

INVESTIGATING THE LIVED EXPERIENCES OF CHILDREN AND THEIR PARENTS WHO HAVE BEEN REFERRED TO A PRIMARY CARE SEDATION SERVICE

Dr P.A. Averley and Dr R. Hobman (*dentists and investigators*), *Queensway Dental Practice & Anxiety Management Clinic, Billingham.*

Prof. S. Bond, *Head, School of Population and Health Sciences, University of Newcastle upon Tyne.*

Dr N.M. Girdler, *Consultant, Sedation Department, School of Dental Science, University of Newcastle upon Tyne.*

Prof. J. Steele, *Professor of Health Service Research, School of Dental Science, University of Newcastle upon Tyne.*

Abstract

Anxiety is a major barrier to accessing dental care for a large group of patients. Anxiety can also be a cause of significant distress to patients undergoing dental treatment.

The study presented here is an investigation of the lived experiences of children, and parents of children, who have received dental treatment under conscious sedation (as an alternative to dental general anaesthesia in hospital) at Queensway Anxiety Management Clinic (a primary care based specialist conscious sedation referral service). Focus group discussions were held separately with children and the parents of those children who had received care on referral. Discussions were facilitated using a topic guide to stimulate dialogue. The dialogue was recorded for subsequent transcription and analysis. The results provided an insight into the lived experiences of anxious children and the lived experiences of the parents of those children. This will direct service developments and our future research agenda.

Acknowledgements

Our thanks to all the children and their parents who took part in the focus groups. Particular thanks to Joanne, Nadine and Sarah at the practice for all their administrative support. Thanks to Pat Baker for transcribing tapes into verbatim transcripts. Thanks also go to the National Coordinating Centre for Research Capacity Development (NCC RCD) for their support through a Personal Development Award.

Keywords

Conscious sedation, dental anxiety, sevoflurane, intravenous midazolam, paediatric anxiety management.

Correspondence

Paul Averley, 170 Queensway, Billingham, Teesside TS23 2NT. Email: paul@averley.com.

Background

Queensway Anxiety Management Clinic (QAMC) is a referral-based primary care dental practice in Billingham, Teesside, UK⁽¹⁾. Referrals are received from dental practices throughout the county and adjoining counties. Each year, approximately 8,000 children and adults are treated at the practice using a variety of anxiety management techniques depending on the individuals' level of anxiety, their ability to cooperate and/or the invasiveness of the intended procedure.

The first line of treatment for children referred to QAMC is a combination of behavioural management and relative analgesia (RA). However, RA does not provide adequate anxiety management for all children in all cases. Extremely anxious children, or those undergoing particularly invasive procedures, may require greater control of their anxiety than RA alone can provide.

In response to this, conscious sedation (CS) techniques were developed at QAMC to provide a greater level of support for patients⁽³⁻⁷⁾. The aim of these CS

techniques was to provide an alternative to dental general anaesthesia (DGA) in hospital⁽²⁾. The first of these techniques to reach publication was sevoflurane and nitrous oxide inhaled conscious sedation (SNICS). This study compared SNICS with nitrous oxide alone. The randomised controlled trial (RCT) of 411 children showed that SNICS reduces the need for DGA by 36.9% when compared with nitrous oxide alone⁽⁷⁾.

In addition, intravenous (IV) CS techniques for paediatric patients were also developed. This involved an RCT to investigate the use of IV midazolam combined with different inhalation agents. This RCT reported on 697 children too anxious for management with RA, requiring invasive dental procedures for which a DGA would usually be required. The 697 children recruited were randomly allocated to one of three groups for different interventions: Group 1, a combination of inhaled medical air and titrated IV midazolam; Group 2, a combination of inhaled 40% nitrous oxide in oxygen and titrated IV midazolam; and Group 3, a combination of an inhaled mixture of 0.3% sevoflurane and 40% nitrous oxide in oxygen with titrated IV midazolam. The primary outcome measure was successful completion of the intended dental treatment with a cooperative child responsive to verbal commands. In Group 1, 54% (94/174 children) successfully completed treatment. In Group 2, 80% (204/256 children) and in Group 3 93% (249/267 children) completed treatment. This difference was significant at the 1% level. IV midazolam, especially in combination with the addition of inhaled nitrous oxide or sevoflurane and nitrous oxide, is an effective technique, with the combination of midazolam and sevoflurane the one most likely to result in successful treatment⁽⁴⁾.

Aim

The principal aim of this study was to gain an overview of the lived experiences of anxious children, and the parents of those children, referred to QAMC to identify areas for service improvement.

