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Memory, Language, Self, and Time: Personhood and Relationship in Dementia.

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award of the degree of Masters of Social Science in Social Anthropology

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Declaration of Originality

This work has not been previously submitted, in whole, or in part, for the award of any degree. This dissertation is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other individuals, the internet and other sources, has been attributed, cited and correctly referenced.

Signed: Jennifer Grant

Date: 28/12/2012

University of Cape Town

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ABSTRACT

This dissertation contributes to an understanding of how the entanglement of language, memory, self, and time in contemporary Western thought shapes assumptions about the personhood status of elderly persons with dementia and their capacity for meaningful relationship. The ethnographic data that informs the study was drawn from a three-month period of in-depth participant-observation conducted in a dementia ward situated in an exclusive retirement community in the Western Cape, South Africa. By taking the relationship between the elderly 'residents' living in the ward and their professional caregivers as the focus, I show how, in the face of dementia-related language and memory losses, this relationship was established and maintained across time. The focus on relationship allowed me to pay close attention to the face-to-face interactions between caregivers and residents so as to identify and discern the assumptions and practices that shaped the possibilities for personhood and relatedness within the ward. I demonstrate that the relationship between caregivers and residents was established and maintained through myriad and ongoing practices of care. This institutionally structured relation of care must be recognized as both an alternative form of sociality within which 'demented' residents are held in life and relationship, and as an instrument through which old people with dementia are subjected to the routines, norms, and temporal structures on the ward. Invocations and denials of personhood occur at the practical level of intersubjective engagement. I show that despite residents' language impairments, and the consequent importance of embodied gestures for communication and mutual interaction, language was fundamental to the relation of care, and thus to the practical engagements through which personhood was invoked and denied. Caregivers frequently engaged in a practice which involved the recollection and narration of the biographical 'facts' that constituted residents' erstwhile social lives and social identities. Defining this practice as an intersubjective memory practice, I argue that it functions to invoke personhood by establishing continuity between past and present and calling forth residents as socially recognized and situated persons. This intersubjective memory practice can be interpreted both as evidence that personhood is emergent within and through relations of care, and as a normative practice which reinforces the currently taken-for-granted assumption that the self is constructed in and through narrative. I suggest that the widespread acceptance of the notion of the narrative self, in both popular and academic domains, is indicative of the manner in and extent to which language, memory, self, and time are entangled in contemporary Western thought. In order to demonstrate the historical and cultural specificity of this entanglement, I draw attention to the way in which memory, narrative, and temporal continuity became inextricably tied to notions of personhood and relatedness within Western philosophy. I propose that expanding an understanding of the ways in which language, memory, self, and time are entangled in everyday practice provides a means of troubling the widely accepted belief that dementia leads to a loss of personhood and relationship, without resorting to the dichotomous thinking that characterizes much of the scholarly and clinical literature that is influenced by the so-called personhood approach to dementia.

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For Mike Grant, in loving memory

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CHAPTER ONE: INTRODUCTION, EMPLACEMENT, AND METHOD

Linda¹ visits her husband Edward in the Special Care Ward every day. See them here in the lounge, sitting close together, heads bent forward, almost touching, holding hands and speaking softly. Linda comments that it's becoming increasingly difficult to communicate with Edward because he is now rarely able to complete full sentences. Linda's concerned about how frustrating it must be for him, not being able to tell her what he is thinking and feeling. Or see Edward, still physically agile and energetic, 'besig' (busy) as the caregivers describe him, trying to engage Helen, a resident, in conversation. He's standing beside her, looking at her intently, struggling to form a sentence: "You see it's..." [Pause, leaning back] "What I'm trying to say is..." [Pause, a pained expression] "I can't, I can't...I don't know." He falls silent and moves away, only to return a short while later to try again.

Elizabeth's daughter mentioned yesterday that while Elizabeth has always been a "worry-wart," it is difficult to witness her current state of anxiety. Elizabeth is anxious because she feels lost in the elsewhere of the ward, asking the same questions day after day: "When can I go home?" "Nurse, please. I must go home. My father will be worried sick about me!" and "I need to go home right now – my children won't know where I am!" Although Elizabeth's language capacities are unimpaired, she is temporally confused, or, framed in another way, effortlessly moves between past and present. Elizabeth remembers the distant past in detail, despite occasional 'gaps,' but her so-called short-term memory is significantly impaired and she is unable to remember events that occurred in the recent past: the lunch that was served an hour ago, her daughter's daily visits, and the fact that she has been living in the ward for two years and no longer has a house to go home to. Despite Elizabeth's sense of confusion and anxiety, she is an empathic listener and has a wry sense of humour.

Christopher, Charles, Edward and Hans are sitting at the dining room table. Throughout the meal, Christopher and Charles intermittently exchange utterances which although sometimes linguistically incoherent, have social coherence in that Christopher and Charles are enacting the social norms of mealtimes. Hans is irritated and is refusing to eat, scowling at his table companions and kicking Edward's chair. Edward, the only person at the table who is able to eat unassisted, mildly objects to Hans's behaviour by responding "No-o-o," but he is absorbed in the act of eating, which he does with great care and fastidiousness. Ella, a caregiver, soothes Hans by gently rubbing his back, saying light-heartedly, "Everyone gets in a bad mood sometimes." Hans grumbles "Ja, ja," but allows her to feed him some soup. After lunch, Christopher, Charles, and Hans, who cannot walk on their own, are waiting to be escorted to their rooms. Christopher creates a flower from the peel of the banana he had for dessert, and points it out to me, smiling. I admire the flower and he laughs. I notice that Hans hasn't eaten his banana and ask if he's full, but he frowns and tells me that it's for Sara, his wife, "because she also has to have something to eat."

¹ The names of all research participants have been replaced with pseudonyms in order to ensure confidentiality and privacy.

Research Question

The preceding vignettes provide an entry into my research topic, the question of how language, memory, time, and subjectivity are folded into the everyday lives of elderly persons with dementia. Prevailing theories of subjectivity anticipate the centrality of language and the persistence of memory to a sense of self and to relationship (see Ochs and Capps, 1996; Hacking, 1995b; Strawson, 2004). What, then, when language falters and memory is recalcitrant? My research explores this question by tracing the forms of relationship that are constellated within a dementia ward and examining how relationships are made and unmade in the context of language and memory loss. I argue that a focus on relatedness offers the means to explore caregivers' assumptions about the relationship between language, memory, self, and time, and to examine how such assumptions shape the possibilities for personhood and relationship within the ward. Further, I assert that an examination of the practices through which relationship is constituted within the ward offers a means to question the notion, currently entrenched within academia, that the 'self' is narratively constructed, and that language, memory, and temporal continuity are therefore fundamental to full personhood and to establishing and maintaining relationships over time.

Contextualizing "The Field"

The Special Care Ward (SCW) is one of three medical wards that constitute the medical facility located in Golden Village², an exclusive residential "retirement village"³ in the Western Cape. I first learnt of Golden Village from a family member who worked as a part-time caregiver in the Golden Village home of an elderly woman diagnosed with Alzheimer's disease. My academic interest in the relationship between dementia, language, memory, and personhood was triggered by the many anecdotes shared with me about the difficulties and rewards of this work.

Golden Village contrasts starkly with the images of hospital-like apartment blocks, social abandonment, and loss of social and financial status that the term "old age home"⁴ evokes. Like other exclusive retirement villages in this area, Golden Village is akin to the exclusive gated communities increasingly found in cities around the world. The layout of the village conforms to the structure of a small (imagined) village – individual houses, located on individual plots arranged according to blocks interconnected via tarred roads. Golden Village is relatively self-contained and has a restaurant, library, hairdresser, four swimming pools, tennis courts, bowling greens, and a golf course. There are also various recreational rooms where the inhabitants, commonly referred to as "villagers" or "residents," gather to attend art classes, choir practice,

² Golden Village is a pseudonym.

³The term "retirement village" is one used by many of the exclusive retirement communities in this area.

⁴ The Elderly Persons' Act (2006; 2011) includes a legislative clause that focuses on naming: the institutions long known as "old age homes" must now be referred to as "Frail Care" centres or institutions.

bridge games, and various other activities. The perimeter of the village is walled for purposes of security and privacy, and the only access to the village is via the main entrance which is guarded by security booms and security personnel.

The houses are aesthetically pleasing, the gardens are lush, and the village is surrounded by mountains and vineyards. It is common to see villagers out on the streets, some walking their dogs, others on their way to or from the tennis courts and bowling greens, and many driving around the village in battery-powered golf carts (popular because the village is built on the lower slopes of a mountain and the inclines and declines are steep). The villagers seem to epitomize the currently popular ideal of “successful aging” that has been embraced by a “young old” population “framed by its ability to avoid the stigma of physical and economic frailty” (Cohen, 2006:7). While most retirement villages in the area refer to their medical care facilities as “frail care centres,” the Golden Village administration rejects this term and refers to the medical facility as Maynard Manor: within the carefully managed and constructed retirement milieu of Golden Village aging is not to be (explicitly) equated with frailty.

Nevertheless, many of the ‘successfully aging’ villagers that I met had decided to leave behind much-loved family homes and established social networks precisely because of the probability that illness and frailty would accompany the aging process. While Golden Village has much to offer as a residential and lifestyle choice for retirement, for many villagers it was the excellent reputation of its medical care facilities that persuaded them to purchase a home there. Moreover, a number of villagers had moved to Golden Village only after their spouses had been diagnosed with Alzheimer’s disease or related dementias (ADRD)⁵ because Maynard Manor is similarly well-known for providing excellent dementia care.

Maynard Manor contains three medical wards which provide various forms of medical care. My research was concentrated in the Special Care Ward, which is separate from the other wards, both spatially and in terms of the medical care it provides. A closed ward, it accommodates only eleven individuals at a time, providing specialised care to residents who have been diagnosed with ADRD. Despite the fact that ten of the eleven ‘residents’⁶ living in the ward during my research period were thus diagnosed, senior medical staff objected to the SCW being referred to as a “dementia ward” due to the stigma associated with dementia. This ward, established in 2005, was one of the first of its kind in the area and preceded legislation - incorporated into The Elderly Persons’ Act (2006, 2011) - that compels all elder care facilities to establish specialized dementia care wards.

I describe the SCW in detail in chapter three, but here point out that while the SCW was spatially separate from the other wards in Maynard Manor, it was not a simple matter to distinguish the wards

⁵ See chapter two for a description of the diagnostic categories that are listed under the general rubric of dementia in DSM-IV.

⁶ I use the term ‘resident’ as it is the descriptor most often used by the village administration, staff and family members to refer to the individuals admitted to the dementia ward. The term ‘patient’ was very rarely used. Henceforth, I use the term resident without inverted commas.

according to “physically frail” old age and “mentally frail” old age. This was due in part to the general difficulty of distinguishing between normality and pathology in the ‘frail old,’ as Cohen (2006: 6) points out, but also to the fact that during my fieldwork period ten residents who had been diagnosed with ADRD had to be accommodated in one of the other wards because the SCW was full. Golden Village’s administrative board was then planning to extend the SCW so that it could accommodate at least twenty individuals at any one time.

The socio-economic distinction between the villagers and those working in Golden Village, caregivers and other staff, is immediately evident. Mirroring the class and race dynamics that characterize much of South African society, historically and currently, residents of Golden Village are upper- or upper-middle class and ‘white’⁷ (although not all are South African), while most staff members are ‘coloured’ and ‘black’ working class men and women. While men are employed as security guards, gardeners, and maintenance workers, all the caregivers are women. Caregiving, also referred to as ‘caring,’ is one of the relatively few employment opportunities available to working class women in this area, and while some of the caregivers I engaged with stated that they were “born to do this work,” for others, it was a job preferable to that in a factory or retail store. The absence of ‘black’ or ‘coloured’ retirees in Golden Village is likely to be an indication not only of class, but of differing cultural attitudes toward aging, but these differences are beyond the scope of this dissertation.

Method and Ethics

Accompaniment as Method

I commenced fieldwork in the first week of January 2011 and spent three months in the ward, returning intermittently thereafter.

With the permission of the matron, I entered the ward as a researcher-cum-volunteer. This role enabled me to embody the participant-observer method fundamental to anthropology, and created a space through which I could participate in the rhythms and activities on the ward. I assisted caregivers⁸ during mealtimes – setting and clearing tables, and later, helping to feed residents who needed assistance; accompanied physically mobile residents on walks within and outside the ward; and helped caregivers to manoeuvre residents into a sitting or standing position. Dressing, bathing, and being “cleaned up” were considered by caregivers to be private functions and happened behind the closed doors of bathrooms or residents’ rooms and I did not participate in these activities.

⁷ I use the terms ‘white,’ ‘coloured,’ and ‘black’ because this racial terminology was used by the caregivers, as by many South Africans, to distinguish and identify differences (race and class) between themselves and the residents, and South Africans in general.

⁸ I use the term ‘caregiver’ to refer to the professional caregivers employed by Maynard Manor.

My willingness to participate in these caregiving practices greatly facilitated my efforts to establish rapport with caregivers and family members. I had intended to conduct informal and semi-structured interviews with caregivers and family members but found that such an explicit question-and-answer approach was not necessary. Instead, by positioning myself as a researcher-cum-volunteer, I was able to participate in and follow the back and forth of everyday conversation and interaction - between caregivers, family members, and residents. This enabled me to pose questions 'naturally' in response to matters and themes that emerged in conversation or practice. Moreover, caregivers and family members, aware of my status as a researcher who wanted to learn and understand, generously shared their experiences, opinions, and concerns.

Additionally, the anthropological method of immersion over an extended period of time, through which I was able to both observe and participate in the making of relationships, and experience the routines and rhythms that marked time on the ward, made possible a mode of accompaniment whereby I was present with and placed myself alongside and in reach of residents. I was introduced to Lingis' notion of accompaniment, framed as the ethical imperative to accompany the ill or dying person, through the work of Ross (2010: 200) and Henderson (2005). In chapter three I suggest that the caregiving practices enacted in the space of the ward can be viewed as a form of accompaniment, which Ross (2010) describes as the relation of care for another in the face of illness and death. Here, I draw attention to accompaniment as a method of ethnographic engagement that uniquely positioned me to focus on "actual forms of lived embodiment in the field[s] of practice in which they [took] place" (Lock and Farquhar, 2007: 11).

While I had anticipated that I would be witness to sadness, distress, and confusion, I had not expected the range and intensity of my own emotional responses – anxiety, discomfort, irritation, boredom, frustration, sadness, affection, aversion, helplessness, and laughter – and was wary because I was conscious of the ways in which emotion is culturally and biographically shaped. However, by paying attention to my emotional and experiential responses, and reflecting on and analysing them when writing up fieldnotes at the end of every day, I gained acute insight into the ways in which language and memory loss mattered within the space of the ward.

Wikan (1992) suggests that an ethnographer needs both thinking and feeling in order to "create resonance" with the persons or 'problem' he or she is attempting to understand. Creating resonance involves the "effort at feeling-thought; a willingness to engage with another world, life, idea; an ability to *use* one's experience" in order to understand the meanings that are "evoked in the meeting of one experiencing subject with another..." (1992: 463). This process extends also to ethnographic writing, where resonance must be created between reader and text.

Aside from a personal aversion to sentimentality and solipsism in ethnographies, Cohen's (1994) claim that the tropes of anger, lament, and ambiguity that characterize many ethnographies of old age impede

rigorous analysis made me cautious about over-emphasizing emotion in my own writing. Despite these reservations, in the succeeding chapters I treat my emotional responses to the myriad interactions I both engaged in and observed in the ward as data alongside that collected through conventional anthropological methods (such as participant-observation, conversation, and immersion over time) in an effort to understand what they reveal about relatedness in this context.

Ethnographic Engagement: Ethical and Practical Challenges

Somewhat apprehensive about conducting fieldwork with individuals whose language capacities were likely to be significantly impaired, I had sought the advice of a psychiatrist who advised, “Just talk to them.”

I familiarized myself with Cohen’s (1998; 2003: 126-127) “ethic of listening” which entails hearing the senile voice “ironically,” that is, in a manner that neither displaces the senile voice by rendering it incoherent and incomprehensible nor attempts the hermeneutic project of revealing “redemptive or hidden speech.” I learnt much about ironic listening from the caregivers’ engagement with residents, which was characterised by a sense of humour that generally offered a reprieve from the norms of social discourse. I also took note of Henderson’s (2005: 83-87) suggestion that scholars conducting ethnographic research with ill and dying persons develop an “ethics of paying attention,” which entails, among other things, the willingness “to listen to silence and the halting nature of speech” and attend to “corporeal presence.”

Given my initial apprehension, I was surprised to discover that when immersed in the rhythms and routines of the ward I felt compelled to address residents and to ask questions not only as a means of initiating conversation, but of establishing connection. Residents made an effort to respond verbally when I addressed them, but it was apparent that for most this involved an intense struggle with language which evoked anxiety, frustration, or embarrassment. I often questioned the ethical implications of addressing individuals whose language capacities were impaired and thereby obliging them to respond, drawing attention to their language losses, and rendering them vulnerable to being misunderstood. It became evident though that despite the struggle it entailed, many residents persisted in their attempts to communicate through speech.

I struggled at first to balance listening and acknowledgement and while I tried to listen to silence without interrupting, in this context my own silence seemed to communicate a lack of comprehension, which invariably resulted in the person turning inward, away from me. On the other hand, acknowledging speech with speech often had the effect of disrupting or confusing the speaker, further discouraging the effort to communicate. I resolved this difficulty by recognizing that attention is also gesturally marked - facial expressions, nodding, and listening sounds offered another, less distracting, form of acknowledgement in this particular context.

Observing caregivers’ engagement with residents demonstrated that words were often an inadequate response to the distress, sorrow, and anger evoked by the myriad losses that residents experienced. The

immediate and tangible presence of the body offered solace, however fleetingly. Caregivers' embodied gestures of care - holding Edward close, stroking Sophia's hair, slow-dancing with Helen, holding Jane's hand – were a material manifestation of allowing one person's experience to “find a home in the body of another” (Lingis, 1996; Ross, 2010: 186).

