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An independent academic psychologist, based in England, who has written extensively on different areas of psychology with an emphasis on the critical stance towards traditional ideas.

A complete listing of his writings at <http://psychologywritings.synthasite.com/> and <http://kmbpsychology.jottit.com>.

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1. A SOCIOLOGY OF DEMENTIA

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1.1. INTRODUCTION

Dementia is an increasingly frequent news story in the media, such that "it has a growing influence on the social representations of old age as the messages about its effects spread more widely among the general population" (Higgs and Gilleard 2017 p176). This has been called the "Alzheimerisation of ageing" (Adelman 1995). "Reinforced by media reports of 'institutional abuse' in nursing homes..., the intensified search for 'a cure', and dire predictions of demographic apocalypse, the Alzheimerisation of ageing seems to contribute to the propagation of an associated and potentially negative 'neuro-culture' spread across the whole of society" (Higgs and Gilleard 2017 p176) ^{1 2}.

Higgs and Gilleard (2017) argued for a sociology of dementia around four themes in their introduction to a special issue of the journal, "Sociology of Health and Illness" (volume 39 number 2):

1. Personhood in relation to dementia;
2. The issue of care ³;
3. The social representations of dementia in contemporary culture;
4. The social contextualisation of dementia.

¹ "Cynically one might speculate that the most long lasting effect of the Alzheimerisation of old age has been to increase public anxiety and channel medical research toward a drive for a variety of cures and away from the previous concerns for improving care provision that dominated research before the era of the 'cholinergic' and the 'amyloidogenesis' hypotheses" (Higgs and Gilleard 2017 p178).

² Listening to patients generally has become more common with "illness narratives" (appendix 1A).

³ Rumbold et al (2017) argued that the individual's right to health, and government-set health-care system priorities are not in conflict if:

- i) a more broader understanding is made of these ideas - ie: "priority setting is not only about a utilitarian drive to maximise health benefits across the population, nor is it the right to health about securing every individual's access to health care regardless of cost" (Rumbold et al 2017 p2);
- ii) there are transparent principles for ensuring allocation of health-related resources;
- iii) appropriate resources (eg: through taxation) are allocated to health-care systems.

1.2. THEME 1: PERSONHOOD IN RELATION TO DEMENTIA

"In the dominant discourse of dementia there is a presumed existential erosion of selfhood 'until there is nothing left' (Davis 2004)" (Kontos et al 2017b p182). The perceived loss of the self is taken as a loss of agency, and thus citizenship status. "An individual's status as citizen, which denotes an entitled connection to a community and country with rights and responsibilities as a community member and freedom from discrimination..., is seen as fundamentally and irrevocably eroded by dementia because communicative competence and intellectual capacities are inextricably linked to the practice and status of citizenship" (Kontos et al 2017b p182) ⁴ ⁵.

Kontos et al (2017b) argued for a new model of citizenship ⁶ called "relational citizenship". "It is a model that is premised on the importance of interdependence, reciprocity, and the support of persons with dementia as active partners in their own care... Another foundational tenet of the model is that the capacities, senses, and socio-cultural dispositions of the body are central to self-expression, interdependence, and the reciprocal nature of engagement" (Kontos et al 2017b pp182-183).

This goes hand in hand with "embodied selfhood", for Kontos et al (2017b), which "considers both the body's pre-reflective power of natural expression - manifest, for example, in basic bodily movements and the co-ordination of visual, tactile, and motor aspects of the body - and the style or content of bodily movements derived from socialisation and cultural upbringing over which the individual has no conscious mastery" (p184).

Kontas et al (2017b) supported their arguments with reference to observations of elder-clown practice in a nursing home in Canada (Kontas et al 2017a). Elder-clowns tend to have less make-up than traditional clowns, but wear clothes of an earlier era, and use different modality (eg: music), props, and body language to interact with their "audience". Analysing video recordings, Kontas et al (2017b) saw evidence of subtle interactions between dementia sufferers and the elder-

⁴ As one consultant said: "As with other disabilities [dementia] can be the occasion of positive changes and opportunities, but these should not be romanticised... Dementia is a harm. Nevertheless, while dementia is a form of disability the person with dementia is still a person to whom respect is due" (NCB 2009 p23).

⁵ Jaworska (1999) argued that individuals with dementia should be viewed as "valuers" (ie: capable of valuing) (NCB 2009).

⁶ Citizenship is "a set of social practices which define the nature of social membership" (Turner 1993 quoted in Birt et al 2017).

clowns. For example, bodily movements by the individual with dementia are interpreted as artistic expression by the elder-clown and developed. Kontas et al (2017b) described this interaction:

Betty is sitting in her wheelchair, which is tilted slightly back so that she reclines with her head against the head rest. Her eyes are closed, and her hands are clasped together across her lap. Zazzie [elder-clown] strums a cord on her ukulele and sings, 'Da, da, da, da, da'. Cherry [elder-clown] begins snapping her fingers to the beat of the tune. Both elder-clowns are gently swaying to the music; Cherry begins using her clutch purse filled with loose change as a tambourine. Without opening her eyes, Betty responds by tapping her left foot against the wheelchair footrest, pivoting her wrists downward so her clasped hands move to alternating beats of the music. As Zazzie continues to sing, Betty interjects melodically, 'Be boop', now moving her clasped hands to every beat of the music. Zazzie responds, 'Da, da, da, da'. Betty moves from interjecting words in the existing rhythm to embellishing and shaping the harmony. She sings, 'Ham and eggs, and ham and eggs', now intensifying the movements of her clasped hands by moving her forearms. Zazzie and Cherry repeat the lyric, 'And ham and eggs'. Cherry leans in close to Betty, as if anticipating she will respond on the next beat. Betty does, warbling, 'Everywhere, there is a place for youuuuu'. The clowns sing in simultaneous reply, 'A place for you'... (pp1889-190).

