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A symbolic interactionism of dementia: a tangle in ‘the Alzheimer Conundrum’

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Abstract The current molecular model of Alzheimer’s disease has a number of inadequacies and has so far provided little improvement to quality of life. The entanglement model of Alzheimer’s disease offers an alternative. It conceptualizes Alzheimer’s disease within a complex range of considerations and advocates public health measures in response. This paper seeks to incorporate a social model within entanglement. To address entanglement’s lack of social considerations, a sociological account of dementia more broadly is proposed. A theoretical account is offered through re-examining influential psychosocial work on dementia, within a symbolic interactionist framework. Dementia is illustrated as a process of excess disability, from the discovery of stigma during diagnosis through to the moral career of cognitive decline. As cures are not forthcoming and dementia is currently addressed socially through care, the pursuit of social solutions is an evident, necessary and achievable goal. This can be realized through education, within a broader public health approach.

Keywords Alzheimer · Dementia · Entanglement · Symbolic interaction

Introduction

This paper builds upon the entanglement model of Alzheimer’s disease (AD) (Lock 2013). Whilst explicitly a response to the entanglement model of AD, the position taken applies to dementia generally. First, dementia and AD are briefly outlined. Second, the current AD research landscape is considered, highlighting the dominance of the molecular model and the need for social considerations within

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an entanglement model. In response, the case is made for a sociological model of dementia via symbolic interactionism. This begins with a brief outline of the theoretical framework. Finally, application of this framework to dementia reveals a dementing process, suggesting potential social responses to dementia.

Dementia and Alzheimer's disease

Dementia is a collective term for the symptoms of multiple conditions causing ultimately fatal progressive cognitive impairment. This results from long-term brain cell damage caused by varied factors. AD accounts for around 60% of dementias. AD is widely attributed to the protein beta-amyloid ($A\beta$) forming plaques in the brain (Lock 2013; Prince et al. 2014).

Dementia correlates strongly with age, affecting 0.9% of the UK population aged 60–64 and 11.1% aged 80–84 (ibid, p. 12). By 2021, demographic ageing is projected to increase the UK's current population of people with dementia of 835,927–1,007,485 (ibid, p. 16). New epidemiological data suggest declining prevalence, possibly due to dietary and educational improvements. However, it is uncertain whether decreasing prevalence will continue amidst global financial turmoil and rising obesity levels (Jones and Greene 2016, p. 508). Dementia is a major public concern due to perceived societal costs, repeatedly expounded by politicians, media and research organizations. As a result, researchers are urgently seeking a cure.

Current landscape

The Alzheimer Conundrum

The molecular model of AD posits the amyloid cascade hypothesis, whereby $A\beta$ aggregation leads to cell death and dementia symptoms. The vast majority of drug trials focus on $A\beta$ reduction (Lock 2013, p. 66). Historically, this model is a late 20th century development. Before this time, dementia was viewed as a normal part of ageing in over 60s. Despite Alois Alzheimer's 1906 declaration of senile dementia pathology, AD remained an uncertain entity amidst paradoxical understandings of ageing as quasi-pathological; simultaneously normal and disease-like (ibid, p. 5). In the 1960s, technological developments began to challenge this paradox, eventually producing contemporary AD neuropathology. In the 1970s, this neuropathology model supported claims that AD was a disease, regardless of age. The extension of the disease category to include over 60s meant that AD transitioned from an uncommon condition to the fourth biggest killer in the US (Fox 1989, p. 71).

In the same year, the National Institute on Aging (NIA) was established. It used emerging molecular understandings of AD as a widespread fatal disease to justify its existence. In 1978, the Neurobiology of Aging programme was established to develop the disease model, and in 1979 the Alzheimer's Disease and Related Disorders Association (ADRDA) was founded to publicize discoveries (ibid, p. 78,



p. 82). The disease model developed rapidly and was a financial success. Between 1976 and 1980, NIA funding increased from \$19.3 million to \$70 million (*ibid*, p. 87). Through this process of “Alzheimerization”, AD has simultaneously gained publicity and become a distinctly molecular entity (Fox 1989).

Whilst successful at attracting funding, the molecular model has been therapeutically unfruitful. Drug trials have removed A β from the brains of people with AD, yet they have subsequently continued to experience cognitive decline (Holmes et al. 2008). Furthermore, many older people exhibit AD pathology without corresponding symptoms. This pathology/symptom disparity undermines the differentiation of abnormal AD pathology from normal ageing physiology (Lock 2013, p. 5).

Molecular model inadequacies have negative practical repercussions. Decades of research funding have produced four semi-effective symptom controlling medications with negative side effects (Lock 2013, p. 1). Meanwhile, carers tackle AD daily at great personal cost, alongside a formal care workforce beset by low wages and low-quality employment (Carr 2014, p. 2). Therefore, molecular research funding may constitute resource misallocation.

The molecular model continues because of its ability to generate funding. To attract public attention and government finance, a consistent overarching image of the foe to be defeated is required, rather than fragmented complexity. A β remains the major target of ‘Big Pharma’, and the conundrum persists (Lock 2013, p. 66).

Emerging trajectories

There are three emerging responses to the Alzheimer conundrum, two of which are interrelated. The first is early diagnosis, evident in government emphasis on early detection of AD processes and widespread adoption of the term Mild Cognitive Impairment. The theory posits that AD pathology begins decades before symptoms and that the process must be caught early (Lock 2013, p. 8).

