PSYCHOLOGY MISCELLANY

No.78 - December 2015

Making Sense of the Sense of Three Conditions: Autism, ADHD and Dementia

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ISSN: 1754-2200

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

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1. MAKING SENSE OF THE SENSE OF AUTISM

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1.1. INTRODUCTION

Eyal et al (2014) observed: "Although autism spectrum disorder diagnoses are applied more and more widely in many countries, there is still no scientific or stakeholder consensus concerning aetiology, diagnosis, prognosis, therapeutic efficacy or even about how to label the new forms of human difference included within the spectrum. Not only is a clinical biomarker [1] still lacking, but paradoxically the search for one is generating still more ambiguous categories of human difference and hybridity, as well as new relationships between stakeholders... Activists and experts of different stripes struggle over how autism should be defined and treated – as a 'disease' to be cured, a 'disability' to be accommodated or a form of neurodiversity' to be accepted and celebrated" (p236) [2].

For example, Baron-Cohen et al (2001) talk of an "autism-spectrum quotient" which everybody possesses, while variations like "Maternal Autoantibody Related autism" (van der Water et al 2013) have appeared [3].

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[1] Biomarkers (biological markers) are physiological indicators of a condition, which ideally can be detected, for example in the blood, before the observable symptoms (Walsh et al 2011).

Walsh et al (2011) distinguished three types of biomarkers:

i) For susceptibility - eg: presence of a version of a gene. Problem - limited knowledge about genetic variants and their effects.

ii) For diagnosis - physiological indicators are seen as more "objective" than behavioural indicators (ie: visible symptoms). Problem - accuracy of biomarkers to distinguish overlapping conditions.

iii) For prediction. Problem - biomarkers do not predict the condition every time.

[2] Talking personally about physical disability, Shakespeare (2008) said: "It is natural for parents to be shocked by the birth of disabled child. But disability need not translate into poor quality of life. The lesson of my father, myself and my children is that disability need make no difference at all. Of course, some forms of impairments are more severe than others, and it is understandable that families, and doctors, should wish to avoid lives which are brief, painful or filled with suffering and restriction. But disability is a hugely diverse experience, ranging from trivial differences to serious difficulties. Social barriers are often a more serious problem for disabled people than their impairments themselves. Most families quickly come to terms with their disabled child, and most disabled people lead good lives. Nor is it possible to get rid of all disability through genetics, or indeed by any other means. Disability is part of the human condition. So perhaps we should learn to accept it, rather than striving to eliminate it at all costs" (p422).

[3] Hacking (1998) referred to "the looping effect of human kinds", that can be seen in "the unintended consequences that follow when a medical classification becomes an identity which individuals apply to

A number of issues arise from the struggles (Eyal et al 2014) including:

- Autism as one disorder or many.
- Who is an expert on autism (eg: academic, autist, or family)?
- Classification based on clinical criteria or genetics.
- Illness or neurodiversity [4].

1.2. RESEARCHING AUTISM

Fitzgerald (2014) summed up the uncertainty about autism generally (an "epistemic murk"): "What has perhaps remained most striking about autism is that even as it has emerged as a focus of popular and political concern, even as clinicians diagnose it in an ever-larger number of people, even as more and more neuropsychiatric and neurogenetic research paradigms are brought to bear on it and even, therefore, as its 'presence' as a phenomenon that 'cannot, and will not, ultimately be removed' becomes more solidified, so has autism continued to resist any sort of easy clinical or biological definition" (pp243-244) [5] [6].

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themselves and which brings them into contact with others who they recognise as the same. The consequence of such looping can often be to confirm and reinforce the initial classification... [For example] Ubiquitously citing the male prevalence of autism as a research model for human sex difference research, biomedical investigators intentionally or unintentionally give scientific credence to the controversial premises of the ‘extreme male brain’ (EMB) theory of autism (Baron-Cohen 1999), which holds that the cognitive and personality traits associated with autism are on a continuum with neurotypical male traits, including ability in science, technology, math and engineering" (Eyal et al 2014 pp238-239) (appendix 1A).

[4] Walsh et al (2011) summarised the issues related to biomarkers for autism as:
i) Heterogeneity - the experience and symptoms of autism are diverse as in the concept of a spectrum, and "it is important that biomarker discovery in autism does not result in children being given a biological label that fixes and defines their potential and treatments" (p606).
ii) Difference versus disability - the prospect of biomarkers opens the question of how to see autism - as disability (ie: all negative) or as difference (ie: positive), or a combination of both.
iii) Uncertainty and reproductive choice - concerns about pre-natal diagnosis and subsequent abortion of a foetus.
iv) Translating biomarker information into clinical practice - eg: "How genetic counsellors communicate to parents the probabilistic and therefore uncertain picture derived from autism biomarkers, and the complex and contested nature of the autism spectrum itself, is likely to have an enormous impact on parental decision making" (Walsh et al 2011 p609).

[5] For example, Rubenstein and Merzenich (2003) proposed that autism arises due to a neurophysiological excitation-to-inhibition (E/I) imbalance. Excitatory and inhibitory neurons establish an E/I balance that is required for typical brain development and functioning. An increased E/I ratio leads to the symptoms of autism. This may occur through increased glutamate activity (excitatory neurons) or reduced GABAergic activity (inhibitory neurons) (Rosenberg et al 2015).

Gkogkas et al (2013) altered the genes in mice to produce an increased E/I ratio and "autistic-like behaviours". Rosenberg et al (2015) provided evidence for the link between E/I imbalance and the behaviour seen in autism with a computational model.

[6] Janesick (2000) coined the term "methodolatry" to describe "a preoccupation with selecting and defending methods to the exclusion of the actual substance of the story being told" (p390).

Fitzgerald (2014) argued that neurobiological autism researchers are in "structural ambivalence" between "a promissory logic of hope and expectation" [7], and "parallel registers of ambiguity, uncertainty and deflation". Moreira and Palladino (2005) described it as the "regime of hope" versus the "regime of truth" [8], while it could be "neuroreductive certainty" (Martin 2004) versus "trouble finding localised structural changes" in the brain (Silverman 2011) [9].

Fitzgerald (2014) showed this conflict in thirty-seven interviews with UK-based autism researchers in 2010-11. The hope and expectation was based in the technological developments in studying the brain. For example, one researcher (R01) talking about magnetoencephalography (MEG): "...it is a beautiful combination of quantum physics, which is the underlying principle of the scanner, and the application to not only biological, but human, and even psychiatric problems, or neurological problems... it was sort of immediately a very sort of appealing way of having the dynamics of the human brain measured with a tool which is capable of capturing these dynamics" (p246). With the technology "the dream is to intervene prior to the onset of the symptoms... to try and divert the developmental pathway before the full core symptoms of autism become embedded in the system" (senior scientist 09), as well as "the hope that neuroscience will one day make autism as instantly diagnosable as a heart attack" (Fitzgerald 2014 pp249-250).