This co-construction of the song, Kontas et al (2017b) explained, supported "embodied selfhood through aesthetic enrichment not only promotes an ethic of mutuality... but also the more robust model of relational citizenship..." (p193).

Birt et al (2017) noted that it is "the notion of 'social citizenship'⁷ that is increasingly relevant to understanding the dementia experience". They continued: Understanding citizenship within a wider context than merely civil or political rights provides opportunities to explore what social structures are needed to enable people with dementia to participate in and belong to a community, and the distinctive ways in which citizenship roles can be enacted following a diagnosis of dementia" (pp199-200).

Individuals with dementia are often positioned as citizens within "discourses of deficit", but Birt et al (2017) argued that "journeying with dementia will not

⁷ Social citizenship "recognises the person with dementia as an active agent with rights, history, and competencies" (Bartlett and O'Connor 2010 quoted in Birt et al 2017).

entail chronological, unidirectional passage along an illness trajectory marked by pathological changes and health-driven structures; rather it is a journey through different life events" (p200) ⁸.

These authors worked within the Promoting Independence in Dementia study (PRIDE).

Chronic illness has been described in sociological terms as having three major phases - crisis, chronic, and terminal (Rolland 1987). The "crisis" period is pre- and post-medical diagnosis, which is an example of "liminality" (ie: "'movement between fixed points', which is 'essentially ambiguous, unsettled and unsettling' (Turner 1974)"; Birt et al 2017 p201). Liminality in dementia is the "social death" - "a non-person who was still making the 'transition from life to death' [Sweeting and Gilhooly 1997]" (Birt et al 2017). "With the social recognition of illness comes then-recognised rites of passage: movement to status of patient, known or unknown norms of behaviour in medical spaces, changes to roles and responsibilities within families and communities" (Birt et al 2017 p202).

The rites of passage lead to the post-liminal states, described variously as "living in the shadow of the fourth age", "living as an active citizen with dementia", and "living in extended liminality" (Birt et al 2017). Within these states, the "non-citizen" or the "passive citizen" are produced by the discourses of deficit (Birt et al 2017).

PRIDE would want to present the "active citizen". For example, in a qualitative study, Beard et al (2009) showed that individuals with dementia demonstrated "agency by actively accommodating dementia into their lives rather than allowing it to be imposed on them by structural forces" (quoted in Birt et al 2017) - as seen in dementia support groups, say (eg: DASNI - Dementia Advocacy and Support Network International). Bartlett (2014) studied individuals with mild dementia campaigning for greater awareness of their condition. She found that "campaigning can be energising and reaffirming of citizen

⁸ The NCB (2009) took this ethical position: "We believe that a person's life is of value even if they are severely cognitively impaired. We do not endorse the view that a life in which a person is cognitively impaired and is experiencing severe behaviour changes is worse than no life at all, even if such developments represent an enormous change from the person's previous functioning. In other words, we reject the view that life is worth living only if there is a certain level of reflective or deliberative awareness" (p25).

Post (1998) used the term "hypercognitive culture" which excludes "the deeply forgetful by reducing their moral status or by neglecting the emotional, relational, aesthetic, and spiritual aspects of well-being that are open to them, even in the advanced stage of the disease" (quoted in Sabat 2001). Sabat (2001) went further in saying that the "hypercognitive culture" is "one which places a great deal of value on a rather small sample of objectively measured elements of cognitive life while ignoring other significant aspects of the individual's cognitive ability" (p324).

identity because it (re)located a person within the realm of work", while "individuals may experience fatigue due to their dementia and oppression linked to normative expectations about what someone with dementia 'should' be like" (quoted in Birt et al 2017).

1.3. THEME 2: THE ISSUE OF CARE

Tolhurst et al (2017) pointed out that person-centred approaches to dementia (as opposed to illness-centred) emphasised that "people live their lives within interdependent relationships, which can enable people with dementia to sustain a positive personal identity" (p212). This is based in Kitwood's (1997) definition of personhood as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (quoted in Tolhurst et al 2017) ⁹.

So, "the relational basis of experience endures for a person with dementia, and this means that those with the condition should not be 'downgraded into carriers of an organic brain disease' (Kitwood 1997)" (Tolhurst et al 2017 p213) ¹⁰.

But Higgs and Gilleard (2015) were concerned about personhood as attributed by others. "Personhood is thus not asserted by people with dementia themselves, which means that their own agency in the process is lacking: it is a status bestowed, rather than something actively shaped by the person with the condition" (Tolhurst et al 2017 p213).

