An audit of perioperative management of autistic children

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Summary

Background: Autistic children are very difficult to manage in the hospital setting because they react badly to any change in routine.

Methods: We have developed a unique management program for autistic children admitted for medical and surgical procedures requiring a general anaesthetic. Details of each patient managed according to this program have been prospectively entered into an Autistic Register.

Results: An audit of this database shows that we have administered anaesthesia on 87 occasions for 59 autistic children over 4 years.

Conclusions: There is great variation in the severity of autism and hospital needs of these children. The focus is on early communication with the patient’s families, flexibility to individualize the admission process and anaesthetic plan with admission and early discharge on the day of surgery whenever possible. Oral midazolam is an effective premedication for the milder cases and oral ketamine is the most reliable for moderate and severe cases. Comparison of oral midazolam and ketamine shows no significant different postoperative recovery and hospital discharge times. Routine intravenous fluids and antiemesis prophylaxis with removal of the i.v. cannula before return to the ward are also seen as important steps to decrease stress and smooth the postoperative phase. This program has also successfully been extended to the management of problem children due to other causes.

Keywords: anaesthesia: children, autism; premedication: ketamine, midazolam

Introduction

Autism is found in 2–5 per 10 000 of the population, affecting boys more commonly than girls in a ratio of 4 : 1 or 5 : 1 with equal distribution in all socioeconomic strata (1). A positive diagnosis of autism requires the presence of four criteria, all must manifest before 3 years of age (The Autism Association of South Australia Incorporated). The four criteria are (i) qualitative impairments in social interactions, (ii) impairment in verbal and nonverbal
communication, (iii) a restricted range of interests and (iv) resistance to change. Characteristically, these children exhibit restrictive, repetitive and stereotyped patterns of behaviour, activities, interests and hyperactivity. Any change in their routine can be very distressing and attendance at a hospital represents a major change which may precipitate panic attacks or temper tantrums making their management extremely difficult. They commonly refuse to cooperate, will not tolerate physical handling, frequently refuse oral medication and may be quite destructive with occasional self mutilating behaviour. This is very distressing for the parents, other patients and staff and disrupts ward routines.

Autistic children appear with significant frequency for anaesthesia and are a neglected group of children with well defined needs that have not been adequately considered in the anaesthetic literature. We previously reported on the management of five cases documenting our early experience with a program for the anaesthetic management of autistic children and reviewed the relevant literature (2). Prior to our report, there were no publications on the topic of anaesthesia management strategies for autistic children. We have since become aware of a paper describing a surgical approach to perioperative management of autistic children undergoing ENT procedures (3).

This report is a prospective audit of our experience of a total of 59 autistic children requiring anaesthesia on 87 occasions for a variety of surgical and medical procedures.

**Methods**

Identification of autistic patients is on admission to hospital or with advanced notification through general staff awareness or the Autism Association of South Australian Inc. advising their members to contact us. In addition, known autistic children are entered into our Paediatric Register of Anaesthetic Problems (PaedRAP) (4). PaedRAP is a database that provides an anaesthesia alert system identifying patients with recurrent anaesthetic problems and their management. When a patient from the PaedRAP is booked for a procedure or investigation requiring an anaesthetic, the computerized theatre booking system will automatically generate an alert for the anaesthesia department so that we can contact the parents and plan the admission and optimize management (2).

A telephone interview with the parents is conducted by an anaesthetist (usually J.H.V.) when the child is booked for a procedure and an Autistic Anaesthetic Questionnaire is completed (Figure 1). This questionnaire elicits information specifically to assist in the admission and anaesthetic management. The *Patient Details* section includes the patient name, date of birth, unit record number, parents’ names and telephone number, the intended procedure and date, surgeon’s name, admission plans (day surgery, day of surgery admission or inpatient). A *Checklist* section is used to elicit specific responses regarding the nature and the severity of the child’s autistic disease. This includes autistic severity; special features; developmental level; likes/fetishes; dislikes/phobias for food, drink, activities and objects; special needs; medication; general health; social circumstances (home and transport) and any other relevant information the parents consider important.

