Journal of Aging Studies 49 (2019) 1–8

Contents lists available at ScienceDirect

Journal of Aging Studies

journal homepage: www.elsevier.com/locate/jaging

Forced continuity: Explorations of biographical narratives in dementia care

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Introduction

In his book *Asylums*, Erving Goffman (1961: 22) famously claimed that North American mental hospitals display the distinctive characteristics of "total institutions". "In our society", he declared, "[total institutions] are the forcing houses for changing persons; each is a natural experiment on what can be done to the self". The 1960s also saw the publication of Cumming and Henry's (1961) *Growing Old* and the introduction of the "disengagement theory of ageing". Ten years later, Atchley (1971, 1989), put forward his "continuity theory", as a foil to disengagement and an expansion of Robert Havighurst's (1968) "activity theory". While helping catalyse the reform of mental health systems in numerous countries and fuelling the anti-psychiatry movement, Goffman'sand other works ended up painting care fairly one-dimensionally. Particularly in dementia care, it has been argued, this is still a commonplace practice, as representations of care institutions are often overdrawn and their depiction can be insensitive to the intricacies of everyday life and the invaluable work care workers perform (e.g. Zimmerman et al., 2005 or Walmsley & McCormack, 2015).

Times have since changed. Over the past decades a rapidly growing and diverse corpus of research has emerged; dedicated to the intersection between ageing, personhood and dementia care. One thinks especially of Gubrium (1975, 1993), Lyman (1989) or Kitwood (1997), as well as Herskovits (1995) or Post's (2000) writings. Likewise, Kaufman (1986, 2000, 2005, 2017), Sabat (2002), Buch's (2010, 2013), Stacey (2011), Jenkins (2014) or Kontos, Miller, and Kontos's (2017) contributions to the discourse on self- and personhood come to mind. It also seems important to mention the proliferation of anthropological writings on "care", as seen with Thomas Gass (2005), Leibing and Cohen (2006)), Leibing (2008), McLean (2007), Rodriquez (2014), Duffy, Aremnia, and Stacey (2015), and particularly Mol, Moser, and Pols's (2010) recent additions.

Along with such paradigm-shifting knowledge and scientific insights; new concepts of care have arisen. They place emphasis on holistic treatments and gave birth to "chronic disease care" models, "palliative care", "community-based care", or "relationship-centred care" approaches (see for example Small & Downs, 2006). These models all share similar characteristics, identifying person-centred care as a core concern. They conceive of patients as a layered and fractured collage of voices who need to be drawn with detail and shade. Moreover, they aim to avoid unwarranted hospitalisation, empower patients to cope with and know about their conditions, and facilitate collaborative decision making between the physicians and patients (Haeusermann, 2014, 2016). Most importantly, they allow patients to remain in control of their own narratives and envision the self as a continually developing story (Kenyon, Clark, & de Vries, 2001; Ricoeur, 1991).

Acknowledging the multiplicity of a person's lived reality bears particular promise for persons with dementia. The prospect of losing one's mind – as dementia's literal translation insinuates – is very frightening indeed. It suggests losing one's place in the adult world. It implies a painful amputation from one's former self. Once one descends into a state of increased cognitive deterioration, one imagines, layer upon layer of one's self disappear along with a lifetime of memories. Yet placing our notions of selfhood merely in the brain 'reads as a curious echo of nineteenth century phrenology with its materialist longing similarly to locate highly complex behaviours, feelings and dispositions', state Dai Rees and Steven Rose (2004: 68) compellingly. We thus need to keep in mind the enormous variability of cognition rather than assume its determining powers. Creating dementia care approaches that are demedicalised, deinstitutionalised and supportive of the person is therefore both vital and humanising. Besides treating elderly persons who show signs of forgetfulness and other cognitive decline as patients who need to be cured, we should also see them as the new persons they have become. Persons who nevertheless require care and protection. And every so often, it does not matter whether care needs in old age result from dementia or the ageing process itself. It is the need for care and how it is delivered that is important.

While person-centred approaches have redrawn the care contours in innovative and often beneficial ways, however, they also pose new ethical questions. For dementia care, in particular, some care models and theories can lose their relevance and explanatory force, as a person's ability to craft coherent narratives is precisely what is at issue (also see Leibing and Cohen's (2006) assembled work on culture, loss, and the anthropology of senility or Haeusermann (2017b)). With the notion of a diminished or diminishing self long underlying the dementia discourse, the questions guiding our inquiry should also mould to different models of selfhood that underpin our culturally sensitive and highly contextualised notions of dementia.