The "regime of truth" was evident as Fitzgerald (2014) noted as "neuroscientific autism researchers consistently drew my attention to, for example, the problem of false positives, the distance between what their methods measured and what they purported to measure, the degree to which neuroimaging simply replicates what is already known through other means – and even the basic inadequacy of brain imaging to mental phenomena in the first place" (p251). As a PhD student (P01) said: "I don't think it's ever going to be as simple as 'there is this point in the brain that is dysfunctional and this is causing autism'... I don't think that ever going to happen. I don't think that true" (p254).

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[7] Tallis (2011) distinguished between neuroscience (the scientific study of the brain) and neuroscientism ("looking to understand humanity in the brain"; Lowe et al 2015).

[8] "Biology is no longer destiny, but probabilistic not deterministic, open not closed, not a truth by which we are determined but a space of intervention and transformation — what Carlos Novas (2006) terms a political economy of hope" (Rose 2008 p431). This can be linked to "recreational genealogy" (appendix 1B).

[9] This conflict is applicable to many psychiatric disorders (eg: Pickersgill 2011).

With the increase in research on autism, there is a need for more research participants (individuals with autism, their families, and controls), and for longer time in the case of longitudinal studies (particularly on gene-environment interactions). Lappé (2014) argued that participants involved in such research "invest in the potential of the science", and "how participating in and conducting research become particular ways of seeking, giving and receiving care in the heightened conditions of uncertainty and urgency that may accompany autism" (p305). Lappé (2014) called this "taking care" - ie: "during a time of 'somatic individualism' (Novas and Rose 2000) it may become a relief to have someone not just to care for you in the therapeutic sense, but care about you, in the social sense" (pp305-306).

There is a risk of "therapeutic misconception", where the participant "fails to appreciate the distinction between the imperatives of clinical research and of ordinary treatment, and therefore inaccurately attributes therapeutic intent to research procedures" (Appelbaum et al 2004 quoted in Lappé 2014). Lappé (2014) noted the possibility of this happening in "high-risk" prospective longitudinal studies, where the biological siblings of autists are observed, say (eg: Markers of Autism Risk in Babies - Learning Early Signs (MARBLES) study - women with a child with autism who become pregnant again). There is no treatment offered here, but possibly a referral to clinical services if symptoms are diagnosed.

However, Lappé (2014) felt that "the concept of the therapeutic misconception fails to capture the nuanced affective and material forms of exchange that are built into these research practices", but there were "ambivalent relationships between research and care that are deeply socially situated and, as such, raise different social and ethical concerns" (p322).

For example, "Eleanor" (mother of child with autism) described the benefits of involvement with a university study: "If you enrol your son in a study with them and they do evaluations, that can help you when you're fighting with the school district if the school says your kid doesn't need services" (Lappé 2014 p318).

Another parent, "Maria", described her motivations for participating: "I've wanted to make sure that if we were going to have another baby I want as many eyes on him as possible. And if he is going to develop autism I want it to be caught even earlier than my other son and get going immediately. Because I've seen the difference between my older son being diagnosed at two and someone being diagnosed at thirteen or even in between. There is a huge difference. And I figured the study says they'll be developmental evaluations at six months, nine months, one year, two years and three years. I'm like, 'That is great. I need that. Otherwise I'm going to have to

pay'. And my insurance company is not going to want to pay for it, or do it, or refer me somewhere where it can get done" (Lappé 2014 p320).

From the researcher's point of view, Lappé (2014) quoted one of them from the MARBLES study: "Prospective data collection is very intensive and it takes a lot out of everybody, the participants and the researchers, to get all this information. It's a burden but I think, if we do it right, there'll be something in it for the families who participate. You know, they'll get something out of it as well as giving a huge amount to the research" (p310).

Another researcher who was involved in repeated interactions with the participants described her feelings: "I'm so attached to the study and it's been so much of my world and life that I have an emotional part of it too. And that kind of takes a toll too... So, because I have such an emotional tie to it – I really care about the study, I really care about what we're doing" (Lappé 2014 p315).

Yet another researcher described the interactions with mothers: "We kind of develop our favourite moms. Like, you have the parents that you're kind of more attached to and you talk to more. Some of it is just you see them over and over... or moms who, you go to their delivery and you're there at such a personal moment. And sometimes you spend hours in the room with them and the whole family is there and you meet the grandparents and aunts and uncles and all the kids. So you're really there at this time, at a really personal moment for them... and some of it is the moms that, I don't know, you just kind of click with... and its really nice. And then there are others that are really just in and out. So there is kind of this range: There's the moms who avoid us, then the moms who are like 'okay, let's just get this done' and then the moms who want to talk for ages and develop relationships with us" (Lappé 2014 p315).

Lappé (2014) summed up: "In the research I have described, the unknown and uncertain elements of autism – when it begins, why and what should be done about it – serve as motivations for participants and researchers alike. These motivations reinforce science as a source for answers that may, or may not, materialise. In these instances, families become potential partners in as well as resources for research. The temporal, affective and material dimensions of these relationships are generating new forms of community and sociality within and through science that deserve ongoing attention" (p323).

1.3. GENETICISATION

Navon and Eyal (2014) began: "In our 'post-genomic era' it is widely accepted that most common traits and medical conditions will not yield straightforward genetic explanations... It turns out that the vast majority of conditions are genetically complex, with a cacophony of genomic, epigenetic, environmental and other factors contributing to disease risk and expression. Conversely, most abnormalities in the human genome are characterised by phenotypic variability – they can bring with them markedly variable physical and psychological effects" (p330).

"Translational research" aims to bridge the gap between "objective" molecular findings (as in genetics), and behavioural systems of classification based on symptoms.

However, Navon and Eyal (2014) felt that " a radical revision of psychiatric diagnosis on a genome basis is unlikely to occur purely because of the sheer force of genomic findings" (p331). It is more likely to happen due to the social processes involved in devising classification systems (eg: geneticists involved for the first time on the DSM task force than produced DSM-5), because "diagnostic classifications derive their force, not from their fidelity to reality or their clarity, but from the extent to which they facilitate collaboration between multiple, often diverse experts and stakeholders who ascribe sometimes radically different meanings to the same classification" (Navon and Eyal 2014 p331).

Using the example of autism genetics, Navon and Eyal (2014) argued that it is a "trading zone" (Galison 1997) [10] "between biomedical research [11], clinical practice, surveillance medicine, patients' and parents' advocacy

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[10] Galison (1997) defined it as the way that "two groups can agree on rules of exchange even if they ascribe utterly different significance to the objects being exchanged; they may even disagree on the meaning of the exchange process itself. Nonetheless, the trading partners can hammer out a local coordination, despite vast global differences" (quoted in Navon and Eyal 2014).

[11] Miller and Crabtree (2000) distinguished nine basic premises of the biomedical paradigm:

i) Scientific rationality.
ii) Focus on individual autonomy (over family or community).
iii) The body as a biological machine.
iv) Mind and body as separate (dualism).
v) Diseases as entities.
vi) The patient as an object.
vii) Focus on the visual.
viii) Diagnosis and treatment from the outside.
ix) Reductionism.

The upshot is that the expert knows more about the body of the individual experiencing it, and this all takes place in the social context of capitalism - the "reigning voice of biomedicine" has been "successfully corporatised" (Miller and Crabtree 2000).

