately located in larger cities. The imbalances cause such divergent priorities within the practitioner community that one local palliative care doctor, who is a pioneer in the field, described the situation as a "gang war." At all levels, from policy to training to practice, there is clear disagreement about the goals and scope of palliative care, who should be providing it, and even what it should be called (O'Connor, Poon, and Hsu 2015).

Despite these inconsistencies, palliative and hospice services are in high demand among patients and families seeking end-of-life care. In the present research, all respondents reported high levels of satisfaction with the care their relatives received while in these units. Compared to other hospital wards, palliative care wards tend to be less crowded and exempt from insurance-based inpatient stay limits. Furthermore, hospice and palliative care departments are among the few departments where morphine is used regularly and pain control is prioritized (Gao 2012). However, providing these services requires first determining that a patient is, in fact, dying, a process complicated by local bioethics, family-based decision-making, and taboos discouraging openly speaking about death.

In Zhang Wei's account above, one can see how the pressures of family-based decision-making converge with available technologies to complicate choice making in the case of sudden decline. His is not a unique case. According to research, only 47% of Chinese doctors report ever applying Do Not Resuscitate (DNR) orders, compared to 95% of doctors in Europe and Hong Kong, and more than 70% claim to not feel comfortable discussing limiting life-sustaining therapies with relatives (Weng *et al.* 2011, 659). This is significant because, in line with Chinese bioethics, doctors first discuss medical situations with families

before revealing diagnoses to patients. Although policies are changing with regard to informed consent, it is a common practice for physicians to withhold fatal prognoses from patients per the family's request, as family members fear that speaking about death may cause it to arrive unnaturally soon (Bian 2015; Fan and Li 2004; O'Conner, Poon and Hsu 2015).

While it is unclear whether or not avoiding the topic actually staves off death, there is no doubt that it interrupts the dying process. As Glaser and Strauss (1968) noted in their seminal work, *Time for Dying*, one must be recognized as dying in order to be treated as dying. Within institutions, death must be "named and expected" (Kaufman 2005, 201) before dying can commence. Death's timing is especially complicated with older patients. As new medical technologies extend lifespans, common old age disease trajectories become even harder to predict (Kaufman 2015). This also holds true in Chinese institutions, and explains why the vast majority of palliative care departments are located within oncology units, and cancer, with its relatively predictable timeline, is almost synonymous with death (Dong *et al.* 2016). Yet, as the following exchange with a thirty-year-old palliative care doctor shows, even within these units, "good" care is pro-life:

Dr. Ming: Once we had this stroke patient, he was completely unable to take care of himself. After that, he, you could say he was living in extreme suffering. The family members requested to stop all treatment, including tube feeding. So, the patient ultimately, to speak frankly, starved to death.

RK: Starved to death?

Dr. Ming: We were unwilling to let this situation happen, but the family members said, "If you want to keep feeding him, then take the patient home with you." This is what they said to us. Our nurses and care workers did not have the heart to do it, and they secretly fed him. The family members got very angry, and said, in the end, us doing this just added to his suffering.

As a result of these complex institutional processes, even though many Chinese elders are frail, declining, and dependent, without a determinable end date or predictable trajectory, few are recognized as "dying." Some, like Zhang Wei's wife, die "suddenly" in intensive care units. Many others, who have surpassed the inpatient stay limit but are not well enough to return home, spend their final years in long-term care institutions unequipped to provide palliative care. In these institutions, death is ever-present, but few are recognized as dying. In this tenuous, ill-defined space carved out by and for the not-quite-living and the not-quite-dying, many struggle to maintain the familial and social balances necessary for a good death. As one nursing home resident explained, "for those who cannot live and cannot die, life is extremely painful."

Chronic Living

"Chronic: Of long duration and slow progression. Illnesses that are chronic develop slowly over time and do not end. Symptoms may be continual or intermittent, but the patient usually has the condition for life."

—Gale Encyclopedia of Medicine

One of my closest informants at Jade Hills Nursing Home, a private institution with about 300 beds, was Wan Long. Compared to other institutions in Kunming, Jade Hills was average in terms of cost,

size, and level of care provided, but was older and shabbier than other institutions I visited. It charged a flat fee of about \$350 USD per month— comparable to the average pension in the city at the time, and it attracting a larger proportion of high-need residents because of the lower flat fee. Wan Long often passed the slow afternoon retelling stories of the path that led him to his current state.