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https://doi.org/10.1016/j.jaging.2019.02.001
Received 3 July 2018; Received in revised form 10 February 2019; Accepted 21 February 2019
Available online 06 March 2019
0890-4065/

Consequently, it seems important to explore how even the most progressive efforts to provide person-centred care may lead to yet new violences. In this article I thus present three case studies of care relations in Germany's first dementia village, based on ethnographic research conducted through participation in care work. Throughout I draw on conversations and observations of interactions among care workers and residents of the dementia village. I argue that selfhood of people with dementia in this setting is emergent - rather than simply being preserved - and that what goes on in the care institution is more nuanced and multifaceted than is allowed for by Erving Goffman's influential writings on the "total institution". By introducing a thesis of what I call "forced continuity", I hope to point to an important, often unforeseen consequence that may be happening as particular visions of what personhood means are being promoted in various facilities. Sometimes this can occur in contradiction to allowing the person to be. Some care approaches may therefore perpetuate a particular concept of person, continuous with the past, even though it might not reflect the relational experiences of the person in the present. As such, this article follows a path carved by many social scientists who have adopted a qualitative approach to add more nuance and complexity to the elderly care discourse.

The care environment

We find one new care model which seeks to address those pressing questions applied in Germany's first dementia village. The village adopts a naturalistic model which attempts to create a sense of community without borders. It aims to encourage freedom and continuity with life before entering the village, arguably to reinforce the residents' functional ability. The concept follows the example of a pioneering Dutch care facility, the *Hogewey* nursing home, which, at its opening, was the world's first and only village for dementia patients. The elaborate experiment was initiated more than 20 years ago, accompanied by polemic and strong opposition from critics who had reservations about the proposal to allow dementia patients to live without locks and with only minimal medication. Despite the vocal opponents, the home was set up in the Amsterdam suburb of Wesp in 2009, almost fully funded by the Dutch state (Carpenter, 2012; Hurley, 2012). The village is made up of different homes, each catering to a small group of residents. These are categorised into diverse 'lifestyle categories', which entail housing for the Dutch upper class, homemakers, trade/craftsmen and women, as well as religious, cultured, Indonesian, or urban citizens (Berry, 2013; Henley, 2012; Tagliabue, 2012).

Germany's first dementia village lies in Hamelin, around 200 km west of the Dutch border and a half hour drive southwest of Hannover in northwest Germany. It features four houses, all decorated in different colours and themes. Within a fenced-off space, the houses allow roughly 50 residents to feel at home away from their former homes. Based on a philosophy encouraging the preservation of the person with dementia by minimising medications and use of locked passages, while encouraging normalisation of life, this model aims to maximise freedom and minimise the medicalisation of dementia care. The particular focus of care workers at this German village is the care and satisfaction of physiological needs like food and decent housing, protection from economic concerns and the satisfaction of relational needs through friendship and affectionate social interaction, and respect from care workers. Despite the many positive features of dementia care in this village setup, however, I will try to demonstrate that through its deliberate effort to preserve the historical person with dementia, the type of persons produced could, inadvertently encourage a kind of pressure that interferes with the flow of life of the residents – by promoting a "forced continuity" of the resident's personhood consistent with their predementia, preadmission status [1].

Methodology

Between May and December 2014, I conducted ethnographic research in the new German dementia village. This included a four-month period of intensive study, during which I lived in Hamlin. I spent nearly every day at the village, observing the typical daily activities and assisting the care workers in their care routine. In August of that year, I accompanied the night shift workers for one month in order to gain insight into the village's night-time care activities. In total, I observed approximately 650 h of care work, which entailed countless conversations with care workers, residents, and administrators, and attended around 60 handover meetings [2]. In a second stage I revisited my fieldnotes and transcripts and translated them from German to English. I then coded the transcripts without preconceived notions in mind (*open coding*). Throughout this process, I wrote up theorising ideas about the codes and their relationships (memoing), which, in a later step helped conceptualising how the different codes relate to one another (theoretical coding). As a result, core categories emerged. Finally, I conceptually sorted my memos and rephrased and reconstructed the narratives into more refined and polished ethnographic texts (also see Bryant & Charmaz, 2007).

As is standard procedure at the University of Cambridge, the initial approval to conduct my study was granted by the departmental ethics review. I also gained approval by the manager, the head nurse, and the foundation council of *Tönebön am See* and the *Tönebön Foundation*. Once I became embedded in the dementia village environment, the head nurse introduced me to all residents as a doctoral researcher and we explained together the aims of my study and what my role as a researcher would entail. To guarantee confidentiality and anonymity, my research complied with the Data Protection Act, which requires data to be anonymised as soon as it is sensible and practical to do so. In this manner, I strived to protect privacy and confidentiality throughout my research analysis and anonymised all my participants during the coding phase. As a result, all participants remain anonymous and in all cases aliases are used to protect their anonymity. As a researcher, I did my very best to limit any invasive, intrusive, or uncomfortable questions that might have caused any psychological harm. Additionally, the residents and care workers were told at the outset of the study that their participation and responses would in no way interfere with their care provision. Before my interactions with both the professional staff and the residents, the participants were also reminded that nothing needed to be discussed against their wishes and that they were free to cease the conversation at any time.

Mrs. Fontana [3]—cooking at play

The village care concept is intended for the residents to find strength and value in the normality of village life. All activities – whether they be cooking, washing clothes, or watering flowers – were supposed to be exercised by both the residents and the care workers. In every house, a workaday companion was supposed to help create this normality. They would usually cook dinner with some residents. One of the project's initiators explained it as follows:

> The village is a residential community. And this is also what I would be looking for in old age, a living community, like a big family. I don't see this in a social romanticist way, but this is just consistent with what we as humans are used to. And cooking is a very essential part of life. In most nursing homes, where the food is just cooked for the residents, the residents not only lose any ability to cook, but forget the value of a homemade meal. So it is worth taking the time to cook with the residents.

