# **Title:** ‘Considering Autistic Spectrum Disorders in the Context of Clinical Nurse Prescribing’

**Abstract**

This article provides an insight for clinical nurse prescribers who may have limited knowledge of the implications of Autistic Spectrum Disorder to their practice. By providing an insight into the common characteristics of the condition, alongside an overview of contextual and situational issues of direct relevance to sensory overload and underload. Through this, awareness is raised of how specific adaptations to practice might best be made to support and empower those people, and their families and carers, living with the condition. Most importantly the need for individualised, holistic care is emphasised alongside information of specific relevance to the practicalities of nurse prescribing in practice. The article also outlines the issues of polypharmacy and pharmacotherapy of relevance to patients with ASD and the precursors to these, which can be readily identified in practice. The paper concludes with an opportunity for nurse prescribers to reflect on their own specific knowledge and applied practice in ASD.

**Keywords**

Autistic Spectrum Disorder | Autism | Intellectual Disability | Communication |Sensory Overload

**Key Points**

1. ASD characteristically presents as a lack of capacity for social interaction and an exacerbated response to everyday sensory experience, which may need to be accommodated in the context of clinical nurse prescribing.

2. All patients with ASD have individual needs, linked to their intellectual and social capacities, which need consequent individual accommodation, so that they are not homogenously labelled in the context of clinical practice.

3. The contextual and situational settings of care are of paramount importance in the management and care of people with ASD. Minimal adjustments to the primary care consulting rooms within which this takes place can make a significant difference to the capacity of them to cope with potential triggers of sensory overload.

4. Whilst there is an evident need for the continued use of antipsychotic and ADHD medications, there is an equally evident need for discernment and limitation of their use, rather than a routine reliance on them for the majority of patients living with ASD.

**Introduction**

In the context of clinical practice, Autistic Spectrum Disorder (ASD) can be defined as a series of developmental conditions with a series of characteristic presentations (LO et al, 2018). In contrast with neurotypical people (people without ASD), the conditions are characteristically presented by a lack of capacity for social interaction and in their different responses to everyday sensory experiences, which may contribute to sensory overload (McDonnell et al, 2015). Having structure and routine can be pivotal to support and enable people with ASD to integrate and function well in relation to societal norms. This degree of formalised structure can often appear obsessive and constraining but often aids people living with ASD to make meaning of the world around them, that is less stressful to them, and which normalises their sometimes anti-social behaviour (Karpin & O’Connell, 2015).

As such these needs ought to be accommodated in all medical and healthcare practice, of which nurse prescribing is an integral part. The relationship of these issues to the intellectual capacity of people with autism is an important one, again with some distinguishing features. Of greatest importance is that people with autism are not homogenously grouped together and labelled, without due regard for their specific needs as individuals.

The condition can vary from person to person, and throughout their life and some may have a decreased intellectual ability. Individuals on the autism spectrum often have other conditions. This can include but is not restricted to epilepsy, metabolic disorders such as Phenylketonuria, sensory impairments and genetic conditions such as Fragile X syndrome and Downs syndrome (Boucher, 2011).

The clinical picture of autism is variable because of differences in the severity of autism itself, the presence of coexisting conditions and the differing levels of cognitive ability, which can range from profound intellectual disability in some people to average or above average intellectual ability in others (Bishop-Fitzpatrick, Mazefsky & Eack, 2017). It is recognized that this population represent a complex and vulnerable group in society and are susceptible to stigma and discrimination.

**Typical Presentations of Autistic Spectrum Disorder in Primary Care**

Typically people with autism have a degree of cognitive impairment, whereas people living with Asperger’s syndrome often have normal or a higher level of cognitive ability, which can lead to intense behaviour in their everyday lives (Duvekot et al, 2018). Having an awareness of these issues can also lead to the detection and diagnosis of autism so that people who have the condition can receive the access to physical and mental healthcare resources that they need to lead fulfilling and empowered lives as an integral part of society. This also permits the effective adaptation of social interaction skills so that communication between people entering primary and secondary care settings can be appropriately accommodated in the context of nurse prescribing and person centred care.