Tolhurst et al (2017) jointly interviewed fourteen men with dementia and their spousal carers to understand the social construction of meanings of personhood, and "couplehood" (Hellstrom et al 2007). The researchers concentrated on one couple as a case study. Both individuals were still employed at the time, and the interview was six months after a diagnosis of Alzheimer's disease.

The concept of "narrative collisions" was highlighted as both individuals sought a balance of different views and taking place in a social context of expectations and roles. The man ("David") wanted to emphasise the positive, while the woman ("Florence") was more negative. For example:

David: I just feel a lot more in charge of myself, with working and doing things. I just feel much

⁹ Kitwood (1997) talked of "a fresh understanding of what it is to be a person" (p144).

¹⁰ Finding ways to improve memory and its loss is popular (appendix 1B).

happier. I've got a goal. I've got something to do.
Being at work helps me dramatically [...]

Florence: But I think for me, it gave me all the responsibility. Having that diagnosis I then felt I've got to deal with this. It will be me managing this situation. And I think for me, it was a huge impact. Absolutely huge (p220).

But, Tolhurst et al (2017) noted, "David and Florence both offered a sense of unity through the use of language and often ascribed the word 'we' to their experiences, which indicates the aim to co-construct a congruent joint narrative... The different conversational strategies that they employ, however, shows how their distinctive subjective positions and responses to social pressures render the attainment of a unified couplehood challenging" (p223). The "we" can be seen in this extract from the interview:

Florence: It's the losing things.

David: I shouldn't have a coat with so many pockets in.

Florence: No, we all lose things. But we've lost a couple of mobile phones haven't we, and hearing aids somewhere. I think we just get on with it don't we.

David: You're going back a bit. We did used to lose quite a few things. We used to leave places and realise I'd not picked something up, whereas now I'm a little bit more...

Florence: Yes, because that's mainly on holiday isn't it. Because I actually go 'have you got it, where is it?' You know, things like that. You'll frequently go out in the evening without a wallet, which is a good ploy! But I can't comment because you'd got your wallet last night, and I'd left my purse at work (p221).

Tolhurst et al (2017) were worried, ultimately, that "a manufactured stance of positivity thus generates a zero-sum situation: the aim to bolster the position of the person with dementia requires the vantage point of the carer to be diminished. The well-intentioned attempt to elevate the status of people with dementia has thereby introduced new imbalances into academic thought. The goal to counter negative societal perceptions of dementia, however, should not lead to the difficulties of carers being invalidated. Moreover, insights into the interpersonal challenges encountered by people with dementia could also be underplayed" (p223).

Person-centred care encourages care workers to "facilitate opportunities for choice and independence rather than prioritising tasks and routines" (Scales et al 2017)¹¹. This is presented as an "empowerment" of patients and of staff (eg: healthcare assistants; HCAs), but Scales et al (2017) wondered how the latter "aligns with their broader disempowerment as a workforce which carries out the 'dirty work' delegated by professional nurses, with little training, remuneration, or opportunity for advancement" (p228).

These researchers reported an ethnographic study of HCAs in three dementia wards in NHS hospitals and one private residential care home in the English East Midlands.

A number of key themes emerged related to empowerment and disempowerment:

i) "Only a carer" - HCAs reported feeling undervalued, particularly because they had no input into decisions about the organisation and delivery of care. Phrases used included "shit shoveller" or "lowly employee" on the "lower rung of it all".

There was a feeling also that others "don't understand what it's like here", particularly managers. One HCA described a manager who "waltzes in", lives in a "fairly world", and "has no idea of what the ward actually needs ... just wants it all to be pretty and lovely" (p233).

ii) "We're the ones that see it" - The HCAs reacted to their feeling of disempowerment by positioning themselves as really knowing what is happening with the patients. One carer said: "We're the ones that see [residents] on a day-to-day basis, we're the ones that... know what hurts us, what hurts them, what's best for them, what's not best for them. Although the nurses have the authority, they don't always see it, you know, we're the ones" (p233).

Clegg (2010) described this behaviour as "institutional entrepreneurship", which was defined as "a strategic face of power reliant on skilled analysis, deployments, and co-ordination grounded in local knowledge with which to outflank dominant actors with superior resources" (quoted in Scales et al 2017).

iii) "Knowing, watching and understanding" - The carers used their "insider" knowledge to provide personalised care. One HCA told the researcher helping to

¹¹ Kitwood (1997) described twelve different types of positive interaction between care workers and individuals with dementia ("positive person work"), and outlined "Dementia Care Mapping" as providing care from the standpoint of the person with dementia. Together these examples are part of "a cultural transformation" of care advocated by Kitwood (1997).

dress a female patient - "she prefers not to wear the net knickers because they are too tight, she prefers to leave her upper body and feet uncovered by the sheet..." (p235).

But this personalised care often came into conflict with institutional routines and practices, and the HCAs tried to challenge this, as reported by one of them: "I don't agree that they should be up for half past 8. If that patient wants to stay in bed, that patient should be able to stay in bed. Where's the patient individuality? ... I tried to talk this out with the deputy manager, and got bawled out... I mean, she's saying 'it's patient care' and 'you're not doing your job', but you are doing your job" (p236).

Scales et al (2017) recommended "the need for better recognition of the care workers' collective claim to knowledge, skills and expertise as an important step towards meaningful empowerment" (p238).

