Special care dentistry Patient management

Learning disability and obesity: a case report of challenges and reasonable adjustments

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Key points

Highlights that higher levels of obesity have been observed in patients with learning disabilities.

Describes the challenges of providing dental care for a patient with a severe learning disability, challenging behaviour and obesity. Suggests reasonable adjustments and a multidisciplinary team approach are required to facilitate care and reduce health inequalities.

Abstract

Background When anxious, patients with learning disabilities may display challenging behaviour. The prevalence of obesity in patients with learning disabilities is rising and can increase the complexity of management. Reasonable adjustments are often necessary in order for treatment to be successful.

Case report A 41-year-old male patient with a severe learning disability, autism and obesity was referred to the dental hospital for dental treatment. The patient frequently demonstrated physically challenging behaviour, particularly when in unfamiliar environments. In order for the patient to access care, a multidisciplinary team (MDT) approach with a number of reasonable adjustments was required. The patient was then able to receive treatment under general anaesthesia (GA) from not only the special care dentistry team, but also additional medical specialties.

Discussion A holistic approach to care is important in this patient group in order to reduce health inequalities. Clinicians should be aware of their role in the screening and referral of patients with obesity.

Conclusion Reasonable adjustments and a team approach are essential to the dental management of patients with learning disabilities. Management is becoming increasingly complex as obesity continues to be a growing problem among this group.

Background

At the Royal London Dental Hospital (Barts Health), the speciality of special care dentistry receives a high number of referrals to treat patients with severe learning disabilities. A person with a learning disability has a reduced intellectual ability and can have difficulty with everyday activities.¹ This can make something like attending the dentist particularly challenging, especially if a person's learning disability is severe and they require full-time care or support with all aspects of their life. Some individuals with learning disabilities can demonstrate challenging behaviour, as described by Emerson *et al.*:

¹ Specialist Registrar in Special Care Dentistry, Barts Health, Royal London Hospital, Whitechapel Road, London, UK; ²Consultant in Special Care Dentistry, Barts Health, Royal London Dental Hospital, Turner Street, London, E1 1BB, UK. Correspondence to: Joanna Dick Email: joanna.dick@nhs.net Refereed Paper. Accepted 12 April 2019 DOI: 10.1038/s41415-019-0468-3 'Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.'²

Challenging behaviours frequently arise due to a person having an unmet need; this could be something as simple as them feeling hungry or needing the toilet. Yet because of the person's cognitive or verbal impairment, physical disability or environmental surroundings, they are not able to express this need and consequently this manifests as a challenging behaviour. This could be demonstrated by the person verbally or physically, either towards those around them or towards themselves; for example, pushing, kicking or shouting out. In 2016-17, 0.46% of the UK population were recorded as having a learning disability,3 and it is estimated that 5-15% of this group will demonstrate challenging behaviour when accessing educational, health or social care services. This number increases further still when in hospital settings.⁴ This challenging behaviour can act as an additional barrier to receiving health and dental care in a group who are known to have increased mortality rates as well as a higher dental need.^{5,6}

In order to facilitate access to care for patients with learning disabilities, we frequently make 'reasonable adjustments'. The Equality Act in 2010 stated that those with disabilities should have the same access to health care as anyone else and it is the responsibility of health care professionals to make reasonable adjustments to aid universal access to our services.⁷ By doing so, as stated by Emerson, we are striving to minimise the impact that challenging behaviour has on preventing access to 'ordinary community facilities' such as health care.² Reasonable adjustments can be physical, such as alterations to buildings in the form of wheelchair ramps or tactile signage. Or they may mean changes to attitude, such as through policies, procedures and staff training, to ensure that services are as accessible for patients with learning disabilities as those without.7