**The Historical Context of Autistic Spectrum Disorder**

Often presented as a modern condition, documented cases of autism can be traced as far back as 1797 (Lyons & Fitzgerald, 2007). Annotations of the condition, written by the French Physician, Jean-Marc-Gaspard Itard, revealed documentation of a young boy, living wild in the woods, who showed several characteristic autistic traits. He later became known as the ‘Wild boy of Avalon’ and Itard treated the boy with a behavioural programme that consisted of a combination of the development of capacity for social attachment with early speech and language therapy. At this stage the prescription of psychotropic medication was not an issue and people with autism were often simply ostracised from the rest of society and labelled as ‘abnormal’. Formal use of the term autism was first recorded as being introduced in 1910 by Paul Eugen Bleuler, a Swiss Psychiatrist. He derived the term from the Greek word ‘autos’, meaning ‘self’. Autism diagnostic terminology developed further in 1938, when Hans Asperger, an Austrian Pediatrician first described ‘autistic psychopaths’ in a group of individuals who all shared common characteristic traits, which were subsequently used to label people and delineate them from society. In 1944, he published the first definition of Asperger’s Syndrome by identifying patterns of behaviour e.g. lack of empathy, little ability to form friendships, one sided conversations and restricted interests (Lyons & Fitzgerald, 2007).

In 1943 Leo Kanner first used autism in its modern sense in English when he introduced the label ‘early infantile autism’ in a report of 11 children with striking behavioural similarities. Almost all the characteristics described in Kanner’s first paper on the subject, notably “autistic aloneness” and “insistence on sameness”, are still regarded as typical of the autistic spectrum of condition today (ibid, 2007).

From the 1960s through the 1970s, research into treatments for autism focused on medications such as LSD, electric shock treatment, and behavioral change interventions, which relied on the infliction of physical pain and punishment (Wachtel, Shorter & Fink, 2018). During the 1980s and 1990s, the role of behavioural therapy and the use of highly controlled learning environments emerged as the primary treatments for many forms of autism and related conditions. Currently, the cornerstones of autism therapy are behavioural and language therapies (Cooper, Loades and Russell, 2018).

**Global Incidence and Prevalence Rates**

Global statistics on autism reveal that there are 7.6 million people living with autism in the world, of which half also have an intellectual disability (WHO, 2013). At a national level, autism is recorded as 1 in 160 people living with the condition in the UK.

Despite high incidence and prevalence rates globally and nationally, the aetiology of ASD remains uncertain and scientifically unconfirmed. What is anticipated though, is that there are several multifactorial contributors to its occurrence, which are combined complex genetic and environmental factors (Vinogradova, 2014).

ASD is one of the commonest diagnosed developmental condition, affecting and impacting upon the lives of 1% of the population in the UK (Taylor, Jick & MacLaughlin, 2013). There is a distinct difference in symptomology between males, in whom it is more common and females who are statistically more likely to be misdiagnosed or even discharged from the diagnostic process, in accordance with the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) criteria.

This set of criteria highlights issues of capacity of communication across various contexts and a restricted and repetitive pattern of behaviour as two of the key diagnostic indicators of ASD.

The continuum along which a diagnosis of Asperger’s syndrome is made represents how people living with the condition can evidence various patterns of intellectual function, such as in the context of recognised cognitive impairment. As such the level of support necessary may vary significantly between individuals with ASD, which is why homogenising the classification of ASD disorders is a serious issue in the context of care and nurse prescribing in particular.

**Epidemiology of Autism in UK**

There are approximately 700,000 people with autism in the UK, which equates to more than 1 in 100 of the general population (Taylor, Jick & MacLaughlin, 2013). In relation to ASD in adults living in households throughout England, the published evidence base reveals that (4.5%) of males has an autistic spectrum condition as opposed to (0.3%) of females (Brugha et al, 2009).

