

Patient experiences and psychological consequences of AAGA



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HEADLINE

7.1 AAGA encompasses a wide range of experiences (from the trivial to something akin to feelings of torture) and a wide range of psychological consequences (from none to life-changing). In NAP5 recall was, in about half the cases, expressed in a neutral way, focused on a few isolated aspects of the experience. In about half of cases there was distress at the time of the experience; distress was particularly likely with sensations of paralysis or pain, but could also occur when only isolated sounds or tactile sensations were experienced. Distress during AAGA was strongly associated with subsequent psychological sequelae. Understanding what was happening, or what had happened, seemed to mitigate immediate and longer-term psychological distress. Active early support may offer the best prospect of mitigating the impact of AAGA, and a structured pathway to achieve this is proposed.

BACKGROUND

- 7.2 At its worst, accidental awareness during general anaesthesia (AAGA) can be terrifying. Common experiences include: hearing voices or noise of equipment; trying to move to alert staff and being unable to; feeling anxious that something has gone wrong with the operation and powerless to do anything, or feeling frightened that things are going to get worse (Aaen & Møller 2010; Moerman et al., 1993; Sebel et al., 2004; Ghoneim et al., 2009, Samuelsson et al., 2007; Schwender et al., 1998).
- 7.3 In Samuelsson et al.'s (2007) study of 46 AAGA cases, auditory (70% of AAGA reports) and tactile (72%) were the most common sensory experiences. Forty six percent of patients experienced pain during AAGA and 65% experienced an acute emotional reaction including helplessness (57%), fear (54%) or panic (43%). Thirty-seven (80%) of the 46 patients felt they understood what was happening, and most (67%) tried to communicate.
- 7.4 In Sebel et al.'s (2004) study of 25 AAGA cases, around half included auditory perceptions and paralysis, 32% tracheal intubation, and 28% pain. Helplessness, fear and panic were again prevalent (36% of cases), with patients thinking "I'm going to die" or "...it is one of the worst scares I've had...". Visual perceptions, for example seeing silhouettes, are also reported (Sandin et al 2000; Schwender et al., 2008). Specific auditory memories usually involve salient information, for example: "It's a boy" (Samuelsson et al., 2007); "how can a man be so fat" (Schwender et al., 1998; "This woman is lost anyhow" (Schwender et al., 1998). Commonly, patients find the experience of paralysis particularly disturbing and traumatic, may not appreciate its reversible nature, and have catastrophic appraisals about its cause and meaning.
- 7.5 Concern about AAGA is an important contributor to pre-operative anxiety (McCleane & Cooper, 1990).

As it is not discussed in routine consent procedures (Chapter 21, Consent), lack of understanding may cause patients to interpret an experience of awareness catastrophically, thinking that they must be dying. There are also patients who experience AAGA but are relatively unconcerned by it (Sebel et al., 2004).

- 7.6 In a large analysis of patient satisfaction, Myles et al. (2000) reported that although overall patient satisfaction with anaesthesia is very high (97%), dissatisfaction was most strongly associated with an experience of intra-operative awareness (odds ratio 54). Even moderate to severe post-operative pain resulted in much lower odds ratios for dissatisfaction of ~4.
- 7.7 As well as dissatisfaction, AAGA can lead to serious psychological disorder. Distress at the time of AAGA appears to be an important risk factor for long-term sequelae (Samuelsson et al., 2007).
- 7.8 It is not yet known if early response to, and sensitive handling of, AAGA reports at the time they are made by the patient can reduce the risk of long-term sequelae, although it seems intuitive that this would be beneficial.
- 7.9 Management of the response to reports of AAGA is complicated by the fact that patients do not always report awareness to medical staff. In Samuelsson et al.'s (2007) study, 85% of patients reported their AAGA experience to someone but only half to hospital staff. One-third of patients reporting their experiences to staff or family received sceptical responses. It is not well understood what triggers patients to report or withhold a report of AAGA, or how they decide to whom to report. Delayed emergence of AAGA memories may determine who receives the report, as patients may have a fear of medical staff resulting from the experience – both discussed below.
- 7.10 Patients may interpret experiences during emergence or conscious sedation as AAGA. Samuelsson et al. (2007) interviewed more than 2000 patients of whom 3.7% reported previous AAGA, but 42% of these were excluded as either having had surgery performed under regional anaesthesia or having reports not consistent with AAGA. Of patients in the ASA Awareness Registry whose medical notes were examined, one-third had not received general anaesthesia (Kent et al., 2013). Mashour et al. (2009) reported that patients who had received anaesthetic interventions that did not include general anaesthesia reported AAGA with the same incidence as those who had received general anaesthesia.