As early intervention progresses, the medical gaze extends into younger populations. This pre-symptomatic expansion represents “extensive medicalization” (*ibid*, p. 4). Furthermore, focus on pre-symptomatic AD encourages reductionism as neuropathology and symptomatology become separated within diagnostic literature. Even if effective, such meticulous molecular surveillance is unlikely to become widely available for economic reasons (*ibid*, pp. 241–242).

The second emerging approach is genetic predisposition. Genetic research focuses on genetic expression precipitating A β aggregation. This process has been identified in family groups with rare genetic variations. These populations are extensively studied as they are considered to have a pure AD, unadulterated by age-related physiology.

Beyond rare familial early-onset AD, genetic research has struggled. The APOE gene allele E₄ is currently most associated with generic AD; however, as genetic research progresses, the overall picture becomes more complicated. The collection of confounding factors, such as other genes and environmental influences, is ever expanding (*ibid*, p. 218).

The reiterated ethical quandary associated with pre-symptomatic medicalization, via early diagnosis or genetic testing, is whether there is utility in anticipating future



illnesses when they cannot be prevented. There are also serious practical issues. Being labelled a pre-clinical person with dementia may have negative repercussions, such as heightened insurance premiums (Lock 2013).

In contrast to these emerging approaches, the entanglement model recognizes that numerous non-molecular factors affect AD across the life course (ibid, pp. 238–242). It is increasingly clear that pathology only partially explains cognitive decline (Kuehn 2015, p. 2492). The entanglement model situates AD within intertwined phenomena beyond the solely pathological, positing that no single element can account for the condition (Lock 2013).

Entanglement proponents argue that suspect distinctions between ageing physiology and AD pathology undermine any one molecular approach. Isolating AD pathology for experimentation produces an artificial entity, removed from clinical realities. Separating AD from ageing becomes meaningless, as an amalgamation of complicated age-related “crap” (as researchers often refer to it) permeates the overall process (ibid, p. 57). Therefore, entanglement understands AD as the result of many diverse factors. It encourages the interrogation of numerous strands to construct holistic approaches, incorporating the “social, political and environmental” alongside the molecular (ibid, p. 15).

A social strand

AD can thus be situated within entanglement as innumerable intertwined phenomena to be addressed together, questioning reductionist molecular models. Social considerations represent one such substantial strand that is currently overlooked within entanglement. Whilst molecular models understand dementia as resulting from neuropathology in the brains of people with the condition, social models have situated it within interpersonal relationships (Kitwood 1997) or broader societal value systems (Gilleard and Higgs 2014). The molecular focus is internal, while the social focus is external.

Psychiatrists in the mid-twentieth century were the first to suggest dementia’s psychosocial implications. Writers postulated that emotional trauma and isolation were as important as biology, and that dementia should be viewed as a mental health issue, bound up with the experience of ageing in modernity. Such thinking remained marginal, and declined in the 1970s as the biomedical approach prospered (Ballenger 2000, p. 84).

In the 1990s, the psychosocial model re-emerged through the work of Kitwood (1997) and Sabat (2001). Both suggested maintaining the identity of people with dementia through interaction. Kitwood introduced the term *personhood*: “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood 1997, p. 8). The focus is on endowing the person with a moral status based on their being a person.

Personhood’s conflation of person with self has been criticized, being perhaps more politically expedient than intellectually robust (Dewing 2008, p. 3). To this end, Higgs and Gilleard (2016) have produced a broad complexification of personhood in terms of metaphysical and moral philosophy. Rather than pursuing



personhood, this paper subscribes to a symbolic interactionist understanding that remains conducive to Kitwood's work, whilst more stringently defining the self (below).

Despite such developments, social science approaches to dementia have not been assimilated into entanglement. Social approaches are often considered as responding to disease outcomes rather than addressing causes, an assumption challenged in this paper. In answer, a sociological model, emerging from consideration of dementia literatures within a symbolic interactionist framework, is now proposed as a contribution towards understanding a social strand of dementia within entanglement. For clarity, this begins with a brief outline of the theoretical framework.

Theoretical framework

The symbolic interactionism (SI) used in this paper stems from Blumer's (1969) theoretical tenets and Goffman's (1963) empirical work. The theory rests upon three principles: people act based on the subjective meanings that things hold for them; these meanings are produced in interaction with others; meanings are negotiated in an interpretative process (Blumer 1969, p. 2).

Every person inhabits a world of objects. These objects are anything that can be referred to, from a physical item like a chair to an abstract concept such as freedom. Interaction with others reveals the meanings which they assign to objects, allowing a person to negotiate others' meanings alongside their own, in an interpretative process akin to self-interaction, whilst facilitating shared meaning (*ibid.*, pp. 10–12). Objects are defined by people's actions towards them; depending upon use, a chair may be a seat, a weapon or a door stop (*ibid.*, pp. 10–12).

