PSYCHOLOGY MISCELLANY

No.166 - May 2022

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1. PREGNANCY LOSS AND AMBIVALENCE

1.1. INTRODUCTION

Pregnancy loss can be "a particularly difficult life event, immediately defying the scripts people may have for their own autobiographies (particularly as these relate to their reproductive lives) and overturning their expectations of grief and bereavement" (Kuberska and Turner 2019 p91).

But "there are few widely accepted culturally-sanctioned ways for dealing with pregnancy loss, such as memorialisation rituals (in particular in the western world), coupled with the often unexpected nature of miscarriage, termination for foetal anomaly, or stillbirth, means that bereaved people - and those around them - are forced to forge their bereavement paths as they go along, questioning many previously held assumptions about pregnancy, parenthood, and grief" (Kuberska and Turner 2019 p91) [1].

Introducing a research project entitled "Death Before Birth: Understanding, informing and supporting choices made by people who have experienced miscarriage, termination and stillbirth", Kuberska and Turner (2019) observed that a recurring theme was "ambivalence", "manifesting in a range of tensions and frictions between what happened and what people expected to happen when it came to having a baby, and between personal experiences and social, political or legal norms" (pp91-92).

Ambivalence exists at different levels, including physiological (eg: no foetus but breastmilk produced), psychological (eg: an impact on the identity as "parent"), and practical (eg: decisions about disposal of "pregnancy remains"). "Frictions can be exposed in a

[1] Riches and Dawson (2000) found "feelings of enormous isolation on the part of bereaved mothers, strengthened in most instances by the approach 'of nurses, midwives, doctors, and even partners, who advised them to forget it and "get on with having another"' " (Smidova 2019 p95). Acquaintances and even close friends could "fail to appreciate that their [mother's] grief is the result of the death of a real, existing person" (Riches and Dawson 2000 quoted in Smidova 2019).

number of areas: a desire to keep a baby close can be incompatible with practical exigencies; a wish for time to stand still clashes with bureaucratic and medical demands that require action; previously welcome comments and questions about the pregnancy become unwanted when the pregnancy is lost" (Kuberska and Turner 2019 p92) [2].

The special issue of the journal, "Women's Studies International Forum" that focused on the "Death Before Birth" project included auto-ethnographical or autobiographical work as well as studies of the "ways in which external political, socio-legal and historical factors impact upon the experience of pregnancy loss" (Kuberska and Turner 2019 p92).

1.2. STILLBIRTH

"Stillbirth" is defined, at least in the UK, as "the death of a baby following 24 weeks' gestation" (Murphy 2019 p35).

Reflecting on the emotional experience for the woman, Murphy (2019) emphasised that stillbirth is "a social experience". From interviews with twenty-two bereaved mothers and fathers in the UK, Murphy (2019) showed how "the experience of bereaved motherhood can be seen to be socially informed by considering how societal perceptions about what it means to be a 'good mother-to-be', conspire to impact negatively on women bereaved by stillbirth" (p35) [3].

The "classic" research in this area was performed by Lovell (1983), who showed that the explanations given to parents about the pregnancy loss varied depending on class and culture, and that a "hierarchy of grief" existed among healthcare professionals. This "suggested that a miscarriage was not as bad as stillbirth which, in turn, was not as bad as a neonatal death" (Murphy 2019 p36) [4]. This work and Murphy (2013) highlighted the ambiguous identity of the woman in hospital after

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[2] Referring to the Czech Republic, Smidova (2019) presented a tension between "emerging more intimate practices of grief, bereavement and last rites related to peri-natal loss in the context of Post-Socialist and late-modern paternalised healthcare, medicalisation of life-events and concealment of death" (p94).

[3] Layne (2000) commented on an idea of the "moral mother" (eg: Chodorow 1978): "[i]t is not surprising, since the 'successful production' of a baby may be credited as a moral achievement, the result of self-discipline and labour, that the inability to bear children is often attributed to a moral failing on the part of the woman" (quoted in Murphy 2019).

[4] Murphy (2019) described her own experience: "My second child died at 27 weeks' gestation and, soon after giving birth, I overheard the midwives discussing my case: one of them said, 'It's more like a miscarriage really'. At that moment my overwhelming feeling was that they had devalued my experience" (p36).

pregnancy loss - patient or mother. While, "for women who lost their first child, the identity of 'bereaved parent' gave rise to a conundrum: how could they be any sort of parent when they had not had a child who had lived outside of the womb? This was exacerbated by a lack of recognition of their parenthood by their social networks" (Murphy 2019 p36). Layne (1997) talked of a "triple whammy" of "taboo, non-existence and silence".

Layne (1997) also noted that stillbirth can be difficult for some feminists. She stated: "...anti-abortion activists base their argument on the presence of foetal and, even more importantly, embryonic personhood, feminists have studiously avoided anything that might imply such a presence. The fear in the context of pregnancy loss is that if one were to acknowledge that there was something of value lost, something worth grieving in a miscarriage, one would thereby automatically accede the inherent personhood of embryos/foetuses" (Layne 1997 quoted in Murphy 2019).

Returning to Murphy's (2019) interviews, she noted one theme called "expectation of success". The talk about pregnancy always assumed a live baby because of factors like the medicalisation of pregnancy, "bodily integrity" (a body "fit" for pregnancy), "maternal competency", and silence about pregnancy loss in social networks.

Concentrating on "maternal competence", this is the idea that "women feel that they should be '...able to protect and foster the growth of their children' (Ruddick 1980...) and that might serve to impact negatively on them if the pregnancy does not go as planned... Competence (or competency) was not a word used explicitly in the accounts but was implicit in 14 of the mothers' interviews" (Murphy 2019 p39). Two sub-themes emerged:

i) "Rule-following" - Women were doing the "right thing" during pregnancy, and so cannot understand the reason for the pregnancy loss. For example, both "Penny" and "Barbara" emphasised that they had not smoked or drank alcohol. Even more than that, as "Bob" explained: "You [to his wife] were also very careful. I mean you did absolutely everything by every book that we could read and knew about. You took all the right vitamins, avoided all the wrong foods. You did, you know, [you] changed your exercises at the gym" (p39).

ii) "Knowingness" - Murphy (2019) described this sub-theme thus: "The mothers interviewed here assumed that they should have an 'instinctual' knowledge of what

was happening within their womb as part of an 'essentialised' discourse of motherhood. In many instances, notions of a 'mother's instinct' were referred to - if problems occurred they would 'know'. For most of the mothers I spoke to they didn't 'know' that something was wrong. This was especially the case for those women whose baby had been dead for a few days or more before they found out: they blamed themselves for not realising that something had gone wrong and this led them to question their competence" (p39). Murphy's (2019) own experience of "Ann Rosemary", who had "died a couple of weeks before the appointment where the midwife failed to find the heartbeat. I had not noticed that something was wrong - does that make me less of a woman?" (p37).

"Grace" expressed the feelings of failure thus: "I think I was sort of ashamed to tell other people that I hadn't, um, I had failed, you see. I had, had failed again. I guess it's that
failure thing, I'd failed to produce a baby and I'd failed to notice when the baby was in distress..." (p39).

Murphy (2019) summed up: "For the women I interviewed their 'actual social identity' was 'moral mother'; however, the stillbirth served to threaten them with the possibility that others might impose upon them a 'virtual social identity' [Goffman 1963]: of 'immoral mother'" (p40). She ended: "The unusualness of stillbirth and the frictions and tensions that parents experience following the death serve to remind us of the regulatory and oppressive character of what is thought to be normal or 'natural'. Pregnancy loss helps us to question what it means to be a (good) parents and what it means to make a family" (Murphy 2019 p41).

1.3. CERVICAL ECTOPIC PREGNANCY

Verdaguer (2019) described her own experience of cervical ectopic pregnancy (where the embryo is implanted outside of the uterus). For example, she recalled the doctor telling her she was losing her pregnancy - "he and the nurse tried to soothe my crying by telling me that nature was wise and that if I was losing this embryo it was because it wouldn't have turned out well. I considered this explanation eugenic, and it seemed to degrade my feelings of love towards the dying being, which only made me cry harder. A few moments later, the nurse added: 'You're only crying because of the high level of pregnancy hormones in your body. This sorrow

will fade away, you'll see'" (p28).

Her pregnancy lasted six weeks, and she had known about it for two of them: "Enough to set up a mother" (Verdaguer 2019 p28). For example, having a headache, she decided not to take a paracetamol, and her father "shouts with joy - This is your first sacrifice as a mother" (p29). Events like this are part of the "making of a mother".

Meanwhile, a child is being "constructed", for example, through the use of "baby" to describe the embryo on websites about pregnancy. Medical technology that allows for images of the early foetus has "become an icon of 'life itself' (Haraway 1997) and, as it turns the foetus into a subject, even into a subject of law, it invisibilises women" (Verdaguer 2019 p30).

These two processes experienced in many ways over the pregnancy produce the identity of "mother", but how to unmake them with the pregnancy loss? In Verdaguer's (2019) case, her life was at risk as the cells multiplied (like a cancer) outside the uterus, and an operation was needed to remove it. In hospital, she said: "I saw my embryo less and less as human and more as a cancer and as a parasite" (p33).

Verdaguer (2019) ended: "Today I make up part of the nameless group of women that are and are not mothers" (p33). She continued: "In a socio-technical landscape like ours, where the ensemble of devices and discourses fosters an early mother-child relationship, the affective bond between women and embryos can start very fast, when there are higher possibilities of pregnancy loss. Too many times, from pro-life positions, churches, governments or medical institutions, but also from positions that protect the women's right to decide over their own bodies, we may have committed the error of making restricted definitions of what is or what is not an embryo, but the boundaries of life and personhood are not definitive and they have to remain thus if we want to recognise early pregnancy loss and at the same time protect reproductive rights. By breaking the taboos around pregnancy loss at all stages of development and listening to our invariably provisory answers on life and personhood, we can help each other to walk together through losses and abortions and in the various fights that surround pregnancy and motherhood" (Verdaguer 2019 p33).