Anaesthesia and memory

- 7.11 NAP5 is a study of *patient reports* of AAGA. The patient must recall AAGA to be able to report it. Because not all episodes of conscious awareness during intended general anaesthesia are subsequently recalled, it is inevitable that they will not all be reported. Studies with volunteers show that post-sedation recall is prevented by doses of anaesthetic agents low enough to permit conversation, voluntary responses and short-term memory functions. In other words, someone who is sedated might be able to recognise a word that was presented a few minutes earlier, but be unable to recall it later when fully conscious again (Andrade et al., 1994; Andrade, 1996). Similar findings have been reported in patients receiving sedation (Andrade et al., 2001).
- 7.12 It is not known how long a period of awareness must last in order to produce a memory that can be recalled on recovery, but these sedation studies illustrate the fact that memory formation is a complex process that does not happen instantly and completely the moment someone becomes conscious. Studies using the isolated forearm technique during general anaesthesia show that patients can be sufficiently conscious to respond to a complex conditional command intra-operatively but have no explicit post-operative memory of such events (Russell, 1989; Russell & Wang, 1997; Zand et al., 2014).
- 7.13 Questioning of patients about their possible experiences during anaesthesia is therefore a test of memory. Prospective studies of the incidence of AAGA use versions of the Brice interview (Brice et al., 1970) post-operatively for this purpose. There is good agreement that in studies using this methodology the incidence is between 1–2 cases per 1000 general anaesthetics, an estimate that has remained stable over more than a decade (Sandin et al., 2000; Wennervirta et al., 2002; Myles et al., 2004; Sebel et al., 2004; Avidan et al., 2008; Avidan et al., 2011).
- 7.14 However, estimates still vary considerably. Errando (2008) used repeated structured interviews and reported an incidence of 1% (1:100) of patients 'stating at interview or spontaneously reporting awareness' whereas Mashour et al., (2013) found an incidence of only 0.02% (1:6,279) when patients were asked generally, one day after surgery, if they had had any problems with the anaesthetic. Pollard et al. (2007) found an even lower incidence of 0.0068% (1:14,705) using a modified Brice questionnaire as part of a quality control program.

- 7.15 A critique of the Brice interview is offered in Chapter 5 (Methods), but it is clear that the role of memory is important to any interpretation of the data.
- 7.16 Recall of a period of awareness, whether spontaneously reported or elicited through questioning, is an example of *explicit or declarative memory*. The person has an experience of remembering something and can articulate the content of their memory. People are generally much better at recalling meaningful or well-organised material (Bransford & Johnson, 1972). The realisation of what is happening during AAGA may help the patient to form a memory that is recalled in its entirety rather than as a series of disjointed events or sensations. On the other hand, lack of comprehension of what is happening may lead to greater distress and formation of a *trauma memory*.
- 7.17 *Trauma memory* is a type of explicit memory with some special characteristics. Normally, memories are stripped of much of their sensory detail as they are encoded, so it is the general gist of events and information that is recalled. Very strong levels of fear and distress can alter this encoding process, leaving memories that are rich in sensory detail and hard to control (Brewin, 2011). Recall of these trauma memories is distressing because it feels like reliving the traumatic event, rather than simply remembering it. AAGA might be expected to lead to rich sensory descriptions from patients who were distressed during their experience.
- 7.18 *Implicit memory* is very different. This is a memory that is not accompanied by an experience of remembering, but can be revealed by changes in mood or behaviour. It results from 'priming', which is temporary activation of existing representations in memory. On tasks that notionally involve guessing, people's responses are biased towards items they have recently seen or heard because representations of those items remain active in memory. Patients who were played words like 'tractor' during general anaesthesia were biased towards responding with those words when asked to say the first word that comes to mind beginning with 'tra-' (Deeprise et al., 2004), even when bispectral index remained <60 during anaesthesia and they could not explicitly recall hearing 'tractor' during surgery (Deeprise et al., 2005). As these findings show, there is evidence for implicit memory after general anaesthesia, but it is unknown if this has any adverse impact (Deeprise & Andrade, 2006; Andrade & Deeprise, 2007).
- 7.19 Memory recall is a process of reconstructing rather than replaying a past event. There is therefore a risk of memories becoming distorted and it is a challenge for anaesthetists to know whether a report of AAGA represents a true recollection or a false memory (Pryor & Root, 2013; Pryor & Hemmings, 2013). False memories can be created by inserting false information into the reconstruction process or by encouraging people to generate that information themselves. In a classic study illustrating how people are susceptible to leading questions, participants watched a film of a car crash. Those who were then asked how fast the cars were going when they *smashed* into each other gave higher estimates of speed than those asked how fast the cars were travelling when they *hit* each other, and recalled, incorrectly, that they had seen broken glass at the crash scene (Loftus & Palmer, 1974). Children who had never been to hospital but were repeatedly encouraged to answer questions about a hospital visit later believed it had happened (Principe et al., 2006), and adults shown fabricated photos of themselves enjoying a hot-air balloon ride as children later 'remembered' the event even though it had never happened (Wade et al., 2002).
- 7.20 These examples of false memories are alike in that people are encouraged to reconstruct an event that is plausible and about which they have been offered false information. Spontaneous reports of AAGA are unlikely to be false memories, because patients are not given the detailed sensory information of anaesthetic and surgical procedures that they would need to construct a false account that felt like a genuine memory.
- 7.21 It is unknown, however, whether Brice interviewing ever induces false memories (discussed in Chapter 5, Methods).
- 7.22 *Source memory* refers to our ability to recall where, when or in what format we did something or learned something, i.e. the context in which the learning occurred. Source memory often fails, so we might remember a witty remark but not who said it or when we heard it. An episode of awareness during an otherwise effective general anaesthetic cuts off the memory of AAGA from its sources, so the patient might recall intra-operative events but not be able to place when they occurred. The difficulty in placing a memory is likely to be compounded if a patient does not understand what is happening during AAGA. In a compelling personal account of AAGA, Aaen vividly describes how she forgot that she was having a Caesarean section and thought instead that she was being raped. She only recalled her experience gradually in the months that followed (Aaen & Møller, 2010).