Developing a historical context of care, Andrews (2017) described the policy in 19th century Britain of placing individuals with dementia in institutions (asylums and workhouses). These institutions performed the function of "absorbing and containing unmanageable and undesirable behaviour, preserving the order of the outside world, and providing care (often in a very minimal sense) to people whose needs had transcended the financial, practical and emotional capacity of the people around them" (Andrews 2017 p244). The researcher quoted the case study of the Middlesex County Asylum at Hanwell (north-west London). She noted: "The presence of people with dementia in lunatic asylums in the 19th-century often surprises people in the 21st. Although it was not uncontroversial, the admission of 'senile dements' to an asylum for the insane was entirely congruent with the way senile dementia was understood, and the way that those institutions functioned" (Andrews 2017 p246).

"Senile dementia" was coined in English by John Charles Prichard in 1835, and described four stages - loss of memory, of reason, of comprehension, and loss of instinct, to end up as, according to writers of the time, "mere physical existence" (Andrews 2017). Senile dementia was viewed as an inevitable part of ageing - it was "the change which time alone will perhaps sooner or later bring on, in those who long survive the allotted duration of man's days" (Prichard 1835 quoted in Andrews 2017). There is still this view held by many today.

Andrews (2017) described the ambivalence towards individuals with dementia at the "very roots of the welfare state". "Nineteenth-century Britain was not an 'ageing society'. Indeed, because of the decline in infant mortality during this period, the proportion of the population aged over 60 was in fact historically

low... Yet,... the treatment of the older population as a burden - specifically old people with dementia - predates the increase in longevity by several decades. It was therefore less the intractable fear of growing numbers, but rather the seeming intractability of dementia itself which turned health and welfare providers away from the challenge of providing adequate care, let alone a life of dignity" (Andrews 2017 p255).

1.4. THEME 3: THE SOCIAL REPRESENTATIONS OF DEMENTIA IN CONTEMPORARY CULTURE

Dementia is "a complex and challenging condition that will be experienced differently depending on one's age, class, gender, other health conditions, life experiences and a plethora of other social differences" (Mc Parland et al 2017 p259). So, the experience mirrors the social diversity in society, or what Hulko (2004) described as the intersectionality of the experience of dementia. Mc Parland et al (2017), thus, argued that dementia should be understood in this way rather than as "a dichotomised experience of tragedy or living well".

This dichotomy fits with the two images of ageing presented as part of "successful ageing", "ageing well" and "healthy ageing" - "the active healthy person who works to deny old age (the third ager)" or "the fourth ager": "frail and dependent" (Mc Parland et al 2017). The "fourth age" is "unsuccessful ageing" which "appears as a horrific apparition that dramatises lack in a rather potent way" (West and Glynos 2016 quoted in Mc Parland et al 2017).

The "fourth age" and dementia are feared by younger individuals as "associated with existing perceptions of care, feelings of hopelessness or futility, and a profound fear of developing a condition that appears utterly arbitrary and totally beyond the control of the individual or the world of science and medicine (Mc Parland et al 2017 p261). Mc Parland (2014 quoted in Mc Parland et al 2017) called this "dementiaism", "with the public visualising a potential future that symbolises loss of control, loss of self, living in poor care and being viewed as 'mad'" (Mc Parland et al 2017 p261). These sorts of feelings are the "tragedy discourse" side of the dichotomy of dementia.

In reaction to this discourse, a movement has developed to present a positive image and experience of dementia (eg: Kitwood 1997). Whatever the strengths of such an approach, the voices of the individuals with dementia speaking positively are privileged male and middle class ones rather than poorly educated female ones (Page and Keady 2010). Let alone, the scarcity of non-Western voices (Mazaheri et al 2013).

Mc Parland et al (2017) observed: "Offering the opportunity for new ways of living with dementia and the potential for more acceptance is a tantalising possibility but..., it in fact offers a new set of social expectations. Furthermore, it is an opportunity that is available only to those meeting certain criteria. Critical gerontologists have raised ethical objections to the idea of anti-discrimination and re-valuation based on achievement and outcome. They criticise the attempt to challenge negative stereotypes of old age with the assertion that older people do contribute to society and are thus worthy and valuable... Based on these criteria, some people living with dementia will no longer be among this group of the valued and worthy" (Mc Parland et al 2017 p264). These authors wanted to find a way to respect individuals who are not "living well" or having "successful ageing". They said: "If we fail to challenge and redress the current dichotomy of these discourses, the risk is that, rather than changing the script around dementia we have simply shifted the boundaries so that some people will live with acknowledged difficulties, accepted and, it is hoped, valued in society for longer periods of time, but some will not" (Mc Parland et al 2017 p265).

Furthermore, Baars and Phillipson (2014) noted that "modern cultures of ageing often have difficulty acknowledging and dignifying limitations that cannot be overcome but must be successfully integrated in ways of living" (quoted in Mc Parland et al 2017). While Lamb (2014) talked of the need to come to terms with the late-life "situations of (inter)dependence, possibilities of frailty, and the condition of human transience" (quoted in Mc Parland et al 2017).

One problematic behaviour of dementia is "wandering"¹², which creates anxiety among carers that the individual will become lost and/or suffer harm (though only 5% of individuals do) (Brittain et al 2017).

