When Frost Happens
A Case Study of an Organization Committed to Care

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ABSTRACT: This article draws from my time spent working as a caregiver in a 350-plus resident not-for-profit Continuing Care Retirement Community (CCRC) in the American Midwest. Caregivers working in CCRCs provide care and support to elderly residents who live out the rest of their lives in these transitional ‘homes’. Yet even these organizations are transforming and changing the way care is being constructed and delivered. This paper examines how a long-term care facility (LTCF) is grappling with specific discourses about the nature of person-centred care, and its self-professed commitment to the journey of life. I show ethnographically how an organization centred on the business of care deals with the process of ageing, and that while the life course has been subject to forms of social and medical regimen, the ageing person is ontologically greater than his or her experiences in the nursing home, no matter how totalizing the institution.

KEYWORDS: ageing, caregiving, corporate culture change, Eden Alternative, nursing home ethnography

The physical marks of ageing are undeniable, and they are familiar to everyone. Even Siddhartha, who was once kept from seeing senescence at an early age, eventually cast his eyes on disease, poverty and the frailty of old age. Despite one’s recognition of mortality, ageing can never be disassociated from the looming prospect of death. One can ask, of course, what agency does a very old person have besides simply just waiting for time? And so the teleological story goes, as one grows older, death creeps closer. Contemporary Western society wages war on ageing; the issue is not just about longevity and the desire to continue experiencing and consuming, but also about capturing and sustaining youth in perpetuity. Therefore, what is or can be eked out of our final hours?

For the residents in a nursing home, death is not an anxious bogeyman, keeping people up at night. Death is a common occurrence in the nursing home, but it is assigned moral valences and significations according to differing personalities, contexts and the way specific acts of dying are seen to give meaning to one’s life course, much like the final chapter of a novel. Therefore, and apart from clinical bouts of psychosis, death does not provoke constant anxiety in the nursing home. At best death is like the sun, something you can look at but not for too long.

There have been plenty of nursing home ethnographies, some of which showcase the helplessness and inert liminality older people face in institutional prison-like settings. We have, on the one hand, the work of Renee Rose Shield, which has detailed the passivity and loneliness of nursing home residents (Shield 1988). Shield argues that residents are
trapped in a liminal space between a lifetime of meaningful ritual passages, and death as the unwanted rite of passage. Judith Okely, prompted by the personal experience of her mother's ageing and dying, has also written about the subject of love, care and diagnosis, including a very sombre article (Okely 2001). Meanwhile, Barbara Myerhoff's classic account of storytelling and ritual among a Jewish community of elders shines on as an optimistic gem, but I cannot help but sense a subterranean tinge of lament and nostalgia (Myerhoff 1979). Early U.S.-based nursing home ethnographies have documented how persons come to be passive recipients of care. They have also shown us how mortification of the self (Goffman 1961) is linked to various institutional practices and ideological constructions. In the U.K., current ethnographic studies of care have taken on a slightly different approach. For example, Jenny Hockey argues for incorporating non-Western notions of personhood into palliative care situations (Hockey 2008). Rather then treating the 'self' as a 'container of identity', examining how the boundaries of bodies can be challenged and fluid is key for her to reversing institutional stigma and social death. The focus on the body leads out into the nexus of contexts. On the one hand we have the shifting political economy. Peace, Kellaher and Willcocks argue that the ethos of residential care is changing; the care industry as a profit business affects the way policy-makers and anthropologists will have to reconsider the analytical divisions between nursing home (medical) and residential care (social) models (Peace et al. 1997). Meanwhile, there has been a focus on new social environments and ageing. Several anthropologists have been keen to study for example how new residential projects are reconceptualizing the tensions between the public and private, domestic and institutional living arrangements, and the interactions between persons and their environments (McCourt 2000; Peace and Holland 2001).

A new discourse is also emerging which is focused on a nursing home culture-change movement in an effort to empower (and reverse the de-skilling of) caregivers so that they can deliver resident-directed care (Rahman 2008). It is this kind of resident or rather person-centred care that is at the heart of this emerging discourse, focused on the promotion of: 'autonomy, and self-determination, and emotional and social wellbeing' (Brownie 2011).