Objectives

- To identify a sample of child patients and their parents who have been referred and received dental treatment at QAMC.
- To identify qualitatively the experiences of the sample in the context of the referral process.
- To use the resulting data in order to develop an understanding of the experiences of children and to make recommendations for service improvement.

Reported experience of CS and DGA in the literature

Focus groups have not been used to investigate patient experiences of CS or DGA and there was no evidence relating to children's experiences of treatment under IV CS.

Veerkamp et al. have produced publications describing patients' experience of treatment with RA. Anxiety reduction was achieved in highly anxious children over multiple visits⁽⁸⁾; this was a long process involving multiple, long appointments over a number of months. RA was generally found to be acceptable by patients, with minimal associated morbidity. Progress, in terms of treatment completion, was slow. However, long-term anxiety was reduced in some cases. The reduction in anxiety achieved was more readily maintained over subsequent months when RA and behavioural management were used than when behavioural management was used alone⁽⁹⁾.

Previous publications relating to patient experiences of treatment under DGA have tended to focus on operative morbidity. Holt et al. studied the acceptability to patients and parents of treatment under DGA at a day-case facility in London⁽¹⁰⁾. When asked in a post-operative questionnaire whether treatment had been acceptable, 97 out of 103 families said that they would consider day-case DGA again in future if needed. Five families would have preferred an overnight stay and one would never consider DGA again. However, it must be considered that parents were making a choice between day-stay and in-patient procedures, and not between DGA and other anxiety management options. With respect to post-operative morbidity in this study, 20% of children suffered post-operative pain on the ward, with 32% of children still in pain at home. Nausea, vomiting and headache affected 20–21% of patients.

Bridgman et al. produced an account of patient experiences of a practice-based DGA paediatric extraction service⁽¹¹⁾. Published in 1999, the paper describes experiences of a service typical of those found in dental practices throughout the UK until stopped by guidance at the end of 2001⁽²⁾. Quantitative data was collected relating to pre- and post-operative morbidity. Qualitative data was also collected through pre- and post-operative interviews with patients and parents to assess the acceptability of treatment. Of 80 children included in the study, 20% of children were distressed during DGA induction, with one child vomiting. In the immediate post-operative period, 28% were in pain, 44%

were crying and 71% were bleeding. More concerning was that, during the journey home, 24% were in pain, 37% were bleeding, 55% were drowsy and 5% vomited. At home, 15% continued to bleed, 37% were crying and 12% vomited. During the post-operative interviews, vivid accounts of the experience were recounted. One patient remembered struggling to remove the anaesthetic mask during gaseous induction. Several remembered crying and feeling sick after the procedure, with some describing nightmares and feelings of reluctance to return to the dental surgery in future.

Enever et al.⁽¹²⁾ compared post-operative morbidity following day-case DGA in patients with and without disabilities. Patients received a range of restorative and surgical procedures. Treatment was significantly more prolonged than in the two studies mentioned above; 76% of procedures lasted over 30 minutes and 20% lasted over an hour. No significant difference in morbidity was found in patients with or without disabilities. 44% reported post-operative symptoms. Nausea or vomiting occurred in 20% of patients and 13% required analgesia at home. All three of the above studies appear to portray treatment under DGA to be associated with a significant degree of morbidity. However, the major flaw with all three studies is the lack of a control group.

Methodology

Methodology is the process by which researchers bridge the gap between philosophical theory and appropriate practical research methods⁽¹³⁾. When deciding on an appropriate method of data collection, it is essential to focus on the research question and aims of the research. The research question in the present study can be expressed as:

'What were the lived experiences of children, and parents of children, who underwent referral and subsequent treatment under CS at QAMC?'

The aims of the study also highlight a desire for an overview of experiences, rather than an in-depth account of one particular aspect of the experience.

Focus groups

Focus groups typically consist of between six and ten purposely selected subjects, and a group facilitator. Groups normally meet on one occasion, with a session lasting between one and two hours. Discussions are recorded, and later subject to systematic analysis. The key ingredient of focus groups is interaction between

group members, prompting them to scrutinise their own way of thinking by listening to others. This in turn is intended to trigger further discussion and produce further information. The intended result is a broad overview of views and experiences. Discussion is guided by a facilitator but members of the group are free to ask questions of each other and discuss issues between themselves. The facilitator's main role is to maintain an acceptable degree of structure and order, while encouraging discussions to take place.

There are some potential pitfalls in the use of focus groups. There is limited potential for collecting data on an individual basis. There is also the potential for alienation of group members and reluctance to express personal feelings in front of others. The facilitator must have the skills to stimulate and guide discussion, and to include all members of the group in the discussion, while maintaining the structure of the session. Focus groups were the most likely research tool to meet the aims of the study.