Brittain et al (2017) were interested in the conceptual shift from walking ("something purposeful, meaningful and healthy") to wandering ("something threatening that needs managing").

Brittain et al (2017) drew on individual and group interviews with carers of individuals with dementia in the north of England. A total of thirty-seven carers recruited in two coastal towns.

The "fear of losing them" was the key theme that emerged from the analysis of the interviews. "Joan", for example, described her concern about her husband: "even

¹² Snyder et al (1978) defined wandering as "a tendency to move about, either in a seemingly aimless or disoriented fashion, or in pursuit of an indefinable or unobtainable goal" (quoted in Brittain et al 2017). However, seventy definitions have been found (Brittain et al 2017).

when he is just at his day care, I am on edge the whole time, because I am thinking, 'is he going to get out when they don't notice him?'" (p274). While "Bill" described the fear with his wife: "I mean, the way she used to wander through the night, and we were in separate rooms then, but I have always been a light sleeper, and if she got up, I was up as well, so I wasn't getting any rest... I was constantly watching her... when she was in the house, the door was always locked, and then it ended up, I got a little dog for her and that seemed to help her because the dog would bring her back, but she would only go across the road, and we have got a little green, and she used to sort of, go round the green, but the dog would drag her back" (p275).

Another theme in the interviews related to "home". Individuals with dementia in care often wandered towards "home". For example, "Jenny" described her husband's 10 km walk while in hospital: "He'd gone down through Seacrest... and he said he had walked along and then he said, 'up by the ice cream place we'd go for a coffee', which was the Seafront cafe, you know, and he had come up that way... and then he'd cut through, through Erston because he knew about the church and he says, 'that place where the church is'... so he'd used all the back... all the places he'd known" (p279). "Home" includes childhood and familiar haunts.

Brittain et al (2017) explained the conceptual shift of walking to wandering as a clear parallel to the mind-body split of the self in dementia: "That is to say, that ideas in the West about walking are clearly bound up in complicated Cartesian dualisms of mind and body. So, too, are ideas on selfhood in people with dementia and the idea of mind being overcome by body. Wandering - a wrong kind of walking - is interpreted as collapsing the division between head and heels, mind and body. Dementia is understood as irretrievably collapsing this divide, with 'body' coming to completely overtake 'mind', and leaving little possibility, in the social imagination, for reclaiming meaning or intentionality, as those are assumed to be simply cognitive matters" (p282).

Ultimately, Brittain et al (2017) wanted to emphasise the meaning to the individual of their pedestrian behaviour - though these individuals could not articulate their purpose, it is walking rather than wandering for them. But concerned carers used wandering with "all the associations it conjures up of the person with dementia being 'aimless' and unable to meaningfully travel on foot", Brittain et al (2017) said, "reinforces the negative and dehumanising notions we have about dementia and about a supposed disappearance of mind and self. Our data, based on the experiences of carers, challenges the simplicity of this equation by highlighting where it is that people wander" (p282).

1.5. THEME 4: SOCIAL CONTEXTUALISATION OF DEMENTIA

Social class can be both a risk factor for dementia and part of the social relations in which dementia is embedded (Jones 2017).

Jones (2017) reflected upon the research on interactions between dementia and social class/socio-economic status (SES) in three ways:

i) "Epidemiological approaches to inequalities in risk" - Though some epidemiological studies find a higher risk of dementia in lower social classes (eg: Mexican Americans), others do not (eg: inner city Canada). Jones (2017) commented: "One of the key problems here is that SES tends to be an umbrella term for a wide range of indicators, from occupational class, subjective measures of status and hierarchy, to measures of income and wealth at different points in time" (p305).

Measures of SES can be vulnerable to income fluctuations over the lifetime, say, and so lifecourse or cumulative approaches look for the relationship between socio-economic environment and dementia over time, and use the idea of pathways.

ii) "The role of social class in diagnosis and treatment" - Differences in social status etc are involved in diagnosis, and in access to treatment and care, though Jones (2017) argued that this is not always clear-cut. For example, Cooper et al (2010) found a relationship between owning one's home and being prescribed dementia-related drugs, but no difference in access to treatment based on socio-economic position after controlling for severity of dementia.

iii) "Class in the framing of care and access to care" - There are class differences in awareness about illness and the consequent uptake of services. Koehn et al (2016), for example, found that "forms of social and cultural capital were important in conferring disadvantage on all people with dementia as levels of social capital declined, but they also conferred a potential advantage for some groups in terms of identifying a problem, having a diagnosis and accessing services" (Jones 2017 p309).

On the other hand, there are common frustrations among carers of middle and working class backgrounds with the "the system" (eg: "it's a huge maze... a terrible maze") (Peel and Harding 2014).

The relationship between social class and its different forms, and the experience of dementia is not a simple one for Jones (2017). There are individuals who face double or multiple jeopardy (Innes et al 2004) because of their lower social position, while

intersectionality highlights the multiple social categories involved (Dressel et al 1997). "Much work remains to be done", stated Jones (2017), "in particular work needs to focus on class relations that are part of the lives of people with dementia and their carers in the context of wider social change" (p311).