When did the sickness begin? The first answer that comes to mind is the day he had his stroke, fourteen years ago, at the age of forty-eight. But, as he sifts through layers of memories, Wan Long traces the symptoms back further. His mother also suffered a stroke. She was in her seventies, and afterwards she lived happily at home in the care of her two sons until she died at eighty-nine. Or it could have been when his wife left him and their one-year-old daughter. But no, even after that he was still living well, still healthy, still working. He got into construction at the very beginning of China's financial boom in the 1980s. He took care of his daughter, gave her everything—probably too much, he admits now with a shake of his head. The money was good, but he worked in the early years of privatization—no pension, no insurance, no security. He took care of his mother, too, but it didn't feel like a burden: "It was what I was supposed to do. I was her son, right? If I didn't do it, who would?" His daughter is smart, so smart, but immature. He pulls himself back into the present, shaking his head and wiping the saliva that leaks incessantly from the loose corner of his mouth with a stained handkerchief. It isn't her fault. He doesn't blame her.

"Yes, yes, forget it, just forget it," Xiao Mei, a fellow resident, consoles, edging her wheelchair closer after a few minutes of tsk-tsking in the background, "don't blame her, blame...the government—"

"Blame this ILLNESS!" Even Wan Long is surprised by his angry outburst. He does not shout. Or complain. He sits quietly in the shade and naps in his broken wheelchair. He sits quietly in his stinking, unwashed clothes and does not make a fuss even when he has to go to the bathroom and the plastic jug he uses as a makeshift commode is full. Once the nursing home director hit Wan's wheelchair with the supply van while making deliveries along the narrow walkway. Wan did not say a word, just grunted and glared while a fellow resident helped him straighten his chair. He walks one lap around the courtyard every morning and afternoon, his right arm drawn in like an insect leg and his drop foot rasping in time to the clack of his metal cane.

During our visits he lights up as he vividly recounts all-night mahjong games and exotic travels, but when the conversation circles back to his present condition, he has little to say: "Nothing changes." "There is nothing I can do." "This illness will last until death." He admits it has gotten much harder to motivate himself, especially now that the headaches have gotten worse.

It was not always this bad. The first nursing home was good, but one day his daughter came and told him he had to move. The fees were too high. The government had razed the home he had built, and the money was gone. She packed up his few possessions and they drove away. "I thought we were going home!" He laughs now at his own naiveté, which triggers violent wet coughs and wheezy gasps. When he catches his breath again, he wipes his mouth and continues. He has not seen his daughter in two years. He understands, though. One day she said to him, "Dad, when you had your stroke the hospital fees were over 100,000RMB (about \$16,600 USD). What could I do?" She left him at Jade Hills and disappeared.

After she stopped paying, the management moved him from his first-floor room to one on the third floor. There are no elevators or ramps at the nursing home, so every morning the nursing assistant maneuvered his wheelchair and two-hundred-pound body down the stairs and every evening she pulled him back up. He stopped reporting the falls to the office once he realized they did not care. One day I arrived at the nursing home to find him with a bandage wrapped around his forehead. He had tipped forward out of his wheelchair while napping and hit his head on the concrete: "I think it would be much

better if I could die, but that is not my decision.” Although the staff had refused to fix his wheelchair’s flat tire for weeks, they did take him to a doctor to patch up his head.

The case of Wan Long is an extreme example of chronic living. Like other chronic illnesses, his did not have a clear cause, but all signs indicated that he could expect no relief or improvement. As Xiao Mei, the resident who had joined our conversation earlier, explained, “There is nothing you can do, nothing you can do, nothing you can do. This is just the situation. The circumstances have led to this place, and you can only obey the circumstances. There is nothing you can do.”

Pathological Pain

As a fundamental component of the human condition, pain is present across the life course. However, the physical, cognitive, psychological and social losses associated with late life can be a deep source of suffering for many elders (Attig 2015; Setterson 2006). In Wan Long’s case, his personal losses were exacerbated by the larger social and historical context he inhabited. His changing body was inextricably rooted in a world that “ceaselessly assails and beleaguers subjectivity as waves wash round a wreck on the shore” (Merleau-Ponty 1962, 241). These waves included the privatization and rising costs of health care, life-extending technological advancements, changing family dynamics, and the increasing individualization of risk (Yan 2009). The disruptions caused by these larger forces made his end-of-life experiences, both in terms of disease and treatment, painful to a pathological degree (Cassell 1991).