- 7.23 Without source memory, it is conceivable that some patients might interpret AAGA as a memory of a dream rather than a real event, but there is little evidence that this is the case. Although recall of peri-operative dreaming is common (6% in Sebel et al., 2004; 22% in Leslie et al., 2007; 50% in Errando et al., 2008), it does not seem to be related to depth of anaesthesia or intra-operative events (Leslie et al., 2007). In contrast to most reports of AAGA, peri-operative dreams tend to have pleasant content (Errando et al., 2008; Leslie et al., 2007) and to be reported close to emergence from anaesthesia. Leslie et al (2007) therefore argued that post-operative recall of dreams reflects dreaming during recovery rather than misinterpreted AAGA.
- 7.24 Memories of AAGA can emerge gradually. In a review of 271 reports of AAGA, 49% were identified on the day of surgery, but 37% were not identified until more than a week after surgery (Ghoneim et al., 2009). In Sandin et al.'s (2000) study using Brice interviewing, only six cases of AAGA were identified during the interview in the immediate post-anaesthesia care unit; seven more emerged at the second interview 1–3 days after surgery, and a further five at the last interview 7–14 days after surgery. Similar findings are reported in children (Davidson et al., 2005). It appears that, even if they experience AAGA, patients may not develop a

clear memory of this until some time after they have left hospital. Reports such as Aaen's indicate that recall of AAGA may even be delayed for months.

- 7.25 Gradual emergence, or spontaneous recovery of memories, is not unique to AAGA (Sara, 2000). The literature on 'hypermnesia' explains how memories can be overwritten by later events and retrieval is impaired until those later memories fade or become less salient (Wheeler, 1995). In the case of AAGA, it is important to remember that the patient regains consciousness at least twice – at least once during anaesthesia and then again on recovery. Recovery may initially be remembered better, because it is more comprehensible. When that memory fades, it becomes easier to retrieve the AAGA memory. Repeated questioning may aid this process (e.g. as in Brice questioning – see Kelley & Nairne, 2003).
- 7.26 There is also a theory that memories of very traumatic events (e.g. childhood sexual abuse) can be repressed, to be uncovered much later, but this hypothesis is very controversial (Loftus, 1993; Patihis et al., 2013) and does not explain the finding that delayed recall of AAGA often involves a neutral recollection of events (Sandin et al., 2000).
- 7.27 The relationship of memory and AAGA (or no AAGA) is represented by Figure 7.1.

