Diagnostic overshadowing in dentistry

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Key points

- Discusses the concept of diagnostic overshadowing and its implications within dentistry.
- Enhances the understanding of learning disability, approaches to clinical assessment and diagnosis.
- Suggests greater awareness of the resources to support education within the dental team is needed, in relation to the care of vulnerable patients.

Abstract

Diagnostic overshadowing can be described as a concept whereby symptoms of physical ill health are mistakenly attributed by healthcare professionals to either a mental health or behavioural problem, or as being inherent in the person's disability. This can lead to a failure to diagnose and treat appropriately. Although widely discussed in medicine, this issue has not been previously highlighted in the dental speciality, yet it can lead to significantly detrimental general and oral health outcomes for vulnerable patients. This article focuses on the care of patients with learning disabilities and the prevention of diagnostic overshadowing in dentistry through the application of reasonable adjustments to care and education within the dental team.

Background

It is estimated that one in 218 people in England have a learning disability.[1] This can be defined as a significantly reduced ability to understand new or complex information or to learn new skills, with a reduced ability to cope independently. It is an impairment that starts before adulthood, with a lasting effect on development. This is described as a continuum, from mild to severe, in addition to profound and multiple learning disabilities.[2] Approximately one third of people with learning disabilities are also diagnosed with an autism spectrum condition,[3] which affects an individual's social interaction, communication, interests and behaviours.[4] The General Medical Council (GMC) has acknowledged the vulnerabilities of people with learning disabilities, and has placed a renewed emphasis on the particular issue of 'diagnostic overshadowing' among this group.[5]

Diagnostic overshadowing was first highlighted in the medical literature in 1982,[6,7] and can be described as a concept whereby symptoms of physical ill health are mistakenly attributed by healthcare professionals to either a mental health or behavioural problem, or as being inherent in the person's learning disability.[8] This can lead to a failure to diagnose and treat appropriately. Although there is little acknowledgement of this issue in the dental literature, other than an isolated case report letter,[9] it is important to recognise that diagnostic overshadowing is not a new concept, nor an issue which is exclusive to medicine.

Challenges to the provision of oral healthcare

It is estimated that 50–90% of people with learning disabilities have a communication impairment.[10] The GMC acknowledges that, without making a basic connection with the patient, clinicians may fail to apply the same diagnostic principles that they would for other patients and risk diagnostic overshadowing.[5]

Obtaining a history, conducting an assessment, reaching a diagnosis and devising an appropriate treatment plan can present challenges for clinicians. The region of the head and neck is particularly complex due to the close proximity of several anatomical structures. In addition, there are many conditions in which pain may not be a significant early feature; therefore, detection of disease is dependent on an understanding of an individual's risk factors and thorough clinical assessment. Failure in this respect can lead to late presentation of disease which is significantly advanced.[9]

History of presenting complaint

An integral element of clinician-patient relationship is building trust. This takes time and is essential to obtaining an accurate history from a patient to guide the consultation and assessment. Patients with a learning disability may not be able to communicate verbally, but may use other forms of communication,[10] as outlined in Table 1. Many individuals, though, might have no recognised formal methods of communication and may solely rely on the

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support of family or paid carers who know them well and are able to identify concerns.

As outlined by NHS Protect,[16] some individuals may display behaviours which challenge the provision of health care. Such behaviours are often the manifestation of a patient's distress and an attempt to communicate an unmet need, with relevant examples displayed in Tables 2 and 3.

Since 2016, all organisations that provide NHS care have been legally required to follow the 'Accessible Information Standard',[17] which sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss. Therefore, in the management of patients with behaviours that challenge how the person communicates, this is an essential aspect of the history and should be documented in the patient's records. This is particularly relevant when new behaviours develop or known behaviours increase in frequency.[18,19] The consequences of such behaviours can be significant, including the deterioration of an individual's physical and mental health, with increased injuries and dependence on anti-psychotic medication, seclusion and physical intervention.[16]

Recognising an individual's vulnerability and anticipating their needs is essential to preventing such behaviour. In instances of diagnostic overshadowing, changes in demeanour among this group may be dismissed as challenging behaviour until the underlying cause reveals itself in another way, such as long-term dental pain, which eventually manifests as a dento-alveolar abscess.