I spent many hours with Diana, Edward, and Helen, recently admitted and struggling to adjust to the routine and confinement of the ward. I accompanied them when they paced up and down the ward corridors or sat in their rooms, compulsively exploring blankets, clothes, shoes, and other once-familiar objects with agitated hands. Accompanying Diana and Helen sometimes situated me in an uncomfortable position in relation to the caregivers. If I allowed Diana draw me away from the lounge when the caregivers wanted her to sit down on the couch, I felt as if I was siding with her against the wishes of the caregivers. Conversely, because Diana and Helen acquiesced more easily to my requests, caregivers would sometimes ask me to intervene to persuade them to sit down to eat or to rest, but when I succeeded in doing so, I felt complicit, as if I had helped thwart their attempts to assert their independence by refusing the ward routines. There were also occasions when caregivers' requests placed me in a difficult position. One such was assisting residents during mealtimes: given that residents' medication was mixed in with their food, in helping residents eat I was in effect also administering medication. Explaining to caregivers that on the advice of my supervisor I could no longer do so was not a simple task and caused some resentment among certain caregivers.⁹

Most caregivers were remarkably loving and gentle toward the residents and engaged them with generosity, empathy, and humour. There were however times when caregivers excluded or neglected residents, often unintentionally, and other times when certain caregivers wilfully neglected a resident who needed attention or used unnecessary force. I found myself struggling with dislike for caregivers who engaged in this behaviour and was torn between intervening on behalf of a resident and being careful not to assert an authority that I did not possess. Although it was tempting to read such behaviour as individual moral failure, moving beyond this narrow focus was necessary in order to reflect on what such failures revealed about how language and memory impairments shaped caregivers' assumptions about residents' personhood status, and by extension, how these assumptions influenced relationship and the ethic of care in the ward.

I also recognised that a judgemental attitude was misplaced, not only because I did not have the “heart and the head”¹⁰ to be a caregiver, but because I struggled with my own less-than-generous responses to certain behaviours. One resident's “table manners,” for example, evoked a sense of aversion which I struggled to overcome, despite being reprimanded by Ella, a ward supervisor, who stated “Shame, she can't help it. Imagine how you would feel if you had Alzheimer's and couldn't eat properly,” when I revealed my aversion in order to find out if caregivers experienced a similar response.

⁹ A further dilemma concerning inappropriate medication is the subject of a forthcoming paper.

¹⁰ A number of caregivers stated that to be a good caregiver, one needs both an understanding of dementia's effects and the emotional capacity to provide compassionate care for demented elders.

As discussed below, I narrowed my focus to six of the eleven residents living in the ward at the time of my research due to issues around informed consent. In addition, I engaged with six family members, four spouses and two children, who were consistently present in the ward during this time. I further engaged with sixteen caregivers, twelve of whom were employed as full-time caregivers in the SCW, and four of whom were employed as private caregivers for three of the residents.

Informed Consent

Prior to my entry into the field I was concerned that the issue of informed consent would be an intractable ethical dilemma because of the complex issues of memory loss, but based on my research proposal, the project received ethical clearance from the Department of Anthropology at UCT¹¹. Anthropologists who have conducted research with persons diagnosed with ADRD have approached the issue of informed consent in various ways. Kontos (2006: 196) sought informed consent to participate by proxy; Davis Basting (2006: 183) secured consent forms from staff and family caregivers and assent forms from persons diagnosed with ADRD; and McLean (2006:160), having received permission to conduct research from the elder care facility, informed staff members and family members or persons designated as responsible parties, of her research focus.

I was granted permission to conduct research in the SCW ward by the matron and administration board. It was decided, in collaboration with my dissertation supervisor, that I would disclose the fact that I was conducting research to all persons I interacted with in the ward – family members, medical and caregiving staff, and visitors – and would work up to formal informed consent documents, if necessary, with those persons qualified to provide it. I also planned to try to get consent/assent from the residents themselves.

On my first day, the matron accompanied me to the ward and introduced me to family and staff members. As I consequently did with those I met later, I briefly explained my research focus and handed out a formal letter outlining my research aims, methods, and ethical considerations.¹² Caregivers and family members readily accepted my presence in the ward, and when I raised the issue of informed consent in relation to the residents, family members invariably responded that signing formal consent forms was unnecessary. I hoped to broach the issue of informed consent with residents by offering a simple introduction in which I identified myself as a student from UCT and requested permission to speak and sit with them.

This proved more complex than I had anticipated. I sat beside Susan on my first day in the ward, and was about to introduce myself as planned, when she grasped my hand and pleaded, “Please don’t go. Stay here with me!” On the second day, I seated myself beside two residents on the couch, and after greeting them, went through my informal introduction. Christopher listened carefully while I was speaking but his only response was to smile at me. Sophia seemed fearful and ignored me. My other attempts were similarly unsuccessful until the second week, when Elizabeth, whose language capacities were unimpaired, asked me

¹¹ University of Cape Town, South Africa.

¹² See Appendix A.

why I spent so much time in the ward. I told Elizabeth about my research and asked if she minded me spending time with her, to which she responded, “Of course not. What a silly question.”

Given that all my attempts, save one, to obtain consent from the residents were met with indeterminate responses, I decided to focus only on the six residents whose spouses and/or children I had met in the ward and who had stated that they had no objection to my presence in the ward as a researcher-cum-volunteer. I nevertheless continued to interact and engage with the five other residents, but have included insights or observations that include these residents only where I deemed it important to the argument of this dissertation. Throughout my time in the ward, I was attentive to residents’ reaction to my presence, and on the few occasions that I suspected I had inadvertently evoked anxiety or discomfort I acted to relieve this tension, either by becoming still or by moving away in a diplomatic manner.

Chapter Outline

In the chapters that follow, I focus on the modes of relationship that shaped the “embodied lifeworlds” (Lock and Farquhar, 2007: 11) of the residents, and explore the exchanges and practices through which these relationships were made and unmade across time. I demonstrate that residents were held in life and relationship through caregiving practices, and thus, that the relation of care between caregivers and residents acted to reconstitute the relational networks of individuals whose dementing illness and subsequent institutionalization had wrenched them from their erstwhile social worlds. I further explore the contexts that precipitated moments and practices of uncaring, specifically focusing on how the entanglement of language, memory, self, and time in contemporary thought influenced caregivers’ assumptions about the personhood status of residents suffering dementia-related language and memory impairments.

In chapter one, I begin by offering a selection of introductory ethnographic vignettes, state my research question, situate ‘the field’ in relation to its broader local social context, and describe the ethnographic methods used and ethical challenges encountered during fieldwork. Chapter two constitutes a literature review which introduces the reader to the anthropology of senility and dementia, and sketches an outline of the anthropological, philosophical, and psychological literature that informs my exploration of the relationship between memory, language, time, and personhood in the succeeding chapters. In chapter three, I describe the intersubjective space of the ward, and explore the caregiving practices I observed as both a form of world-making and a form of subjection that acted to bring into being a certain kind of embodied subject. Chapter four focuses on language and examines how dementia-related language losses shaped both the possibilities for relationship and caregivers’ assumptions about the personhood status of residents. Further, I consider how language framed caregivers’ understanding of residents’ behaviour, and demonstrate that such understandings had various material consequences - for residents, relationship, and the ethic of care in the

ward. In chapter five, I explore how memory loss mattered subjectively and intersubjectively in the space of the ward. I describe an intersubjective memory practice whereby caregivers narrated residents' biographies as a means to establish continuity between residents' past and present social worlds. I further demonstrate that dementia-related memory losses impaired both residents' 'cognitive' and 'embodied' skills and capacities, and argue thus, that the shift away from memory and cognition that characterizes many anthropological analyses of dementia inadvertently perpetuates a mind/body dualism. Chapter six outlines the conclusions of the present study and suggests further possibilities for research.

University of Cape Town

CHAPTER TWO: ANTHROPOLOGICAL APPROACHES TO SENILITY AND DEMENTIA

[W]e sit in her room while the conversation wheels in smaller and smaller circles. I sense that sometimes she is happy, a lot of the time she isn't. She is unhappy not because she is ill-treated but because she does not have what you or I would call a life ... Her speech remains lucid but what she says no longer describes reality. I suppose that speech will go one day and all that will be left will be howls or laughter.

(Linda Grant, 2000: 298-299)

This excerpt, from a memoir by a novelist whose mother was diagnosed with multi-infarct dementia¹³, offers a glimpse of the problems that are explored in this dissertation.

First, the author's claim that her mother "does not have what you or I would call a life," illustrates that dementia has entered the domain of the "ethics and politics of life itself" since it elicits negotiations about "quality of life,' 'loss of personhood,' and 'diminishing life'" (Kaufman, 2006: 23). Second, the author's assumption that her senile mother will eventually become incapable of meaningful utterance, her expressive capacity limited to "howls or laughter," reflects the widely held notion that the demented voice and by extension, the demented subject, is "radically exterior to the order of language, kinship, and culture" (Cohen, 2003: 126). That the author, in one short paragraph, evokes "the three great figures of mental anguish that haunt[ed] European thought before for the nineteenth century," namely, dotage, melancholy, and lunacy (Cohen, 2006: 3-6), alerts the reader to the possibility that dementia cannot be understood only as a neuropathological disease but must also be considered in historical, social, and cultural context.

In cultural contexts where reasoned conversation and memory of a shared past are understood to be fundamental to establishing and maintaining relationships across time, the relation between 'demented' and 'normal' persons is, in the face of dementia-related language and memory losses, "subject to extraordinary pressure to name itself as a failure" (Cohen, 2008: 338). It is thus precisely this relation, Cohen argues, that must be the object of anthropological enquiry, and in this dissertation, I follow Cohen's prescription by focusing on the making and unmaking of relationships between 'residents' and their professional caregivers within the space of a dementia ward.

¹³ Multi-infarct dementia is a form of vascular dementia, one of the diagnostic categories that fall under the rubric of dementia.

The Anthropology of Senility and Dementia

The anthropological focus on senility and dementia only emerged in the 1990s (see Herskovits, 1995; Cohen, 1995, 1998) and drew on the work of scholars in the social sciences and humanities which sought to historicize and contextualize the proliferation and popularization of the Alzheimer's disease discourse in North America and Western Europe in the 1980s (see Fox, 1989; Gubrium, 1990). Accordingly, anthropologists have analysed the contemporary 'age of Alzheimer's' - in which it has become increasingly difficult to imagine dementia in terms other than neuropathological disease - in relation to the medicalization of senility, the political economy of age, generational politics, and cultural anxieties about aging and dependency (see Herskovits, 1995; Cohen, 1995, 1998, 2003, 2006; Kaufman, 2006; Ballenger, 2006).

The value of such analyses lies in their effort to question and problematize the "ever more inescapable obviousness of dementia" (Cohen, 1998: 6) by drawing attention to the cultural and historical specificity of the notion that troubling behavioural change – memory loss, disordered speech, irritability, confusion - in persons defined as old, signifies a neurophysiological disease state (Cohen, 1998). In contrast to an erstwhile medical anthropology characterized by a tendency to situate the materiality of the body in opposition to the cultural and social dimensions of illness (see Lock and Farquhar, 2007), anthropological analyses of senility and dementia have sought to understand the widespread acceptance of dementia as a disease category in a comprehensive manner that includes the materiality of the brain, generational politics, professional knowledge, political economy, and culture (see Cohen, 1998; 2006).

Scholars have traced the gradual shift in the perception of senility. Formally perceived as synonymous with old age, in the late nineteenth century senility began to signify the "weakness and decrepitude" of old age, and over the course of the twentieth century, came to be viewed as a pathological state (Kaufman, 2006: 25). As Kaufman (2006: 26) notes, this shift – "from 'senility' to 'senile dementia' to 'Alzheimer's disease'" - has entailed the progressive separation of 'normal aging' from brain pathology and has been "widely documented as the 'medicalization of senility.'" Significantly, senility was a broad concept, referring to the physical and mental deterioration associated with old age, even within biomedicine in the 1960s and 1970s (Ballenger, 2006: 112). Only in the 1980s was senility recast as "irreversible progressive dementia in old age" (Hinton et al, 2006: 46), produced by neuropathological disease, and distinct from aging. Within biomedicine, both the gerontological effort to distinguish normal and pathological aging (Ballenger, 2006), which drew on earlier debates about whether old age itself should be considered a normal or pathological process, and the re-biologization of psychiatry, where the brain came to replace the unconscious as the "primary site of mental health" (Leibing, 2006: 252), contributed to the "apparent total biologization of senility" (Cohen, 2006: 7).

However, like Herskovits (1996), Cohen (1998: 6) insists that the impetus for the shift in the perception of senility does not lie "primarily with a purportedly hegemonic abstraction called biomedicine." Instead, the proliferation and popularization of the Alzheimer's discourse in so-called Western contexts over the last three

decades must be understood in relation to a “culturally and historically located embodiment of the anxiety of getting old” (Cohen, 1998: 125). A neuropathological disease model allows old age to be freed from its association with inevitable mental and physical decline, and cements the distinction between normal and pathological aging, at least in popular thought (see Cohen, 1998, 2006; Herskovits, 1996; for related discussions).

The authors cited in this dissertation variously use the terms *senility*, *dementia*, and *Alzheimer’s disease*, at times interchangeably, a practice which highlights Cohen’s (1998: 32) assertion that none of these terms is stable or invariant. Cohen (1998: 33) prefers the term *senility* because it best evokes the “changing and contested meanings” attributed to behavioural change in old age, but the terms *dementia* and *Alzheimer’s disease* are indispensable because they have become dominant referents in popular and medical representations. *Dementia* is currently uttered “as a gloss for any neurological condition that slowly or rapidly destroys cognition, memory, reflexivity, and expressive capacity” (Kaufman, 2006: 24). However, as Cohen (1998: 26) points out, *dementia* is a clinical rather than diagnostic term, and while dementia describes a “particular behavioural picture,” a person cannot be diagnosed with dementia, but rather, with one of the discrete disease entities that are understood to produce the signs and symptoms of dementia.

DSM-IV, the fourth edition of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, defines dementia as “a clinical syndrome characterised by cognitive impairment that represents deterioration from a previous state and is associated with functional decline” (Hinton et al, 2006: 46), and outlines multiple diagnostic categories or causal models classified under the general heading of dementia. These diagnostic categories include “a cluster of what are commonly referred to as the degenerative dementias: Alzheimer’s disease, vascular dementia, and frontotemporal dementia” (ADRD), which are understood to cause irreversible, progressive dementia in old age (Hinton et al, 2006: 46). Moreover, the clinical and diagnostic emphasis is on cognitive impairment, with memory loss defined as primary, and other cognitive disturbances - aphasia, agnosia, and apraxia - as secondary (see Cohen, 1998; Hinton et al, 2006). This emphasis on cognitive deficits as opposed to behavioural or affective disturbances has been the focus of critique in numerous anthropological analyses (see Cohen, 1998; Kontos, 2006; Ballenger, 2006).

In contemporary Western contexts, *Alzheimer’s disease* has all but replaced the term *senility* in both popular and medical usage. According to Herskovits (1996) and Cohen (1998), the proliferation and popularization of the Alzheimer’s discourse in the 1980s and 1990s entrenched in popular thought, “the status of Alzheimer’s as a real and biological disease” (Cohen, 1998: 7), and thus the distinction between normal and pathological aging. However, in gerontology and the medical sciences the debate about whether Alzheimer’s disease is pathological and distinct from normal aging persists (see Kaufman, 2006: 26; Cohen, 1998).

Cohen's (1998; 2003; 2006) understanding of senility has been seminal because he draws attention to senility as "acutely attributional" in that it usually involves two classes of bodies: a senile body and another body that recognizes troublesome change in the first (1998: 33). Cohen (1998; 2003) also elaborates an understanding of the multiple ways in which language and voice are central to understanding senility, with particular emphasis on how the dynamic relationship between language and practice shapes the perception, understanding, and embodied experience of dementia (see Cohen, 1998; 2003). Here, I focus on Cohen's (1998: 38) assertion that "to speak of dementia is to call upon an aging body in a certain way ... and in a sense to materialize the body." Cohen argues that the "diagnostics and discourses" of dementia function to reduce the "interpersonal and existential crises of aging" (1998: 82) to the signs and symptoms of neuropathological disease (2003: 126), and thus call forth a particular embodied subject – the 'Alzheimer's victim' or 'demented elder.'

While not denying its biological basis, Cohen (1998: 33) argues that senile dementia is a "fundamentally dialogical process" in that it is difficult to distinguish medical ontology - a pathological disease state – and the specific cultural and historical contexts in which certain behaviours or utterances are defined as abnormal or pathological. Cohen (1998: 33) further suggests that the "types of knowledge and practice that structure the experience of senility and make it comprehensible emerge within a particular relation of desire between the senile and the attributing body."

This understanding resonates with that of scholars (see, for example, Goffman, 1967; Hacking, 1996, 2004; Kitwood, 1997; Desjarlais, 2000) who draw attention to the ways in which embodied subjects are brought into being through social exchanges between individuals, where words, glances, responses, silences, withdrawals, and body language, shape "the ways in which the actual and possible lives of individuals are constituted" within institutional environments (Hacking, 2004: 278). As discussed in chapter one, I have used this insight as a means to structure my work in the ward.

Biomedical and Personhood Approaches to Dementia

Anthropologists have drawn attention to the fact that much popular and scientific literature on dementia, particularly Alzheimer's disease, is characterized by narratives of loss and abjection, a trend which has had a significantly adverse effect on how 'demented elders' and dementing illness are perceived (see Herskovits, 1995; Cohen, 1998, 2003; Leibing, 2006; Kontos, 2006; Taylor, 2008). Dementia is commonly represented as a "virulent brain killer" (Cohen, 1998: 54) that destroys the very attributes – memory, expressive capacity, reason, autonomy – fundamental to cultural assumptions about what constitutes full personhood, in so-called Western contexts at least (Kaufman, 2006: 24; Cohen, 2006). It is widely accepted that dementia erases the 'self,' rendering the person an 'empty shell' no longer capable of meaningful interaction and relationship; and

diminishes life “via a pattern of developmental regression,” culminating in the person’s complete dependence on others for ‘bare life’ (Kaufman, 2006: 29). Cohen (1998: 54) points out that within much of this literature, the representation of demented persons as “aphasic, confused, and angry” offers a logic that “denies any possibility of continuity and meaningfulness” and thus confirms the “death of selfhood.”