Verdaguer (2019) is an example of auto-ethnography, which Ellis and Bochner (2000) defined as "an autobiographical genre of writing and research that

displays multiple layers of consciousness, connecting the personal to the cultural" (p739).

Verdaguer (2019) specifically described auto-ethnography as "a feminist research method that breaks the emotion-reason dichotomy... that standardises women as pre-eminently emotional beings and excludes them from intellectual discussions. This is especially true during pregnancy, when women's reasoning is too often considered to be overtaken by hormones" (p28).

1.4. FOETAL ABNORMALITY

Lafarge et al (2019) described ambivalence in the experiences of women who underwent pregnancy termination for foetal abnormality (TFA) in England and France. TFA is three times more common than stillbirths and infant death together (Lafarge et al 2019).

TFA is both like and unlike other pregnancy losses. It is similar in terms of grief, but "TFA differs from miscarriage and stillbirth in that parents elect to terminate their pregnancy, and from abortion for non-medical reasons in that the pregnancy is, in most cases, wanted and the decision is based upon characteristics of the foetus" (p43). There is a moral dimension in terms of disability-related issues including what kind of life is considered worth living, and TFA is a relatively new phenomenon with the development of screening (Lafarge et al 2019).

Data were collected from twenty-seven women in England via an online qualitative questionnaire in 2010-11, and seventeen women in France between 2015 and 2017 (as part of a larger research project on pre-natal diagnosis). The analysis and synthesis of the two sets of data produced eight "significant points at which women experience ambivalence, from the moment a severe abnormality is suspected to sometimes long after the termination" (Lafarge et al 2019 p44).

i) "Hope and despair" - The discovery of a foetal anomaly challenges the hope felt when the pregnancy began. "In many cases, the first suspicion that all may not be well signals the end of innocence (Rillstone & Hutchinson 2001) with women facing an uncertain future and difficult decisions to make, not least about the management of the pregnancy. As the pregnancy's outcome no longer matches their initial expectations, women are left wondering which other areas of their life they may harbour a false sense of security for" (Lafarge et al

2019 p46).

ii) "A choice but no choice" - "Ambivalence is also manifest in the decision to terminate the pregnancy as it involves conflicting feelings between doing what they consider to be the right thing, whilst wishing they never had to make that decision: 'I ended the life of my baby and I wanted him so much' (Gemma, UK)" (Lafarge et al 2019 p46).

iii) "Standing still versus rushing" - On the one hand, feelings of the world stopping, as expressed by "Ulrika, UK": "The moment I was told my baby had trisomy 21, my world stopped. Everything stopped, there were no birds, nothing in the sky and the trees did not even seem to be moving... I remember looking at the world and thinking how dare the world carry on as if nothing has happened" (p46). On the other hand, the urgency of the medical staff as action was needed quickly.

iv) "Bonding versus detaching" - "From the moment an anomaly is suspected, women are conflicted between 'giving life while thinking about taking it' (Leichtentritt 2011). As they wait for the diagnosis, women find themselves in a state of limbo, unsure about the way they ought to relate to the baby" (Lafarge et al 2019 p47). "Claire, France" described the limbo thus: "It was a weird sensation. Being happy, being sad, trying to feel all the little joys. I hummed, I listened to music, as if he was going to live, as if I was going to welcome him. It was weird. At the same time, I was crying and explaining to him. I was explaining to him what was going to happen" (p47).

v) "Trauma and peace" - The pain of the termination (eg: "the needle going through my tummy and knowing I was stopping my baby's heartbeat was so bad"; "Ellie, UK"; p48), and "an unexpected peaceful moment" when the foetus was delivered (eg: "knowing that our baby was at peace now"; "Laura, UK"; p48).

vi) "Disclosure and secrecy" - Whether to tell others, who to tell, and what to say. "Women's ambivalence about whether or not to disclose their story is grounded in the belief that should they choose to disclose it, they risk being misunderstood and/or judged for it. These experiences are testament to the stigma surrounding TFA, and more generally abortion..." (Lafarge et al 2019 p48).

vii) "Bridging past and future" - Eg: "Laura, UK": "I want to acknowledge the experiences, my emotions and feelings and have time to feel sad and remember my baby, but I do not want it to take over my life in a negative way – to become absorbed in grief" (p49).

"A new pregnancy presents another opportunity to bridge past and future. However, it is often an additional source of ambivalence for women as they feel hope and excitement concurrently with anxiety, guilt for 'replacing' the baby and sometimes disengagement towards the new pregnancy. This phenomenon has been referred to as 're-emergence of anguish (... Rillstone & Hutchinson 2001) in the literature..." (Lafarge et al 2019 p49).

viii) "Individual and societal experience" - A deeply personal experience that is "largely shaped by local laws and policies governing termination of pregnancy, local professional practices, as well as societal attitudes and beliefs about TFA and, more generally, disability... These factors contribute to shaping women's expectations for the pregnancy, underpin their decision to terminate and influence the way they grieve for their loss" (Lafarge et al 2019 p49).

Lafarge et al (2019) ended: "Women's ambivalence may also stem from the gradual transformation of pre-natal diagnosis practices over the past four decades, in which the concept of responsibility has moved from the public health sphere to the more private sphere of the person and informed choice. This evolution has gradually placed women at the centre of the decision-making process... Yet, if women have become more empowered to make decisions about their pregnancy, they are also expected to make these decisions in the absence of social scripts" (p50).

1.5. INTERNET AND "GRIEFWORK"

Davidson and Letherby (2019) also used auto-ethnographic methods [5] in their study of the use of the Internet and social networks after peri-natal loss (defined as miscarriage, stillbirth, neonatal death, termination, adoption, and selective reduction of a twin, say).
"The Internet provides new opportunities for screening and giving support following peri-natal (and other) loss" (Davidson and Letherby 2019 p52), in what

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[5] Davidson experienced two peri-natal deaths and Letherby a miscarriage.

Chambers (2006) described as "virtual communities of care" where "griefwork" (eg: Davidson 2010) can take place. This is "where the work of grieving is shared and negotiated between and among grieving persons and supportive others, rather than the work done alone as in grief work" (Davidson and Letherby 2019 p52).

Grief following peri-natal loss is similar to stigmatised or taboo experiences, like death by suicide, and is "disenfranchised" (Doka 2002), and not socially recognised. "A common response is 'Never Mind, Better Luck Next Time' or even 'Well it's all for the best' if the mother or the baby are seen as less than 'perfect'" (Davidson and Letherby 2019 p54).

The Internet allows individuals in this position to find validation from others who have shared experiences. "In this instance, as in others, social media may facilitate self-disclosure, and griefwork, that is 'hyper-personal' (Walther 1996) and more intense... than in-person communication. And yet, because Internet users themselves determine their involvement in site participation they control the context of disclose and the emotion work involved" (Davidson and Letherby 2019 p54).

Davidson and Letherby (2019) explored threads on specialist forums (eg: "Remembering Our Babies"). Some posts were written to the lost baby (eg: "I only knew you for a few days... but I miss you every day"; p55), while others were stories shared (eg: "we lost our son at 20 weeks, he will always be in our hearts"; p55). Some others posters talked of their "second round of IVF", for instance, and yet others just thanked the site for its existence. Occasionally fathers and grandparents posted among the majority of mothers.

The researchers commented on one observation: "It is clear that site users often feel the need to control or hide their emotions 'off line' and value the 'space' provided by the Internet to 'talk' about how they really feel. So whilst they may feel the need to make others feel better about their loss, or feel they have to deny their feelings when talking to family and friends and others... online they are free to share, with similar others, how they really feel" (p56). Participation on such sites were part of meaning making of the loss.

Previous research on online peri-natal loss groups, like Gold et al's (2012) survey of over 1000 users, found certain key themes, including (Davidson and Letherby 2019):

- Comfort of a shared experience (ie: not being alone).
- Validation (in a "safe space").
- The convenience of the Internet (eg: 24-hour access).
- Help with moving forward.

1.6. ABORTION

Ambivalence can also be applied to the "24-week foetus" in England, where a legal abortion can be only be performed up to that point, while "from a legal and medical perspective, the 24th week also marks the lower end of foetal viability, the point at which a prematurely born infant is considered to have a reasonable chance of survival and at which life-preserving interventions may be ethically provided" (Eades 2019 p20).

Twenty-four weeks is thus a "grey area" contested by pro-life and pro-choice activists, and so producing what Kilshaw (2017) described as the "multiple realities" of the foetus. She stated that foetuses "are a combination of what they are and what they may come to be. Additionally, where they are actively positioned and placed leads to very different realities: the foetus is made into a certain reality as much by its specific location in the body, in the social world, and in the cosmology" (Kilshaw 2017 p189). The "multiple realities" manifest in "a womb, an incubator, or an abortion clinic" (Eades 2019 p21) (or "in the womb, on a scan [6], on a dissection mat, at the grave site" (Kilshaw 2017 p189)) (appendix 1A).

Exploring these ideas, Eades (2019) reported ethnographic work in 2017 in England with pro-life and pro-choice activists. The pro-life (or anti-abortion) position emphasised the 24-week foetus as a baby, and there was no ambiguity or ambivalence as life begins at conception. "The emphasis is very much on biological reality, which is here understood to be objective, universal and incontrovertible. There is a sense of absolutism inherent to this conceptualisation – an absolutism that is perhaps hinted at in the tagline for March for Life UK: 'life from conception – no exception!'" (Eades 2019 p22).

The pro-choice (or pro-abortion) position emphasised

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[6] "A scanned foetus may be alive or dead: it may reassure that it is alive by moving or revealing its heartbeat or the image reveals it to be dead. An unexpectedly small creature may appear, its development ceased and so different from the 'baby' of the woman's imagination" (Kilshaw 2017 p190).

women's rights, health, and autonomy, and "the foetus generally did not figure" (Eades 2019 p24). The notion of life at conception was rejected, as, for example, shown by pro-choice activist "Georgia": "I don't believe in the whole 'life in the moment of conception', 'human rights from the moment of conception' thing. I'm quite woolly on when I believe a foetus becomes a human and that sort of thing. But that, for me, is definitely a no-no. [...] I don't believe that that clump of cells at one week, two weeks, etc is a child" (p24).

