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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://kmbpsychology.jottit.com>.

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1. THE MENTAL STATE OF OLDER ADULTS

- 1.1. Mental disorders
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1.1. MENTAL DISORDERS

The distribution of a disease or disorder is not equal across a society, and there will be clusters related to social variables (eg: socio-economic status/social class; income/wealth; gender). Social epidemiology is the study of such unequal distribution (Cairney et al 2008) ¹.

Cairney et al (2008) looked at five psychiatric disorders among older Canadians and the distribution in relation to socio-economic status, age, gender, marital status, and ethnicity (based on language) using data from the Canadian Community Health Survey: Mental Health and Well-Being (CCHS 1.2). This was a nationally representative multi-stage stratified cluster survey of adults aged fifteen years and above undertaken in 2002. Cairney et al (2008) concentrated on the 12 792 respondents aged 55 years old and above.

The CCHS 1.2 focused on major depression and bipolar disorder (affective disorders), and social phobia, panic disorder, and agoraphobia (anxiety disorders) using DSM-IV criteria.

Around 3% of the sample were classed as having an affective disorder, and about two and a half percent had at least one anxiety disorder. The following pattern of social variables was found:

a) Suffering from one of these disorders declined with age after 55.

b) The increased risk of a disorder for formerly

¹ There are also differences between countries. For example, in a ten European country study of 050s, depression was higher in Latino ethno-lingual group of countries (France, Italy, and Spain) (Castro-Costa et al 2007).

married (separated and divorced), and widowed individuals as compared to currently married. Perceived social support was key here - ie: less support and more likelihood of a disorder ².

c) The other variables (eg: gender) were not significant.

There is a debate as to whether mental disorders increase or decrease with age. For example, symptom measures of depression produce a U-shaped curve with a low around 45-50 year-olds, and high rates of prevalence for 20-24 years old, and 80 years and above (eg: Kessler et al 1992). But when DSM criteria are used for depression, Myers et al (1984), for example, found a negative correlation (declining depression with increasing age). While Wade et al (1997) reported a variation of this - a J-shaped curve: a decline in depression with age until around 75 years old, and then an upturn in prevalence.

The time period used (eg: last month, six months, lifetime), and the population sampled (eg: community-dwelling older adults) are relevant factors. For example, individuals at high risk of psychiatric disorders (eg: institutionalised or homeless) are more likely to refuse to participate in studies or are excluded from samples for practical or ethical reasons (Streiner et al 2006).

Using CCHS 1.2 data. Streiner et al (2006) asserted a decline in mood, anxiety and other mental disorders after age 55. For example, the lifetime prevalence of any psychiatric disorder declined from one in five for men aged 55-59 years to about one in sixteen after 75 years old, and from one in four to about one in twelve for women ³.

Different explanations have been proposed for the decline in mental disorders with age. These include (Cairney et al 2008):

a) Age-related hormonal changes.

² Perceived social support was measured by the Medical Outcomes Survey Social Support Scale (MOS-SS) (Sherbourne and Stewart 1991). It has four subscales - tangible support (eg: "Someone to help you if you were confined to bed"), affection (eg: "Someone who shows you love and affection"), positive social interaction (eg: "Someone to have a good time with"), and emotional-informational support (eg: "Someone to give you good advice about a crisis"). Each item is rated on a five-point scale from "none of the time" to "most of the time".

³ The CCHS 1.2 is a cross-sectional study (ie: compares groups at one point in time), so it is not possible to know if the decline is due to the cohort effect or selective attrition. A longitudinal study could establish this information.

b) Other physiological changes with age.

c) Methodological problems with study - ie: no real decline but a product of research design (eg: older adults less likely to report or admit to psychiatric problems, or more likely to forget about past experiences) (Hocking et al 1995).

d) Selective attrition - only the healthiest individuals survive.

e) Cohort effect - specific to the cohort being studied. "Proponents of the cohort interpretation argue that individuals born prior to 1920..., for some yet to be determined reason, are simply psychologically healthier than individuals born after (or considerably earlier) that time period. Older adults report fewer psychiatric symptoms because they have always been healthier than younger cohorts" (Streiner et al 2006). On the other hand, younger adults have not experienced such adversity as World War II, and are less able to handle adversity. Thus, reporting more psychiatric problems (Streiner et al 2006).

1.2. DEMENTIA AND COGNITIVE DECLINE

"Cognitive decline refers to a wide continuum of changes in cognitive function across the life course, including both age-related decline and pathological decline. Poor cognitive status, even in the absence of clinical dementia ⁴, is perhaps the single most disabling condition in old age" (Hagger-Johnson et al 2013 p120). This has led to an interest in modifiable risk factors for such a decline. Two candidates of interest are lifetime cigarette smoking and heavy alcohol consumption. The way to study the effects of these behaviours is through the longitudinal study method, which follows individuals/groups over a period of time ⁵.

1. Cigarette smoking - Early studies suggested a protective benefit (ie: smoking reduced cognitive decline ⁶) (eg: Graves et al 1991) ⁷. But selection bias may have

⁴ Late-onset Alzheimer's Disease (ie: after 65 years old) is common, but "the exact cause... remains largely unknown" (Mawanda and Wallace 2013). Infection is one possibility (appendix 1A).

⁵ Cross-sectional studies compared different age groups at one point in time, while the case-control method uses individuals already showing the problem/disorder (cases) and looks backwards at their lives (compared to controls without the disorder). This is a retrospective study, while the longitudinal study is prospective (ie: follows the group from the starting point).

⁶ The relationship being possibly due to the effect of nicotine on the neurochemistry of the brain and cell deterioration in Alzheimer's disease (eg: inhibits amyloid function) (Graves et al 1991).