Since the early 1990s, in reaction to such representations, a proliferation of clinical, academic, and popular writing has sought to challenge the construction of demented elders as nonpersons (see Leibing, 2006). Much of this writing is characterized by the effort to rescue or recover “the person within,” and such efforts have variously been described as the “personhood turn” (Cohen, 2006; 2008) and the “personhood movement” (Leibing, 2006). The focus on personhood in the social sciences long preceded the relatively recent focus on the person in dementia care and research (Leibing, 2006: 246 - 247), but like much of the social science literature on personhood (see Harris, 1989: 599), the concepts of self and person are often conflated in the ‘personhood’ approach to dementia. Those writing within the “personhood movement” generally use the term personhood to refer to the person *within* – “the reflexive, immaterial, communicable essence of a person that is located deep within the body, but that is sometimes veiled by symptoms” (Leibing, 2006: 243). This usage contrasts with the more widely accepted definition of personhood in sociology and anthropology where ‘person’ refers to a “socially recognized and engaged human being” (Desjarlais, 2000: 478).

In an effort to challenge the construction of demented elders as nonpersons, clinical and scholarly writing within the “personhood movement” is generally marked by a tendency to view the personhood and biomedical approaches to dementia as dichotomous. Scholars have problematized the biomedical approach to dementia, informed by a cognitive model of personhood and the “assumed materiality of the brain” (Kaufman, 2006: 243), which is focused primarily on cognitive impairment, specifically memory loss, as is evident in the diagnostic criteria contained in DSM-IV. Scholars point out that this cognitive focus renders behavioural and affective symptoms or changes secondary, despite the fact that disruptive behavioural symptoms often precipitate institutionalization (see Cohen, 1998; 2006; Hinton, et al 2006). Scholars have also problematized medical and popular representations of dementia that equate memory loss with the loss of self and death of the person, by demonstrating the cultural and historical specificity of the notion that memory and cognition are fundamental to personhood (see Kontos, 2006; Taylor, 2008).

In contrast, the personhood approach, which draws on the “‘soft’ psy sciences,” is based on the notion of the “immateriality of the person or the self, comparable to what once was the soul,” and is “linked to a personal narrative, to communication, and to the ethics of good caring” (Leibing, 2006: 243). Such writing has problematized, at least in scholarly and clinical contexts, the biomedical approach by challenging taken-for-granted assumptions about the relation of cognition and memory to personhood. Nevertheless, Leibing (2006: 242) cautions that situating the personhood and biomedical approaches as dichotomous disguises the fact that

these two approaches are, historically and currently, “much more complex and intertwined,” and that many aspects of the “personhood movement have been incorporated into biomedical care.”

Many anthropological analyses of dementia have adopted the personhood approach and, in keeping with this approach, have advocated a move away from memory and cognition toward behaviour and coherence (Cohen, 2006: 10). Drawing on an anthropological legacy of personhood studies, such work offers alternative conceptualizations of personhood which emphasize the relational aspects of the ‘self,’ the making and unmaking of personhood in intersubjective contexts (see Taylor, 2008; Chatterji, 2006; Cohen, 1998; McLean, 2006), and the embodied nature of selfhood (Kontos, 2006). Unlike the majority of anthropological analyses influenced by the personhood turn, Janelle Taylor’s (2008) essay takes memory as its focus. Taylor considers how dementia-related memory impairments, specifically the impaired ability to recognize others, often lead to the perception that demented elders are no longer capable of maintaining meaningful relationships. Taylor notes that for elderly individuals living in elder care facilities, “the ability to recognise others appears to be the most important determinant of whether or not social death occurs” (Sweeting and Gilhooly, 1997; Taylor, 2008: 320). Here, Leibing’s (2006: 248) notion of ‘biosocial death,’ which describes the form of social death that occurs when a particular medical condition diminishes a person’s capacity to engage in society to the point where they are no longer considered full persons, is relevant to dementing illness. In such instances, “a social death occurs because of a person’s biology, and biology cannot be described apart from the social body” (p. 248).

Taylor (2008) argues that those suffering dementia-related memory impairments endure a ‘biosocial death’ not only because memory is understood to be fundamental to personhood, but because of the development of an “ethics of memory” in contemporary Western cultural contexts, where memory, recognition, and caring are intertwined to form the basis of an ethic of relatedness. Within this understanding, remembering a person and one’s relation to him or her in terms of a shared history demonstrates that one cares; conversely, not “only is it tragic, but it is *wrong* for a person to forget their close relations, especially family relations” (2008: 318). Taylor states that neither personhood nor caring resides in the capacity to remember, and argues instead that attention to gesture, facial expression, utterances, and movement reveals that demented persons are yet capable of meaningful interaction and relationship. Taylor’s analysis provides insight into how the relation between memory, recognition, and relatedness in contemporary Western contexts shapes the relation between ‘demented’ and ‘normal’ individuals, and her formulation of an alternative “ethics of good caring” (Leibing, 2006: 243) situates her work within the “personhood movement.”

Although Cohen (2008) acknowledges that the “personhood turn” has provided a necessary challenge to the biomedical approach to dementia, he suggests that the “ethics of care” that personhood scholars and clinicians generally advocate is based on “pedagogies of attention” (p. 337) that require the non-demented person to attend to the gestures, utterances, and embodied skills which are offered as evidence of the

persistence of the selfhood or personhood of those diagnosed with dementia. Cohen (2008: 337) notes that firstly, such practices of care may only be available to the fortunate few, and secondly, may only enable a 'recovery' or recognition of personhood in demented persons still capable of gesturing, moving, and vocalizing. Cohen (2008: 338) is concerned that at best, "the hermeneutic power of the personhood turn" may evade "the demand that the person with dementia be positioned on one side or the other of the binary between a comprehensible and an incomprehensible form of life." In this dissertation, I aim to overcome this limitation by developing an understanding of how the entanglement of language, memory, self, and time in contemporary thought shapes notions of personhood and relatedness.

Memory, Narrative, and Personhood

[We understand by 'person'] a thinking intelligent being, that has reason and reflection, and can consider itself, as itself, the same thinking thing, in different times and places...
(John Locke; Puccetti, 1977).

Cohen (2006: 6-7) points out that although senility became marked as a disorder of memory over the twentieth century, senility, unlike multiple personality disorder (Hacking, 1995) and traumatic memory loss (Young, 1995), did not stimulate an exploration of the ways in which self, language, and memory have become intertwined in Western thought. Cohen (2006: 4 – 8) asserts that this is because senility, until the proliferation and popularization of the Alzheimer's discourse in the 1980s, was viewed as a "problem of life but not of the subject," that is, the relevance of senility was seen to lie in the social problem of old age rather than of the modern subject.

Despite the general shift away from memory and cognition described above, some 'personhood' scholars (Kitwood, 1997; Davis Basting, 2006; Leibing, 2001; 2006) suggest "a reformulation of the concept of memory as a more inclusive notion, conceived of as social and interactive" (Leibing, 2006: 253). Leibing notes that shifting the widely held understanding of memory as an interior, individual capacity to an understanding of memory as social and interactive is an ideal prescription given that redefining 'memory as interactive' would only be possible after a major shift in our deeply rooted thinking and practice: that memory is "the carrier of individual identity and personhood" (2006: 255 – 256). In chapter five I define a form of engagement between caregivers and residents as an *intersubjective memory practice* and situate this practice in relation to an interactive conceptualization of memory. Here I turn to a consideration of the relationship between memory, language, and self in Western philosophical thought.

In Western philosophical tradition, memory has long been tied to identity, an understanding vividly expressed by philosopher John Locke's assertion that "the person is constituted not by a biography, but by a

remembered biography” (Hacking, 1996: 91, *emphasis added*). Within this philosophical tradition, memory, identity, and temporality are inextricably tied as it is the capacity to remember that establishes the continuity of identity over time. Moreover, memory is considered necessary to morality or ethics because the assumption is that individuals’ sense of their identity as continuous enables them to be accountable for their actions and to others (Strawson, 2004).

Antze and Lambek (1996: viii) suggest that memory can be understood “as part of a moral discourse taken up by individuals and groups, often unself-consciously, as a means to articulate, legitimate, and even constitute their selfhood and relationships to others.” As in much of the anthropological literature discussed thus far, the terms identity, personhood, and selfhood are used interchangeably. Pucetti (1977: 147) points out that ever since John Locke established memory as essential to identity and personhood, philosophers have tended to “conflate the problem of the self with the problem of personal identity.” Pucetti (1977: 147) argues that “since memory is clearly essential to a sense of one’s identity through time,” philosophers mistakenly tend to assume “that having a concept of self requires memory too.” He states that “knowing *who* you are, [that is], with what past self you are personally continuous, is not the same as knowing *that* you are” and it is therefore erroneous to assume that a person whose memory is impaired or disordered does not “retain a sense of self” (pp. 147-148, *original emphasis*).

The ubiquitous tendency to conflate the notions of self, identity, and personhood can be better understood by drawing on Galen Strawson’s (2004) critique of the taken-for-granted belief, at least in so-called Western cultural contexts, that human beings experience their lives as a story that unfolds over time and moreover, that such narrative understanding is essential to full personhood and ethical relationships. Strawson offers an understanding of how memory, language, self, and time have become entangled in contemporary Western thought. Strawson disagrees with Locke, Heidegger, and others who argued that maintaining a coherent identity across continuous time, through memory and narrative, is essential to self-experience, meaningful ongoing relationships, and ethical living. Strawson (2004: 432) states that establishing and sustaining relationship is dependent on “how one is in the present” rather than on the capacity to remember “past shared experiences in detail.” To understand why memory, narrative, and temporal continuity have come to be viewed as essential to personhood and relationship, it is useful to consider Hacking’s (1996) genealogical account of the emergence of the “memory sciences.” Hacking’s writing, like Strawson’s, creates a space to stand back from the now taken-for-granted assumptions about memory and its centrality to current conceptions of personhood and relatedness.

According to Hacking (1996: 81-91), while “memory in Western thought has always been close to notions of identity and soul,” as strongly expressed by John Locke, the notion that everyone, “even the lowest of the low,” has a biography became widespread only in the nineteenth century, concomitant to the emergence of the memory sciences - neurological, psychodynamic, and experimental – when memory came to

be seen as an entity that could be known through scientific investigation. Hacking (1996: 81) points out that with the emergence of the “new technologies of anatomy” – such as criminal records and medical case histories - the growing understanding of life as a story was further reinforced by the demand to “know which body goes with which life,” a form of identification achieved by the “hooking of a narrative onto a person.” It is within the context of these shifts and developments that the “importance of memory and forgetting” (Hacking, 1996: 81) became entrenched in modern scientific and popular thought.

Broadening the Scope of Memory

Anthropologists (see Kontos, 2006; McLean, 2006) who have advocated a shift away from memory and cognition have, like other clinicians and scholars who adopt the personhood approach to dementia, employed a narrow interpretation of memory as one capacity – the ability to bring “past thoughts, events, or faces to mind” (Hacking, 2005: 224). Both Kontos (2006) and Taylor (2008) suggest that selfhood persists in the movements and expressive capacity of the body, and while Taylor refers to dancing, walking, and singing as “embodied procedural memory” (p. 328), it is evident that both scholars view such embodied practices as distinct from cognition and memory. This distinction not only inadvertently perpetuates a mind/body dualism but also employs a narrow conception of memory and cognition (see chapter five).

Memory - if defined as a capacity for learning and remembering – stands for a wide range of “abilities and performances” (Hacking, 2005: 224). Since the emergence of the memory sciences in the late nineteenth century, experimental psychologists have sought to “operationalize memory in order to understand and measure it” and have done so by developing a taxonomy of memory which distinguishes different classes of memory, albeit not un-controversially (Rose, 2010: 200). Thus, over time, *long-term memory* was distinguished from *short-term memory*; *declarative memory* – the capacity to remember facts and the names of things – from *procedural memory* – the capacity to remember how to do something; and declarative memory was later divided into *semantic memory* – memory of numbers and dimension - and *autobiographical* or *episodic memory* – the memory of one’s past experiences and relationships (Rose, 2010: 201).

Hacking (1996: 70) notes that the “location of distinct memory functions, in distinct parts of the brain, has confirmed a materialist approach to memory.” However, anthropologists remain critical of cognitive science (see Antze and Lambek, 1996: xi) and neuroscience (see Emily Martin, 2000) because these sciences are held to advocate brain-based theories of human action that ignore the cultural and “social dimension[s] of experience” (Martin, 2000: 574-585). While the “ever more inescapable obviousness of dementia” (Cohen, 1998: 6) attests to the power of “neuroreductive” (Martin, 2000: 574) explanatory models (see Cohen, 2006), some scholars suggest that the aforementioned critiques are based on a “stereotyped image of cognitive science” (Sutton, Harris, and Barnier, 2010: 209) that does not take into account the developments that mark

its recent history. Sutton et al (2010: 210) point out that within contemporary cognitive science, the scope of cognition has been broadened to “include emotion and motivation, embodiment and movement” and to address “factors below conscious awareness and control as well as beyond the individual.” Moreover, the concept of memory has been expanded to encompass its “neural, cognitive, affective, bodily, social, material, and cultural” aspects (Sutton et al, 2010: 210)

Importantly, contemporary cognitive scientists’ recognition that personal memory is not only “relatively vulnerable and permeable” but co-constructed in relationship with others (Sutton et al: 2010: 220), corroborates the view that memory is a fundamentally interactive, relational process that transcends the boundaries of the self (see Leibing, 2006; Kitwood, 1997; above), and may contribute to unsettling the long-held Western understanding of memory as “the carrier of individual identity and personhood” (Leibing, 2006: 257). However, as Radstone and Schwarz (2010: 6) note, while it has been widely “accepted that memory’s purchase extends beyond the individual, the question of how the social dimensions of memory are to be theorized continues to provoke debate.”

My work contributes to this debate by exploring the manner in which the entanglement of language, memory, self, and time in contemporary Western thought shapes the possibilities for personhood and relatedness within the institutional space of dementia ward.

CHAPTER THREE: PRACTICES OF CARE, WORLD-MAKING, AND SUBJECTION

Subjection is not only a subordination but a securing and maintaining, a putting into place of a subject, a subjectivation (Butler, 2007: 169).

When I began fieldwork I was told that I had come at a time when the “peace and quiet” in the ward had been disrupted by the recent admission of Helen, Diana, and Edward, all three of whom had been diagnosed with ADRD. This proved to be a fortuitous, but distressing, ethnographic coincidence in that I was witness to their struggle to adjust to being wrenched from a familiar social world and confined in a closed ward, which they would not, in all likelihood, leave until their death.

In this chapter, I describe the physical and intersubjective space of the ward, outline the routines, rhythms, and temporalities that shaped everyday life on the ward, and explore the relation of care that structured the interactions between caregivers and residents. I argue that it was through practices of care that residents were held in life and relationship and that these practices can therefore be understood as acts of world-making. I further argue that the language and practices that established and sustained relationship simultaneously enacted a certain kind of “embodied subject” (Cohen, 1998: 36), which following Foucault (1977; Butler, 2007), I refer to as the ‘docile body,’ brought into being through subjection to institutional routine and temporal structure, and physical, verbal and pharmaceutical restraint. I demonstrate, however, that even old bodies marked by dementia-related impairments and disciplined and restrained in various ways, resisted such subjection.

The Ward as a Space of Intersubjective Engagement

Wards in medical institutions, Cohen (2006: 16) suggests, can be viewed as “spaces of intersubjective engagement.” Kitwood, a leading advocate for a “person-centred” approach to dementia, proposed that dementia wards be viewed as intersubjective spaces that can be shared by caregivers and demented elders alike, and that thus have the potential to offer demented elders “community life” and possibilities for developing a “lifeworld” (see Chatterji, 2006: 218). Kitwood’s focus was on the ways in which intersubjective engagement could act to restore personhood through a “special kind of care relationship” based on a “model of nonverbal communication” (Chatterji, 2006: 218). Irving Goffman, by contrast, viewed such institutional interactions – constituted by glances, gestures, postures, words, and silences – as coercive and as the means through which persons confined within an institution learn to “conform to a particular diagnostic category or

classification” (Goffman, 1967; Hacking, 2004: 378). As I demonstrate throughout this dissertation, both these possibilities existed in dynamic tension within the ward.

The Special Care Ward is a closed ward. One exits the ward through a door that is opened with a swipe card; as residents do not have access to such a card they cannot leave the ward without assistance. While this ensures that residents do not “wander”¹⁴ outside the ward and become lost, providing for the safety of the residents also acts to confine them. Four of the residents seemed acutely aware of this confinement, three of whom consistently, albeit unsuccessfully, attempted to leave the ward. Elizabeth, by insisting every afternoon that the caregivers open the door so that she could “go home,” and Helen and Edward, by standing near the door and attempting to slip through when it opened.

I had expected the ward, located in an exclusive retirement community, to be luxuriously furnished, and was surprised by its sparseness - there were no lamps, vases, or carpets in the lounge, very few pictures on the lounge and dining room walls, and the sofas and chairs were stained and quite worn. The physical space of the ward: eleven individual rooms leading off a long corridor; a dining room with four square tables variously arranged at mealtimes; a lounge looking out onto a small garden and furnished with sofas, reclining chairs, and restraining chairs, side tables, and a CD player; two communal bathrooms with toilet, shower, and bath; a laundry room; and a nurses’ station. Each individual room contained a standard built-in cupboard and washbasin, and had space for a single bed, ‘normal’ or ‘hospital’ type. Residents’ rooms were decorated by family and/or friends, some with familiar furnishings – paintings, favourite chairs, framed photographs, books, soft toys, cashmere throws – brought from home; others with a flat-screen television or one or two framed photographs.

