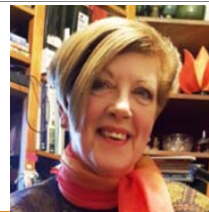


ASA 2016: Anthropology of mental health: at the intersections of transience, 'chronicity' and recovery

Personhood and dementia: challenging models of personhood and wellness

Dr Gaynor Macdonald
Department of Anthropology
University of Sydney



Meeting Gaynor



Meeting Charlie



Dementia: life experience or life denial?

Personhood in the context of dementia

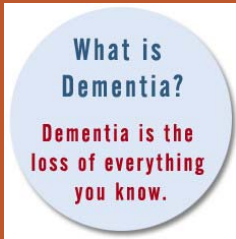
Meet my husband, Charlie, the reason for this journey of ideas

Being a carer as fieldwork-style immersion

Grounded in life experiences, this paper privileges critique of the ideas that shape the negative 'dementia habitus'



Dementia as denial



Little understood, greatly feared, stigmatised

'Loss' of personhood

A life no longer lived – unravelling

Dementia challenges our experience of being-in-time:

- will cease experiencing time in linear way
- carers must manage their time differently – they are encompassed in the dementia-person's altering temporal experience
- regarded as an 'end' to a life lived well

Temporal dimensions contribute to negativity

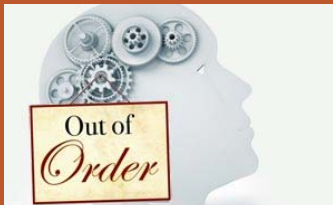
Dementia confronts us with our mortality



Is dementia

a

'mental illness'?



Supreme Court judge, NSW , mid-1980s

Dementia, whether caused by age or disease, is 'infirmity of mind', as is intellectual disability

Dementia is explanatory in physiological terms, so not mental illness

The distinction between infirmity (physiological) and illness (mental) reflects the medical dualism stemming from the influence of Decartes (1637) and his mind-body split – as well as the fear of inexplicable 'mental illness'

Cartesian dualism is the foundation of western medicine




Core questions,
entangled threads

What does it
mean to be
'human'?

- A bio-psycho-social being
- Inextricably social, requiring economic/social organisation of others from inception
- embedded in a mutually-constitutive world which it will in turn help to reproduce
- distinctive for a brain capable of consciousness, self-reflection, thought, language, imagination, innovation – extraordinary capacities by which to produce meaningful worlds, and to change and adapt to myriad environments and circumstances

Our extraordinary brains makes us aware that we die

The dilemma of human life:
it is lived in the shadow of death





Life
lived in the
shadow of death

'Living well' is a cultural construction

Intrinsic to all understandings = embodiment

Bodies enable or disable - mediated through cosmology


We all die - meanings of death and mortality are linked to meanings given to 'the future'

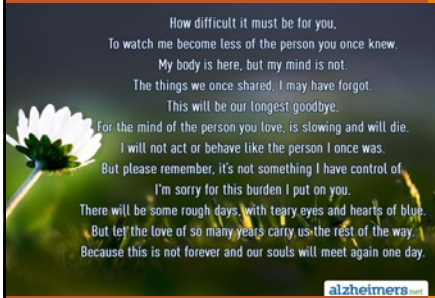
Beliefs about future emerge from capacity for transcendence

Ernest Becker (1973) – 'heroic illusions'

The necessary denial of our mortality

In immortality human beings enable themselves to live with the consciousness of inevitable death





CURE makes threat transient



Hard to die when no life after death – so seek to prolong life

Disease is threatening = contradiction of life lived well

Dysfunction = a deficit of being

Illusion of immortality offered by the medical sciences is 'cure'

The promise of the cure:

moves us back from deficit and death, to re-engage with life

Disease and illness are transitory

Cure is death defying



Living in the shadow of dementia's contradictions



No cure – no moving beyond - living death

Confronts medicine-as-cure and cure-as-illusory-hope

The body is mortal but minds/memories/influence can be immortal – so we want our body to die, not our mind

Dementia is body (brain) + mind (consciousness/cognition)

No wonder dementia is seen as threat, tragedy, denial, loss

The mind dies before the body – the mind kills the body

Have to cure dementia because

we deny a future to those who experience it



Dementia
as living death?
Charlie as tragedy?

"ALZHEIMER'S IS A DEVASTATING DISEASE. IT WAS PAINFUL FOR ME AND MY FAMILY TO WATCH MY GRANDFATHER DETERIORATE. WE MUST FIND A CURE FOR THIS HORRIBLE DISEASE."