An alternative (qualitative) approach includes "what is missing, what is silent, invisible, ignored" (Miller and Crabtree 2000).

groups and other actors" (p331).

Navon and Eyal (2014) noted that the "geneticisation" of autism (ie: a focus on and search for relevant faulty genes) was able to take the blame and stigma from parents (who were seen as the cause in early theories, like the "refrigerator mother" idea), but the process was key in how "autism was transformed from a rare disorder with 'cardinal symptoms' into an increasingly prevalent spectrum of communicative and social deficits" (p335).

For example, the genetic mutation linked to the rare genetic disorder Phelan-McDermid syndrome (PMS) (or 22q13.3 Deletion syndrome) [12] can be "exchanged" by autism researchers and advocates as potential autism susceptibility genes (Navon and Eyal 2014). Over half of PMS cases also have a diagnosis of an autism-spectrum disorder (ASD), while 22q13.3 deletions (eg: SHANK3 gene) account for 1% of ASD cases. "Thus, we can speak of a burgeoning trading zone of autism genetics, where 'autism' itself and rare genetic mutations like the 22q13.3 deletion function as boundary objects that coordinate the endeavour of parties with divergent interests and worldviews. The mutations remain at one and the same time distinct syndromes and nested within the autism spectrum" stated Navon and Eyal (2014 p344).

1.4. VIEWS ON AUTISM

Hart (2014) described a changing view based around "a greatly enriched understanding of autistic personhood and experience, replete with emotional and cognitive depth where actions are saturated with meaning and intention. Along this shift in view, autism has come to be seen in some quarters more as a form of difference than a disease or disorder" (p285). The autism-as-different view comes from "autistic autobiographies" (eg: Grandin 1995), autistic self-advocates and the neurodiversity movement (which challenges "what they see as a tyranny of 'neurotypical' (read: non-autistic) forms of sociality and communication that fail to recognise autistic personhood, and they correctly point out that this sort of devaluation has led to serious abuses"; Hart 2014 p285).

Hart (2014) used Hacking's (eg: 1998) work to show autistic "forms of life" have emerged. Hacking (1998) used the idea of "making up people" to describe how science, in particular, creates new categories of kinds

[12] Symptoms include poor eye contact, stereotypic movements, decreased socialisation, and language impairment (Phelan 2008).

of people through labels. Though individuals with the characteristics of autism are throughout history, "autistic", for example, did not become "a way to be a person" until the description of autism by Kanner (1943).

The "looping effect" (Hacking 1998) is the interaction between the label/classification and the individuals labelled/classified. "Once a new kind of person is 'made up', knowledge is developed, institutions are founded, people are diagnosed, social practices are elaborated and experts emerge" (Hart 2014 p286).

Hart (2014) spent four years in participation observation with twenty-two families with autistic children in the USA and forty in Morocco, which included the use of applied behavioural analysis (ABA) [13], and complementary and alternative treatments.

The parents could be divided into two groups in the "autism wars". One group with "low-functioning" children described therapy as "a rescue mission" to "bring out the real person inside" in the face of the disorder ("autism-as-disorder" view). The other group with "high-functioning" autists can be seen as holding the "autism-as-difference" view. "The 'real person' is not hidden beneath their autism, but can and should be found precisely amidst all that seemingly crazy rocking, rubbing, spinning, buzzing, squealing, humming, tapping and hand flapping. The 'veil' of autism, then, is more like static in the transmission resulting from the fact that autistics and non-autistics communicate on different frequencies and experience the world in radically divergent ways" (Hart 2014 pp289-290).

This disagreement can be seen in the autistic behaviour of "hand flapping". The meaning given to the behaviour by the parents (eg: sign of distress versus meaningless) "indexes a particular model of autistic subjectivity and personhood" (Hart 2014). Hart (2014) described this example in Morocco: "one Sunday morning, I sat around a table in Youssra's family living room. I was sitting with Mounir, her non-verbal autistic teenage son, his sister, a behavioural therapist and a speech

[13] Through rote and repetition, and rewards, individuals are taught everyday skills. Parents often prompt or guide the child through the behaviours, and this makes them very aware of the child's world. "Thus, prompting can become a technology that allows autistics and their companions to find their way around in the world together, to create the shared ‘forms of life’" (Hart 2014 p296). Hart (2014) called this behaviour "joint embodiment", as seen in this example: "A Moroccan mother named Kaoutar, who lives with her 31 year-old son Hakim in Rabat, told me that he had elaborated a whole referential universe distinctly his own, a sort of idioglossia. He had novel names for objects and special ways of asking for things, and she had come to speak to him in his idiosyncratic language. Like so many parents I met, she also interpreted subtle signals in his speech and demeanor as indexes of change in his mood; these prompted her to act in particular ways, just as she often prompted him" (pp296-297).

Hart (2014) summed up: "The child's personhood is, in fact, co-performed by the parent-child duo" (p298).

therapist. The speech therapist was new, and she asked why certain therapeutic programs introduced years ago had stalled out. Just then, Mounir laughed loudly. His mother laughed too and added, ''he's responding to you, saying, 'oh, you guys don't know why it's not working?' ''. Youssra's interpretation established Mounir as an active, understanding participant in the interaction. She considered his laugh meaningful, even sardonic. Instead of considering Mounir as too disabled to benefit from therapy, Youssra's interpretation positioned him as a cunning resistor of therapeutic intervention" (p294). Hart (2014) called this behaviour of the parents "radical translation" (ie: making the behaviour meaningful as in the production of autistic personhood).

Hart (2014) argued that both views of autism as difference or disorder were, in fact, producing the same thing - a view of the autist as an agent in the midst of "seeming disconnection and disorganisation".

1.5. APPENDIX 1A - GENDER DIFFERENCES

Theories like the "extreme male brain" are used to support "a view of stereotypical sex differences as fixed, innate and lodged in the brain" (Gillis-Buck and Richardson 2014).

Furthermore, in recent years, "two popular archetypes - the autistic mathematical savant and the scientist-mathematical-tech wizard with Asperger's - have helped to cement the idea that autism and outstanding science-related abilities are inseparable" (Gillis-Buck and Richardson 2014 p266). This is due to two assumptions, argued Gillis-Buck and Richardson (2014). Firstly, the view that the prevalence of males with high-functioning autism and Asperger's (which are less than one-fifth of all autism-spectrum disorder cases) "carries insight" about autism as a whole. Secondly, the gender differences in diagnosis of autism is "not gender stereotypes in diagnostic practices", but "reflect organic facts about autism".

Gillis-Buck and Richardson (2014) described autism as a "biomedical platform" for research into sex differences [14]. A biomedical platform, they defined as "a

[14] A different example with some similarities in relation to sex differences can be seen with facial feminisation surgery (FFS). Male-to-female trans individuals not only undergo genital sex reassignment surgery, but also, in recent years, FFS. This involves modification and reconstruction of facial bones and soft tissue. Plemons (2014) described the historical process by which skulls/faces became gendered through the work of Douglas Ousterhout (a plastic surgeon) asked to perform the first FFS in 1982. "Because faces are not easily recognisable as sexually dimorphic in the way genitals often are, framing facial reconstruction as a sex-changing procedure requires rhetorical labour" (Plemons 2014 p671). Ousterhout devised measurements of different areas of the skull (eg: forehead smaller in females).