Eleven residents were living on the ward when I began fieldwork, seven women – Claire, Jane, Sophia, Elizabeth, Helen, Diana, and Susan - and four men – Charles, Christopher, Hans, and Edward – their ages ranging between 73 and 99 years. Ten of the residents were diagnosed with ADRD prior to admission to the ward. While dementia is clinically defined “primarily by a set of multiple and relatively stable cognitive deficits, and in particular a deficit of memory” (Cohen, 1998: 26), it was evident that there were marked differences among residents in terms of cognitive impairment, such as language and memory loss, as well as the impairment of embodied skills. Moreover, it was apparent that each resident’s unique history and personality, not only shaped the ways in which he or she responded to the distressing and confusing experience of memory and language loss and institutionalization, but also to the ways in which he or she was able to form and maintain relationships with other people, and to space and time.

While residents shared the space of the ward, many residents’ lack of physical mobility meant that they were only able to engage with others when seated within relative proximity. Elizabeth, almost blind, listened attentively to conversations, commenting or empathising when appropriate, complaining when Susan

¹⁴ “Wandering” is the term used in medical and popular literature to describe the ‘excursions’ that many individuals diagnosed with ADRD engage in, both within and outside the space of the home or institution.

sang too loudly, and intervening when she thought caregivers were unfairly refusing to allow Charles to get up from his chair, “Let him stand up if he wants to!” Christopher observed everyone very closely, laughing at or disapproving of certain comments or behaviours, and reaching out to grab a caregiver’s hand when he wanted to get up from his reclining chair. Edward constantly interacted with other residents, accompanying Diana as she paced along the corridor, following Helen as she explored residents’ rooms, and trying to engage in conversation with Sophia and Jane, both of whom were usually seated in restraining chairs. Helen often “harassed”¹⁵ the other residents, either mocking their gestures and/or speech or trying to remove a shoe or a glass from their hands. Jane often reached over to someone seated beside her, especially if he or she was distressed, and fluttered her fingers along an arm or leg in a gesture of comfort.

A number of family members were a constant presence in the ward – Sara (Hans’ wife), Linda (Edward’s wife), and Johan (Diana’s husband) spent at least three hours in the ward every day, while Isabel (Charles’ wife) and Alice (Elizabeth’s daughter) visited for an hour most afternoons, and Catherine (Helen’s daughter) visited at least twice a week. Four institutional caregivers, including a ward supervisor, were present in the ward on each twelve-hour shift. Additionally, three of the residents had full-time private caregivers who provided personalized care to them, and also assisted other caregivers and residents as needed¹⁶.

Practices of Care: A Form of World-making

It’s an honour to be with them during the last years of their lives ... to give back and take care of people who have taken care of others all their lives ... to make them as comfortable as possible and treat them with dignity (Ella, ward supervisor)

I had not anticipated the degree to which the residents would be dependent on the caregivers. Every morning, caregivers bathed and meticulously dressed residents in clean, ironed clothing, and ensured that they were carefully groomed - hair neatly brushed or combed, skin perfumed with cologne or talcum powder, and for some female residents, make-up carefully applied. Throughout the day, caregivers assisted residents who could not stand or walk on their own to move around the ward, ensured that their “adult nappies” were regularly changed, helped them eat, and administered their medication. Caregivers talked and joked with residents, comforting them when they were sad or distressed, and reprimanding or restraining residents when their behaviour was deemed potentially harmful or when it transgressed the norms operating in the ward.

Caregiving thus involved both caring for residents’ emotional and bodily needs and maintaining control over residents’ behaviour. While there were times when a caregiver would engage with a resident as if

¹⁵ ‘Harassed’ was a term used by caregivers when a resident’s behaviour was deemed to violate another resident’s ‘personal space’ or ‘boundaries,’ for example, touching or talking in a manner that evoked discomfort or anxiety.

¹⁶ Institutional and private caregivers alike were contracted to Maynard Manor.

she or he were merely a body that needed to be fed, bathed, or dressed as efficiently as possible, for the most part caregivers approached caregiving as engagement, their words and actions an important means of daily establishing a 'good enough' intimacy with individuals whose memory and language impairments are widely assumed to render relationships difficult to sustain across time (see Chatterji, 2006; Cohen, 2006; Strawson, 2004; Taylor, 2008). It is noteworthy that proponents of the personhood approach to dementia care place more value on the care of the 'person within' than the "body work" (Chatterji, 2006: 227) which sustains bodily, and by extension, social coherence and continuity (see Henderson, 2009). Such distinctions, as Leibling (2006; chapter two) points out, are borne of the effort to explicitly oppose the personhood and biomedical (purportedly focused solely on the physiological body) approaches to dementia.

While numerous scholars influenced by the "personhood turn" (Cohen, 2006), advocate an understanding of personhood or selfhood as fundamentally embodied so as to challenge the cognitive model of personhood which informs the biomedical approach to dementia (see Kontos, 2006), it seems that the phenomenal, experiencing, expressive body that is the focus of such approaches is distinct from the body of flesh, urine, sweat, blood, and faeces. Many caregivers claimed that it was through care of the intimate physical needs of the body, which requires compassion for the fleshy body, its frailties and secretions, that they were able to ensure that residents lived this "last phase of their lives" with the "dignity they deserve."¹⁷ Lingis (2010: 267-268) notes that dying is "held in the endurance of time" and that for the dying person, enduring this time with dignity is not an outcome of intention or will, but "a side effect of doing other things well." Within the ward, it was through caregivers' ongoing efforts to ensure residents were bathed, groomed, dressed, and 'toileted' in the privacy of their individual rooms or bathroom, a privacy which caregivers, with rare exception, strictly protected – even from other residents and non-family members – that residents could be said to endure this time with 'dignity.' Ella, a ward supervisor, stated that it was necessary to teach new caregivers that they could not treat residents as they would their parents because, "These are educated people," a view that reflects assumptions about class and cultural differences between 'coloured' working class caregivers and 'white' upper-class residents. Here, caregiving practices are shaped by institutional norms that act to extend "the values of privacy and autonomy" understood to be fundamental to the socially and culturally shaped patterns of "social interaction" (Chatterji, 2006: 223) among the 'white' and upper-class residents.

Enacting caregiving practices was not always a simple matter: caregivers noted that the vast majority of newly admitted residents go through an "adjustment period" where they balk at the idea of allowing a stranger to assist them with the intimate acts of toileting, bathing, dressing, and eating. Additionally, dementia-related cognitive impairments frequently lead to a loss of inhibition which at times supersedes ingrained norms of social interaction (Chatterji, 2006: 233). It was not unusual for caregivers to reprimand

¹⁷ The quotes indicate caregivers' words and phrases.

Helen, Diana, and Edward, who were physically mobile when they first entered the ward, for intruding on other residents' privacy. Helen often undressed and entered the lounge wearing only underwear, and while caregivers exchanged amused glances or comments, they pretended to be shocked in order to persuade Helen to allow them to dress her. Helen was unruffled by caregivers' appeals to norms of propriety and usually refused to be led back to her room, insisting that caregivers did not have the right to tell her how to dress. While Helen's undressing can certainly be attributed to a dementia-induced lack of inhibition, the ward was often hot – many residents could not tolerate air-conditioning – and the “adult nappies” that Helen, like most residents, had to wear were clearly uncomfortable, evident from the way in which Helen constantly plucked at them. Caregivers noted that five of the eleven residents had been transferred from the adjoining wards to the SCW when they began engaging in “inappropriate behaviour” because the SCW was “much more relaxed.” Thus, like many dementia wards, the SCW can be described as an “enclave of tolerance” (Chatterji, 2006: 219) where inappropriate behaviour is attributed to dementing illness rather than to will or intention, and the “norms establishing and representing the ordered body [thus] less strictly adhered to” (Chatterji, 2006: 235).

Ella stated that it was “love” that enabled her to attend to residents' every emotional and physical need, and this capacity for love is all the more remarkable because it transcends a centuries-long social history of racial discrimination. While acknowledging that Ella's capacity for love and empathy is a testament to her spirit (see Das, 1996), I suggest that to engage in caregiving practices in a manner that does not shame or humiliate, is to overcome the modernist aversion to dependence and the vulnerability and frailty of the human body that a philosophy of individualism has produced. Judith Butler (2010) points out that in contemporary Western societies, the “false idea that the able-bodied person is somehow radically self-sufficient” is pervasive. Butler suggests that forms of impairment that render individuals dependent on others for their basic needs draw attention to what may be at stake in “re-thinking the human as a site of interdependency.” For Gibson (2006: 188-190), at stake in such a re-thinking is the development of an alternative ethic of relatedness, based not on the “rights of the generalized autonomous subject,” but on the understanding that the subject, re-conceptualized as a “becoming-with-others,” is fundamentally “dependent upon networks of mutuality.”

It is precisely such alternative conceptualizations of personhood and relatedness that anthropologists, drawing on an anthropological and sociological heritage of cross-cultural comparison of modalities of personhood, have contributed to the debates about the personhood status of persons diagnosed with ADRD (Kaufman, 2006: 27). In lieu of the dominant model of personhood prevalent in contemporary Western contexts, where full personhood hinges on memory, cognition, reason, expressive capacity, and autonomy (Leibing, 2006; Kaufman, 2006; chapter two), anthropologists have emphasised a relational model where personhood is “emergent in practices of care” (Taylor, 2008: 326), and its “preservation or dissolution” influenced by “intersubjective practices” (Chatterji, 2006: 235).

Here, I expand on this scholarship by exploring caregiving practices in relation to Ross' (2010) discussion of accompaniment as a relation of care and Henderson's (2009) notion of processual personhood. Following Lingis (1996), Ross (2010: 198–200) contends that accompaniment, the relation of care for another in the face of illness and death, has the potential to create “sustaining forms of sociality” in situations where usual forms of relatedness are disrupted or displaced through illness. The “making and holding of relationships in the presence of illness and the face of death” (Ross, 2010: 188) takes on special significance in the context of the ward, where residents' relational networks, already strained by dementia-related impairments, are disrupted by institutionalization. It was evident that many of the residents endured – whether knowingly or not – a ‘biosocial death,’ which for some involved abandonment by lifelong friends, and for others, an almost complete abandonment by family members, save for rare visits¹⁸. While five of the residents' family members visited every day, in the ward it is the caregivers who stay with residents “until the end comes” (Lingis, 1996: 10) and who, through the enactment of myriad and ongoing practices of care, bring residents into relationship and draw them into an alternative form of sociality.

Ross' (2010) contention that the relation of care for another in the face of illness and death sustains an alternative form of sociality ties into Henderson's (2009) discussion of a processual model of personhood where personhood is “immersed within and emergent through sociality.” Here, personhood is not a “teleological goal which has an endpoint,” but an “ongoing project” which unfolds and emerges through practices of care and obligation. Conceptualizing personhood as processual and emergent provides a way to understand how personhood can both be invoked through practices of care and denied through acts of ‘uncaring’ (see Desjarlais, 2000).

In the context of the ward, witnessing acts of empathy, kindness, and generosity alongside acts of neglect and cruelty necessitated an acknowledgement of the complex and dynamic nature of caregiving. Scholars have sought to understand “uncaring,” defined as the denial of another's pain (Das, 1996) or the failure to respond to another's suffering (Ross, 2010), by variously interpreting such denial as a failing of the spirit (Das, 1996: 88), or, as “symptomatic of a social failure” (Ross, 2010: 193) rather than solely of individual shortcoming. Ross (2010: 193) asserts that paying attention to the circumstances and assumptions that precipitate a breakdown in care encourages an examination of the social context of uncaring. While caregivers undeniably differed in their capacity for generous and empathic caregiving, it was evident that caregivers' fluctuating physical and emotional states also influenced the ways in which they engaged with residents at different points in time. Moreover, as demonstrated in chapters four and five, I observed that caregivers' assumptions regarding the relationship between language and memory loss and personhood were frequently implicated in a breakdown in care.

¹⁸ While the context of such ‘biosocial death’ is important, limited space has precluded a discussion of the specific circumstances of family members or friends who only very rarely visited their institutionalized loved ones.

Making Embodied Subjects: Dependency and Discipline

In response to Cecilia's instruction to change the soiled blouse that she was wearing, Helen pretended to cry like a baby, calling out "Mama, mama." Cecilia was irritated but softened when the other caregivers present laughed.

The practices of care that are the basis of the interactions between residents and caregivers not only reconstitute and maintain residents' relational networks but also act to bring into being particular forms of embodied subjectivity (Cohen, 1998). Following Elias (1978a [1939]); Shilling (2003: 144) describes the process of "civilizing bodies" as one which involves the "progressive socialization, rationalization, and individualization" of the body. Dementing illness can be understood as a process that 'unmakes' the civilized body - the impairments associated with dementia not only undo the process of "rationalization" associated with cognitive functions, but also the control, learned through years of socialization, of bodily functions. Caregiving practices, which are structured by institutional routines and temporal rhythms, thus constitute an externalization of the disciplining practices once internalized through various forms of subjection across a lifetime, but now unsettled or undone by dementing illness.

Further, it was evident that certain institutional practices, specifically verbal, physical, and pharmaceutical restraint, were an attempt to bring (back) into being "docile bodies" (Foucault, 1995) that more easily submitted to externally imposed routines, rhythms, and practices of bodily care. During the day, residents were encouraged to remain seated in the lounge for hours at a time, an immobilization (partially) achieved through the administration of pharmaceuticals, which were an essential mode of care in the ward. All but two of the residents were administered a range of medications - anxiolytics, anti-depressants, and anti-psychotics - undoubtedly to alleviate 'symptoms' such as anxiety, depression, agitation, and hallucinations. However, many of these medications also had a direct or indirect sedative effect, albeit temporary, and were a key means of rendering residents more docile. Some of the medications prescribed to calm and sedate residents have pernicious side-effects, and the use of anti-psychotics in elderly people diagnosed with ADRD is contra-indicated and highly controversial¹⁹. Their use was justified, by some of the staff members, in terms of the effective management of the ward.

While docile bodies, made docile through physical and pharmaceutical restraint, were unarguably easier to care for and manage than the "busy" bodies of the recently admitted residents, caregivers were ambivalent about docility. Caregivers used a specific hand gesture to describe the effects of long-term institutionalization: fingers together, palms facing down, the hand moves across in a motion that indicates a steady, constant state, and then, a sudden flip of the wrist, and the hand sweeps down to indicate rapid

¹⁹ An internet search provides a multitude of scholarly and newspaper articles describing the controversy surrounding the administration of anti-psychotics to elderly persons diagnosed with ADRD.

decline. While many caregivers attributed this deterioration to the progression of dementia, some wondered whether it was an effect of anti-psychotic medications, or alternatively, of the long hours residents were expected to do nothing other than remain seated in the lounge. Kitwood (1997) refers to such deterioration as “catastrophic decline” and is adamant that it is not only progressive organic brain damage, but also the social-psychological institutional milieu, that precipitates such decline. Cohen (1998: 33) concurs that the rapid deterioration that commonly follows the institutionalization of persons diagnosed with ADRD cannot be solely attributed to the inevitable progression of neuropathological disease, but to institutional practices which are more akin to control than care. Despite these restraints and various dementia-related impairments, residents continued to assert themselves and their preferences through words, gestures, and movements, albeit within a limited range of possibilities.

From one perspective the ward can be understood as a liminal space where old people, displaced from erstwhile social worlds through illness and institutionalization, were merely waiting for death. The wait could be very short – Diana and Edward died within three months of being admitted to the ward – or seemingly interminable – four residents had lived in the ward for more than five years. From another, the ward constituted a “living, palpable, interpersonal reality” (Kitwood, 2007: 63) which, despite certain constraints – social, structural, temporal, spatial, and physiological – nevertheless provided a space in which residents could be brought into relationship with their caregivers and family members. Rendered another way, it is through the above-described caregiving practices that residents emerge as persons, their bodily and social coherence daily re-established through the caregiving relationship. And at the same time, it is these very practices of care, which are as much a form of discipline as a form of world-making, that function to subjectify elderly persons with dementia, calling them forth as docile embodied subjects.

Temporality, Rhythms, and Routines

Lingis’ (1996) description of the temporality imposed by illness and dying as “a strange time,” where anticipation and intention are replaced by “a time without a future, without possibilities, where there is nothing to do but endure the presence of time” (Ross, 2010: 198), is reminiscent of Samuel Beckett’s depiction of human existence as “nothing but time passing” (Hoffman, 2009: 111). Whether the endurance of time characterizes human existence in general or suffering in particular, it is a notion that is poignantly relevant to the temporal atmosphere of the ward where time seemed to pass excruciatingly slowly and to stretch and “drift” (Lingis, 1996; Ross, 2010:198). Time in the ward, as in the homeless shelter that Desjarlais (1994: 892) describes, “consist[ed] of concrete activities marked by expanses of silence and waiting.”

A structured temporal regime regulated the ward’s everyday rhythms and routines - the fixed schedule of mealtimes served as the axis around which other routine practices of bodily care such as bathing, dressing,

and the administration of medication were structured. Breakfast was served at 8h00 and the ward was filled with activity from 6h30 until then, the caregivers occupied with waking, bathing, dressing, and attending to residents to ensure that they were ready for breakfast. The medication regime also significantly impacted the rhythms and temporalities structuring the ward and was moreover tied to the mealtime routine. At breakfast, lunch, and dinner, residents' medication was separately ground to powder form in a mortar and pestle and mixed into one of the foods that made up a particular meal – yoghurt, soup, dessert or sandwich - to facilitate ingestion. Thus, eating not only nourished but medicated, and residents who refused to eat the food containing their medication, were likely to miss a dose of one or more medications. All but two of the residents were prescribed medication that had a sedative effect and most of the residents became drowsy and slept within an hour of finishing a meal, although the sedative effects seemed to wear off relatively quickly.

