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NATIONAL MENTAL HEALTH RESEARCH STRATEGY

BACKGROUND PAPER: Personality disorders (Session 3A)

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Introduction

Personality disorder suffers from a crisis of legitimacy in the health system and in psychiatric research. Long considered controversial, unreliable, and untreatable,[1] robust evidence indicates that personality disorder is common, costly, clinically important and treatable. By any measure, the great personal, social and economic costs, associated morbidity, persistent functional impairment and premature mortality[2,3,4] mark personality disorder as a severe mental disorder and provide a compelling case for personality disorder to be considered a public health priority.[5] Yet, personality disorder research lags behind most other domains in mental health. Moreover, personality disorder is not included in key policy-informing initiatives, such as the Global Burden of Diseases Project.[6] Consequently, there are limited data to guide health policy and planning for personality disorder.[7]

Background

There is broad empirical support for the following:

- Personality disorder categories are not supported by evidence.[8] The field is currently shifting toward empirically derived, dimensional models.
- The most prominent models are the DSM-5 section III Alternative Model for Personality Disorder (AMPD) and the ICD-11.[9,10] Both conceive of personality disorder as a single dimensional construct in which: (1) impairments in self and interpersonal functioning represent general features and severity of personality disorder; (2) maladaptive personality traits represent stylistic differences in the expression of personality disorder.[8,9,10]
- In AMPD and ICD-11, severity of personality disorder ranges from normal (non-disordered) personality at one extreme to severe personality disorder at the other. Severe personality disorder is essentially synonymous with borderline personality disorder (BPD).[11]
- Maladaptive personality is common, can be recognised early in life, evolves continuously across the lifespan and is more plastic than previously believed.[12]
- The prevalence of categorically-defined personality disorder is 9.6% (95% CI 7.9–11.3%) in high-income countries, compared with 4.3% (95% CI 2.6–6.1%) in low- and middle-income countries.[13]
- Personality disorder occurs in up to half of psychiatric patients[14] and ¼ of primary care attenders.[15]
- Severe (or borderline) personality disorder occurs in 1–3% of the population, with higher prevalence in young people.[16,17] Prevalence is high in treatment settings, affecting ⅕ of psychiatric outpatients[18,19] and 6% of primary care visits.[20]

- Heritability of severe (borderline) personality disorder is high, around 0.7.[21]
- Adverse childhood experiences are common among and strongly associated with BPD[22,23,24] but are neither necessary nor sufficient for developing the disorder.[25,26]
- Neuroscience research has mainly addressed aspects of self-referential processing, cognitive self-control and self-awareness.[27] Neurobiological models of BPD propose interactions of genetic and environmental influences that affect brain development via hormones and neuropeptides, leading to prefronto-limbic dysfunction.
- The clinical onset of severe personality disorder usually occurs between 12–25 years of age.[5]
- Delay in the diagnosis and treatment of personality disorders is the norm, with many clinicians still reluctant to give a diagnosis at the earliest possible stage.[5]
- Impairment in functioning in patients with personality disorder tends to be persistent, even beyond apparent improvement in personality pathology itself. Severe (borderline) personality disorder is associated with substantial and enduring impairments in social and occupational functioning.[2,28,29,30,31,32]
- Severe personality disorder is associated with an almost two decade reduction in life expectancy[33,34] and a suicide rate of around 8%.[35]
- Discrimination against people with personality disorder is widespread, and the stigma associated with personality disorder is greater than for other psychiatric disorders.[36]
- There has been significant progress in the treatment of BPD, with a range of psychosocial interventions showing small to medium effects for improvements in psychopathology.[37]
- No treatment has proven effectiveness for functional impairments in BPD.[38]
- All specialised treatments for BPD seem to have similar effects, despite distinct theories and interventions.[38]
- Pharmacotherapy is only advised as an adjunctive treatment for BPD.[38,39]

Gaps and uncertainties

Classification and models of personality disorder

Choosing a dimensional model of personality disorder has proven to be controversial.[40] While the DSM-5 alternative model of personality disorder diagnosis allows limited systematic comparison of categorical and dimensional classifications and continuity with past research, the ICD-11 proposal suggests a more radical change. It restricts personality disorder to a single dimension, basing clinical service provision exclusively upon severity, without defining cut points. While scientific support is strong for a hierarchical taxonomy of psychopathology,[41] clinical utility is still lacking for many frontline clinicians. Moreover, the break in continuity with previous research for BPD poses challenges.

The move towards assessing severity and functioning in both classification systems indicates a shift in the way personality disorder is conceptualised. Arbitrary thresholds for diagnosis (e.g. five out of nine criteria) are avoided in the revised ICD and proposed DSM systems, allowing for identification of targeted and staged treatments dependent on severity, which may be more clinically relevant.

