Management of mental ill health in people with autism spectrum disorder

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Background

Adults with autism spectrum disorder (ASD) may require medical assessment and care, especially for mental health conditions. Although substantial knowledge and resources are available regarding the management of mental ill health in children with ASD, substantial gaps remain for adults with ASD. Diagnostic overshadowing, limitations of communication skills and the heterogeneous nature of this patient population can make practice in this area more challenging, and can contribute to poorer outcomes, including overprescribing of psychotropic medications.

Objectives

This article aims to describe mental ill health and identify specific considerations for GPs during the assessment and management of adults with ASD.

Discussion

The incorporation of specific knowledge and adaptations in the areas of communication, awareness of physical health comorbidities, management of challenging behaviour, impact of the environment, role of carers and an approach that values neurodiversity has the potential to positively influence mental health outcomes of adults with ASD.

Autism spectrum disorder (ASD) involves persistent deficits in social communication and interaction, as well as restricted, repetitive patterns of behaviour and interests.[1] Prevalence of autism in children varies according to the methodology and country of the study. Yet, it is widely accepted that autism affects approximately 1% of children,[2] which is an increase since the 1970s.[3] This may reflect the increased availability of diagnostic services and awareness among professionals and parents, widening of diagnostic criteria, and/or a real increase in prevalence.

Service provision for individuals with ASD is dominated by paediatric services, with adult services reported as inadequate.[4] Barriers to service access and appropriate care for adults with ASD include inadequate training and awareness in health professionals, diagnostic overshadowing, lack of specific autism mental health services, and a lack of coordination and communication between agencies.[5,6] Primary care physicians have reported that they would like more training in caring for adults with ASD.[7] A surprising 23% of a large cohort (n = 1580) of physicians reported never having any ASD-specific training,[7] highlighting the unmet need for training in developmental disabilities in undergraduate and postgraduate medical courses.

Adults with ASD represent a heterogeneous population; individual skills and challenges range considerably and change depending on environmental factors, available supports and stressors.[8] The prevalence of ASD in adults has been reported to be approximately 1%, which is similar to that for children.[9] This article describes mental ill health in adults with ASD and outlines specific considerations that general practitioners (GPs) could implement to improve consultations with adults with ASD. Table 1 summarises some of the key factors for GPs to consider when caring for these individuals.

Mental ill health in adults with ASD

The reported prevalence of mental ill health in adults with ASD varies because of methodological variations between studies. These include variations in sampling (eg size, bias and inclusion of clinical samples), diagnostic difficulty in individuals with limited communication (eg difficulty explaining their emotions) and difficulty distinguishing symptoms of mental ill health from ASD symptoms.[5] However, it is widely accepted that mental ill health in adults with ASD is more common than in the general population and is associated with long-term negative outcomes.[10,11] Over-representation is evident in neuropsychiatric disorders such as psychotic, mood, anxiety, attention deficit hyperactivity and tic disorders, and catatonia.[12,13] This over-representation, coupled with the reported rise in ASD prevalence,[9] highlights the importance of GPs in the recognition and management of mental ill health in individuals with ASD.

Prevalence of mental health disorders in individuals with ASD

Most of the research describing the prevalence of mental disorders in adults with ASD comes from younger adults, and there is a lack of data concerning older adults. Depression, anxiety and obsessive compulsive disorder are reported to be particularly common in younger adults with ASD.[14,15] Anxiety has been reported to occur in about one-third to one-half of younger adults with ASD.[14,16] Reported rates of depression in ASD vary considerably, with up to half of the individuals with ASD being affected.[14] Neurodevelopmental disorders are common in adults with ASD, with ADHD being reported in 38% of the group.[14] Schizophrenia appears over-represented in adults with ASD, but the reported prevalence varies widely (0–10%),[17] making firm conclusions difficult. The prevalence of neurodegenerative disorders including Alzheimer's disease (AD) in ASD is unclear.