Approximately 60-70% of these people also have an intellectual disability (IQ below 70) as opposed to a global prevalence to be 1 in 160 people accounting for more than 7.6 million with the condition (WHO, 2013).

Emerson & Baines (2007) estimated that between 20% and 33% of adults known to councils who have learning disabilities also have autism. Across England, this suggested that between 35,000 and 58,000 adults who are likely users of social care services have both learning disabilities and autism. The number of adults in the population who have both learning disabilities and autism (including those who do not use specialised social care services) is likely to be much higher. There are also 70% of people with autism in the UK who also meet the diagnostic criteria for at least 1 other often unrecognized difficulties such as self-injurious behaviour, anxiety and aggressive behaviours (Russell et al, 2016).

**Consequences of Autism and Implications for Nurse Prescribing Practice**

Although many people with high functioning autism can live independently in our communities, those with co-morbid intellectual disabilities often require a life time of specialist support (Matson & Shoemaker, 2009). Complexities of autism are further pressurised due to people reporting more mental health issues, aggressive behaviour and stress within families (Totsika et al, 2011). The consequence of this is a predictor for psychotropic medication and hospital admission.

It is well researched that individuals with autism exhibit higher levels of challenging behaviour than those with intellectual disabilities (Birch et al, 2017). As a result of these behaviours people with autism are more likely to endure more restrictive practices such as control and restraint (Lunsky et al, 2018).

**Managing and Caring for People Living with ASD in Prescribing Practice**

The care of people living with ASD is a professional role in itself. The complexities of ASD mean there is no definitive presentation of autism and the fact that it impacts on the capacity of these people to communicate, behave and cope in social and professional settings is a challenge. Within the context of nurse prescribing, where informed consent and the ability to rationalise decision making is paramount to the successful interaction with patients and their families and carers, then awareness and effective planning for the care of this unique caseload, is pivotal to the provision of high quality care. A lack of preparedness on behalf of healthcare professional can also be attributed to the increased need for restrictive practice, which consequently impacts on the quality of life for people living with ASD and can send patients into a spiral where their condition, in turn makes their behavioural response even worse (Murphy et al, 2016). As a consequence of these interactions in clinical practice, emphasis is often placed on these behavioural responses, rather than on the emotional and physical needs of vulnerable members of our society. Whilst having a specifically tailored infrastructure and environmental adaptation to support people with autism may not always be possible due to resource limitations and the contextual constraints of clinical provision in primary and secondary care, it is possible to better accommodate patient need in relation to forward planning and the notion of patient centred care. The possibility of this happening lies in the need to raise awareness of the needs of people living with ASD in practice. Comorbidities are also common in autism and include conditions such as Down’s syndrome, epilepsy, tuberous sclerosis and Fragile X syndrome alongside more generalised sensory deficits (Boucher, 2011).

**Emphasising the Need for Delineation of Autistic Spectrum Disorder from Autism**

Delineating ‘Autistic Spectrum Disorder’ from a more generalised definition of ‘Autism’ is an important part of delineating and addressing the individualised needs of people living with either (Duvekot et al, 2018). Whereas ASD is an overarching term for a whole range of conditions such as Asperger’s syndrome, and Pathologic Demand Avoidance (PDA), autism is predominantly a developmental condition, impacting on the capacity of people to socialise and interact with the world around them, which is often characterised by rigidly structured and repetitive routines, which have wrongly led to the negative stereotypical labelling of the condition, which in turn has led to heightened levels of societal discrimination (Mademtzi, 2018; Rodgers et al, 2017).

**Best Practice for Autistic Spectrum Disorder for Nurse Prescribers in Practice**

What is clear from the body of literature available to date, is that any care pathway initiated in the context of primary or secondary care ought to take a holistic overview of the individual needs of the person and the support that implementing a care pathway may necessitate (Punshon et al, 2009). Research over the last decade has highlighted that the levels of specific knowledge about ASD are relatively limited and as resources in healthcare are increasingly scarce that this will be a group of vulnerable people needing special consideration with regard to their access to physical healthcare resources.

