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### Dementia and the inter-embodied self

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## **TITLE: Dementia and the Inter-Embodied Self**

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## **ABSTRACT**

In the 21<sup>st</sup> century, new forms of community in dementia are emerging. The existence of these communities challenges the individualisation of the self, which has come to characterise 'person-centred' approaches to dementia care over the last 30 years. In this paper, an alternative approach (the inter-embodied self) is presented. This approach to promoting selfhood in dementia is based on the premise that the self is not an intrinsic aspect of embodied Being but is instead a transactive phenomenon which exists in a perpetual state of becoming. As such, the primary goal of practitioners should *not* be the fixing, reviving or re-unifying of a pre-morbid self but, instead, enabling a rich and polyphonic *montage of selves* to emerge. Drawing on a short documentary film about experiences of friendship in dementia, the paper concludes by highlighting the potential contribution of the inter-embodied self to contemporary dementia care.

### **Keywords:**

Dementia  
Dividuality  
Intercorporeality  
Dialogical Selfhood  
Person-centred care  
Ethic of care

## Part I: Introduction

### The shifting landscapes of dementia

Dementia is an umbrella term incorporating a wide variety of neurological conditions, including Alzheimer's disease, vascular dementia, dementia with Lewy Bodies, Pick's Disease, alcohol related brain disease and Creutzfeldt-Jakob disease (Alzheimer's Society, 2012). The term dementia is derived from the Latin *demens* (without mind) and emerged in medical parlance during the early 19<sup>th</sup> century in order to describe patients whose disability was related to acquired brain damage (Mckeith and Fairbairn, 2009).

In the 21<sup>st</sup> century, the landscapes of dementia are shifting rapidly (Bartlett, 2012). The population of people with dementia is expanding and, according to the World Health Organisation, there will be an additional 646 million people with dementia over the next 40 years; taking the global population to 682 million by the year 2050 (World Health Organisation, 2012). Developments in medical technologies, such as advances in genetic and pre-symptomatic screening (Sheinerman and Umansky, 2013, Stokholm, *et al*, 2013), increasing efficacy of pharmaceutical interventions (Bishara, 2012), and changes to diagnostic criteria (Lopez, *et al*, 2011) are facilitating earlier diagnoses and increasing the number of people living with dementia as a chronic form of illness (World Health Organisation, 2012). Parallel to these developments, people with dementia are increasingly coming together to share experience, forge new communities, establish shared-identities and campaign for social change (Bartlett, 2012, Bartlett and O'Connor, 2007, Williamson, 2012). This has been facilitated by the rapid expansion in internet technologies, creating new opportunities for sharing lived-experience of dementia (via blogging, tweeting and podcasting). The establishment of trans-national dementia communities, such as *Dementia Advocacy and Support Network International* (DASNI) and [dementiasupportnetworks.com](http://dementiasupportnetworks.com)

have inspired new visions of dementia in the 21<sup>st</sup> century; as Dr Richard Taylor, founder of [dementiasupportnetworks.com](http://dementiasupportnetworks.com) highlights:

‘My vision is a world with many folks living successful and purposeful lives with the symptoms of dementia. In this world, each of us is connecting, and connected to each other. We are kindred spirits. Indeed, each of our spirits is connected to each other through shared beliefs, similar life experiences, and feelings. Although persons living with the symptoms of dementia and their caregivers may differ slightly from each other, we are all wrestling with the same symptoms and the same disability. We are all trying to do what is best for each other and ourselves.’

(Taylor, 2013)

These shifting landscapes of dementia inspire us to revisit established ways of thinking about the self and the self’s relationship to neurological disease. In particular, these 21<sup>st</sup> century developments provoke us to question whether the promotion of *individuality* is a legitimate goal for dementia care policy and practice. In this paper, I develop an alternative approach to promoting selfhood in dementia. This approach, which I term the inter-embodied self, is based on the understanding that human selves are *dividual*; that is, transacted and reproduced across persons. Thus, the process of becoming self is achieved through dialogical (self-other) interaction, both at the reflexive (discursive) and pre-reflexive (embodied) levels. As I will argue, viewing the self in this way leads us to consider new principles for organising dementia care, which I label as: respecting dividuality, promoting dialogicality and embracing intercorporeality.