Most importantly, a person has a self because he or she is an object to himself or herself. The self is defined in interaction, allowing each individual to view themselves through the eyes of others. This looking glass self is interpreted alongside the individual's existing self-object to renegotiate the self (*ibid.*, pp. 12–13). This article relies on an object-based understanding of the self as self-aware (albeit not solely consciously) because one interprets oneself as an object (Mead 1934, p. 136). SI can incorporate Kitwood's aforementioned interactional writing because self-object interpretation is arrived at via interaction with others, and is therefore neither absolutely dependent nor independent, but rather a bit of both (*ibid.*, pp. 136–137). The SI self is therefore notably irreconcilable with notions of complete agency. This SI understanding of self is central to this paper by virtue of its centrality to SI generally.

People act upon their world of objects, interpreting meanings as the basis for an appropriate line of action. Based upon their self-objects, people enact roles framed by consensual meanings, indicating which actions befit which roles (Blumer 1969, pp. 12–13). Frames establish guiding boundaries, but are advisory rather than formative, allowing variation in action, even when actors share similar worlds of objects (*ibid.*, pp. 15–16).

Overall, SI situates interaction and interpretation within worlds of objects at the heart of human existence. Existing dementia and mental illness literatures are now



combined and situated within the outlined framework. The result is a novel theoretical account, providing a basis for the refinement of a holistic sociological understanding of dementia.

A symbolic interactionism of dementia

A SI of dementia is now outlined, charting a process whereby the selves of people with dementia and those around them are transformed under the influence of the dementia object. First, it is argued that the dementia object has transformative potency as a known and feared condition. Second, this transformative quality is explored in terms of continuity and change, and agency and determinism. Third, the necessity of interpretive interaction in negotiating these competing tendencies is considered regarding language, embodiment and space. Finally, the trajectory of becoming symptomatic is discussed. This is presented in terms of malignant social psychology and the moral career.

Social theory is applied to lived experiences within a narrative of the overall illness process. This is an account of excess disability, whereby social processes render impairment disabling. Such an understanding suggests potential social approaches to minimizing disability in interaction. In the concluding remarks, the SI of dementia is repositioned within entanglement and broader repercussions for dementia.

The discovery of stigma

Dementia can exert substantial influence over the interactionist processes of meaning negotiation via interaction and interpretation. Participants in Beard and Fox's (2008, p. 1516) study of social disenfranchisement in AD experienced immediate changes in interpersonal interactions following diagnosis. The dementia object arrives in a pre-existing social context, introducing instability into existing relationships and challenging existing worlds of objects. This arrival threatens both existing meanings and the negotiation of new ones (Snyder 2006).

Labelling a person as having dementia is potent, particularly in light of media alarmism sensationalizing the condition, reinforcing negative stereotypes. This extends beyond dementia to wider ageism. Ageism constitutes "stereotyping of and discrimination against people because they are old" (Butler 1975, p. 12). Dementia stereotypes may be viewed as one aspect of broader negative stereotypes around older people (Dobbs et al. 2008, p. 517). Associated stereotypes compel the diagnosed individual to renegotiate their identity, accommodating the appropriate disease element, fitting their diagnosis. For example, Beard and Fox (2008, p. 1513) found that people with dementia began to interpret their previously unremarkable memory lapses as symptomatic, following diagnosis.

Goffman (1963, pp. 47–49) described this process as the discovery of stigma. Stigma is "the situation of the individual who is disqualified from full social acceptance" (ibid, p. 9). Stigma permeates interaction, driving transformation. This is not to suggest that transformation is exclusively attributable to stigma, for



dementia is a progressive condition, but rather that stigma can be a substantial influence. Interaction with a stigmatized individual risks tainting the non-stigmatized actor through association (ibid, p. 64), compelling non-stigmatized actors to renegotiate interaction with the stigmatized actor to preserve their own self-object. For example, older people often seek to assert the otherness of those with dementia. One resident in Dobbs and colleagues' (2008, p. 521) ethnography of long-term care refused to associate with people with dementia. Therefore, dementia not only affects the person with dementia; it transforms the actors around that person (Sabat 2001).

Thus joint action becomes influenced by the dementia object; relationships are reshaped in light of the new object's meanings, altering each individual's actions. For example, people may undertake tasks on behalf of a person with dementia due to perceived incapacity, that is, the incapacity that one perceives rather than objectively measured incapacity (Piiparinen and Whitlatch 2011, p. 192).

These transformations in joint action are driven by negotiated meanings of the dementia object in interaction. In Öhman and colleagues' (2008, p. 46) study of awareness of people with AD, one participant measured his rate of decline by interpreting the reactions of others to him. The interactive process is not terminated by dementia, and in the early stages the person with dementia and their immediate relations will commonly attempt to maintain familiar joint action. There simultaneously exists inevitable change and desire for continuity (Sabat 2001).

Continuity and agency

SI reveals change and continuity within the world of objects of those affected by dementia to be central considerations. Studies reveal that people affected by dementia desire continuity in order for those with dementia to maintain active and meaningful lives (Beard and Fox 2008, p. 1511, 2009, p. 233, 2012, p. 2). However, continuity is not universally beneficial, and the possibility of positive transition is often unrecognized (Orr and Teo 2015, p. 2). Öhman and colleagues (2008, p. 47) found that participants with AD experienced stress when maintaining activities such as paying bills, and felt great relief when such tasks were relinquished. Thus adaptive transformation can be positive (Robinson et al. 2005, p. 344). Adaptation is central to SI due to its processual rather than structural nature.

