Clinical Practice Guidelines for Autism Diagnosis in adults and children in the UK: a narrative review



Introduction

The diagnosis of autism poses particular challenges: there are no biomarkers utilised in diagnostic tests (Vllasaliu et al., 2011) and the condition represents a heterogeneous group of disorders, with wide ranging levels of severity and symptom expression, and symptoms that are common to autism may occur with other conditions (Huerta and Lord, 2012). Research suggests that diagnostic procedures are not consistent across practice (NICE, 2012).

Background

Some studies show that social factors such as individual patient preference, availability of resources or local organisational factors can shape diagnostic practice, in, for example, heart disease (Fuat, Hungin, & Murphy, 2003).

Studies in autism have also shown the existence of 'diagnostic clusters', where autism diagnosis is high, especially where there is greater availability of assessment resources (Liu, King, & Bearman, 2010); Mazumdar, Winter, Liu, & Bearman, 2013).

Where there is diagnostic uncertainty, clinicians may 'upgrade' to a diagnosis of autism if they believe it would be in the best interests of the patient; if the diagnosis would trigger appropriate services and funding; or counteract the limitations of diagnostic tools (Rogers et al., 2016; Skellern et al., 2005).

Thus it seems in practice, clinicians may adopt a pragmatic, practical or functional approach.

Aim

The aim of the study was to consider the content of clinical practice guidelines (CPGs) shaping diagnosis of autism in the UK. Given that research identifies inconsistency across clinical practice, alongside evidence of clinicians taking a pragmatic or social approach, we were interested in investigating where, within clinical guidelines, social factors and influences are taken into account, if at all.

Method

We electronically searched multiple databases and relevant web sources for clinical practice guidelines. A process of data extraction synthesized key diagnostic elements such as assessment process and diagnostic tools. A qualitative narrative analysis was conducted to identify social factors and influences.



Results

Twenty-one documents were found and analysed. Guidelines varied in recommendations for use of diagnostic tools and assessment procedures.

Although multidisciplinary assessment was identified as the 'ideal' assessment, some guidelines suggested in practice one experienced healthcare professional can diagnose.

Social factors in operational, interactional and contextual areas added complexity to guidelines but there were few concrete recommendations as to how these factors should be operationalized for best diagnostic outcomes.

References

Vllasaliu L, Jensen K, Hoss S, et al. (2011) Diagnostic instruments for autism spectrum disorder (ASD) (Protocol); Huerta M and Lord C (2012) Diagnostic evaluation of autism spectrum disorders. Pediatric Clinics of North America 59(1): 103–111; NICE (2012) Autism Spectrum Disorder in adults: diagnosis and management; Fuat A, Hungin APS and Murphy JJ (2003) Barriers to accurate diagnosis and effective management of heart failure in primary care: qualitative study. British Medical Journal (online) 326(7382): 196–201.; Liu K-Y, King M and Bearman PS (2010) Social influence and the autism epidemic. American Journal of Sociology 115(5): 1387–1434; Mazumdar S, Winter A, Liu K,-Y and Bearman P (2013) Spatial clusters of autism births and diagnoses point to contextual drivers of increased prevalence. Social Science and Medicine 95: 87-96; Rogers CL, Goddard L, Hill EL, et al. (2016) Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. Autism 20(7): 820-831; Skellern C, Schluter P and McDowell M (2005) From complexity to category: Responding to diagnostic uncertainties of autistic spectrum disorders. Journal of Paediatrics and Child Health 41(8): 407–412.

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Social factors in clinical guidelines

Recommendations for systems & tools for diagnosis are inconsistent & lack a high quality evidence base, meaning that diagnostic choices are likely to be strongly influenced by local resources & organisational

interactional

Interaction between clinicians & between clinicians, patients & families are key to diagnosis; but most guidelines do not consider how patient preference, disagreements & desires impact on decisionmaking.

Conclusion

Clinical practice guidelines vary in their recommendations, making the choices available to healthcare professionals complex and confusing. Guidelines present a context of uncertainty as central to the diagnosis of autism. We argue that clinical guidelines for autism diagnosis illuminate the process of diagnosis as social rather than straightforwardly clinical.

We recommend a more explicit acknowledgement of social factors in CPGs with advice about how these factors should be managed and operationalised when making diagnostic decisions. This would aid consistency of practice and provide increased transparency for patients and families.



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operational

factors

contextual

Symptoms are impacted by age, setting and stressors; cultural context can affect judgement; diagnostic cut-offs are open to interpretation, making particular social contexts key to decisionmaking

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