## The regime of the (individualised) self in dementia

According to Taylor (1989) and Rose (1996) the self in Western societies is predominantly defined in terms of a *profound inwardness*, or *internal psyche* that is bounded within the body and that houses the unique stock of the individual's biography. This view of the self has evolved over centuries as a result of key geo-political developments; specifically, the Protestant Reformation, development of capitalist modes of economic production, the rise of liberal democracies and the growth of *Psy* forms of governmentality (e.g. psychiatry, psychology, psychotherapy). These developments, Rose argues, has led to the *regime of the self*; implicit expectations that persons are (required to be) autonomous, independent, self-governing individuals.

Current UK policy initiatives such as the Personalisation Agenda in England (Department of Health, 2007), which sets out the principle of self-directed support, and the Dementia Care Standards in Scotland (Scottish Government, 2011) which enshrine the right to be treated as an individual, exemplify this *deep respect* (Hughes, Bamford and May, 2008) for the principle of individuality. As Nolan *et al* (2004) argue, this emphasis on the promotion of individuality is a direct consequence of the rise of 'person-centred' approaches to health and social care. In dementia, person-centred care has been developed primarily through the work of social psychologist, and former school chaplain, Tom Kitwood and that of the *Bradford Dementia Group*, which Kitwood founded in 1992.

Prior to this period in dementia care history, the onset and progression of dementia was widely associated with an equally progressive and irretrievable *loss* of self on the part of the sufferer (Cohen and Eisdorfer, 1986, Sweeting and Gilhooly, 1997). Family members, friends, colleagues and acquaintances were thus exposed to a process of gradual dis-

integration whereby the personality and unique characteristics of the person, that they have hitherto known and loved, were steadily eroded during '*a funeral that never ends*': (Aronson and Lipkowitz, 1981: 569). Kitwood was one of the first authors to radically de-stabilise this view, arguing that the notion of social death fundamentally de-humanises the person with dementia. Citing social death as an example of malignant social psychology - '*the unconscious defences, compulsions and interpersonal processes that pervade this field of work*' he seeks to recast the loss of the self in dementia as, less the progression of neurological disease, and more the result of '*failure of understanding and care*' (Kitwood, 1999: 3).

Since its inception, the person-centred dementia care movement has produced new *regulatory technologies* (Foucault, 1988, Rose, 1996) such as Dementia Care Mapping (Bradford Dementia Group, 1997) and PIECE-dem (Brooker, *et al*, 2011), designed to monitor the impact of malignant social psychology and evaluate care quality according to person-centred criteria. These criteria specifically include the extent to which the individuality of the person with dementia is recognised and promoted; as emphasised, for example, in the person-centred '*VIPS*' framework (Brooker, 2007).

Whilst the affirmation of individuality in dementia is, at least in part, a valiant response to perceptions that selfhood is under threat, one of the consequences of these new regulatory technologies is, I believe, the embedding of regimes of individuality within the *whole gamut* (Prior, 1993) of care relationships. Individuality, as a state of Being, is not a pre-social phenomenon but is instead, part of the '*collective frameworks within which people organise and report upon their social existence*' (Prior, 1993: 6). Neither is individuality accepted across all cultures, as the anthropologist Clifford Geertz (1975: 48) highlighted:

‘The Western conception of the person as a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgment and action, organized into a distinctive whole and set contrastively against other such wholes and against a social and natural background is, however incorrigible it may seem to us, a rather peculiar idea within the context of the world's cultures.’