The possibility exists of incorporating the dementia object into a person's self-object. Beard and Fox (2008, p. 1511) advocate a "bidirectional" approach, both maintaining previous selves as much as possible, whilst also incorporating new aspects. Incorporation may offer a positive alternative to false permanency. All selves are transient. This understanding facilitates self adaptation and acceptance of hardship whilst recognizing the potential for humour in absurdity, and love in interdependency (Radden and Fordyce 2006; Sabat 2001).

It is important to remember that SI does not suggest helplessness. Individuals can skilfully negotiate identity and illness tensions (Beard and Fox 2008, p. 1518). Blumer (1969, p. 5) emphasized the importance of the interpretative element within the interactionist process to counter meaning-enforced determinism. One flaw of molecular models is a false degree of generalizability, undermining the validity of



experiential diversity (Sabat 2001). Research indicates both continuity and modification of self within dementia. SI engages with both simultaneously (Caddell and Clare 2010, p. 115).

SI conceptualizes such diversity through acknowledging agency in interpretation, avoiding imposing determinist prescriptions on independent intentional actors (Aquilina and Hughes 2006). The flexibility of interpretation ensures that interaction is not solely formative, advancing, rather than imposing, meaning. Actors can work to establish order and disorder, ameliorating the condition whilst highlighting its tribulations (Gubrium 1987, p. 2). Supporting this, Graham and Bassett (2006, p. 346) note that dementia's "dynamic relationships involve simultaneously resistance and acceptance, cooperation and conflict, unity and detachment, and negative and positive reciprocity".

Actors exercise agency within dementia in many ways. For example, Langdon and colleagues (2007, pp. 994–995) found that people with early dementia actively managed disclosure of their diagnosis due to people's "misconceptions" about dementia. Humour may also be employed, challenging the commonly melancholic dementia object meaning. Thus the person with dementia is agentic (Beard and Fox 2008, p. 1517).

Inevitably, perpetual continuity is as implausible within dementia as within all life. A difficult navigation of multiple roles ensues as the condition progresses and role boundaries require re-evaluation (Lloyd and Stirling 2011, pp. 904–905). An individual may be compelled to perform the actions of both spouse and nurse simultaneously. This is problematic because relationships are usually conceptualized with a single noun, a single role identity guiding coherent action (Beard et al. 2012, p. 8).

Such role difficulty can impel the separation of joint action, as impairment of communication skills reduces the person's ability to contest meanings, impeding normative interaction (Beard et al. 2009, p. 228). When an actor significantly transgresses normative expectations in interaction, fellow actors react by interpreting the other as "tainted" by abnormality (Goffman 1963, p. 12). "Normative expectations" here refer to "righteously presented demands", assumptions that we make about the individual that they then must satisfy to assert their normality (ibid, p. 12). Actors stigmatize the originator of action that fails to satisfy these demands, assigning a stigma based on that specific failing (ibid, p. 12).

Language, embodiment and space

Failure to interact normatively is most starkly evident in spoken communication. Language is the most tangible medium of communal meaning-making. When wielded by meaning-making actors in relational contexts, language conveys inconceivable power (Snyder 2006). Imagine a woman named Norma. If everybody besides Norma referred to Norma as 'Demetria' it would likely not take long until Norma began to answer to 'Demetria'. There exists no immutable linguistic inscription of any object's meaning, solely the unceasing renegotiation of interpretative interaction (Hughes et al. 2006).



Sabat (2001) outlines numerous linguistic difficulties associated with dementia, such as problems with pronunciation and syntax. As the condition progresses, speech is increasingly considered indicative of disease (Beard et al. 2009, p. 228). Deemed symptomatic, the linguistic divide between the person with dementia and others emphasizes their abnormality (Adams 1998, p. 616). Linguistic misunderstandings fuel agitation, which is likewise deemed symptomatic (Sabat 2001). Declining ability to contest interpretations reinforces their potency.

Many have chronicled the importance of language to inter-relational meaning construction in dementia (Adams 1998, p. 616; Beard et al. 2009, p. 228). However, a narrow focus on speech misrepresents interaction. Interaction is also inherently physical (Kitwood 1997). Therefore, the body must enter into an interactionist understanding of dementia.

Embodiment recognizes that bodies enact not only biological processes, but also their sociocultural environments, having internalized them through lifelong exposure. This is pertinent regarding dementia as “the self is understood to reside in the ways that the body moves, perceives, and behaves, thus persisting despite cognitive dysfunction” (Kontos 2003, pp. 166–167). Kontos and Martin (2013, p. 291) write that coherence and distinctiveness can be found in the person with dementia’s bodily enactment of selfhood, for example through religious actions or occupational practices. This embodied self also extends to intimate objects such as clothing (Twigg 2010). Kontos has criticized SI for failing to incorporate the body (2003, pp. 159–160, 2012, p. 2), and highlights the need for corporeal understandings of interaction (2003, p. 160, 2012, pp. 3, 11).

In highlighting the physical self, embodiment is a useful contribution to a SI of dementia, especially considering dementia’s associated language difficulties. After all, SI is concerned with (inter)action, of which language is one component. Communication transcends language: consider intonation, posture and gesture (Sabat 2001). Moreover, there is a fundamental relational quality to humanity that surpasses language, residing in an intuitive unarticulated acknowledgement of and by others. The physical domain entails an authenticity that the linguistic cannot emulate (Snyder 2006).