The meals in the village were always freshly prepared but, often, the care workers struggled with the unequal task of motivating the residents to help out with the cooking. Most residents had neither the ability nor the interest to cook a daily meal for nine other residents. And

those who were capable of performing the manual cooking tasks often did not feel it was their duty and responsibility to help cook. The following excerpt vividly presents the complicated geometry of normality:

It is a hot and humid Tuesday morning. I have volunteered to cook lunch with some residents: mashed potatoes and a marinated pot roast, with a light salad on the side. The ingredients have been pre-ordered and are ready for collection in the village shop. I ask Mrs. Fontana to accompany me to the village store. Originally from Sicily, she only speaks Italian [though her family argue that she understands German]. Mrs. Fontana is the quintessential Italian grandmother; petite yet strong-bodied, with a loud, melodic voice. She is chattering, moving her hands in all directions while fiddling with her hearing aid. When she moved to the home, most care workers were baffled at the management's decision to have an Italian-speaking resident move in. No other residents speak the language; neither do any of the care workers. Within the past few weeks, some care workers have tried to learn a few sentences of Italian to manage some basic discourse. Since I am the only one who speaks at least a little bit of Italian, she seems to enjoy my company. Trying to climb the fence, she fell on her head a few days ago and half of her face is severely bruised and rigid with tension. The bruise had been changing colour over the past few days, from green and blue to yellow and brown. Nevertheless, she does not seem to feel any pain when I ask. Rather, she feels shame that other residents would see her like that. When we pass a mirror, she points out how 'unflattering' her face looks.

We take the shopping trolley, to which Mrs. Fontana holds on triumphantly, at the same time leaning on my shoulder like a crutch. I hold on to her arm while she erupts into an Italian monologue on how we should be taking a little bit of a longer stroll and ideally a bit more into nature. Her conduct reveals a shifting mix of vulnerability and iron will. We stroll towards the reception area. Caring and cleaning staff bustle around the village square, the manager rushes past, all greet us with a hearty *Good morning* or *Buongiorno*. At the store, we hand the list of ingredients to the receptionist. Mrs. Fontana takes delight in perusing the merchandise in the store, she wants to feel them, touch them, and tries hard to convince me to buy some bananas and biscuits for later. It is surprising how vigorous and alive she appears after last week's fall. We buy the items and pretend to pay. Once back in the kitchen, we begin peeling the potatoes. It appears that peeling vegetables comes natural to Mrs. Fontana, and she needs no assistance or surveillance. However, she complains about having to do all the work herself. With the lunch hour rapidly approaching, I agree that she is overburdened. Tired from the shopping spree, Mrs. Fontana decides to take a nap in her room. I thus decide to approach Mrs. Griffin and Mrs. Heyes. Dubbed the 'token residents' by some care workers, they remain very independent. Although they display some difficulties with memories, they dress themselves, go for walks together, and have bonded over the past few weeks. They have also been a big help when cooking for the other residents. They sit on the patio, playing cards in the shade. I sit down on a chair next to them and greet them.

Me: Mrs. Griffin and Mrs. Heyes, I'm making mashed potatoes and a pot roast for lunch today.
Mrs. Griffin: [smiles politely] Oh, sounds wonderful. I cannot wait to taste it.
Mrs. Heyes: [while deliberating which card to play] I am getting a bit hungry actually…
Me: I could use another pair of hands and I was wondering if you'd like to help me with the cooking. Ms. Fontana has already peeled most of the potatoes.
Mrs. Griffin: [stares at me in astonishment] So we need to cook again today? Haven't we helped you enough?
Mrs. Heyes says volumes simply by sitting very still, with a perfectly grim expression on her face. She does not want to cook.
Me: Well, it would be a nice collaboration, no?
Mrs. Griffin: So typical, we have to do everything on our own here. I thought we were on holiday here. See, we can't help you now, don't you see we're busy.
Me: [realising that I won't be successful in convincing them] All right, but how about if you got me some fresh parsley from the spice garden?
Mrs. Heyes: All right, but that's it. I want to keep playing.
Mrs. Griffin: [in a huff] Ah, when you thought you could just relax for once.

I go back to the kitchen and continue cooking. After a few minutes they both come in, holding up a fistful of fresh herbs.

Mrs. Griffin: Here you go. Hope that's enough. I'm not going out there again.

They both return to the patio to resume their card game.