Co-occurring psychopathology is common among people with personality disorder and is a natural consequence of the hierarchical structure of psychopathology. However, this causes confusion for clinicians

and researchers when it is seen through the lens of 'comorbidity', leading to suboptimal care. For example, auditory verbal hallucinations (AVH) are reported in 13.7%–50% of adults with BPD.[42,43,44] The presence and severity of AVH has been correlated with a greater number of co-occurring psychiatric diagnoses, along with a greater number of suicidal plans and attempts, and more hospitalisations in patients with BPD.[45] The presence of psychotic symptoms in BPD might be indicative of a more severe form of the disorder.[46] However, these symptoms are often omitted from treatment planning.

Aetiology, developmental neuroscience and developmental pathways

Prefronto-limbic dysfunction appears to be a transdiagnostic phenomenon that is related to negative affectivity in the context of social stress[47] or in healthy individuals who have been exposed to adverse childhood experiences.[48] Many of these 'developmental' studies are in fact retrospective. There are few prospective developmental studies and none has the breadth and depth of measurement, or the statistical power, to examine the complex pathways involved in homotypic or heterotypic continuity in personality disorder. Importantly, such personality disorder research is often isolated from such research in 'mainstream' mental disorders.

Functioning, disability and quality of life

When measured, severe personality disorder appears to be among the leading causes of disability in high-income countries. For example, among 15- to 34-year-old Victorians, BPD is the 4th leading cause of disability-adjusted life years (DALYs) for females and the 6th leading cause for males.[49]

Australians with personality disorder are up to 20 times more likely than those without personality disorder to be disabled in terms of total lost days of role functioning.[50] Yet, there are limited Australian data and personality disorder does not feature in the Global Burden of Disease study.

The long-term outcomes for people with personality disorder in Australia are largely unknown. One Australian study found that severity of personality disorder at age 24 was associated with receipt of welfare benefits and lack of post-school qualifications a decade later.[2] International studies consistently demonstrate that BPD features naturally attenuate over time, whereas impairments in social and vocational functioning persist, even decades after the diagnostic features of BPD are no longer clinically evident.[51,52,53,54] In particular, around two-thirds of adults with BPD are not engaged in a vocational pursuits during long-term follow-up.[55] In population-based studies, the presence of any BPD features is associated with poor work performance[56] and increased risk for being on a disability pension.[57] Use of new data linkage methods would provide a valuable insight into forensic, mental and physical health and functional outcomes, providing necessary targets for care.

Physical, sexual and reproductive health, and premature mortality

Personality disorder is associated with a number of physical health problems, including arthritis, cardiovascular and gastrointestinal disease.[58,59] Patients who endorse features of personality disorder are more likely to report poor physical health and a greater number of illnesses than those without personality disorder.[60]

In common with other severe mental disorders, severe personality disorder is associated with an almost two decade reduction in life expectancy and a high suicide rate. There is little Australian data on this subject and the mechanisms for premature mortality are poorly understood. Severe personality disorder rarely features in suicide prevention research and policy.

Substance use

Substance use is alarmingly high among young Australians with severe personality disorder.[61] Personality disorder is also common (up to half of attendees) among those attending substance use services.[62] However, the two fields of research and treatment rarely communicate.

Cost of illness

There is evidence to suggest that severe personality disorder is among the most costly mental disorders to treat in Australia on a per case basis.[63] International data indicate that severe personality disorder is associated with high direct and indirect economic costs[64] but there are no reliable Australian data. A recent Danish national study found that the societal cost for those with BPD were 16 times greater than matched non-BPD controls.[65] In addition, spouses of those with BPD had more direct healthcare and lost productivity costs than matched controls. Neglecting these population-level effects of personality disorder is likely to impede progress in reducing the burden of disease.[6]

Treatment

Treatments for patients with personality disorder have advanced considerably over recent decades, with the advent of a number of specialised psychotherapies[37] and early intervention programs.[5,66] Nevertheless, the evidence base for treatment is underdeveloped, with the majority of studies pertaining only to BPD[67] and with small to medium effects that are not sustained over time. There is currently no evidence that one treatment is more effective than others.

Research increasingly suggests that specialist psychotherapy might not be the only option in the treatment of personality disorders. Comparisons with more generalised, supportive treatments, which are less intensive and do not necessarily require trained psychologists for delivery, reveal that these approaches may be equally effective.[68]

Despite international consensus that personality disorder can be reliably and validly diagnosed in young people,[5] the field remains preoccupied with validity-related issues and reticent to address barriers to delivering effective early detection and treatment in clinical practice.

There is an 'absence of evidence', rather than 'evidence of absence' for pharmacotherapy in personality disorder. The literature is mostly industry-funded research and is marked by small studies, short-term outcomes and inconsistent outcome measurement.

Challenges

Many of the problems of personality disorder are common to all mental disorders and there appears to be a 'narcissism of small differences' in the field. These issues will already be covered in background papers to other disorder categories (lack of funding, 'comorbidity', measurement, workforce, translation and implementation). However, personality disorder does pose some distinctive challenges.

Stigma and discrimination

This is possibly the greatest barrier to improving the lives of people with personality disorder. Personality disorder is the most stigmatised of all mental disorders. Uniquely, this mostly emanates from other health professionals. While programs have demonstrated changes in clinicians' knowledge and attitudes regarding personality disorder, no study has demonstrated behavioural or systemic changes.