Moreover, "closer attention is needed to the way that feelings of shame, embarrassment and contempt, as well as notions of compassion, dignity and respect, are closely tied up with class relationships, if we are to better understand the attitudes to frailty and cognitive decline that are part of the social imaginary of the fourth age. In short, rather than seek to insert class into an aetiological model of dementia, it may be more productive to bring to bear a class perspective on the social relations that initiate, support and maintain the capacity of people to live well with dementia" (Jones 2017 p311).

Dementia can be viewed as "a 'failed' or 'frailed' old age" because of the emphasis on successful and active ageing (Grenier et al 2017). "Frailty" is seen as an indicator of the "fourth age", which "represents not so much a particular cohort or stage of life but [...] a kind of terminal destination - a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expression and pleasure in later life" (Gilleard and Higgs 2010 quoted in Grenier et al 2017) ¹³.

Grenier et al (2017) used the concept of "precarity" to describe a "new form of ageing". Waite (2009) used precarity originally to describe "life worlds characterised by uncertainty and insecurity".

Grenier et al (2017) drew on the ideas of Standing (2010) and Butler (2009) to bring "attention to the risks and inequalities across the life course and into late life, underscoring the importance of unburdening ourselves from the age and stage-based fixations that are implicit in notions of the 'fourth age'. Considering late life frailties as precarious deepens our understanding of the ideological power inherent within constructs, practices and the 'social imaginary of the fourth age'. Using precarity to understand late life illuminates the 'fourth age' as a location distinguished from youth and adulthood, and one where the devaluation of life is based on impairment and the associated costs of dependency. This assists our understanding of the multiple layers that structure deep old age as disadvantage, whereby

¹³ The NCB (2009) stated that "enabling autonomy entails providing active support to the person with dementia so that they can be encouraged to retain and express their sense of self, rather than simply being protected from harm or interference" (p27).

older people with physical or cognitive frailties become 'othered' by means of the contradiction between autonomy and dependence" (p324).

Standing (2010) focused on the insecurity of the labour market resulting from globalisation and neo-liberalism, including a "precarity trap" that forces older adults to remain in the labour market to an older age or re-enter in a disadvantaged position. But also: "Older people with limited financial resources may themselves rely upon precarious workers as carers, and family networks may be reduced or drained by means of their own precarity" (Grenier et al 2017 p322).

Butler (2009) argued that individuals experience "precariousness" at different points in their lives, and this is seen in the "interdependence" that is common to life. Precarity is a "politically induced condition in which certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence, and death" (Butler 2009 quoted in Grenier et al 2017).

Grenier et al (2017) solution is "to link the analysis of precarity with an inclusive form of citizenship that challenges the responses to older people with physical and cognitive impairments" (p326), similar to "cosmopolitan citizenship" (Delanty 2000). The term refers to a "deep moral contradiction at the heart of the modern state" (Delanty 2000 quoted in Grenier et al 2017).

Linklater (1998) stated: "The argument is that, if it is to have real meaning, cosmopolitan citizenship must involve rather more than moral commitments not to exploit the weaknesses of others - more than the ethical resolution to treat all other human beings with care and compassion. It requires political action to build communication communities in which outsiders, and especially the most vulnerable among them, have the power to 'refuse and renegotiate offers' and to contest unjust social structures" (quoted in Grenier et al 2017).

Grenier et al (2017) summed up: "Shifting the focus from constructs that reinforce the negative valuations of age, to a recognised shared vulnerability, acceptance of the limitations of life and death, and shared political responsibility can help to unhinge dementia and impairment from a 'frailed' and 'failed' late life into a foundation from which to develop new types of care relationships" (p327).

1.6. APPENDIX 1A - ILLNESS NARRATIVES

The views of the sufferer of an illness were once entirely ignored by the medical profession, but now the

"narrative perspective" is more widely valued ¹⁴.

"Narrative provides a medium whereby one can articulate and transform the symptoms and disruptions of illness into meaningful events and thus relate them to our lives and life courses. Through the narrative, the experience of illness is articulated, especially the suffering associated with illness. By arranging the illness symptoms and events in temporal order and relating them to other events in our lives, a unified context is constructed and coherence is established" (Hyden 1997 quoted in Klusmeier 2017).

Soled (2017) put it this way: "A severe illness is a gaping rift in one's life story, one with significant effects on the sufferer, whose experience is forever etched in memory. In medical anthropology, scholars often use illness narratives to explore how individuals stitch this gap. Such narratives embody the memory of an illness experience. This is a contrast to traditional medical case histories that present patients' illnesses as generalised diseases with a focus on the characteristic symptoms and relevant pathological processes" (p226).

The construction and expression of an "illness narrative" is also a social process. "Expressing experience in a narrative form apparently implies a process in the individual, where feelings of fragmentation and alienation are overcome and replaced by congruence and direction. Confusing personal experiences become coherent and well-structured narratives. Partly this is an introspective process, where individual meaning is created as experience is forced into verbal expression. But on the other hand it is important to remember that these experiences are expressed in groups of listeners—that is, in a context of interpersonal relationships between fellow-sufferers" (Steffen 1997 quoted in Klusmeier 2017).

Illness narratives are "'performed' by patients who are characters in their ongoing stories, actors constantly influenced by their social environments [...] 'The narrative 'emplots' human action in a story with (often) no conclusion. By contextualising meaningful events, illness narratives contribute to the understanding of individual experience by showcasing social relations and cultural values" (Soled 2017 p226; p231).