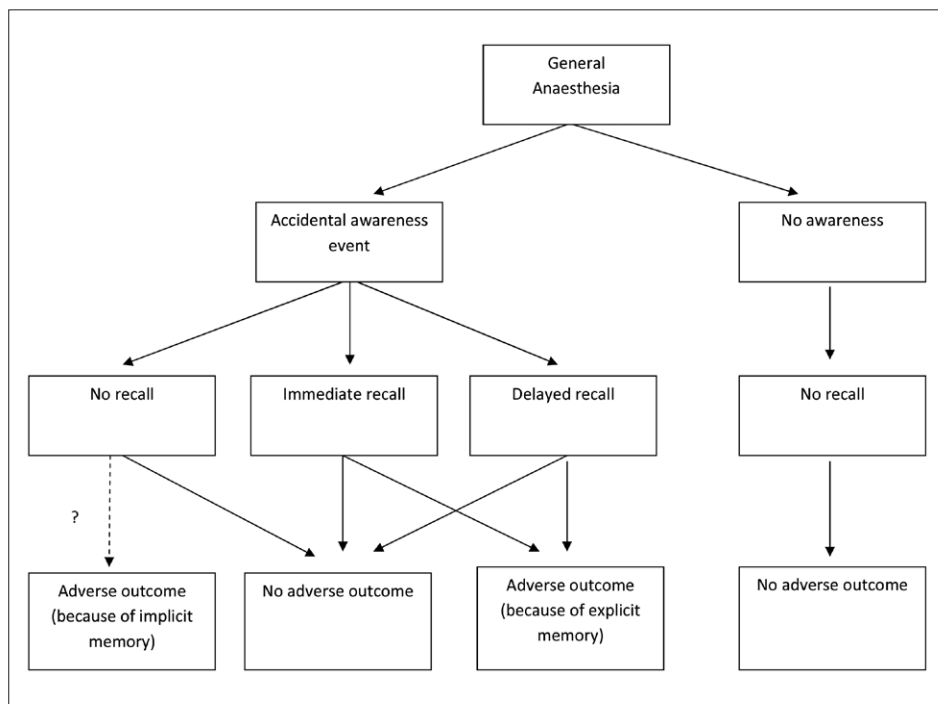


Figure 7.1. General anaesthesia most commonly involves no AAGA and there is no explicit recall or adverse psychological outcome (notwithstanding the possibility of adverse outcome due to implicit memory despite adequate general anaesthesia). An accidental awareness event might lead to no recall, immediate recall or delayed recall. Where there is no recall, the outcome from anaesthesia itself might be expected to be neutral, but there remains a possibility that implicit memories lead to adverse outcome. Recall of AAGA can lead to a neutral or adverse outcome

Post-traumatic stress disorder (PTSD)