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Table 1 The Impact of obesity on dental care	
Consideration	Impact on dental care
Medical co-morbidities	Obesity is strongly associated with the following, all of which can have a significant impact on dental care and may require further tailored approach: Hypertension ¹⁵ Cardiovascular disease ⁸ Diabetes mellitus ¹⁶ Increased coagulation of the blood ¹⁷ Impaired immunity ¹⁸ Asthma and chronic obstructive pulmonary disease (COPD) ¹⁹ Fatty liver disease ²⁰ Osteoarthritis ²¹ Obstructive sleep apnoea ²² Gastric-oesophageal reflux disease (GORD) ²³ Cancer ²⁴ Depression and anxiety ²⁵
Medical emergencies	Due to increased co-morbidities the obese patient is at greater risk of a medical emergency, however these are often more difficult to manage in this group of patients for the following reasons: Increased fatty tissue can hinder venous access making administration of emergency intravenous drugs more challenging ²⁶ Intramuscular injections are more likely to be into fat rather than muscle, which having comparatively poor blood supply, can lead to unpredictable therapeutic effects ²⁷ The standard emergency drug doses may be ineffective, as the drug doses are designed for those of average weights ²⁸ In the event of hypoxia, airway management is also more difficult in this group of patients, owing to their often more restricted airways ²⁹ Chest compressions are more challenging to deliver due to reach across patient and achievement of correct depth
Access to the dental surgery	Severely obese may be wheelchair users (or have significantly impaired mobility) and require hospital transport to attend appointments. Dental clinics may require close parking facilities, wheelchair ramps, wider doorways/corridors, disabled toilet facilities and larger waiting room chairs ²⁷
Specialist equipment required	The average dental chair has a maximum lifting weight of around 140 kg (23 stones), therefore a bariatric dental chair may be required ²⁷ If a patient is in a wheelchair, specialist manual handling equipment may be required to transfer them to the dental chair or they may be treated using a wheelchair recliner May also need larger blood pressure cuffs and bariatric weighing scales ²⁷
Treatment practicalities	Larger cheeks and tongue: Lack's tongue retractor may have to be utilised by the nurse instead of the dental mirror in order to safely retract ²⁷ Locating the position of the mandibular foramen when administering an inferior alveolar nerve block may be difficult Patients may need to be treated upright, as may become breathless when supine, making staff positioning more challenging Larger cheeks and tongue can also make moisture control difficult
Intravenous conscious sedation	Increased adipose tissue can make cannulation difficult ²⁶ Increased risk of respiratory depression due to increased weight on the thoracic cage and abdomen and higher prevalence of obstructive sleep apnoea owing to increased adipose tissue in the neck and pharynx ¹⁵ Increased risk of a medical emergency as a result of higher incidence of cardiovascular disease and diabetes in this group Risk of gastric regurgitation leading to aspiration or vomiting ¹⁵ Drug absorption, distribution, metabolism and excretion are all affected by an increase in BMI, meaning that lipophillic drugs such as midazolam and propofol may have longer distribution and elimination times due to increased body fat ¹⁵
General anaesthesia (GA)	As with sedation, increased co-morbidities and increased adipose tissue around the neck and airway can make the provision of GA more challenging. ²⁹ An anaesthetist specialising in bariatric care may be necessary as well as trollies with a greater width and weight limit
Increased risk of dental disease	Association of obesity with increased prevalence of periodontal disease ³⁰ Tooth surface loss due to erosion may be present due to GORD Impaired immunity may put individuals at a greater risk of oral infection and complications with healing following dental extractions There is conflicting evidence regarding caries prevalence in this group, but increased caries levels may be observed ³¹

Obesity is defined by the World Health Organisation (WHO) as being 'abnormal or excessive fat accumulation that may impair health'.8 Nationally, obesity levels are rising9 and healthcare professionals will also be managing increasing numbers of patients with obesity in the learning disability population; between 2017 and 2018, obesity was found to be twice as common in patients with a learning disability aged 18-35 than those without.10 The reason behind this is thought to be multifactorial, with people with learning disabilities often having poorly balanced diets, more sedentary lifestyles and in some cases a genetic predisposition to weight gain, such is the case in Prader-Willi syndrome¹¹ or in Down syndrome.¹² In addition, anti-psychotic medications, such as clozapine and olanzapine, predispose patients to weight gain.13 Obesity is often associated with co-morbidities such as cardiovascular disease and diabetes,14 and it may be that these conditions are undiagnosed in the obese patient with learning disabilities due to the complexities in accepting annual health checks and potential barriers to care. The impact that obesity can have on the dental care of an individual can be considerable, as outlined in Table 1.

Hospital and community dental services delivering special care dentistry need to ensure therefore, that not only are they equipped and trained to manage patients with learning disabilities and potentially challenging behaviour, but are also able to accommodate those with obesity. This may warrant the need for reasonable adjustments to be made as well as utilisation of specialist bariatric equipment such as specialised dental chairs, wheelchairs and monitoring equipment, as detailed in Table 1.

Case report

Referral

A 41-year-old male patient was referred to special care dentistry at Barts Health by his local community dental service (CDS), as outlined in Box 1 (contains reference to Figure 1).