Long-term care facilities are not quite what they once were. I do not have time here to get into the history of care homes and religious manor communities, but rather the point is that nursing homes in the U.S. which were once more like geriatric hospitals and psychiatric wards, have given way over the past few decades to new models and organizational settings for the elderly. Long-term care facilities come in various shapes and sizes now. This paper is based on my fieldwork, where I worked as a caregiver in a long-term care facility, known as the Continuing Care Retirement Community or CCRC. This CCRC is situated in the American Midwest, which I will refer to as Tacoma Pastures.

Unlike the traditional nursing home, CCRCs allow residents to remain with one institution including its buildings and grounds, permitting them to move in accordance with their medical/ageing needs and levels of care. In other words, CCRCs are designed to allow people to age in place. The rationale behind this type of senior housing model is that moving rooms within an institution is less stressful than external moves, and that transitions can be better monitored and controlled. By engaging with the work of G.J. Andrews, we can see that healthcare institutions such as CCRCs can be viewed as therapeutic landscapes or rather contextual settings that are complex and full of symbolic constructions (Andrews 2004; Pranikoff and Low 2007). For some, CCRCs are therapeutic because they allow caregivers and care receivers to: ‘understand more about how
transitions in activities are related to the various dimensions of well-being in older adults’ (Cutchin et al. 2010).

CCRCs are also equipped with a range of amenities like gardens, small golf courses, small libraries, beauty salons, etc. Places like CCRCs are becoming more popular, because they are sold on the basis that once a person decides to invest in the community, they are guaranteed a place and continuing professional care no matter how they age. In one conversation with the Executive Director of Tacoma Pastures, I was told that: ‘There is a continuum. Life has a continuum and we match services and living spaces with that continuum. Life is a journey, and we are committed to that journey.’

Frost Happens in the Garden of Eden

Nursing home reformers – colloquially known as nursing home ‘abolitionists’ in the U.S. – can trace their roots back to the work of Harvard-trained doctor Bill Thomas. In the early 1990s, Dr Thomas and his wife founded the non-profit Eden Alternative culture change model in order to work towards deinstitutionalizing long-term care facilities by alleviating their professed ‘three plagues’ of ageing: boredom, helplessness and loneliness. These plagues soon blossomed into principles, a biblical ten to be precise, and today the international not-for-profit organization has grown in size. According to Brownie: ‘at least 200 American aged care facilities have adopted the Eden Alternative’, and there are ‘Eden Alternative facilities in the United Kingdom and Ireland; European countries, including Germany, Austria and Switzerland; Scandinavia countries, including Sweden, Denmark, Finland, and Norway; Japan, and other countries’ (Brownie 2011). The founders of the Eden Alternative idea describe their mission as being: ‘Dedicated to transforming care environments into habitats for human beings that promote quality of life for all involved’. It is a powerful tool for inspiring wellbeing for elders and those who collaborate with them as care partners. Furthermore, managers working in long-term care facilities that wish to ‘Edenize’ their institutions are encouraged to: A) Treat employees appropriately, B) Ensure that decision-making is nearest the resident, C) Commit to changing the living/working environment and D) Persuade everyone to grow continuously.

In a nutshell, Eden’s ten principles are aimed at granting elders more decision-making powers by reversing what is perceived as top-down bureaucracy. Eden is also about creating more human spaces: so that plants, pets, and visits by community children to the CCRC provide, as stated on their website – ‘a pathway to make life worth living’. Principle seven stands out in particular, which states: ‘Medical treatment should be the servant of genuine human caring, never its master’.