The social conditions into which unwanted pregnancies are born was also important. "Ultimately, the pro-choice foetus is a contingent foetus, its ontological status not fixed by biomedical or religious narratives, but dependent on the context in which the pregnancy and abortion decision occur" (Eades 2019 p25).

1.7. APPENDIX 1A - MULTIPLE REALITIES

Kilshaw (2017) examined the "multiple realities" of the foetus in Qatar.

The terminology of the medical profession can be quite different to the meanings to ordinary women. For example, miscarriage is defined by the World Health Organisation (WHO) based on a weight of less than 500 g, while a stillbirth is born without signs of life after 28 weeks gestation. "Others use greater than any combination of 16, 20, 22, 24, or 28 weeks gestational age or 350, 400, 500, or 1000 g birth weight (Nguyen and Wilcox 2005). There is 'probably no health outcome with a greater number of conflicting, authoritative, legally mandated definitions' (Nguyen and Wilcox 2005)" (Kilshaw 2017 p193).

Among the Arabic-speaking women in Qatar, the term used included "tefel (child/ baby), janeen (foetus), baby, qetat lahem (piece of meat), Toyoor fe al Jannah (bird in heaven). Some women indicated a lost hemel (pregnancy) rather than a lost being. 'Janeen' and 'baby' were most commonly used and were often used interchangeably, the latter often referring to later stages of pregnancy" (Kilshaw 2017 p193).

The understanding of "alive" or "human" also depends on religious views, as one religious leader explained to Kilshaw (2017): "In Qatar we follow Madhab Al Hanbali [a school of Sunni Islam] and so the borderline between living and non-living human being is four months. In other madhabs this is not the case, a foetus or baby will not be treated like an adult unless he came out screaming

and shouting" (p194).

Add to this that pregnancy is illegal for unmarried women in Qatar, and such a foetus is "neither legitimate nor acknowledged" (Kilshaw 2017 p195). The aforementioned religious leader suggested that "a married woman's foetus is legitimate and sacred and must not be destroyed unless its presence threatens the life of its mother. An unmarried woman's foetus, however, is not recognised and, according to some scholars, can be legitimately aborted. Islamic law has a strict taboo on sexual relations outside wedlock (zina): the taboo is designed to protect paternity (ie: family), which is designated as one of the five goals of Islamic law" (Kilshaw 2017 p196).

On the other hand, the medical view of the miscarried foetus was "as meat". Kilshaw (2017) described meeting "Dr Ali" in the hospital mortuary, and he said: "'the foetus is not a living thing so is sent as a sample or tissue of the mother'. The tissues/foetus waited for collection by the family, but if not collected within two to three weeks, the hospital would bury it. Once enough body parts, tissues, and foetuses amass, they are collected and taken to the graveyard, accompanied by an official hospital request form, which says: 'Kindly bury the dead foetuses and the remnants of body parts that are listed in this letter'" (p197).

Kilshaw (2017) described the experiences of women with miscarried foetuses in a society where a child gives women social status, but they "largely blamed for reproductive failings" (p198). "Najah", for instance, was thankful to God because "[A] dead foetus secures a woman's position through demonstrating of fertility and being a mother" (Kilshaw 2017 p199).

"Samia" took solace in the foetus/baby going to heaven: "When they informed me... I cried and I didn't accept it... the doctor said; 'this is from Allah'. So, though I was shocked at the beginning, but being a Muslim and our faith that whatever happens to us is God's will... God rewards. My baby will be a bird in heaven and he [will act on behalf] of his parents" (p199). Kilshaw (2017) explained: "As the foetus has no soul and was never meant to be more than it was, women are advised to find comfort in the fact that one has not really lost anything" (p200).

"Foetuses occupy a liminal category somewhere between person and human tissue", asserted Kilshaw (2017 p201). This was shown in Qatar in terms of the gestational age of death and medical definitions, and the religious views including whether the mother was married.

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2. SOME RESEARCH ON MENTAL HEALTH

2.1. SKIING AND DEPRESSION

Physical activity has been shown to be "a promising strategy to reduce the burden of depressive disorders" (Svensson et al 2019 p1).

Svensson et al (2019) took the case of long distance ski racing as the physical activity. Swedes who competed in a long-distance cross-country ski race ("Vasaloppet") between 1989 and 2010 (n = 197 685) were compared to non-skier controls in the general population (n = 197 684) (who were matched based on sex, age, and geographic location). Data on depression were taken from the Swedish National Patient Registry.

The skiers were half as likely to be depressed in the follow-up period as the controls, even after adjusting for sex, age, and education level. Men, but not women, who completed the race in a shorter time ("a proxy for the effect of extreme exercise"; Svensson et al 2019 p4) had a lower incidence of depression than slower skiers (ie: <50% longer than the winning time vs >50%).

Explanations for the findings include that "exercise might be protective by reducing the amount of inflammation in the body..., and ultimately in the brain" (Svensson et al 2019 p5), or by the release of endorphins.

Svensson et al (2019) did not measure regular physical activity. It was assumed that because the ski race was physically demanding the participants had an active lifestyle in order to prepare.

Depression as diagnosed by a medical professional and thus included in the patient record was used, which excluded non-treatment-seekers. Individuals with mental

disorder prior to the race, however, were excluded from the study.

2.2. CHILD MARRIAGE AND MENTAL HEALTH

Child (or early) marriage (CM) is defined as marriage before eighteen years old, and is "a harmful practice that occurs globally and can limit the developmental outcomes of girls, and children born into these unions" (Burgess et al 2022 p2). Globally, estimates suggest that one in five under-eighteens are married in this way, with South Asia and sub-Saharan Africa being the hotspots, though prevalence rates vary (eg: 2% in Tunisia vs 76% in Niger) (Burgess et al 2022).

Three key drivers of CM are poverty, protection of young females, and reinforcing social ties (Nour 2009).

Godha et al (2013) outlined five categories of health risk with CM - vulnerability to sexual transmitted infections, and cervical cancer, pregnancy (ie: low uptake of contraceptives), physical and sexual violence. While a survey of ninety-seven countries (Raj and Boehmer 2013) found that "CM posed significant risk for HIV, infant mortality and maternal health given higher rates of unprotected sex among young wives who have difficulties negotiating condom use when husbands have multiple partners, and refusal of unwanted sex" (Burgess et al 2022 p2).

In terms of mental health, this last study alluded to depression and suicide risks, but "significant gaps remain in understanding morbidity, experiences of distress, and the direct and indirect consequences of CM on mental well-being" (Burgess et al 2022 p2).

Burgess et al (2022) attempted to fill the gaps with a literature review. Twenty-one relevant articles published between 2000 and 2020 were found using search terms like "early marriage", "pre-pubescent marriage", "child bride", and "teenage marriage". General emotional distress, and specific mental health conditions were covered. Only publications in English were included, and nine of the articles related to the African region.

The most common mental health consequence of CM was depression, followed by psychological distress, stress, suicidality (thoughts and/or actions), substance misuse, and other mental disorders. For example, women married before eighteen years old were over twice as likely to experience depression as women married after that age, and there were similar risks for suicidality (Burgess et al 2022).

Four key factors emerged as linked to CM and general emotional distress - intimate partner violence, poverty, isolation (from family and friends), and difficult childbirth experiences (eg: complications; death of child).

The mental health problems did not occur in isolation, but showed the "intersecting structural factors at work" (Burgess et al 2022 p13) - eg: CM and poverty and violence. Burgess et al (2022) commented that "CM likely produces poor mental health outcomes not only due to the practice itself, but also linked to the impact of socio-structural factors at work in young people's lives. However, the bi-directional relationship between these factors may be under appreciated. For example, while poverty was discussed in half of the studies it was often treated as a confounding variable rather than considering interactive effects" (p14).

The researchers identified some key gaps in the literature, including on sexual orientation, disabilities, and male CM, as well as the impact of the mother's mental health on her children. "Further research is needed to understand the complex power and gender inequities that are embedded within families and also contribute to poor mental health outcomes" (Burgess et al 2022 p14).

The studies in the review were cross-sectional (which limits the ability to establish causality), and collected self-reported data (with the risk of social desirability bias) (Burgess et al 2022).


2.3. DEMENTIA AND CHRONIC HEALTH PROBLEMS

Data from the ongoing Whitehall II cohort study has shown a link between chronic health problems in mid-life and subsequent dementia (Ben Hassen et al 2022).

Whitehall II began in 1985-88 with over 10 000 British civil servants in London aged 35-55 years at the time. Follow ups have taken place at five year intervals, and the 30-year data collection was in 2015-16.

Health problems, or more correctly, multi-morbidity was defined as at least two chronic conditions from a list of thirteen (eg: coronary heart disease, diabetes, liver disease).

The prevalence of multi-morbidity was 6.6% at 55 years old (mid-life). These individuals were over two times more likely to be officially diagnosed with dementia at seventy years old than participants with no or one chronic condition. This was fivefold greater for

individuals with three or more chronic conditions in mid-life (figure 2.1).