Plemons (2014) observed: "The application of statistical measurements transformed the

dynamic infrastructure - including tools, assays, conventions, protocols and definitions - upon which scientific claims relevant to human medicine can be built" (p263). The high male prevalence of autism is attractive for sex difference researchers. "Typing autism as a male disorder has facilitated the advancement of autism along several dimensions: as a diagnostic category; as an object of biomedical research; as a worthy matter of public concern, advocacy and investment; as a biological explanation for male dominance in the science professions; and as a pop culture archetype associated with male genius" (Gillis-Buck and Richardson 2014 p263).

Gillis-Buck and Richardson (2014) were cautious: "while there are sex differences in the prevalence of the cluster of signs and symptoms currently described as autism, several compelling lines of evidence suggest that sex differences are not as dramatic and homogenous as imputed by this growing research platform" (p263).

The biomedical platform is evident in research grants to study, for example, the "sex-specific dissection of autism genetics", testosterone and sex differences in brain anatomy, and non-human animals (Gillis-Buck and Richardson 2014).

Gillis-Buck and Richardson (2014) summed up: "The notion that autism presents a toolbox for exploring the exceptional qualities of the male brain helps to support a positive autism archetype that recognizes special qualities or capabilities among those with an otherwise stigmatising and disabling disorder. It also offers a biological explanation for male prevalence in science-related careers, a claim that finds a significant receptive audience in debates around this hot topic of popular, social scientific and public policy concern" (p277).

1.6. APPENDIX 1B - RECREATIONAL GENEALOGY

Rose (2008) used the term "recreational genealogy" to describe the use of DNA for ancestry tracing. However,

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feminine type from an aesthetically driven idealised version of what young, White women should look like, into a biological category used to describe what females do look like. It is the generalised and idealised feminine type, authorized by anthropological knowledge and objectivised through statistics, that enters surgical practice" (p669).

such interest often runs into "race".

"In the early years of this century, editorials in the New England Journal of Medicine and elsewhere argued that while there are genetic distinctions between population groups, within-group differences exceed between-group differences, and most genetic differences are 'only skin deep' – relating to the small number of genes governing skin pigment, physiognomy, etc... Some geneticists sought a middle position, claiming it is possible to identify genomic differences which have some correlation with population groups and ethnicity, but that any characterisation of such differences should not use terms like race or ethnicity, but focus on the genetic markers themselves... While most commentators agreed that self-defined race or ethnicity was a poor proxy for genetic variation, Neill Risch and his colleagues [15] argued in favour of the use of self-identified ethnicity... Like other population geneticists, they took the view that Africans, Caucasians, Pacific Islanders, East Asians and Native Americans formed five major groups defined by 'out of Africa' date. And they argued that, despite migration, and except in recently separated or admixed groups such as Hispanics, mating patterns had preserved most of these distinctions, and there was not much heterogeneity in these groups with regard to common allelic variants. Further, they claimed that self-identified race was not, as many asserted, a poor proxy for genetic make-up, but a very good guide: that individuals were well able to characterise themselves in genetically meaningful ways" (Rose 2008 p427).

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[15] Eg: Risch (2000).

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2. ATTENTION DEFICIT HYPERACTIVITY DISORDER AND THE "REAL SELF", MOTHER-BLAME, AND RITALIN

2.1. Mother-blame
2.2. Ritalin and "authenticity"
2.3. Appendix 2A - Adult-onset ADHD
2.4. References

2.1. MOTHER-BLAME

It is estimated that 7% of 6-11 year-olds in the USA have a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) (of which three-quarters are boys), and 3% of all American children take methylphenidate (eg: "Ritalin") (that is 85% of the world's use of the drug) (Singh 2004) [16].

The response to ADHD and Ritalin is often in terms of who to blame. "Answers are situated within a web of vigorously pointing fingers. Accusations have been made against cultural forces such as competition, masculinity, stress and speed...; institutional forces such as schools, pharmaceutical companies, insurance structures, and the clinic...; and organic factors such as the brain and genes... Perhaps the most commonly fingered factor in ADHD diagnoses and Ritalin use is parents" (Singh 2004 pp1193-1194).

"Parent-blame" (or more specifically "mother-blame") seems unfair to researchers who see a biological basis to ADHD, and so "a brain-blame narrative has become a primary means of absolution for parents of children with ADHD-type behaviours" (Singh 2004 p1194) [17].

Mothers, interviewed mostly in the USA by Singh (2004), talked of feelings of self-blame and inadequacy in relation to their sons' behaviour. This was in the context of the "good mother" (versus the "inadequate mother"). Such women are idealised as selfless, without conflict with their children, and having qualities like understanding, protection, and wisdom. "The inadequate mother was characterised by her lack of sufficient care,

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[16] Last attention is paid to adult ADHD, and particularly adult-onset ADHD (appendix 2A).

[17] "For mothers with problem boys, the news about drug treatment and the emphasis on the organic nature of children's behaviour problems appears to have been very welcome. Schooled to give their children up to expert treatment, weary of mother-blame, and anxious to look good in the eye of society, mothers represented in... [women's] magazines appeared to herald drug treatment for their sons' problem behaviour as a true miracle" (Singh 2002 p593). Singh (2002) surveyed 200 articles on child-rearing and child behaviour in two US women's magazines between 1945 and 1965. She could find no negative articles on the use of stimulant medication like Ritalin.

positive emotion, knowledge, insight and action" (Singh 2004).

Mothers of boys with ADHD felt like failures as good mothers in three ways:

i) Responsibility - Because the mothers could not solve their sons' problems, they were seen as "possibly to blame for the problems in the first place".

ii) Connection - Good mothers are seen as connected to their children. As "Paula" showed, this is not easy with an eight year-old with ADHD: "...nothing I did could reach him; I just couldn't reach him, you know? I'd ask him, 'Why don't you listen? Why are you acting so crazy?' But he'd just shake his head and not say anything. It made me nuts! I wanted to shake him and hug him and cry all at the same time. I was so frustrated, so upset and angry that I couldn't do anything for him. I kept thinking that I should be able to do something, you know, something to pull him out of this" (p1197).

iii) Anger - Good mothers do not get angry with their children. The mothers' stories of anger were grounded in self-loathing - eg: "Sue": "The smallest thing would make me upset and either drive me to the point of tears or make me start screaming uncontrollably" (p1198). Other mothers referred to themselves as "a bitch" or "a psycho" when they became angry.

The mothers' self-blame was reinforced by the blame from others, specifically by the fathers, and the wider community. For example, "Mary" said this about her husband: "He... said to me, not in a mean way or anything, that maybe things would get better if I wasn't so soft on [son]. Maybe I was babying him too much and needed to let him grow up some" (p1200).