A boxed section sets out *Management Guidelines* to help formulate the anaesthetic plan and guide anaesthetists to implement a standardized approach. Based on this information and the advice of the parents, an anaesthesia plan is formulated, discussed with the parents and written on the Autistic Anaesthetic Questionnaire. This *Anaesthesia Plan* section includes special admission needs, premedication, type of induction and postoperative strategies. The completed form is then handed to the Nursing Unit Head of the Day Ward who contacts the parents a few days before the admission for more detailed planning and instructions about the admission process which is streamlined to minimize any waiting on arrival at the hospital.

Virtually all elective theatre admissions at our hospital are managed through the Day Unit on day of surgery admission basis. For autistic patients, we aim for direct admission to the Day Unit and, in many cases, more severe cases bypass the Day Unit to a special quiet room adjacent to theatre. Because most of the admission details have been processed in advance, autistic patients are admitted a short time (approximately 45 min) before the theatre list commences and scheduled to be first on the operating list. The child’s specific likes and dislikes are noted in order to either make use of particular distractions or to avoid activities and situations known to cause
distress. For example, a vacuum cleaner may be a source of wonder for some autistic children but may be an object that will always trigger a massive panic attack in others. If possible, these patients are returned to their homes and normal routines as soon as practical. When postoperative overnight admission is indicated, we attempt to place the patient and family in a side room of a ward for ease of management and to decrease potential disruption to the rest of the ward. We encourage the parents to contact us a few days after discharge for feedback of their hospital experience.

Where premedication is indicated, oral midazolam (0.5 mg·kg\(^{-1}\)) (5) for mild cases or ketamine
(7 mg·kg\(^{-1}\)) (6) for moderate and severe autistics have been the preferred drugs given 30 min before theatre. I.m. ketamine (5 mg·kg\(^{-1}\)) is occasionally administered when the oral premedication is refused. The chosen oral drug is mixed in a favourite clear fluid according to the information on the Autistic Anaesthetic Questionnaire checklist. This usually is lemonade, a proprietary cola drink or apple juice. A topical anaesthesia cream is applied if an i.v. induction is indicated. Depending on the degree of sedation and cooperation achieved, a gaseous or i.v. induction of anaesthesia is used and, on one occasion, rectal thiopentone (35 mg·kg\(^{-1}\)) was successfully used. Sevoflurane is only used for induction before changing to either halothane or isoflurane as the maintenance volatile agent. Whenever possible, these patients are discharged early and returned home on the day of surgery so appropriate anaesthetic agents are used to achieve this goal. I.v. fluids and tropisetron (0.1 mg·kg\(^{-1}\) up to a maximum of 2 mg) (7) is administered for antiemesis prophylaxis as the i.v. cannula is removed in the recovery area before return to the ward for a smooth postoperative course. Benzodiazepines are not administered to counter dysphoric reactions of ketamine. All patients having a surgical procedure are given oral paracetamol 20 mg·kg\(^{-1}\) approximately 60 min before theatre. If this is refused, rectal paracetamol 40 mg·kg\(^{-1}\) is administered after induction of anaesthesia. Analgesia is supplemented with an intraoperative opioid or local anaesthesia block or infiltration as indicated.

Reaction to induction is recorded according to the anaesthetist’s assessment and entered in a tick box in the anaesthesia record as cooperative or uncooperative. A photocopy of the anaesthetic record is filed in the Autistic Register folder which is kept in the anaesthetic department. In addition, comments made in the PaedRAP entry are assessed to ascertain any other issues. The case notes are also examined for details of postoperative events and discharge times from the Recovery Unit and the Day Unit if managed as a day case. Postoperative vomiting (POV) is recorded as a single event irrespective of the frequency or the size of the vomitus.