■ 2 chronic conditions   ■ 3 or more chronic conditions
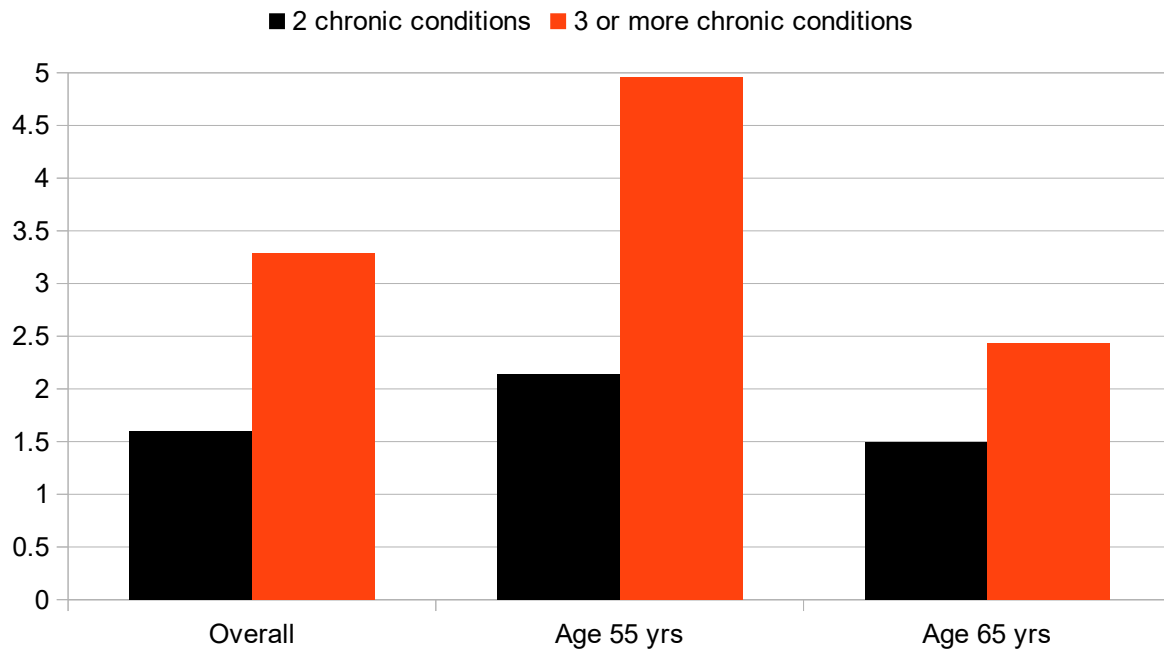
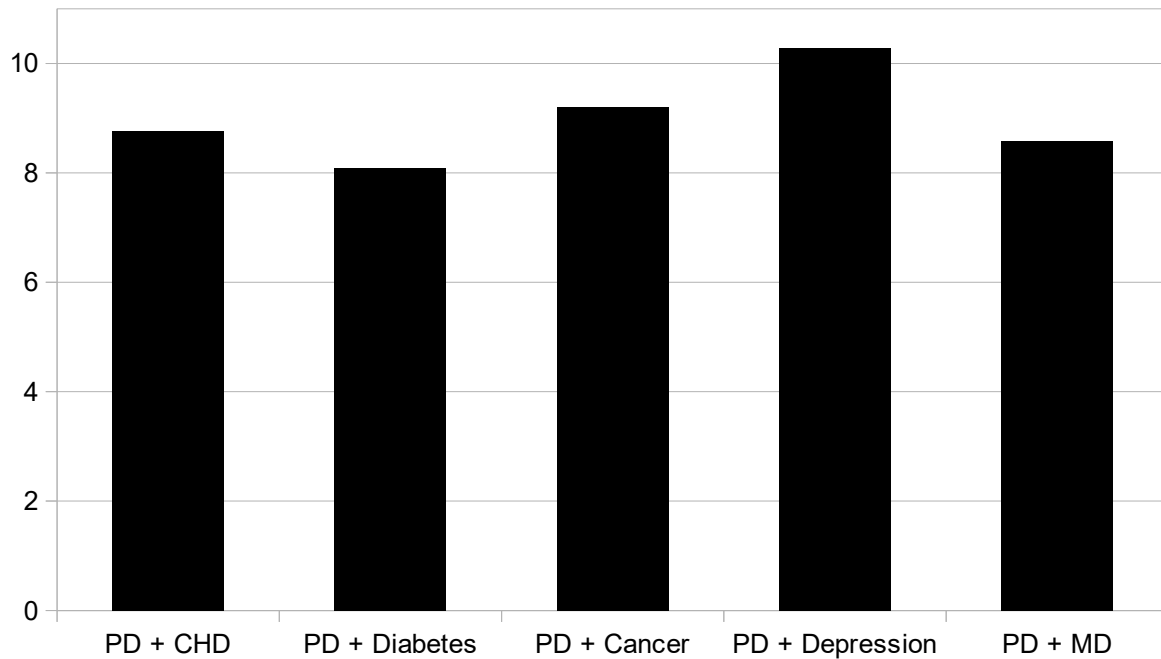(Data from Ben Hassen et al 2022 figure 2)

Figure 2.1 - Fully adjusted hazard ratio for dementia in later life based on multi-morbidity (where 0 or 1 chronic condition = 1).

    Put another way, of the 679 cases of dementia, 70% had multi-morbidity in mid-life.
    Onset of multi-morbidity at a later age (eg: 65 years old) weakened the association with dementia.
    There were different risks for dementia based on the combination of chronic conditions. For example, the greatest risk was Parkinson's disease and another condition (eg: cancer; coronary heart disease) (figure 2.2).

    In terms of the limitations of this study, dementia was classified from official diagnosis in health records, and may have missed milder or undiagnosed cases. "Another limitation is that the Whitehall II study is based on participants who were all in employment at recruitment and are likely to be healthier than the general population, in terms of both incidence of disease and risk factor profiles" (Ben Hassen et al 2022 p8).

(PD = Parkinson's Disease; CHD = Coronary Heart Disease; MD = Mental Disorder other than depression)

(Data from Ben Hassen et al 2022 figure 3)

Figure 2.2 - Five highest hazard ratios for dementia in later life based on two chronic conditions (where 0 or 1 chronic condition = 1).

2.4. KETAMINE AND DEPRESSION

De Giorgi (2022) commented that the "repurposing of ketamine for use in mental disorders is a noteworthy yet disputed development in psychiatry over the past two decades" (p1).

Ketamine blocks N-methyl-D-aspartate (NDMA) receptors, and has been found to produce "rapid (within hours) and long-lasting anti-depressant effects in patients who are resistant to other anti-depressants" (Zhang et al 2021 p301). This compares to conventional anti-depressants that focus on the monoaminergic system, take weeks to produce a benefit, and are ineffective for one-third of individuals with major depressive disorder (Zhang et al 2021).

As part of the benefits of ketamine for depression, it "could also rapidly reduce suicidal ideation in a way that is at least partially independent from its effect on mood" (De Giorgi 2022 p1). Only a small number of individuals with suicidal ideation go on to attempt suicide, but the general treatments for suicidal ideation

are "unsatisfactory" (De Giorgi 2022).

In this context, Abbar et al (2022) performed a six-week randomised, placebo controlled trial ("KETIS") in France with 156 patients voluntarily admitted to hospital with severe suicidal ideation between 2015 and 2019. The participants were recruited from three groups - those with bipolar disorder, depressive disorder, or other non-psychotic disorder. Suicidal ideation was measured by the standardised Scale for Suicide Ideation (SSI) (Beck et al 1979) (table 2.1). Participants were randomised to receive two forty-minute infusions of ketamine or a placebo over 24 hours.

- Wish to live - moderate to strong (0), weak (1), or none (0).

- Wish to die - none (0), weak (1), or moderate to strong (2).

- Duration of suicidal ideation/wish - brief, fleeting periods (0), longer periods (1), or continuous (chronic) or almost continuous (2).

- Suicide note - none (0), started but not completed; only thought about (1), or completed (2).

- Deception/concealment of contemplated suicide - revealed ideas openly (0), held back on revealing (1), or attempted to deceive, conceal, lie (2).

(Source: Beck et al 1979)

Table 2.1 - Items from SSI.

By Day 3 63% of the ketamine group and 32% of the placebo group were classed as full remission of suicidal ideation. This was a significant difference. By Week 6 the remission rates were 70% and 56% respectively (which is not significantly different).

The participants with bipolar disorder benefited more than those with depressive disorder. The researchers could not explain this finding.

The effect of the ketamine was very swift (eg: after two hours), but Abbar et al (2022) warned that "the rapid resolution of suicidal ideas after receiving ketamine does not equate to a reduced risk of suicidal acts, notably after hospital discharge.
Indeed, the rates of suicide attempts during follow-up were similar between the groups. Moreover, ketamine is a drug with a potential for abuse. Longer follow-up of larger samples will be necessary to examine benefits on

suicidal behaviours and long term risks" (p7).

The main limitation of the study was the use of saline solution as the placebo, while other studies "have used midazolam as the comparator; therefore, masking could have been affected by recognisable acute effects associated with ketamine, such as depersonalisation" (De Giorgi 2022 p1). The study was designed in 2013, and since then "newly synthesised esketamine has been approved for the treatment of resistant depression (not without criticism) by most international regulators" (De Giorgi 2022 p1).

2.5. RESILIENCE

Children who have experienced victimisation (ie: abuse, neglect, domestic violence and/or bullying) are at risk for negative consequences not only in childhood (eg: lower educational attainment), but also in adulthood (eg: more likely to be unemployed, and/or involved in criminal offending) (Latham et al 2021). "Polyvictimisation" (Turner et al 2010) (ie: more than one type of victimisation) exacerbates the problems.

But many victimised children do not experience negative consequences. These individuals are considered as "resilient" (eg: around half of an UK cohort; Latham et al 2019), and "promotive" and "protective" factors are important here. Latham et al (2021) performed a review of these factors for victimised children at age eighteen (ie: the transition to adulthood). Twenty-six relevant studies published in English up to the end of 2019 were found.

The researchers divided the outcomes into different categories because of the variety in the studies included and that different resilience factors were important in different situations:

a) Education and work - eg: attending a good school; supportive adults.

b) Housing and independent living - eg: homelessness was less likely if individuals placed in care were reunited with their family.

c) Criminal behaviour - eg: being employed and educational qualifications lowered the odds of contact with the legal system.

d) Receiving victimisation in adulthood or

perpetrating it - eg: having two married parents was associated with lower levels of these in relation to dating.

e) Social outcomes - eg: "resiliency characteristics" like thinking of self as a strong person, and bouncing back after hardship or illness.

f) Psychological outcomes - eg: spirituality (but not religious practices) was associated with life satisfaction.

g) Multiple outcomes - eg: perceived social support from friends and family.

A variety of resilience factors were found linked to the individual (eg: personal characteristics), the family (eg: supportive), and the community (eg: support from peers). but the researchers could not draw firm conclusions because of the variations in different studies. They stated: "More broadly, our review suggests that a resilience factor for one psycho-social outcome may not necessarily be a resilience factor for a different outcome. For example, positive/supportive relationships were often associated with positive outcomes (eg: educational attainment and life satisfaction) during the transition to adulthood following childhood victimisation; but in the context of severe childhood maltreatment and exposure to domestic violence, close family relationships were associated with increased vulnerability for perpetration and experience of victimisation" (Latham et al 2021 p13).