Between breakfast and lunch, and lunch and dinner, residents were seated in the lounge where they were encouraged to remain seated, with the exception of 'toileting' and occasional walks. However, despite verbal, physical, and pharmaceutical restraint, residents who were not confined in a restraining chair constantly tried to get up from their chairs, even those unable to stand or walk on their own. This restlessness was on the one hand a meaningful response to the excruciating monotony of sitting in one place for hours at a time, day after day; but the compulsive quality of some of the residents' restlessness seemed also an effect of neuropathology. Although caregivers occasionally went for walks outside the ward with those residents who could walk on their own, for many residents the only distraction from the monotony of immobility was music, impromptu dancing, and the interactions between caregivers, residents, and family members.

Dementia-related cognitive impairment, specifically memory loss, is widely assumed to disrupt temporal continuity, severing the demented person from his or her past and rendering the present meaningless and relationships across time unsustainable. In chapter five I discuss these assumptions in relation to culturally and historically specific notions of modes of being in time, personhood, and ethics. Here, I draw attention to the possibility that temporal discontinuity may be an effect not only of dementia-related cognitive disturbances, but also of institutional practices and structures. A number of caregivers commented that the routines and structures on the ward functioned to contain the fragmenting effects of dementia-related losses and were thus essential to the well-being of residents. Although this may be so, Desjarlais (1994: 896-897) observes that among persons defined as homeless and mentally ill, the temporal 'disturbances' caused by memory loss are exacerbated by institutional structure: "the routines of the clock, the realities of power, the influence of pharmaceuticals, the constant exchanges, and the relative lack of privacy and structure," produce an episodic mode of being in time, where "momentary occupations" and the "constant but purely episodic unfolding of events," are antithetical to establishing psychic coherence, continuity, and integration.

A focus on temporality is relevant also in terms of the fluctuations of mood and desire for interaction or solitude that residents experienced. Moreover, while a single visit to the ward at a particular moment in time may have created the impression that a resident could not speak coherently, immersion over an extended period of time revealed that some of the residents' linguistic capacities or desire for spoken communication fluctuated across time. Sacks (2010: 29) notes that such "spontaneous fluctuations" are "typical of any neural system that has sustained damage, irrespective of the cause," confirming Ella's assertion that, "You have to be on your toes in this place – you never know what someone's going to say to you."

Conclusion

In this chapter I demonstrated that it is through ongoing practices of care that residents are brought into relationship and an alternative form of sociality is created and sustained. I introduced Henderson's (2009) processual model of personhood that constructs personhood as emergent within practices of care and obligation, and argued that this model offers the means to reconceptualise personhood in terms of interdependence and contributes to the anthropological efforts to challenge the perception of demented elders as nonpersons. I then described how the very practices and interactions that invoke personhood and reconstitute relational networks, simultaneously act to bring into being a docile and immobilized embodied subject (Cohen, 1998). Finally, I argued that a consideration of temporality is necessary for understanding how residents' embodied lifeworlds were shaped not only by dementing illness, but by the routines and temporal regimes that structured the ward.

CHAPTER 4: LANGUAGE, RELATIONSHIP, AND PERSONHOOD

Jane is sitting in a restraining chair, tirelessly “playing the piano,” a gesture that is at first strange to witness but which can be interpreted as her way of reaching out to the individuals around her. If you went to sit next to Jane, she’d probably smile at you, take your hand and gently kiss it, and tell you, “You’re beautiful, I love you.” Lena has been Jane’s private caregiver for the past five years and took care of Jane when she was still living in her own home in Golden Village. Lena speaks proudly of Jane’s erstwhile career and travels and has mentioned on numerous occasions that Jane was known for being a very generous and loving person who would help anyone who asked. One afternoon, I’m sitting with Jane and Lena at the dining room table; Lena is distractedly ‘feeding’ Jane while discussing her future plans with me. She comments loudly, “When Jane dies I’m going to get myself another old lady to look after.” I’m completely taken aback, am worried about how Jane must feel, and blurt out, “You’re not going to die Jane!” As soon as the words leave my mouth I recognize them as an untruth, and I backtrack, saying, “I mean, everyone’s going to die, but you’re not going to die soon Jane.” Lena looks at me curiously, Jane looks down, and I’m not sure if I’ve made matters worse. Lena doesn’t think that it’s inappropriate to say these words in Jane’s presence because, as she has said numerous times, “Jane’s not there anymore.”

Language is not just about communication but about social relations: about one’s being in relation to others. We inhabit the world through language. It pre-exists us; we are always already implicated by it and in it.... Language acts with force in the world... it shapes our notions of truth and gives form to social institutions (Ross, 2010: 163-164)

In this chapter I explore the multiple ways in which language mattered within the space of the ward. If human beings indeed “inhabit the world through language” and language is fundamental to social relations, how do dementia-related language impairments affect the ways in which residents are situated in relation to others? What consequences do “disordered speaking” (Cohen, 2003: 126) and the potentially diminished ability to use language to act in the world have for the ways in which the residents are understood as persons, and how do these assumptions then shape the ethics of care within the ward?

I discuss the following aspects of language and relationship: the uses and characteristics of speech/language within the ward; language as a marker of class difference; modes of address; and the material effects of language and naming. I focus on these multiple aspects of language in order to better understand how the culturally and historically specific entanglement of language, memory, self, and time

shapes the possibilities for personhood and for relationship between ‘demented’ elders and their ‘normal’ caregivers.

Language within the Context of the Ward

Speech Communities and Difference

Aphasia – a general clinical term that refers to various forms of language function deficits, including speaking, understanding what others are saying, and naming common objects²⁰ - is one of the domains of cognitive impairment, secondary to memory loss, included in the clinical definition of dementia (Hinton et al, 2006: 46).

While some scholars (see Kontos, 2006) advocate a shift away from the “presence of language to the ground of embodiment” (Cohen, 2006: 13) in order to challenge the assumption that cognition and memory are the “decisive carrier[s] of personhood” (Leibing, 2006: 259), my ethnographic data highlighted the continued importance of language to the making and unmaking of relationships in the ward. Although the language function of ten of the eleven residents could be described as impaired, albeit differentially, many residents made a concerted effort to communicate with caregivers and/or one another through speech, despite sometimes great difficulty and the risk of being misunderstood or ignored, as well as through gesture, touch, and movement. I argue that an understanding of dementia-related impairments of “expressive capacity” (Kaufman, 2006: 24) requires a focus both on voice (see Cohen, 1998; 2003; 2006) and on embodiment and culturally and socially shaped gestures (see Kontos, 2006). Speech is after all fundamentally embodied, and like gesture, emanates from the body in culturally and class-specific ways. However, within the ward, speech alone was often inadequate to communication, to directing and manoeuvring someone from the lounge to their room, and as importantly, to giving consolation and comfort or establishing intimacy. Conversely, there were occasions when certain speech acts had material consequences that extended beyond and were abstracted from the words uttered by an embodied speaker at a specific moment in time.

I had not anticipated the degree to which language, English, Afrikaans, and occasionally Dutch, would be present in the ward: caregivers talking, comforting, persuading, cajoling, scolding, directing, and joking; residents commenting, protesting, asking, joking, and talking. Speech styles were a significant indicator of social status within the ward, reflecting the ways in which English and Afrikaans languages have been interwoven with the historical and geographical contours of colonialism and apartheid. Marked differences in tone, volume, intonation, and accent – in English and Afrikaans – distinguished the ‘white,’ upper-class residents and family members from ‘coloured,’ working-class caregivers. Moreover, caregivers spoke a colloquial form of Afrikaans: lively, emotionally expressive, exuberant, and humorous.

²⁰ Sourced from Alzheimer’s Weekly, “Aphasia in Dementia: Word Jumbles,” <http://alzheimersweekly.com/content/aphasia-dementia-word-jumbles>, 08/08/2012.

Ross (2010: 152) points out that Afrikaans and English are “imbued with racialised, class and status hierarchies” and that not surprisingly, South Africans are generally acutely attentive to the “linguistic codes” that indicate social status. The persistence of this form of attentiveness, despite dementia-related language and memory impairments, was evident in Helen’s various responses to caregivers’ speech style. Helen’s sense of what constitutes ‘proper’ speech was acute and she seemed to revel in mocking caregivers’ uniquely accented English. One afternoon, Judith was telling me that she was going to have her hair done when she finished work, when Helen, who had just entered the lounge, stopped and said in a condescending tone, “Not ‘*heh*’ – ‘hair,’” denigrating the flattened vowel-sound that characterizes many South Africans’ pronunciation of the word. Judith blushed, looked down, and it was evident that Helen had succeeded in undermining Judith and asserting her own ‘superior’ class status in three short words. The pronunciation that Helen considered proper approximates an upper-class British accent which characterises the speech of many Golden Village residents.

However, while Elizabeth and Charles, both residents, would occasionally complain about the volume of caregivers’ speech or laughter, their speech style undeniably added a much-needed levity to the ward. It was evident that caregivers engaged in two different levels of discourse in the ward: the first, in which speech was fundamental to caregivers’ engagement with residents; and the second, which took the form of ongoing conversations among caregivers, spoken in the colloquial Afrikaans familiar to caregivers. These different levels of discourse created two different speech communities (Dell Hymes, 1974) in the ward, which although overlapping, nevertheless had the effect of partially excluding residents from the conversations among caregivers. Despite dementia-related language deficits, most residents listened attentively to caregivers’ conversations, often smiling or laughing in response to humorous comments. Although possible that some residents were responding to the tone and inflection rather than the actual meaning of the words, their attentiveness and response indicated an understanding of the social meaning of conversation. Moreover, Sacks (2010: 34-37) points out that while there are many forms of aphasia, a distinction is generally made between *expressive aphasia* – which impairs speech capacity but not the ability to understand language; *receptive aphasia* – which impairs the ability to understand language but not the capacity for speech; and *global aphasia* - which impairs both expressive and receptive language capacities. Such distinctions highlight that even specific domains of dementia-related cognitive impairments are heterogeneously manifested, strengthening the argument that persons diagnosed with ADRD cannot be considered a homogenous category.

Referring to different levels of discourse or different speech communities also provides a means of discussing the ways in which caregivers constantly shifted between speaking *to* residents, a mode of direct address, and speaking *about* residents while in their presence, a mode of indirect address. These modes can be further differentiated. Thus, caregivers addressed residents directly under the following conditions: when engaged in practices of bodily care at various times throughout the day; when attempting to engage residents

in 'normal' conversation; when comforting residents; and when controlling speech or behaviour that was considered inappropriate. Caregivers addressed residents indirectly: when making another person witness to a caregiver's statement about a resident so as to corroborate for the resident's benefit; when drawing attention to inappropriate behaviour; and when talking about a resident to other caregivers or family members as if the resident was inconsequential to the conversation.

Addressing Residents Directly/Speaking To Residents

A mode of direct address was fundamental to practices of bodily care, and speech was used to both communicate and to reinforce caregivers' embodied actions – "Lift up your feet when you walk;" "Come one, take another bite;" "Let's go brush your teeth" - in tones variously cheerful, cajoling, insistent, impatient, and encouraging.

Second, caregivers addressed residents directly at various times throughout the day by speaking or calling their names in an animated or emphatic manner, usually positioning their bodies so that they were at eye level with or at least facing residents. It was as if by speaking a resident's name/s, the caregiver was appealing to his sense of self, situating or grounding the resident in relation to his identity, and thereby calling him forth, materializing him as a person. Thus, Ella would call, "Doctor Charles Williams," or, "How are you today, Charles Christopher Williams?" or, "Doctor Williams, guess who's coming to visit you today!" Charles responded in various ways: looking up at Ella, raising his eyebrows, smiling, and winking; saying "Marvellous, absolutely marvellous;" exclaiming "Shush!" if he was tired and trying to nap; and sometimes, mumbling incoherently.

Caregivers also initiated conversations with residents by asking easy-to-answer questions such as, "How are you?" "Do you want to go for a walk later?" or by commenting on something in the present, "You're wearing a beautiful dress today," or more often, by referring to a resident's past, "You used to be a nurse, didn't you?" I discuss caregivers' narrative telling of residents' life histories in the next chapter, where I refer to this form of remembering as an intersubjective memory practice, but here draw attention to the ways in which caregivers' knowledge of a resident's life history and personality facilitated conversational coherence by allowing a caregiver to fill in gaps in or substitute for a resident's response. This was the case for a number of family members as well. For example, Hans's wife, Sara, noted that much of the time she understood what Hans wanted to communicate to her, even when he did not speak coherently, because they had lived together for more than fifty years. When she did not, she answered, "Ja, ja," as if she did understand, and Hans seemed satisfied with her response.

Despite these efforts, communicating through speech was not a simple matter for either caregivers or residents. There were many ways in which residents' speech efforts were silenced or ignored. At times it was evident that caregivers had neither the time nor patience to make an effort to understand words spoken or

interpret intended meaning. Often, caregivers' desire to participate in a lively conversation with one another led them to dismiss residents' efforts to communicate, but this dismissal or silencing was sometimes unintentional. Such was the case one afternoon when Susan, a resident, was entertaining caregivers with some no-nonsense relationship advice: "You can talk, talk and talk and then it's finished... Don't let anyone fight with you! [Long pause] You should kick him out and don't get another one [laughing to herself] ... One is enough!" Susan was quiet for a minute and then started speaking again, "It doesn't have to be so long." At that moment Charmaine, a caregiver, looked over at Charles who had begun groaning and asked him, "What's wrong?" Susan exclaimed, "Not wrong, *long!*" but the caregivers' attention was now directed toward Charles and Susan fell silent, not speaking again for the rest of the afternoon.

As previously indicated, while recognizing that voice/speech emanates from and through the body, in a context where individuals' receptive and/or expressive language capacities are impaired, the body's expressive capacity is essential to engagement and relationship. For both caregivers and residents, gesture, facial expression, movement, touch, and laughter offered the means to convey feeling, meaning, and comfort when language faltered. Moreover, when caregivers responded to a resident's distress, sadness, fear, or confusion, they did so primarily through comforting forms of touch; the soothing tone of words spoken more important than their meaning. Some residents also responded to others' distress through gesture and touch and sometimes, speech.

Last, caregivers addressed residents directly when reproaching them for inappropriate behaviour, "Sis Helen, that's not a nice thing to say," "Leave Christopher alone," "Table manners!" or when combining speech and movement to control a resident's behaviour, as when a caregiver placed her hands on Edward's shoulders and pushed him down onto a chair, saying, "Sit down now!" Desjarlais (1996: 883) notes that institutional structure allows caregivers to feel "secure in their power to tell residents what to do," and frames caregivers' speech, bodily stance, and movements with a "set of subtle linguistic and semantic markers" which underscores their authority. In the context of the ward, South Africa's history of racialised class dynamics at times undermined this systemic authority. This was the case with Helen, who became enraged when caregivers reproached her or tried to control her behaviour, one day telling a caregiver, "This is disgusting! You can't tell me what to do – *you* have to listen to *me!*" Here Helen was referring to her erstwhile social world where a 'coloured' working-class woman would not have the authority to tell a 'white' upper-class woman how to behave. Edward responded to the caregiver's use of force by highlighting its unfairness, crying out plaintively, "Why? Why?" For the most part, the principle, "Force is crime," that caregivers stated was central to the ethic of care in the ward, limited the use of such overt force and encouraged gentler forms of persuasion.

Speaking About Residents

Modes of indirect address were employed in both a positive, affirming manner and in a negative manner which acted to deny residents' status as persons.

First, caregivers often engaged in indirect conversation with residents by constructing an interaction where two or more caregivers would indirectly speak 'to' a resident, while seated or standing in close proximity to him, by talking 'about' him, including him in the conversation by looking at or gesturing toward him: "Did you notice how strong Christopher's getting?" "Ja, he's walking by himself again!" This form of address was used with those residents who struggled to speak more than one or two words and with residents who were withdrawn or anxious. Residents responded in various ways, some acknowledged caregivers by smiling or blushing, some looked away or became irritated, and others responded verbally.

Second, caregivers responded to behaviour they interpreted as particularly disruptive, inappropriate, or offensive by drawing other caregivers' attention to the behaviour when it occurred. This was usually accomplished through two phrases, spoken in an exaggeratedly emphatic tone: "*Luister nou hier*" ("Listen to this") or "*Kyk nou hier*" ("Look at this"); which elicited humorous comments from caregivers, or at times, exchanged glances or raised eyebrows. It was a response that seemed to accomplish a number of things. As with caregivers' general interactions with residents and one another, these comments were underscored by a humour that enabled caregivers to relate to speech or behaviour that was perceived as inappropriate from an 'ironic' or sideways stance (Cohen, 1998; 2003). Cohen's focus is on ironic listening, but speaking of an ironic "modality of interpretation" as does Desjarlais (1996: 883), encompasses the perception of behaviour as well. Interpreting senile speech and behaviour within an ironic modality provides a way to situate a demented elder in the space between comprehensibility and incomprehensibility, neither demanding that he or she conform to normative modes of speech and behaviour nor positioning him or her outside of language and reason (Cohen, 2003: 127-132). On the other hand, the act of drawing other caregivers' attention to speech or behaviour perceived as disruptive or inappropriate can be understood as a "normalizing practice" (Chatterji, 2006: 236) which, through collective vigilance and disapproval, was aimed at discouraging speech/behaviour that was at odds with institutional norms. Moreover, these phrases were spoken in colloquial Afrikaans, which simultaneously appealed to those who were part of this speech community and excluded residents who were not. While this mode of address may have functioned to elicit the support of other caregivers, it also acted to distinguish 'demented' residents from 'normal' caregivers.

Last, I discuss an indirect mode of address that was both so commonplace and troubling to witness that it demanded an exploration of how the impairment of residents' capacity to speak on their own behalf shaped caregivers' assumptions about their status as persons. The introductory vignette describes the callous manner in which Lena spoke *about* Jane as if she were either incapable of understanding what Lena was saying or as if her presence were of no consequence.

I suggest that speaking *about* Jane in her presence without attempting to include her in the conversation through verbal or gestural acknowledgement, was to relate to her as object rather than subject, and to place her outside the norms of social discourse. Given that Lena spent much time in Jane's company, she would have been aware that Jane's responses to others' speech indicated that she *did* understand speech, despite the fact that she habitually repeated the same phrase, "I love you, you're beautiful" when addressed. Although Jane spent long hours of each day in near silence, her hands rarely ceased gesturing and she was keenly aware of the people, interactions, and sounds around her. These observations challenge the veracity of Lena's oft-repeated claim that "Jane isn't there anymore" and suggest an alternative interpretation.