At Tacoma Pastures, there are plenty of bird-cages (with birds), plants, and motivational posters presenting life as a journey, and a tree – a somewhat obvious yet elusive symbol. I came to Tacoma Pastures shortly after their Culture Director (an official position created at Tacoma Pastures to help the community realize Eden principles) was fired. After he was let go, Tacoma Pastures decided not to fill his position again, and not surprisingly, no-one at Tacoma Pastures took on board the mission of Eden very seriously thereafter. People working in long-term care facilities pay money to attend various Eden workshops in order to become certified and sponsored. Once they do so, they are Eden Ambassadors, and sometimes are seen by the management as overly proselytizing provocateurs. Harry, the Culture Director, went out of his way to go against the grain of ‘business as usual’. For one thing, he never wore scrubs (a protective garment worn by doctors and nurses) and very much wanted caregivers to abandon wearing them as well. Some people dressed down and joined Harry in extricating the scrubs from their wardrobes.
When he left, however, people slowly returned to their scrubs. Even I caved in to the social pressure of wearing scrubs. I soon noticed that wearing the uniform gave me a sense of self-congratulatory professionalism, security and acceptance among my fellow caregivers. I had the looming sense that an elder would listen to me more, or rather allow me to take them to the toilet after a meal, or every two hours, without any refusal or complaint. It was a requirement to take each resident with dementia to the toilet every two hours. There was even a computer programme we had to enter in in order to document the tasks we performed, including the type of stool that someone produced or did not.

Fellow caregivers often commented to me that when the Culture Director was still at Tacoma Pastures, things were fun. Caregivers were allowed to eat pizza with the residents, and people generally had a more laid back attitude. Even workers in the kitchen and the hospitality department were able to postpone some of their cleaning chores to hang out with the residents, and they were paid for this time. There was certainly a shortage of caregivers; on average one caregiver was in charge of assisting and caring for twelve people. Because of this and the incessant nature of the task-list system, caregivers did not have time or feel comfortable socializing with their residents. Moreover, there was a ‘social defence system’ being resurrected, a system eliminating situations that involved the experience of anxiety, guilt, fear and indecision (Menzies Lyth 1960).

We are familiar with corporate mission statements about change, innovation, transformation and customer service. Long-term care facilities use the Eden certification as a marketing scheme to demonstrate to a prospective family member, usually the daughter of an elder, that their ‘community’ is a friendly and humane place. Although, I could not help but feel that this made people feel less guilty about checking their loved ones into the CCRC. At Tacoma Pastures, especially with Harry gone, the Eden marketing ploy became a set of jokes and empty signifiers.

Eden did leave a few lasting impressions. For one thing, the directors at Tacoma Pastures decided to embark on altering the everyday language. During my first day on the job as a caregiver, I was given a sheet of paper as part of my orientation, entitled: Culture Change Terminology. Patients or seniors were now referred to as residents or elders. Other categories were given a make-over: facility/building gave way to community; the main dining room was now the scenic view dining room; a welcoming replaced the traditional ‘admission’; tours were visits and a room or bed was replaced by the preferred ‘apartment’. Additionally, sweetie or honey was replaced by people’s real names or sir/madam, and passed or passed away was to be used instead of expired. The scheme was simple enough, one did not need a meditation on the Sapir Whorf Hypothesis to recognize that ‘culture change’ in the words of an Eden Ambassador: ‘was about transforming a facility into a home, a patient into a person, and a schedule into a choice’. The intentions were certainly well placed.

Instead of herding old people together into some kind of care factory, Tacoma Pastures wanted to focus on personalized, or rather person-centred care as part of the marketing strategy. Additionally, Tacoma Pastures wanted to make its space more homely and familiar to its residents. The Director of the Resident Center once said to me, ‘Our elders are the first and the last, we are trying to make Tacoma Pastures a place, a community, and a home for everyone. You can think of it as a home of homes.’ The managers and finance directors at Tacoma Pastures were also very aware that people could cash out of their investment at any time, but they wanted people to stay and age there in order to continue receiving their monthly fees. Checking into a CCRC is a kind of life annuity policy, and there is a whole actuarial science around the accounting and calculation of bed replacement rates.
To put it flippantly, Eden did not interfere with the regimen of toileting, dressing, bathing, feeding, poking, prodding, moving, measuring, and surveillance. Tacoma Pastures’ recreation department aligned their activities to some of Eden’s principles. For instance, in combating boredom, the recreation department put together daily events. These events included movie showings, one-on-one visits, sing-alongs, making dog food snack mix (which is made from Crispix cereal, peanut butter, marshmallows, and chocolate chips), bingo, having people sit together and bounce a balloon around the circle, and even bringing local school children to whisk bubbles in a plastic bowl of washing up liquid with the elders.