Table 1. Summary of key considerations for GPs

	General considerations for GP consultations with adults with autism spectrum disorders	Potential influence on mental health
Prior to the consultation	• Ask the patient or carer to bring their personal health record • Determine any specific requirements (mobility or sensory) • Arrange for a longer appointment time where appropriate	• Improves clinical assessment • Optimises experience in further medical appointments
Communication	• Simplifying language • Leave pauses and wait • Communicate one idea at a time • Speak in a normal tone • Avoid ambiguous language • Consider most appropriate communication style (eg written, verbal) • Consider using multiple techniques (eg message supported by written materials)	• Improved communication will improve accuracy and quality of assessment • Changes in communication may reflect changes in mental health
Challenging behaviour	• Perform a hierarchical assessment, which considers the contribution from medical and psychiatric disorders • Refer to appropriate specialist behaviour support or specialist psychiatrist	• Untreated medical and psychiatric disorders commonly exacerbate challenging behaviour • Poorly managed challenging behaviour leads to exclusion from participation, which may have a negative impact on mental health
Carers	• Carers can assist GPs with valuable personal information about the adult on the spectrum (eg changes in behaviour, communication, nutritional uptake and previous medical history) • Refer carers to support services where appropriate	• Carer stress and poor mental health can influence the mental health of individuals on the autism spectrum
Physical health comorbidities	• People on the autism spectrum experience similar physical health problems to the general population • Screen for common comorbidities • Annual general health checkups and routine preventive screening measures are recommended	• Strong interaction of both physical and medical health • Chronic conditions such as pain, epilepsy and gastrointestinal disorders may increase likelihood of mental ill health and challenging behaviours
Sensory environment	• Consider the lighting of waiting rooms and office (eg avoid bright fluorescent lights if possible) • Consider a referral to an occupational therapist for an assessment of the adult's sensory processing	• Sensory sensitivities may complicate assessment and management of mental disorders • Overwhelming sensory environments can increase stress and anxiety

While a hypothesis has been proposed for reduced risk of AD related to brain hyperplasticity in ASD,[18] this theory remains unsubstantiated. The prevalence of psychiatric disorders is increased in those with both severe intellectual disability and ASD.[19]

GPs' role in identifying and managing mental ill health

Although the assessment of mental ill health in individuals with ASD can be complex, GPs possess core skills that can be adapted to enhance clinical practice in this area. Key adaptations identified for patients with intellectual disability include altering communication methods, providing additional time for consultations, appropriate engagement with carers, and consideration of the sensory and physical environment.[20]

Specific considerations for assessment

A number of specific considerations for GPs that may help in providing mental healthcare to adults with ASD are outlined below. These are likely to be significantly influenced by the level of cognitive function of the adult with ASD and need to be carefully considered for each individual patient.

Table 2. Recommended pharmacological and psychological treatment for mental ill health in adults with autism spectrum disorders

Mental illness	Pharmacological treatment	Psychological treatment
Anxiety disorders	• Psychological therapies are recommended as first-line management • Selective serotonin reuptake inhibitors (SSRIs) are first-line medication. Commence on a low dose and increase slower than in the general population • Unless advised differently by a specialist, benzodiazepines should only be used as a short-term medication. Benzodiazepines may, paradoxically, heighten agitation, impulsivity or disinhibition	• There is some evidence of the effectiveness of cognitive behavioural therapy (CBT) in treating children and adolescents with autism and anxiety[33,34] • Mindfulness-based therapy may be useful[35]
Depression	• Follow treatment recommendations for the general population • Psychological therapies are the recommended first-line management for mild depression • SSRIs can be used to treat depression and aggression • Lithium may be useful, particularly if underlying bipolar disorder is suspected, or in situations where there are high levels of impulsivity and aggression	• A structured form of psychotherapy, including CBT, is often suggested in the literature; however, there is little evidence of the effectiveness of such interventions
Bipolar disorder	• Follow treatment recommendations for the general population • Lithium[36] may be useful along with other standard mood stabilisers such as sodium valproate and carbamazepine • Atypical antipsychotics such as quetiapine and olanzapine may be useful adjunctive medication	• No clear evidence base but psycho-education, cognitive and mindfulness-based therapies may be of benefit
Schizophrenia or schizoaffective disorder	• Follow treatment recommendations for the general population • Consider potential heightened sensitivity to side effects and the impact on medical comorbidities • Avoid depot medication administration (greater vulnerability to side effects such as tardive dyskinesia) • Clozapine may be considered for confirmed cases of treatment-resistant psychosis • Extra precautions include: – Ability to cooperate with blood test and other monitoring is necessary – Consider medical comorbidities such as epilepsy or elevated baseline cardiometabolic risk profile	• No clear evidence base but adapted cognitive and rehabilitative approaches may be of benefit
Attention deficit hyperactivity disorder (ADHD)	• Follow treatment recommendations for the general population • Treat with caution if comorbidities such as tic disorders and anxiety are present	• There may be benefits from social skills therapy, individual and family psychotherapy and/or behaviour therapy; however, minimal evidence[37]
Obsessive compulsive disorder	• Follow treatment recommendations for the general population	

Valuing neurodiversity

It is important for GPs and health professionals working with individuals on the autism spectrum to recognise the strong self-advocacy movement within the autism community, which embraces positive self-image and neurodiversity.[21] Autism is seen as a fundamental part of the person, and is viewed as a neurological 'difference' rather than deficit. There is no single way to describe autism that is universally accepted,[22] and many adults with ASD prefer to identify themselves as 'autistic',[23] whereas others continue to prefer person-first language. The self-advocacy movement has a significant influence on the types of interventions and treatments preferred by adults with ASD. It is therefore important for GPs to identify the terminology and therapeutic approach preferred by the individual. Acknowledgement of the individuals' preferences and self-identity are key to the development of a positive therapeutic relationship.