⁷ In a meta-analysis, Almeida et al (2002) found that current smokers had less Alzheimer's disease

been a problem in these studies (eg: greater mortality among smokers producing the "healthy survivor effect") (Hagger-Johnson et al 2013)⁸. Thus, more recent (better designed) studies have found an association between cigarette smoking and cognitive decline (eg: Peters et al 2008⁹), or dementia (eg: Anstey et al 2007¹⁰).

2. Alcohol consumption - For example, a meta-analysis by Anstey et al (2009) found that moderate drinkers had less dementia than non-drinkers, and heavy drinkers a greater risk. Moderate drinking was defined as up to fourteen units per week for women and up to 21 units per week for men.

3. Together - The combined effect on cognitive decline may be larger for cigarette smoking and alcohol consumption rather than individually, but the evidence is mixed (Hagger-Johnson et al 2013).

The most recent study (Hagger-Johnson et al 2013), using the Whitehall II cohort (appendix 1B), found a faster cognitive decline in smoking heavy drinkers. The Whitehall II cohort study was established in 1985-8 with over 10 000 British civil servants aged 35-55 years in twenty London-based departments (Marmot and Brunner 2005).

Cognitive testing was introduced in 1997-9 (when the cohort was aged 45-69 years), and this was the baseline measure for Hagger-Johnson et al (2013). Subsequent measures were taken in 2002-4 and 2007-9. The sample comprised 6473 individuals^{11 12}. Four cognitive tests were

(relative risk 0.74) than never smoker from 21 case-control studies, but a greater risk of dementia based on eight cohort studies.

⁸ Methodological differences between studies include type of study (eg: cross-sectional), length of follow-up; sample size; characteristics of sample; outcome measures; criteria for assessing Alzheimer's disease, for example; and measure of smoking (Peters et al 2008).

⁹ A meta-analysis of 28 papers, current smokers had a greater risk of Alzheimer's disease (1.59 times), vascular dementia (1.35), unspecified dementia (1.16), and cognitive decline (1.20) than never smokers, but only the first was significant. There was no difference between former smokers and never smokers, but Peters et al (2008) pointed out: "A note of caution should be sounded with regard to the interpretation of the data relating to ex-smokers as the studies were not always consistent or clear with regard to the time since stopping smoking and the level of smoking that had been previously been usual".

¹⁰ Anstey et al (2007) performed a meta-analysis on nineteen prospective studies (with at least twelve months follow-up) involving over 40 000 individuals. Current smokers had a significantly greater risk for Alzheimer's disease (1.79 times), incident vascular dementia (1.78), and any dementia (1.27), and greater yearly decline in cognitive performance than never smoker. Former smokers had a greater cognitive decline than never smokers, but less of a risk than current smokers.

¹¹ This is a larger sample than other studies on the topic.

¹² Note that as civil servants they are all white-collar workers, and the civil service is not representative of other employers with its rigid hierarchy. The cohort also reflects employment in the 1980s (ie: less women, and ethnic minorities in civil service) (Marmot and Brunner 2005).

used:

- 65 verbal and mathematical reasoning items in ten minutes.
- Short-term verbal memory - two minutes to recall twenty words.
- Two tests of verbal fluency - eg: as many words beginning with "L" in one minute (phonemic fluency), and as many types of animals in one minute (semantic fluency) ¹³.

The combination of scores of each test created the global cognitive score. This score was converted into a z-score (or "standardised score") to overcome any measurement error on the individual tests. The z-score is based on the mean and standard deviation of the baseline measure (table 1.1).

- Assuming a normal distribution of data, a z-score is "the number of standard deviations a score is from the mean" (Coolican 1999).

$$z = \frac{\text{individual score minus mean}}{\text{standard deviation}}$$

- For example, with a mean of 10 for the cognitive tests and a standard deviation of 2, an individual with a test score of 7 has a z-score of -1.5.

$$z = \frac{7 - 10}{2} = \frac{-3}{2} = -1.5$$

Table 1.1 - Z-scores.

Reports of smoking status (current, ex-, or never smoker) and units of alcohol per week (no, moderate, or heavy ¹⁴) were self-reported. Heavy drinking was defined as greater than 14 units per week for women and 21 units for men ¹⁵. Together nine groups were produced ¹⁶, of which "never smoked/no alcohol" (n = 597), and "current smoker/heavy drinker" (n = 209) were the two extremes.

¹³ Some of the tests were dependent on writing speed (Sabia et al 2012).

¹⁴ Hagger-Johnson et al (2013) admitted that "participants reporting 0 alcohol units per week in the past 7 days were a heterogeneous group comprising occasional drinkers, lifetime abstainers, those with existing morbidity (including 'sick quitters') and those not drinking alcohol for other reasons." (p123).

¹⁵ These are the recommended limits by the UK Government.

¹⁶ (1) never smoked/no alcohol, (2) never smoked/moderate drinker, (3) never smoked/heavy drinker, (4) ex-smoker/no alcohol, (5) ex-smoker/moderate drinker, (6) ex-smoker/heavy drinker, (7) current smoker/no alcohol, (8) current smoker/moderate drinker, and (9) current smoker/heavy drinker.

The latter showed a cognitive decline of 36% faster than the former over the ten years of data. This was calculated as an age effect of an additional two years over the ten-year follow-up for current smoking heavy drinkers (Hagger-Johnson et al 2013) ¹⁷.