Kitwood (1997) exemplifies the power of action through understandings of physical disempowerment. For example, whilst some activities will inevitably be impractical for a person with dementia, carers may undertake tasks which the person with dementia would be capable of, removing agency. Nobody can enact self without some physical compliance from others; the conductor needs musicians and the shop owner needs customers. Again, physical attempts at communication can be interpreted as symptomatic. Given opportunity, people with dementia can consciously embody personal meaning, for example, through dancing or applying make-up (Sabat 2001).

When considering embodiment, one must not propagate the fallacy of Cartesian duality in separating the mental from the physical. The psychological is intractably entwined with the neurological, bodily action is social action. Dementia entails neurological and social degeneration, but these descriptive categories are impossible to disentangle and the proposition of distinction is misleading (Kitwood 1997).



SI recognizes the futility of separating such categories, externalizing this existential amalgamation, and locating self enactment in a formative and expressive social world. This understanding contests the plausibility of objectively classifying a circumscribed self. The proposition that self is manifested relationally in action challenges dualist misconceptions of being, and is instead conducive to an entanglement perspective (Aquilina and Hughes 2006).

Furthering externalization, space must be considered in terms of maintaining self. Environmental gerontology highlights the importance of space in constructing meaning, not only concerning assistive technology but also as memory is intimately linked to place (Beard et al. 2012, pp. 1–2). Contemporary human environments have been developed by and for hypercognitive society and can impede a person with dementia's line of action. For example, the proliferation of self-service technologies across transport and retail assumes dexterity and technological familiarity, often causing frustration. Neither actor nor action can be understood independently of environment (Brittain et al. 2010).

Being symptomatic

Such understandings challenge notions that people with dementia are unable to interact. Instead, their ability to interact normatively is contextually impeded, often excluding them from the interactionist process. Graham and Bassett (2006, p. 346) have found that people with dementia retain the interpretative abilities described by Mead (1934) far into the condition's progression. Dementia may not directly inhibit interpretation, but rather subsequent action (Gubrium 1986, pp. 40–43). In response, novel forms of action are developed to circumvent impairment. These creative solutions are often considered symptomatic (Sabat 2001). Under the influence of the offending object, one may interpret adaptive action as maladaptive, reactively re-enacting a communal denigration of difference which characterizes human collectives. In such a situation, incapacity can surpass impairment (Laing 1960).

Actors interacting with the person with dementia increasingly interpret the person with dementia's self-object in light of the dementia object, transforming the meaning of the person (Piiparinen and Whitlatch 2011, p. 187). Interpreting action as symptomatic removes agency from the person with dementia (Beard et al. 2009, p. 228). The stigmatized actor's indignant response is commonly interpreted as additional evidence of abnormality, justifying discrimination (Goffman 1963, p. 16).

Even the past can be reinterpreted by those who knew the person with dementia before the discovery of stigma, with personality traits becoming symptomatic. For example, one may retrospectively frame name-forgetting as an early indication of disease. Our experience of temporality commonly fuels a false acceptance of biography as fixed, yet sociologically, biography is subject to retrospective reconstruction (Goffman 1963, p. 81). Biographies are as malleable as their constitutive actions. The biography of the person with dementia is reconstructed as symptomatic, essentially reconstructing the entire person as symptomatic (Beard and Fox 2008, p. 1510).



The construction of the person with dementia as symptomatic helps others to contest incoherence because establishing a comprehensible disease entity facilitates defined action in response. For example, a carer may seek power of attorney. A carer's agency is reasserted in the face of the condition, whilst minimizing perceived transformation of their self (Graham and Bassett 2006, p. 344). Almost anything can be interpreted via the dementia object. For example, a person with dementia fighting to maintain their occupational identity might be met with "she still thinks she's a..." Legitimate responses become symptomatic as "we see what we expect to see" (Sabat 2001, p. 20).

Maintenance of coherent identity, incorporating an illness, is an established principle of medical sociology (Beard and Fox 2008, p. 1510). Kitwood (1997) recognized the importance of such biographical coherence in person-centred care. The risk is that coherence is achieved in spite of the person with dementia, rather than with them.

Indiscriminate interpretation of action as symptomatic expedites the person with dementia's need to reject or accept the interpretation. For example, if ignored in conversation, a person with dementia must choose to either remain silent or to interject. Either option risks being interpreted as symptomatic (Graham and Bassett 2006). When endeavouring to retain normative interaction, acceptance becomes the only sustainable option. Pressure to accept is intensified through interactional inequalities resulting from diminished communicative abilities (Snyder 2006). The person with dementia begins to act appropriately as all actors are semiotic subjects, basing action on meaning. Thus dementia becomes self-fulfilling, exacerbating decline. The maintenance of a self-object requires a degree of cooperation commonly denied to people with dementia, which consequently must yield to the weight of meaning levelled against it (Sabat 2001).

Malignant social psychology and the moral career

The person with dementia's appropriation of the dementia meanings ascribed to them can be understood as a moral career. A moral career is a visible pattern in action and interpretation that falsely appears determinist due to its predictable repetition (Goffman 1963, pp. 45–55). The moral career resides in the individual's interpretation of their stigmatized self-object, within the parameters of normative assumptions. The actor interprets their self-object's meaning as stigmatized and initiates the appropriate enactment of abnormality. Thus a moral career is a line of action based upon a stigmatized self-object (ibid, pp. 45–55).