Communication

Impairments in social communication are a core part of ASD. In some individuals, reliance on verbal reports may result in the failure to detect core signs and symptoms of mental disorders. Communication can be assisted by allowing extra time during the consultation, using brief and concrete language, pictorial aids, or supplementing communication using written reports of symptoms.[24] GPs should avoid continually rephrasing information, as this can cause confusion. Information given by the patient

Table 3. Resources for GPs working with adults with autism spectrum disorders

	Resource	Description	Source
Autism specific	• National developmental team for inclusion – includes publications such as the *Green light toolkit 2013* • Amaze (previously known as Autism Victoria) – Fact sheets • Autism CRC – Health hub • *Medical comorbidities in autism spectrum disorders: A primer for health care professionals and policy makers*	• Reasonable adjustments that should be made to mental health services to enable people with ASD to have equal access and effective treatment • A variety of fact sheets are available, including *Modifying your message: Communicating effectively with individuals with ASD* • Up-to-date health and wellbeing resources relevant to ASD • Summary report of medical comorbidities in ASD	• www.ndti.org.uk/major-projects/current/green-light-toolkit-2013 • www.amaze.org.au/discover/about-autism-spectrum-disorder/resources • www.autismcrc.com.au/health-hub • http://nationalautismassociation.org/pdf/MedicalComorbiditiesinASD2013.pdf
Intellectual disability specific	• *Accessible mental health services for people with an intellectual disability: A guide for providers* • Intellectual disability mental health e-Learning modules • *Convention on the rights of people with disabilities* • Comprehensive Health Assessment Program (CHAP)	• A framework for mental health professionals to improve the accessibility and quality of mental healthcare for people with intellectual disability • Free e-learning about intellectual disability to professionals, carers and consumers • United Nations convention • A tool to enable improved identification and documentation of health needs of adults with an intellectual disability	• http://3dn.unsw.edu.au/project/accessible-mental-health-services-people-intellectual-disability-guide-providers-guide • www.idhealtheducation.edu.au • www.un.org/disabilities/convention/conventionfull.shtml • www.communities.qld.gov.au/disability/support-and-services/for-service-providers/service-initiatives/comprehensive-health-assessment-program-chap
Resources for carers	• Carers Australia • Commonwealth Home Support Programme	• Carers Australia is the national peak body representing Australia's carers • This program provides respite for carers	• www.carersaustralia.com.au • www.myagedcare.gov.au/aged-care-services/commonwealth-home-support-programme
Other	• 'Find a psychiatrist' tool from the Royal Australian & New Zealand College of Psychiatrists	• A directory of consultants in private practice in Australia where GPs can search for psychiatrists specialising in certain areas of practice (eg ASD – adults)	• www.ranzcp.org/Mental-health-advice/find-a-psychiatrist.aspx

should be interpreted in the context of their social communication impairments. Avoidant eye contact and differences in the use of gesture and facial expression should be factored in to the interpretation of the mental state examination. This will be an easier task in the context of prior knowledge of the person's communication style. In non-verbal adults, changes in functioning and regression of skills are potential markers of deteriorating mental health.[25] Diagnostic assessments should therefore include consideration of reported changes in function and skills, including those reported by carers.

Physical health comorbidities

Comorbid medical conditions are common in adults with ASD. These present a significant burden and may increase a patient's vulnerability to some mental health disorders.[26] For example, epilepsy occurs in approximately 20–25% of individuals with ASD, particularly in the context of intellectual disability, and has been associated with depression,[27] anxiety and psychotic disorders. Although there is limited research exploring physical health comorbidities in adults with ASD, two recent large-scale studies from the US have reported significantly elevated rates of many medical and psychiatric conditions in comparison with the general population. In regards to physical health, Kohane and colleagues found increased prevalence of bowel disorders, sleep disorders and type 1 diabetes mellitus.[26] Croen and colleagues confirmed these findings and also reported elevated rates of hyperlipidaemia, epilepsy and constipation.[12] The rates of type 1 diabetes mellitus and inflammatory bowel disease may also increase with age in individuals with ASD.[26]