Hagger-Johnson et al (2013) adjusted their analysis to take account of potential confounding factors.

a) Possible cognitive impairment at baseline - The removal of such individuals from analysis did not change finding.

b) Reverse causation (prior cognitive decline produces heavy alcohol consumption) - This could not explain the combined effect of alcohol and smoking on cognitive decline.

c) Behaviour change during study (ie: smokers who stopped or heavy drinkers who cut down) - When these individuals are excluded from analysis, the cognitive decline for smoking heavy drinkers is slightly more.

d) Distortion by outliers - Excluding heavy smokers (more than thirty cigarettes per day) and very heavy drinkers (more than thirty-five units per week) did not alter finding.

e) Male smoker effect - Men are more likely to smoke (two-thirds of current smoker group), but this did not account for finding.

f) Combined cognitive test hid specific differences in cognitive decline - Separate analysis of the memory test score found no significant decline, but decline for non-memory tests did show some relationship as overall results.

g) Healthy survivor effect - "The combined effect of current smoking and heavy alcohol drinking on decline may be underestimated, as a result of healthy survivor effects from baseline to end of follow-up" (Hagger-Johnson et al 2013 p124).

h) Cumulated risk - Data on smoking and alcohol use before 1997-9 was added (ie: since 1985-8), and the cognitive decline is greater for smoking heavy drinkers.

Hagger-Johnson et al (2013) pointed out the following implications from their study in relation to previous research. Firstly, "that people should not drink

¹⁷ Assumptions were made about the missing data, but this had a limited effect (Sabia et al 2012).

more heavily in the belief that alcohol is a protective factor against cognitive decline", and secondly, "that alcohol use and cigarette smoking do not appear to 'cancel each other out'. Their combined effect appears to accelerate cognitive decline" (p124).

1.2.1. Depression and Other Factors and Dementia

da Silva et al's (2013) review of fifty-one studies found that adult depression was associated with increased risk of Alzheimer's disease in later life ¹⁸.

There are three possible relationships (Richards et al 2014):

i) Anxiety and depression cause later cognitive impairment (or reduce the threshold for its manifestation).

ii) Anxiety and depression are responses to emerging cognitive impairment.

iii) Anxiety and depression are risk indicators of cognitive impairment (ie: common cause).

However, Richards et al (2014) found that affective symptoms (eg: depression and anxiety) aged 13-53 years old predicted self-reported memory problems at age 60-64 years, but not objectively measured cognitive performance. This study was based on 1668 individuals born in one week in March 1946 in England, Scotland and Wales (known as British 1946 birth cohort or Medical Research Council National Survey of Health and Development).

The objective measure of short-term verbal memory was the immediate recall of three sets of fifteen words or after one-minute delay. There was also a visual search task which involved crossing out as many of the letters "P" and "W" on a page of 600 random letters in one minute. Both speed and accuracy were scored. Cognitive impairment was defined as one standard deviation below the mean or more. The subjective measure of cognitive impairment was answering "often" or "very often" to memory problems in the past twelve months (eg: finding the right word, remembering where put things). Measures of anxiety and depression had been taken at 36, 43 and 53 years old.

Of the 57 individuals classed as the "severe depression" group, 49.1% reported memory problems compared to 13.9% in the "no depression" group (n = 741).

¹⁸ Richards et al (2014) noted two key problems with the studies - (i) the timing and length of depression varies over adult life, and (ii) the type of cognition affected.

There were no significant differences in the means of the objective tests.

Chang et al (2013) reported that depression and physical health problems among older men had a greater impact on cognitive decline than these conditions individually¹⁹. This observation was based on a study of 207 cognitively impaired men 75 years or older in Taiwan, who were divided into three groups - cardiovascular problems (eg: coronary heart disease; hypertension) (CVC), late-life depression (LLD), and late-life depression and cardiovascular problems (LLD + CVC), along with healthy controls (HC). Cognitive functioning scores (eg: recall test) were lowest for the LLD + CVC group (and highest for the HC group).

Mild cognitive impairment (MCI) can be a forerunner of dementia as up to a quarter of MCI sufferers progress to dementia (Bruscoli and Lovestone 2004). Diabetes mellitus is a risk factor for both MCI and dementia.

Velayudhan et al (2010) recruited 103 White European men and women aged at least 65 years old in south London. These individuals were classed as suffering from MCI, which is memory impairment without a decline in general cognitive functioning or affect on daily living. Technically, it was a memory score 1.5 standard deviations below age norms. The presence of diabetes was based on self-report and doctors' information, but no measures of glycaemia to ascertain undiagnosed cases. Four years later, sixty-one participants²⁰ were found and assessed for dementia.

Nineteen individuals were diagnosed with dementia (31%). After controlling for sociodemographic factors and other medical history, participants with diabetes were nearly three times more likely to be in this group of nineteen.

Poor sleep quality is also related to cognitive impairment. For example, Amer et al (2013) found that, among over 60s in a residential home in Egypt, significantly more individuals with self-reported poor sleep²¹ had cognitive impairment based on a test of

¹⁹ Late-life depression and structural brain changes link to cognitive deficits. Kohler et al (2010) performed magnetic resonance imaging (MRI) scans on thirty-five adults with major depression and 29 controls in England. At a follow-up eighteen months later, individuals with depression had more severe white matter lesions in the brain, and greater deficits in memory and executive functions than controls.

²⁰ Seventeen had died, six researchers lost contact with, three moved far away, and sixteen withdrew.

²¹ As measured by the Pittsburgh Sleep Quality Index (PSQI) (Buysse et al 1989). This has nine questions about sleep quality and disturbance in the past month (eg: sleep duration and efficiency - amount of time asleep as percentage of time in bed). A score of six or more is defined as "poor sleep" and five or less as "good sleep".

cognitive ability ²² than good sleepers (52% vs 24%). The PQSI score (higher equals poorer sleep) was significantly negatively correlated with the MMSE score (lower score equals impairment).

1.2.2. Physical and Cognition Decline

The "common cause hypothesis" (eg: Christensen et al 2001) sees the decline in physical and cognitive abilities with age as "driven by a unifying process" (a common cause) (Clouston et al 2013) ²³. Common causes hypothesised include changes in the cerebellum, which regulates motor co-ordination and balance (physical) and links to the cortex (cognitive), or telomere shortening when genes copy themselves (Clouston et al 2013).