DISTURBING Disruptive **Harder**
Demented Challenging **VIOLENT** Non-Compliant
Wanderer Repetitive **AGGRESSIVE**

One family member commented shortly after Charlie was diagnosed, 'how tragic'

I had not at that time thought of our experience, Charlie's or mine, as tragic – I found myself wondering whose tragedy it was and why . . .

The dementia habitus is steeped in the discourse of loss



IMAGINATION
CREATES
REALITY



Vulnerability and imagination

Cognition is not lost in dementia

Lose ability to operate in very specific ways – produces vulnerability

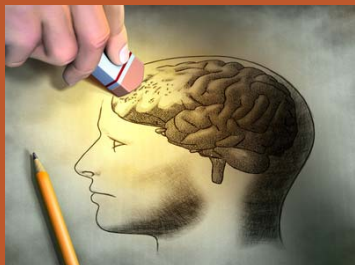
My task is to avoid anything that exacerbates this vulnerability

Need reassurance that a seemingly out-of-control world is in control – only the carer can provide this

Not difficult to live with a tricky memory – but means unlearning the taken-for-granted that we have come to depend on



Memory



The familiar face of Alzheimer’s:
‘the withered person with a
scrambled mind,
memories sealed away’

Vulnerability is linked to forgetting

Forgetfulness disturbs carers – not taught respond

the consequences of memory loss are difficult to describe, the disorientation, hallucinations, inability to complete a sentence, not having a sense of reality. *It’s one of the worst things that could affect a family*

... Since you carry much of their lives in your own memory, you become tormented at being stuck in a groove, like a needle riveted to a scratch in the record playing the same bit of song repeatedly.

People often wander – to find the familiar place or person

To get away from unrecognised strangeness

We all latch onto the known to orient us

Recognition-as-memory

Some memories do not require rationality



Memory as identity-forming

You spend your whole life -- decades and decades -- accumulating memories and association, and you develop a personality of who you are based on your experience and memories. And this disease (Alzheimer’s) comes in and rips all that right out. So it literally steals who you are from you.

Many implicit understandings of memory are linked to identity politics, cognition-driven, privilege linear time

The important memory for people with dementia:

Simple tasks of everyday life

Significant people – family and friends

Not to recall these is more debilitating than forgetting a birthday or event

I am fascinated by what Charlie does or does not remember

Positive vs negative ‘memories’

Emotions are implicated in his ‘remembering’.



“We didn't realize we were making memories we just knew we were having fun.”



Memories are also statements of value
They reinforce continuities in the face of disruption.
The desire for reassurance is constant
because the vulnerability is constant

Emphasis on memory places more value
on yesterday than today
Is it worth doing anything if it is not remembered?
One might ask: why (and what) do we *need* to remember?



Medicine and Cartesianism



Power of medical profession is challenged by dementia
It remains stubbornly incurable, untreatable
It is the point at which medicine itself disintegrates
Western medicine is steeped in Cartesian dualism: its strength but also its weakness
It narrows the understanding of personhood and living well
Descartes' dictum: 'I **think** therefore I am'
Mind /Body dualism - body = material, mind = unlocatable
The self/person/individual is a conscious, rational, autonomous agent defined by mind as distinct from body: the body is the container



What is 'personhood' that it can be gained and lost?

'people with severe dementia, whilst members of the human species are worse off than animals in some respects in that they have no capacity for integrated and goal-directed behaviour and that due to memory loss cannot forge links across time that establish a sense of personal identity across time' (Brock 1993)

Rationality permeates medical, social, legal thinking

Understandings of personhood - capacity to:

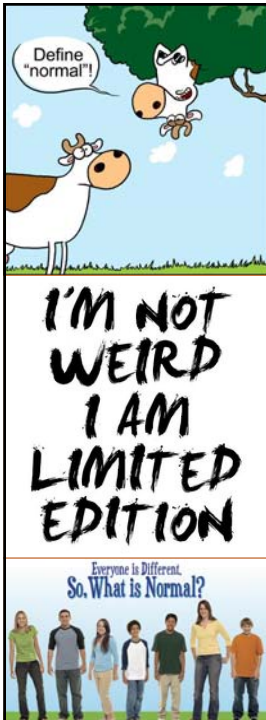
- Think/reason logically and communicate
- Engage in integrated, goal-directed behaviour
- Create links across time to establish personal identity
- See oneself as extending over time
- Maintain continuity with people, engage morally

