

Implementation of a CBT-based dental anxiety management pathway for patients with learning disabilities

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Abstract

Dental anxiety is a common phenomenon in the general population and may be more prevalent in people with learning disabilities. There is growing interest in the use of cognitive behaviour therapy (CBT) approaches including within dental anxiety management. However, relatively little is known regarding the application of CBT approaches in dental anxiety management for patients with learning disabilities. This paper outlines details of the implementation of a CBT-based dental anxiety pathway for patients with learning disabilities treated in a special care dental service in England. The pathway is modelled on the utilisation of skills from the dental team (dental nurses and dentists) to deliver a combination of talking sessions, desensitisation, and positive affirmation in five distinct stages. Early feedback from service users following implementation of this pathway indicates successful acceptance of dental care with a decreased use of sedative adjuncts.

In brief points

- People with learning disabilities are often excluded from cognitive behaviour therapy-based interventions for reducing anxiety.
- Reducing dental anxiety for patients with learning disabilities may reduce the need for dental treatment under general anaesthesia.
- Cognitive behaviour therapy-based dental anxiety management may be a useful tool for reducing dental anxiety in this cohort of patients and requires further research.

Introduction

Anxiety can be defined as 'an uncomfortable feeling of nervousness or worry about something that is happening or might happen in the future'.¹ Anxiety is a common condition affecting most people at some point over the life span and can be categorised into two broad groups, (i) trait anxiety and (ii) state anxiety. Trait anxiety is defined as an individual's tendency to appraise situations as threatening, avoid anxiety-provoking situations, and demonstrate high baseline physiological arousal. In a dental context this can be summarised as lasting apprehension when considering or experiencing dental treatment.² State anxiety relates to a specific point in time or a specific situation, for example, needle anxiety.³

Dental anxiety may be considered as common within the UK, with the most recent Adult Dental Health Survey indicating that over one third of adults (36%) demonstrated moderate levels of dental anxiety, with a further 12% reporting severe anxiety.⁴ Dental anxiety is a barrier to dental treatment and those with severe dental anxiety tend to seek emergency management only, prompted by pain. Consequently, the visit is associated with discomfort and heightened anxiety, reinforcing the belief that dentistry is painful and perpetuating a cycle of non-attendance.⁵ Historically, dental anxiety management has primarily focused on pharmacological intervention. However, working within the definition of conscious sedation⁶ and using the sedatives available to most dental practitioners, sedating an uncooperative patient can result in an uncooperative sedated patient. This is an unsatisfactory outcome for both clinician and patient.

As access to dental care is a life-long need, behaviour management approaches are an important consideration in terms of rehabilitation for patients with severe dental anxiety.² The Clinical Standards for Dental Anxiety Management² describes low level anxiety management techniques, to facilitate dental treatment. Examples include rapport building, environmental change and enhancing control for the patient. The guide also recommends cognitive behavioural therapy (CBT): a talking therapy usually lasting between 6-10 sessions, and pharmacological adjuncts for patients with high levels of anxiety.

Learning disabilities

A learning disability is a lifelong condition affecting an individual across all facets of their life. It may be characterised by the need for additional support to understand new or complex

information, learn new skills, or live independently.⁷ There are approximately 1.5 million people with a learning disability living in the UK.⁸

People with a learning disability face greater health inequality across a range of outcomes and are more likely to die at a younger age. In 2022, the National Learning Disabilities Mortality Review (LeDeR) programme found that men with learning disabilities died on average 20 years younger, and women 23 years younger when compared to the general population.⁹ It also concluded that avoidable medical causes of death occurred nearly twice as frequently in those with learning disabilities. Those with learning disabilities are more likely to experience 'diagnostic overshadowing' where comorbid health problems are wrongly attributed to a disability.⁹

In terms of dental health, people with learning disabilities are more likely to have poor periodontal health, higher caries rates, edentulism, higher rates of unmet oral health needs and dental anxiety.^{10,11} Many patients with learning disabilities have serial general anaesthetics for dental treatment. The treatment is typically more radical to prevent repeated general anaesthetics and pre-general anaesthetic oral examinations are often performed with physical or chemical restraint.¹² Several studies advocate the use of CBT for long-term reduction in dental anxiety.^{13,14} Yet historically, people with learning disabilities have been excluded from CBT interventions due to a perceived inability to participate and engage in the cognitive component of therapy.¹⁵