In her influential thirty year old, yet still widely quoted paper, sociologist Lyman (1989) writes about the importance of power relationships in dementia care, in both family and institutional settings. And the above excerpts do indeed illustrate how the idea of normality eventually stems from a decision made by an authority figure. More importantly, however, these excerpts illustrate how the idea also assumes that normality is, in truth, something every ageing person yearns to preserve and that the demands we make of our environment will not change over the course of our remaining years. This equally evokes Lawrence Cohen's (2003) examinations on the tensions which arise when seeking to displace the elderly to preserve the time- lessness of culture. As Sarah Lamb (2014:41) rightfully points out, "the cultural assumptions in the successful aging discourse merit scrutiny". And the excerpts indeed illuminate a tension between independence as a stated care goal and the residents' evident tendency to orient their own self-empowerment in terms of being catered to, and cared for, by others. The subject becomes even more complex, however, if we turn to the concept of personhood.

The notion of personhood at the dementia village was based on literature and training manuals for staff in nursing and residential homes (Walsh, 2006). In general, the concept has gained in cohesion and resonance since the early 1980s, following an upsurge in more controversial portrayals of biomedicine's increasing universal significance throughout the 1970s. Most prominently, Michel Foucault's (1989 [1963]; 2000) theory of the clinical gaze suggested that social control was commonly camouflaged as biomedical expertise and knowledge, confining the care seeker to a docile body (Scambler & Higgs, 1998). Sociologist Irving Zola (1972) coined the term "medicalisation" to describe the medical jurisdiction's propensity to enclose ever broader sections of the human experience. By increasingly meddling with inherently social problems, he argued, professional medical authority "is becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law" (1972: 487). To counteract these trends, the care seeker should take centre stage – as a person and not merely as a disease or body with illness. Along these lines, many attempts have been made to devise a theoretical (and arguably idealistic) model of dementia care. Kitwood's (1997: 246) critique of what he refers to as the "standard paradigm", for instance, famously led him to propose the aforementioned theory of personhood. He describes it as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust". He then proposes three characteristics that are essential for enhancing personhood: recognition of a person's uniqueness, acceptance of subjectivity, and acceptance of relatedness (also see Kitwood & Benson, 1995 or Leibing (2008) on the moral positioning of claims such as personhood or biomedical reductionism).

This is a salient objective and, indeed, most care settings have incorporated the notion of personhood into their care philosophy. And certainly, few would argue that care ought to be performed without the guiding principles of recognition, respect, and trust. Buch (2010, 2013),

for instance, beautifully describes how care workers develop a profound embodied empathy to imagine and reconstruct the social and sensory worlds of their clients. Similarly Gass (2005), Stacey (2011), Rodriquez's (2014) notable work on dementia and personhood—much of which touches on issues of recognition, continuity, and coherence—lends itself pre-eminently for further research on, and a better understanding of, the issue. Meanwhile, Janelle Taylor (2017) has expanded the discourse by writing about the topic of dementia and friendship.

Since the status of 'personhood' is bestowed upon an individual, however, it becomes a fathomable status. As long as it can be granted by others, it can equally be denied, without fixed boundaries and firm foundations. Another criticism often voiced is that, despite Kitwood's insistence that person-centred care be reflexive and applied in principle to people with dementia and their care workers, the concept of personhood is primarily realised unidirectionally and is individualistically centred on the person with dementia. While personhood is bestowed on them, they might not be able to reciprocate (Baldwin & Capstick, 2007).

Caring is, of course, not a one-way street. Mrs. Heyes and Mrs. Griffin's example indeed elicits scepticism about the unidirectional personhood concept. "Both the patient and the care worker have the opportunity to grow authentically through the caring process", David Malloy and Thomas Hadjistavropoulos suggest (2004: 153–54). They continue:

In cases of extreme dementia, it may only be the care worker who is capable to grow – to take this opportunity away from the care worker by putting emphasis upon institutionalisation and frozen roles and procedures is to lessen the authentic possibilities of the health care profession.

Yet, Mrs. Heyes and Mrs. Griffin's example, also brings another question to the surface. If the notion of personalised care is grounded on an idea of the person prior to their cognitive decline, should this 'person' be maintained at all cost? If we posit that the person post-cognitive decline remains precisely the same person as they were before, we could liken this to expecting someone to remain the same person after an accident. Do we force the person to remain the person they were previously? Today's "hypercognitive" society, ethicist Post (2000) puts it succinctly, places "inordinate emphasis on people's powers of rational thinking and memory". And as a culture, Herskovits (1995:146) maintains, "our struggle with the nature of the self in Alzheimer's reflects our struggle to grapple with what it will be like, and what it will mean, to be and become old" (also see Ryvicker (2009)). Do we determine that no new personality traits, no new 'selves' are possible? Do we do this because the pre-dementia part of someone's life is the part in which the person has organised their world and the framework through which they see the world and which we can affiliate to (also see (Ranzijn, 2010)? It appears that, with regard to a person with dementia, they are someone who we once understood, whose behaviour and conduct we could once decode. But now we do not understand them anymore. It seems only natural to take the former person as a point of reference to make sense of this change. But are we right to do so? In truth, no one has ever returned from dementia, with a crystal clear mind, coherently arguing in a rationally sound manner how it felt. Nonetheless, feelings, desires, and fears are communicated, as the following account will demonstrate.