Assessment

As the patient's behaviour was known to become heightened in unfamiliar environments, we were advised that his dental assessment should be undertaken outside of the hospital environment and confined spaces were to be avoided. By way of a reasonable adjustment,

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Box 1 Details of referral

Complaint: recent behaviour change: self-harm through hitting the side of face, carers were concerned regarding pain of possible dental origin

Medical history: severe learning disability: frequently displayed physically challenging behaviours at home, such as biting and hitting himself, in addition to shouting and kicking others

Autism: visually impaired following self-harm: having previously poked his left eye to such an extent that he can no longer see out of it

Hypertension

Hay fever

Obesity: difficult to monitor patient's weight as reluctant to stand still on scales and in addition specialist bariatric scales required. Weighed as 28 stone but as standard scales only measure up to a maximum of 28 stone, in reality the patient's weight could be much higher

Undiagnosed co-morbidities.¹⁰ the patient possibly had undiagnosed conditions associated with obesity such as diabetes

No known allergies

Medications: amlodipine, aripiprazole, cetirizine, bisacodyl, hypromellose eye drops, lorazepam as required

Social history: recently moved into his current residential support home and adapting to new accommodation. Always accompanied by three carers when in the community. Non-verbal but could use some Makaton (a basic sign language). Has a specially adapted van with internal plastic windows, to minimise risk of self-injury and damage to the vehicle (Figure 1). Dislikes unfamiliar environments, but likes routine such as going out in the van every day.

Family: one sister and a brother who were involved in his life.

it was agreed that the best location for initial assessment was a nearby park (Fig. 2). Prior to this a risk assessment was undertaken, the

In an attempt to minimise patient anxiety, the special care dentist and nurse wore plain clothes to the park rather than hospital uniform. There they met the patient, accompanied by three carers. Unfortunately, the dental team were unable to get close enough to the patient for assessment, as being outside of his normal routine was causing him some distress and this was manifested physically, by the patient kicking and punching his carers and trying to pull windscreen wipers off nearby parked cars. This level of distress meant that communication with Makaton was simply not possible. The closest to any kind of assessment was taking a photograph of the patient. The taking of this photograph had been discussed

with both the patient's sister and carers before this assessment appointment. It was felt to be

in the patient's best interests for treatment planning purposes, so that the extended

members of the team could understand the

patient's body habitus when making reasonable

adjustments to support his care; for example,

justification for use of one of the hospital's

bariatric wheelchairs and illustration of the

patient's neck/airway to the anaesthetic team.

details of which can be seen in Box 2.

Dental history: examination was twice attempted by the CDS on a domiciliary basis, however became agitated on both occasions, pushing and hitting the staff around him and even ripping the dentist's clothes. **Oral hygiene:** enjoys brushing his teeth with a fluoride toothpaste and a manual toothbrush every morning, however also enjoys breaking the toothbrush afterwards.

Diet: although has a large appetite, generally low sugar diet but occasionally has carbonated drinks.



Fig. 1 Adapted van and associated damage caused by the patient. This damage had been repaired by the time of patient admission



Fig. 2 Altab Ali Park, East London

Best interests discussion

Capacity to consent was assessed as per the Mental Capacity Act 2005.³² It was deemed that the patient did not have the capacity to consent to assessment and treatment. When making a best interests decision regarding the patient's dental treatment, there was input from his carers, sister and social worker, as well as medical and learning disability colleagues across hospital and community services. Attempts were made by carers to include the patient in the decisionmaking process, however the patient's level of use of Makaton, visual aids or other communication prompts were not sufficient for this to be possible. The carers also supplied the team with an extensive support plan regarding the patient's



Box 2 Risk assessment

Communication with family and carers

Time was taken prior to the appointment to understand the patient's behaviours and daily routine in order minimise the risk of heightened behaviours, including triggers, responses and methods of de-escalation.

Dental staff safety

The team were experienced in the management of this patient group and comprised a consultant in special care dentistry accompanied by a special care dental nurse. They had mobile phone access should any problems arise. The patient was to be accompanied by three carers who knew his behaviour patterns well. All staff were trained and experienced in clinical holding.

Consideration of patient safety

It was felt that seeing the patient in an open environment would be safer for the patient, as well as for his carers and the dental team. The park offered an open space where he should feel more comfortable and would be able to return quickly to his vehicle if needed. Prior to leaving his residence, the patient was given PRN lorazepam in view of anticipated anxiety.

Consideration of public safety

If the patient became upset, he could potentially cause harm to the general public. This park was chosen as it was generally quiet and staff were confident that they could safely manage the patient.



Fig. 3 a) Hospital Passport . A hospital passport provides key information about a patient with a learning disability. This includes personal details, the type of medications they are taking and any pre-existing health conditions. It also includes important information regarding how a person communicates and their likes and dislikes³³ b) Extract from the patient's support plan

care as well as a hospital passport (Fig. 3). These documents helped us to understand any potential triggers for challenging behaviour in the patient and were a vital part of the decision-making process.