- 7.28 Much of the literature on AAGA stresses that it is a traumatic event. It is not therefore surprising that individuals who experience AAGA may develop post-traumatic stress disorder (PTSD), but it is not known what proportion of patients does so. Aceto et al. (2013) systematically reviewed existing research and reported a range of PTSD rate across all studies (which included cohorts of medicolegal cases, self-reporters and prospective studies) of 0–70%. The highest rate was reported by Leslie et al. (2010) in a high risk surgical group but a very small cohort (just 5 of 7 patients). They calculated an aggregate rate of ~15%. This compares well with Mashour's estimate (in an accompanying editorial; Mashour 2010a) of 13%. It is not known if the likelihood of developing PTSD is influenced by early intervention, or by time delay in reporting AAGA, or whether there is a difference in incidence between self-reported AAGA and that revealed after Brice interview.
- 7.29 Hospital admission, surgery and anaesthesia may include numerous events and patient experiences that can later lead to adverse psychological impact. AAGA is only one of these. However, it seems probable that AAGA is a risk factor for developing PTSD over and above other aspects of surgery and hospitalization. Leslie et al. (2010) found 5 of 7 patients (71%) reporting AAGA developed PTSD whereas only 3 of 25 matched controls (12%) without AAGA did so. Avidan, Whitlock et al. (2014; personal communication, unpublished results) using a symptoms checklist rather than a formal diagnosis of PTSD, have found symptoms of post-operative PTSD in ~16% of elective surgery cases without awareness and 43% in matched cases with AAGA.
- 7.30 PTSD is a very serious outcome that can last many years and greatly impair function and quality of life (National Collaborating Centre for Mental Health, 2005). It is associated with increased risk of suicide (e.g. Hendin & Haas, 1991). Classically, PTSD comprises three categories of psychopathology: hyperarousal, re-experience and avoidance. Hyperarousal refers to persistent anxiety-related symptoms such as tachycardia, hypertension, sweating and hypervigilance. Re-experience includes flashbacks in which the patient experiences an unexpected return to the traumatic situation with associated perceptions, such as the sound, smell and sight of the operating theatre, along with extreme distress. The flashbacks may be so intense that they interrupt routine activity such as driving or work tasks. Understandably, patients tend to avoid behaviours and stimuli that might trigger a flashback, so in the case of PTSD triggered by AAGA, the patient will exhibit behavioural avoidance (phobia) of aspects of the medical environment associated with the trauma, e.g. hospitals, anaesthetists, doctors, medical settings on television. In Samuelsson et al.'s (2007) study, 41% of patients who had experienced AAGA reported a lack of trust of medical staff, though for most this resolved over time.
- 7.31 These disturbances are variable in duration. Some may only be troubled by PTSD symptoms for a matter of weeks. Others will be disabled for many years, possibly for the rest of their lives. Generally the intensity and frequency of disturbance will decline with time. The general trauma literature includes descriptions of late onset PTSD in which symptoms only emerge more than six months following the initial incident. This can take the form of 'anniversary' reactions in which symptoms begin exactly one or more years after the initial incident (Ehlers & Clark, 2000). With AAGA, PTSD symptoms may be precipitated by the need for further surgery after a significant interval (Ostermann, 2000).
- 7.32 There are effective treatments, such as exposure-based cognitive behavioural therapy or Eye Movement Desensitisation and Reprocessing (NICE, 2005), and these should be made available to those PTSD cases caused by AAGA as much as to those triggered by other causes.
- 7.33 It is important to note that there may be a range of psychological harm following AAGA. Patients may experience a sub-set of PTSD symptoms that is insufficient for a formal diagnosis of PTSD yet sufficient to cause lasting distress and change in behaviour (e.g. avoidance of medical settings). For example, in Avidan & Whitlock et al.'s unpublished (2014 – personal communication) study of psychological sequelae of surgery, 15 of 35 AAGA patients experiencing AAGA exceeded the screening cut-off for PTSD symptoms but only 5 of those patients had the full range of symptoms consistent with a diagnosis of PTSD. Some AAGA patients develop clinical depression shortly after the AAGA experience, while others may suffer acute PTSD followed by a period of depression. Some may develop acute *de novo* anxiety states such as complex phobia, the content of which may not obviously relate to the AAGA experience (Jones & Wang, 2004).
- 7.34 Individuals vary in terms of psychological resilience. Previous psychiatric history or previous trauma increase vulnerability to developing PTSD after a traumatic event (Ehlers & Clark, 2000), as do

personality variables such as introversion and neuroticism (McFarlane, 1989). An important element is that the person perceived a threat to their life and responded with fear or helplessness. This is a critical point to consider in the case of AAGA, for two reasons. First, the perceived threat to life depends on the patient’s understanding and interpretation of what is happening. Second, neuromuscular paralysis prevents the patient from moving (leading to ‘helplessness’) and this is predicted to be influential in catastrophic interpretations of what is happening.

7.35 Patient experience during AAGA is usefully classified using the Michigan Awareness Classification Instrument (Mashour et al., 2010b)

- Class 0: No awareness
- Class 1: Isolated auditory perceptions
- Class 2: Tactile perceptions (e.g. surgical manipulation or tracheal tube)
- Class 3: Pain
- Class 4: Paralysis (e.g. feeling one cannot move, speak, or breathe)
- Class 5: Paralysis and pain

An additional designation of ‘D’ is used for patients who experience distress during AAGA, so a classification of ‘1D’ means the patient reported hearing voices and feeling distressed (e.g. scared that something has gone wrong or anxious that they will start to feel pain).

7.36 Severity of sequelae after AAGA in NAP5 was categorised using a modification (specifically for this project by Ms Helen Torrevell, Panel member) of the NPSA severity outcome scale (NPSA 2008) in order to include psychological harm.

- None – 0. No harm occurred.
- Low – 1. Resolved (or likely to resolve) with no or minimal professional intervention. No consequences for daily living, minimal or no continuing anxiety about future healthcare.

- Moderate – 2. Moderate anxiety about future anaesthesia or related healthcare. Symptoms may have some impact on daily living. Patient has sought or would likely benefit from professional intervention.
- Severe – 3. Striking or long term psychological effects that have required or might benefit from professional intervention or treatment: severe anxiety about future healthcare and/or impact on daily living. Recurrent nightmares or adverse thoughts or ideations about events. This may also result in formal complaint or legal action (but these alone may not be signs of severity).
- Death – 4. Caused death.