Study design

SUBJECTS

Ethical approval was sought and granted. A purposive sample of children between 6 and 14 years old were allocated into focus groups. Allocation was determined by two variables. The first variable was the age of the child (groups were 6–9 years, 10–12 years and 13–14 years). The second variable was the type of CS received. Recruited children had all taken part in a recent RCT described in the background section⁽⁴⁾. Allocation was based on the CS intervention they had been allocated to and whether the technique had facilitated the successful completion of their planned treatment or not. This gave two focus groups for each age group, making six child focus groups in total. Each focus group was intended to contain between six and eight subjects who had had a variety of techniques and a variety of outcomes. Six additional and separate groups were composed of the parents of the selected children, giving a total of 12 groups.

DATA COLLECTION

Focus group discussions took place at a local hotel. A standardised topic guide was used as a framework around which discussions were based.

Data was collected by digital audio recording. The recordings were later transcribed verbatim into a Microsoft Word document. Data from the transcripts was transferred to a Microsoft Excel spreadsheet. Along the vertical axis were coded details of the participants. Along the horizontal axis were subheadings corresponding to

REFEREED PAPER

themes that had surfaced within the dialogue. Direct quotations from the transcripts were transferred into the relevant part of the spreadsheet. This allowed the grouping of all dialogue relating to a particular theme into a single column of the spreadsheet, to allow analysis of the information gathered.

RESEARCH PROTOCOL

Children were selected who had participated in the previous RCT described⁽⁴⁾. Parents or legal guardians of suitable children were then contacted by post to enquire as to their willingness to take part in the study. Willing participants were offered payment for taking part and to cover travel expenses. The documentation sent included a written consent form, a written patient information sheet and a pre-paid envelope for reply. Completed consent forms were returned using the envelopes provided. Responses from those who had agreed to take part were assessed. Children were then purposefully selected and allocated into appropriate focus groups. Selected participants were contacted again to make arrangements for the focus group meetings.

CONFIDENTIALITY

All researchers involved in the study signed codes of confidentiality and conduct. Recommended data security and storage procedures were followed by the researchers (MRC Guidelines on Personal Information in Medical Research, 1999). All personal data collected and held was registered in accordance with the 1998 Data Protection Act, and the Newcastle University data protection policy was followed.

RESULTS

Data was recorded from a total of 59 participants: 25 children and 34 adults. The number of participants in each group ranged from four to eight, with some groups falling below the minimum target of six participants. Due to technical difficulties with recording equipment, no data was collected from one adult focus group and one child focus group. This unfortunately led to the exclusion of these two groups from the study, with data collected from a total of five child groups and five adult groups. The results are presented under a series of subheadings, based on the themes that arose during the focus group discussions. Beneath each subheading, the results are illustrated where necessary with quotations from the focus group transcripts.

BEFORE TREATMENT

Reason for referral

Anxiety and the need for multiple or invasive interventions were by far the most common reasons

for referral, accounting for most of the dialogue in this section.

*'He was very, very scared of the dentists. **** was really, really terrified to the point of shaking, he wasn't sleeping at the thought.'*

One child was referred primarily for medical reasons. *'It must have been because he was diagnosed epileptic, they weren't very happy to treat him.'*

Previous treatment experience

Two children had no previous experience of dental treatment, other than check-ups.

'Me own dentist just looks at me teeth.'

Three children had previously coped with simple treatment with their own dentist, but had been referred to this service for more invasive or extensive treatment. The majority of children had undergone treatment under either LA or DGA in the past. Without exception, this had caused some degree of anxiety to the child (see 'Anxiety History').

Anxiety history

The majority of children's anxiety seemed to originate from an unfavourable treatment experience in the past. This was most likely to have been associated with treatment under LA.

'She tried to remove the teeth on the right side which wasn't frozen. So you can understand what he was like. But that experience frightened him, and scared the hell out of me, to see him go through it.'

'Needles' were cited most commonly as the aspect of treatment which children feared most. However, there was no significant correlation between age and anxiety stimulus. Anxiety was related to previous treatment under DGA in two cases.

***** had a bad experience with gas when having her teeth out. She didn't like it all, and was just one of these kids that fought having the mask put on. Once she came round from the gas, she was hysterical, and that's frightened her from going to the dentist. And we've had a hell of a job just to get her to go to the dentist for a check-up after that.'*

One child's anxiety arose purely from tales of dental treatment related to her by her sister. The child herself had received no previous dental treatment. In another isolated case, a child had received an injection in hospital at an early age for the purpose of blood testing. The incident was not related to dental treatment but had created a general fear of needles.