Table 1

<table>
<thead>
<tr>
<th>Procedure</th>
<th>n</th>
<th>Numbers admitted</th>
<th>Emergency procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental</td>
<td>31</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td>Ear nose and throat surgery</td>
<td>19</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>General surgery</td>
<td>8</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Orthopaedic surgery</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Ophthalmology</td>
<td>3</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Gastrointestinal endoscopies</td>
<td>4</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Cardiac catheter</td>
<td>2</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>Magnetic resonance imaging</td>
<td>6</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Computerized axial tomography</td>
<td>9</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>Brainstem evoked response</td>
<td>2</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>16</td>
<td>4</td>
</tr>
</tbody>
</table>

Results

Analysis of our database shows that 59 autistic patients have been entered into this program for a total of 87 procedures requiring anaesthesia with 21 patients requiring two or three procedures. The ages ranged from 26 months to 17 years with the average age being 7 years. The majority required dental treatment and a smaller number were for ear nose and throat and general surgical conditions (Table 1). A large number (n = 23) were anaesthetized for investigations (CT, MRI, BSER, endoscopy, cardiac catheter). Most patients (n = 71) were treated as day cases and 16, for nonanaesthetic reasons, were admitted for overnight postoperative management (Table 1). Three patients presented for emergency care (one facial laceration, one fractured arm, one dental trauma).

Twelve patients received no sedative medication because they were assessed at the time as not requiring sedation (Table 2) and four were uncooper-
erative or required restraint for induction of anaesthesia, suggesting that they would have benefited from sedation. Six patients rejected or refused outright the oral agent after one sip and, of these, five needed restraint. Some parents have developed their own strategies for administering drugs which we utilize to give the premedication drugs. The incidence of rejection has become rare with their help and the use of administering midazolam or ketamine in a flavoured drink, e.g. no refusals in the last 24 patients anaesthetized in 2000. Of the 68 patients who consumed an oral sedative, 30 received midazolam, 29 ketamine and nine received a combination of oral ketamine and midazolam syrup due to the preference of one anaesthetist. Three received additional i.m. ketamine. The effect of premedication at induction, on time spent in the recovery area (all 87 patients) and time to discharge (for day cases) are shown in Table 2. The group who received no sedative (Nil or Refused) had a significantly ($P < 0.05$) shorter stay in the recovery area compared with the midazolam and ketamine groups. There was no statistical difference in the discharge time for 71 day cases from hospital between all the groups. The ketamine/midazolam was not subjected to statistical analysis due the small number of patients.

Table 2
Effects of preoperative sedative drugs and anaesthesia on autistic children undergoing 87 procedures requiring general anaesthesia

<table>
<thead>
<tr>
<th>n</th>
<th>Uncooperative</th>
<th>Tropisetron</th>
<th>POV</th>
<th>Time (min) in recovery</th>
<th>Time (min) to discharge from hospital (excludes recovery time)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No premedication or refused premedication</td>
<td>18</td>
<td>9</td>
<td>11</td>
<td>5</td>
<td>32 (20–70) SD 15.5</td>
</tr>
<tr>
<td>Oral midazolam</td>
<td>30</td>
<td>9</td>
<td>13</td>
<td>2</td>
<td>42 (20–60) SD 13.6</td>
</tr>
<tr>
<td>Oral ketamine</td>
<td>29</td>
<td>4</td>
<td>20</td>
<td>10</td>
<td>42 (30–70) SD 13.8</td>
</tr>
<tr>
<td>Oral ketamine/midazolam</td>
<td>9</td>
<td>2</td>
<td>8</td>
<td>4</td>
<td>47 (30–100) SD N/A</td>
</tr>
</tbody>
</table>

The group who received no sedative (Nil or Refused) had a significantly ($P < 0.05$) shorter stay in the recovery area compared with the midazolam and ketamine groups. There was no statistical difference in the discharge time for 71 day cases from hospital between all the groups. The ketamine/midazolam was not subjected to statistical analysis due the small number of patients.