The subjective nature of pain makes it difficult to measure, but research suggests that nursing home residents report higher levels of pain than their community-dwelling peers (Abdulla *et al.* 2013). However, the typical treatments for pain—opioids and adjuvant drugs like antidepressants—are tightly regulated in Chinese hospitals, and virtually nonexistent in nursing home settings (Wang 2004). Without hope for relief, pain and life merge for many residents. “Now everyone says a long life is long suffering,” reported one elder in her eighties. She was relatively healthy, but had witnessed the lingering lives of those around her, including her husband’s, whose dementia was rapidly advancing: “I am not afraid of death. I am only afraid of being unable to die.”

However, it is not simply untreated pain that differentiates these cases of chronic living from non-pathological aging in China. Pain itself is a symptom of deeper disorder. According to principles of Chinese medicine, pathology arises out of disharmony or imbalanced energy. In proper balance, even disability, dependency, pain, and death have a place in the flow of existence. For example, Wan Long’s mother had also suffered a debilitating stroke, but, by his account, had a positive end-of-life experience and a good death. What differentiated Wan Long’s case from his mother’s was the series of familial disruptions he experienced and the corresponding dismantling of his family-based safety net. It is this deeper relational disharmony that gives rise to the pathological pain of elders suffering with chronic living.

It is difficult to overstate the importance of family bonds in the Chinese psyche. The character for filial reverence, *xiao* (孝), is made up of the symbol for “old” above the symbol for “young.” Although this can be interpreted in multiple ways, the two parts are clearly arranged in a relationship of balance (Ikels 2004). If the top becomes too heavy or the bottom too weak, the structure will be compromised. Increasingly, this is indeed becoming the new image of eldercare in contemporary China: an upside-down pyramid with aging baby boomers at the top and decades of singletons making up the tapering bottom.

This imbalance emerges at the intersection of larger social forces and shifting interpersonal relationships, and is a key concern in discussions about eldercare in China. While many focus on the burden this imbalance puts on younger generations, few recognize the disorienting effects it is having on older

generations. One female nursing home resident in her eighties echoed many of her peers when she asserted, “Life is meaningless!” As fertility rates have declined, elders, especially women, have had fewer opportunities to contribute informal labor to the family economy. Adult children have also become less dependent on their parents for formal economic support as China’s economy has developed, further eroding elders’ sense of purpose. These factors have also contributed to an ideological shift about intergenerational co-residence (Yan 2009). This shift is not simply happening among younger people. The majority of older respondents, both living at home and in nursing homes, expressed that they were not willing to live with their adult children. According to one hospital patient in her seventies, “We older people are accustomed to certain foods and ways of living that are different from younger generations. It is very difficult to bring these into harmony. There is also a generation gap between ways of thinking.”

Although fewer families are living in intergenerational households, family bonds still persist. For those suffering from chronic living, both the withholding and the demonstration of filial reverence have contributed to their condition. In Mr. Wang’s case, he suffers now because his daughter has stopped paying and visiting, but the thousands of dollars she did pay for life-saving procedures over the years also contribute greatly to his current state. Combined with the rising costs of medical care and caregiving services, elders who suffer from disabling illnesses, and even those who do not, recognize that they are not needed, only needy. As one nursing home resident in her eighties explained, “If I could die now, it would be a relief. No regrets. Because now each generation is better off than the one before. Seeing they have good lives, good jobs, is great. I don’t worry.”

Although very few elders I spoke to were living in nursing homes against their will, for many it was exceedingly difficult to maintain the health of relationships that distinguish a good life—and a good death—when physically dislocated from family members. Even when the decision was made voluntarily and out of love for one’s family members, it is true that “the most grievous components of human suffering take place in the experience of broken relationships and lost connections to those individuals and contexts that bestow on our lives positive meaning” (Wilkinson and Kleinman 2016, 9). So, it was for Zhang Wei, introduced earlier. Although he enjoyed keeping up with current events and suffered only minor physical aches and pains, he spoke often about the ache of this separation from family members: “At this [nursing home], what weighs most on my mind? There is just one thing: the absence of family. For people like me, whose minds aren’t yet confused, the biggest lack is family. For example, on Saturdays and Sundays, kids, grandkids, great-grandkids all come to see you. But they stay for about a half hour and then leave...I never ask them to come. I never make any request like that. But in my heart, the thing I lack most, is family.”