Mrs. Reed—morbid humor

Another nightshift. It is nearly midnight. A care worker and I do our usual rounds. We stop by Mrs. Reed's room. Mrs. Reed has been a widow for more than 30 years. Based on the many photographs on her walls, she used to be an elegant and most stylish woman. Over the past months, however she has developed a disdain for the house rules. She will sometimes leave the room half naked and disturb other residents with her free-spirited approach to fashion. When other residents reprimand her, she will answer with a condescending and clever reply. At night, however, Mrs. Reed looks vulnerable and unsteady. She has to be turned three times during the night. Her skin condition ought to be assessed on each occasion. In German this practice is called *Lagern*, which literally means store or stack. We walk in and the care worker wakes Mrs. Reed up, apologising for doing so. There is a turning protocol which the care workers need to sign and fill out. 'You know, I find that a bit sad for the residents at times, we always need to wake them up to turn them, so they never really have a full night's sleep. But on the other hand, we need to do it, otherwise they get bruised. I mean, Mrs. Reed is so incredibly skinny, she has no padding, so if she just sleeps on one side all night, she'll get a haematoma [a bruise].'

Mrs. Reed signals that she would like to go to the bathroom. She is a small woman, emaciated, and fragile. Her thinning, silver hair is widely dishevelled as one would expect after a few hours of sleep. We help her up and accompany her to the loo. She walks in a teetering manner, as if her body is collapsing under the uneven weight of her well-worn dressing gown. The care worker helps Mrs. Reed into the bathroom and, after some difficulty, eases her down onto the toilet. The care worker asks me if I can stay with Mrs. Reed while she responds to another resident's call. I accept and the care worker flies out the door. Mrs. Reed sits there for a few minutes, gazing with unblinking indifference. Then she begins to weep. After a while, we slowly walk back to bed.

Over the past weeks, Mrs. Reed has begun to utter the same words again and again: 'I wanna die, I wanna die, I wanna die', repeating the phrase as though it is the line of a song. Back in bed, Mrs. Reed has trouble falling asleep again, and I decide to stay with her and talk to her. She takes my hand and I tell her a story about my childhood. From our first encounter, I remember that Mrs. Reeds has a great dry sense of humor so I try to make the story funny. But Mrs. Reed does not change her song. She grabs my hand with a gentle touch and refuses to let go: 'I wanna die, I wanna die, I wanna die'. After a while I ask, 'Mrs. Reed, I'd really love to help you, but is there anything else you'd like to do other than dying?'. She looks at me with a serious face and says: 'Fuck!' She waits for my reaction and seems to enjoy my shocked expression. 'I think we have to think of something else to do', I say. 'That's what I thought', she responds with a smirk. I set myself in motion to move away, but Mrs. Reed holds on to my wrist. 'Stay a little longer please', she pleads.

During the care routine, there seemed little to Mrs. Reed but despair. It was as though I was witnessing how Mrs. Reed – the once witty and nimble-minded woman – was beginning to fall irreparably apart. On hearing her powerful statement 'I wanna die, I wanna die, I wanna die', everything else seemed trivial. Perhaps there is nothing like death to render any other dialogue pointless. Yet the above extract offers a more nuanced narrative. Mrs. Reed may have made a crude joke ("Fuck"), but she also made a point. Her example not only puts a human face on a woman who seemed to have given up, but it also helps us see the peculiar strength and flexibility of old age. If I listened closely, I found that her statements were not as much about dying as about connection. The words were there ("I wanna die"), but behind the sorrowful woman lay a wickedly funny and provocative lady trying to fill a void in her life. In old age, nobody touches you besides your care workers. Mrs. Reed, I surmised, missed that sense of touch. And I think she sometimes missed that touch so much that she resorted to a call for dying to convey her inner loss, which she knew would never again be filled: the sense of touch, passion, and indeed sex. Was it her loneliness that made her "maladjusted"? Was Mrs. Reed's vulgarity a new trait of her personality or merely a hidden one that had lingered beneath the surface of the formerly elegant and stylish woman?

Mrs. Worth – fearless hysteria

We arrive at Mrs. Worth's room. Her suitcase is obstructing the door. She's one of the residents who incessantly declares that she will be leaving the village tomorrow. 'You know', the care worker says, 'some relatives just drop their mother or father off, spend a few hours with

them and then leave without really telling them why they're here for good. So of course they think they're just on holiday. And what are we supposed to do? Are we the ones who have to break the news to them? So of course we play along and buy into their going home story'. When we enter the room, Mrs. Worth is sitting in an armchair behind the door in the dark like a perfect iceberg.