In relation to the wider community, "Anna" reported: "I'd be in church with him and he just wouldn't sit still; he'd be fidgeting and I couldn't get him to stop at all, and people would just be turning around and looking at me like why couldn't I do something about him. My husband is sitting right there too, but they're looking at me" (p1200).

The blame for the problem behaviour of the son is partly absolved by a diagnosis of ADHD (with the emphasis on the biological basis [18]), and the offer of Ritalin.

Singh (2004) observed: "Ritalin wielded enormous power in the construction of an alternative understanding of boys' behaviours. Freed from the burden of responsibility for causing their sons' behaviours, mothers felt they were finally empowered to 'do

[18] Eg: One mother said: "It's not his problem, it's his brain's problem" (Singh 2004).

something', and Ritalin was an important aspect of this doing. Medication became part of the daily ritual at home and at school, necessitating discussion, monitoring and repeated dosing. Mothers became advocates for their sons, educating others about their medical needs and treatment procedures. In this process Ritalin served as a material authority, proving the legitimacy of the biological causation narrative through its work in settling a boy's body and focusing his mind" (p1201) [19].

Singh (2004) summed up her view: "The success of ADHD diagnosis and Ritalin is built on the back of an oppressive cultural ideology of the good mother. Ultimately, I think ADHD diagnosis and Ritalin affirm cultural stereotypes of good mothers and successful boys and give mothers a better chance of achieving the ideals inherent in those stereotypes. The trick of the binarism mother-blame-brain-blame is that the brain-blame narrative contains, supports and reconstitutes opportunities for mother-blame. Unfortunately for mothers, the binarism is finally, false, and promises of absolution are simply seductive rhetoric" (p1204).

2.2. RITALIN AND "AUTHENTICITY"

The idea that a drug used to treat a mental disorder may change the individual was raised by Kramer (1993) in reference to the anti-depressant "Prozac", and "cosmetic psychopharmacology" (ie: enhancement of the personality). More widely, "enhancement technologies" is the term used "to describe those treatments that improve human performance, appearance, and/or behaviour where such

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[19] "Pre-theoretical assumptions" (Lloyd 1993) played a role in the creation of ADHD diagnostic categories and the use of Ritalin. These are "the social assumptions and prior commitments of scientists [that] play a major role in the practice of science itself" (Lloyd 1993 quoted in Singh 2002). Singh (2002) described these assumptions: "the construction of certain kinds of 'problem behaviour' in boys as a medical problem; the belief that science had superior methods for raising psychologically healthy boys; and an association between problems in boys and problems in mothers. These social assumptions do not just shape the way science is done. They also shape the way scientific knowledge is received and incorporated back into society, thereby creating a complex inter-relationship between social assumptions and scientific knowledge" (p596).

Singh (2002) saw a presentation of ADHD categories as objective, which fitted with the ideas of Foucault (1965). That is that "the processes by which social behavioural norms become codified in psychiatric categories. Foucault argued that these categories appear to be divested of social 'subjective' meaning even while psychiatric practices continually reproduce normative social standards and (re)inscribe them on the social body. Psychiatric categories thereby reify social norms as objective truths by removing them from the social body and from the historical space the body inhabits. Scientific understanding of ADHD... has actively promoted a disembodied reality to ADHD through a brain-based discourse of neurotransmitters, receptor sites, and chemical processes. The brain, divorced from the body, is divested of time and history in which the body moves, and so ADHD, which resides in the brain, would also appear to have no history" (Singh 2002 p598).

improvement is not medically warranted (or financially justified given limited resources)... [So] legitimate medical intervention is viewed as morally justified and necessary, while enhancement treatments are viewed as excessive, artificial, and morally suspect" (Singh 2005 p34). "Enhancement technologies" are a challenge to the "ethics of authenticity" (Taylor 1991) (ie: "the self's sense of its own uniqueness and individuality, and the desire to be true to the self" [20]; Singh 2005 p34).

Ritalin [21], prescribed for ADHD, is an example of a drug the could be both treatment and enhancement. It also raises ethical questions about the rights of parents to shape the behaviour of their children, maybe even confer a competitive advantage, and the child's personal autonomy, as well as the use by caregivers and teachers to make life easier for themselves (Singh 2005).

Singh (2005) explored these issues in participation-observation research with twenty-two mothers and twelve fathers of boys attending a paediatric neurodevelopment clinic in Rhode Island, USA, and seventeen more mothers and ten fathers recruited elsewhere. All the boys had a diagnosis of ADHD, and were on medication for at least three months.

Singh (2005) found a number of themes in how the parents viewed Ritalin and their son - ie: the mothers and fathers made different sense of the self, disorder, and behaviour.

1. Mothers

a) "Locating the self" - ADHD behaviours were seen as "part of who their sons were", and Ritalin was "opening their sons up to the possibility of better understanding this aspect of themselves". This is summed up by "Delores" (talking about her son "Gregory"): "I hope he... will be able to understand who he is as a person and what his limitations are, and how he has to find a balance that lets him be on his own. He needs to be aware that he can be pretty impulsive and what he can do if he can't control himself. Ritalin will help him with that, but he needs to understand that he will probably have to take it even when he's older. These are the things he needs to learn about himself, so that he is able to function and be happy" (p40).

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[20] This, of course, assumes a "real" self or "natural" identity.

[21] Ritalin appeared in the USA in 1955 as a treatment for mild depression and narcolepsy, and it was in 1961 that its use for "various behavioural problems in children" began (Singh 2002). The producer of the drug, "Ciba Pharmaceuticals" (now called "Novartis") has been very active in promoting Ritalin since the 1960s (Singh 2002).

b) "Authenticity" - It is the "authentic self" that is able to control the unwanted ADHD behaviours with Ritalin. For example, "Josie" said of "Joseph": "... The real Joseph is the one on medication. That's the real one. I know that because he doesn't like what he is not on medication. So that can't be the real one. The real one is the one he is most comfortable being. Where he just feels best about himself" (p40).

Singh (2005) pointed out: "This distinction between a boy's behaviour and his real or essential self has deep moral implications. It justifies the need for medication as a moral imperative to free the real self, and it justifies the use of medication as a relatively superficial intervention that does not in fact penetrate to the child's real self. This kind of reasoning maps on to the frequently echoed similes for Ritalin work in the popular and clinical literature on ADHD. Ritalin is likened to insulin for diabetes, or to glasses for myopia..." (p40).

c) "Real boys and male success stories" - The "freed authentic self" is a "success narrative" that allows "a culturally valued story of male development", as seen in "Fiona" talking about "Jimmy": "Ritalin opened a doorway... It gave him away to go. It gave him a way to focus and... gave him a direction... I think he feels better about himself... I want him to know that he is successful. I don't want him to keep hitting walls and feel like he is a failure and that he can't accomplish this or that, or you know, that he is so different. Well, he is different, but so is everybody. He has a value and he can do it, he just needed to realise that..." (p41).

d) "Weekend dosing dilemmas" - Much of what has been previously said is contradicted by the mothers not wanting to medicate at weekends and school holidays. "Beth" said: "Why should we drug him on the weekend? That's who Stuart is. If he wants to be off the walls, why not?... It's the weekend for god's sake. He doesn't have to be successful now" (p42).