One of the other Eden principles, however, was also being simultaneously neglected, namely Principle 6: meaningless activity corrodes the human spirit. The opportunity to do things that we find meaningful is essential to human health. When there is no scheduled recreation event, or field trip to the local shopping mall or garden, people spend most of their time wheeling back and forth, circling around common spaces in front of the elevator, sleeping in their wheelchairs, and just plain waiting.

After Harry left, the term Eden became an adjective. People referred to certain acts of caregiving or attitudes as either being Eden or not. For example, when I took my own time after a work shift had ended to sit with an older woman in her room just to chat, a fellow caregiver said to me, ‘that’s very kind of you, very Eden’. Caregivers also attended mandatory bi-weekly staff meetings in order to receive announcements, and to discuss issues with the management about the work schedule, or the implementation of a new lifting device. During these meetings, they would often remark to each other after hearing the director go on again about creating a human habitat, ‘I was always Eden. Even ten years ago before all this shit, I was Eden before Eden. I just don’t understand all these new pillars. They are stupid’.

The people at Eden have come to realize just how hard it is to implement their sense of change. And partially because of the business need to remain lucrative, the Eden Alternative requires its long-term care participants to recertify every three years. Re-certification is not a lengthy process, but it does require a new application. The submission package consists of indicating the number and nature of events and activities that have been put on by the long-term care facility. The application also comprises of resident surveys that are actually filled in side by side with a caregiver on the computer, and other fundraising information. There is also a form, requiring such data as: caregiver drop-out rates, evidence of team scheduling, pertinent training sessions attended, if and how care plans have addressed the three plagues of ageing, and even marking down whether or not the manager is present in the dining room during meals. Eden has not been scripted into the care plans, which are compartmentalized into sections denoting: bathing times and special needs, vision and hearing abilities, mobility and transfer requirements (for example, whether or not the use of a mechanical lift is needed or whether two people are needed to help move someone), degrees of incontinence, allergies, and dressing and grooming habits.

There is a division of labour at Tacoma Pastures. Med-Techs primarily hand out medicine, caregivers do all the bed and body work, while recreation assistants organize and entertain residents with a calendar of ‘fun stuff’. But there is something odd going on. Recreation is blocked off as a time for fun, but not for self-expression. For example, residents are evaluated even during their sing-alongs by the recreation assistants. When someone appears to be anti-social, meaning that they do not want to participate, or are not interested in making dog food snack mix, this information is jotted down, and may come to resurface during a meeting with Tacoma Pastures’
resident counsellor. But what happens when someone is receiving care? What kind of self-expression is allowed? Is crying and screaming allowed? Even though care is personalized, too much of someone’s unique behaviour or habits is looked upon as an interference to care. Giles Perring’s study of the cultural phenomenon of non-disabled artists working with learning disabled persons in London sheds light on the embeddedness of our assumptions in various social artistic and recreational practices (Perring 1999). Even though the elderly are not disabled in the same sense of learning disabled persons, a ‘deficit’ model of personhood arises in both instances. In Tacoma Pastures, bingo, for example, was not a therapeutic exercise. The social and recreational activities that were put on as part of Eden were also not ‘functional’. Unlike certain approaches to art therapy, whereby the process of experiencing/creating art leads to some kind of healing, old age is not something to overcome. Rather, the trivial and mundane activities were arranged to fill in the emptiness of time in the long-term care facility. There was nothing countercultural or empowering about the disciplining nature of these institutionalized recreational activities.

Fred: The Care Receiver

Let me take a slight turn and briefly explore care from the other side, from the side of the recipient. McKechnie and Kohn tell us that the ‘view of recipients of care as passive subjects is being challenged on several fronts’ (McKechnie and Kohn 1999: 7). Even paying-residents in your average nursing home are more than aware of, ‘[…] the individualization of responsibility and sequestration of experience. The importance of choice, consumption of self care and self-help is creating new kinds of ways for individuals to experience and participate in their own care’ (McKechnie and Kohn 1999: 9). And so, it is with this backdrop that I introduce one of the residents I took care of, and cared for – even after his death – Professor Fred Lieberman.