Scholars have pointed out that the widespread belief that dementia destroys or erases the self is derived from cultural assumptions in which 'cognitive' capacities – memory, language, and reason – are understood to be essential to the constitution of personhood (see Cohen, 1998; Herskovits, 1995; above, chapter two). However, as argued in the next chapter, I suggest that it is the currently taken-for-granted – but historically and culturally specific – notion that the self is narratively constructed that is implicated in the dissolution of personhood for those suffering dementia-related language and memory losses. Within this narrative model, one's life is not only experienced as a narrative or story, one must speak in one's own name and answer for what one is and does (Deleuze and Guattari, 1987; Lingis, 2007: 113), an ontology of being that weaves language, memory, self, and time into unique relationship (see Strawson, 2004; Hacking, 1996).

I argue that it was Jane's perceived inability to narratively account for her 'self' that shaped Lena's understanding of her as an absence, and denied her recognition as a person. There were however times when Lena did attribute personhood to Jane, which attests to Desjarlais' (2000: 485) assertion that the invocation and dissolution of personhood within the pragmatics of intersubjective engagement is dynamic across context and time. My presence in the ward undoubtedly increased the frequency with which caregivers' spoke *about* residents, at least in the beginning when caregivers generously shared their substantial knowledge of residents' life histories. In chapter five, I define such narrative telling as an intersubjective memory practice that functioned to invoke or call forth personhood. However, as argued above, when residents were viewed as the objects rather than the subjects of narrative telling, such telling acted to deny their status as full persons.

Significantly, while many caregivers shared the belief that residents could not understand their conversations, not all instances of speaking *about* residents were as markedly callous as the one described here. Nevertheless, this mode of address constituted a form of exclusion which placed demented elders outside of language and relationship (see Cohen, 2003). I witnessed many such interactions, and without exception, the person being spoken *about* in this manner appeared embarrassed, uncomfortable, self-conscious, or dismayed. I found this mode of address and the effects it had on residents very troubling and responded by trying to include residents in these conversations in various ways. My efforts were viewed with puzzlement, amusement, or suspicion and I sensed that some caregivers interpreted this behaviour as an

attempt to undermine their authority or expertise, or to align myself with the residents. I was sensitive to the possibility that my actions could be read in terms of racialised class dynamics, given that speech acts are also political acts in both the sense of their aims and outcomes, and in the sense of the histories that inform their reception.²¹ To draw attention to the way in which this mode of address excluded residents from norms of sociality, intentionally or unintentionally, is not to detract from the ways in which language was simultaneously used to comfort, acknowledge, invoke personhood, and draw residents into relationship.

The Material Effects of Naming and Interpretation

Cohen (1998: 38), following Judith Butler, suggests that “to speak of dementia is to call upon an aging body in a certain way and not in another and in a sense to materialize the body.” In this section I discuss the language caregivers used to frame behaviour that was deemed inappropriate and disruptive, and explore how such framing was in turn situated in relation to the language of diagnosis.

Ross (2010: 184-187) observes that naming an illness – diagnosis – is inherently ambiguous in that diagnosis may have both positive and negative repercussions for the persons diagnosed. Thus, while diagnosis may provide a framework for understanding and normalizing certain forms of behaviour, it may also act to diminish persons by interpreting their behaviour and reactions as signs or symptoms of illness, thus rendering their subjective experience and particular social world incidental. This ambiguity was certainly evident in the context of the ward, but it was further complicated by caregivers’ ambivalence about how to frame ‘inappropriate’ behaviour – in relation to dementing illness, as reaction to institutionalization, or in terms of residents’ personalities/histories - an ambivalence which manifested in a constant shifting between interpretive frames.

There were four main descriptors for residents’ ‘inappropriate’ behaviour: “*onbeskof*” (rude); “*baie besig*” (very busy/agitated); “aggressive;” and “violent.” The term ‘rude’ was usually applied to forms of verbal inappropriateness but also to breaches of social etiquette. ‘*Baie besig*’ referred to the disruptive actions - unmaking beds, unpacking cupboards, shifting furniture around - of residents who were capable of moving around the ward on their own, and which created extra work for caregivers. The term ‘aggressive’ referred both to speech – shouting, arguing - and to behaviour – pushing, slapping, and kicking, while ‘violent’ referred to behaviour only. When I first entered the ward I took the terms ‘aggressive’ and ‘violent’ at face value, but over time came to understand that this framing not only misrepresented behaviour that could be interpreted as a normal response to institutionalization, but also exaggerated the force of the above-described actions. One of the nursing sisters who worked in Maynard Manor commented that she did not like it when her mother, who had recently been diagnosed with Alzheimer’s disease, was described as aggressive. She stated

²¹ Fiona Ross, n.d., personal communication.

that it was too harsh or forceful a term for someone who could better be described as “*kwaai*” (‘irascible’ is the closest English equivalent). As discussed below, such framing had material consequences in the context of the ward where pharmaceutical intervention was a primary mode of care.

Caregivers are taught that inappropriate and disruptive behaviours are symptoms and signs of dementing illness, and are familiar with the disease model of dementia which locates the loss of inhibition and behavioural restraint in the cognitive disturbances caused by neuropathology (Cohen, 1998; Chatterji, 2006). Helen’s tendency to assert an erstwhile authority based on her racialised class status not surprisingly provoked caregivers. Ella, a ward supervisor, stated that “It’s only human to get angry when someone is rude to you,” but noted that caregivers tried not to take such behaviour personally because the residents “can’t help what they say and do” because they “have dementia.” In this instance, interpreting Helen’s ‘rude’ behaviour within the framework of disease pathology provided a means to bracket the historical, social, and political relevance of such remarks, which no doubt offered Helen a “reprieve from judgement” (Ross, 2010: 186).

Herskovits (1995) however, argues that such framing has particularly negative repercussions for persons diagnosed with ADRD because interpreting a demented elder’s behaviour within a disease model further contributes to the current widespread acceptance of the notion that dementia destroys the self. Gubrium on the other hand, points out that this form of reasoning enables caregivers to accept and forgive behaviour and language that would otherwise be interpreted as a deliberate intention to harm, emotionally and physically, and that may thus result in “punishment or punitive social sanctions” (Gubrium, 1986; Herskovits, 1995: 152). In my ethnographic context, it was evident that both assertions were valid: at times behaviour that seemed a reasonable response to restraint was attributed to dementing illness in order to justify caregivers’ use of force; at other times, as described above, attributing behaviour to dementing illness offered the means to bracket the social and personal implications of such behaviour.

Additionally, as discussed in chapter five, residents’ habits, styles of interaction, preferences, and behaviours were also interpreted within a ‘life history’ model which established continuity between residents’ erstwhile and present identities and social worlds. Contextualizing ‘inappropriate’ behaviour in relation to a resident’s past experiences offered a redemptive narrative which not only protected residents from punishment, but also worked against the reductionism of diagnosis (Cohen, 1998: 54). Moreover, residents’ ‘aggressive’ and ‘violent’ resistance to caregivers’ efforts to feed, bathe, dress, and ‘toilet’ them, was normalized via the notion of an ‘adjustment period’ that all individuals were said to go through when first institutionalized. Caregivers had much empathy for the recently admitted residents who were not only suffering dementia-related losses but also the loss of their erstwhile social worlds. It was evident however, that there was a perceived limit to the length of time that such adjustment required. ‘Adjustment’ signified residents’ resignation to confinement, a loss of autonomy, and submission to imposed routines and structures. Residents who engaged in ‘inappropriate’ behaviour beyond the adjustment period or who refused to submit

to the norms and routines operating in the ward, came to be identified as aggressive, violent, and unmanageable 'patients.'

In the ward, a focus on language was important not only for understanding how explanatory frameworks shaped caregivers' perceptions and practices, but also for identifying the ways in which specific styles of speech framed actions, experiences, and persons. Over time, I learnt that caregivers' conversations about residents involved humorous anecdotes told with a fair degree of exaggeration, which undoubtedly made for a more entertaining telling. Such anecdotes drew on the amusing, surprising, inappropriate, and socially unacceptable things residents said and did, and many of these anecdotes were undeniably funny. This story-telling offered a respite from the difficulties of caregiving work and a means to reframe loss in terms other than abjection (see Cohen, 1998). Further, I suggest that such narratives were essentially accounts of demented life within the spatial and temporal confines of the ward, and hence, can best be described as *demented biographies*.

In chapter five I discuss caregivers' narration of residents' life histories/biographies as an intersubjective memory practice that invoked personhood by establishing continuity between the person in the past and the person in the present. In contrast, demented biographies were told for the benefit of caregivers rather than residents, notwithstanding the fact that this 'knowing' also offered a frame for interpreting behaviour. I suggest that the telling of demented biographies can be understood as a "characterization," that is, an effort to "cast residents as 'characters'" (Desjarlais, 2000: 471) by defining and delineating their 'demented' characteristics. While Desjarlais (2000: 471) usefully describes psychiatric diagnosis as a form of characterization that attempts to "figure out" what is 'wrong' with a person in order to identify what kind of character he or she is, for example 'Alzheimer's victim,' I here draw attention to the fact that forms of characterization are culturally shaped (see Ross, 2009; 2010) modalities of interpretation that both render persons knowable and situate them in socially and culturally-specific categories.

The often exaggerated and amusing anecdotes that informed these demented biographies became problematic when caregivers exaggerated the force of a resident's actions or misrepresented the context in which a resident engaged in 'aggressive' or 'violent' behaviour. While acknowledging that it was caregivers who experienced the pain of being pushed, slapped, and kicked, I was witness to numerous occasions where a caregiver's anecdote significantly overstated the 'aggression' or 'violence' of a resident's behaviour. More importantly, I observed how such framing – when repeated often enough across time – constructed certain residents as "violent" and "unmanageable." This had material consequences: for example, exaggerated descriptions of Helen and Diana's 'aggressive' and 'violent' behaviour were told often and with much relish, not least because their 'inappropriate' behaviour was more extreme than other residents' and persisted beyond the 'normal' adjustment period. Diana and Helen were soon identified as violent and unmanageable patients who posed a threat to caregivers and other residents. This framing was in turn related to the disease

model of dementia which justified a significant increase in the range and dosage of anti-psychotic and sedative medication administered to Helen and Diana. Despite the fact that such pharmaceutical intervention only succeeded in temporarily rendering Helen and Diana sedated and docile, senior staff members were adamant that such measures were necessary for maintaining control of the ward.

Over time, Helen, who actively sought to re-make relationships – temporarily unmade through ‘aggressive’ or ‘violent’ behaviour - through gestures of affection, came to be appreciated as a “character” (see Ross, 2010) whose ‘rudeness’ and ‘aggression’ enlivened the ward. In contrast, although Diana eventually allowed caregivers to bathe and dress her, her distress, agitation and fear were neither alleviated by pharmaceuticals nor time spent in the ward. Diana refused relationship with the caregivers, declining to engage in conversation even though her speech was relatively unimpaired, and it was evident that she was distressed by caregivers’ habitual vigilance and she usually avoided the lounge and dining room, preferring to stay in her room. Within two months of Diana’s admission, there was consensus among the staff that Diana did not “have dementia,” and that she thus did not “belong” in the ward and should be transferred to a psychiatric hospital. In effect, Diana’s ‘behaviour’ was placed beyond the explanatory frameworks of diagnosis, life history, and response to institutionalization, and she was sometimes referred to as “the psychiatric.” As it turned out, Diana was not transferred to a psychiatric hospital; instead, doctors increased her medication, to little positive effect, and while some of the caregivers persisted in trying to care for and establish a relationship with Diana, I was witness to numerous occasions when she was left alone for long periods at a time, neglected.

Conclusion

In this chapter I explored the multiple ways in which language mattered within the space of the ward and demonstrated that language was essential to the making and unmaking of relationships across time. Not only did residents persist in their efforts to engage others through language (and gesture), despite dementia-related language impairments, but the modes of direct and indirect address that shaped the exchanges between residents and caregivers acted to variously invoke and deny residents’ personhood status. I argued that moments of uncaring were precipitated by caregivers’ assumptions about the relationship between language and self, specifically, the assumption that a resident’s inability to speak for him or herself indicated an absence or destruction of the self. I explored how behaviour deemed inappropriate was framed by different interpretive or explanatory models and argued that caregivers’ anecdotes about such behaviour acted to construct *demented biographies* for each resident. I demonstrated that language – naming, interpretation, telling - had material effects in that such linguistic acts not only influenced perceptions of and responses to behaviour, but also called forth or materialized elderly individuals with dementia as particular embodied subjects.

CHAPTER 5: THE COMPLEXITY OF MEMORY - RECOLLECTION, PERFORMANCE, PRACTICE

Helen was admitted to the ward a week before I commenced fieldwork and it was apparent that her language and memory capacities were significantly less impaired than most residents'. Over three months, I was witness to Helen's frustration, confusion, and distress as she struggled to come to terms with the further deterioration of these capacities.

During the first two months, Helen was very active and when not walking around the ward or wandering into residents' rooms, she was attempting to engage caregivers and residents in conversation. I spent many hours with Helen, accompanying her on walks outside the ward, sitting beside her in the lounge or her room when she grew tired of walking, and trying to be the 'listener' that she clearly needed. The following statements made by Helen during this time express her experience of memory loss: "All I've got are shattered remembrances;" "Everything's disappearing;" and "I try to think, but then it's just gone," and her efforts to deal with this loss: "If I can only hold onto one thing then I'll make it through this."

Helen constantly tried to share her memory of a particular time or event with me and although the same 'facts' – a man, a lake, mountains, and animals – emerged in each telling, she was unable to ever complete the telling. One afternoon, sitting on the couch in the lounge, Helen touched my arm and began speaking: "I see him standing there with his back to the lake, surrounded by mountains..." but at this point she seemed to lose the thread of her story and was unable to continue. But it was apparent that not all memory of the past had "disappeared." Helen sometimes spoke of her husband: "My husband was a wonderful man. I loved him so much," and once, as she paused at the door to her room, of her mother: "My mother never looked at me." At other times, it seemed that remembering was as painful as forgetting, as when Helen would place her head in her hands, saying, "I've got so many regrets," or "I destroyed everything, everyone."

Helen's daughter brought some of Helen's favourite CDs to the ward one afternoon, noting that Helen loved music, and as is common among persons afflicted with dementia-related memory- and language losses, Helen could sing along to the lyrics of an impressive number of songs. Helen also liked to participate in the impromptu afternoon dance sessions, and like Edward, she was not only one of the few residents who were physically able to dance, but she could dance - in the sense that she had rhythm. During one session, I played a CD compilation of Latin songs, and when the tango came on, Helen started dancing the tango, slowly, but with precision, grace, and passion. The caregivers present laughed with pleasure, clapping, and calling out Helen's name. From then on the caregivers often played the tango, encouraging Helen to dance, but over the next few weeks it became evident that she was struggling to remember the sequence of the dance steps, her movements becoming hesitant, uncoordinated. Helen stopped dancing the tango, ignoring the caregivers when they tried to persuade her to keep trying. She seemed to have resigned herself to 'slow dancing,' leaning her body into her

partner's (a caregiver) body, arms around her waist, head resting on her shoulder, and slowly, but still with a sense of rhythm, moving round and round in time to the music.

The above vignette describes some of the multiple and complex ways in which memory loss affected Helen, who was diagnosed with Alzheimer's disease. Memory is generally understood to be a cognitive faculty, of the mind or brain, and memory loss in dementia is usually associated with the loss of memory of past experiences, places, relationships, and events – classified as autobiographical memory. The tendency to equate memory with cognition is likewise present in much of the anthropological literature referred to in this dissertation (see chapter two), but, as Hacking (2005: 224) appropriately points out, that the term *memory* encompasses a range of abilities, skills, and performances. My observations demonstrated that dementia-related memory losses impaired not only autobiographical memory, but also what cognitive psychologists have classified as procedural memory - memory/knowledge²² of how to execute embodied skills and performances like walking, bathing, eating with cutlery, and dressing.

In this chapter, I consider the myriad ways in which memory loss mattered, subjectively and intersubjectively, in the everyday context of the ward. First, I describe how caregivers engaged in what I have termed an *intersubjective memory practice*, whereby they reiterated the biographical 'facts' of residents' lives. I argue that this practice can be interpreted as an attempt to invoke the personhood of residents narratively and to establish continuity between residents' past and present social worlds. Second, I problematize the widespread tendency, in academic and popular thought, to equate memory solely with cognition or mind by describing the ways in which dementia-related memory losses also impaired embodied skills and abilities. Finally, I consider how taken-for-granted assumptions about the relationship between temporality, memory, and language involve the notion that continuity across time is essential to actualizing a coherent sense of self. This temporal mode of being is further assumed to be essential to 'authentic' life, and to establishing and maintaining relationship. I explore how the modes of relatedness within the ward were both shaped by and challenged such assumptions.

Intersubjective Memory Practices and the (Re) Construction of Personhood

Remembering Identities/Invoking Personhood

I was struck by how much caregivers knew about residents' life histories. This knowledge was drawn both from information shared by family members and from caregivers' care-based interactions with residents and their family members prior to residents' admission to the ward. Nine of the residents had retired to Golden Village many years prior to entering the ward and most caregivers had been working in the village for more than a decade.

²² I use the term memory/knowledge to indicate the inextricable relation between memory and knowledge: knowledge is remembered knowledge.

Ella, a ward supervisor, had worked in Golden Village for almost twenty years and had an impressively detailed and wide-ranging mental record of most residents' lives, such as: family network; work and family history; likes and dislikes (past and present); and residents' erstwhile relation to one another. Three of the residents had private caregivers who had taken care of them for many years and who had intimate knowledge of their personalities and lives – family, careers, relationships, travels, hobbies, likes, dislikes, and habits. Hannah, Susan's private caregiver for the past five years, stated that Susan was "like a mother" to her and that Susan's children were "like family." Lena had worked with Jane for five years, first as a home-based caregiver, and then as a private caregiver when Jane was admitted to the ward. Given that caregiving work is historically and currently one of the relatively limited employment options for coloured working class women in this area, caregivers' intimate knowledge of residents is also socially shaped (see chapter one).