Parental anxiety

A minority of parents stated that they experienced no feelings of dental anxiety themselves. However, most

described some feelings of dental anxiety, which could usually be attributed to a traumatic dental experience in the past.

'I had an abscess, and he gave me injections and pulled it, it was absolutely agony. I won't go... if something bad needs doing, I'll get it done but I won't go back again. Like me, he's not happy going to the dentist. My teeth are rotten, but I won't go to the dentist.'

A number of parents specifically mentioned that receiving dental treatment under DGA as a child had been a key causative factor in their own anxiety.

'I remember being three or four having to be sat on me mother's knee and there'd be a mask coming towards you, and emm, I particularly don't like going to the dentist now myself.' Several parents were aware that their own anxiety had influenced their children.

'I think a lot of the problem with children going to the dentist is that they hear so many people, adults and kids, saying "I hate the dentist" and they don't know why, but they just know it's something to be disliked.'

A proportion of parents mentioned that they undergo routine dental treatment under CS themselves. One parent said that she was so anxious that she could only receive dental treatment under DGA.

Patient/parental perceptions of CS

As mentioned earlier, there was some confusion as to exactly how anxiety would be controlled, in terms of the use of CS and DGA. Only four parents specifically stated that CS would be used. Some children struggled with the concept of CS.

'Is sedation when you get put to sleep?'

However, others had a good understanding of CS.

'Sedation is just where it relaxes you and you go to sleep if you want to go to sleep.'

Several parents were under the impression that their child had been referred for treatment under DGA. Perceptions of the service were generally based on information from the referring dentist, but also word of mouth, particularly in children.

'When he talked to his friends at school, a lot of them have said "I've been there, I've been there". And everybody was saying good things, so he felt it can't be that bad if they've been there.'

There was a general feeling that it was not ideal for children to receive dental treatment under DGA. Two parents made the point that DGA is a means to an end (achievement of oral health).

'I don't think it solves the problem, with my first daughter it didn't solve the problem with her fear of the dentist. She had the treatment done, but she has still has that fear.'

'The answer isn't to go to the hospital and get your teeth pulled

out. That isn't the answer at all. It doesn't get rid of his fear. It gets rid of the teeth that needed removing, he's not awake and he's not aware of what's happening, but it doesn't solve the problem.'

However, it was accepted that DGA could be used as a last resort, if all other attempts at treatment had failed. *'You don't obviously want to be knocking every kid out with general anaesthetic, it's not ideal by any means. Well if you've tried everything you've got in your armoury and it still hasn't worked for one reason or another, you don't really have any choice do you.'*

DGA was perceived to be less safe than CS.

'There's always a risk with a general anaesthetic. I don't think there's always such a risk with sedation. When somebody is sedated the sedation will work off. When you're using anaesthetic, there's induction agents, and sometimes, well I'd think more often than not, when they are under general anaesthetic, somebody else is doing the breathing and everything for them. I think that's a risk.'

TREATMENT

Was a separate assessment visit useful?

This question created a definite difference of opinion between subjects. A slim majority were in favour of a separate assessment visit. Those who were in favour liked the opportunity for explanation of procedures and discussion of anxiety management options. It also provided the chance for children to familiarise themselves with the practice and staff.

***** wouldn't have gone if she thought it was all going to be done there and then. She wanted to go and have a look and see what was going to happen.'*

Those who were against the concept of a separate assessment visit found it inconvenient in terms of time taken off work (parents), or school (children) or would just have preferred to have got the treatment over and done with. Where incorrect information was given regarding separate assessment and treatment visits, unnecessary anxiety was caused to the child involved.

'We went to the first appointment thinking she was getting it out there and then and she was petrified.'

Explanation and involvement

The involvement of parents, but particularly children, in discussion of treatment and anxiety management options was strongly felt to be a positive feature. Children generally liked to be treated as individuals and to be actively involved in the decision-making process.

'They tell you what's going to happen and they say if you don't feel comfortable with that happening you have other options.'

'I think involve him in the process, and give him the information he needs and let him decide if he wants it or

REFEREED PAPER

not. He's 11 years old, he knows what he wants and what he doesn't want. I think it's good to involve children from the start.'

What was the treatment under CS like?

Children generally reported feelings of comfort and relaxation during CS.

'I wasn't scared or anything, I just felt very comfortable.'
'I was awake but I was like I was flying if you can imagine that, I felt like I was above the ground, hovering.'