Singh (2005) felt that the "contradictions, and mothers' lack of awareness of them, illuminate the moral struggle parents undergo when they must make their own decisions about whether or not to medicate their sons [...] In the case of ADHD and Ritalin, these contradictory narratives also serve a strategic purpose. Dosing decisions are emplotted in moral narratives that present a particular set of relations among authenticity, boy, disorder, and medication" (pp42 and 43).

2. Fathers

There was more emphasis in the fathers' narratives on "authentic male behaviour". Singh (2005) reported: "Unlike mothers, many fathers I spoke to did not see their sons' behaviours as evidence of underlying pathology. They provided a different explanatory model for problem behaviours: 'boys will be boys'. Their sons' 'wound up', 'crazy' behaviours were evidence of their authentic boy-ness; as one father said, my boys are all boy" (p43).

The gender-related concern was seen in playing sports as one father said: "It's hard to watch him out there [during a game]. He's kind of different than the other boys. He can't play a simple game without messing up... Sometimes I'm embarrassed watching him play; he's pretty bad..." (p44). Interestingly, "some fathers presented a kind of psychological explanation that saw boys' poor performance resulting from poor motivation. This explanation allowed fathers to view their sons as potentially in control of their behaviours, and suggested that non-medical responses might be adequate to change these boys' behaviours" (Singh 2005 p44).

Singh (2003) categorised the attitudes of fathers along two dimensions - "reluctant believers" and "tolerant non-believers". Thirteen of the 22 fathers were seen as the former because "they saw the positive effects of drug treatment on their sons' behaviours, while also continuing to wonder whether their sons' behaviours actually warranted drug treatment" (Singh 2003 p312). Singh (2003) categorised six fathers as "tolerant non-believers" (with three fathers non-categorised). They did not believe that the drugs were helping, but they did not challenge the use of Ritalin.

Only four fathers initially accepted that their sons needed medical treatment, though most fathers recognised that there were problems. The fathers tended to offer three explanations for the problems:

- Indulgent mothering - eg: "Ralph" described how his wife "babied" their son.

- Boys' lack of motivation - eg: "Ralph" also said: "If he's interested, he's motivated".

- "Boys will be boys" - eg: one father said: "I did crazy things as a kid... And I always pulled it out when I had to. I figured he'd do the same" (Singh 2003 p312).

Singh (2005) summed up: "Parents may draw upon 'predictable'... moral concepts and language to justify their dosing decisions – the language of self-transformation and authenticity – but the substance of

these moral concepts, and parents' moral resolutions to dosing dilemmas, are anything but predictable; rather they are inconsistent, contradictory, strategic and incomplete. Parents' definitions of authenticity shift according to what parents value in particular contexts. Their shifting conceptions of 'the real child' across different contexts are embedded in cultural and gendered norms and ideals about behaviour, development, success, the self, mothering, and fathering. Moreover, parents' personal histories shape the ways in which they understand, confront and engage with these ideals and norms and how they translate them into parenting practices and dosing decisions" (p45).

2.3. APPENDIX 2A - ADULT-ONSET ADHD

It is assumed that adults with ADHD have a continuation of their childhood condition (table 2.1). But a study using a cohort in Dunedin, New Zealand, did not find this (Moffitt et al 2015). Over one thousand individuals [22] have been followed to age 38 years with regular self, parent, and teacher ratings. Sixty-one participants (6% of sample still available) were diagnosed with ADHD as children (DSM-III criteria) [23], and thirty-one at 38 years old (3.1%) (DSM-5 criteria) [24], of which three individuals were in both groups. So, there were a number of individuals who showed adult-onset ADHD, and they "exhibit impairing symptoms [eg: cognitive impairments] that are consistent with ADHD in all aspects except childhood onset" (Castellanos 2015). It seems to be a "bona fide disorder" (Moffitt et al 2015) rather than a facet of changing DSM criteria, say.

Moffitt et al (2015) asked: "if these impaired adults do not have the neurodevelopmental disorder of ADHD, what do they have? At 38, this cohort is too young for prodromal dementia. The possibility of malingering has been raised, but this can be discarded, as Dunedin Study members lack any motive to fabricate their reports to us" (p975). Many of the adult cases had substance dependence, but the researchers' data could not "resolve the question of whether substance abuse led to ADHD symptoms or whether adult ADHD symptoms antedated substance abuse" (p975). The researchers raised the "intriguing possibility" that adult-onset ADHD is a separate condition from child-onset ADHD, and has yet to be classified by the American Psychiatric Association in

[22] All infants born between April 1972 and March 1973 in Dunedin.

[23] Assessments for ADHD were made at 11, 13 and 15 years old (between 1984 and 1988) using the Diagnostic Interview Schedule for Children - Child Version by child psychiatrists and trained interviewers.

[24] Assessment was made by trained interviewers.

DSM.

Moffitt et al (2015) highlighted the strengths of their research: "Our four-decade study supported both follow-forward and follow-back analyses of a representative birth cohort, in which ADHD cases were ascertained without bias by referral or treatment. Participants' self-reports could be supplemented by independent sources: parents, teachers, informants, formal cognitive testing, and administrative records" (p972). However, there were the following limitations admitted by the researchers:

- Different versions of DSM were used to diagnose ADHD in childhood and adulthood.

- There was not a hypothesis of the findings (ie: the researchers looked back rather than predicting forward).

- Assessment of ADHD in the participants' 20s was not made because DSM-III-R, in use in the 1990s, did not see ADHD as an adult condition. "Thus, we were unable to trace the decline in symptoms for childhood cases or the emergence of symptoms for adult cases", admitted Moffitt et al (2015).

- The adult cases were small in number, which "limited statistical power and... ability to examine heterogeneity within this group" (Moffitt et al 2015 p972).

- Personality disorders were not measured at any time. These can account for some of the symptoms classed as ADHD.

- No neuroimaging data were collected at any time (eg: to show brain differences between participants).

- There was a lack of data from clinical referral and treatment (ie: many cases previously undiagnosed).

The New York Longitudinal Study (Klein et al 2012) did find a small number of adults with the adult-onset version of the condition (using DSM-IV-TR criteria), and it was categorised as "ADHD not otherwise specified". In terms of their brain structure, these individuals did not differ from non-ADHD controls, but did vary from child-onset adult ADHD sufferers (Castellanos 2015).

1. Follow-up in adulthood of individuals diagnosed with ADHD in childhood. But the samples tend to be clinical (ie: those seeking and/or receiving treatment), which produces an "initial referral bias" (Moffitt et al 2015).

2. A random survey of the adult population to see who fits the criteria for ADHD now, and then asking them if they were diagnosed or showed symptoms as a child. This is a community sample, but it relies on recall accuracy (ie: retrospective study).

3. A longitudinal cohort study which follows a group of individuals over time, like the Dunedin Multi-Disciplinary Health and Development Study.

Table 2.1 - Three designs to study whether ADHD in adulthood is a continuation of childhood ADHD.

