Recognising autism in healthcare

Abstract

Recognition of autism and the associated co-occurring physical and mental health issues has increased over recent years. However, undergraduate and postgraduate curricula take time to adapt and to impact on what is delivered in training so healthcare professionals, including doctors, report little training on these topics. Doctors need to know when someone might be autistic in order to respond to them appropriately. This article sets out the reasons why recognition of autism is important and the positive impacts of recognising and understanding autism on health outcomes, service delivery and patient experience. The negative consequences of not recognising autism or understanding the impact of autistic traits on the person are also explored. A companion article then covers how practice can be made more appropriate for autistic people to improve outcomes.

Key words: Autism; Autistic; Integrated care; Mental Health; Physical health; Recognition

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Introduction

This article focuses on why identification of autism is important, both for autistic individuals and to help health and social care services respond appropriately. It sets out the common traits, sensitivities and factors which can help a clinician to identify someone as likely to be autistic. An accompanying article (https://doi.org/10.12968/hmed.2021.0314) looks at how to respond appropriately, and the reasonable adjustments that health and social care services can and should make to maximise the health and wellbeing of autistic people. Both articles place special emphasis on these in relation to hospital medicine. Please note that although the principles described here will be common in all countries, the exact wording of legislation and policy will vary between jurisdictions.

Incorporating autism into a care plan helps healthcare systems deliver the triple aim of improved patient experience, better population health and reduced per capita cost (Berwick et al, 2008). In addition to this, it has benefits to the doctor. It will increase the chances of a successful consultation and good outcome, reduce frustrations and anxieties that can come from unusual, unexplained presentations, reduce the risk of adverse events or complaints and, therefore, reduce the risk of burnout.

Terminology

The number of terms used related to autism can be confusing, but this article uses the term 'autism' as the all-encompassing term (regardless of any sub-divisions in classification systems such as the International Classification of Diseases (ICD) 10 or 11, Diagnostic and Statistical Manual of Mental Disorders (5th edition) (DSM-V) or Snomed CT) and 'autistic people', a term preferred by the autism community in the UK (Kenny et al, 2016), although it is important to note that individuals have the right to use other descriptors by their own choice.

What is autism

Autism is a neurodevelopmental condition that is present from birth and is lifelong. Historically it was characterised as a 'triad of impairments' based around the three areas of reciprocal social interaction, communication, and restrictive and repetitive behaviours and interests. Diagnostic classifications such as in the DSM-V (American Psychiatric

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Association, 2013) use impairment-based diagnostic criteria, noting 'persistent deficits' in those areas. It is increasingly recognised that these are differences rather than deficits, but that those differences can give rise to significant difficulties if not understood and considered. These difficulties in turn can then lead to impairments and disabilities.

Challenging the myths and misconceptions

Myths and misconceptions surround autism, for example that autism is indicative of or is only present in people with a learning disability, is primarily a male condition or is only an issue in childhood. There is increasing awareness of the heterogeneity of autism and that autistic traits and sensitivities positively and negatively impact on autistic people throughout their life course. Doctors and staff in all types of healthcare services, specialties and settings need to learn how to recognise such patients, understand their unique strengths and challenges, and understand how to respond effectively to their needs.

It can be difficult for clinicians to identify autistic people presenting to them, as while increasing numbers will have a diagnosis, most autistic adults will not have one or it may not be recorded in their health record. Access to diagnostic assessments has improved over recent years, but huge variance remains in the services on offer across the UK, with a range of barriers being identified including getting a referral, lengthy waiting times and inconsistent pathways (Rutherford et al, 2016; Crane et al, 2019). Under-recognition of the heterogeneity of autistic people has been a significant contributory factor to the higher rates of preventable and treatable physical and mental disorders being detected.

Prevalence

Knowledge about autism, including its prevalence, has been increasing, especially in the last 20 years. This is not covered in detail here as this article is about recognition in clinical practice, but some key points are highlighted. For those seeking more information on particular aspects of prevalence, UK Parliament's (2020) autism research briefing is recommended as a good starting point with extensive references.