Table 1 Non-verbal communication methods

Method	Description
Makaton[11]	Manually signed and spoken communication
Symbols[12]	Meaning-based symbols which can be used by people to communicate without speech, such as 'Blissymbols'
Objects of reference[13]	Three-dimensional object to represent an activity or person, often unique to the individual
Picture exchange communication system[14]	A picture that is exchanged for an item or activity
Eye gaze[15]	Communication controlled through movement of eyes in relation to words or symbols which are highlighted or vocalised by a computer

Table 2 Examples of unmet needs[16]

Unmet need	Examples
Physical	Pain, lack of sleep, hunger, thirst
Psychological	Anxiety, social isolation
Environmental	Excessive noise, lighting, temperature, long waiting time
Cognitive	Inability to articulate needs, retain or understand new information

Table 3 Examples of behaviours that challenge the provision of care[16]

Type	Example
Non-verbal	Agitation, pacing, withdrawal, refusal to move
Verbal	Shouting, screaming, crying, swearing
Physical	Scratching, biting, hitting self or others

Table 4 Signs of possible pain in the head and neck

Feature	Example
Changes in behaviours	Crying or excessive giddiness Biting objects, grinding teeth Physical behaviours: self-directed such as hitting head, or directed towards other people
Change in diet	Refusal to eat and drink, change in ability to chew foods or preference for hot or cold items
Change in usual sleeping pattern	Some people do not have typical night time sleep, but may experience change in sleep-wake patterns usual to themselves
Refusal of supported oral and facial hygiene	Moving of head away from contact Avoidance of toothbrushing, washing of face and shaving
Refusal to take medications	Routine oral medications not taken or with difficulty
Change in salivation	Excessive drooling
Aberrant soft tissue movements	Sticking out tongue or sucking on cheek

Recognising pain

Pain is a complex phenomenon, as individuals have different experiences and responses to pain. People with a learning disability may experience extreme discomfort yet not understand what is happening, nor have the ability to ask for help.[20] Pain may manifest in an atypical manner, particularly among individuals who are unable to communicate their needs verbally. Signs of possible pain in the head and neck are suggested in Table 4.

In view of such complexities, a number of tools have been developed to evaluate pain and distress in patients with cognitive impairment and communication challenges, as outlined in Table 5. In some instances, there may be chronic pain which is misinterpreted, such as 'they always make that noise', 'it's attention seeking behaviour' or 'it's just the way they are'. Clinicians can become desensitised to signs that an individual may be experiencing discomfort because information passed on by carers is thought to be evidence-based,[25] or they may have provided care for patients who have displayed similar behaviours but in a different circumstance with a different meaning.

When pain is considered in the context of general wellbeing, it must be acknowledged that individuals may deteriorate rapidly as a consequence of unrecognised pain in the head and neck. Table 6 summarises situations of particular concern for the dental team. Box 1 summarises the complexity and impact of pain on behaviours, correlation with clinical findings and treatment received by a patient

Table 5 Examples of pain assessment tools

Tool	Description
Pain Profile[21]	Summary to help guide supporters to think about the recognised signs that an individual is in pain and how best to manage
Disability Distress Assessment Tool (DisDAT)[22]	Each person has their own 'vocabulary' of distress signs and behaviours. The tool builds on the ability of supporters to identify different signs of distress in individuals. It can be used to record the signs and behaviours of the person when they are content or distressed
Non-Communicating Adults Pain Checklist (NCAPC)[23]	18-item checklist with scoring based on vocal and emotional reaction, facial expression, body language and physiological reaction, with scores ranging from zero (no pain) to 51 (maximum duration of all pain behaviours)
FACES pain rating scale[24]	Series of pictures of faces to help people to communicate the intensity of pain from 'no hurt' to 'hurts worst'

Table 6 Situations of significant concern

Situation	Consideration
Acute infection/facial/ dento-alveolar trauma	Patient may require pharmacological support such as sedation or general anaesthesia to facilitate urgent assessment and treatment
Systemically unwell	May manifest in atypical manner such as sweating, dehydration and hypoglycaemia, seen as change in alertness, urinary frequency and reduced opening of bowels
Challenging behaviour	Outwardly physical behaviour to a degree that this is physically endangering the patient, carers or a vital structure, such as hitting the orbit or putting fingers inside/ pulling ear

with severe learning disability at The Royal London Dental Hospital (Barts Health).