Caregivers seemed occupied with remembering and reiterating residents' 'biographies.' When I first entered the ward, my presence elicited detailed narrations of the residents' lives, or at least, the biographical 'facts' commonly thought to constitute persons – relationships, careers, travels, family, likes, dislikes, character traits, experiences profound and mundane, to name just a few. While these narratives had the intended effect of making the residents known to me in the sense of knowing the facts about someone's life and situating him or her in relation to a personal past, the experience was also discomfiting because most residents did not comment on these stories about their lives and selves, either to agree or disagree, and caregivers were thus not only speaking about but for the residents.

Caregivers frequently addressed residents, directly and indirectly, in terms of the past and this often took the form of questions or comments designed to bring the past back into the present in order to 'flesh out' a sense of self. Most caregivers were sensitive to residents' memory loss and couched answers within their questions, "You used to love baking, didn't you?" or stated their knowledge of residents' past as fact, "Jane lived in Greece with her husband." Others were not as sensitive, "Do you remember your husband's name?" This question was on one occasion addressed to Elizabeth, who answered indignantly, "Of course I remember my husband's name! What a silly question," but in general, residents responded to such questions or comments by looking away, blushing, or rarely, smiling. This was true even of those residents whose speech capacities were sufficiently intact to respond with a few words. Significantly, the majority of such comments were not addressed directly to residents, but to other caregivers and to me, "Jane was such a generous woman, everyone loved her," or "Lucille never got married, she was a free spirit." Susan was an exception – caregivers enjoyed 'reminding' Susan that she had been a teacher because Susan would respond by launching into a laughing tirade about "naughty children." Fortunately Susan seemed to enjoy the telling as much as the caregivers did.

Further, residents' behaviours and ways of being were also situated in relation to the past, and this acted to establish continuity between the person in the past and the person in the present. Thus, Edward's

insistence on helping the caregivers tidy up – clearing the table, washing teacups – was interpreted in terms of the fastidious person, his wife informed caregivers, he had been before he became ill and was institutionalized. As described in chapter four, while behaviour that was deemed inappropriate, disruptive, or asocial was usually attributed to dementing illness, caregivers' knowledge of residents' life histories was also used to interpret behaviour in the present in various ways. Thus: to establish a 'life circumstances' context for such behaviour; to establish a continuity between past and present personality traits; or to posit a discontinuity - due to dementing illness - between past and present.

In a context where memory losses and institutionalization have displaced residents from their erstwhile social worlds, the caregivers' acts of reminding and remembering can be understood as an intersubjective memory practice. Memory is not a passive recording of the past: the act of remembering or recollection actively constructs the past (Rose, 2010: 207), and narration involves the selection of memories through which people represent themselves to others as certain kinds of persons, depending on time and context. Ochs and Capps (1996: 31) note that people's accounts of their past usually involve co-narrators who shape the telling in various ways, although the principal narrator may challenge or confirm co-narrators' interpretations and recollections. In the context of the ward, residents' language and memory impairments made it difficult for them to challenge caregivers' narratives and this rendered them vulnerable to others' projections and assumptions.

I discovered over time that certain biographical facts were not accurate - for example, Lucille had in fact married - but the accuracy of these narrated biographies mattered little in comparison to the way in which their telling constructed residents as persons understood in relation to their past rather than as demented subjects. This practice had consequences for the ethic of care in the ward, as was evident in caregivers' reference to Helen's past to contextualize behaviour that was clearly classist and racist. While caregivers generally interpreted Helen's behaviour in terms of dementing illness, there were times when her vehement resistance to being told what to do by caregivers rendered this interpretation insufficient. It was apparent that Helen's resistance was an attempt to maintain her autonomy, but that she did so by invoking her erstwhile social world where she was situated in a socially superior position to coloured and working class women, made such behaviour difficult to tolerate. But over time, a redemptive narrative, based on information from various sources, emerged – Helen was “always a tigress,” had owned and managed a very large farm, and had spent much of her life telling people what to do, and for these reasons, could not adapt to being told what to do. Her current behaviour was thus interpreted in relation to the person she was and to the life she had lived before entering the ward. Caregivers' willingness to tolerate and forgive such behaviour is extraordinary in the context of South Africa's history of racial discrimination.²³

²³A private caregiver told me she had witnessed the “terrible way” in which “Zulu carers” treated ‘white’ elderly people in a frail care centre in Durban, and stated that “coloured people are different. We forgive.”

Problematizing the Notion of the Narrative Self

Caregivers' intersubjective memory practice can be interpreted as an attempt to invoke residents' personhood through a narrative co-construction of self which re-establishes continuity between past and present. This practice makes sense in a contemporary cultural context in which narrative and self are viewed as inseparable: the act of narrating is understood to "actualize" selves; narrative is viewed as essential for establishing continuity between past and present selves; and narrative is deemed necessary for bringing embodied experience to consciousness. It is only on the basis of the assumption of the inseparability of self and narrative, that the claim that it is through narrative that "we come to know what it means to be a human being" and the assertion that "lives are the pasts we tell ourselves" (Ochs and Capps, 1996: 20 – 31) can be made. The conflation between self and identity, that Pucetti (1977) claims has haunted Western philosophy (see chapter two), is evident in the notion that the self (rather than identity) is constructed in and through narrative.

The caregivers' acts of narrating residents' biographical facts and stories no doubt enabled them to relate to residents not only as demented subjects, but as persons understood in relation to their past experiences and to a social world outside of the narrow confines of the ward. These practices can be understood as a form of interactive remembering that resonates with Kitwood's assertion that memory be "redefined as 'interactive and not individualized'" (1997; Leibing, 2006: 260). Given the widespread notion that the loss of memory – of past events, relationships, experiences – is tantamount to the death of the self, caregivers' practices of remembering and reiterating residents' biographies can be interpreted as an attempt to invoke residents' personhood through narrative telling. Such practices seem to come close to Leibing's (2006: 260) notion of "blurring the boundaries of self and other" in order to extend the "life in life" of persons diagnosed with dementia.

The assumption or belief that, "if the life *story* is over, then the life must be over too" (Taylor, 2008: 321, original emphasis), is so entrenched in contemporary academic and popular thought (in so-called Western contexts at least), that it is difficult to imagine, as Hacking (1996) reveals, that before the nineteenth century only "exceptional lives" were deemed worthy of telling and ordinary people were not seen to have biographies. In his essay "Against Narrativity," Strawson (2004: 428) critiques the "intensely fashionable" view that all "human beings typically see or live or experience their lives as a narrative or story of some sort." Strawson claims that the dominant view of narrativity in contemporary academia is based on two interrelated theses. The first thesis is ontological and posits that human beings understand and experience their lives as or through narrative. The second is a normative, ethical thesis that posits that humans *should* experience and understand their lives as a narrative, that a "richly narrative outlook" is essential to a good or ethical life, to "true or full personhood" (2004: 428).

Strawson traces the emergence of this view in Western philosophy and argues that it is concomitant to the value placed on different modes of “being in time” (2004: 429), an argument which I discuss in the section below. Strawson is adamant that neither thesis is true: there are many people who don’t experience or conceive of their lives as narrative; and “there are good ways to live that are deeply non-narrative” (2004: 429). Further, he states that the pervasiveness of the view that people not only do but should experience their lives as a narrative, can have potentially destructive consequences. This is borne out in the context of dementia where persons suffering from language and memory losses are persistently constructed as nonpersons in much of the popular and medical literature on Alzheimer’s disease or related dementias (ADRD).

The intersubjective memory practice described above can be said to exemplify the ethic of care that Taylor (2008: 326) proposes is essential to establishing relatedness with persons diagnosed with dementia: one where “selfhood” is understood to be “distributed among networks, sustained by supportive environments, emergent within practices of care.” However, this practice can also be understood to inadvertently perpetuate normative assumptions about the relationship between language, memory, time, and self: residents’ life stories must be remembered and narrated in order for them to be recognized as full persons.

Expanding the Scope of Memory

Cohen (2006: 10) notes that anthropologists influenced by the personhood approach to dementia generally advocate a shift away from memory and cognition toward embodiment, behaviour, and coherence. This shift constitutes an effort to challenge the so-called cognitive model of personhood - wherein memory and reason are posited as fundamental to full personhood - that informs biomedical and popular (at least in ‘Western’ contexts) understandings of the subjective and intersubjective effects of dementia-related memory loss. Moreover, this shift is undergirded by the above-mentioned tendency to equate memory with cognition and thus to associate memory loss in dementia with the impairment of the capacity to recall one’s personal past – classified as autobiographical or episodic memory in cognitive psychology.

My focus on memory was likewise initially directed at the loss of autobiographical memory, but it became evident that dementia-related memory loss also impaired residents’ embodied skills and capacities, rendering them wholly dependent on caregivers. Caregivers’ used both verbal instructions and their own bodies to guide, inform, and direct residents as to the “how” of walking, eating, dressing, and so forth.

Cognitive psychologists note that the ability to perform embodied skills is dependent on procedural memory which involves the knowledge/ memory of *how* to do something. Procedural memory was previously defined as *implicit* memory because once embodied skills are mastered, through repeated practice across

time; they become habitual and are generally enacted without conscious thought. Bourdieu, by contrast, argued that dispositions and practices are “embodied in the sense that the memory of them is not confined to the brain but is actually encoded in the muscles, nerves, and sinews of the body” (Kontos, 2006: 209). However, dementia-related memory impairments seem to unsettle any understanding that posits a separation or distinction between embodiment and cognition, practical and discursive memory/knowledge that certain personhood scholars advocate. Kontos (2006), for example, challenges the cognitive model of personhood, a model she suggests is a legacy of Cartesian mind/body dualism, and argues instead that “selfhood resides in corporeality” (p. 203) and is “irreducibly embodied” (p. 196). Kontos integrates Merleau-Ponty’s phenomenology of perception and Bourdieu’s exploration of the social logic of practice in order to encompass “the existential immediacy of the body as well as its interrelationship with culture and history” (p. 196). Accordingly, she argues that selfhood emerges from a “complex interrelationship between the primordial and the social characteristics of the body, all of which reside below the threshold of cognition; grounded in the pre-reflexive level of experience” (p. 203).

Kontos’ conceptualization of “selfhood” is valuable because it offers a means to critically challenge the widespread belief that dementia erases the ‘self’ – assumed to be constituted by memory and cognition – leaving behind the body as empty shell. However, the notion of a “primordial, pre-reflexive level of experience” that “resides below threshold of cognition,” has been problematized by contemporary neurological studies that demonstrate that perception and memory are inextricably linked (see Hoffman, 2009). I suggest that Kontos’ distinction between embodiment and cognition/memory not only perpetuates the very mind/bodily dualism that she sets out to problematize, but is based on a narrow definition of cognition that does not take into account the broadened scope of cognition that has emerged in cognitive science over the last few decades (Sutton et al, 2010: 210, see chapter two).

More importantly, the fact that dementia-related memory loss impairs not only autobiographical memory but also procedural memory, suggests that shifting the locus of “selfhood” from mind/cognition to corporeality/embodiment will not resolve the dilemma of personhood for demented elders who are no longer capable of gesture, movement, or expressive communication. Cohen (2008) concurs that reconceptualizations of personhood cannot effectively challenge the widespread belief that dementia-related cognitive impairments destroy the very abilities or capacities that are fundamental to personhood and meaningful relationship. He argues instead for the establishment of a “politics of care” (2008: 338) that is based on the recognition that ‘we’ have an obligation to care for persons with dementia, regardless of whether or not they are recognized as persons. Although I concur with Cohen’s assertion that there is an obligation to provide care for persons with dementia no matter their capabilities or impairments, I suggest that given that personhood is a fundamentally social category, understanding the social contexts and cultural assumptions that frame invocations and denials of personhood is essential. The above-described

intersubjective memory practice, which can be interpreted as method of invoking personhood, hinges on caregivers' knowledge - emergent from a particular historical and social context - of residents' erstwhile personal and social worlds, and importantly, of residents' current needs and abilities. Moreover, an intersubjectively remembered and narrated biography can only function to invoke personhood in a time and place where the notion that 'self' is formed in and through narrative is comprehensible.

Memory Loss, Temporality, and Relationship

Elizabeth's autobiographical memory and language capacities are relatively unaffected by her illness, but her short-term memory is significantly impaired. Events that occurred in the 'recent' past – lunch served, her daughter's visit the day before, her admission to the ward two years previously – are forgotten. This absence of temporal continuity at times overwhelms Elizabeth. One afternoon, Elizabeth suddenly cried out, "Please! Does anyone here know me?" Ella, a caregiver, responded, "Of course we know you Elizabeth," and Helen, who was sitting across from Elizabeth added, "I know you, Elizabeth." Elizabeth, cautiously hopeful, asked "Do you really know me?" Helen did not respond, and Elizabeth concluded tearfully, "You see, nobody here knows me." Elizabeth's daughter later confirmed that Helen and Elizabeth had been neighbours in Golden Village for many years.

Helen enters the lounge, looking exhausted and angry. Amelia, a caregiver, calls out to her, "Come here, Helen my darling. Come and sit next to me." Helen acquiesces and lays her head on Amelia's shoulder. Amelia gently strokes Helen's hair, encouraging her to "Just relax and experience the moment."

While Edward can no longer complete a sentence, he persists in engaging with caregivers and other residents. He often initiates his "yoga arms" exercise which requires two people to stand facing one another, holding hands, while turns are taken in "leading." The point is to follow the other person's arm movements – arms moving upwards in an arc, arms moving downwards in an arc, arms pushed back and forth in front of the chest, and so on. Edward does not speak during the exercise, except to express his approval with a drawn out, "Y-e-e-e-e-s," but it is an interaction that involves a level of intimacy uncommon in everyday interactions between adults – holding the other's gaze for an extended period, allowing oneself to follow the other's movements, and then, through some unspoken agreement, taking the lead and trusting that the other will follow. When the exercise ends, Edward thanks and acknowledges his partner by bowing and applauding softly.

Cohen (2006: 14) notes that the 'loss of memory, continuity, and apparent coherence, and of a familiar voice' is commonly identified with "the loss of a possible present [and] with the end of the person."

I argue that the above assumption can be problematized by considering how the relationship between time, language, memory, and self has been confabulated in contemporary academic and popular thought. This relationship is unwittingly revealed in Eva Hoffman's (2009: 100) description of Borderline Personality Disorder – characterized by an “unravelling of temporality” – which is remarkably similar to the assumptions Cohen describes above. Drawing on a psychoanalytic interpretation, Hoffman (2009: 101) asserts that for individuals diagnosed with this psychiatric disorder, “disparate experiences remain entirely disassociated from one another ... sensations never accumulate into personally felt meanings; [and] ongoing relationships cannot be formed or maintained.” The disruption of temporal continuity, that is, of “time as a continuum that extends into the past and the future” not only “creates a now without depth – and without personal meaning” but results in the “fragmentation of the narrative self” (p. 102). Hoffman's description of Borderline Personality Disorder suggests that it may not be memory loss per se, but rather the fact that memory loss disrupts temporal continuity, a mode of being in time which is fundamental to philosophical notions of subjectivity, moral being, and experience (see Strawson, 2004; Desjarlais, 1994), that constructs the person diagnosed with dementia as a nonperson.

Desjarlais (1994; 1997) points out that within most ethnographies the category *experience* is undefined and used to refer to a supposedly “fundamental, authentic, and unchanging constant in human life” (1994: 887). He argues that on the contrary, this notion of experience is historically and culturally specific because its distinguishing features – “reflexive interiority, hermeneutical depth, narrative flow, temporal unity” – are tied to “the Western genealogy of the self” (1994: 886). Drawing on ethnographic research in a shelter housing persons defined as homeless and mentally ill, Desjarlais (1994: 889-891) offers the notion of “struggling along” as an alternative form of subjective experience or being in time. His description of the mode of lived experience in the shelter, which is marked by cognitive and affective disturbances, the “wear and tear of pharmaceuticals,” an episodic orientation to time where “unconnected episodes” are interspersed by long periods of waiting and doing nothing, and “a ragtag collection of words, memories, [and] images” seems powerfully reminiscent of the lifeworld of the dementia ward. Desjarlais (1994: 889-896) notes that within the “temporal order” of ‘struggling along,’ the “future, present, and past need not have much to do with one another” and the notion of narrative – “wholly dependent on a poetics of coherence, continuity, and climax” – seems completely inappropriate. Desjarlais' concept of “struggling along” is valuable in that it highlights that *experience* is shaped by “political, social, cultural, and environmental forces.” However, his claim that this temporal order emerges from the “politics of displacement” reveals that he understands it to be a less than ideal mode of being in time, which reinforces the notion that temporal continuity is the norm.

Strawson's (2004) challenge to the now widespread belief that people do and should experience their lives as a narrative that unfolds across continuous time, offers an understanding of temporal discontinuity as different, rather than pathological. Strawson delineates two possible “styles of temporal being”: episodic and

diachronic. A person who is “naturally” diachronic has a sense of his or her self “as something that was there in the (further) past and will be there in the (further) future – something that has relatively long-term diachronic continuity, something that persists over a long stretch of time, perhaps for life.” Diachronic self-experience is usually narrative. On the other hand, a person who is “naturally” episodic is aware that he/she has “long-term continuity considered as a whole human being” but has little or no sense that “the self that [he or she] is [in the present] was there in the (further) past and will be there in the future “and has “no particular tendency to see [his or her] life in narrative terms” (2004: 430).