Some children found the experience of CS unpleasant.
'I didn't know who anyone was around us and I was all confused and like dazed I suppose. I was like all by myself and I was dead scared.'

Children who were classified as having 'failed' treatment (according to the definition mentioned previously) were no more likely to recall unpleasant aspects of treatment. On the contrary, these children often had pleasant memories of treatment. Amnesia was a strong feature in this study, as would be expected with the sedative agents used. The majority of children either had no recollection of treatment or a small amount of recall without any feelings of pain or distress.

'I can't really remember anything. I didn't know I had a needle. When they told me I'd had ten needles I didn't realise I'd had one.'

A small number of children recalled some unpleasant aspect of treatment, which had not caused significant distress.

'I felt something getting pulled and a snapping sound, and I hit the dentist, then I went back to sleep, I felt something, but it wasn't pain, I just felt the tooth getting pulled out.'

One child in the study recalled that she had undergone an unpleasant experience of treatment under CS, which had caused significant distress.

'I can remember everything that happened, in terms of needles and things like that... I knew what was happening and I was like getting panicky.'

Amnesia seemed to be highly selective, with children often remembering very specific details of their treatment.
'I was just laying down, and on the ceiling there was a big telly, and I was watching Harry Potter, and then I just fell asleep.'

Anterograde amnesia was described vividly by a number of children.

'I remember seeing the little tube in my hand. All I can remember is just seeing the tube in my hand and nothing else until like I stood up and I looked at my watch and it was like an hour later.'

Interpretation of what was happening also seems to have been altered, particularly with respect to the ECG electrodes that were placed on the children's wrists.

'[They were] putting clamps on my arms so my arms were attached to the chair.'

Were the parents present during treatment?

The presence of parents in surgery during treatment is normally dependent upon the preference of whichever dentist is operating at the time. Some dentists prefer parents to leave the surgery once the child is sedated, whereas others are happy to have an audience throughout the treatment. None of those parents who were asked to leave had any objections to this.

'I think maybe it was better I wasn't in the room, because he would respond differently to you than he perhaps would to me, so I think that's quite a valuable thing.'

Of those who were given a choice and stayed in the surgery, the majority found the experience unpleasant.

'I stayed in the room, and I wished I hadn't.'

The parents who chose to leave were all glad that they did.

'I think I was making him more nervous because of my nerves... I did leave. I was glad I did, because I don't think I could have watched.'

Parental feelings during treatment

A number of parents specifically stated that they felt anxious for their child during treatment. Of those parents who did feel anxious, the feelings of anxiety were often brought about by the thought of their child experiencing pain or discomfort.

'For me, it's like you just want to say "that's my kid that, stick a needle in me, if there's any pain I'll have it, don't give it to my child" you know... You want to take away what you think might be an unpleasant experience, and you'd sooner have it yourself every time.'

Sitting in the waiting room during treatment was a particularly difficult experience for some parents.

'...you're living it for them, aren't you...'

'Nothing happens between that time when you're in the room and you're waiting, it seems to take ages for somebody to come. If somebody just popped their head out and said "he's OK" it would have made me feel better. When they came out and said "everything's done", it seemed like ages.'

AFTER TREATMENT

Recovery

Children generally reported feeling 'strange' during the recovery phase, although no children described recovery from CS as unpleasant. One child experienced prolonged bleeding in recovery, (although hopefully not for as long as described), and found this quite distressing.

'I had to wait four hours because I couldn't stop bleeding, so it was horrible.'

Many parents were pleasantly surprised with the recovery of their child.

‘He bounced straight back. He was wide awake when we went to recovery, and he was anxious to get going. But he certainly wasn’t unsteady on his feet. He was raring to go.’ However, recovery was more prolonged in some cases. *‘**** took a long time to come round from it. She was very, very wobbly for ages.’*

One parent felt that their child had been discharged prematurely by recovery staff. On the other hand, a proportion of parents felt that the time spent in recovery was excessive.

Home

At home, most children remembered the feeling of having a numb mouth, but all recovered well. There were no reports of post-operative vomiting or headaches. Some remembered feelings of post-operative pain.

‘After I got home, I had a little bit of pain, but I fell asleep.’ *‘I just couldn’t talk because of the pain, because of the cold air hitting my mouth.’*

Two children experienced some minor post-operative bleeding at home.

THE FUTURE

Changes in attitude to future treatment

A proportion of children experienced a subjective reduction in their level of anxiety following treatment under CS.

‘She’s been a lot better since, she’s not scared of dentists. In fact, now when she does need an appointment, she makes it herself. She phones up and makes the appointment herself.’