Care worker: Oh, you've given me a terrible fright.
Mrs. Worth: Rightfully so. Haven't you any sense of privacy? You should have knocked. I'm on the watch, you never know…
Care worker: So what are you watching out for Mrs. Worth?
Mrs. Worth: Never mind the Mrs. Worth stuff. My name is Ruth. Call me Ruth. Anyway, I've been noticing, and I'm not implying anything, but I've been noticing that every now and again, someone enters my room and, I mean, I'm not sure, but I wouldn't put it past them, that they, you know, take something.
Care worker: So you've put yourself in their way?
Mrs. Worth: Precisely. You know, some of them, and I've known them for many years, they have a propensity for hysteria, is that what you call it?
Care worker: Yes, you can call it like that.
Mrs. Worth: So that's why I'm here, just to make sure they get the message. If they've seen me sitting here for the third time, they won't do it again.
Care worker: Sounds like a plan.
Mrs. Worth: [motions us to lean close] But please don't tell anyone that I'm doing this. I'd be embarrassed. I mean, I'm embarrassed even as I'm telling you all this!
Care worker: Don't worry, it will be our secret.
Care worker 2 joins us in order to measure Mrs. Worth's blood sugar level.
Care worker 2: Good evening Mrs. Worth, I'm here to have a look at your blood sugar level.
Mrs. Worth: Yes, do that dear.
Care worker 2: Now let me see [she pricks Mrs. Worth's finger].
Mrs. Worth: And, what does it say?
Care worker 2: It's much better than this afternoon.
Mrs. Worth: [quickly licking the blood off her finger]. That's great then. But you know, even if I died now because of it, so what! I'm of an age that I can die of anything. There's no point in making a fuss about it. If I go, I go. I'm not afraid. I'm over 80 years of age, everything can get you now, so why bother.
Care worker 1: That's a good way to see it.
Mrs. Worth: I have five children, you know. And married a farmer. I'm good to go. But you know, he never really wanted to work, so one day I just decided to go to work myself. He wasn't that happy about it, but once he saw the money coming in, he didn't mind anymore. But now I don't care anymore.
Care worker 2: We're going to come by later to see if everything is still all right. So goodbye for now Mrs. Worth.
Mrs. Worth: Ruth, call me Ruth! You go ahead and do what you have to do.

Considering dementia care in a predominantly normative optic tends to dictate hegemonic principles that can create an illusion of abstract norms and choices, when, in actuality, care takes place across ambiguous and changing interactions. A person-centred care approach, by its very nature, is grounded in the particularity of localities, as the concept's inherently relational nature calls for sensibility to context and human deliberation (also see Kontos et al.' (2017) work on embodied selfhood and relationality in dementia care). Though the home often stressed the versatility of the dementia care approach, there were elements that were, at least officially, not negotiable. How the residents should be addressed was one of them. To follow is a brief outline of an internal dementia care guideline:

The care workers are to:

1. Adopt the attitude of a learner, not of someone who already knows.
2. See the world respectfully from the other person's view.
3. Make first-person statements (refer to themselves and not to 'one')
4. Listen without qualification
5. Not consider their own assumptions as final
6. Substantiate opinions with concrete observations
7. Refrain from 'baby talk' (It is derogatory!)
8. The person with dementia *evidently* [own emphasis] needs to be addressed using the formal form (call them 'Sie')

Set against these abstract, normative guidelines, Mrs. Worth's example provides a vital sliver of the dementia care reality. As we see under point 8, care workers in the village were encouraged to address the residents by their last names and to use the formal *Sie*. The latter is a practice that is foreign to speakers of modern English. In German, conversely, there are two forms: *du* (the informal address) and *Sie* (the formal address). The informal you is applied when talking to those with whom one is on intimate and familiar terms, as would be the case with family, friends, children, acquaintances, and neighbours. The polite form, in turn, implies a certain formality between the speakers and takes into account social considerations [4]. By and large, addressing residents using the formal form is seen as a means to preserve the residents' dignity and former social status. "As a rule, the informal You is not allowed when addressing patients or residents", declare Simone Schmidt and Martina Döbele (2010: 39). "Even people suffering from dementia should always be addressed with their family name to create a professional distance, which is essential for mutual respect" [own translation from German]. In the care literature and the home's guidelines, and also among the majority of the care workers, this rule was rarely questioned. But Mrs. Worth's example demonstrates that there are gaps in the logic of these norms. Mrs. Worth and other residents did not want to be addressed in a formal manner, with their surnames. When sharing her intimate and, for her, shameful secrets, Mrs. Worth wanted to be called Ruth. Systematically neglecting the deeply consequential desires of how a resident wants to be addressed prevents us from appreciating how people in old age want to be seen.

While a handful of care workers would indeed start calling some residents by their first names and using the informal you, the majority did not. This put them in a predicament, enacting an undignified practice that felt nonetheless right [5]. In light of these realities, we might reconsider how much familiarity truly resides in our dementia care models – and how much intimacy we are prepared to give up in the name of what we construe as dignity and personhood. By the same token, a similar question ought to be asked of professional care. How much familiarity do we concede in a dementia care facility, and how much professionalisation are we prepared to surrender (also see Kamp & Hvid, 2012)? The above examples also show how, in the village, the residents were defined by a specific social status – a formal status – that they might not have necessarily enjoyed. This was a practice that appeared so overdetermined that, ultimately, both care workers and residents, at times, seemed as constrained as they would have been within the strict medical hierarchy and protocol of a hospital. The residents were allocated a social role to warrant a continuity of a type of dignity imagined by the facility, which was not always desired by the residents, as it came at the cost of being expected to behave differently than what they preferred. This practice I call "forced continuity".