Understanding the stress that visiting the different context or environment of care management in practice can cause a person living with ASD is fundamental to accommodating the challenges this poses in relation to their predisposition to sensory overload and their potential to exhibit challenging behaviours. In relation to the concept of informed consent, this can blur boundaries of best practice, where levels of cognitive capacity can be obscured by the situational factors impacting on their condition. This is where building effective relationships with families and carers is fundamental to the care of people living with ASD, so that their individual needs can be best accommodated.
From a purely pragmatic perspective, optimising the opportunity for people living with ASD to be empowered in contributing to decisions about their medication, and their resultant capacity to comply with advice given in relation to it, can be practical and straightforward in approach.

**Pragmatic Approaches to Health Service Provision for People Living with Autism**

Coping with everyday appointments and check-ups is something that the majority of people take for granted in terms of being able to attend for regular healthcare. However this capacity to cope with difference in routine and the potential for sensory overload can become somewhat overwhelming for people living with ASD. In best accommodating these issues and hence making healthcare provision in the context of nurse prescribing more accessible to patients and their families and carers, pragmatic issues can be implemented, with minimal implications for clinical practice.

**Overview of Psychotropic Drug Use in People with Autistic Spectrum Disorder**

There has been a significant increase in the use of antidepressant medications, alongside a correspondingly significant increase in the use of antipsychotics, alpha- agonists and beta blockers for people with ASD, living with the often broad scale implications of the condition (Wink et al, 2017).

A systematic review, covering a total of 47 studies over a 36 year period and incorporating the data of over 300, 000 people living with ASD revealed a longitudinal picture of pharmacotherapy, indicative of a characteristic trend (Jobski, 2017). The study revealed a prevalence rate of psychopharmacotherapeutic interventions ranging from 3% to 80%, with a median overall as high as 48% in paediatric caseloads. In adult caseloads the equivalent values were in 5.4–54%, with a median of 23%. Formal classification of drug classes revealed that antipsychotics were the most common pharmacotherapeutic intervention, followed closely by attention‐deficit/hyperactivity disorder (ADHD) medication and pharmacological antidepressant therapies. Polypharmacy, as with the general neurotypical population is more common with an increase in chronological age and psychiatric disabilities. Certain residential accommodation settings are also associated with the prescription and administration of several drug classes, yet awareness of this is relatively limited amongst those living with ASD and those caring for them on a daily basis. Research to date reveals an apparent lack of tailored pharmacological treatment options for the characteristic psychiatric issues related to ASD, and an overuse of anti-psychotic medication as a consequence. Whilst there is an evident need for the continued use of antipsychotic and ADHD medications, there is an equally evident need for discernment and limitation of their use, rather than a routine reliance on them for the majority of patients in practice (Rasmussen et al, 2018).

**Accommodating Care Needs in Practice**

Where a patient with autism is either unfamiliar with staff, or a new process of consultation in nurse prescribing, it is advisable for them to be able to make a very informal visit to the setting or context beforehand. This means that the person with ASD can familiarise themselves with treatment/consultation areas and new environments that could potentially cause them distress or sensory overload. Where the person living with ASD has a carer or family member with them can make a difference to their capacity to cope due to the opportunity for additional reassurance and the consistency in the people surrounding them. It can be helpful for them to attend appointments with friends or family undergoing a similar experience, so that in the future they can anticipate and have realistic expectations of their own appointment in the future. In terms of timing, additional appointment time may be needed to accommodate the additional needs of the person and also to ensure that as a clinician, the nurse prescriber has adequate time to accommodate optimal care provision alongside this. It can often be helpful in relation to patient need to give them the very first or last appointment of the day, as waiting for appointments can be an unintentional means of stressing a patient with ASD. Depending on the patient’s relative degree of independence it might be feasible to identify a suitable collection or waiting area whilst the consultation takes place. What matters most is that the patient is afforded the same dignity and access to physical and healthcare resources as any other patient without the condition. The communication of specific need in the context of primary care settings may be an issue for patients who can struggle to recall their specific detail of their medical history and present need. This is where effective communication between interdisciplinary and multi-disciplinary professionals is paramount. Formalisation of this may take the form of a Health passport, where information can be made accessible to nurse prescribers, enhancing their holistic management of patients in their care.