However, only one child expressed a willingness to undergo future treatment without CS.

‘I’d rather go to my normal dentist because I’ve been there since I was born, since I started going to the dentist, so I’m used to my dentist.’

Most parents and children still felt it likely that CS would continue to be required for treatment in future, but that the child would be less anxious about having CS.

‘As and when the time comes when she needs an injection from the dentist that could be another matter.’

‘I think if he needed treatment I think he’d prefer to come back to you.’

‘[I’d feel] a lot happier, ’cos I know what’s going to happen.’

‘If she needed major treatment she understands now what’s going to happen.’

However, this was felt to be an acceptable situation. A proportion of children continued to be severely anxious of dental treatment and would not undergo treatment under CS in future if offered.

‘I’d rather have the general anaesthetic.’

‘I’m no further forward with dentists with him than I was before I went there.’

Changes in attitude to oral health

A disappointingly small number of children seemed to have improved their attitude to dental health and prevention of further disease. However, there were some successes.

‘I think it’s made him realise that he has got to look after his teeth, because they really did drum it into him. I don’t let him drink Coca-Cola or Pepsi or anything like that now, and I think that has made a big difference to him.’

‘[I’m] just looking after them more carefully I suppose.’

Focus group study conclusions

ANXIETY

The major cause of anxiety in most cases was a traumatic experience of treatment, or attempted treatment, under LA. Often, the administration of LA itself provoked anxiety, which suggests that children should be supported with CS before trying and failing with LA and behavioural techniques alone. Improved training of dental practitioners in reducing pain on LA administration may be beneficial.

Traumatic experiences involving DGA were less common. This may be a reflection of the relatively low numbers of DGAs being provided for dental treatment in the region in recent years. Of 25 children only two had undergone treatment under DGA in the past.

Anxiety was not always related to previous dental experiences. One child had become generally needle-phobic following a blood test in hospital. Another child had never had dental treatment, but her sister’s accounts of her own treatment had caused anxiety.

This study shed little light on any relationship between the age of the child and the cause or stimulus for their anxiety. A specific fear of ‘needles’ or a more general fear of ‘pain’ was common. According to previous research, signs of Separation Anxiety Disorder (SAD) may have been expected in some of the younger children involved in the study, particularly given that the children were placed in a stressful situation⁽¹⁴⁾. No obvious cases of separation anxiety or evidence of SAD were found in any of the children involved, although the author is not an expert in this condition. In addition, although very few parents remained in the surgery during treatment, most stayed until their child was sedated.

Parental anxiety has been identified in previous research

REFEREED PAPER

as a significant aetiological factor in the dental anxiety of children^(15,16). The findings of the present study agree. A direct cause and effect relationship between parental and child anxiety is yet to be proved, although the amount of circumstantial evidence is persuasive. Several parents admitted feeling that their own anxiety had affected their child's attitude to treatment.

The parents of this group of children, who were predominantly dentally anxious, were predominantly dentally anxious themselves. Taking steps to address parental anxiety and attitudes, as well as those of children, is required. Taking time to demonstrate to parents that pain and anxiety management techniques have advanced since their formative years benefits parents and children alike.

EXPECTATIONS

Expectations of the practice are based partly on information imparted to the patient by professionals and partly on word of mouth via friends and relatives. We have no influence on what the patient hears on the grapevine, but we can improve the way that information is given to them by referring practices and their own dentists.

Although both parents and children clearly understood their reason for referral to the practice, most commonly anxiety or the invasiveness of planned treatment, very few understood what to expect from the practice.

It was not explained to some participants that no treatment is generally carried out at the first visit, which is normally set aside for assessment, treatment planning and discussion only. This caused significant distress to one young patient, which was completely avoidable.

Of more concern was the apparent confusion with respect to the use of DGA. A proportion of parents were still under the impression that DGA would be used. Several children also mentioned that they were going to be asleep during treatment, although it is unreasonable to expect all children to grasp the finer points of CS and DGA.

Referring dentists do receive information packs from the practice, and open days have been held but poorly attended. All patients are sent an information sheet with their appointment slip. However, it would seem that the current system has its flaws, and communication between us, our patients and our referring dentists could be improved.

THE ASSESSMENT VISIT

Although some parents and children objected to making a separate assessment visit, most found it to be beneficial.

It gave the opportunity to acclimatise the child, and to discuss anxiety management options. Children appreciated being involved in the selection of treatment options, as it gave them a sense of control.

Selecting the most appropriate anxiety management option for an individual patient is crucial to the success of treatment. An assessment visit that included a discussion of anxiety management options was appreciated by most patients.