Despite sharing every meal with hundreds of residents and caregivers, Zhang Wei felt emotionally isolated. Zhang Wei was stunningly intelligent, and he feared too much contact with fellow residents would make his brain soft. For Zhang Wei, and many other institutionalized elders, the physical separation from family members weakened their connections to their social worlds. For the individual, active reciprocal relationships, or *guanxi* connections, constitute the self, and their disappearance amounts to a social death (Kipnis 1997). Although weekly visits fulfilled an emotional need, they were not enough to maintain the strong reciprocal bonds necessary for establishing one’s place in the social fabric. As Zhang Wei’s links to the wider world withered and fell away, his chronic living became chronic dying. He expected to live out the rest of his days in the nursing home, but whether that would be days or years, no one could say. “So now I’m here just, as I like to say, just ‘waiting’,” explained Zhang Wei, “Waiting for what? Waiting to die.” Resigned to the pain and intractability of their condition of chronic living and chronic dying, many institutionalized elders are nonetheless impatient for a cure: “Death hurry up! Now is just suffering, death would be better.”

Delayed Death

In conversations with the adult children of nursing home residents, a main reason cited in their decision to institutionalize was that parents were “safe” there. On the one hand, they meant safe from accidental falls and sudden illnesses, but on the other, they meant safe from themselves. Much scholarly attention has been given to the high rates of suicide among Chinese elders, which are more than double those found in the US—44% vs. 18%. (Wang, Chan, and Yip 2014, 933). The motivations for elderly suicide range from poverty to family conflict to serious illness, and rural women are especially at risk (Fei 2011). Institutionalized elders, though they may have similar motivations for self-harm, lacked the means. Rooms had bars on the windows, and sleeping pills were locked up. They were supervised at all times. This lack of control, chronic living with no access to a cure, weighed on the minds of many informants. On more than one occasion, elders asked me if I could buy some sleeping pills and sneak them into the institution. Suicide and euthanasia were common conversation topics. For example, as I was leaving Jade Hills one afternoon, I stopped to talk with Ma Meili, an outgoing resident in her late seventies, who was sitting alone in the shade. “Life is meaningless,” she sighed. I asked if she was in pain, but she said no, no pain, but “everything is uncomfortable.” She had no energy and just wished she could die. “It would be so much better if there was euthanasia, just an injection and then you’re done.” Life had meaning when she was younger, she explained, but now she can’t do anything. Looking out into the overgrown courtyard she cried, “I wish the water in that pond was deeper so I could drown myself in it.”

In her work on organ donation in Japan, Margaret Lock (2002) describes the emergence of a biomedically-informed “new death” that is timed and managed. Most of the elders in my research had also experienced biomedical interventions, but unlike Lock’s comatose patients, my informants were often outside the biomedical sphere as they waited for death, unfit for curative or salvage operations. As Ma Meili’s story shows, the “new death” they faced was one decidedly unpredictable and unmanageable.

Ma Meili, Zhang Wei, and Wan Long all experienced acute pain from being cut off from former social roles and relationships, an “interpersonal social suffering” (Kleinman and Hall-Clifford 2010, 250) characteristic of other chronic illnesses. In Ma Meili’s and Wang Long’s cases, suffering stemmed from inhabiting unproductive, consuming bodies in a society geared toward economic dominance, of being too-long in time and too slow to die in an era that put a high value on efficiency and speed. As with Zhang Wei, these elders experienced social death long before their unmanageable bodies released them (Biehl 2005; Lock 2002).

Wang Hua, a former schoolteacher, lived at Singing Meadows with her husband. She was nearing ninety, but her round face was still full and her eyes bright. Warm and gregarious, she played piano for the nursing home choir and penned their theme song. Although she was glad to bring happiness to others, she admitted she was “very tired.” Her husband’s dementia had progressed quickly over the past year, and she spent most of her time keeping an eye on him. Her one hope for herself was that she would die quickly, that the phone call to her children would be, “Your mom is already gone.” She did not want to linger in the hospital and experience all that comes with a prolonged death. She did not want to be saved from death, Wang Hua told me, she just wanted someone to hold her hand when it hurt.