Discussion

This audit shows that good results are possible with a planned, coordinated and flexible programme for the perioperative management of autistic children. Prior to the introduction of our program, autistic children were managed on an ad hoc basis by up to 20 different anaesthetists in a variety of ward settings with some very unsatisfactory scenes and outcomes. Restraint for induction of anaesthesia was invariably necessary and, on occasion, as many as three adults were required as these patients exhibit extraordinary strength. Parents regarded a hospital attendance as a major ordeal which our program has now effectively turned into a manageable experience for them.
The requirement of each child and family is different and there is a wide variation in premedication requirements depending on the situation and the individual anaesthetist’s assessment. Careful assessment, based on the severity of the child’s autism and the parent’s advice, is therefore needed to judge what drug to prescribe. A large proportion (50%) of those assessed as not requiring premedication or refusing medication were uncooperative, suggesting that premedication is desirable in most of these children. The group who refused premedication is a self selected group of severe cases anyway. Lack of patient cooperation at induction has become less of a problem over the 4 years this audit has been running as we have developed a greater understanding of the needs and principles in managing these children (i.e. 50% lack of cooperation in 1997, 42% in 1998, 30% in 1999 and 17% for the 24 patients managed in the first 10 months of 2000).

The most important principle is to be notified in advance that an autistic child has been scheduled for a procedure requiring an anaesthetic. Once notified, we immediately contact the parents to plan the admission of these children. As our interest in providing a special program has become more widely known, the frequency of advance notification has increased. However, some patients still arrive unheralded on elective lists or for emergency treatment. These patients are then assessed and managed according to the exigencies of the situation and we try to apply as many of the principles that we would use for the planned cases.

Our experience has led us to prescribe oral midazolam for mild cases of autism and ketamine for moderate and severe cases. The 18 patients who did not receive a premedication had significantly shorter recovery times compared with those who had been given midazolam or ketamine (Table 2). However, there was no statistically difference in the discharge times from hospital in the 71 day cases, regardless if they had received a premedication or not. Ketamine has been the most reliable oral agent with minimal adverse effects and we recommend its use more frequently, even for milder cases. Administered orally, it is very effective with 16% bioavailability compared with 93% when given i.m. or i.v. (8). Other studies have demonstrated minimal side-effects and emergence phenomena are said to be less frequent in children (9). We gave the first few children i.v. midazolam (2) to avoid emergence delirium but have not continued the practice and have not seen any emergence problems in hospital or from feedback from parents confirming the results of others (6,9). We do, however, acknowledge that this is difficult to assess in autistic children. Emergence agitation, which could be ascribed to sevoflurane, was not seen because sevoflurane was only used for induction and halothane or isoflurane were used for maintenance of anaesthesia.

I.v. drug preparations have a marked bitter taste, which has to be masked in syrup that will be acceptable to the patient. We have resorted to administering ketamine mixed in a small volume of clear fluid of the child’s choice and the parents often simultaneously also share in the drink (but without the drug agent!). This strategy works very well with most of the refusals evident in the early part of the series. The most common drink has been cola flavoured drink (6). Restraint for induction of anaesthesia is still occasionally required and is not necessarily seen as a failure because most parents expect noncooperation. Our aim is to avoid restraint if possible but to discuss in advance the possibility of noncooperation with the parents. Lack of cooperation and restraint is now uncommon as our management has become more refined.