THE TREATMENT VISIT

The treatment visit was a tense time for parents and children. Anything that could be done to create a relaxed atmosphere was appreciated. Distraction was particularly important for children both before and during treatment. The DVD player in the treatment room seemed to be universally popular. However, the waiting room was felt to be a sterile environment.

Management of parents during treatment is often overlooked, because the focus is naturally on the child. However, it would seem that there may be some quite simple things that could be done to make their experience more bearable. The presence of parents in surgery during treatment is a contentious issue. Anxious parents are often keen to leave the surgery, and this is usually for the best. Less anxious parents will also often leave of their own accord, 'so as not to get in the way', or stay in the surgery and provide constructive support for the child. Difficulty can arise with anxious parents who insist on staying in the surgery. These parents require careful management. Indeed, it is not unheard of for these parents to be found sharing a recovery bed with their child – the child recovering from CS and the parent from a faint. Whatever the outcome, parents appreciate being involved and informed.

Although this study is far from being a comprehensive investigation of the amnesic effects of midazolam, it does suggest that it is unwise to rely on the amnesic properties of this drug when treating children. Although some children demonstrated classic anterograde amnesia, a proportion of children remembered very specific details of their treatment.

Success or failure of treatment under CS had little bearing on whether a child provided a positive or negative account of treatment. Whereas it may have been assumed that children who had failed treatment were likely to provide a negative account of their treatment, this was not found to be the case. The reason for this is likely to be twofold. Firstly, the amnesic effect of midazolam. Secondly, the definition of treatment failure used in this study, i.e. the need for the use of different sedative agents

from those originally planned to achieve cooperation, rather than failure to achieve cooperation outright.

THE POST-OPERATIVE PERIOD

Practice protocol dictates that any sedated patient must be 'street-fit' and able to walk unaided before discharge. In most cases, discharge occurred within a reasonable time. Some parents and children felt that discharge was unnecessarily delayed. In one case, a parent felt that discharge was premature. It is not possible to speculate on exactly why this was the case. Anecdotally, the last patient of the day tends to be discharged more speedily than the first. This is a well-known phenomenon, but is clearly unacceptable.

Post-operative pain was not a major issue but was experienced by some children. Analgesics are commonly prescribed for adults following surgical treatment but are not routinely prescribed for children under similar circumstances. This may be an area for further investigation. There were no reports of nausea, vomiting or headaches as described in previous studies into morbidity and DGA^(10, 11, 12).

Pharmacological anxiety management may be considered to be a compromise between cooperation and morbidity. At one extreme, DGA largely removes cooperation from the equation, but has been shown to create relatively high morbidity levels. At the other extreme, RA is associated with very little morbidity, but cooperation is by no means guaranteed. The ideal anxiety management method would strike an acceptable balance between morbidity and cooperation. A combination of inhalation and IV CS may achieve this balance to a greater extent than DGA or RA for many children.

PERCEPTIONS OF ANXIETY MANAGEMENT

CS was felt to have two advantages over DGA. First, CS was perceived to be safer than DGA. Second, treatment under CS at QAMC avoided the need for a visit to hospital, which was perceived to be more traumatic than treatment in a primary care setting. However, it was acknowledged that CS was not successful in all cases, and that DGA may be considered as a last resort, once all other options had been explored.

Logistics

Local access to specialist services continues to be an issue within the NHS. The majority of anxiety management services in the area are provided by QAMC and the

CDS. The CDS runs clinics in many major towns in the North East. However, these services are often stretched to the limit, and access may be impaired by waiting lists of several months. This may well explain the wide distribution of the practice referral base, up to thirty miles in this study.

Within the study group, opinion was divided on the subject of access to specialist services. Some parents were prepared to travel halfway across the country if required, whereas others were unhappy with a journey of five miles. Waiting times at the practice were not considered to be excessive. There is an urgent referral system in place for children with acute problems. This system seems to work effectively on the evidence of this study. Those children with acute problems were seen within one to two weeks. One child waited up to two months for an assessment appointment, but appeared to be asymptomatic during that time.

Attitude to future dental care

One of the aims of treatment at QAMC is to reduce anxiety towards future treatment. In this respect, QAMC seems to be achieving only limited success. The vast majority of children believed that they would continue to require treatment under CS in future. Ironically, the only change was that children would be less anxious about the actual process of CS in future, because they knew what to expect.

It was surprising that most children in this study did not seem to make the connection between preventive care and a reduced requirement for dental treatment. Even though these children were dentally anxious, they were doing very little to avoid the need for more dental treatment in future. Significant efforts are made to provide preventive advice as children pass through QAMC. However, priority is often given to completion of the operative treatment. Referring dentists remain the main source of ongoing preventive advice for most children.