The National Institute for Health and Care Excellence (NICE)¹⁶ recommend the use of cognitive behavioural therapy via a tailored approach adapted for people with learning disabilities and in keeping with the individual's level of understanding, receptive vocabulary, strengths, and needs. Consideration should be given to any physical, neurological, cognitive, or sensory impairments and communication needs.¹⁶ Other research has demonstrated that a modified CBT approach can yield positive outcomes for people with learning disabilities who experience anger problems and depression.^{17,18}

This paper outlines an approach to dental anxiety management for people with learning disabilities, focusing on behaviour management and CBT-based interventions tailored to the individual patient. The pathway described is currently being used in the Special Care Dental Service in Hertfordshire Community NHS Trust.

Dental Anxiety Management pathway (dental AMP) for patients with learning disabilities

Design of a pathway for this patient group incorporated a structured combination of conventional CBT approaches incorporating talking sessions with desensitisation and graded exposure to the dental environment, staff, and equipment. The overall aim being to identify sources of anxiety (both trait and state anxieties) and challenge these anxieties in a supportive atmosphere, allowing the individual to learn new strategies to address the issues related to their thoughts and behaviour, and work towards specific goals.¹⁹ This is followed up with positive affirmation for any achievements made, and support to manage catastrophising thoughts if there is no evidence of progress. In this way, this pathway seeks to challenge patients about their thoughts and behaviour regarding dentistry, the healthcare environment and how affects them physically and emotionally. This type of anxiety management focuses on the current situation but can help reframe long held negative connotations of health interventions that may be acquired by patients with learning disabilities, due to previous poor experiences, lack of autonomy in health-related decision making, and health professionals' refusal of care due to demonstrations of behaviours of distress by patients.

There are five key stages in the Dental Anxiety Management Pathway (Figure 1).

Stage 1

Nurse led Telephone appointment

An initial telephone call from a dental nurse is used to engage with the patient, parent, or supporter. The aim of this conversation is to build rapport and explain the pathway. A discussion of patient likes and dislikes is also initiated; this is used to gauge cooperation and plan the clinical visits, along with a social history, allowing the dental professional to assess available patient support. The outcomes of this conversation will also determine whether the first visit is in a clinic setting or on a domiciliary basis. A brief discussion regarding key oral health messages (diet and toothbrushing advice) in line with Delivering Better Oral Health ²⁰ is also included at this point. An important exclusion criterion for this pathway is patients who are assessed as having dental pain or infection, due to the protracted time to active intervention.

Stage 2

Nurse led clinic appointment 1

From the initial telephone conversation, a rapport is built between the dental nurse, the patient and their supporters. Using the knowledge gained in the previous stage the dental nurse will meet the patient, to introduce themselves in person and converse on subjects favoured by the patient. It is essential that the same member of staff makes the phone call and subsequently meets the patient, thus establishing a 'safe' relationship. This dental nurse will continue to accompany the patient on the pathway, introducing the patient to the dentist around stage 4, depending on the number of nurse led visits required for the individual. Creating a calm, friendly, safe space is paramount given the potential for poor previous dental experiences. Patients are seen on a domiciliary basis or start their nurse led clinic consultation in the sensory room (figure 2) rather than clinical rooms. At this visit an extended Modified Dental Anxiety Scale (MDAS)²¹ is completed by the patient with explanation and assistance from the dental nurse as required²². After meeting the dental nurse in person, following the initial telephone call, most patients are happy to rapidly progress to a clinical space. This natural progression enables the appropriately trained nurse to provide hands on oral health education, involving tooth brushing instruction to acclimatise patients to having their mouths touched, holding a mirror in the patient's mouth, placing radiograph film holders in the mouth, and a demonstration rotation inside the panoramic radiograph machine. A formal assessment of dental anxiety is carried out (supplementary appendix 1). For those patients with generalised health anxiety who had not been able to visit other healthcare environments recently, blood pressure and pulse oximetry readings are also taken.

Stage 3

Nurse led clinic appointment 2

The nurses arrange subsequent appointments as needed, advising patients to bring adjuncts such as music, soft toys, or a blanket as appropriate, and incorporating patient-led equipment desensitisation, teaching relaxation and distraction techniques based on patient preferences and interests. Completion of a modified 'Message to the dentist'²³

(supplementary appendix 2) at this stage encourages discussion of the patient's thoughts and behaviours that might arise during the next stage and looks at individualised methods for the patient to manage these thoughts and behaviours.