¹⁴ "Doctors from the turn of the century [20th] onwards have been inclined to treat the reports of their patients with considerable skepticism. The clinical gaze of the medical profession was focused on the inner bodily world of the patients. How patients spoke about their ills, symptoms and problems was regarded at best as a pale reflection of the language of the organs and tissues and their pathological changes" (Hyden 1997 quoted in Klusmeier 2017).

1.7. APPENDIX 1B - IMPROVING MEMORY

Deep brain stimulation (DBS) of memory-associated brain areas does not enhance, but impairs human memory, according to a recent study (Jacobs et al 2016). Forty-nine participants were shown a hidden object in a virtual environment, and had to find it from a different starting point after DBS or sham stimulation in the entorhinal region of the cortex or hippocampus.

This finding contradicts a study with seven individuals where stimulation of the entorhinal region enhanced spatial memory (Suthana et al 2012).

The difference in the position of the electrodes in the brain may explain the contradictory findings (eg: in white matter (axons) or grey matter (cell bodies) in the entorhinal cortex) (Young and Deisseroth 2017).

Other areas of the brain stimulated with mixed success for memory improvement include the fornix (which links the hippocampus in each hemisphere) (Young and Deisseroth 2017).

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2. "BIG DATA HUBRIS" AND PREDICTIVE POLICING¹⁵

- 2.1. Introduction
- 2.2. Issues
- 2.3. Evidence
- 2.4. Appendix 2A - Hunt et al (2014)
- 2.5. References

2.1 INTRODUCTION

"Predictive policing" (PP) refers to the use of "an algorithm to identify instances of increased crime risk" and "an associated prevention strategy to mitigate and/or reduce those risks" (Saunders et al 2016 p348). The predictions may relate to the where/when (area and time of risk) of crimes, or to the who (high risk individuals). Individual-focused PP tends to focus more on predicting the who.

PP is an extension of "Intelligence-Led Policing" that developed in the 1990s, where "intelligence" (information - eg: tip-offs) is used as a "decision-making tool" (Ratcliffe 2012) in police prioritising their resources.

2.2. ISSUES

There are a number of general concerns with PP, including:

1. The prediction is not precise enough to be used - eg: a large geographical area or a long period of time (Saunders et al 2016). Little support for predictive policing in terms of location (Shapiro 2017).

2. Small improvements may appear large because of the low baseline. For example, PP could increase the identification from 1 in 100 000 people to 6, which is a 500% improvement, but there are still over 99% of perpetrators not identified. It will also mean that 100 000 people would need to receive the prevention strategy to avoid five crimes (Saunders et al 2016).

3. The algorithm may be effective, but the prevention strategy is not, or the police may choose not

¹⁵ "Big data hubris" - Moraff (2016) at <https://nextcity.org/daily/entry/big-data-police-reform-police-transparency-sites> (accessed May 19th 2017).

to use the predictions. For example, Saunders et al (2016) observed local police briefings where nearly three-quarters did not refer to predictive information given by headquarters.

4. Any prediction method faces the issues of "false positives" (incorrectly predicting a potential offender who is actually a non-offender), and "false negatives" (incorrectly predicting a non-offender who is a potential offender).

5. Targeting certain individuals with proactive interventions, like selective apprehension (increased arrest of perceived high risk individuals) and selective incapacitation (longer prison sentences when guilty), can have negative unintended consequences. Policing decisions in this context "may advance the continued marginalisation of economically- and politically-disenfranchised populations..., which could be more detrimental in a policing context compared to someone in custody who has already been found guilty" (Saunders et al 2016 p351).

Furthermore, selective apprehension can create the illusion of success when it actually involves "false positives", and the identification of high-risk offender groups that do not exist (Saunders et al 2016).

"Focused deterrence" (aimed at high-risk groups) can be successful, but they tend to be based on "manual police and community efforts, not through predictive analytics" (Saunders et al 2016 p353).

6. Models depend on data from reported crimes (Shapiro 2017). Lum and Isaac (2016) pointed out that "police records do not measure crime. They measure some complex interaction between criminality, policing strategy, and community-police relations" (p16).

Because of the bias in police data, which PP software are using, PP is actually "predicting future policing, not future crime" (Lum and Isaac 2016).

Lum and Isaac (2016) showed that drug crimes known to the police in Oakland, California, for example, were not a representative sample of all drug crimes using self-reported data in the 2011 National Survey on Drug Use and Health (NSDUH). The "PredPol" software, which makes predictions based on past type of crime, place of crime, and time of crime, was applied to the Oakland police database to predict drug crime in 2011.

It was found that the "hotspots" would target, for example, Black individuals twice as much as White ones, but drug use is "roughly equivalent across racial

classifications". Likewise low-income households would be disproportionately targeted. Lum and Isaac (2016) stated that "rather than correcting for the apparent biases in the police data, the model reinforces these biases. The locations that are flagged for targeted policing are those that were, by our estimates, already over-represented in the historical police data" (p18).