Addressing all residents by their last names and with the formal "you" fit the residents like a tailored uniform. They had worn it before; in many social situations, during formal exchanges, when enacting the individual that the social environment identified as a respectable adult person. Yet in their present experiences, living in a dementia village, with care workers having taken up the role of those closest to them, this uniform could feel foreign and out of tune with their personal experience in their new present. The formal address seemed to situate them in a social and environmental context in which they could function according to their former formal role – as a publicly identifiably person in

a worn-in uniform; returning to the polite language of their upbringing. The residents' self-understanding, however, might take a different shape – now fitted for an individual in a familiar, intimate environment outside social conventions. Mrs. Worth desired an informal approach, Mrs. Griffin and Heyes wanted to withdraw from their roles as cooks and housewives, Mrs. Reed chose to no longer conceal her sexuality, whereas Mrs. Fontana felt at home when shopping for groceries, enacting a practice that had accompanied her for decades. Accordingly, the residents' present personal conduct stemmed from their engagement with the past – anchored in perceptions of the broader narrative of a person they used to be; or their present personal experiences – tied to performances of a new narrative of the self they now were or had recently discovered. Yet, far from being separate, the two regularly intermingled.

Conclusion

In the above excerpts I presented several residents' encounters with ageing. I demonstrated that such encounters are not only particular to the residents' own experience but also inharmonious [6]. The case studies speak to facets of the residents' selves that emerged in response to their circumstances. Whether they were suppressed selves that emerged under pressures of the situation, or newly formed selves really is beyond the point. The fact is that they exist. And these selves need not be a departure from personhood or a sense of continuity experienced by the person, as Ewing (1990) compellingly argues. Yet, living and caring in the dementia village frequently meant living with a past that was imagined through a former role as the public persona and as a biographical benchmark. The present, in turn, was often experienced as an internally coherent self that was different from the self prior to being observed to exhibit cognitive disabilities. The links between the two were made meaningful by a process of “forced continuity”. Such a process was legitimised through applying the formal Sie to address residents and referring to them by their surnames. This, I argue, was done to establish professional boundaries but it simultaneously exposed a paradoxical professional intimacy balance – one that requires an informal, familiar exchange on the one hand and a hard-headed ability to deal with everyday care practices on the other (also see Haeusermann, 2018). In the village, care workers had to reconcile what they had learnt on a generic professional training level with the indeterminacy and uncertainty of personal accumulated experience.

Culturally-informed perceptions of normality (women like to cook, women conceal or lose their sexuality in old age); I highlighted, spanned a carefully constructed and reconstructed arc between an imagined or documented past and a messy real life. In the process, care workers may unintentionally, and at times unavoidably, perpetuate hegemonic and socially idealised notions of the elderly [7]. Yet the arc was at times spanned by residents and care workers, alike. When the imagined public persona and the actual conduct of the resident did not align, dementia would occasionally be employed as an explanation. As I emphasise in my analysis, however, dementia in the village routinely became enmeshed with the residents' selves and identities. This is not to suggest that the different forms of dementia can be boiled down to mere social roles or discursive categories, narrative accounts or even myths. And indeed, there's a way in which we are all “forced” to be somewhat continuous across everyday life, to keep recognisable. Rather, I suggest that people, in general, display a tendency to incorporate suffering into a coherent life narrative and to weave a chronic condition into a person's identity. As Charmaz (1999: 374) puts it eloquently:

A story provides a way of making sense of suffering, of locating the self in life, and of coming to terms with an altered existence. The story makes claims for both storyteller and audience. The storyteller makes identity claims for being a certain type of person and reality claims for the audience to support. Both types of claims may be buttressed with a moral righteousness that enhances the significance of the story and, moreover, the moral status of the storyteller.

In the dementia village, I did not encounter a lack of care, insufficient care, or bad care. The care workers did care, and most of them with sensitivity, rather than sentimentality. Since residents in care homes are there to stay, however, it is just as important to understand that they bring their individual stories with them, in both their personality and behaviours. They also create new stories that spring from the authentic voice that is theirs, and not from an illness. In the dementia village, care workers often weaved between past and present to give residents opportunities to create new narratives. Familial care, in turn may be orientated towards conceptions of an elderly person's selves, which may resonate more with the care workers and family members than the elderly, themselves.

Despite their modest validity, the above accounts are the stories of the residents I met and cared for. They remind us of the individual experiences tied to dementia and ageing. They show how a unilaterally negative connotation bears the potential to dramatise one's cognitive decline. During both my care and my ethnographic work, I was not surrounded by cognitively bankrupt residents exhibiting the same signs and symptoms. Rather, I worked among multi-layered individuals whose behaviour seemed inextricably entwined with their personalities and life histories. What is more, even though the loss of self is very prominent in the dementia discourse, my findings at times plainly depict residents who are highly cognitive functioning individuals. And sometimes new, or perhaps hidden, personality traits emerged (also see Sabat, 2002).