Improving care

The 'Confidential inquiry into premature deaths of people with learning disabilities' (CIPOLD) highlighted that two in five patients had issues having their illness diagnosed due to investigations not being carried out or posing difficulties.[26] The Equality Act 2010 states that reasonable adjustments are a legal requirement whereby healthcare providers have a responsibility to adapt the way that they deliver services to ensure that they are as effective as they would be for people without disabilities.[27]

In recent years, following reports such as the events at Winterbourne View Hospital and CIPOLD, the vulnerabilities of this group have been brought to light. The GMC highlighted that, although no healthcare professional or institution intentionally discriminates against patients, sometimes this can happen inadvertently when service providers and policies fail to consider the reasonable adjustments that an individual may need in order to receive care.[5] It also acknowledges the need to transform healthcare services, centred on changes in culture and education.

The GMC has recently developed a comprehensive online educational resource,[5] dedicated to raising awareness of guidance in good medical practice and the issue of diagnostic overshadowing when caring for people with a learning disability. Significant emphasis is placed on the need to change attitudes of the workforce towards people with learning disabilities. In a survey undertaken by Mencap, the UK's leading charity for people with learning disabilities, it was found that public attitudes are positive in many respects towards people with learning disabilities, however there remains a significant level of misunderstanding, with nearly a third of respondents considering a learning disability to be a mental illness and not understanding that it is in fact a lifelong condition.[28] In its latest campaign, 'Treat Me Well', Mencap also highlighted that, at a national level, healthcare professionals are not consistently receiving the education or resources they need to provide good care to people with a learning disability, with one in four healthcare professionals having never received any training.[29]

Within the dental speciality, many patients with severe learning disabilities are cared for as children in the sphere of paediatric dentistry and as adults in special care dentistry across community and hospital dental services. However, as learning disability is a spectrum, it is important to recognise that a significant proportion of patients will also receive care in general dental practice. Although speciality training programmes exist for dentists, which highlights the need for a specific skill set in the management of patients with learning disabilities, this only provides education to a small proportion of the national workforce involved in the care of this group. There is a need for broader training in the care of patients with learning disabilities across settings for all members of the dental team.

The Care Act 2014 sets out Health Education England's (HEE) remit and range of roles and responsibilities, including its duty to ensure an effective system is in place for education and training in the NHS and public health system.[30] In 2016, HEE developed the 'Learning disability core skills education and training framework' in collaboration with voluntary sector partners following a mandate from the Department of Health.[31] The framework set out a number of core competencies for healthcare professionals to successfully support people with a learning disability and thereby ensure consistent cross-sector training and education. While this holds significant potential to engender positive change, this framework remains to be widely adopted, including across the dental speciality.

Conclusion

Society's view of people with learning disabilities has changed over the last century. Until the 1970s, large numbers of children and adults with learning disabilities in the UK were confined in institutions. Today, almost all children with learning disabilities live with their families and most attend inclusive schools. Among adults with learning disabilities, many live in their own homes with varying levels of support, and few remain in segregated educational day care or residential provision. Despite increased physical integration, individuals with learning disabilities often still exposed to negative perceptions,[32] including within healthcare which can lead to issues such as diagnostic overshadowing.

Guidelines are available within dentistry which focus on the care of patients with learning disabilities.[33] However, the issue of diagnostic overshadowing has not been previously highlighted or discussed. An appreciation of this issue is essential, as is the understanding that this can be extrapolated from learning disability to other vulnerable patient groups that frequently have communication and behaviours that challenges the provision of healthcare, including those with severe mental illness and dementia.[34,35,36,37]

This article has outlined that the concept of diagnostic overshadowing is complex, however as clinicians we must remember that the underlying principle is simple: see the person, not the disability.