- In the UK the most established prevalence rate is 1.1% (Brugha et al, 2016) and this is used by UK government as a minimum prevalence rate.
- Historically, autism was considered to occur in boys with learning disabilities. This perception meant that autism was not even considered, never mind assessed, in many people who did not fit that category. If something is not considered, it is very unlikely to be identified. While it is true that boys with a learning disability are more likely to be autistic, it is not true that autistic people are likely to be boys with learning disability. Therefore, as awareness grows, the proportion of autistic people who are males is dropping, from estimates of over 85% of autistic people being male at the end of the 20th century to an estimated 75% of autistic people being male in 2017.
- The majority of autistic people do not have intellectual disability. Early studies based on data collected in the late 20th century showed great variability, for example, a review by Emerson and Baines (2010) found a range from 15% to 84% having learning disability across multiple studies, with an unweighted mean of 52.5% and a weighted mean of 38.4%. They noted that as the numbers of people identified as autistic increased, the proportion with learning disability decreased. The significant expansion of access to diagnoses in the 21st century has meant a great increase in the numbers identified as autistic. Two studies in Scotland (Kinnear et al, 2019) and in England (Roman-Urrestarazu et al, 2021), with rates of intellectual disability of 15% and 18% respectively, show that the trend to reducing proportion of identified autistic people having learning disability has significantly impacted the figures in the last decade. The vast majority of autistic people seen in general clinical practice will therefore not have learning disability.
- Most autistic adults, particularly older adults, were not identified in childhood, although diagnoses can be made at any age, including well into older life (70 years and over). More children are being diagnosed as autistic now and many of those will transfer to adult services with co-occurring health disorders.

- People from ethnic minority backgrounds appear to be under-represented in the number of people being diagnosed. The interaction between ethnicity and access to diagnostic pathways is an area that has not been researched but there is no reason to suspect that autism will be less common in people from ethnic minority communities.

Recognition

Ideally, an autistic person should be identified as such in the health records, along with individualised person-centred information on how best to meet their needs. This may be through an alert in the health records or by the person, family or supporter showing the clinician an autism alert card or a hospital passport. Having and using this information enables the whole interaction with health services to run more smoothly, with fewer misunderstandings and better outcomes. Many autistic people do not have a diagnosis, or it is not brought to the clinician's attention, for example by an alert in the electronic patient record. It is therefore important to recognise that somebody may be autistic to enable specific questions to be asked which will inform reasonable adjustments.

Doctors tend to underestimate the number of autistic patients under their care, in both primary care and hospital-based practice, even when the diagnosis is already known and recorded (Zerbo et al, 2015; Nicolaidis et al, 2021). Conversely, patients may be reluctant to disclose a diagnosis because of their previous experiences of stigma and unconscious bias. It is important to note that unconscious bias is a valid concern for autistic patients. Outside of the healthcare setting, it has been shown that non-autistic people quickly form negative opinions or 'thin slice judgements' towards autistic people, with reduced intention to pursue further interaction (Sasson et al, 2017). There is evidence that this is mitigated where an autism diagnosis is disclosed (Sasson and Morrison, 2019). This phenomenon has not been tested in a healthcare setting, but may be more likely to occur when contacts are new and there is less continuity of care.

Autistic people frequently experience additional difficulties accessing care and interacting with healthcare providers. This not only increases stress but can discourage or even prevent people from accessing healthcare in a timely manner. They are likely to present late, with high levels of acuity and distress, which can lead to them being less able to explain themselves or to process information. In addition, many autistic people try to camouflage their autistic traits in order to fit in and avoid social stigma (Mandy, 2019), and may therefore not appear to be showing common autistic traits. Camouflaging requires intense and sustained effort, which can be exhausting (Hull et al, 2017). This can further increase stress levels and potentially lead to 'autistic burnout' (Tierney et al, 2016; Livingston et al, 2019). This can result in an apparent sudden decompensation during a consultation into a state of marked agitation, often described as a 'meltdown', or the person becoming increasingly non-responsive or unable to access fluent speech, through to catatonia under severe stress. Autistic people typically have smaller social networks than non-autistic people, so may be less able to have an informal supporter in attendance to help explain things. It is important to note that the difference between their presentation when calm and well and their presentation when distressed or ill may be much greater for an autistic person than for a non-autistic person.