Even relatively healthy residents worried about becoming one of those whose “bodies in time mean far too much” (Cohen 1998, 302). One eight-seven-year-old informant, who still lived in his own apartment, candidly told me: “I just wish I could go more quickly. I don’t want to be in pain and suffering. This kind of thinking isn’t like that of religious belief. Religions teach that while you are here, think about the next life. I just want a quicker death! Ha-ha! A sudden one would be best, but that is not good. For people who

care about you that is not good.” Through death, elders sought to liberate not only themselves, but also their loved ones from the burdens of chronic living.

Resignation: *Mei Banfa*

In the face of their intractable conditions, elders’ most common response was resignation. In fact, all those involved in the caregiving situation frequently expressed feelings of resignation. The phrase, *mei banfa*, which literally translates “there is no way”, has a meaning closer to “there is nothing you can do about it.” For example, when I asked care workers if they found their jobs monotonous or residents if they were used to living at the nursing home, they would frequently answer, “*Mei banfa*.” Residents frustrated about their inability to move forward to death or backwards toward life also concluded: “*Mei banfa*.” One nursing home resident summed up the whole nursing home experience as simply a “*mei banfa de banfa*” or “what you do when there is nothing you can do.”

In her recent book *Resigned Activism: Living with Pollution in Rural China*, Anna Lora-Wainwright (2017) noted that *mei banfa* was also the most common response her respondents gave regarding pollution. She saw it as her respondents’ “way to convey their own feelings of powerlessness” and “a means through which they comfort themselves about the limits of their agency” (xxvii). This functions in a similar way in eldercare institutions. Even though Zhang Wei told me “living is a very boring thing,” as with many events in his life, his power to control or change it was limited.

Conclusion

Not all nursing home residents suffered from chronic living. Some derived great joy from the company of fellow residents and caregivers or busied themselves with games, crafts, and music. Others found hope and peace in religious beliefs of heaven or reincarnation. Even those who did find themselves suspended between living and dying experienced moments of delight, excitement, and laughter. Indeed, Ma Meili, who often seemed hopelessly hopeless, once surprised me by exclaiming, “What fun this life is! We are constantly learning.” The point of this article is not to create a spectacle of suffering, but rather to portray the full experiences of those whose lives are caught in the eddies of change (Kleinman 2010), not out of pity, but out of “respect for great misfortune, for great ugliness, for great failure.” (Nietzsche 1977, 378).

Through the experiences of today’s elders, one can see flows of desire—economic, technological, and individual—moving ever outward and forward, each driven to expansion, to creating better lives for future generations. New possibilities are celebrated and new forms of living realized. Today, huge portions of the Chinese population can travel freely for work and play, adult children can afford their own homes, and patients can recover from previously incurable diseases. However, this mountain has a dark side as well. Demographic changes have transformed the shape of families and increasing life expectancies and rates of chronic illness have extended the period of decline. Many who are saved from death but not disability or dependency are left in economic ruin and have to choose from a range of poorly regulated caregiving facilities in which to spend their final days. As a result, growing numbers of elders no longer experience the dying process surrounded by family members. Isolated from the primary source of meaning-making and identity-formation, social death occurs long before physical death releases them.

As health care practitioners, policy makers, elders, and family members search for new and better ways of extending life, it is necessary to also expand notions of and possibilities for a good death. Recognizing and identifying chronic living brings these lives out of the “zone of indistinction” (Kaufman

2005) and into serious discussions about quality of life and end-of-life care. For Chinese elders in particular, more attention needs to be paid to the role social isolation plays in end-of-life suffering. Strategies to maintain meaningful social connections could go a long way in improving quality of life, especially among institutionalized elders. Many of the elders I spoke with were adamant in their belief that there should be more public discussions about right-to-die policies in China, and discussions of suffering and death are necessary counterweights to reports of institutional eldercare investments and life-extending technological advancements. Out of compassion for our current elders and future selves, our pursuit of life's creative potential must be balanced with equally brave explorations of aging, dying, and death.

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