The studies included the following limitations:

i) Mostly cross-sectional designs.

ii) Concentration on one factor only rather than the combination or interaction of resilience factors.

iii) Almost all studies in Western countries.

iv) Convenience or other non-representative sampling was common (eg: university students).

v) Use of recall measures of victimisation.

2.6. MENTAL HEALTH OF AMERICAN NATIVES

In the USA, American Indian and Alaska Native (AI/AN) adolescents is "one of the most diverse and fastest-growing populations" (Munnelly and Hishinuma 2020 p1). A number of different factors have been found to impact these individuals, including poverty, low educational attainment, and violence (risk factors), and cultural support and connections with the past (protective factors) (Munnelly and Hishinuma 2020).

Munnelly and Hishinuma (2020) focused on stressful and negative life events as risk factors for mental health problems. Key negative life events, like death of a close relative during childhood, and being a victim of crime, have been established as "robustly associated" with mental health symptoms, substance use, and exposure to violence, for example (Munnelly and Hishinuma 2020).

AI/AN groups live in different parts of the USA, and have different experiences dependent on that (eg: more negative life events reported by upper-midwest AI/AN adolescents than rural Iowan ones) (Munnelly and Hishinuma 2020). Those living in Hawaii are a small number (0.3% of the state's population), but have differences to other AI/AN groups in the USA (eg: greater percentage of mixed ancestry), and to Native Hawaiians. For example, a higher rate of violence victimisation (4.4% in 1992-6 vs 3.2% for Hawaii as a whole) (Hishinuma et al 2005).

Munnelly and Hishinuma (2020) analysed data from the Hawaiian High Schools Health Survey (HHSHS) 1991-96 (n = 7214), and compared four adolescent ethnic groups: AI/AN (full or part, no Hawaiian ancestry), AI/AN-Hawaiian (AH), Native Hawaiian (no AI/AN ancestry) (H), and Other (non-Indigenous; no AI/AN and Hawaiian ancestry) (O).

The Major Life Events Scale (MLES) (Andrews et al 1993) had been completed. This listed fourteen events related to family members, close friends, and the self, and covered the last six months (eg: "got pregnant"; "lost job or finances got worse"; had an illness or accident requiring hospitalisation"). A number of standardised measures of mental health were used, including of depression, and anxiety, and substance use.

Overall, the AI/AN and AH groups more negative major life events to self and close friends than the other two groups, while the AH group had the highest number related to family member. The AH group scored highest on the mental health measures and the O group lowest. But after controlling for nine co-variates, like gender, family support, and main household wage earner's education

level, the H group was the highest scorer on the majority
of mental health measures.

The implication of the findings was that AI/AN and
AH individuals experience more negative life events as
found in previous studies, but the higher score of the H
adolescents on the mental health measures "reinforces the
unfortunate status of Native Hawaiian youth in their own
homeland and the social determinants of health and mental
health" (Munnelly and Hishinuma 2020 p13).

Munnelly and Hishinuma (2020) accepted limitations
to the data set from the 1990s, but that "it was the only
large existing database that included an adequate number
of AI/ANs with raw data at the individual level" (p12).
However, the numbers were still relatively small - 287
AI/AN and 614 AH respondents compared to over 4000 H and
over 2000 O adolescents surveyed (Munnelly and Hishinuma
2020).

2.7. ETHNICITY AND PREVALENCE OF MENTAL HEALTH PROBLEMS

In England, for example, the prevalence of mental
disorders in 5-19 year-olds is higher among those from
disadvantaged socio-economic backgrounds compared to the
average, while it is lower for those from Black and Asian
backgrounds compared to White British (Ahmad et al 2022).

"In the UK, people from ethnic minority backgrounds
are more likely to face socio-economic adversity than
their White British peers, and are more likely to be
living in deprived areas. Ethnic minority status exposes
young people to experiences of racism, discrimination,
and social marginalisation, which have been
associated with adverse mental health problems. The lower
prevalence of mental health problems in young people from
some ethnic minority groups therefore run counter to
expectation" (Ahmad et al 2022 p818).

There are a small number of studies on ethnicity and
child and adolescent mental health. Goodman et al (2008),
for instance, found that, compared to White British,
those from Black African and Indian backgrounds had less
mental health problems, but those from other ethnic
minority backgrounds had similar levels. The sample sizes
of such studies were not particularly large.

Ahmad et al (2022) analysed data from the Millennium
Cohort Study (MCS), which begun in 2000-2 with 19 519
families from the UK. It included "purposefully
oversampling economically disadvantaged and ethnically
diverse areas" (Ahmad et al 2022 p818). By 2015-16 (14
years old), over 11 000 families were still involved (and

Ahmad et al 2022 analysed this wave).

Mental health problems were measured by parent responses to the SDQ. Eight "harmonised categories" of self-reported ethnicity were used - White, Mixed, Black African, Black Caribbean, Indian, Pakistani, Bangladeshi, and Other.

The overall prevalence of mental health problems was 9.9%, with variations among ethnic minorities from 15.8% (Black Caribbean) to 2.9% (Black African) (figure 2.3). Mental health problems were exacerbated by socio-economic disadvantage generally, but reduced by social support.
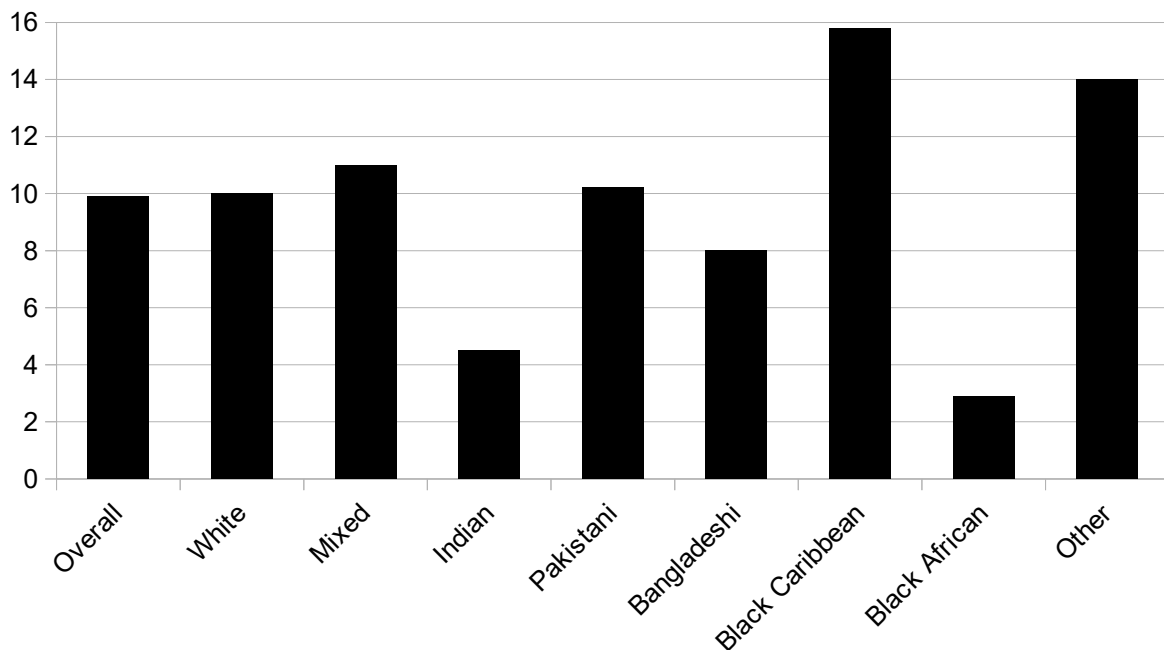
(Data from Ahmad et al 2022 table 1 p821)

Figure - Prevalence (%) of mental health problems based on ethnic group.

Putting the factors together, ethnic differences in mental health prevalence interacted with household income, and social support. Gender differences also emerged. A complex picture was found. The researchers concluded that "ethnic differences are partly but not fully accounted for by income, social support, participation [eg: attendance at a religious service], and adversity", and "[A]ddressing income inequalities and socially focused interventions may protect against mental health problems irrespective of ethnicity" (Ahmad et al 2022 p817).

The following key methodological limitations are relevant:

i) Despite the oversampling of ethnic minorities, the sample sizes for some ethnic groups were very small (eg: 102 Bangladeshi families; 187 Black Caribbean families).

ii) The ethnic categories used. Ahmad et al (2022) explained: "Ethnic diversity in the UK has changed considerably since 2000, when this birth cohort was recruited. Diverse populations have been homogenised into limited categories which have varying levels of relevance for individuals. The Black African, Black Caribbean, Mixed, and Other Ethnic Groups, amongst others, encompass immense diversity. The White group includes young people from Irish, White Other, and Gypsy or Irish Traveller backgrounds, who have been noted to have different mental health and social outcomes to White British adolescents. Recently migrated or undocumented young people were not included. These findings should be critically appraised in recognition of this complex heterogeneity of cultures, class status, and migration histories, as essentialising these differences runs the risk of racial determinism" (Ahmad et al 2022 p824).

iii) No information was collected about experiences of racism and discrimination, which are known to impact mental health negatively.

iv) The SDQ was parent-reported, rather than self-reported. Having both parties complete the questionnaire would have given comparison data. Do parents know the full extent of their offspring's mental health problems, and/or are they willing to admit to such problems (particularly if there is stigma associated with them)?

v) The SDQ was in English. Some parents may have limited English, and/or the "differences in idioms of mental distress across populations may not have been captured" (Ahmad et al 2022 p826).

vi) This was a secondary data study, which meant that the data were collected by others and Ahmad et al (2022) analysed the data made public. This meant that Ahmad et al (2022) had no control over the design of the study or the questions asked.

2.8. SOCIAL ISOLATION AND DEPRESSION

Individuals who experience episodes of depression through their lives often have the first episode in adolescence. The context of that first episode is very important (eg: stressors) (Viduani et al 2021).