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3. THE EXPERIENCE AND MEANING OF DEMENTIA

3.1. Introduction
3.2. Experience
3.3. The self
3.4. Life story
3.5. Vulnerability
3.6. In workplace
3.7. Appendix 3A - Happiness and memory
3.8. References

3.1. INTRODUCTION

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" (Jenkins 2014 p125).

Zeilig (2015) pointed out that dementia is "a contested category" that relates to "a group of syndromes rather than one single disease entity" (with over 200 sub-types). "Thus it is crucial to recognise that 'dementia' represents more than a medical condition and that the wider social, cultural and political context also influences the ways in which people live with this diagnosis" (Zeilig 2015 p13).

The lack of clarity about dementia leads to a horror, or what Sontag (1978) called "old-fashioned" kinds of dread in relation to cancer and TB. "The disease then becomes a metaphor... and is also used as an adjective to describe all that is morally and socially pernicious" (Zeilig 2015 p14).

Representations of dementia in the media show such concerns. Zeilig (2015) pointed out some of the common metaphors, like "rising tide", "silent tsunami", and "millennium demon", to describe the increasing (actual and predicted) number of sufferers. "The overall impression is of dementia as huge and ancient – beyond our grasp or understanding, that can only be understood through reference to massive natural phenomena (usually disasters) or in biblical/mythic terms" (Zeilig 2015 p15).

3.2. EXPERIENCE

Tolhurst and Kingston (2013) noted that the experience of dementia is "not simply determined by neurological factors, but also by people's subjective interpretations and their negotiations with others within various social contexts" (pp178-179).

One way to understand the experience of dementia is through the theory of "status passage" (Glaser and Strauss 1971). This is the idea that individuals move from different stages or statuses during their life course. "Such passages may entail movement into a different part of a social structure; or a loss or gain of privilege, influence or power, and a changed identity and sense of self, as well as changed behaviour" (Glaser and Strauss 1971 quoted in Tolhurst and Kingston 2013).

Glaser and Strauss (1971) outlined six concepts associated with "status passage":

i) Reversibility - The experience of the passage will be influenced by whether it is reversible or non-reversible. In relation to Alzheimer's disease, say, "reversibility is not possible given the current state of scientific knowledge; however, there is scope to reduce the onset of vascular dementia. This is a public health message that has yet to be used effectively. It could be argued that the condition suffers from 'preventative marginalisation', as the link between risk factors for heart disease and vascular dementia has received insufficient attention" (Tolhurst and Kingston 2013 p180).

ii) Temporality - This is whether the passage is predictable and scheduled, and the rate of change. "Different types of dementia have different impacts upon the individual, with both life expectancy and the rate of neurological decline varying significantly from case to case. The temporal expectations with regard to an individual's experience of dementia cannot be known with certainty, but these temporal expectations will still be framed by the knowledge of how a condition is likely to progress" (Tolhurst and Kingston 2013 p180).

iii) Shape - The shape of the passage is affected by the amount of control and who is in control. In the case of dementia, the individual, their family, and health professionals. "A person who has not received a diagnosis or lacks professional support may not formulate a clear notion of the projected shape of the dementia-related status passage, and this absence of guidance could generate a sense that the trajectory of their condition is following an inappropriate unsupported route" (Tolhurst and Kingston 2013 p186).

iv) Desirability - The degree of desirability or undesirability of the passage, which is influenced by social context. With dementia, "a status passage will not be experienced in isolation: a dementia-affected person's partner and family members will also be entering a status passage as a result of this illness. For example, when a person is diagnosed with dementia, their partner may be

commencing a status passage of carer" (Tolhurst and Kingston 2013 p187).

v) Circumstantiality - Whether the passage is experienced as part of a group/collective (eg; social supported) or alone.

vi) Multiple status passages - The potential to experience more than one passage at a time.

Glaser and Strauss (1964) used the concept of "awareness context" to describe how much information is available about the status passage. A closed awareness could include concealing the dementia from others, or the process of diagnosis of dementia (ie: early, late or not at all) (Tolhurst and Kingston 2013).

An alternative model for understanding dementia is "biographical disruption" (Bury 1982). There are three elements to the disruption - a challenge of taken-for-granted assumptions, a "fundamental re-thinking of the person's biography", and the resources needed to deal with this disruption" (Tolhurst and Kingston 2013).

3.3. THE SELF

Jenkins (2014) advocated a different way of viewing the self in dementia - rather than the "promotion of individuality", an "inter-embodied self" "based on the understanding that human selves are dividual; that is, transacted and reproduced across persons" (p126).

The individual self fits with the idea of the "regime of the self" (Rose 1996) with "implicit expectations that persons are (required to be) autonomous, independent, self-governing individuals" (Jenkins 2014 p127). Thus, dementia care focuses on the affirmation of individuality in response to the selfhood under threat.

The inter-embodied self idea promotes a "montage of selves" in dementia care based on three core principles (Jenkins 2014):

i) Respect for dividuality - the "transactive qualities of persons".

ii) Promoting dialogicality - the self is seen as "a polyphonic novel" ("a story told by a combination of competing authors") with "a plurality of consciousnesses and worlds".

iii) Embracing intercorporeality - this refers to "the belief that subjective experience does not originate purely within the body, but is instead formed through our

interactions with other embodied Beings" (Jenkins 2014 p130).

Jenkins (2014) summed up the implication of the inter-embodied self thus - "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" (pp133-134). Taylor (2013 quoted in Jenkins 2014) put it this way: "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", and Barnes (2012) referred to a solidarity of care.

3.4. LIFE STORY

The "life story" (personal biography) is viewed as beneficial in ageing - "locating and articulating a biographical connection between past and present life events is one way of preserving the narrator's personal identity and affirming a sense of agency and self" (Kindell et al 2014 pp151-152). This is a challenge for individuals with dementia, and maybe even more important to maintaining personal identity (Kitwood 1997).

Kindell et al (2014) reviewed the specialist resources available for life story work (ie: one-to-one rather than shared reminiscence) with individuals with dementia in the UK. They found eleven different resources.

The researchers noted:

a) The "limited guidance for people with dementia to develop their own life story and have control over what they wish to share now and for the future" (Kindell et al 2014 p158).

b) The emphasis of resources on chronological order, while "the fragmented nature of communication and memory in dementia may make it difficult for many people to recall and recount events in such an ordered fashion and therefore compromise their ability to play a part in the process [25]. Instead, a more flexible and naturalistic encounter might allow the worker to follow the lead of the person with dementia in conversation and, in the process, find out those things that are particularly

[25] Positive emotions are involved in memory (appendix 3A).

important to the individual concerned" (Kindell et al 2014 p158).

c) The issue of "upsetting memories" or "the revelation of private stories".

3.5. VULNERABILITY

Individuals with dementia are vulnerable, including to financial abuse (which is defined by the UK Government as "theft, fraud, exploitation, and pressure in connection with wills, property or inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits"; quoted in Samsi et al 2014). Flannery (2003) classed it as a form of domestic violence and abuse.

Pinsker et al (2009) distinguished the vulnerability between individuals based on factors like intelligence, cognitive functioning, personality traits, and social skills.