NAP5 CASE REVIEW AND NUMERICAL ANALYSIS

7.37 There were 141 Class A and B cases (i.e. Certain/probable or Possible respectively). Reports varied considerably, from recall of isolated sensory experiences, to detailed recall of pain and paralysis with catastrophic interpretations of the experience. Distress was particularly likely with paralysis, but all forms of distress were strongly associated with longer-term psychological impact, which included nightmares, flashbacks, insomnia and fear of future surgery. Data supporting these findings is presented below.

7.38 Figure 7.2 shows to whom the report was first made, for all categories of report. Generally, in all case types, reports were made to the same anaesthetist that administered care, or to another anaesthetist, and occasionally to the ward staff. Statement Only cases (largely historical cases) were generally reported to another anaesthetist or to pre-operative nursing staff (presumably because in these historical cases, there was unlikely to be any opportunity to report to the same anaesthetist that administered care).

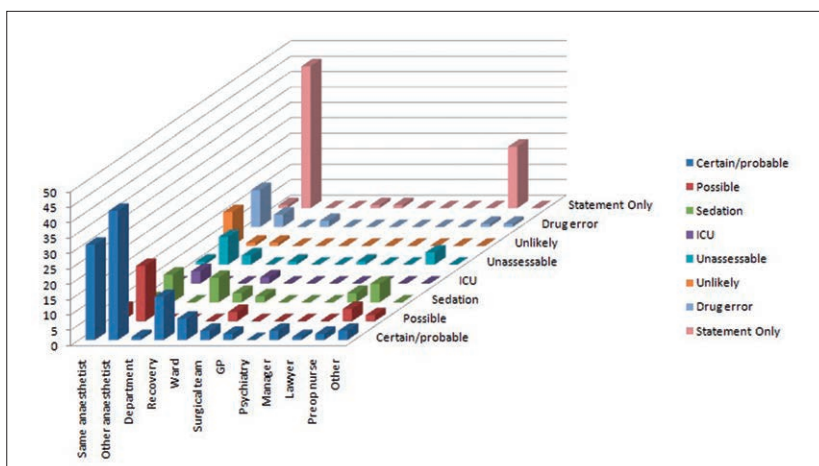


Figure 7.2. Histogram of to whom the report of AAGA was made. Data from all Classes of reports of AAGA. Department = anaesthetic department (e.g. by letter or telephone); GP = general practitioner; Pre-op nurse = pre-operative nurse)

7.39 For (Certain/probable and Possible) cases, the majority were first reported to another anaesthetist (most often during assessment for a subsequent procedure; 60; 43%), followed by reports to the anaesthetist who provided care (36; 26%). Other routes of reporting were recovery nurses (14; 10%), ward nurses (7; 5%), pre-operative nurses (6; ~4%) or surgical team (6; ~4%). Very rarely, reports were to a hospital manager or anaesthetic department (e.g. as part of a complaint 4); General Practitioners (2), a lawyer (1); and other staff groups such as ODPs, pharmacists, or the pain team (5, collectively). No Certain/probable or Possible reports were received via a psychologist or psychiatrist.

7.40 For Certain/probable and Possible reports, the commonest time to report AAGA was on the day it occurred (34% of reports). Another 11% of reports were made the day after surgery. Altogether, 52% were made within a week of surgery. There were also some very long delays in reporting (See Chapter 6, Results), with 35 (25%) of cases reported after a year or more. Reasons for delay were generally not given, although one patient reported being reluctant to report the incident earlier due to fear of ridicule and not wanting to re-live the incident.

7.41 Although it might be expected that experiences that were distressing would be reported immediately, this was not always the case. There was no clear association between reporting delay and distress during AAGA (captured by Michigan score D) (Figure 7.3) or between reporting delay and longer-term sequelae (Figure 7.4).

Word cloud based on responses to question 'illustrate the patient experience' for class A and B reports. Size and colour vary with count as reported in NAP5 results. Created at worditout.com