To a non-autistic healthcare professional, an encounter with an autistic person can feel in some way unusual, often with a quality that is hard to pin down. The answers to questions and the body language can seem out of sync or eccentric, and relapsing and remitting conditions may not be responding to interventions in conventional or expected ways. This can be the first alert. Common indicators that someone might be autistic are included in Table 1.

There are no traits or sensitivities which are unique to autistic people, they are all human traits and sensitivities. It is the number, lifelong nature and significance of such traits and sensitivities which lead to the diagnosis. The more of the traits and sensitivities identified, and the more evident they are, the more likely it is that the person is possibly autistic. If you think someone may be autistic, then make the person-centred reasonable adjustments, even if there is no formal diagnosis. This is covered in the accompanying article (https://doi.org/10.12968/hmed.2021.0314).

Table 1. Indicators which are more common in autism

Communication and social interaction differences	■ Unconventional ways of integrating verbal and non-verbal communication (often appears 'odd' to a non-autistic person) ■ The use of social scripts in conversations that may appear more superficial and not used conventionally or well timed ■ Not demonstrating conventional patterns of listening (if you are not sure if they are listening, ask them to repeat what was said) ■ Doing better with single questions than multiple questions (autistic people do better with time allowed to process each question separately) ■ A longer time to process information (autistic people tend to reflect on things, so may come back later with questions that the clinician thought had already been covered) ■ Repeated questions (autistic people prefer precise direct language and explanations, so can struggle to understand euphemisms or talking around a topic, leading to more questions to try to get a precise answer – they can and will accept 'don't know' if that is the correct precise answer) ■ Answers to questions may be unconventional – either too brief or too lengthy and detailed ■ Difficulty identifying or describing their own specific emotions, feelings or physical sensations, such as alexithymia ■ Literal interpretation of language ■ Missing common social cues or not recognising the conventional etiquette in a situation ■ Not picking up on subtle non-verbal cues from others ■ Lack of conventional eye contact, facial expression, intonation or gesture ■ They typically answer the precise question asked without adding in context unless they are directly asked ■ Unexpected responses ■ Dislike of small talk ■ Less likely to initiate or reciprocate in a two-way conversation so the clinician can end up feeling that they are interrogating the autistic person ■ Less likely to bring in social interest questions or comments ■ More likely to have a limited or no support network
Preferences for predictability, routine, repetition	■ More likely experience higher anxiety with regards to uncertainty, change, going into new situations and meeting new people ■ Needing extra details and time to plan and prepare – autistic people do best if they can see the logic and relevance of any proposed change ■ More rule based so they typically expect things to happen as per the plan or the instructions set out ■ More likely to focus on intense or narrow interests ■ Repetitive behaviours, including repetitive body movements, different body posture. These can be caused by stimming (self-stimulating behaviours that help reduce stress and can look like elaborate fidgeting)
Sensory differences	■ Hypersensitivity in any sensory modality can increase stress or distress, whether caused by lighting, noise, touch, temperature, inactivity, smell or taste ■ May experience difficulties recognising hunger, thirst or the need to go to toilet until it is urgent ■ More likely to experience pain differently, for example an oversensitivity or undersensitivity to pain
Executive functioning issues	■ While most autistic people have generally good cognitive functioning, they may find it more difficult to initiate, sequence or plan tasks, especially when stressed or faced with too many choices ■ They can get overstressed leading to difficulties with working memory, attention or organising tasks and may need a few minutes to compose themselves and reset

Why does it matter?

Autistic people are more vulnerable to a range of co-occurring physical and mental health conditions (Croen et al, 2015). Getting the best treatment for these can be hampered by differences in communication, social interaction, presentation and help-seeking behaviours, which can lead to secondary and tertiary conditions and premature death (Hirvikoski et al, 2016).