From their literature review, Clouston et al (2013) found correlations between grip strength and mental state, and between changes in walking speed and changes in fluid cognition (ability to learn new things).

Clouston et al (2013) found thirty-six longitudinal studies, published in English between January 2000 and October 2011, of adults over 40 years old that included objective measures of physical and cognitive functioning. The studies varied in size (n = 60 to over 17 000), in length of follow-up (1-20 years), and age of participants (41-100 years old). All but one study was based in a Western country. The common measures of physical functioning included grip strength, walking speed, and flamingo stand times (stand on one leg), while cognitive functioning was assessed by mental state examinations primarily.

1.2.3. Early Life and Dementia

Could early life factors, like birth weight and experience, or parental socio-economic status, influence

²² The Mini-Mental State Examination (MMSE) (Folstein et al 1975), which measures, for example, immediate and short-term memory, and attention.

²³ Ramsar and Baayen (2014) argued that cognitive decline with age was not inevitable, and the lower scores on tests by older adults was a product of the tests.

A common test of memory is paired associate learning (PAL). Individuals are given word pairs to learn, and then tested by the presentation of one of the pair in order to recall the other. The word pairs can be common (eg: dog-bark) or uncommon (eg: ball-ostrich). Ramsar and Baayen (2014) stated that "PAL tests paint a misleading picture of our cognitive abilities because they do not take into account prior knowledge of the words being tested, which grows with age and experience" (p28). Learning the uncommon (or nonsense) pairs of words is harder for older adults because of their greater experience of which words are associated together in everyday life. PAL tests assume that all participants have equal knowledge of the words used in the test, which is not the case. "Learning increases the amount of information that our brains have to process, which inevitably affects test performance" (Ramsar and Baayen 2014 p29).

cognitive decline in old age? For example, lower birth weight is associated with lower IQ scores in childhood, adolescence, and adulthood (eg: Richards et al 2002).

To answer this question properly requires longitudinal data from a birth cohort. One such is the Hordaland Health Study (HUSK) based on all residents of the city of Bergen, Norway, born in 1925-7. Skogen et al (2013) traced and tested 346 (of original 3341) at age 72-74 years (ie: between 1997 and 1999). Data were available on the child at birth, the mother's health, and father's occupation. Six tests of cognitive abilities were used (eg: generate as many words beginning with "S" in one minute).

The researchers concluded that "the environment present around birth" had little association with cognition in old age. Parental socio-economic status was the only significant association with the overall cognition score (ie: positive correlation).

1.2.4. "Demented"

Naue and Kroll (2008) argued that individuals receiving a diagnosis of dementia are assigned the negative identity of "demented other"²⁴, and are treated as no longer "full persons capable of making reasonable decisions". Thus, a "them" and (healthy) "us" is created.

The terminology used can hide who the individual is such that "the individual loses his identity as a person and is identified as a disease... assuming the person to be a passive substrate of the disease" (Mintz 1992 quoted in Sabat et al 2011). Furthermore, the "positioning of the patient as passive through the use of language constitutes a type of identity formation through the development of a narrative or an implied narrative about the person who is a patient" (Sabat et al 2011 p285). This can lead to the depersonalisation of the individual.

This can be seen in interactions between carers and the sufferers of dementia. "For example, a person diagnosed with Alzheimer's disease expresses anger for

²⁴ Whether an individual is called a "demented person" or a "person diagnosed with dementia", for example, is important "because language is not 'neutral'. It is always a reflection of the context, in which it is used. It may be used in an unreflected and automatic way, and the particular vernacular may vary across time, class, education, and scientific discipline. Language reflects power relationships within society and its use may have a particular motivational significance for those who inhabit a socially dominant position over others" (Naue and Kroll 2011 p294). Yet, at the same time, Naue and Kroll (2011) admitted that renaming is only the first step because "the diagnosis of dementia does exist and is present in a person's life and in the term 'person diagnosed with dementia'. Hence, it is a description of an actually occurring process which labels a person as being demented" (p295). Most important is the attitude towards such individuals (whatever term is used) - "The demented other' is not demented by herself or himself, she or he is perceived as being demented" (Naue and Kroll 2011 p295).

reasons that 'healthy others' (formal or informal carers) do not understand. Given that the carers have already viewed the person with Alzheimer's disease principally in terms of the diagnosis, they label the person's anger as 'irrational hostility'. That is, because the carers do not know the reasons for the person's anger, it is therefore interpreted as 'irrational'... The reasons for the anger may, indeed, not be readily apparent to the observers, but that, in itself, does not mean that the person with Alzheimer's disease is angry for no reason and that the anger is symptomatic of Alzheimer's disease rather than a logical reaction to being treated in an objectionable way" (Sabat et al 2011 pp286-287).

Sabat et al (2011) distinguished between three different aspects of selfhood. "Self 1" is personal identity experienced through memories and expressed through "I", while "Self 2" refers to mental and physical attributes of an individual (eg: eye colour; religious beliefs). Sufferers with dementia are more often seen as "Self 2" only by "health others". The key attribute being the diagnosis, and that becomes everything about the person - the "demented patient" (similar to Goffman's (1968) idea of "spoiled identity"). "Selves 3" describes the social personae created through social interactions, and it requires the "co-operation" of others. So, if an individual is perceived as the "demented patient", then other possible identities are blocked. "As a result, the social life of the person diagnosed will be greatly restricted and the treatment given to him or her will verge more and more on what Kitwood (1997) called 'malignant social psychology'. Thus the person may be humiliated, depersonalised and have his or her self worth unremittingly diminished. If the person then becomes depressed or withdrawn, the depression and withdrawal will be viewed as a symptom of dementia rather than as a reaction to being treated in dysfunctional ways..." (Sabat et al 2011 p289).