**Specific Communication Needs for People Living with Autistic Spectrum Disorder**

Being able to communicate effectively with patients living with ASD is pivotal to the success of treatment intervention and compliance. Providing an explanation of all interventions is at the heart of this, as this minimises the potential for catastrophizing on behalf of the patient and ensures that expectations can be appropriately managed at all times. This is also essential to the process of gaining informed consent from patients with special needs who have the same rights and dignities as other patients in practice. The use of dolls can provide an insight into the process of procedures or examinations that might otherwise distress them, for example in relation to specific parts of the body that needs to be examined, or if instrumentation use is an integral part of patient monitoring. Picture books can provide a similar physical overview of planned treatments. Providing a clear justification of why a treatment and accompanying prescription are necessary is a way of being able to present information clearly and concisely. The sensation of unexpected touch can be distressing to people with ASD and pre-warning can be helpful as a treatment intervention proceeds. Similarly, establishing whether a family member or carer can support the patient during their appointment is a useful approach, especially where alternative mechanisms of communication are preferred by the patient in practice. Straightforward language ought to be adopted as literal interpretation of information by people with ASD is commonplace, particularly with regard to ambiguous terminology such as ‘ it might hurt a little bit’, which they might find difficult to comprehend as opposed to just saying ‘it will or it won’t hurt’. This rather straightforward approach can minimise unnecessary stress for a patient where binary decision making might be much easier for them. In order to support them in compliance with proposed treatment, it can be useful to provide direction, rather than a rhetorical questioning approach – for example ‘please put your finger over this small dressing now’ rather than ‘can you hold this little dressing in place?’ Checking what has been said is understood, is also a great means of establishing that the patient understands and complies with the continuation of treatment. Using overt facial expressions and elaborate gesturing or articulation of non-verbal instructions can also confuse patients with autism. In summary, a direct but at all times compassionate approach is best, so that the person living with ASD feels as reassured and relaxed as they possibly can (Wong et al, 2017).

**Differences in Active Dialogue with Patients with Autistic Spectrum Disorder**

A tendency to reach sensory overload is a common characteristic of people living with ASD in practice and there are key approaches that can be adopted to support and facilitate people as they access physical and mental healthcare provision (Tager-Flusberg, 2017).

Being able to ascertain features of this are an important part of discernment and the decision making underpinning high quality care provision.

**Key Indicators of Stress:**

**Lack of Eye Contact**

Distressed patients may often use avoidance of eye contact as a strategy to stabilise their condition. This does not mean they cannot listen to instructions but it may mean that they need additional time and support to interpret and understand what is being communicated to them and to make meaning of the information you are trying to articulate. Similarly those patients who appear particularly non communicative are just as capable of this degree of interpretation and meaning making but also may need additional time to do so.

**Lack of Relativism or Perspective**

Neurotypical people usually demonstrate the capacity for relativism or a perspective of the needs of others, whereas people with autism may not and there might be an expectation that you can determine what they are thinking and feeling, without them first having articulated it to you (Candini et al, 2017). This obviously necessitates practitioner understanding, particularly with regard to the information you may be articulating in relation to your prescribing practice. It also carries implications for the notions of informed consent that are expected when working with all patients, regardless of their health status (Volden, 2017).

**Lack of Awareness of Appropriate Spatial Parameters**

Autistic people may also not exhibit signs of awareness of the need to respect the personal space of others or themselves and as a consequence this may be projected in their overt actions in clinical practice, which is often carried out in a relatively confined space. This is something which ought to be considered in the planning and execution of clinical practice for nurse prescribers (Weill, Zavodny, & Souders, 2018).