People with dementia recognize this process, articulating a loss of social status and former roles. For example, one participant in a study of people with early dementia claimed that people no longer valued his opinions because his dementia undermined their validity (Langdon et al. 2007, p. 996). Beard and Fox (2008, p. 1513) have shown acceptance of inevitable decline in group settings compared with expressions of scepticism individually. This highlights the influence of the collective in compelling the individual to appropriate accepted roles.

Perversely, the moral career reveals that ordinary abnormality is normative. The enactment of abnormality is aided by the norms of abnormality. Goffman (1963)



noted that an abnormality is often commonplace, entailing normative prescriptions because a consensual stereotype of a specific abnormality proliferates. Dementia is neither quantitatively uncommon nor qualitatively unfamiliar. Thus a dementia stereotype replete with associated traits abounds. Gilleard and Higgs (2014, p. 224) posit that dementia is one aspect of the social imaginary of the fourth age, a negative societal conceptualization of “ageing and agedness” based upon “fears of mental and physical decay”. Widespread fears surrounding dementia and “ageing without agency” are key components of this imaginary (ibid, p. 242). Such collective negative views of dementia furnish the requisite social conditions for moral careers. Stereotypes inform a general awareness of what actions a stigma entails, befitting a specific moral career and facilitating acquiescence. For example, one participant in Langdon and colleagues’ (2007, p. 996) study of people with dementia felt that she could not contest people treating her as though she was “daft” because she knew that people like her were “daft”.

As the actions of the person with dementia are increasingly interpreted as symptomatic, others begin to act on their behalf, negotiation giving way to unilateral action. Such action becomes necessary amidst dependencies arising from disease progression. As the self requires interaction, this unilateralism is commonly articulated as a *loss of self* (Beard and Fox 2008, p. 1510). The person is replaced by the dementia sufferer and thus dehumanized. People with dementia can be constructed as neither dead nor alive, viewed as merely biological bodies (Sweeting and Gilhooly 1997, p. 114). This non-human person with dementia is disqualified from the human world, because “we believe that the person with a stigma is not quite human” (Goffman 1963, p. 15).

Dehumanization is enacted in malignant social psychology, degrading a person with dementia’s status due to their being interpreted through the dementia (Kitwood 1997). Kitwood (1997) and Sabat (2001) have shown that malignant social psychology can exacerbate the disease process, restricting people with dementia to acceptable roles (Beard and Fox 2008, p. 1510).

Such enactment is commonly unconscious. For example, in assisting a person with dementia with a routine task, one may unknowingly symbolically strip them of power (Sabat 2001). Kitwood (1997, pp. 46–47) outlines seventeen forms of malignant social psychology. For example, one may talk about a person in their presence as though they are not there. The unconscious nature of the process renders it resistant to conscious modification.

Evidently, the moral career necessitates some cognition. As discussed, studies attest interpretative abilities far into dementia’s progression. Additionally, malignant social psychology ascribes much of the process to external actors. However, though practically unverifiable, it appears unlikely that such processes could continue in the most advanced dementias.

Excess disability

Many early interactionist scholars attributed mental illness entirely to interaction (Shalin 2014, p. 124). This view implicitly blames carers (Higgs and Gilleard 2016, pp. 778–779). The interpretation of dementia outlined here does not apportion



blame. Actors respond to disease-based dependencies from positions of care. All actors cause unintentional and irreproachable harm through everyday action.

An interactionist understanding recognizes dementia as a biological condition, whilst revealing social mediation. This addresses excess disability: the degree of disability beyond that caused by the condition alone. Biomedical generalization undermines recognition of excess disability through reverence of standardized pathological cause and effect. Awareness of these processes, and actively combatting them, can improve outcomes, impeding symptom progression (Sabat 2001). Evidently all should endeavour to improve the social environments of people with dementia.

Finally, whilst the potential of consciously modifying interaction to benefit people with dementia is evidenced in numerous studies, this is not universally accepted (MacRae 2011). There is, however, robust evidence for developing more socially supportive ideals, pursuing health through positive interaction (Sabat 2001). This understanding is vital in overcoming reliance on medical innovation, given the current paucity of progress in the field. In the place of molecular cures, social science offers potential in addressing dementia.

Conclusion

Entanglement positions dementia within a vast amalgamation of diverse factors, from the molecular to the social. Recognition of entanglement as an alternative to a single molecular pathway necessarily requires the deconstruction of innumerable strands. This paper identifies social interaction as one strand, and SI as one window onto that strand.

SI offers a unique conceptualization of contextual agency in dementia. Dependence on others' action and individual cognitive processing has unavoidable ethical ramifications. Logically, to identify the self as dependent upon interaction and interpretation implies that the loss of self is possible. One may imagine an individual lacking both interpretation and interaction, and therefore self. However, there is no conclusive evidence that a person with dementia is entirely non-interpretative, and the inclusion of embodiment and space within the concept of interaction prevents a completely non-interactive existence. In reality, these extreme counterarguments are unhelpful. Instead, developing understandings of meaningful interpretation and interaction could advance a SI of dementia.