Viduani et al (2021) explored adolescent depression with a variety of key informants in Porto Alegre, Brazil. In total, fifty-four interviews, which included adolescents who had experienced depression (n = 6), parents (n = 6), health workers, and policymakers. Both individual and group interviews were undertaken.

Four main themes emerged mainly from the adolescents:

i) "Depression in relation to the self" - Emptiness, and sadness were the two key dimensions of the experience of adolescent depression. For example, "Adolescent 6" said: "I felt empty, like I didn't want anything else. I didn't want to do anything, I didn't want to study or talk to anyone, I didn't want to be friends with anybody. I just wanted to be quiet, and be by myself" (p4).

ii) "Depression in relation to others" - Relationships with parents and peers were the most common perceived causes of depression. For example, "Adolescent 1" focused on bullying: "The adolescent wants to be part of a group, and when they face bullying, they feel threatened" (p5).

Many of the symptoms go unnoticed, as "Mother 4" admitted: "I noticed that she was more closed, but I thought it was just a teenager thing, because of adolescence" (p5).

iii) Isolation as a key characteristic of depression - eg: "Adolescent 6" said: "I want to be alone. The first time [first depressive episode], all I could think was that I wanted to be alone, wanted to be in my own corner. All I could think about... I want to be alone" (p5).

iv) Coping - eg: "Adolescent 5" said: "Lately, when I feel bad, I try to look more on the positive side. Then I see that it's not just that, that there are good things (...) I talk to my cousin, too, like... It's good to let off steam" (p6).

The researchers concluded that "we were able to emphasise isolation as a core component of the perceived experience of depression. Isolation is here described as

an active exclusion from spaces of social relations, and this experience seems to connect depression both in relation to the self and in relation to others" (Viduani et al 2021 p7).

2.9. MISCELLANEOUS

2.9.1. Pregnancy After Concussion

Women who experience concussion are less likely to become pregnant in the following two years compared to injury to other areas of the body (Anto-Ocrah et al 2021). In the USA, 102 women with concussion and 143 with other injuries were followed for twenty-four months.

Explanations for the findings include dysregulation of hormones related to pregnancy after concussion, or post-concussion depression which reduces the motivation for intimacy (Murugesu 2021).

The study did not account for intention to become pregnant, which was a limitation (Anthony Kontos in Murugesu 2021).

2.9.2. Polygenic Risk Scores

Polygenic risk scores (PRSs) are "estimates of an individual's susceptibility to a specific complex trait obtained by aggregating the effects of dozens, thousands, and potentially millions of genetic variants associated with that specific trait into a single figure" (Forzano et al 2021 p1).

They are being offered by private companies to prospective parents on embryos in artificial reproduction. Forzano et al (2021) argued that this practice is unproven and unethical. They explained: "Complex traits are determined by a combination of genes and environment, and PRSs can only capture a part of the genetic component – that which is derived from the cumulative effects of many genetic variants of small individual effect" (Forzano et al 2021 p1). Along with other problems, the PRS can thus only be very approximate.

"Research on PRSs is not aimed at the development of pre-symptomatic tests in embryos but rather at the advancement of understanding of disease mechanisms, and the management and treatment of live-born individuals, most frequently when they reach their adulthood" (Forzano et al 2021 p2).

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3. "HALAL DATING"

3.1. "HALAL DATING" IN THE UK

Ali et al (2020) observed: "Young Muslims in the UK are making space to gain greater control over their personal lives through the diction of 'halal' [permissible] and 'haram' [not permissible] when reflecting on and negotiating personal relationships" (p775) [7]. These researchers explored the idea of "halal dating" in fifty-six in-depth interviews with young British Muslims of Pakistani heritable (16-30 years old) in 2016 and 2017. The interviewees came from three parts of the UK (Yorkshire, Glasgow, and Tyne and Wear), and the vast majority were heterosexual (appendix 3A).

Ali et al (2020) noted that talking about dating was culturally prohibited, and was linked to tradition and honour. "Zarah" (female 23) described her relatives' views thus: "I think when they hear the word dating, like: 'Oh God no, that's a very western thing, that's completely haram'" (p781). "Ayisha" (female 27) expanded on this issue: "Most of my friends have had boyfriends and it has been like they have had a double life, so they are hiding it from home" (p782).

"This secrecy and silence has mixed effects. When it is possible to say one thing and do another, as some Muslims do when they enter into same-sex relationships..., it is also possible to contain contradictions between cultural and religious conventions on the one hand, and desires and lived experiences on the other" (Ali et al 2020 p782).

The language of "halal dating" ("dating but within the boundaries"; "Maryam" (female 23); p783) helped deal with such situations. The line between halal and haram dating was based on three principles - the presence of a chaperone, no physical intimacy, and an intention to marry. "Clearly, these features are common to arranged marriage practices... However, the divergence from tradition comes from one or more of the following

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[7] **"By speaking about halal (and haram) dating, young Muslims are applying terms that have traditionally been more commonly associated with food consumption..., clothes..., branding... and finance... In doing so, Muslims are representing themselves in innovative ways that recognise recent interest in thinking through everyday life" (Ali et al 2020 p778).

characteristics: selecting one's own date or marriage partner; being away from parental supervision (the chaperone may be a friend rather than a relative); the use of a public venue; and interacting remotely through new technologies such as smartphones and social media" (Ali et al 2020 p783) (appendix 3B).

Online dating sites and apps are particularly helpful as "Janan" (female 29) described: "We met through an app called Muzmatch ["Muslim dating app"]. We matched each other last December, so a year ago in December. And just got talking through that. But we didn't meet up like in physical person until May... maybe like five months later" (p785).

Some interviewees found "halal dating" difficult, either as a concept (eg: "I do think it's a contradictory term, to combine the words 'halal' and 'dating' together"; "Zarah" (female 23); p786), or "too restrictive" (eg: gay "Yusuf" (male 22)). "Hassan" (male 29) was honest about the challenge of no physical intimacy: "It is so difficult to explain because a part of me is saying that in an ideal world this is what you do, but in a realistic world that is not what happens. So in an ideal world like you would go out... but there wouldn't be any like touching, kissing, anything sexual in an ideal world. But again, that doesn't happen" (p787).

Ali et al (2020) noted: "Halal dating is gendered. Within our interviews, it was mostly the women who explored the pressure not to date, nor to be seen dating, nor to talk about dating. This analysis is unsurprising, given what is known about relationship practices within Asian-heritage families. Male interviewees, by contrast, refer to the unwritten rule that they should not be seen to date. This means that, while both sexes have a stake in dating, more is at risk for women. There was also a difference between the ways in which women and men spoke about the ideals and realities of halal dating. It was usually the men who debated the temptations of physical intimacy and their limited powers to resist these once out on a date" (p788).

Ali et al (2020) concluded: "Engagement with ideas about halal dating is opening up spaces of agency for young British Muslims. They are negotiating cultural and religious rules against dating, and being open about dating, by breaking silences on the subject and advancing the idea that dating can, in certain circumstances, be halal. They are finding ways to make choices, mediating between family expectations - that they will marry -...,

cultural heritage and religious convictions, and ideas about sex and relationships that are more associated closely with western and British culture – that they will date. It might be too strong to say these Muslims are finding ways to 'have it all' (Hussain et al 2017). More precisely, they are searching for ways of 'being modern and modest' (Franceschelli and O'Brien 2015)" (p788).

3.2. APPENDIX 3A - MUSLIM SEXUALITY

Western media stereotypes can portray "Muslim men as tyrannical, Muslim women as downtrodden or exploited" (Chambers et al 2019 p67). Thus, the Muslim world is "a metaphorical place of misery" in this view (Chambers et al 2019 p68).

Rejecting such simplistic ideas, as part of the of the "Storying Relationships" research project, Chambers et al (2019) looked at the depictions of "Muslim sexualities" by different writers.

One mainstream depiction is "Sexualised Orientalism", which historically has presented the "East" "in some cases depicted as sensuous and hyper-sexualised, in others as sexually repressed, and in certain cases as embodying both of these contradictory tendencies at once" (Chambers et al 2019 p71). These images have been applied, for example, to the sexual abuse cases between 1997 and 2013 in the English town of Rotherham, where the perpetrators, according to the UK press, were "Muslim, Pakistani or Asian" (showing a "far too regular (and unexamined) slippage between categories" in the press; Chambers et al 2019 p71) (Sobolweska and Ali 2015). Put into base language, young men "fizzing and pooping with testosterone" with no "healthy sexual 'outlet', allegedly driving them to take action in extreme ways, such as through the sexual exploitation of [White] children" (Chambers et al 2019 p72). Though, some of the victims were Asian women, and the majority of abusers are White (Chambers et al 2019).

Some parts of the mainstream media have responded to this negative picture with more positive stories (eg: speed dating in Muslim communities). "Working alongside, and sometimes within, the mainstream media, a new wave of young Muslims are also finding ways to present their friends, families and communities as confident, contented people who enjoy life and engage in well-rounded relationships" (Chambers et al 2019 p74). Sadly, many of these images are counter-stereotypes (ie: simplistic).

A more nuanced picture of Muslim sexuality has

appeared in modern writing (eg: Shelina Zahra
Janmohamed's memoir: "Love in a Headscarf"). "'Love in a
Headscarf' narrates the author's wearisome relationship
journey as she deals with interfering aunties and
matchmakers, hapless and unsuitable rishtas [photographs
of potential partners in arranged marriages] and the
emerging rules of (Muslim) Internet dating - all the
while striving not to compromise her faith" (Chambers et
al 2019 p78). However, the market-driven industry of
publishing pushes for "a commercial 'Muslim Bridget
Jones'" (p84).

Same-sex Muslim relationships are also covered in
modern writing, though only in a few texts (eg: Amjeed
Kabil's novel: "Straightening Ali").

Drawing to a conclusion, Chambers et al (2019)
stated that a "challenging but valuable component of some
Muslim-identified literature is the acknowledgement that
sexual intimacies and relationships can be both joyful
and difficult, and that many of these contrasting
experiences stem from being Muslim. In this
acknowledgement, which moves beyond negative stereotypes
of miserable Muslims but refuses to counter these with
equally simplistic stories of happy Muslims, it is
possible to move beyond the repetitive cliches that
dominate the mainstream media" (p87). The authors hoped
that they had avoided "both Islamophobia and Islamophilia
in scrutinising literary texts" (Chambers et al 2019
p67).