Challenging behaviours

Challenging behaviour (CB) is common in adults with ASD and has a significant impact on the adult, carers and families.[28] CB is defined as behaviours that jeopardise the safety of the individual or others, or results in an individual being denied access to community facilities.[29] Behaviours that are sometimes exhibited by adults with ASD include aggression, tantrums, self-injury and pica, and are more likely to occur in those with intellectual disability.[30] An in-depth assessment of the causes of CB is crucial as these can be triggered by new onset or exacerbations of mental disorders, altered sensory processing, pain, physical health comorbidities (eg gastrointestinal disorders), and environmental factors. If no obvious psychiatric or medical cause is apparent, detailed assessment and management by an experienced behaviour support specialist is essential. In this context, interventions could include behavioural therapy, sensory assessment and implementation of a sensory diet, alterations to the environment and, if necessary, pharmacotherapy.[31]

The importance of the environment

Sensory processing differences are now included within the diagnostic criteria for ASD.[1] Heightened or lowered tolerance to sound, vision, touch, movement, taste and smell can be experienced by individuals with ASD. Inability to tolerate sensory input can have an impact on the adult's ability to participate in the community, and have significant implications for their mental health (eg as a driver of anxiety and avoidance symptoms).[32] Referral to an occupational therapist for a sensory assessment and therapy may be useful. However, practitioners should be aware that evidence for the effectiveness of sensory interventions is limited at this time. In view of issues with sensory tolerance, adaptations to consultation rooms in general practice may improve the consultation experience for adults with ASD. These include avoiding fluorescent lighting, dimming the lights, reducing visual distractions, minimising auditory distractions including those from machines and loud ticking clocks, providing a comfortable chair, and fidget, tactile and/or weighted items that the person may hold or touch to aid in self-regulation.

The carer role and experience

Formal or informal carers have an essential role in the assessment and management of mental health disorders in adults with ASD. They can provide invaluable information to assist GPs in identifying changes to behaviour, nutritional intake and communication, and help to provide a detailed medical history. The health and wellbeing of family caregivers is very important to the health and wellbeing of the individual with ASD. The carer of an adult with ASD may be an ageing parent, an adult sibling, a son or daughter, a significant other or a friend. Parent carers of adults with intellectual and developmental disabilities report poorer mental health status than parents of those without disability.[33] GPs should therefore consider the needs and supports of the carer as essential to the wellbeing of the person with ASD. Referrals for family carers to services and supports including respite and support groups may be required.

Treatment

The approach to the treatment of mental illness in adults with ASD is multifaceted, and typically involves both psychological and pharmacological interventions. Despite the growing evidence base for mental health intervention for children with ASD,[34] the evidence to guide practice in adults is limited (Table 2). GPs may find it helpful to seek the input of a specialist psychiatrist to assist in treatment planning. A useful tool to identify specialists is the 'Find a psychiatrist' tool through the Royal Australian and New Zealand College of Psychiatrists (RANZCP; Table 3). Referral to a psychologist under a mental healthcare plan may also be appropriate. However, there are challenges associated with cost and accessibility. Access to specialised mental health supports can be a challenge in rural and remote regions. However, implementation of programs such as the 'Better Outcomes in Mental Health Care' program is having a positive influence.[35]

Despite the limited evidence of effectiveness,[36] the use of psychotropic medications in adults with ASD is common and

was prescribed in approximately half of the adults in a large study.[37] Prescription of psychotropic medications, especially antipsychotics, has important health implications. Decisions to prescribe should involve careful appraisal and discussion of the risks versus perceived benefits (Table 2). Practitioners have a key role in monitoring associated cardiovascular and metabolic effects as well as other possible side effects of psychotropic medications.[38] Undertaking standard assessments of these risk factors may be difficult in the context of challenging behaviours, sensory sensitivities and limited communication skills. GPs should address these challenges by allowing more time for the consultation, adjusting their communication style, involving support workers or carers, and trialling therapies (eg sensory desensitisation to venipuncture). The need for pharmacotherapies should be reviewed regularly, and medications that are no longer required should be withdrawn.

Conclusion

Mental health disorders are common in adults with ASD. As the bulk of mental healthcare for adults with ASD occurs in the primary health context, GPs have an integral role in planning, implementing and reviewing mental health treatments, and as gatekeepers to specialised services. A number of key adaptations to practice will improve the quality of the experience for both the adult with ASD and the GP. There are a number of resources and tools available to GPs to support their practice. Optimising the mental health of adults with ASD is important in recognising the right of adults with ASD to high-quality healthcare, and is likely to enhance engagement and participation of adults with ASD in Australian society.

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