Beyond such issues, an interactionist dementia model also respects the existential necessity of interconnectivity. Interdependence offers an appealing counter narrative to individualism, challenging conventional wisdom, which proposes that illness is an individual's problem, concealing relational existence. Again, this disputes negative dementia narratives, viewing dependence on others as emotional strength rather than moral weakness. This recognition has ramifications for older people more generally in ageing societies characterized by disregard for social care and communality (Sabat 2001).

A SI of dementia also suggests broader possibilities for sociological contributions. For example, the gendered and classed nature of dementia is often



acknowledged without substantive conceptualization (Beard et al. 2012, pp. 8–9). For this to be worthwhile, methodological innovation is required. Current research concerning dementia and identity is methodologically heterogeneous, producing disparate results. Although at an early stage, this appears to engender diverse interventions lacking robust evidence bases (Caddell and Clare 2011). Thus an important caveat must be affixed to the diversification of research approaches: results must be collated, interpreted and developed meaningfully, and all to develop a single strand of a broader entanglement approach.

Identifying one strand is the easier of two steps. Following the identification of various strands, they must be explored in terms of their intimate interrelations, potentially causing conflict. The advancement of critical perspectives need not provoke hostility. Offering contrasting alternatives can promote nuanced holistic understandings through the proliferation of numerous voices. Differences should be considered complementary rather than contradictory; no one approach will holistically summarize dementia, but the contribution of diverse approaches will strengthen understandings generally.

Following incorporation of social understandings into a broader entanglement perspective, the question of intervention arises. A SI of dementia suggests the mitigation of excess disability in interaction. Conceptualizing the dementia object relationally could inform social solutions accessible to the people who contend with dementia daily. As the majority of dementia care is informal, targeting services may not be sufficient. Improvement could potentially come firstly through education, within a public health approach, and secondly through the improvement of care work in terms of employment conditions, qualification structures and a broader cultural shift towards valuing such work.

Finally, this discussion has implications beyond dementia itself. Dementia symbolizes the confluence of many significant debates in medical sociology. It is perhaps the starkest reminder of the inadequacies of current thinking regarding the self. The advancement of understandings offers potential benefits extending beyond the boundaries of a single condition, into the broader realm of health, self and society. Through society's action towards it, dementia becomes a reflection of society. What more fertile ground for social enquiry can there be?

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References

- Adams, T. 1998. The discursive construction of dementia care: implications for mental health nursing. *Journal of Advanced Nursing* 28 (3): 614–621.
- Aquilina, C., and J.C. Hughes. 2006. The return of the living dead: agency lost and found? In *Dementia: Mind, Meaning and the Person*, ed. J.C. Hughes, S.J. Louw, and S.R. Sabat. Oxford: Oxford University Press.
- Ballenger, J.F. 2000. Beyond the characteristic plaques and tangles: mid-twentieth century US psychiatry and the fight against senility. In *Concepts of Alzheimer Disease: Biological, Clinical and Cultural*



- Perspectives*, ed. P.J. Whitehouse, K. Maurer, and J.F. Ballenger. Baltimore: The John Hopkins University Press.
- Beard, R.L., and P.J. Fox. 2008. Resisting social disenfranchisement: negotiating collective identities and everyday life with memory loss. *Social Science and Medicine* 66: 1509–1520.
- Beard, R.L., J. Knauss, and D. Moyer. 2009. Managing disability and enjoying life: how we reframe dementia through personal narratives. *Journal of Aging Studies* 23: 227–235.
- Beard, R.L., S. Sakhtah, V. Imse, and J.E. Galvin. 2012. Negotiating the joint career: couples adapting to Alzheimer's and aging in place. *Journal of Aging Research*. doi:10.1155/2012/797023.
- Blumer, H. 1969. *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs: Prentice-Hall Inc.
- Brittain, K., L. Corner, L. Robinson, and J. Bond. 2010. Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health & Illness* 32 (2): 272–287.
- Butler, R. 1975. *Why Survive? Being Old in America*. New York: Harper & Row.
- Caddell, L.S., and L. Clare. 2010. The impact of dementia on self and identity: a systematic review. *Aging & Mental Health* 30: 113–126.
- Caddell, L.S., and L. Clare. 2011. Interventions supporting self and identity in people with dementia: a systematic review. *Clinical Psychology Review* 15 (7): 797–810.
- Carr, S. 2014. *Pay, conditions and care quality in residential, nursing and domiciliary services*. York: Joseph Rowntree Foundation.
- Dewing, J. 2008. Personhood and dementia: revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing* 3 (1): 3–13.
- Dobbs, D., J.K. Eckert, B. Rubinstein, L. Keimig, L. Clark, A.C. Frankowski, and S. Zimmerman. 2008. An ethnographic study of stigma and ageism in residential care or assisted living. *The Gerontologist* 48 (4): 517–526.
- Fox, P.J. 1989. From senility to Alzheimer's disease: the rise of the Alzheimer's disease movement. *The Milbank Quarterly* 67 (1): 58–102.
- Gilleard, C., and P. Higgs. 2014. Studying dementia: the relevance of the fourth age. *Quality in Ageing and Older Adults* 15 (4): 241–243.
- Goffman, E. 1963. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs: Prentice-Hall Inc.
- Graham, J.E., and R. Bassett. 2006. Reciprocal relations: the recognition and co-construction of caring with Alzheimer's disease. *Journal of Aging Studies* 20: 335–349.
- Gubrium, J.F. 1986. The social preservation of mind: the Alzheimer's disease experience. *Symbolic Interaction* 9 (1): 37–51.
- Gubrium, J.F. 1987. Structuring and destructuring the course of illness: the Alzheimer's disease experience. *Sociology of Health & Illness* 9 (1): 1–24.
- Higgs, P., and C. Gilleard. 2016. Interrogating personhood and dementia. *Aging & Mental Health* 20 (8): 773–780.
- Holmes, C., D. Boche, D. Wilkinson, G. Yadegarfar, V. Hopkins, A. Bayer, R.W. Jones, R. Bullock, S. Love, W.J. Neal, E. Zotova, and J.A.R. Nicoll. 2008. Long-term effects of A β 42 immunisation in Alzheimer's disease: follow-up of a randomised, placebo-controlled phase I trial. *Lancet* 372: 216–223.
- Hughes, J.C., S.J. Louw, and S.R. Sabat. 2006. Seeing whole. In *Dementia: Mind, Meaning and the Person*, ed. J.C. Hughes, S.J. Louw, and S.R. Sabat. Oxford: Oxford University Press.
- Jones, D.S., and J.A. Greene. 2016. Is Dementia in decline? historical trends and future trajectories. *New England Journal of Medicine* 374 (6): 507–509.
- Kitwood, T. 1997. *Dementia Reconsidered: the Person Comes First*. Buckingham: Open University Press.
- Kontos, P.C. 2003. "The painterly hand": embodied consciousness and Alzheimer's disease. *Journal of Aging Studies* 17 (2): 151–170.
- Kontos, P.C. 2012. Alzheimer expressions or expressions despite Alzheimer's?: Philosophical reflections on selfhood and embodiment. *Occasion: Interdisciplinary Studies in the Humanities* 4: 1–12.
- Kontos, P., and W. Martin. 2013. Embodiment and dementia: exploring critical narratives of selfhood, surveillance and dementia care. *Dementia* 12 (3): 288–302.
- Kuehn, B.M. 2015. The brain fights back: new approaches to mitigating cognitive decline. *The Journal of the American Medical Association* 314 (23): 2492–2494.
- Laing, R.D. 1960. *The divided self: an existential study in sanity and madness*. London: Tavistock Publications.