**Withdrawal and Solemnness**

Withdrawal and solemnness can also be a key sign of distress for people living with autism, particularly, although not exclusively children (Adams et al, 2018; Baumer & Spence, 2018). When carers are present they are usually able to judge early stages of sensory response and provide valuable information about the likely impact of sensory experience, which can then be accommodated in practice (Foley et al, 2017). It may also be useful if they are able to stay with the patient during a consultation regarding their prescribed medication, if the patient is willing, so that any supplementary information they provide, can be used to support the patient and also support and effectively manage their behaviour, if this does become an issue (Hayes et al, 2018).

**Sensory Overload or Sensory Underload**

In relation to specific sensory stimulus, consideration ought also to be made of those aspects of clinical care provision that might be completely overlooked in the treatment of those who are neurotypical (Deboth et al, 2017). For example:

* **Clinical Lighting**

Whilst designed to enhance the clinical working environment for clinicians, clinical lighting can often prove overwhelming for people living with autism who can be extremely sensitive and responsive to the fluorescent nature of many clinical contexts. Alongside this, at least 20-30% of people with autism are susceptible to seizures, a trigger of which can be light sensitivity to pen lights for ophthalmic examination or other more focused clinical examination of problematic areas.

* **Clinical Sounds**

Whilst the unfamiliarity of the sound of equipment operating in medical surroundings is an expected norm for the majority of neurotypical patients, for some patients with autism can inflict severe levels of distress and suffering. These typically can be worsened by an elevation in the pitch of surrounding sounds, which in the context, for example of emergency care provision, or dental healthcare, might be much more difficult to minimise than in the context of nurse prescribing.

**The Normalisation of Patient Coping Strategies**

Some patients with autism will provide a distracting sensory stimulus, such as rocking or flicking, in order to counteract the stress around them. Under no circumstances should this be stopped as it may be an effective and established mechanism of them calming themselves. It may also distract the patient from their innate sense of postural positioning and unnecessarily cause them to fall and hurt themselves if they are prevented from consoling themselves (Ke, Whalon & Yun, 2018).

**Pain Sensory Thresholds. Stress and Excitability**

In certain instances people living with autism can have an inordinately high pain threshold where they may present with what can be perceived as an excruciating pain for a neurotypical person. Their responses to pain may also be simply characterised by a different reaction, such as uncontrollable laughter, singing or the unexplained removal of their clothes. This is pivotal in understanding potentially painful interventions such as injecting, where a normalised response to slight pain may be very different in practice. For this reason skin creams to numb dermatomes are advisable to minimise pain for the patient. Similarly signs of agitation may present as a level of unintentionally aggressive behaviour, purely as a means of response. Using toys such as dolls or teddy bears to demonstrate the anatomical positioning of specific medical or healthcare interventions can be a useful process (Spain et al, 2017).

**Conclusion**

Whilst this article has covered the implications of ASD it also reveals the evident gaps in practice based knowledge that constitutes the published evidence base for clinical prescribers in applied nursing practice. Core emphasis ought to be placed upon the accommodation and recognition of specific relevance to the manifestations of sensory overload or underload and the means of managing these effectively. Most significantly, those people living with ASD and their families and carers ought to be treated with the respect and dignity afforded to all patients in the context of nurse prescribing (Howlin & Magiati, 2017). The ambiguous nature of presenting conditions can often prove challenging. However, with the outlined modifications to both situation, context and recognition of need, this is something which can become an integral part of empowering an often overlooked and under acknowledged sector of patient care in nurse prescribing.

**Areas for Critical Reflection in Nurse Prescribing Practice – Reflective Questions**

1. Contemplate the new information (if any) that this article has raised awareness of. How might you adapt your new knowledge of ASD to support people and their families and carers living with the condition on a daily basis?
2. Which constraints to the adaptation of your own workplace might there be in accommodating the specific needs of people living with ASD? How might you address and raise awareness of this in practice?
3. In your next interaction with a person with ASD, what will your first priority be, and why?

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