Sabat et al (2011) want the individual with dementia to be seen as "principally a person whose behaviour is not completely driven by a disease process".

1.2.5. Carers

Whitebird et al (2012) noted that "few tasks are more challenging than caring for a family member with dementia", and the stress involved can have a negative effect on the health and well-being of the caregiver.

Different programmes have been developed to help with this stress. One is mindfulness-based stress reduction (MBSR), which trains individuals to focus attention on the present, with non-judgmental awareness, and accept all experiences with openness and curiosity.

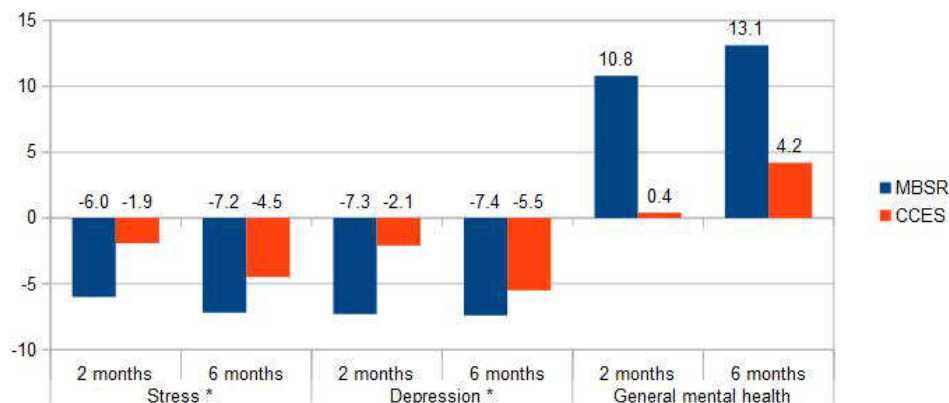
Meditation is a key element of the programme (Whitebird et al 2012).

MBSR programmes have been reported as beneficial for sufferers of different medical conditions (eg: pain; cancer). Whitebird et al (2012) detailed a randomised controlled trial called the Balance Study that showed its benefits for family caregivers of an individual with dementia (as compared to standard community caregiver education and social support; CCES).

Seventy-eight caregivers recruited in the upper MidWest USA (eg: Minnesota) were randomly assigned to MBSR or CCES programmes for eight weeks. The MBSR programme involved instructions about meditation and yoga, while the CCES programme was based around education on issues related to caregiving, and social support.

The outcome measures taken at baseline, end of programme (2 months) and at six months included the 10-item Perceived Stress Scale (PSS) (Cohen et al 1983), and self-reported questionnaires on depression, anxiety, general mental and physical health, and caregiver burden (eg: perception of demands of caring).

Individuals in the MBSR condition reported significant improvements in general mental health at two and six months, while the CCES group showed little change. The former also showed significantly less stress and depression than the CCES participants at two months, but not at six months (figure 1.1). This was due to a steady improvement in the CCES group over the six months compared to immediate improvements in the MBSR group. All other measures showed small improvements over the six months.



(* Lower score = less of disorder, otherwise higher score = improvement)

(Data from Whitebird et al 2012 table 3 p 682)

Figure 1.1 - Mean changes in scores on selected measures compared to baseline.

Table 1.2 outlines the main strengths and weaknesses of the study.

Strengths

1. Real-life study with programmes that are not expensive or difficult to administer.
2. Use of well-established psychometric questionnaires to measure outcomes.
3. Programmes "matched for time and attention" - ie: 8 weekly 2.5-hour small group sessions and a 5-hour day.
4. Random allocation of participants to conditions.
5. Low drop-out rate - 72 of 78 completed programmes, and 70 completed 6-month follow-up questionnaires. The average number of the weekly sessions attended was 7 of 8.

Weaknesses

1. Short-term study only.
2. Outcome measures self-reported (as was adherence to programme) and no independent verification.
3. Sample not necessarily representative as volunteers - 98.7% White, and 97% of sample female.
4. Sample could be seen as "cherry-picked" (ie: most likely to respond) because of long list of exclusion criteria: "they self-identified as a primary caregiver of a community-dwelling family member who had memory loss consistent with dementia; were older than 21; spoke English; could read the course materials; were willing to attend all group sessions; had not participated in a community caregiver support program; had not practiced meditation, yoga, or tai chi in the previous year; had to score 5 or higher on a single-item measure of self-perceived stress (scale of 1-10); had no psychiatric hospitalizations or diagnoses of mental illness in the previous 2 years; had not been taking antipsychotic or anti-convulsion medication; and had no thoughts of harming themselves in the previous 6 months" (Whitebird et al 2012 p678).
5. Not blinded as both researchers and participants knew which condition allocated to.

Table 1.2 - Main strengths and weaknesses of Whitebird et al (2012) study.

1.3. APPENDIX 1A - ALZHEIMER'S DISEASE AND INFECTION AS A CAUSE

Infections could lead to inflammation of the brain, which causes Alzheimer's Disease (AD), or produce an immune system response that creates inflammation in the brain. "Although such possibilities have been suggested, no specific pathogen has been linked to late-onset AD in humans" (Mawanda and Wallace 2013 p162).

Mawanda and Wallace (2013) reviewed the evidence from seventy-seven studies around four questions.

1. Does AD behave (its neuropathology) as if it has an infectious cause?

Inflammation within the brain is a key aspect of AD. "Although inflammation is not triggered only by infectious pathogens, it is typical of most infectious diseases; hence AD neuropathology could be a manifestation of an infection" (Mawanda and Wallace 2013 p163).