Stage 4

Introduction to the dentist

During this stage, the dental nurse introduces the dentist. If the patient consents, a cursory exam is carried out and ideally, a polish using a slow speed handpiece (this gauges the patient's reaction to vibration of a dental handpiece) plus radiographs as indicated. This stage can be repeated as required and is followed by positive affirmation and for some patients, a post visit bravery letter can build confidence and act as a reminder of a positive dental visit (supplementary appendix 3).

By this stage the dentist will have obtained information from the dental nurse, such as the views of significant people in the patient's life and patient likes and dislikes. This information will be used to support shared decision making. At this point, the dentist can decide whether to continue with the dental anxiety management pathway, use sedation as an adjunct or refer the patient for a general anaesthetic depending on the level of cooperation and anxiety. Any sedation provided from this point in the pathway, is likely to be less anxiety provoking for the patient, as it will be secondary to familiarisation with the team and environment, and consequently lead to a better sedation experience for the patient and dental team.

Stage 5

Dental treatment

The dental treatment is carried out by the same dentist and dental nurse as in stage 4 for continuity. By this stage there is some trust between the patient and the dental team and small amounts of dental work are usually possible. Local anaesthetic is delivered using the WANDTM single tooth anaesthesia system²⁴ and if required, sedation provided by the same dental team carrying out the anxiety management pathway, and although not measured, this seems to facilitate a smoother sedation visit. Some patients who had not been able to have a dental examination previously, other than under a general anaesthetic, are managing

a brief dental examination. If no treatment is required, patients are discharged back to the referring dentist within the service, with instructions on how to continue with behaviour management in the longer term, with the hope that this will further decrease the patient's generalised dental and health anxiety for future visits.²⁵

Initial findings from implementation of the pathway

Referrals, at this initial stage, are internal and received from dentists who have exhausted all other adjuncts to facilitate dental treatment, ranging from behaviour management to sedation, but excluding general anaesthesia. To date, this pathway has been used for 20 patients. Within five sessions, all these patients, who have not tolerated dental treatment without general anaesthesia previously, allowed radiographs and preliminary dental examinations in the dental chair. Of the patients who require treatment, 17 are managing minor dental treatment with local anaesthesia alone or with single agent conscious sedation. The remaining 3 patients are being treated under a general anaesthetic for dental treatment, justified by radiographs and a dental examination which had previously not been possible. This has facilitated treatment planning prior to the general anaesthetic. A small number (4) have gone on to access general medical practitioner services, phlebotomy, and routine vaccinations prompting referrals from, and a new shared care pathway with, the learning disability nurse team within the Trust to explore decreasing generalised health anxiety within this patient group.

Discussion

This pathway is coordinated and led by members of the dental team who have received training in dental CBT-based methods. The inclusion criteria comprised patients with the ability and willingness to engage with the pathway, mental capacity to consent to specific treatment options used for acclimatisation, and a diagnosed learning disability. It is particularly suitable for patients with an ability to recognise links between certain situations and elicited emotions. It is not suitable for patients with suicidal ideation or more significant mental health problems, who would benefit from an appropriately trained and registered mental health professional. As any CBT-based intervention is time-consuming, it is also unsuitable for patients in pain or those unwilling or unable to participate in such a pathway.

Such patients would be seen via a conventional pharmacological pathway such as sedation or general anaesthetic as appropriate. Conscious sedation remains a vital adjunct for those with limited co-operation, complex treatment needs or disproportionate anxiety levels.² Anecdotally, conscious sedation following the dental anxiety management pathway has been smoother and the patients seemed less anxious on the day of the sedation visit. This could be attributed to trust built with staff members over the preceding visits and familiarity with the setting.

The questionnaire used in this pathway is an extended form of the MDAS with added photographic representation of the items described. No dental anxiety assessment tool is ideal in terms of incorporating assessment of all triggers appropriate to individual patients. The MDAS is a simple, well known, validated assessment tool completed by the patient. The MDAS measures dental trait anxiety in adults and comprises five questions each with five answers, relating to the different components that make up average dental treatment. A score of 19/25 or greater denotes a severely anxious or phobic patient, with a score of 10-18/25 denoting a moderate trait anxiety. Patients with specific state anxiety triggers can be identified using this scale, or with subsequent questioning. One disadvantage of the MDAS is that it does not contain a question regarding dental extractions, which is a disproportionate fear for some individuals, especially those with learning disabilities. This can be from poor previous experiences, or inaccurate information or beliefs about what extractions entail.