Strawson (2004: 460-449) notes that in Western philosophy, the episodic mode of being in time is, following Heidegger, viewed as an inauthentic, inferior, less vital way of being in time. Moreover, the absence of a sense of temporal continuity that characterizes episodic self-experience is believed to render the person incapable of sustaining meaningful, ongoing relationships and of living ethically. Strawson (2004: 432) strongly disagrees with this view, asserting that episodic life is “one normal, non-pathological, and indeed one good form of life for human beings, one way to flourish.” Moreover, Strawson (2004: 450) states that establishing and sustaining relationships is dependent on “how one is in the present” rather than on the capacity to remember “past shared experiences in detail.” By challenging the notion that temporal continuity and a remembered past, both disrupted by dementia-related impairments, are essential to personhood, ethical being, and relationship, Strawson provides a means by which to reformulate the dominant Western concept of personhood premised on cognition, memory, and rationality. Moreover, the understanding that there are various, equally valuable, forms of good life, modes of being in time, and ethics of relatedness – not dependent on memory, reason, and cognition – contributes to ongoing scholarly efforts to recalibrate the “politics and ethics of life itself” (Kaufman, 2006: 23).

Moreover, I suggest that within the ward, caregivers and family members shifted between two distinct but co-existent temporal modes which, after Strawson, I term episodic and diachronic. The episodic was marked by a focus on the moment-to-moment demands of providing care and maintaining the daily functioning of the ward. Intimacy was borne not of temporal continuity but of proximity and practices of care. Relatedness emerged in the immediacy of the present, through mutual engagement, and was dependent not on a remembered shared past, but on a willingness to open oneself up to another’s touch, gestures, words, and presence, generously and cruelly offered.

The diachronic was marked by a sense of temporal continuity and a reckoning with loss across time. The remembered past and the present were juxtaposed, by caregivers, family members, and even residents, drawing attention to losses associated with the progressive impairment of language and memory. It was within this temporal mode that the person diagnosed with dementia became “unrecognizable” as the person he or she once was. Catherine noted of Helen, “This is not the mother I grew up with,” but gradually acquiesced to Helen’s uncharacteristic displays of physical affection. Elizabeth’s daughter noted that it was only after she

read an autobiographical account of Alzheimer's disease, *Still Here*, that she could comprehend her mother as more than an absence. I was taken aback by this comment, because Elizabeth's speech was intact, she was an empathetic listener, offered helpful advice, and had a wry sense of humour. That the 'cognitively unimpaired' person in the past could seem more vivid, more real, and more substantial than the 'cognitively impaired' person in the present, is, I argue, an effect of a normative mode of being in time where temporal continuity and hence memory are assumed to be fundamental to the continuity of the 'self' and to relationship (see Taylor, 2008). My assertion that the importance of memory and temporal continuity to personhood and relationship is culturally and historically shaped, is not to deny that the residents and their family members suffered myriad losses due to dementia-related impairments and the disruptions of relationship that followed institutionalization.

Conclusion

In this chapter, I explored the ways in which dementia-related memory loss shaped the embodied lifeworlds of residents, demonstrating that both residents' autobiographical and procedural memory capacities were, albeit variously, impaired. I argued that broadening the definition of memory to encompass the myriad capacities and abilities that memory stands for is essential to ethnographic analysis. I described caregivers' habit of narrating residents' life histories as an *intersubjective memory practice* that functioned to establish continuity between past and present and to invoke personhood. I suggested that this practice encouraged caregivers to engage with residents not only as demented subjects, but also as socially situated persons. I asserted that this intersubjective memory practice can only be understood in relation to a contemporary 'Western' context where memory, language, self, and time are interrelated in a culturally and historically specific manner. Moreover, while acknowledging that this practice functioned to invoke personhood and positively shape the ethic of care in the ward, I contended that it simultaneously perpetuated a normative understanding of the self as narratively constructed. Finally, I considered how the importance attached to temporal continuity in Western philosophical thought has fundamentally shaped conceptions of personhood, relatedness, and ethics. I argued that acknowledging that there are various, equally worthy, modes of being in time will contribute to scholarly efforts to develop an understanding of dementia as a comprehensible rather than incomprehensible form of life.

CHAPTER 6: IN CONCLUSION

[T]he study of senility can and must set out to do more than improve the care and treatment of demented persons: it must use senility to understand the critical stakes in persistent and emergent forms of reason, memory, care, aging, medicine, and life itself (Cohen, 2006: 3)

The dissertation has contributed to an understanding of how the entanglement of memory, language, self, and time in Western thought shapes assumptions about the personhood status of elderly individuals with dementia.

Since the 1980s, dementia has been widely represented in popular and academic literature as a disease that progressively destroys the very attributes – memory, language, reason, autonomy – fundamental to personhood in ‘Western’ social contexts (Kaufman, 2006: 24; Cohen, 2006). Such representations have elicited ethical and political debates about whether or not old people with dementia, suffering language, memory, and other cognitive losses and dependent on others for the care of their basic needs, can yet be recognized as full persons, capable of engaging in meaningful relationships.

The “personhood turn” (Cohen, 2006: 13) in popular, clinical, and scholarly writing emerged in response to such ‘loss of personhood’ representations and is central to these debates. The personhood approach to dementia is focused on recovering the personhood (Cohen, 2008: 337) of old people with dementia who are widely depicted as nonpersons. As with other clinical and scholarly writing, anthropological analyses that adopt this approach attempt to achieve the recovery of personhood by critiquing the biomedical approach to dementia and problematizing the dominant ‘Western’ notions of personhood and relatedness (Leibing, 2006). Moreover, these analyses generally offer reconceptualised notions of personhood and relatedness as alternatives to the ‘Western’ notions critiqued, and as such, are usually marked by a shift away from cognition, memory, language, and the autonomous subject toward coherence, behaviour, embodiment, and a relational model of personhood (Cohen, 2006: 10).

My research both builds upon and differs from the above-described anthropological analyses of dementia. While I shared an interest in questions of personhood and relatedness, my aim was to develop an understanding of the ways in which memory, language, time, and subjectivity were folded into the everyday lives of elderly persons living in a dementia ward. In order to accomplish this aim, I focused on how the relationship between elderly residents and their professional caregivers was established and maintained across time, despite dementia-related language and memory losses. Further, instead of shifting the analytical focus away from language and memory, I chose to pay close attention to the ways in which language and memory loss shaped the possibilities for personhood and relationship within the ward.

My research confirms the importance of taking the relationship between ‘demented’ and ‘non-demented’ persons as the object of anthropological study (Cohen, 2008: 338). It also substantiates Hacking’s (2004: 278) assertion that it is necessary to combine a “bottom-up” approach, that takes into account that invocations and denials of personhood occur on the practical level of human interaction, and a “top-down” approach, that recognizes that models of personhood derive from “particular historical and cultural heritages” and are “founded on complex webs of political, social, and linguistic, [and historical] forces” (Desjarlais, 2000: 467-485). It was by paying close attention to the myriad and varied interactions between residents and caregivers – words, glances, gestures, withdrawals, silences (Hacking, 2004: 278) - across an extended period of time, and seeking to understand and interpret these interactions in relation to the various historically and culturally shaped forms of knowledge and practice that structured the institutional space of the ward, that I was able to develop the arguments presented in this dissertation.

I demonstrated that it was through myriad and ongoing caregiving practices that the relationship between residents and their professional caregivers was established and sustained. I suggested that this relationship could best be described as a relation of care that was structured by institutional norms, rhythms and routines, as well as by the cultural and personal attributes of both residents and caregivers. I argued that the caregiving practices that constituted this relation of care could be understood as a form of world-making as it was through and within these ongoing practices of care that residents, displaced from their erstwhile social worlds by dementing illness and institutionalization, were held in life and relationship.

My observations confirmed that residents’ personhood was invoked through the mutual interactions between caregivers and residents that caregiving necessitated. This resonates with the view proposed by scholars who conceive personhood as emergent within relations of dependence, care, and obligation (Henderson, 2009; Taylor, 2008). Recognizing that interdependence is fundamental to personhood unsettles the dominant ‘Western’ model of personhood which hinges on ‘cognitive’ capacities, assumed to be located within the mind of the autonomous individual.

Contrary to the assumption which characterizes much of the literature influenced by the personhood approach to dementia, namely, that a relational model of personhood will make it possible for old people with dementia to be recognized as full persons, my research demonstrated that it is imperative to recognize that all notions of personhood and relatedness are simultaneously productive and normative. World-making and subordination existed in dynamic tension within the ward: the very relation of care that made invocations of personhood possible and reconstituted residents’ relational networks, simultaneously functioned to bring old people with dementia into being as docile demented subjects (Cohen, 1998). On the other hand, the observation that residents were held in life and relationship through an institutionally structured relation of care offers a challenge to Irving Goffman’s assertion that “total institutions,” like the dementia ward, are essentially “places of coercion” (1961; Hacking, 2004: 294). These findings highlight the necessity of

recognizing the complexity that is inherent in all “forms and practices of relationship” (Cohen, 2008: 337) and caution against the assumption that alternative conceptualizations of personhood and relatedness will resolve the ‘personhood dilemma’ for elderly persons with dementia.

An emphasis on temporality is a common thread throughout the ethnographic chapters. The temporal disruptions or confusions that many residents experienced were not only an effect of dementing illness, but also of the routines and rhythms on the ward. It was evident too that everyday life on the ward was marked by two distinct but co-existent temporal modes, which I defined as episodic and diachronic (Strawson, 2004). Unlike the diachronic mode, the episodic mode was characterized by a focus on the ‘present tense,’ a mode of being in time that allowed caregivers to focus on the immediacy of the present in their interactions with residents. This temporal mode made possible a form of intimate relationship not dependent on the memory or knowledge of past interactions, but on the mutual engagements and proximity that caregiving practices necessitated. The observation problematizes the view, long held in Western philosophy, that temporal continuity is essential to establishing and maintaining relationships across time.

The dissertation described the multiple ways in which language mattered to relationship, personhood, and the ethic of care within the ward. Paying close attention to language – speech, forms of address, explanatory models – offered a nuanced understanding of the complex ways in which language, memory, and self are intertwined, historically and currently, in ‘Western’ notions of personhood and relatedness. A focus on language revealed the presence of different speech styles and speech communities within the ward. I asserted that such differences could not simply be attributed to the distinction between ‘demented’ elders and their ‘normal’ caregivers, but also to a particular social history of racialised class difference which extended into the present. Moreover, a focus on language demonstrated that the language capacities of residents were differentially impaired, highlighting the importance of acknowledging individual difference and of distinguishing between various forms of language impairment. Old people with dementia are generally portrayed as having lost all ability to speak or understand language - as uncomprehending, silent, or babbling - but my research showed that residents’ capacity to speak and understand speech was differentially impaired and further, that individuals experienced temporal variations in their capacity and/or desire for speech.

It was evident that in the face of dementia-related language and memory losses, ‘bodily’ communication – gesture, touch, tone, facial expression – was fundamental to the relationship between caregivers and residents (Chatterji, 2006). While this observation validates the assertion that embodiment is an important and necessary focus in dementia studies (see Kontos, 2006), I argued that including a focus on language was essential to rigorous analysis. Not only did residents persist in the effort to engage others through language, despite the attendant difficulties and frustrations, but the caregiving relationship was crucially shaped by language and linguistic acts. In describing how caregivers made use of various explanatory models to frame and interpret ‘inappropriate’ behaviour, I showed that although the biomedical model of

dementia was referenced frequently, other context-based explanatory models were also regularly drawn on. Such linguistic framing, variously punitive or redemptive, shaped the manner in which caregivers perceived and responded to 'inappropriate' behaviour, which in turn had material effects on the well-being of residents, both beneficial and detrimental, as numerous dementia studies have established.

A focus on the interactions between caregivers and residents allowed me to identify the various forms of address that caregivers used to engage residents. I demonstrated that while certain speech acts functioned to invoke personhood and hold residents in relationship, others were used to coerce and restrain and, seemingly inadvertently, functioned to deny personhood. Such denials of personhood were often precipitated by caregivers' assumption that residents who could not speak of and for themselves were no longer "there." Anthropologists have proposed that the widely accepted notion that dementia is a disease that destroys the 'self' is a consequence of the cognitive model of personhood that informs 'Western' understandings of the person (see chapter two). I argued, however, that the tendency to equate a loss of language with a loss of self can be better understood in relation to the currently "intensely fashionable" (Strawson, 2004: 428) notion that the self is narratively constructed.

My focus on the narrative construction of self was inspired by the observation of caregivers' practice of recalling and describing the biographical 'facts'—relationships, career, travels, preferences, and habits—that identified residents as socially and temporally situated persons. I defined this practice of recollection and narration as an intersubjective memory practice and asserted that it functioned to invoke personhood by portraying residents as persons still connected to their erstwhile social identities and social worlds. I traced the historical association between memory, personhood, temporal continuity, and narrative in Western philosophy and asserted that the now taken-for-granted notion that the self is brought into being and maintained across time through narrative can only be understood in relation to this history.

Dementia, which impairs language and memory capacities and disrupts temporal continuity, renders impossible the narrative construction of self. However, rather than contest the validity or universality of the notion of the narrative self, dementia is widely represented as a disease that destroys the self and the possibility for meaningful life and relationship. While the intersubjective memory practice described above functioned to invoke personhood and constituted an instance of interactive remembering that blurred the boundary between self and other (Leibing, 2006: 260), it simultaneously perpetuated a normative understanding of the self as narratively constructed. This underlines the importance of understanding all concepts of personhood and forms of relatedness as both productive and normative.

A focus on memory not only revealed important insights about the relationship between memory, narrative, temporal continuity and personhood, but also demonstrated the necessity of expanding the concept of memory that informs many scholarly and popular perceptions of dementia-related memory impairment. Dementia is generally associated with the loss of autobiographical or episodic memory, that is, the ability to

bring “past thoughts, events, or faces to mind” (Hacking, 2005: 224), but as was evident in my research context, dementing illness also impairs procedural memory – the knowledge/memory of how to perform embodied skills like walking, eating, or dressing. It is thus necessary to adopt a broadened concept of memory that incorporates the many skills, performances, and abilities that are dependent on memory. This allows for a more comprehensive understanding of the relevance of dementia-related memory losses to questions of personhood and relatedness, and also offers a means to overcome the tendency, evident in the personhood approach to dementia, toward viewing mind/cognition and body/embodiment in dualistic terms (see Kontos, 2006).

This ethnography has demonstrated that a critical analysis of senility/dementia can provide important insights into how the intertwining of language, memory, time, and self was fundamental to the genealogy of the modern subject. I proposed that the loss of personhood debates that contemporary representations of dementia have generated can be usefully interpreted in relation to the notion of the narrative self. The dissertation has also demonstrated that this notion is a present-day manifestation of a “persistent and emergent” form of reason (Cohen, 2006: 3) that draws memory, language, self, and time into a culturally and historically peculiar relationship. The resulting entanglement has rendered memory, narrative, and temporal continuity essential to personhood and relatedness in ‘Western’ socio-cultural contexts. By pointing out that temporal continuity has long been viewed as central to notions of personhood and relatedness in Western philosophy, my research introduces the possibility, not yet fully explored in anthropological studies of dementia, that it may not be memory loss per se, but the disruption of temporal continuity that undergirds the characterization of dementia as an incomprehensible form of life. The theoretical insights presented in the dissertation thus open up numerous further possibilities for the anthropological study of dementia.

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Appendix A

Formal Letter Submitted to All Research Participants

Proposed Research

I am a student in the Department of Social Anthropology at the University of Cape Town and am undertaking research toward a minor dissertation in fulfilment of my Master's degree.

My research focus is on dementia and my aim is to contribute to academic knowledge of the everyday intersubjective and relational worlds of persons who have been diagnosed with dementia and are living in a medical institution.

I am hopeful that my research findings will be of benefit to the residents, family members, and medical and care-giving staff at Golden Village. As discussed in greater detail below, I will protect the rights and privacy of all persons involved in the research process and will treat all information gained during the research process as confidential. My research aims, methods, and ethical considerations are outlined below.

Research Aims

I aim to explore the kinds of relationship that are present within the dementia ward at the Golden Village medical facility, and to examine the everyday practices of caring, generosity, and communication through which such relationships are constituted. I hope to gain insight into how relationships are formed, negotiated, and maintained despite the memory loss and language difficulties associated with a diagnosis of dementia.

Research Methods

I will join the dementia ward as a volunteer willing to assist the residents and staff in whatever way needed while simultaneously engaging in participant-observation research. I will observe the routines, activities, experiences, and interactions that make up the residents' daily lives on the ward, focusing on the interactions and practices of care that constitute the relationships between them and their caregivers, medical staff, and family members.

During the research process I will use field-notes based on my observations, and request informal and semi-structured interviews with staff, family members, and friends. All information gained during the research process will be treated as confidential, as discussed in the ethics section below.

Ethical Guidelines

My research will be conducted in accordance with the ethical guidelines set out in the Anthropology Southern Africa Code of Conduct (2004).

My primary concern is to interact with the residents in as sensitive, empathetic, and non-intrusive manner as possible, and to respect at all times their rights, dignity, and privacy. While I am volunteering and conducting research, I will follow the lead of the medical staff and acquiesce to the experience of the matron, nursing and other medical staff, and caregivers.

In order to protect the identity and privacy of research participants, including residents diagnosed with dementia, family members and caregivers, all staff working at the medical facility, as well as any other potential research participants that I meet during the course of my research, I will use pseudonyms in place of real names and will avoid using identifying characteristics. All information gained during the research process will be treated as confidential and will only be used for academic purposes.

As to questions of informed consent, before I begin my research, I will obtain informed consent from the matron and the relevant administrative board at Golden Village. I will disclose to all persons that I interact with - residents, family members, medical and care-giving staff, and visitors - that I am volunteering at the facility with the aim of conducting research. Where appropriate, I will obtain verbal assent from residents, or alternatively, from substitute decision-makers. I will obtain informed consent from family and staff members who agree to participate in informal interviews. If necessary, I will obtain informed consent documents from those persons qualified to provide it.

I will also explain my research aims and intended methods verbally to residents, family members, and staff, and will ensure that potential participants are aware that they can ask me to reiterate my research aims and intentions at any time. I will ensure that all research participants are aware of the fact that informed consent is a dynamic and continuous process that is open to negotiation and can be withdrawn at any time during the research period.

I will make my research dissertation available to any of the research participants who wish to obtain a copy, and will in addition prepare a summary of my research findings for the medical care facility at Golden Village.