2. What infectious agents could be causing AD?

i) Herpes simplex virus type-1 (HSV-1) - Post-mortems have found a significantly higher frequency of HSV-1 (a double-stranded DNA virus) and an AD susceptibility gene (ApoE4) in AD sufferers than controls, and HSV-1 anti-bodies have been found more often in the blood of AD-free individuals who later develop AD than those who do not. But there are many studies which do not have the same findings. "Thus, lack of consistency leaves studies linking HSV-1 to the causation of AD inconclusive" (Mawanda and Wallace 2013).

ii) Chlamydia pneumoniae (CP) - This intracellular bacterium, most often associated with lower-respiratory-tract disease, has been found in post-mortem brains of AD sufferers (eg: 17 of 19 vs 1 of 19 controls; Balin et al 1998). In another study, Paradowski et al (2007) found CP in the cerebro-spinal fluid of just under half of 57 AD patients compared to 10% of controls. But there are studies which do not support these findings. Of nine post-mortem studies, five found no evidence of CP. In total, only 44 of 113 (39%) AD sufferers had CP in the brain tissue analysed. Mawanda and Wallace (2013) felt: "Again, ambiguous study findings leave the exact role of C. pneumoniae in the pathogenesis of AD unclear" (p166).

iii) Borrelia burgdorferi - This is a bacterium transmitted to humans via the bite of infected ticks. Little evidence from rigorous studies, and so, "the role of B. burgdorferi in the aetiology of AD remains unclear" (Mawanda and Wallace 2013 p168).

iv) Helicobacter pylori - These bacteria, associated with gastrointestinal disorders, have been found in the gut of significantly more AD sufferers than controls. But the problem is how this pathogen causes AD as it does not live in the brain. The effect would have to be indirect

(eg: through the immune system response to it which produces brain inflammation).

v) Prions - These are abnormal prion proteins, and are the cause of neurodegenerative disorders like Creutzfeldt-Jakob disease (CJD). But "known prion disease are generally rare, which is not compatible with the incidence and prevalence rates of AD" (Mawanda and Wallace 2013).

vi) Others - eg: HIV; influenza viruses. Many different pathogens have been discovered by a small-scale study, but not replicated.

3. Could an infection cause AD indirectly?

For example, children who experience severe infections have cognitive impairments in adulthood. The idea is that the infection, in some way, damages the developing central nervous system, and this is manifest as later life AD. Such children tend to develop cognitive impairments soon after the infection rather than just in older age.

4. Could an infection simply exacerbate central nervous system damage already present?

There are few studies here, and the results are contradictory (Mawanda and Wallace 2013).

Mawanda and Wallace (2013) concluded their systematic review: "The evidence compiled from the literature linking AD to an infectious cause is inconclusive, but the amount of evidence suggestive of an association is too substantial to ignore" (p161).

1.4. APPENDIX 1B - WHITEHALL II STUDY

The Whitehall I study began in the 1960s (Reid et al 1974), and showed that, among middle-aged male British civil servants, the risk of death (eg: coronary heart disease) was negatively correlated with grade. Clerical staff (lowest grade) were over twice as likely to die as senior staff. This is the social gradient and health. The Whitehall II study added women in a new cohort of British London-based civil servants with follow-up every five years (questionnaire and/or medical screening) (Marmot and Brunner 2005) (table 1.3).

| | | |
|--------------------|---------|------------------------|
| Phase 1 (baseline) | 1985-8 | n = 10 308 |
| Phase 2 | 1989-90 | n = 8133 |
| Phase 3 | 1991-93 | n = 8637 |
| Phase 4 | 1995-96 | n = 8629 |
| Phase 5 | 1997-99 | n = 7830 ²⁵ |
| Phase 6 | 2001 | n = 7344 |
| Phase 7 | 2002-4 | n = 6914 |
| Phase 8 | 2007-9 | n = 6473 |

(Source: Marmot and Brunner 2005 table 2 p253)

Table 1.3 - Phases of Whitehall II study.

Using the whole Whitehall II data, Sabia et al (2012) reported that middle-aged men who smoked had a faster cognitive decline than never smokers. But there was no difference among women, and for men who were ex-smokers for over ten years. As well as the categories of current, ex-, and never smoker, the researchers distinguished persistent smokers (current and continuous) from intermittent smokers (quit but started again).

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2. THE (POSITIVE) EXPERIENCE OF STRESS

- 2.1. Coping with stress
 - 2.1.1. Types of MFC
- 2.2. Phenomenological approach
- 2.3. References

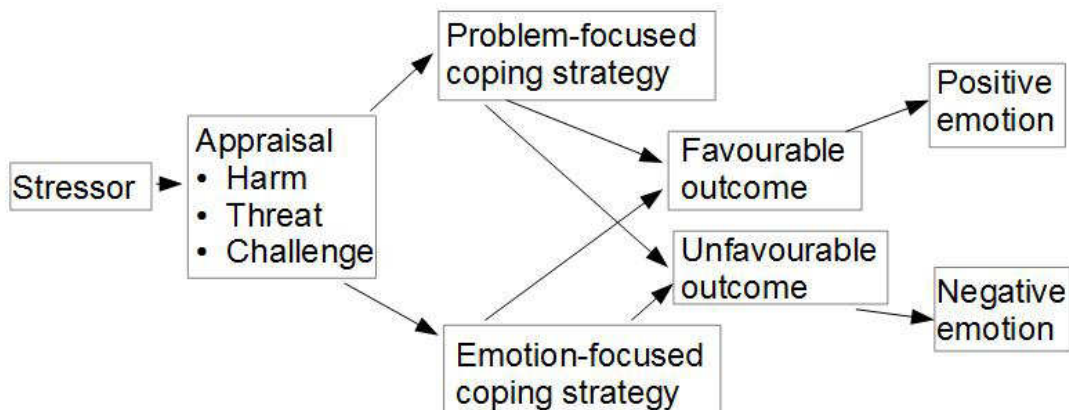
2.1. COPING WITH STRESS

The Cognitive Theory of Stress and Coping (Lazarus and Folkman 1984) proposed that a stressor is appraised as harm, threat, or challenge. Harm appraisal leads to negative emotions like sadness or anger, while anxiety and fear are the negative emotions associated with threat appraisal. A challenge appraisal produces positive emotions like excitement and confidence (Folkman 2008). Then coping strategies are implemented (figure 2.1).