Ideas of normal personhood construct deficits of personhood

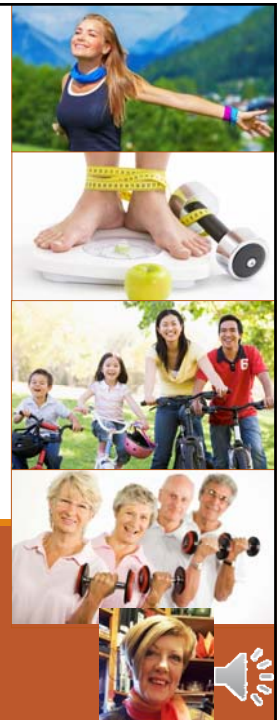
Excludes people with cognitive impairment - judged as having lives not worth living, non-persons

Dementia literature may

acknowledge a *qualified* person



Neoliberal subjectivity = 'normal' and 'healthy'
 Normal = pernicious, a form of cultural violence
 Crippling standard of judgment – 'conformity' not 'typical'
 Deviations are abnormal, deficits, stigmatised, severed
 Reality: all people exist in shades of grey – the 'normal' is diversity
 Healthy? By what standards? Who controls the power of diagnosis?
 Living well: Body-centred health vs Life-centred health



'Normal' and 'Healthy' in the management of persons



Out from under the Cartesian shadow

Creative	Emotional
Relational	Music/Rhythm
Symbolic	Sight/aesthetics
Tactile	Somatic (touch, pain)
Mirth	Taste Smells
Speech/sound/language	

There are critiques to draw on:


Heidegger: the essence of being-in-the-world is *existence* rather than thinking, desire, volition

Merleau-Ponty: the body is not merely the object for a transcendent mind but *the primary site of knowing the world*

Zigon: Humans are always in the world first and foremost as *affective beings* rather than thinking and contemplative ones


Post: Hypercognitive definitions of personhood fail to take account of *emotional and relational needs and capacities; they neglect social, expressive, imaginative dimensions of human experience*

Consciousness/cognition required to experience these through the body, but not instrumental rationality



Personhood

Towards
a
new approach



We need a processual, contingent model

Personhood as lived experience not abstract model


Personhood is dynamic, fluid,
frequently disturbed and disturbing

Dementia would take on a different, less threatening, dimension, as one – very common – experience of personhood

The first challenge - deconstruct Cartesian models of personhood and the notion that we are individuals

Restore interdependency and an ethics of care as the socially recognised requirements for living well

We are all implicated in each other's experiences
of living and ageing well



The caring society

A caring society
needs a new
morality

The philosophical tenets informing western medicine and neoliberal personhood work against establishing the caring society

Critique and avoid them – make diversity the normal

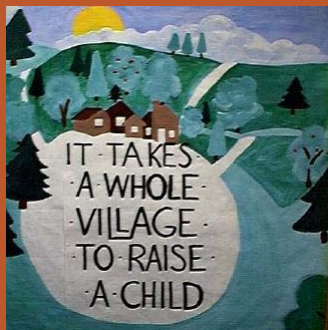
Morality and ethics need to move away from arbitrary moral concepts such as good and evil

Zigon: An ontology of relational-being would redefine moral personhood and dissolve the self-other dualism

‘Most moral lives and ethical projects—what we might call moral experience—are lived according to an entirely other set of moral concepts that are concerned with dwelling in the world, that is, with expanding, maintaining, repairing, or even disentangling from constitutive relationships’



Concluding thoughts

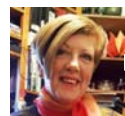





Dementia makes intense social demands, as great as those involved in parenting

If, as the old African saying goes, ‘it takes a whole village to raise a child’,

then it also takes a whole village to tend an old person to a worthy and respectful death

There would be nothing fearful about old age or dementia if we lived in a caring society



<p>Analysis of cultural understandings of personhood reveals who is and is not 'a person' in a given social world</p> <p>Dementia is a deficit of personhood in the Cartesian medical model</p> <p>We can choose to explore and write within understandings that do not produce deficits of personhood – in doing so, we will transform the negativity that pervades the dementia habitus and other forms of social stigma, including mental illnesses</p>	<p>Today I interviewed a woman who is terminally ill.</p> <p><i>'So', I tried delicately to ask, 'What is it like to wake up every morning and know that you are dying?'</i></p> <p><i>'Well', she responded. 'What is it like to wake up every morning and pretend that you are not?'</i></p> 	<p>What would it mean to live each day as if every one of us will experience cognitive decline?</p>  
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