3.3. APPENDIX 3B - ARRANGED MARRIAGE

Talking about the UK, Pande (2015) stated: "The
rights of immigrant women and their choices in relation
to marriage have become a cause for concern for Western
governments and organisations who see arranged marriages
as an extension of patriarchy where women have no say in
whom they marry" (p172). This researcher suggested a more
nuanced picture.

Puar (1995) has talked of the "universal arranged
marriage", "which views arranged marriage as a
characteristic of patriarchal societies and conflates it
with the practice of forced marriage" (Pande 2015 p173).
Pande (2015) explained: "At the onset, it is important to
make clear the distinction between arranged and forced
marriages. In arranged marriages, the parents and
relatives of the person concerned take the lead in
introducing them to a prospective spouse, and the choice
to agree or disagree with the choice of the match is

always present. In current arranged marriage practices, the two people involved are encouraged to meet with each other in chaperoned or unchaperoned dates to find out whether they are suited as marriage partners. It is only when both parties agree that the marriage takes place. South Asians make a distinction between arranged marriages and 'love marriages', where the latter do not always include the active involvement of the parents and other relatives in the arrangement. In contrast, forced marriage practices provide no such opportunities and are performed without the full consent of the two people getting married" (p173).

Pande (2015) made use of data from her forty-four semi-structured interviews with men and women in North-East England of Indian, Pakistani and Bangladeshi descent in 2007-8. She quoted the example of three women who had experienced an arranged marriage.

a) "Shabnam" (Bangladeshi descent) - "I arranged my own marriage" (p176). This quote did not mean her "just simply telling her parents whom she wanted to marry because 'they don't do things like that' in her family. Instead, she worked with the joint-family structure, manipulating and negotiating her way around a culture which, though otherwise hostile to her speaking her mind directly, would happily submit to demands if made by following the proper channels of formality and ceremony" (Pande 2015 p177).

b) "Kanta" and her community (Indian descent) - Her experience can be explained thus: "The social premium of being part of a community that comes with having an arranged marriage was thus a significant factor in her plan for a married life" (Pande 2015 p179).
In "Kanta's" own words: "You see... I cannot boycott my own... society. We are a community, especially as Asians in Britain... community support is important. I want to have kids... we want a social circle... and at the end of the day if I am not a part of a community and participate in their give and take... who will come to my funeral?" (p179).

c) "Khadija" (Pakistani descent) - Cousin marriage was the norm in her family, but she was able to resist with a compromise "when her childhood friend suggested that her family was looking for a bride for her brother and that perhaps Khadija and her family members would be interested. She did confess that she was lucky to be able to have this choice and that not everyone would always

have the courage to defy community norms when it came to cousin marriages. When I asked her what had contributed to her luck, Khadija's view was that 'sometimes you make your own luck'. She had been aware of the family expectation about cousin marriages from a very early age. Since she did not approve of the practice she decided that she had 'to work on' her parents' views..." (Pande 2015 p180).

The three cases, Pande (2015) argued, showed elements of agency by these individuals that countered the stereotype of passive women. "The individual power tactics of these three women were central to their success in achieving what they wanted from an arranged marriage. In this process, they were also instrumental in redefining and readapting the customs and rituals of arranged marriages to suit their identities as Asian women in Britain" (Pande 2015 pp181-182).

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4. NEUROSCIENCE AND EVOLUTION

Cisek and Hayden (2021) began: "Like all biological entities, the brain and nervous system are products of evolution. That is, they were produced slowly, over millions of years, through a long series of modifications yielding a diversity of forms that were pruned by natural selection" (p1). This is not disputed by neuroscientists, but neuroscience has not paid it as much attention as it deserved, argued Cisek and Hayden (2021).

They observed: "Indeed, we believe a great deal of neuroscience research, especially at the systems level, proceeds almost as if it doesn't take evolution into account. For the most part, this work does not reject evolutionary principles, but rather it fails to consider just how much those principles can guide our research" (Cisek and Hayden 2021 p1).

Understanding the evolution of the vertebrate brain over time needs to be aware of conservative elements (ie: common areas between divergent species). For example, Suryanarayana et al (2021) compared the brain of the mammal and the lamprey (with a common ancestor about half a billion years ago), and found similarities in, for instance, locomotor control and the midbrain, and the visual system and the pallium. "This does not mean that these regions did not adapt and alter their function, but they could do so only within the constraints of their history" (Cisek and Hayden 2021 p4).

Concentrating on fear LeDoux (2021) explored the evolutionary basis. He argued that "the primary response to threatening stimuli is clearly an ancient property of many animals, but the subjective experience of fear is something quite different, and possibly much more recent to our lineage" (Cisek and Hayden 2021 p6).

Leopold and Averbeck (2021) introduced the idea of "self-tuition" to explain how the vertebrate brain "trains itself" to learn information needed for basic survival functions. "Self-tuition involves co-ordination between functionally distinct components of the brain, with one set of areas motivating exploration that leads to the experiences that train another set" (Leopold and Averbeck 2021 p1). The hypothalamus is key in this process with the basic motivations with send signals that interact with other areas of the brain. "These interactions gradually train the non-hypothalamic telencephalon to take over important aspects of perception and behaviour, including the direction of its

own education" (Leopold and Averbeck 2021 p7).

An example of the application of evolutionary considerations to neuroscience is Murray et al's (2017) proposal of seven different memory systems which have evolved at different times and in different contexts (Cisek and Hayden 2021):

i) Reinforcement memory - Evolved first with the control of movement.

ii) Navigation memory - Evolved as movement became common.

iii) Biased competition memory - Brain areas compete to control behaviour.

iv) Manual foraging memory - To guide visual search for food.

v) Feature memory - eg: object features.

vi) Goal memory - To help with goal-focused behaviours.

vii) Social subjective memory - Evolved in relation to the social structures of hominids.

Cisek (2021) argued that the control of the state of the organism in the environment is uppermost. So, "the fundamental function of the brain is not to build knowledge about the world, but rather to complement and counteract the dynamics of the world such that the entire organism-environment system stays within desirable states and away from undesirable ones" (Cisek 2021 p1). This is done by a feedback system between the body and the brain.
Cisek (2021) proposed "a hypothetical but plausible sequence" (p2) of evolutionary changes leading to humans based on the feedback system. Two undesirable states are particularly important - the threat of a predator (which produces "stimulus-response behaviour"; an "external" state), and hunger (which drives "goal-directed behaviour"; an "internal" state). These states result in "functional architecture consisting of parallel control systems, each dedicated to specifying the affordances for guiding particular species-typical actions, which compete against each other through a hierarchy of selection mechanisms" (Cisek 2021 p1).
Using this framework Cisek (2021) described changes

in the brain from ancient mobile animals, aquatic to terrestrial life, and to mammals. For example, the transition to terrestrial life presented new challenges including regulation of body temperature, new sensory information, and navigational demands which drove the evolution of the brain.

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5. MAD STUDIES

5.1. OVERVIEW

"Mad Studies" is a critical approach to psychiatry, and to "the marginalisation and oppression of people experiencing madness and distress" (Beresford 2021 p1). Beresford (2021) saw a "growing informal alliance" between psychiatry and neoliberalism which pathologises "the subjects of social problems" (p1).

Mad Studies is different to previous critical approaches to psychiatry in being "survivor-led and theoretically grounded" (Beresford 2021 p1).

Beresford (2021) outlined three "defining characteristics" of Mad Studies:

i) An "explicit divorce from a simplistic biomedical model" (Beresford 2021 p7) (ie: the use of social sciences).

The objectivity of scientific knowledge underpinning the biomedical approach has been increasingly challenged as "the influence of the pharmaceutical companies has been shown to be both self-interested and lacking in transparency" (Faulkner 2017 p501). While Thomas (2013 quoted in Faulkner 2017) summed up a deeper criticism: "There is no empirical evidence to demonstrate that psychiatric diagnoses are related to an underlying theory about the cause of disease".

"Mental distress, or the 'varied negative emotions that individuals experience in their daily lives', is inextricably linked to social contexts and cultural expressions (Gu 2010). This definition of mental distress abandons biomedical frameworks and terminology for a critical exploration into the various forms of subjective negative emotional states. Gu (2010) posits that an inclusive enquiry into understanding distress should explore issues related to mental well-being rather than classifying experiences into specific mental ill health diagnoses" (Mengistu 2021 p3).

ii) An "emphasis on first person or experiential knowledge" (Beresford 2021 p7).

iii) It is "survivor-led but it is not limited to survivors" (Beresford 2021 p7).

On this point, Le Francois et al (2013) stated: "We are not locating 'Mad Studies' as originating solely within the community of people deemed Mad, but also as including allies, social critics, revolutionary theorists, and radical professionals who have sought to distance themselves from the essentialising biological determinism of psychiatry whilst respecting, valuing and privileging the Mad thoughts of those whom conventional psychiatry would condemn to a jumble of diagnostic prognostications" (quoted in Beresford 2021).

Reaume (2021) considered the differences between Mad Studies, and Anti-Psychiatry and Critical Psychiatry. One immediate problem is "the diffuse nature of the writers and activists in this area and the absence of one central person as an ideological leader to follow as the ultimate source of original reference" (Reaume 2021 p98).

The term "anti-psychiatry" can be attributed to Cooper (1967), but it includes diverse individuals like Thomas Szasz, RD Laing, Michel Foucault, and Erving Goffman (Reaume 2021). Key ideas include the abolition of psychiatry, and forced treatment, as well as criticising "the connection between legal systems, medicine, coercion and the impact of the pharmaceutical industry on contemporary treatments of people in psychiatric facilities or under psychiatric jurisdiction in the community" (Reaume 2021 p99).