Individuality, then, does not merely reflect subjective experience of dementia but, instead, actively serves to shape it; in as much as persons are *expected* to think, feel and act as individuals in their dealings with care services. This reification of individuality and the promotion of it in dementia as *qua* ‘good’ must be treated with a degree of caution. This is because individuality is not the only means through which selfhood can find full and creative expression in dementia. Indeed, if we suspend our sense of awe for individuality and consider, instead, how families, friendship networks, practitioners and policy makers can contribute to the realisation of Taylor’s vision of dementia in the 21<sup>st</sup> century (see above), we begin to see alternative goals and avenues for the promotion of selfhood. In contrast to individualism, the project of the self that I outline is based on the assumption that the self is engaged in a constant process of becoming; a process in which people, like the Roman God Janus, look simultaneously to future and past states of Being. Person-centred interventions such as Reminiscence Therapy (Woods, *et al*, 2005) and Validation Therapy (Bleathman and Morton, 1992) seek to either recognise, preserve or re-unify the self by enabling the (coherent) construction of the person’s biographical narrative. In contrast, our goal is not to attempt to revive or repair a hitherto ‘broken’ self but, instead, to facilitate a rich socio-interactive environment through which a plurality of selves may thrive. Enabling this



*montage of selves* thus requires a concerted effort to refrain from seeking to impose a unifying narrative on the self. Instead, promoting *montages of selves* can be achieved by adhering to three core principles: respect for dividuality; promoting dialogicality; and embracing intercorporeality.

## Part II

### Respecting dividuality

Dividuality (opposed to individuality) is an approach to personhood that is widely recognised within the anthropological literature yet has, to date, received surprising little attention in relation to dementia. As Marriot (1976) and Strathern (1988) have argued, dividuality is based on the belief that persons are created through processes of sharing and transaction, as opposed to being bounded '*motivational and cognitive universes*' (Geertz, 1975: 48). Whilst dividual approaches to personhood were originally observed in studies of non-Western cultures, the extent to which dividuality is unique to such societies has been the subject of considerable debate (see Smith, 2012). There is insufficient space to reproduce these arguments here, nor is it essential to the progression of this paper; suffice to say that, '*In all cultures there exists ... both dividual and individual modalities or aspects of personhood*' (Lipuma, 2000: 131).

Whilst recognising that the promotion of individuality continues to serve important functions in dementia care, Lipuma's observation prompts us to temper our deep respect for individuality with equal respect for the dividuality of persons. Recognising dividuality in dementia involves developing an appreciation of the transactive qualities of persons; specifically their ability to give out, from them-selves, '*particles of their own coded substances that may then reproduce in others, something of the nature of the persons in*

*whom they have originated*' (Marriott, 1976: 111). We have all seen this process in action; for example, whenever a parent tells their child '*I see a lot of my self in you*' or when a wife may refer to her husband (or vice versa) as '*My other half*'. Within these everyday sayings, the literal overlaps with the metaphorical in ways that highlight the complex and multi-faceted sharing of selfhood between bodies (insert footnote). It is precisely through such capacity for transaction that the rich and diverse montages of our selves are able to emerge. Hence, recognising that we can transmit-and-receive the best of our selves is crucial to the creation of meaningful, egalitarian relationships in dementia.

### Promoting dialogicality

Dialogicality has been defined as the ability of the human mind to conceive and communicate in relation to otherness (Marková, 2003). Since the turn of the 21<sup>st</sup> century, a number of social psychologists have sought to explore the utility of this concept in their attempts to develop more inter-subjective (as opposed to intrinsic) models of selfhood. One of the most influential, Dialogical Selfhood Theory (DLT), was developed by Herbert Hermans. According to Hermans, self and other are not mutually distinct but instead co-exist within a single body; as '*a multiplicity of positions among which dialogical relationships can develop*' (Hermans, 2001: 243). In this context, the self may be conceptualised not as a single, unifying perspective, but as a polyphonic novel; that is, a story told by a combination of competing authors. Within our polyphonic selves, therefore, exists '*a plurality of consciousnesses and worlds*' that develop in dialogical relationship with each other (Hermans 2001: 245). Promoting dialogicality in dementia therefore involves attempting to enable this rich (polyphonic) variety of consciousness and worlds to develop, by facilitating the conditions through which dividual selves may enfold-and-transmit aspects of their polyphonic consciousness. This can be done discursively, through the sharing of lived experience, or pre-reflexively, at the level of embodied interaction (see below). Either way,