As to the amount of financial abuse, Samsi et al's (2014) survey in England in 2011 found that nearly half of staff of the charity "Alzheimer's Society" reported seeing at least one case in the past year. Eighty-six staff completed a short survey through "Surveymonkey", which included support workers, and dementia advisers.

Problems with money management were reported as common (eg: 48% of respondents answered "frequently" - more than six cases per year). The signs of money management problems becoming financial abuse were divided into three types:

i) Changes in the client's relationship to money - eg: giving someone their PIN number; signing a blank cheque.

ii) Personal vulnerability - eg: "being approached repeatedly by traders"; family or friends being "unco-operative with health care professionals, voluntary sector etc when wanting to discuss financial matters".

iii) External influence or interest that was suspicious - eg: "unnecessary repairs or home alterations being carried out"; "suspicious visitors to a client's house".

3.6. IN WORKPLACE

Individuals with dementia are usually perceived as economically inactive, but with the potential growth in diagnosis (including earlier diagnosis), and the recent

abolition of a default retirement age in the UK, it is possible that more individuals with dementia will be working. What is the experience of such individuals?

Ritchie et al (2015) undertook a literature review to answer this question. Six relevant papers were found (table 3.1) using keywords like "dementia", "Alzheimer's disease", "older workers", and "early onset dementia" in multiple databases.

STUDY	DETAILS
Chaplin & Davidson (2014)	Interviews with 5 workers with dementia
Cox & Pardasani (2013)	Online survey of 103 HR (Human Resources) professionals
Harris & Keady (2009)	Interviews with 23 younger individuals with dementia and 15 family carers
McGurk & Mueser (2006)	Survey of coping strategies used by 50 employment specialists to support workers with cognitive impairment
Ohman et al (2001)	Interviews with 9 younger individuals with dementia still in work, and 6 colleagues
Pipon-Young et al (2012)	Interviews with 8 women with dementia (in 60s) who had left work

Table 3.1 - Relevant studies found by Ritchie et al (2015).

Memory failure was the most common initial symptom reported, followed by word-finding problems, and learning new material using technology. This led to increased stress and anxiety for the individuals, and a decline in confidence in their own ability, with, not surprisingly, a reluctance to acknowledge the signs of cognitive impairment, "passing them off as personality traits or linking them to normal ageing: for example. poor eyesight" (Ritchie et al 2015 p27). Coping strategies included writing notes and memos, and spending more time planning tasks. Eventually, "a crisis point was reached where participants realised they could no longer cope in the workplace and had to seek support" (Ritchie et al 2015).

Ritchie et al (2015) also reported the analysis of qualitative interviews with eight younger individuals with dementia (ie: below 65 years) at work in Scotland. The impact of early symptoms had practical problems (eg: forgetting passwords) as well as the inconsistency of symptoms, and a diminishing interest in work.

In the literature review, on the employer's side, there was limited knowledge about how to deal with individuals with cognitive impairment. "Employees were likely to be put on sick leave or have their employment terminated, either by being offered early retirement or being dismissed when they received their diagnosis" (Ritchie et al 2015). Only 2% of 103 HR (Human Resources) professionals who responded to an online survey worked in an organisation that had a policy for dealing with employees who developed cognitive impairment.

Other staff were generally positive about wanting to support colleagues with dementia, but there were difficulties, "including economic problems related to paying a full salary to someone who was unable to undertake all duties relating to a role, and the negative reaction observed from employees who had to take on additional duties to compensate" (Ritchie et al 2015). One study found that "while the participants reported having struggled at work for a long period of time, workplace respondents did not report noticing any differences in their colleagues until much later" (Ritchie et al 2015 p28).

3.7. APPENDIX 3A - HAPPINESS AND MEMORY

Kahneman (2011) distinguished between the "experiencing self", which is concerned with how the individual feels now, and the "remembering self" (how an individual remembers feeling in the past). Happiness can be experienced in relation to both of them - ie: "as a response to an event in the present or to a recollection of - or 'fantasy' about - the past" (Hyman 2014).

Hyman (2014) concentrated on this and the meanings that individuals make from them - "people can gain happiness from reflection upon past experiences, as well as from present conditions, and happiness felt in the past can manifest itself in the here and now" (Hyman 2014). The meaning is derived from culturally dominant discourses or narratives.

Twenty-six adults in the UK aged between 22 and 80 years old were interviewed about their perceptions and experiences of happiness. Two key themes emerged from the qualitative interviews by Hyman (2014):

1. "Life was happier in the past" - Older interviewees expressed the view that both society and their own lives were happier in the past than now. For example, "Laurence" (aged 65 years) felt that "we've got very materialistic" ("a modern 'malady of infinite aspiration' Durkheim (1925/1961) whereby people's heightened expectations in an increasingly affluent society have led, for some, to a feeling of discontentment or unhappiness"; Hyman 2104). "Eileen" (63

years old) lamented: "When I was young, there was camaraderie, with people... you helped one another then. People are not so ready now, to help one another. You know, there's a lot of jealousy, and I think jealousy is the worst thing".

Hyman (2014) noted: "What is interesting here is that these accounts pose a challenge to Ruut Veenhoven's (2011) claims that improved living conditions can raise levels of happiness. These older people perceive the quality of society and living conditions to have worsened (though this worsening may or may not have actually taken place), but yet - for Eileen and Laurence particularly - they can nevertheless reflect on the happiness that they felt in the past. Thus, it could be said here that people's subjective perceptions of living conditions are just as important as actual living conditions for understanding how people evaluate their lives".

At a personal level, "Maureen" (aged 80), for instance, reflected: "when we were young they were good days". Reflections on a happy past is one culturally dominant discourse or narrative (Hyman 2014).

Dowd (1986) referred to a "past-situated social identity where "'the world has changed so significantly, it is no longer a world that is recognisable to the aged or one in which they feel ''at home''' (Dowd 1986)... Therefore, it may be that if older people feel that they have less of a place in 'contemporary cultural experience' (Dowd 1986) they are also less likely to draw happiness from the present than they would do from the past. Therefore, drawing upon the narrative outlined here, whereby life was deemed happier in the past than in the present, is one way in which such individuals may articulate their memories and their happiness as well as their relationship with the social world" (Hyman 2014).

2. "Happiness can be gained from reminiscing about the past" - Interviewees of all ages expressed ideas similar to "Gillian" (aged 46), who said: "I get a lot of pleasure from reminiscing. And that's why I said it's experiences that make you happy. Because it's those things that stick with you, you know, the happy times that stick with you... good memories are important to your well-being".

"Nick" (aged 25 years old) emphasised the importance of experiences now to remember with pleasure later: "I find people get more sentimental as they get older, and they begin to appreciate things more. I think that's what... before, I'd like, go out, and have experiences and go 'oh this is fine', but now I look back on nights out and times with friends and I go 'this is great'. And sometimes I have nights out and I go 'I'll remember this night, this is brilliant'...".

Hyman (2014) argued that "memories and reminiscence are used as 'technologies of the self' with which people can make themselves feel better about their lives. In other words, the act of reminiscing and reconnecting with the past is a technique that people perform on their own minds, 'so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality' (Foucault 1988)".

3.8. REFERENCES

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