Limitations of this study

Ideally, the views of more than 59 parents and children would have been obtained in this study. Fewer people were included in the study than was intended due to a combination of failed attendance and sound engineering. This was particularly true of the youngest age group, 6–9 years. Of the 25 children involved in discussions, only two

REFEREED PAPER

were from this age group. As a result, it was difficult to investigate age as a factor in patient anxiety and treatment experience.

Steps were taken to reduce bias and increase validity and rigor^(17, 18). This included peer-reviewed ethical approval; purposive sampling; adherence to a topic guide; four focus group facilitators with different backgrounds; independent verbatim transcription of study data; enough focus groups to cater for the variety of lived experiences; a systematic approach to analysis by two individuals in an attempt to ensure consistent capture of themes and a balance of experiences within those themes; attention to negative cases and systematic reporting of results consistent with all the identified themes.

By providing an overview of the lived experiences of parents and children who have received treatment at the practice, this study has achieved its main aim. It has also identified areas for service improvement. Work will progress to form a patient questionnaire, which will further investigate how we can better meet the needs of our patients. It is hoped that the establishment of a patient user group at QAMC will direct its future research agenda.

Reference list

1. QAMC. Queensway Anxiety Management Clinic Referral Protocols. www.anxietymanagement.co.uk. 2004.
2. Department of Health. A conscious decision: a review of the use of general anaesthesia and conscious sedation in primary dental care. Department of Health. 2000. London.
3. Averley PA, Lane I, Sykes J, et al. A RCT pilot study to test the effects of IV midazolam as a conscious sedation technique for anxious children requiring dental treatment; An alternative to general anaesthesia. *British Dental Journal* 2004;197:553–558.
4. Averley PA, Girdler NM, Bond S et al. A randomised controlled trial of paediatric conscious sedation for dental treatment using intravenous midazolam combined with nitrous oxide or nitrous oxide/sevoflurane. *Anaesthesia* 2004;59:844–852.
5. Averley PA. Sevoflurane and nitrous oxide inhalation conscious sedation for children having dental treatment. MPhil. 2002. Cardiff, University of Wales. Thesis/Dissertation.
6. Lahoud GY, Averley PA, Hanlon MR. Sevoflurane inhalation conscious sedation for children having dental treatment. *Anaesthesia* 2001;56:476–480.
7. Lahoud GY, Averley PA. Comparison of sevoflurane and nitrous oxide mixture with nitrous oxide alone for inhalation conscious sedation in children having dental treatment: a randomised controlled trial. *Anaesthesia* 2002;57:446–450.
8. Veerkamp JS, Gruythuysen RJ, Hoogstraten J, van Amerongen WE. Anxiety reduction with nitrous oxide: a permanent solution? *ASDC J Dent Child* 1995;62:44–48.
9. Veerkamp JS, Gruythuysen RJ, Hoogstraten J, van Amerongen WE. Dental treatment of fearful children using nitrous oxide. Part 4: Anxiety after two years. *ASDC J Dent Child* 1993;60:372–376.
10. Holt RD, Chidiac RH, Rule DC. Dental treatment for children under general anaesthesia in day care facilities at a London dental hospital. *British Dental Journal* 1991;170:262–266.
11. Bridgman CM, Ashby D, Holloway PJ. An investigation of the effects on children of tooth extraction under general anaesthesia in general dental practice. *British Dental Journal* 1999;186:245–247.
12. Enever GR, Sheehan JK, Nunn JH. A comparison of post-operative morbidity following out-patient dental care under general anaesthesia in paediatric dental patients with and without disabilities. *International Journal of Paediatric Dentistry* 2000;10:120–125.
13. Byrne M. Data analysis strategies for qualitative research. *AORN Journal* 2005;74:904–905.
14. Jellinek M, Kearns M. Separation anxiety. *Paediatric Review* 1995;16:57–61.
15. Milgrom P, Beirne OR, Fiset L, et al. The safety and efficacy of outpatient midazolam intravenous sedation for oral surgery with and without fentanyl. *Anesthesia Progress* 1993;40:57–62.
16. Peretz B, Nazarian Y, Bimstein E. Dental anxiety in a students' paediatric dental clinic: children, parents and children. *International Journal of Paediatric Dentistry* 2004;14:192–198.
17. Barbour RS. Checklist for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal* 2001;322:1115–1117.
18. Mays N, Pope C. Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal* 2000;320:50–52. ■