enabling people to come together (both literally and metaphorically) is central to creating the conditions through which dialogicality in dementia can develop.

### Embracing intercorporeality

Traditionally, the body has been a neglected focus in relation to selfhood in dementia (Kontos, 2005, Martin, *et al*, 2013, Twigg, 2010). Although this omission was originally recognised by Kitwood (1999) the subsequent evolution of person-centred care has paid surprisingly little attention to the body as a vehicle for selfhood, which has led to an over-emphasis on discursive interventions (Kontos, 2005). According to Kontos, the person *is* his or her body, in as much as the self is maintained through the gestures, movements and bodily habits generated by the '*primordial capacity of the body to pre-reflectively perform*' (Kontos, 2005: 560). These aspects of the self, which Kontos describes as *embodied selfhood*, endure throughout the dementia journey, '*despite the ravages inflicted by neuropathy*' (Kontos, 2005: 566).

Whilst Kontos' work is useful in highlighting the role of the pre-reflexive aspects of the self, it is important to recognise that *embodiment* and the '*socio-interactive environment*' (Kontos, 2005: 557) are not separate entities. Bodies do not exist in a pre-social state but are, instead, constituted and experienced *through* socio-interactive behaviour (Weiss, 1999). Embracing this *intercorporeal* aspect of the self therefore, is to recognise the ways in which selfhood is transacted, pre-reflexively, through embodied interaction.

In this context, intercorporeality refers to the belief that subjective experience does not originate purely from *within* the body, but is instead formed through our interactions with other embodied Beings. This theory was initially developed by phenomenologist Merleau-Ponty. In his posthumously published work, Merleau-Ponty (1968) describes the body as a

*Chiasm*; an entity that is simultaneously a material object - with an objective physical presence - and a hub of subjective experience:

‘[O]ur body is a being of two leaves, from one side a thing among things and otherwise what sees them and touches them; we say, because it is evident, that it unites these two properties within itself, and its double belongingness to the order of ‘object’ and to the order of the ‘subject’ reveals to us quite unexpected relations between the two orders.’

(Merleau-Ponty, 1968: 137)

Whilst, according to Merleau-Ponty, the chiasmic nature of the body provides the basis for intercorporeality, it is through the *Flesh Of The World* that intercorporeal experience is made possible. This is not flesh in a conventional sense but, rather, an *element of Being* previously un-categorised within philosophy (Merleau-Ponty, 1968: 139). According to Merleau-Ponty, *Flesh* creates a nexus between the objective and subjective realms, through ‘*the coiling over of the visible upon the seeing body, [and] of the tangible upon the touching body*’ (Merleau-Ponty, 1968: 146). His conceptualisation of feeling bodies as *Chiasms*, and of the role *Flesh* plays in weaving relations between them, positions bodies as mutually constituting – the product of a complex milieu of physiological (e.g. touch), emotional (e.g. empathy) and psychological (e.g. discursive) interaction. Following this approach, the aspects of the embodied self which Kontos describes (the gestures, movements and mannerisms) are not solely the resource of ‘individuals’ but, instead, may be transmitted, and enfolded, through embodied interaction. Embracing intercorporeality in dementia therefore involves promoting and celebrating the sharing of embodied selfhood.