When I first met Fred, he had just moved to the fifth floor of the nursing home. He was a retired Jewish professor of Humanities and East Asian Culture at the local state university. A couple of things immediately caught my attention. Fred always wore a grey golf flat-cap, and behind his square glasses, a pair of deep-set intense eyes was always scanning you and reaching for some truth that even you were not aware of. I assisted Fred in the mornings and afternoons, particularly with transferring him out of bed and into various chairs. He could not bend his knees, and because of this he had very swollen calves and feet, which I had to lotion up every morning while wearing disposable transparent latex gloves. Additionally, Fred did not fit my false and preconceived notions of what old people smelled like; he was a chemosensory lesson. He ate chocolates like a kid on Christmas morning, and watched Fox News with a set of headphones which he had on full blast – all the time.

Fred took a liking to me very quickly, although I soon found out that he preferred female caregivers. I was only the top of his list regarding male caregivers. Upon learning that I was an anthropologist-in-training, he enjoyed telling me of his trips to Japan and his papers on Chinese poetry and the sociology of the Bolsheviks. As we started to get to know each other more, or rather as we chattered on while I was holding Fred half naked in my arms positioning him into the wheelchair, he wanted more of my time. This began with him trying to solicit me in helping him write a paper called ‘Pee and Poop’. This was his way of wanting to ‘get to know how things worked, who was showing up, calling the shots … there are so many decisions and whispers here’. I knew that his proposal was not serious; he did
not have the strength or the focus to write. He did not even have a laptop or typewriter in his room.

Fred became very aware of me trying to read him, and even picked up that I was trying to negotiate a little distance. I was spending too much time with Fred, and I really needed to help the other residents. Other caregivers soon noticed Fred’s ‘passive aggressive attention seeking’. To be fair, Fred was not the only resident clamouring for attention, ‘customer service’, and time. It was only Fred, however, who pushed his call button necklace incessantly. Our beepers were literally going off every five minutes, and when we came to Fred to enquire if there was something we could do for him, he either looked at us in disgust, or feigned some kind of wheezing condition. On many occasions, I saw caregivers simply ignoring his call button, but rather than give up, Fred turned his attention to the next available caregiver and yelled help!

It was not more than a month after I first met him, that I started noticing that he did not help me at all during any of the transfers. This made lifting Fred incredibly difficult and dangerous. On one morning, I was not paying attention to Fred’s usual line of complaints and accusations. As I secured him onto the toilet (or so I thought), and turned away, Fred had managed to pull himself off of the toilet and halfway onto the floor. I immediately rushed to him, and said, ‘What happened?’ He replied, ‘What are you doing?’ He looked mean and purposeful; he also added with spite, ‘I am dying.’ Fred slipped and fell a few more times during my care. Whenever he did so, he would look up and say, ‘Are you happy now?’

Fred was a resident who struggled to understand the fragmentary ‘system’ of care unfolding around him as he tried desperately to evoke empathetic responses from his caregivers. If those who give care do so in a non-reciprocal fashion, their power is overturned by recipients who use time to exploit and challenge the boundaries and regimes of care.

Conclusion

As a key concept, care is contested and articulated at various transitional points and spatio-temporal sites within Tacoma Pastures. More than this, care is transversal in the way that informal and formal caregiving continue to co-exist even though one tends to think that checking someone into a CCRC means outsourcing care completely. It must be noted that while many long-term care facilities do not participate in the Eden Alternative, they are certainly becoming more sensitive to the ambivalence, challenges and complexities surrounding care. Tacoma Pastures is a workspace for formal caregivers, and a home space for residents and their visiting family members who continue to visit them and supplement formal caregiving with acts of informal caregiving. The division between informal caregiving (care provided by family and friends, usually in the context of one’s domestic household) and formal caregiving (care provided by paid professionals in a setting like an assisted living complex) is not clear-cut, because care plans do not spell everything out. They are necessary but not sufficient in and of themselves.