Following discussions, a review of the support plan, the outcome of the assessment in the park and in view of the patient's size, it was felt that a single visit day-case general anaesthetic (GA) was in the patient's best interests and would facilitate a more holistic multidisciplinary approach with input from other medical specialties. It was not considered appropriate for the patient to be admitted overnight, as a stay in the hospital would have been extremely anxiety provoking and could have led to increased risk of injury to himself, property and others around him.

As part of this best interest decision, the need for use of a covert pre-medication and clinical holding with input from security teams was also discussed, for patient and staff safety. Clinical holding is a method of safely holding a person when safety is at risk and is only carried out by appropriately trained staff.34 A covert medication is defined as a medication that is given to a person without their knowledge by disguising it in a food or drink.35 As per National Institute for Health and Care Excellence (NICE) and Care Quality Commission (CQC) guidelines, this should only be administered if it is considered to be in a person who lacks capacity's best interests and must be included in a best interest discussion.^{35,36} In this case, the covert administration of an oral sedative was felt to be in the patient's best interests to facilitate access to dental care.

Acclimatisation

Four acclimatisation visits were arranged to familiarise the patient to the hospital environment. These were conducted on consecutive Wednesday mornings at 7 am, before the start of the weekly special care GA list. This had the benefit of being a time when the hospital was quiet and would also reflect a similar time to which the patient would be arriving for treatment, with a hope to habituate him to this routine. Although he had PRN lorazepam before these acclimatisation visits, it was minimally effective. However, there was some slight headway; over the course of these four visits the patient progressed from refusing to leave his van to entering the hospital building and sitting on a bench in the main entrance. However, he would only sit for a few minutes at a time before becoming agitated and also refused to sit in a wheelchair. This was a specialist bariatric wheelchair with a weight limit of 315 kg (50 stones). The problem remained of how the patient was going to access our anaesthetic room in the day stay unit on the third floor and be discharged in a way that was safe for the patient, staff and the general public.

Delivery of treatment

As there had been little success with lorazepam pre-medication during the acclimatisation visits, it was decided for the day of treatment to use an alternative pre-medication: promethazine, an antihistamine with sedative effects. The patient took this at home to aid his journey and admission in to the hospital.

It was agreed for the security team to cordon off an area for the patient's van to park outside the closest entrance to the unit to minimise journey distance. The patient arrived, accompanied by three carers and a driver, and was met at the entrance by the special care dentistry team, the anaesthetic team, the lead nurse for learning disabilities and members of the security staff, all dressed in plain clothes.

In preparation for the GA, the patient had been starved; however, there was concern that, as detailed in his support plan, his behaviour could soon deteriorate with increasing hunger levels. Therefore, to aid the patient's journey to day surgery on the third floor and provision of his planned GA, the discussed additional covert oral pre-medication was given consisting of ketamine and midazolam in a small cola bottle by the anaesthetist. Ketamine was administered in addition to the midazolam as there was concern

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Fig. 4 a) Bariatric wheelchair; b) the additional of towels to help comfort the patient; c) demonstration of the size of the wheelchair

that the patient may have some tolerance to benzodiazepines given the limited effect of lorazepam previously. A fine balance was required so that some sedative effect was achieved, but the patient was not so sedated that he was unable to mobilise; in view of his body habitus, it would be difficult to transfer him out of his vehicle. In addition, over-sedation could also pose an airway risk and so it was ensured that the anaesthetic team were fully equipped with sufficient staff, in terms of numbers and experience, in addition to anaesthetic equipment. The pre-medications and their administration were successful, but safe transfer out of the van onto a hospital trolley required multiple pillows, a pat-slide, a slide sheet and eight people.

Transfer of the patient thereafter to the anaesthetic room was complex and required further reasonable adjustments. The Royal London Hospital is a major trauma unit with a helicopter landing space on the roof and the most direct route to theatre was via the hospital helicopter lift; this is usually reserved for urgent use by hospital staff transferring emergency patients only, therefore special permission was necessary for its use. On arrival at the day stay unit on the third floor, the usual admission process was bypassed and the patient was taken directly to the anaesthetic room for intubation.

Examination under GA revealed poor oral hygiene, but no evidence of caries or significant periodontal disease, as confirmed by taking intraoral radiographs. Full mouth scaling was completed and fluoride varnish applied. It was also arranged for other medical specialties to assess the patient under GA so that all potential causes of pain could be eliminated. This included ear, nose and throat (ENT) assessment, in which copious amounts of wax was found in the ears. The patient's eyes were also assessed by the orthoptic/ophthalmology team, who confirmed that the patient had no sight in the left eye, but also found cataracts to be present in the right. Routine blood tests were also taken as per annual health check recommendations from the Royal College of General Practitioners for people with learning disabilities.³⁷ Results were consistent with iron deficiency anaemia.