The extended MDAS is an unvalidated anxiety measurement tool based on the MDAS scale, with an additional question regarding dental extractions (supplementary appendix 1). Smiley faces were incorporated rather than words or numbers, as evidence suggests that patients with learning disabilities demonstrate a significantly better response rate to smiling and frowning faces as opposed to numerical or word scales.²² Photographs were also added to make the questionnaire as inclusive as possible in terms of age, level of previous dental experience and cognitive ability. Some individuals with a learning disability will have processing disorders, so pictorial representation to enforce the language was deemed valuable as a reasonable adjustment. The authors are aware that the photos might act as a trigger for some individuals, but after involving a small number of patients and experts by experience, it was felt that this would make identifying these triggers easier and facilitate

goal setting. Due to the inclusion of an additional question, a new score of 19 /30 indicating moderate - high anxiety, was given for inclusion onto the pathway. This is demonstrated by those who score higher than a total of six neutral face scores in the 6-question assessment, where the most anxious face receives a score of 5 and the happiest face, a score of 1. Whilst the questionnaire was well received by the small number of participants, the use of an unvalidated tool is a recognised limitation of this work.

The efficacy of the described dental anxiety management pathway is reliant on the skill and consistency of the team members. The 'safe space' created by the rapport between the dental nurse and patient, and the familiarity of the environment, is important and should not be overlooked. At the point when the patient meets the dentist, the dental nurse is acting as an advocate for the patient, which may facilitate a decrease in anxiety just by their presence in the room. This use of skill mix is a cost-effective method of incorporating dental anxiety management into everyday dental practice. Within salaried dental services, dental nurses are typically paid at Band 4 to Band 5 (agenda for change) and this is in line with most dental nurses working in general dental practice^{26, 27}. At the time of writing this is a salary range of £25,147 - £34,581. For dentists the range is £47,653- £101,923 with many self-employed dentists achieving more. In addition to the financial gains, utilising dental nurses with extended duties allows dental care professionals to take on more autonomy and responsibility within their role, possibly increasing job satisfaction.²⁸

This approach is aligned with the Clinical Standards for Dental Anxiety Management ² which suggests that CBT-based interventions could be delivered by registered psychological professionals (i.e., psychologists and CBT therapists), or any specifically trained dental professional; this could be a dentist, dental hygienist/therapist, or dental nurse.

Whilst the authors recognise this work is based on a small number of patients, the cost savings compared to a general anaesthetic is not insignificant. In addition, this pathway not only produced positive outcomes in terms of compliance with dental examination and treatment, but anecdotally also in terms of lowering generalised health anxieties for some of the patients. This provides numerous potential benefits, particularly for those in whom a negative dental experience could be detrimental to health care access more generally. Behaviours of distress are often seen in this patient group and using a CBT-based approach

can be effective in challenging the patient to address the thoughts, and subsequent feelings, that lead to these behaviours, leading to a safer dental visit for both the patient and staff involved. Taking a different and more cognitively focused approach with patients, to change their attitudes and beliefs towards dental care, can also improve recall attendance.^{29,30} The development of this pathway represents the local adaptation and implementation of national clinical standards for dental anxiety management. It has shown a need for further research to verify the initial findings and explore the attitudes of this cohort of patients in more detail. In order to collect qualitative and quantitative data to assess trends in anxiety reduction, the next step will be to apply for ethical approval and start a formal pilot.

Conclusions

Clinicians may be less likely to attempt dental treatment under local anaesthetic in patients with learning disabilities, for fear of upsetting the patient or triggering behaviours of distress. However, with time and understanding, more patients with learning disabilities can be successfully treated in general dental practice. Using this systematic approach may decrease dental anxiety, improve dental outcomes, and access to general dental care so decreasing the health inequalities faced by people with a learning disability.

Declaration of interests

The authors declare no conflicts of interest.

Author contributions

SH conceived and drafted the original manuscript. MS, LD, and UM edited and revised the manuscript. All authors edited and approved the final text prior to submission for publication.

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