Box 1 Case study of a 20-year-old male

Complaint: parents were worried that the patient was in pain as he was biting his arm and clothing frequently. Low mood with reduced engagement and oral intake on occasions. Concerned that this was possibly a dental cause as he had not an assessment or treatment for more than ten years.

Medical history: Chromosome 15 deletion, severe learning disability and epilepsy

Medications: Clobazam, sodium valproate, topiramate

Allergies: None known

Communication: Non-verbal with no regular communication method

Known behaviours: Bites himself when anxious or in pain. A rubber bracelet was being used to prevent further trauma to forearm

Mobility: Wheelchair user, can weight-bear and transfer with assistance

Social history: Lives with mother, father and sister, carers attend twice daily for support

Dental history: Previous treatment under GA as a child

Clinical course:

Examination was very limited due to the patient moving his head and biting. Extra-orally, the patient did not have any swelling in his face or neck, but noticeable bite marks on his arm (Fig. 1) which had started healing since placement of a rubber bracelet (Fig. 2). Intra-orally, it was not possible to fully inspect the dentition. Although oral hygiene was fair, generalised gingival inflammation was noted and retained roots were suspected in the 16. Radiographs were not possible. The patient lacked capacity to consent to further assessment and treatment. After a best interests discussion with his parents, comprehensive dental assessment and treatment under GA was agreed.

Findings under GA:

Generalised gingival inflammation, no pocketing or recession

Cavitation: 47 36

Special investigations:

Blood tests: No significant anomalies detected, but results forwarded to GMP as a holistic approach to care

Intra-oral radiographs: demonstrated no bone loss, confirmed carious lesions as detected clinically and retained roots in the 16

Diagnoses:

Gingivitis

Caries: 47 36

Retained roots: 16

Treatment:

Generalised supra- and sub-gingival debridement

Restorations: 47 36

Extraction: 16

Outcome:

In the following weeks after treatment, the frequency of biting had reduced, oral intake improved and his mother reported a generally improved demeanour.

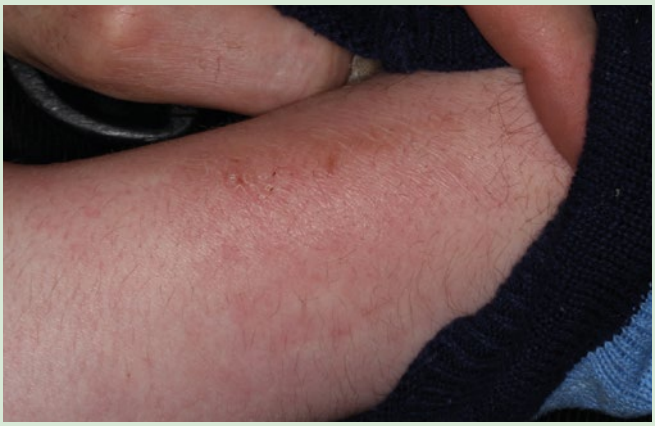

Fig. 1 Healing bite marks in arm

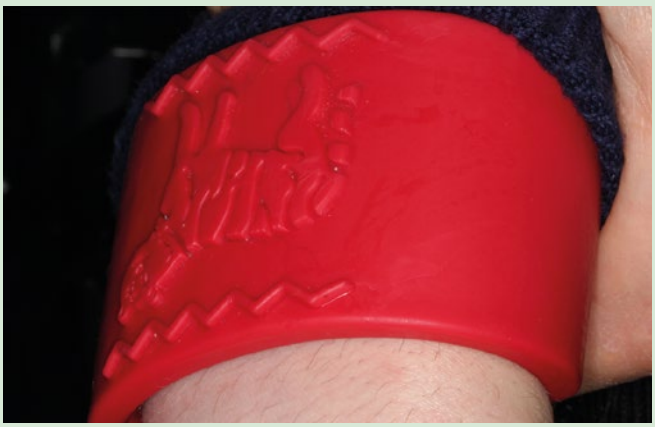

Fig. 2 Rubber bracelet to prevent skin trauma

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