### Part III

#### Case study: friendship in dementia

In order to illustrate the importance of respecting dividuality, promoting dialogicality and embracing intercorporeality, this section draws on the experiences of two friends, Agnes and Nancy, who are members of the Scottish Dementia Working Group. Empirical data are extracted from the documentary film *Agnes & Nancy* (<http://vimeo.com/32903503>; accessed 02/13/2013), directed by Anne Milne and commissioned by Dr Ruth Bartlett and Caroline Hick as part of the ESRC-funded *No Limits – Re-Imaging Life With Dementia Exhibition*. The film provides a series of vignettes that highlight Agnes' attempts to re-define her self in light of her diagnosis of dementia, through her relationship with Nancy. As such, it provides valuable insights into the processes of becoming-self with dementia. According to Agnes, this process involves a “*blending and merging*” of past and current selves into a hybrid, “*third person*”.

**Agnes:** “I think what I was doing is clearing my head into saying, “This is how I was. This is me with dementia”. And I want to have another head and say “This is me now” the blending and the merging of these two images into the one; into as I am now.”

During the documentary, Agnes travels to the Black Isle to visit Nancy, who has been living with dementia for eight years. During their conversations, Agnes tells Nancy of her desire to *dialogically transact*; in other words, to achieve the self that she perceives in Nancy and which she attributes, in part, to membership of the Scottish Dementia Working Group.

**Nancy:** “Do you remember the first time we met?”

**Agnes:** Do you know I can hardly remember that. I remember going in; see, at the beginning, when I went into the group, I was cowered and I was quiet and I could hardly string words together, and I was quite intimidated, and I was in awe of the laughter and the energy in the room. I was attracted to your personality because of the laughter and the calm and I was drawn like a magnet.

**Nancy:** Wow

**Agnes:** You know, and that's the way it was. Time-wise, we've talked about that; time means nothing ...

**Nancy:** That's right

**Agnes:** ... and I don't have an essence of time. That, the dementia has distorted that. So, you've obtained what I'm hoping to obtain and, with laughter and humour and insight you know, so I think that's what it is; it's just your total humanness."

We are presented with several examples of how Agnes seeks to develop her-self *through* her transactions with Nancy. Crucially, we see examples of how this *dividual self-work* is achieved through intercorporeal, pre-reflexive relating. Agnes, for example, is shown by Nancy how to use her body to saw, axe and prepare wood for the fire; a routine feature of Nancy's daily life and therefore part of her embodied selfhood - the gestures, movements and bodily habits performed by Nancy at the pre-reflexive level (Kontos, 2005) - that, until this point, are alien to Agnes. Agnes and Nancy are also filmed mirroring each other's bodies in more synchronised ways; as they practice Tai Chi and Yoga together in the sunshine of Nancy's garden. Through these intercorporeal exchanges, the embodied aspects of Nancy's self become infolded, by Agnes, through a process of '*osmosis*'.

**Agnes:** ‘You couldn’t get any further away from the Black Isles than where I am, and I brought home here, a bit of essence of the Black Isle and hope. Immediately I’ve transformed me into that third person that we spoke about. I’m re-inventing the new Agnes I think with the help of some of the strategies that Nancy taught me by osmosis... And it will go on, yes, we will go on in our journey. But wow, what a journey and what are we creating out of it; some really magical, special moments...’

## Discussion

I have argued that the changing nature of community in dementia is increasingly prompting us to consider new ways of conceptualising selfhood and of encouraging the self to thrive despite of the presence of neurological disorder. Person-centred approaches to dementia, whilst producing many tangible benefits, have contributed to the reification and lionisation of individuality; a culturally specific and normative framework for ordering subjectivity. In contrast to the individual self, I have sought to develop an alternative framework; namely, that of the inter-embodied self. Based on a dividual understanding of personhood, the inter-embodied self is intended to highlight the transactive capacity of the self. This quality allows for aspects of the self to be infolded and transmitted between embodied Beings, as part of their perpetual process of becoming-self. Contrary to person-centred approaches, the inter-embodied self does not require a unified or coherent narrative in order to thrive. On the contrary, our inter-embodied selves may be more fruitfully conceptualised as montages; polyphonic repertoires of voices and experiences that co-exist in dialogical relationship to one-another; constantly updating, constantly changing. This dialogical process of becoming-self is, following Agnes, characterised by a ‘*blending and merging*’ of self-identities, through which new selves (‘*third persons*’) emerge and are added to the montage. This, as we have