- Langdon, S.A., A. Eagle, and J. Warner. 2007. Making sense of dementia in the social world: a qualitative study. *Social Science and Medicine* 64: 989–1000.
- Lloyd, B.T., and C. Stirling. 2011. Ambiguous gain: uncertain benefits of service use for dementia carers. *Sociology of Health & Illness* 66 (3): 899–913.
- Lock, M. 2013. *The Alzheimer Conundrum: Entanglements of Dementia and Ageing*. Woodstock: Princeton University Press.
- MacRae, H. 2011. Self and other: the importance of social interaction and social relationships in shaping the experience of early-stage Alzheimer's disease. *Journal of Aging Studies* 25: 445–456.
- Mead, G.H. 1934. *Mind, Self & Society*. Chicago: University of Chicago Press.
- Öhman, A., S. Josephsson, and L. Nygård. 2008. Awareness through interaction in everyday occupations: experiences of people with Alzheimer's disease. *Scandinavian Journal of Occupational Therapy* 15 (1): 43–51.
- Orr, D.M.R., and Y. Teo. 2015. Carers' responses to shifting identity in dementia in Iris and away from her: cultivating stability or embracing change? *Medical Humanities* 41: 81–85.
- Piiparinen, R., and C.J. Whitlatch. 2011. Existential loss as a determinant to well-being in the dementia caregiving dyad: a conceptual model. *Dementia* 10 (2): 185–201.
- Prince, M., M. Knapp, M. Guerchet, P. McCrone, M. Prina, A. Comas-Herrera, R. Wittenberg, B. Adelaja, B. Hu, D. King, A. Rehill, and D. Salimkumar. 2014. *Dementia UK*, 2nd ed. London: Alzheimer's Society Ltd.
- Radden, J., and J.M. Fordyce. 2006. Into the darkness: losing identity with dementia. In *Dementia: Mind, Meaning and the Person*, ed. J.C. Hughes, S.J. Louw, and S.R. Sabat. Oxford: Oxford University Press.
- Robinson, L., L. Clare, and K. Evans. 2005. Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples. *Aging & Mental Health* 9 (4): 337–347.
- Sabat, S.R. 2001. *The experience of Alzheimer's disease: life through a tangled veil*. Oxford: Blackwell Publishers Ltd.
- Shalin, D.N. 2014. Goffman on mental illness: Asylums and “the insanity of place” revisited. *Symbolic Interaction* 37 (1): 122–144.
- Snyder, L. 2006. Personhood and interpersonal communication in dementia. In *Dementia: Mind, Meaning and the Person*, ed. J.C. Hughes, S.J. Louw, and S.R. Sabat. Oxford: Oxford University Press.
- Sweeting, H., and M. Gilhooly. 1997. Dementia and the phenomenon of social death. *Sociology of Health & Illness* 19 (1): 93–117.
- Twigg, J. 2010. Clothing and dementia: a neglected dimension? *Journal of Aging Studies* 24 (4): 223–230.