It is important to realize that autistic children react badly to any change in their routine and therefore waking up in strange surroundings can be very alarming for them. Involving the parents early in the recovery phase and removal of i.v. drips and cannulae is important in our regimen. For these reasons, we routinely administer i.v. fluids and antiemetics to allow early removal of the i.v. cannula before the child becomes distressed by its presence. Management as ambulatory cases with early discharge is also aimed for in order to return patients to their normal environment at the earliest opportunity. If they need overnight admission, we attempt to provide a sideroom in the ward to minimize exposure to other people. Postoperative management, especially pain therapy, is as for other patients and has not proven to be a problem. Where we are aware of multiple pending procedures, we attempt to coordinate these to be performed during a single anaesthetic.

Some patients have been anaesthetized on more than one occasion and the Autistic Register has
allowed us to identify and modify our management based on previous experiences. For example, early in our program, a 7-year-old boy was referred from another hospital because he was unmanageable. He was a known severe autistic with minimal language, only recently toilet trained, and usually would refuse oral medication. He had had seven previous general anaesthetics, with the last requiring four people to hold him down with marked behaviour deterioration postoperatively. For the first anaesthetic at our hospital, he was given oral midazolam which he spat out requiring i.m. ketamine. On the second occasion, the procedure was myringotomy and insertion of grommets. A preadmission telephone call allowed arrangements to be made for direct admission to the ‘quiet room’. Oral ketamine in clear apple juice produced moderate sedation allowing a smooth calm inhalation induction with sevoflurane, with the mother applying the facemask. Paracetamol 40 mg⋅kg\(^{-1}\) was inserted rectally soon after induction. Postoperatively, in the Day Unit, he was cooperative and drank the rest of the apple juice and was discharged approximately 1 h later. The parents reported that he returned to his normal behaviour soon after return to their home with no discernible effects.

The nature of this audit does not provide controlled research conditions and the numbers are relatively small. In addition, with the exception of the postoperative times, there was no statistical analysis. Nevertheless, this is a unique series providing some insight into a group of patients with special needs that has not been previously considered in the anaesthetic literature.

Anaesthetists and nursing staff feel very comfortable and enthusiastic with this program because it has proven to be very effective with strong positive comments from parents even if restraint had been used for induction. The ability to plan in advance and to have a flexible admission system with minimal preoperative waiting and a special quiet room available has also been mentioned by Seid et al. (3). The quiet room has proven so successful that we have incorporated this concept into the design for the new day surgery unit which will manage over 95% of all elective theatre cases on a day of surgery admission basis.

The nursing care for autistic children in the Day Unit focuses on a true partnership in care and the needs of the family and child. We acknowledge the wealth of knowledge which the parents have of the disease and their child’s individual needs. This allows families to have maximum control in an environment which can be overwhelming and stressful. One mother’s experience indicates the relief that parents state with our process. She expressed her thanks in a letter and she felt that our programme demonstrated an understanding and an assurance that we knew more than she did about her child’s management, and that she and her husband could relax and concentrate on being parents rather than feel they had to be the autistic experts.

Another parent’s unsolicited letter graphically illustrates some of the features of autism that our program has addressed. ‘I very much appreciated John’s [not his real name] special needs being taken into account and the extra trouble you all took to reduce his stress. I know that providing as little waiting time as possible and a quiet, private waiting room, with toys to distract John was a huge success. John remained calm and happy during his waiting time. Autistic children respond very well to reducing the noise, movement and light (reducing the amount of distressing sensory input – particularly in unfamiliar surroundings which will already be upsetting for them). New places and a break from their routines is usually enough to upset a lot of autistic children. John in particular has had bad associations with doctors and hospitals and by creating an environment that didn’t look like a hospital waiting hall, or doctor’s surgery, he could distract himself with his own play. It is a wonderful idea to get them sedated in this private room and keep the gurney (trolley) outside, so that they don’t become frightened and have tantrums (or add more bad experiences to their list of fears). I also appreciated being able to hold John and take him to the induction room to administer the gas’.

In addition, we have also successfully used this program for difficult children with a range of other diagnoses, e.g. attention deficit hyperactivity disorder, intellectual retardation, behavioural problems or children with extreme anxiety states.
References


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