Lazarus and Folkman (1984) proposed two types of coping responses to deal with stress:

a) Problem-focused - This deals actively with the cause of the stress (eg: remove stressor).

b) Emotion-focused - This concentrates on the emotions experienced during stress (eg: learning to relax).

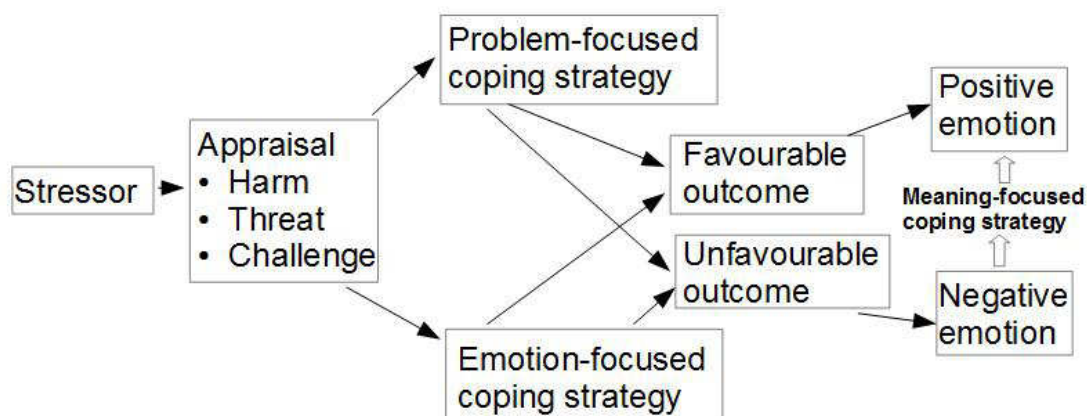


(Based on Folkman 2008 figure 1 p6)

Figure 2.1 - Basic Cognitive Theory of Stress and Coping.

Folkman and Moskowitz (2007) added another category of responses called meaning-focused coping (MFC) (figure 2.2), particularly for when the other two types have

failed ²⁶, which has five types. Folkman (2008) defined it thus: "the person draws on his or her beliefs (eg: religious, spiritual, or beliefs about justice), values (eg: 'mattering'), and existential goals (eg: purpose in life or guiding principles) to motivate and sustain coping and well-being during a difficult time" (p7) ²⁷.



(Based on Folkman 2008 figure 2 p6)

Figure 2.2 - Adapted Cognitive Theory of Stress and Coping.

Park and Folkman (1997) saw three positive consequences of MFC - strengthening social (eg: better relationships) and personal resources (eg: changing values, and new coping skills. Tedeschi and Calhoun (2004) went further and referred to "post-traumatic growth", which is "the positive psychological changes that occur when an individual responds to serious life stress. It is a constantly changing process that may involve personal characteristics, self-exposure and social support. After cognitive processing, individuals' objectives and assumptions about life change, and they develop a new reference system for their cognitive structures..." (Guo et al 2013a p88). Individuals who use MFC strategies show such behaviour.

Guo et al (2013a) questioned over 300 adolescent survivors of the earthquake in Sichuan Province, China, on 12th May 2008, two years later. Strong MFC was associated with more post-traumatic growth, higher well-

²⁶ In uncontrollable situations, MFC may be the best strategy, and, in fact, active coping has negative consequences in such situations (Guo et al 2013a).

²⁷ "Meaning-focused coping does not attempt to change a problematic situation, nor does it directly decrease the pressure caused by negative emotions or distress. Instead, MFC aims to change the evaluation of a situation and to make beliefs, goals, and stressful situations more consistent so that individuals are more open to dealing with stressful situations" (Guo et al 2013a pp87-88).

being and positive mood scores, and less depressive symptoms. Problem-focused coping was associated with less negative outcomes only (eg: depression), and emotion-focused coping had little benefit ²⁸.

2.1.2. Types of MFC

a) Benefit-finding - The most common type of meaning-focused coping, and reported as a "growth in wisdom, patience, and competence; greater appreciation for life, greater clarity about what matters, strengthened faith or spirituality; and improved quality of social relationships" (Folkman 2008 p7) or "the process of deriving positive growth from adversity" (Cassidy et al 2014).

Benefit-finding has been linked to lower levels of depression and more positive well-being in situations of extreme stress (eg: chronic illness; war) (Helgeson et al 2006).

However, it can be maladaptive if it discourages problem-focused coping (Folkman 2008).

Recent research has suggested that benefit-finding is a multidimensional construct. For example, Tomich and Helgeson (2004) distinguished six elements in their seventeen-item ²⁹ Benefit Finding Scale (BFS) - acceptance, empathy, appreciation, family domain, positive self-view, and reprioritisation. The Perceived Benefit Scale (PBS) (McMillan and Fisher 1998), however, has thirty items ³⁰ covering eight factors - lifestyle changes, material gain, increases in self-efficacy, family closeness, community closeness, faith in people, compassion, and spirituality.

The BFS was designed to use with breast cancer sufferers (or chronic illness), while the PBS asks respondents to think of the most negative event experienced in the past five years. Cassidy et al (2014) wanted to develop a more generic multidimensional measure of benefit-finding. They collected forty-four items from other scales, and asked 855 undergraduates in Northern Ireland to consider difficult times in their lives. Factor analysis of the results produced six factors covering twenty-eight items (table 2.1). This is the General Benefit Finding Scale (GBFS).