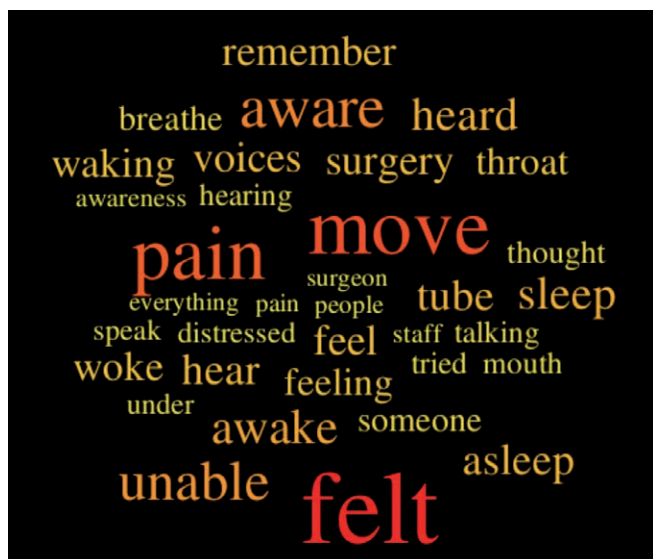


Figure 7.3. Boxplot showing the lack of an association in Certain/probable and Possible reports between the distress at the time of AAGA. Michigan score with distress (grey bars, no distress (white bars) and delay in reporting

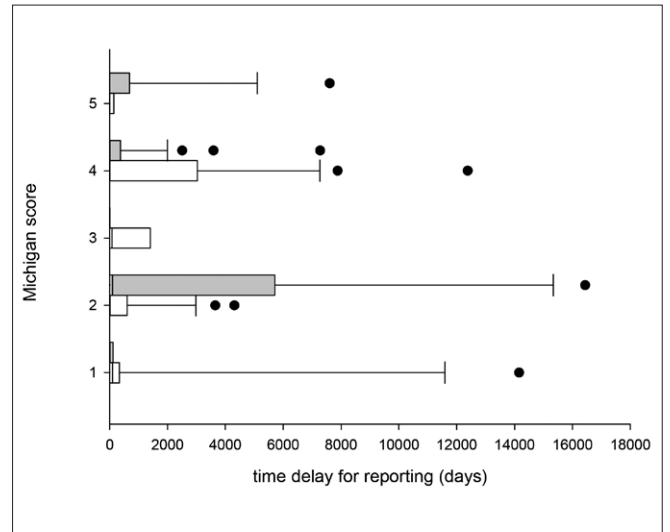
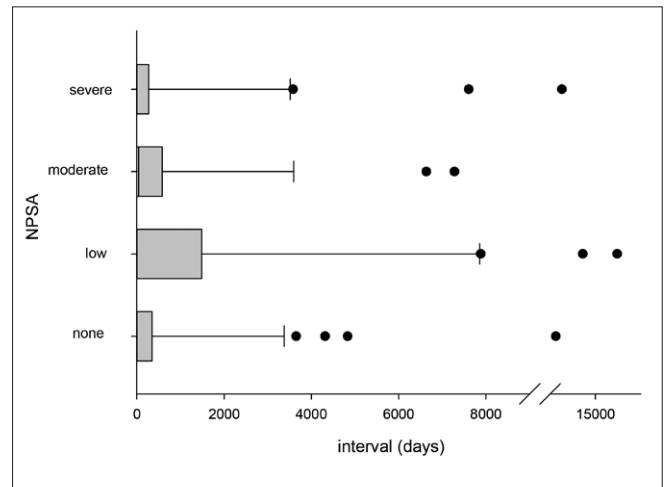


Figure 7.4. Boxplot showing lack of any clear relationship in Certain/probable and Possible reports between psychological impact at the time of the report (i.e. modified NPSA score) (grey bars) and delay in reporting



7.42 Experiences reported in the 141 Certain/probable and Possible cases included (*indicates symptoms consistent with paralysis):

- inability to move (42%)*
- inability to communicate (41%)*
- hearing noise/voices (37%)
- touch without pain (21%)
- awareness of tracheal intubation (21%)
- pain (18%)
- inability to breathe or suffocation (11%)*
- movement or being moved (9%)
- visual sensations (3%)
- dreamlike experiences (5%)

Patients reported between 0 (a report of simply 'being awake' with no further detail) and eight of these experiences (median 2). Although patients sometimes interpreted AAGA as a dream, there was only one assessable case (Class F – judged Unlikely) where the patient seemed to interpret a vivid dream as AAGA.

- 7.43 Tactile sensations and paralysis were common at induction, paralysis most common on emergence, and pain and paralysis most common during surgery.
- 7.44 Sixty five (47%) of 138 Certain/probable and Possible cases with known Michigan scores were judged not to be associated with distress, including some cases where the patient experienced pain and paralysis. There was a range of such neutral reports, with occasional positive reports where the patient felt thankful for the efforts of staff or had had a dreamlike experience.