Reaume (2021) emphasised: "Given the vast differences in outlook and motivations behind what is a diffuse group of people described as anti-psychiatry, it should be no surprise that this term ends up in many cases to be confusing at best or meaningless at worst. It has been used as an easy way of slapping a convenient, intellectually inconsistent, and even unexplained label on critics of psychiatry in a way that is intended to diminish the seriousness of such criticisms" (p99).

Critical Psychiatry developed in the 1980s as a reaction to the either/or debate of psychiatry versus anti-psychiatry. "Critical psychiatry argues for a place within a hospital setting, while critiquing aspects of the mental health system, ranging from opposition to forced treatment, excessive use of medications particularly in regard to children, and systematically challenging the western orientation and racism in the mental health profession" (Reaume 2021 pp99-100).

Both of these approaches were developed by people "who saw themselves as allies of mad people" (p100),

whereas "the main premise of mad studies from the start has been and remains the centrality of empowering and engaging individuals who have had direct experience of the psychiatric system..." (Reaume 2021 p100).

Menzies et al (2013) made the important point that Mad Studies "subsumes a loose assemblage of perspectives that resist compression into an irreducible dogma or singular approach to theory or practice" (quoted in Reaume 2021).

Mad Studies "faces a conundrum. If its advocates want to disassociate it from a biomedical model, then understandably they must reject medicalised terminology. Understandably they have turned to 'mad' because it is a concept with international currency that has historically been used to describe the constellation of behaviours, experiences, feelings and issues that nineteenth century science onwards has subsumed as 'mental disorder'. They encourage us to connect with the wider world and explore different perspectives on it rather than focus on 'individual abnormality'... 'Mad' is a frightening word, but this is because madness and being driven to madness can be frightening. At the same time 'mad' is a word that sparks fear, threat and danger to many mental health service users/survivors because of its continued pejorative use against them" (Beresford 2020 p1339).

Faulkner (2017) noted some "significant challenges to the sustainability of Mad Studies" (p515), including:

- Going beyond the "White-centred core of survivor knowledge and research" (Faulkner 2017 p515).

- Helping academics teaching Mad Studies to "remain true to our roots" (Faulkner 2017 p515). Faulkner (2017) continued: "This requires conscious effort and an ability to look in several directions at once: towards the academy and towards our many and diverse communities. It requires a permeable membrane around the academy – something that is a challenge, as I know from personal experience. The bureaucracy inherent in our higher education institutions does not lend itself easily to infiltration by 'mad' people. But we are getting there. More service users and survivors are teaching on mental health practitioner courses and more are studying for PhDs. The lunatics are gradually infiltrating, if not taking over, the academy" (p515).

Along similar lines, Beresford (2020) offered an agenda for action for Mad Studies, including:

- Recognising that the "movement" is at the early stages, and, in a sense, get on with it without waiting for everything to be solved before study, like terminology.

- Support diversity and build alliances with other movements (eg: disability rights).

- "To spread the word in ordinary ways and places, to explain that there is an alternative to the psych system and thinking. We do not have to be framed in terms of individual pathology and transcending this is better for everyone" (Beresford 2020 p1341).

5.2. TERMINOLOGY

Jones and Kelly (2015) observed that there is "no single, universally accepted, term for individuals labelled with serious mental illnesses. Instead, the proliferation of terms and labels underscores the many ways in which unusual psychological or mental experiences play out in terms of identity, activist goals and socio-political positioning. This multiplicity of positions is further complicated by the fact that the meanings of existing labels themselves fluctuate depending on the particular contexts in which they are deployed" (p44). These authors were unhappy with madness as a single category, and preferred "varieties of madness" (Jones and Kelly 2015 p44).

Mental health system survivors, when asked (eg: Beresford et al 2016), felt that a biomedical model dominated, which was seen as "stigmatising and unhelpful", while there was "much stronger support for a more social approach to understanding distress. Many survivors made connections between their distress and broader social causes and consequences, including poverty, isolation and stigma" (Beresford 2020 p1338).

Individuals were divided about the terms "mad" and "madness". "Some thought they could be reclaimed, reflected their experience and were empowering. Others expressed strong feelings they had too many negative associations. Most had reservations about the terms... These included that such terminology encouraged the romanticisation of distress; had no clear or agreed meanings and could create division" (Beresford 2020

p1338).

Jones and Kelly (2015) outlined five areas of heterogeneity in understanding madness:

i) Language - "In the United States, key identifying terms include: consumer, service user, survivor, person with lived experience, person with (or labelled with) a mental illness, person with a psychiatric disability, and mad or mad-identified. On the surface, each of these terms privileges or centres a particular aspect of psychiatric experience: use or survival of mental health services; first person experience in a general or more specific sense (eg: of mental or psychological differences or protected legal status); distancing from or centring of mad experience as a core sense of personhood (ie: person-first vs. mad-first language); and legal status" (Jones and Kelly 2015 p46).

ii) Severity and dimension - "Although explicit hierarchies of severity or suffering are often discouraged in activist discourse, experiences of madness and the severity and dimensions of such experience are in fact extremely heterogeneous. These heterogeneities, in turn, carry important implications with respect to social acceptability, degree of risk for discrimination and social exclusion, centrality to identity, and access to valued social roles and norms" (Jones and Kelly 2015 p46).

iii) Course - ie: the temporal pattern (eg: improving or deteriorating symptoms; episodes; "recovery"). "Recovery and ongoing madness may also be positively or negatively valued. For instance, narratives of recovery may in some cases be offered as examples of desirable individualistic, neo-liberal self-overcoming... or as testaments to effective external (ie: clinical or pharmacological) intervention. Conversely, among other stakeholders, ongoing experiences of madness or mental diversity may be positively formulated as sources of creative maladjustment, positive mental diversity or spiritual transformation" (Jones and Kelly 2015 p49).

iv) Treatment - Some individuals avoid the mental health system, others choose treatments, while others are "captured" by the system (eg: involuntary hospitalisation).

v) Intersectionality - The interaction of the

madness with factors like ethnicity, gender, and social class, particularly where social marginalisation or exclusion is worsened.

The fear is that whatever the term used, the negative attitudes in society about "mental distress" "catches up with you... It certainly seems to be a case of a rose is a rose by any other name - we may change the words, but mean the same" (Beresford 2020 p1339).

5.3. EXPERIENTIAL KNOWLEDGE

The "dominant paradigm in mental health care reflects the professional model which is predicated on the existence of mental illness as having biomedical origins. This has resulted in an emphasis on technical expertise and the use of an individualist framework which 'not only obscures people's social-material world in our understanding of people's experiences, behaviour and distress, it also marginalises the lived experience and knowledge of those deemed mad' (Coles et 2013...)" (Faulkner 2017 p501).

Taggart (2021) began in a similar theme: "Mad persons have historically been excluded from knowledge production in the field of mental health. Having our faculties of 'reason' fundamentally challenged necessarily placed people outside the arena where knowledge about mental health problems was produced. However recent years have seen a move towards valuing 'experiential knowledge' [EK] based on the work of people who have used psychiatric services" (p154).

This type of knowledge is important in Mad Studies. EK "can be loosely described as knowledge that is generated from people with direct experience of the social issue under investigation, in this case living with madness and using mental health services, or indeed refusing to use those services" (Taggart 2021 pp154-155).

Beresford (2010) made this argument for EK: "The shorter the distance there is between direct experience and its interpretation (as for example, can be offered by user involvement in research and particularly user controlled research), then the less distorted, inaccurate and damaging resulting knowledge is likely to be" (quoted in Faulkner 2017). "Standpoint theory" (Harding 1993) fits with this idea. All research on mental health comes from a particular standpoint, but "marginalised groups have a more complete knowledge because they have access to the mainstream discourse as well as their own"

(Faulkner 2017 p506).

"Glasby and Beresford (2006) describe a review of hospital care they carried out, which included user-focused studies and qualitative research and highlighted issues of abuse and discrimination. They point out that, if the review had only included systematic reviews or RCTs [randomised controlled trials], it would have found almost no evidence and would have missed significant issues of human rights in relation to quality of care" (Faulkner 2017 p506) [8].

The value now being place on EK can be seen in, for example, the British Psychological Society having an "Expert by Experience" strategy, but "the Royal College of Psychiatry in the UK seem to have a more traditional, patient and carer involvement approach which does not grant any form of expertise to experience explicitly. This may reveal a more consumerist approach to involving service users, which positions their views as important by virtue of their service use" (Taggart 2021 p156). There is a risk that EK can become "co-opted into an essentially undisturbed orthodoxy" (Taggart 2021 p156), whereas in Mad Studies the desire is "for the telling and hearing of experience to have value in and of itself" (Taggart 2021 p157).

Another concern, for Taggart (2021), is a situation "whereby people's experiential knowledge can be invalidated by contradictory experiential knowledge of another person. Given the emotional labour it takes to describe aspects of our 'experience' this invalidation is likely to be personally costly for many" (p157).

Yet another potential issue is "the appropriation of psychiatric survivors' experiential knowledge in the form of narratives" (Taggart 2021 p162). Costa et al (2012) have talked on "disability tourism" and "patient porn", while Taggart (2021) used the phrase "the theft of experience" to describe "the use of experiential knowledge as a commodity, which can be traded in a marketplace, and discarded when no longer needed" (p162). Jay (2005) pointed out that "the very notion of experience as a commodity for sale is precisely the opposite of what many... have argued an experience should be... something which can never be fully possessed by its owner. Instead because experiences involve encounters with otherness and open onto a future that is not fully contained in the past or the present, they defy the very attempt to reduce them to moments of fulfilled intensity

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[8] Sweeney (2013) described EK as the "bedrock" of survivor research, while "peer support (and self-help) is, arguably, the bedrock of experiential knowledge" (Faulkner 2017 p509).

in the marketplace of sensations" (quoted in Taggart 2021).

Ending with reference to his experiences as "a survivor of institutional sexual abuse in childhood", Taggart (2021) stated that "I try to ensure my experience of past traumas can be faithfully rendered in the present to inform an experiential knowledge, but not so much that they keep me stuck there" (p163).

Qualitative research methods that seek to understand the individual's experience are more appropriate to "survivor research", but Faulkner (2017) warned that used in the "wrong way", within existing paradigms, "qualitative methods can be just as disempowering as any other research method" (p507).

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