The way dementia is managed today reflects broader societal issues (also see McLean & Perkinson, 1995 or Theurera et al., 2015). As scholars and as a society, we often yearn to find meaning in illness and ageing. In fact, we even forge meaning to integrate illness into a coherent narrative of life. But sometimes we would do well to make allowances for new narratives that emerge in old age. In this article I thus revealed many glimpses of humanity and showed how the internalisation of cultural values shapes the way in which notions of the person with dementia are transmitted and reproduced. By introducing various residents, I looked at the ways in which the past imposes itself on, and is made meaningful for, people with dementia, through a process I called “forced continuity”. This process, I argued, does not lead to either exclusively good or exclusively bad care. But it very much centres on the notion of a former self of the person with dementia, which ought to be continued. I concluded that – despite a range of ad hoc and multiple orientations to care – the societal pressures on the resident to remain the person they were before their cognitive abilities declined does not halt at the dementia village's borders. It moves right into the village with the residents. Indeed, care models which intend to support the person with dementia, may defeat this positive intention. This could be the case when those in control envision a particular kind of person that differs from the way the person with dementia may want to live. In other words, the effects of power, as Foucault (1989 [1963]; 2000) famously claimed, can be seen where least expected and efforts to correct the loss of personhood may in unexpected ways reinforce exisiting structures while claiming to reconfigure them.

In view of today's emerging elderly care models, many open questions remain. If the total institution is a forcing house for changing persons; have we turned his cautionary note upside down? Have we turned the modern nursing home into a forcing house for unchanging persons, a total institution where the goal for the residents is to stay the same rather than change? And does promoting a particular vision of personhood, based on past selves, in fact always benefit residents and what are the stakes of such continuity? Certainly, care approaches in elderly care have always been shaped by conceptions of the past and Goffman's now fifty-year-old treatise on total institutions left its mark, both on our care approaches and our concepts of how we want to be treated in a care institution. Likewise, Cumming and Henry's “disengagement theory” along with Atchley's “continuity theory”, and Havighurst's “activity theory” have innovated the studies of ageing and the theories become revisited by many later generations of scholars.

The concept of 'forced continuity' is a way to reconcile these theories and develop a common language when they are speaking of the same thing, and discover the situations and context where each may be useful.

Notes

1. Paragraphs discussing the home's care philosophy are primarily based on extensive interviews with the head of care and manager of the village, as well as internal documents and guidelines to which I was given access. For more on the "dementia village" context and the care philosophy, see Haeusermann (2017a, b) and Haeusermann (2018).
2. The 650 h correspond with the care workers' work schedule. I generally conducted participant observations during entire work shifts. Nightshifts would usually last up to eleven hours whereas dayshifts spanned over a period of 8 h.
3. To protect the residents' identity, I have followed the usual tradition of changing the name and defining characteristics.
4. The rules can indeed be confusing. By and large, *the formal you (Sie) applies to all formal contacts* (e.g. *strangers, someone* in a position of authority, or coworkers) *and only changes to the informal you (du) when explicitly suggested. Traditionally, once one becomes acquainted with a person in a more personal capacity, one may suggest the informal you over a meal or a glass of wine*. The older person normally proposes changing to the informal you (du) to the younger person and the woman to the man (Stevenson, 1998).
5. In *Street-Level Bureaucracy*, Lipsky (2010 [1980]:147) persuasively contends with such ambiguity inherent in most public institutions. He maintains: "Public institutions generally have conflicting or ambiguous goals for good reason. They embrace ambiguity, contradictions, and complexity because the society is unable and unwilling to abandon certain fundamental aspirations and expectations in providing public services".
6. In her lauded book *The Ageless Self: Sources of Meaning in Late Life*, Kaufman (1986) maintains that old age does not necessarily hold intrinsic meaning to the elderly. Rather, the elderly have an ageless sense of self and highlight continuity of identity in the face of the physical and social changes that come with old age. While I agree that a continuity of the self can play an essential part in the adaptive process in later life, my findings call for a more sensitive and nuanced attitude to the framework of a continuous and coherent self in old age.
7. Some of my findings support the position taken by Luborsky (1993: 12) in his article *The Romance with Personal Meaning in Gerontology: Cultural Aspects of Life Themes*. He contends: "The meanings represented in life stories may be those that are still being made, are yet unresolved, or were the resolutions to prior meaning dilemmas for the individual and now are an important frame for the self".

Funding statement

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Acknowledgements

I want to thank the carers, colleagues, and residents at Tönebön am See. They remain anonymous, but their hospitality, openness, and generosity made this research and publication possible. They allowed me into their lives with warmth and trust and helped me to understand their worlds. For this I remain extremely grateful and thank them for their many kindnesses.

I would also like to thank Darin Weinberg, my supervisor and mentor, for his faith in me as well as his unwavering encouragement, astute criticism, and careful guidance. Equally, I am indebted to Jeannette Pols. I benefited from their keen intellect and scholarly acumen. Finally, my thanks go out to Sarah Franklin and Dana Rosenfeld. Every part of this article is better from our conversations and their thoughtful comments and advice.

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