The PP models have an implicit assumptions that "the presence of additional policing in a location does not change the number of crimes that are discovered in that location. But what if police officers have incentives to increase their productivity as a result of either internal or external demands? If true, they might seek additional opportunities to make arrests during patrols. It is then plausible that the more time police spend in a location, the more crime they will find in that location" (Lum and Isaac 2016 p18). Increasing police officers in certain areas in response to PP leads to more crimes being discovered, which is added to the data used by PP software for future predictions, thereby producing a confirmation bias (Lum and Isaac 2016).

7. Other issues include the conflict with an individual's rights, and the lack of transparency about the use of the data by the police or in the software creation by the companies (Lum and Isaac 2016).

2.3. EVIDENCE

In terms of the evidence for PP, there are a limited number of studies (Saunders et al 2016). For example, in a field experiment, Mohler et al (2015) found that PP software ("PredPol") was better at identifying micro-places at high risk of crime than human crime analysts.

But Hunt et al (2014) (appendix 2A) found no difference in the reduction of property crime between PP software and "hot spots mapping"¹⁶. "The authors concluded that the failure to identify an effect could be because the programme did not in fact work (theory failure), low statistical power, and/or lack of programme fidelity in some treatment units (implementation failure)" (Saunders et al 2016).

Saunders et al (2016) found limited benefits in their evaluation of a pilot programme in Chicago in 2013 using PP to reduce gun violence. Individuals at highest risk for gun violence were placed on a Strategic Subjects List (SSL) and prevention strategies were employed.

¹⁶ "Hot spots mapping" is the geospatial modelling of future crime locations from past crime locations.

The prediction model used social networks of previous homicide victims to predict future victims, and it was based on the work on gang homicides of Papachristos (eg: 2009), who found correlations between victim and social connections to others who were victims.

A "first-degree link" referred to "a relationship between a subject and an individual with whom the subject was previously co-arrested who later became a homicide victim", while a "second-degree link" was "a relationship in which a subject was co-arrested with another person, who, in turn, was co-arrested with a later homicide victim" (Saunders et al 2016 p354). Co-arrests over the previous five years were used.

Local police stations used the SSL as they felt appropriate - eg: arresting SSL individuals for minor offences; paying particular attention to their "suspicious" behaviour; watching them covertly.

Saunders et al's (2016) evaluation of the pilot programme involved analysing data on monthly homicides from January 2004 to April 2014 for Chicago (city-level analysis), and details of arrests and co-arrests prior to March 2013 of nearly 900 000 individuals (general comparison group) and nearly 18 000 arrestees with at least one first- or second-degree link with a homicide victim since 1980 (individual risk data). Within this latter group, 426 individuals were placed on the SSL as highest risk.

Monthly homicides were found to be declining over the study period, and the introduction of the pilot programme in April 2013 "did not cause further reduction in the average number of monthly homicides above and beyond the pre-existing trend" (Saunders et al 2016 p361).

Individuals on the SSL were "not more or less likely to become a victim of a homicide or shooting than the comparison group" (Saunders et al 2016 p347). In the period of the pilot programme, there were 405 homicides, of which most victims had a criminal history (79%), while 16% had at least one association with a homicide victim (ie: first- or second-degree link), and three individuals (1%) were on the SSL. Controlling for demographic variables and criminal history, being on the SSL "did not significantly reduce the likelihood of being a murder or shooting victim, or being arrested for murder" (Saunders et al 2016 p362).

However, SSL individuals were nearly three times more likely to be arrested for a shooting. "The pilot effort does not appear to have been successful in reducing gun violence, although it may have improved justice by identifying more perpetrators. It does not appear that there were any unintended crime consequences, such as a violent backfire effect" (Saunders et al 2016 p366).

Saunders et al (2016) noted that the pilot programme

used the first version of software, which did not distinguish between "high-risk" (to be victim) and "high-threat" (to be perpetrator) individuals in its algorithm.

2.4. APPENDIX 2A - HUNT ET AL (2014)

This is the National Institute of Justice-funded evaluation of the Predictive Intelligence Led Operational Targeting (PILOT) programme used by Shreveport Police Department in Louisiana to reduce property crime. Data were collected at the city block level, and the blocks with a predictive probability of property crime above 60% in the next month were marked as "predicted hot spots". Police officers received this information and paid particular attention to these areas, including stopping anyone acting suspiciously, collecting intelligence from residents, and increasing resources to these areas (eg: two patrol cars dedicated to these areas).

For evaluation purposes, Shreveport was divided into six districts, three of which received the PP intervention and three were controls with usual policing. Overall, there was no statistical evidence that crime was reduced in the intervention than control districts.

Hunt et al (2014) outlined three possible reasons for the findings:

i) Low statistical power - A small amount of data for statistical tests to find differences within.

ii) Programme implementation failure - Two intervention districts had a significant reduction in property crimes relative to control districts in the first half of the programme when the level of effort of the police was high, but this became a non-significant increase in the second half as the effort declined. The third intervention district showed no change at all.

Also "the preventive measures within predicted hot spots were never fully specified, much less standardised across the experimental group. This ambiguity regarding what to do in predicted hot spots may have resulted in interventions not being defined sufficiently to make an observable difference" (Hunt et al 2014 pxv).

iii) Programme theory failure - "The predictive models may not have provided enough additional information over conventional crime analysis methods to make a real difference in where and how to conduct the intervention" (Hunt et al 2014 pxv).

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