The Hirvikoski study showed that, compared to the non-autistic population, autistic adults who did not have co-occurring intellectual disability had 16 years premature mortality

Table 1. Indicators which are more common in autism (continued)

Common co-occurring conditions	■ Attention deficit hyperactivity disorder ■ Other neurodevelopmental conditions such as dyspraxia, dyslexia, dyscalculia ■ Anxiety or depression ■ Suicidal ideation and attempts, and deliberate self-harm ■ Cardiovascular issues ■ Hypertension, diabetes, stroke, high cholesterol ■ Endocrine disorders ■ Epilepsy ■ Ehlers–Danlos syndrome or hypermobility ■ Eating or weight disorders ■ Intellectual disability ■ Sleep issues ■ Gastrointestinal disorders ■ Emotionally unstable personality disorder or borderline personality disorder (can be a co-occurring disorder, but can sometimes be a diagnosis given to an autistic person in error)

and 30 years for those with co-occurring intellectual disability. The study explored cause-specific mortality and found increased mortality rates for autistic people across all diagnostic categories, apart from infections. Multiple other studies show similar mortality patterns (Bilder et al, 2013; Smith DaWalt et al, 2019).

Even in-hospital mortality is increased for autistic adults, with autistic inpatients one and a half times more likely to die during admission than non-autistic patients. The risk is even higher for autistic women, who face almost twice the risk of dying during admission compared to autistic men, and three times compared to non-autistic women (Akobirshoev et al, 2020). Reliance on emergency care is increased, with autistic adults three times more likely to use emergency departments, to require inpatient admission, and to die after attending emergency care (Vohra et al, 2016).

Although interest and the number of publications is rising, the reality remains that many doctors have little training in autism. Both GPs and hospital specialists commonly describe difficulty understanding and communicating with autistic people (Unigwe et al, 2017; Nicolaidis et al, 2021). A small minority of primary healthcare providers report high levels of confidence in communicating with adult patients with autism or identifying and making necessary accommodations (Nicolaidis et al, 2021). Difficult doctor–patient relationships negatively affect doctors' interactions with patients, including reduced motivation to spend time with a patient in person and to consider diagnostic and therapeutic challenges (Zhang et al, 2020). There is some evidence that standards of care may be reduced and short-term outcomes worse for patients who are perceived as being difficult (Hinchey and Jackson, 2011; Mamede et al, 2017). Recognising autism where appropriate can prevent such difficulties. It is increasingly being recognised that doctors and other healthcare professionals may be autistic – gaining peer support can be beneficial. For doctors who identify as autistic, peer support group Autistic Doctors International (founded by the first author) can be accessed at https://www.facebook.com/AutisticDoctors/ and there are similar groups for other autistic professionals.

England has a specific law relating to autism (the Autism Act 2009) with its own statutory code of practice. In England this is additional to, but in tandem with, the general duties set out in the Equality Act and the protected characteristics described within that. Other jurisdictions will have similar but differing legislation and policies designed to reduce and address disabilities autistic people may experience. These include the recognition of autistic people as a distinct group and the need for person-centred reasonable adjustments for autistic people. Reasonable adjustments and strategies to optimise the management of autistic people are covered in the accompanying article, but suffice to say that all doctors should improve their expertise in autism through training and experience, and particularly, by familiarising themselves with the reality of being autistic (Royal College of Psychiatrists, 2020).

Key points

- Autistic people face substantial health inequalities and have high rates of co-occurring health conditions.
- Autistic people are at increased risk of premature mortality from preventable and treatable illness, and are at an increased risk of death by suicide.
- Autistic people experience multiple barriers in accessing support for their mental or physical health, and are more likely to end up in hospital care or using emergency services.
- Autistic people are less likely to be satisfied with the healthcare they receive and to understand and be understood by health professionals.
- All the above can be prevented, or at least substantially mitigated, by better recognition and reasonable adjustments.

Conclusions

Failure to identify and respond appropriately to an autistic person is likely to lead to a range of negative consequences for the individual and the service. A negative patient experience can prevent autistic people seeking support again or holding off until their health has deteriorated significantly.

Improving health outcomes for autistic people requires clinicians to be more aware and able to recognise autism, to ask the right questions and make appropriate adjustments. Increased appropriate contact with clinicians will enable autistic people to know when to seek support, how to seek support and offer assurance that the effort of seeking support early will be worth the effort of overcoming barriers.

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Conflicts of interest

The authors declare that they have no conflicts of interest.

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