Discharge

The standard recovery area was a ward on the third floor. There was concern that if the patient was recovered in this area, there could be an adverse incident. Therefore, a treatment room was identified on the ground floor which offered the fastest route out of the hospital and had the additional benefit of being close to a fire exit and being located in the accident and emergency (A&E) unit, should any medical assistance be required. The patient was taken directly to this room from theatre still intubated, once again via the helicopter lift. It was ensured that the patient's carers and two members of security staff would be present on the patient's waking. The patient was successfully extubated and once able, was transferred onto a bariatric wheelchair. In another example of reasonable adjustments, the wheelchair was draped in towels; as these are something that the patient found particularly comforting (Fig. 4). In order to be safely discharged, the patient needed to be sufficiently awake for his airway to be uncompromised and mobile enough so that he could safely transfer back into his vehicle. However, to wait too long for this would increase the risk of challenging behaviours. This was successfully executed and the patient was discharged safely.

Although no definitive cause for the patient's change in behaviour could be attributed, the patient's carers reported that his behaviour had improved in the weeks following his treatment. Both hearing and sight problems in patients with learning disabilities have been cited to have a detrimental impact on behaviour.³⁸ Therefore, this could account for the patient's previous deterioration and the subsequent improvement following removal of wax in the ears, in addition to carers' enhanced knowledge regarding his visual fields and relevant adaptations at home.

In view of the high level of complexity in this case, it is important that steps are made to try and reduce challenges for the future. The importance of taking the patient to recall appointments in the CDS to acclimatise him to the dental environment has been stressed to carers. Although success in terms of achieving a dental examination may be limited, it is hoped that this may improve over time with increased familiarity to the people and environment. Failing this, a domiciliary approach could be reinstated. Appointments will serve as an opportunity for the clinician to deliver diet and oral hygiene advice to the carers.

Discussion

This clinical case serves to illustrate not only the potential complexities of treating a patient with a severe learning disability, but also the additional layer of challenge brought by obesity. It demonstrates how reasonable adjustments, good communication with carers and colleagues, and excellent teamwork can allow a patient who otherwise would not have been able to access care to receive high level comprehensive treatment. Blood testing under GA also enabled iron deficiency anaemia to be detected, which, due to the patient's limited compliance for blood tests, would have otherwise continued to go undiagnosed. This demonstrates a patientcentred approach, avoiding further repeat (and potentially very challenging) hospital visits, improving health care outcomes and equality in an already disadvantaged group.39,40

The recognition of the need to improve the health care experience of patients with learning disabilities has also been reflected on a national scale with Mencap's 'Treat me well' campaign.⁴¹ Tools such as the 'hospital passport' should not be underestimated;³³ they can significantly assist healthcare staff in understanding a patient better and that, combined with effective communication

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with the patient's carers, can greatly improve the patient's healthcare experience. In a patient who cannot express themselves verbally, a thorough history should be taken from those close to the patient, asking if there has been any change in the patient's behaviour such as not eating or sleeping, a change in general mood or holding the side of his or her face. Healthcare professionals must also always be aware of the danger of diagnostic overshadowing, that is to attribute a change in a person to their learning disability rather than looking for a pathological cause.⁴²

Public Health England's document Making reasonable adjustments to obesity and weight management services for people with learning disabilities highlights the issues of obesity and its management in the context of the patient with a learning disability, as well as providing easy-read material for the patients themselves.43 When considering the co-morbidities that accompany obesity, we as practitioners should consider our role in screening, giving preventative advice and necessary referral to medical services; that is, having a more holistic approach to our patient care as per Public Health England's campaign 'Making every contact count'.44 In this case, the learning disability team followed up with the patient's carers, the patient's diet and behaviour patterns, to see if there was a possibility that food was being used as a reward, which in view of his size could have represented a potential safeguarding issue. This was not the case and the patient's carers were already taking steps to try and improve his diet. The patient was also in the process of being assigned to a new local learning disability team with the hope of further understanding and managing his challenging behaviour.

Conclusion

Reasonable adjustments and a team approach are essential to the dental management of patients with learning disabilities, particularly those with challenging behaviour and additional complexities such as obesity. The importance of listening to those close to the patient cannot be underestimated and a multidisciplinary approach can help provide holistic patient care.

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