This article has been motivated by three questions I have been carrying around for a while, and which we may now be in a position to begin addressing. Firstly, why are so many of the residents and working caregivers at Tacoma Pastures dissatisfied with the quality and level of their interactions between and amongst each other? There is a ubiquitous ambivalence over the nature of care. Caregiving can be an invidious task. Part of this has been taken up by the management in trying to adopt new strategies and certifications like the Eden Alternative in order to champion a Western-inflected notion of individuation and person-centred care. Perhaps, part of the reason is that care is a never-ending project; it is not a stable practice because people are ageing and changing all the time. Furthermore, practices of care must square with the fact that people consist
of contraries; the field of care, and of need is always emergent and one step ahead of care practices and its various manifestations.

The second question is why has it been hard for Tacoma Pastures, despite some of its limited investment in the Eden Alternative principles and governing practices, to change its ethos? Eden principles have not infused the practice of care in any holistic sense. Eden has been a tag word, and a concept, which via the CCRC’s division of labour has been relegated to the recreation department. When Tacoma Pastures first embraced Eden, it went on a mission collecting residents’ biographies, hobbies and interests. Nailed to the inside door of every apartment, was a one page ‘CV’, a summary of that resident’s interests, including location of birth and even favourite ice cream flavour. Such information was provided by the residents themselves, and probably with the help and nudge of their family members. But these interests were of and in the past. Someone may have enjoyed fishing before, but that was because it was a social activity, an activity between friends and brothers. Simply putting up posters and magazine cut-ups from fishing magazines just did not resonate with most of them anymore. Tim Ingold recalled a particularly frustrating discussion he had with a GP working with older hospital patients (Ingold 2012, pers. comm., 29 June). The GP recognized the importance or rather the linkage between nature and wellbeing, and so he supported having pictures of nature, of waterfalls around. But according to Ingold, this particular GP had missed the mark. Windows need to be open, so that patients and residents at long-term care facilities alike can witness that nature is a process and going on outside them and in them. The linkage is not merely a word-game or a style of Pictionary therapy, but rather understanding that when people meld with their natural surroundings, it alters their ontological projections and processes.

Meanwhile, care plans have remained close to objectifying the body, both physiologically and as a kind of bed to be made and cleaned. The care plan gives the basic outline of tasks to be performed, so that even a part-time caregiver can understand the nature of functions to be performed and plan his/her work accordingly. It also, however, objectifies people so that they are, become, what is done to them. Therefore, for example, Emily is the cumbersome one (she is picky about how her sheets are made), and Grace is the demanding one, because she requires two and often three people to assist with her mobility transfers. The residents are often defined by what the caregiver needs to do to them, so there is a relational structure indexed to particular care plans, and even how those care plans break down in the face of change.

The last question is, just what kind of organization/institution is Tacoma Pastures? Does it even make sense to regard Tacoma Pastures and for that matter other kinds of long-term care facilities as ideological constructions and bounded instantiations of values, norms and historical configurations of social relations? One approach is that it may no longer be tenable to treat organizations and/or institutions such as the CCRC as bounded entities populated by rational utility-maximizing persons. Instead of trying to figure out just what kind of institution a CCRC might be, the anthropologist is probably better off stepping back, and realizing that the ‘problem’ and fear of old age and ageing sits out there in society without any formal and/or ritual binding. There are no doubt legal and financial/secular rituals involved in ageing, but as a concept and a process which is given over to biological and cultural over-determinisms, ageing itself is being re-instituted and quarantined in new contexts such as the CCRC. Being in the presence of the residents and interacting with them under the guise of formal caregiving has allowed ageing to become more than just a discourse or an object of medical gaze. There is a complex and generative space opening up to think critically about the life course not as a cycle or succes-
sion of stages, but as a series of moments of instability and disorder – bringing forth its own re-orderings. This may not amount to an argument about the non-institution (De Pina-Cabral 2011), but if care is institutionalized along with the ideology of ageing, persons may not fit into such neat materializations, organizationally or even socially. In Tacoma Pastures, I saw many flowers, some withering, but I could not imagine the garden.

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