Discrimination against people with personality disorder seems to blend with discrimination toward the field of personality disorder research and treatment. Personality disorder has not been a funding priority for research and personality disorder is rarely considered in large-scale epidemiological or prevention initiatives, including in suicide prevention.

'The missing middle'

Personality disorder is a high prevalence problem. Even severe personality disorder occurs in around 3% of young people, making this a major challenge for the community. People with moderate to severe mental health difficulties can slip through the cracks of current care systems. The so-called 'missing middle' often have difficulties that are too severe and complex to be treated in primary care, however they are not severe enough to access the intensive and continuing care that may be required. Personality disorders often have high levels of comorbidity with other mental health diagnoses, amplifying complexity. Lack of service availability for those with personality disorder is underpinned by a lack of evidence around efficacy and cost effectiveness, and a focus on specialised therapies that might not constitute the best treatment. The exclusion of people with personality disorder from many treatment studies and from appropriate treatment services further compounds the shortage of meaningful research information that is available.

Families and friends

Carers and friends of people with personality disorder have often been excluded or blamed. Yet, they appear to experience high levels of burden and health problems. There is growing evidence that support for carers and friends can improve outcomes for those with personality disorder.[69]

Workforce

Strategies are required to attract and retain both research and clinical staff into the field of personality disorder. The existing lack of specialist clinical programs and research groups in this area further compounds the difficulty of expanding the already inadequate workforce in the field.

Studies suggest that peer workers can be useful in aiding recovery in mental health settings.[70] Given the entrenched prejudice, bigotry and discrimination among the clinical workforce, peer workers might provide a more open-minded approach to people with personality disorder. However, the workforce is in its infancy, without standardised training, and lacks a solid evidence base.

New technologies

The utilisation of new technology to deliver therapy and other mental health support has shown promise in recent studies.[71] However, such interventions including personality disorder specific content have not been trialled to date. Further investigation is required to ensure adequate uptake and efficacy of digital interventions, and how these might be best utilised to improve outcomes.

Funding

Mental health research is significantly underfunded globally. In Australia, mental health has consistently received less National Health and Medical Research Council (NHMRC) funding than other National Health Priority Areas, such as cancer, cardiovascular disease and diabetes.[72] Mental health funding from government, philanthropy and not-for-profit organisations is not equivalent to the burden of disease for personality disorder. Personality disorder in particular lacks much needed resources, with one US study noting that BPD received less than one-tenth of the funding of bipolar disorder over a 25-year period.[73]

Classification

Research into the DSM-5 AMPD and ICD-11 has produced promising results. However, the above section highlights the challenges of transforming the diagnostic system.

Opportunities

Personality disorder needs to 'come in from the cold' in clinical research and care. Breaking down the silos of categorical disorder research is a key strategic priority for personality disorder, as no area of mental ill-health is untouched by personality disorder.

Key priorities include:

- prevention and early intervention
- improving and expanding effective treatments, including pharmacotherapies, novel interventions and new technologies
- improving the quality of clinical trials in personality disorder
- improving functional outcomes for people with personality disorder
- improving the physical, sexual and reproductive health of people with personality disorder, especially premature mortality
- research addressing the needs of service users, family and friends. Engagement with these groups or supporting their own initiatives is crucial
- fostering research networks, which are largely absent in the personality disorder field
- improved measurement, common measures and inclusion of personality disorder in routinely collected administrative data. The International Consortium for Health Outcome Measurement (ICHOM) is in the final stages of developing such a set of measures and these should be considered for national implementation.

Global Burden of Disease

A principal mechanism to bring personality disorder into the spotlight is the Global Burden of Disease (GBD) study. Hitherto, when personality disorder has been considered in the GBD, this has been done after adjusting for all other mental disorders. The structure of psychopathology makes it extremely unlikely that cases of 'pure' personality disorder exist. It stands to reason that a disorder that presents early in life and is associated with many years of disability, followed by premature mortality, is likely to be a major health problem. Quantifying this problem is a key task.

Youth mental health

Early intervention for personality disorder is a key public health priority and a key pillar of youth mental health. Personality disorder research and treatment shares common priorities and methods with early intervention for other mental disorders.

Novel, empirically derived classification

Both the clinical staging model of mental disorders and the Hierarchical Taxonomy of Psychopathology (HiTOP) model provide opportunities to bridge current research silos to create a more rational, empirically useful, unified and integrated model of prevention, early intervention and treatment of mental disorders.

Conclusion

The personality disorder field has matured substantially over the past three decades, albeit from a small research base. However, it has largely done so in relative isolation from the rest of mental health research. Many of the challenges for personality disorder research are shared with all mental health research. True transformation of the field will come when personality disorder has a seat at the main table of mental health research, policy and advocacy. In order to do so, the field must overcome a deeply embedded culture of

discrimination toward people with personality disorder and research related to them. If this can be achieved, this would be transformative for people living with personality disorder, families, friends, clinicians and the community.

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