seen, is not contingent upon our capacity for reflexive engagement, as much occurs, via ‘*osmosis*’, at the pre-reflexive, intercorporeal level.

How then, might this conceptualisation of the inter-embodied self help facilitate advances in dementia care? Writing from an *Ethic of Care* approach, Tronto and Fisher defines care as:

‘[A] species activity that includes everything that we do to maintain, continue and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to weave in a complex, life-sustaining web.’

(Tronto, 1993: 103)

One of the main contributions of the inter-embodied self, as I see it, is the dissolution at the conceptual level of unhelpful and artificial distinctions between *carer* and *cared-for* in dementia; for a corollary of this distinction is that people with dementia are defined solely in terms of their *need to receive* - as opposed to their *ability to provide* - care. Such qualitative distinctions serve to construct the care relationship as a *one-way street* as opposed to a ‘*life-sustaining web*’. Yet, the existence of online communities such as DASNI, and campaigning organisations such as the Scottish and European Dementia Working Groups, are testaments to the agential role that people with a diagnosis of dementia bring to the care assemblage. In addition to obscuring the abilities of people with a diagnosis of dementia, defining persons without a dementia diagnosis as ‘carers’ risks relegating them to a secondary division within the care assemblage; in that we become interested in their subjectivity only in so far as it impacts upon the (cared-for) person. As Taylor (2012) states, ‘*Although persons living with the symptoms of dementia and their caregivers may differ slightly from each other, we are all*



*wrestling with the same symptoms and the same disability.*' In contrast to person-centred approaches, where care is provided by carers and received by people with dementia, inter-embodied selves that are located within the dementia care assemblage are simultaneously conceptualised as carers and cared-for; as they infold these properties within them-selves and give out, from them-selves, '*particles of their own coded substances that may then reproduce in others, something of the nature of the persons in whom they have originated*' (Marriott, 1976: 111). Thus, promotion of inter-embodied selfhood is based on an appreciation of the similarities, rather than the individual differences, of people (both with and without a diagnosis of dementia) which, I believe, is crucial to the promotion of *solidarity* in care (Barnes, 2012), which Taylor aspires to.

Thus, by offering an alternative model to that contained within the regime of the self (Rose, 1996) the inter-embodied self leads us to consider new techniques and interventions for the promotion of selfhood in dementia, based upon more holistic definitions of what care is. Whilst alternatives to person-centred care have previously been developed, these frameworks tend to retain implicit assumptions regarding the individuality of persons (see Hughes, Bamford and May, 2008). As core principles, *respect for dividuality, promoting dialogicality and embracing intercorporeality* have much to offer the development of practice frameworks, which seek to build solidarity (as opposed to individualism) in care. This paper provides some initial groundwork upon which practice-based models can be developed. Whilst the work presented here is largely theoretical, there is, after all, '*nothing more practical than a good theory*' (Lewin, 1952: 169).

## Summary and conclusions

In the 21<sup>st</sup> century, the landscapes of dementia are shifting (Bartlett, 2012). These developments are inspiring new theoretical approaches to selfhood and challenging established views that people with dementia are passive recipients, as opposed to active facilitators, in care and in the perpetual process of becoming-self. As we move further into the 21<sup>st</sup> century, in which new approaches to the constitution and dynamics of care in dementia are evolving, the artificial distinctions between self and other, carer and cared-for, are beginning to dissolve.

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