²⁸ Guo et al (2013b) developed the meaning-focused coping (MFC) scale, which has 26 items divided into eight dimensions (eg: rumination, acceptance, values and outlook on life), and each item scored 0-4.

²⁹ Eg: "Having breast cancer, has helped me become a stronger person, more able to cope effectively with future life challenges".

³⁰ Eg: "I am a more effective person because I went through this event".

- Acceptance - "Taught me how to adjust to things I cannot change".
- Family bonds - "Brought my family closer together".
- Growth - "Made me a more effective person".
- Relationships - "Helped me become more aware of the support available from others".
- Empathy - "Made me more compassionate to those in similar situations".
- Reprioritisation - "Led me to live my life more simply".

(Source: Cassidy et al 2014 table 1 p275)

Table 2.1 - Examples of items on GBFS.

b) Benefit-reminding - This is "effortful cognitions in which the individual reminds himself/herself of the possible benefits stemming from the stressful experience" (Folkman 2008 p8).

For example, among sufferers of fibromyalgia, on the days where they made greater efforts to remind themselves of the benefits that had come from their chronic pain and illness, they reported more positive mood in their diaries (Tennen and Affleck 2002).

c) Adaptive goal processes - This involves setting "higher order" goals that give meaning to life when the everyday valued goals are hampered by the stressor. It is the substitution process that is key. So, for example, the loss of a desired job is stressful in terms of the valued goals of promotion and higher earnings being blocked, but a new goal of seeking alternative meaning in life could be substituted to help cope with unemployment.

d) Reordering priorities - Similar to the previous coping strategy, but the emphasis is upon narrowing the focus of goals to the most important. For example, in a study of mothers caring for children with chronic illness, half gave up paid employment to stay at home with the child (Wilson et al 2005).

However, Folkman (2008) offered a note of caution: "The reordering of priorities can be a very stressful process in itself. To acknowledge that priorities need to be reordered involves an acceptance by the individual that his/her world has changed, that things are not as they were or as they were expected to be. The person appraises his or her world differently now than before" (p10).

e) Infusing ordinary events with positive meaning - Folkman (1997) found that caregivers of AIDS sufferers took ordinary events during that time, like watching a beautiful sunset or enjoying a good film, and

"deliberately infused them with positive meaning in order to experience a positive moment" (Folkman 2008).

Folkman (1997) found that both positive and negative emotions occurred together during the highly stressful situation of caring for a loved one dying of AIDS. This challenged the assumption that negative emotions only occurred with stress appraised as harm or threat.

Subsequent studies have shown the role and benefits of positive emotions in stressful situations. For example, Fredrickson et al (2003) reported that positive emotions aided in resilience to depression after 9/11, while Keltner and Bonanno (1997) found that bereaved individuals who laughed at least once while telling a story about the lost one had better adjustment.

2.2. PHENOMENOLOGICAL APPROACH

The phenomenological approach concentrates on subjective lived experience and the personal world of the individual. The meaning of the experience and the lived world is crucial (Denovan and Macaskill 2013).

Denovan and Macaskill (2013) used interpretative phenomenological analysis (IPA) in their semi-structured interviews with ten first-year social science undergraduates at a UK university. The interviews began with the following vignettes: "Think about your experience of coming to university last September. Now I'd like you to vividly imagine that a friend of yours is starting university next year and is interested in studying for the same degree as you. They have asked you for advice" (p1006). The aim was to encourage the interviewees to talk about their experiences of coping with the transition to university and related stress. The transcripts of the interviews were subsequently analysed for themes.

Denovan and Macaskill (2013) noted five main themes:

1. All the change - This covered issues like independent living, homesickness, and the difference between school and university. "John" summed up the many changes at the same time: "Having to sort myself out and being more independent and with all the change I found it quite hard to like begin with and it's really quite scary in the first few weeks just thinking 'oh God I'm here by myself, what am I doing now?' It was like a lot of things were changing and happening all at once" (p1008).

2. Expectations of university - The greater the gap between expectations and reality produced more stress. For example, "Claire" said: "I came expecting like that

you'd come here and make sort of loads and loads and loads of friends and it would be great but it didn't really happen like that for me. I feel upset it didn't work out better" (p1011).

3. Academic focus - Self-discipline in relation to work was important, as summed up by "Lynn": "Try and stick to like a planned timetable cos it really does help cos I've started doing that now in semester two, and I should've done it in semester one but I didn't, and I'm a lot more at ease. I'm not panicking about what I've got to do and where I've got to be" (p1012).

Those individuals with a clear goal were more positive and less stressed than those lacking focus. As "Jane" said: "I can see my goal and the end of it so I'm going towards it so I know that I'm going to get it so it actually makes me closer you know to my goal and my dreams so I try not to see it as a very stressful thing to do, instead I see it as a very beneficial and very interesting thing to do, so I try to concentrate on the positive side of it not the negative" (p1013).

4. Support network - Making friends and establishing a support network was seen as important "for enjoyment, fitting in, avoiding isolation, and for encouraging interest and attendance" (Denovan and Macaskill 2013).

5. Difficulties - The interviewees mentioned problems relating to studying, housemates, and finances. For example, with housemate difficulties, the interviewees confronted the situation and took action to change it (including moving). This was an example of adaptive coping, which is seen as more effective. But, in other situations, like study-related problems, the students did not use such coping (eg: focusing on social life to avoid stress of essay deadline).

Overall, the students used a variety of coping strategies. Positive psychological strengths, like optimism, helped in positive adaptation to stress. Stress can be reduced by optimism, for example, as higher optimism leads to active coping and greater use of social support. Higher self-efficacy, self-control, and confidence are also important (Denovan and Macaskill 2013).

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