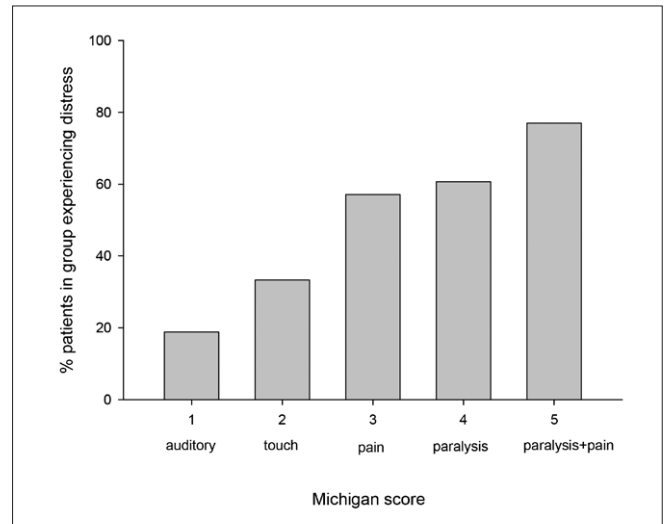
A patient mentioned to the surgeon overhearing a conversation between surgeons regarding the position of incision, and quoted exactly what had been discussed. The conversation had taken place in the middle of surgery, for a few seconds. The patient was interested rather than concerned.

A patient whose trachea was difficult to intubate recalled anaesthetists trying to "get the tube down and struggling" but was reassured by their care and thanked them. The patient was not distressed and thanked the anaesthetists for their care and attention.

A patient reported dreaming that they had felt paralysed and unable to communicate during surgery for a few minutes, but they had been comfortable and not in pain. The vaporiser had not been turned on during the procedure, for a time approximating to the patient's dream recollection.

- 7.45 The proportion of patients judged to have experienced distress at the time of the AAGA increased with Michigan score (Figure 7.5): distress was most common when pain and paralysis were experienced together, with 17 of 22 patients reporting distress (77%).

Figure 7.5. Percentage of Class A and B patients experiencing distress in each Michigan category



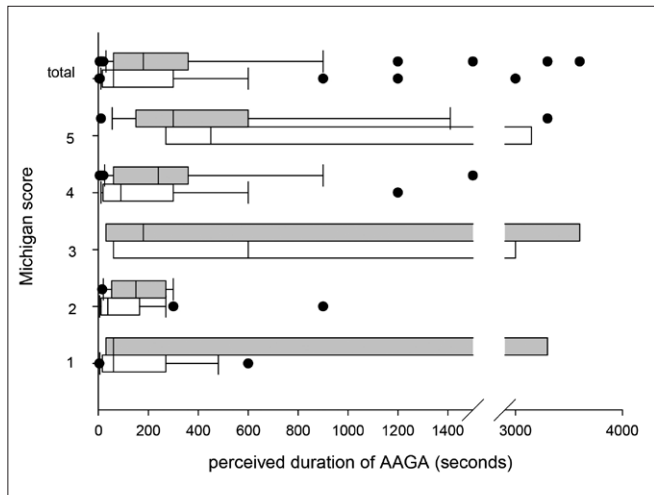
- 7.46 For the majority of those in distress, this was primarily because of the experience of paralysis (67%), but a few more reported pain first, followed by paralysis as upsetting (6%). Some patients were particularly troubled by breathing difficulty (15%) and four specifically mentioned they feared they were going to die. Two patients thought they were actually dead at the time of the intra-operative awareness episode because of the experience of paralysis. Chapter 19, Neuromuscular Blockade, highlights the experience of 'awake paralysis' as being the common central feature of traumatic AAGA. Of those reporting intra-operative distress, only 11% identified pain alone as the problem and did not report paralysis.

A patient reported auditory and tactile recall of laryngoscopy and intubation and the start of surgery. The patient wanted to scream but could not move or speak. The patient developed nightmares, waking up crying in a cold sweat recalling events repeatedly. The patient described feeling imprisoned in their own body.

A patient reported neither pain nor the experience of being paralysed (even on direct questioning), but did report severe distress at "being alive only in the head". The patient felt as if just their brain and ears were still working. "It felt like being in a crypt". The patient could hear everything (and reported conversations) but felt no pain, only some touch when somebody lifted their leg, and something being drawn along the leg with a pencil (as did happen), some humming, and then with no pain, an incision. This case was associated with a psychotic episode post-operatively and PTSD.

7.47 There was no clear association between distress and perceived duration of AAGA, i.e. it was not the case that the longer the perceived experience, the greater the distress, across any of the Michigan scores (Figure 7.6). For all Michigan scores combined, the median duration for no distress was 60 (15–300 [3 – 10,800]) and for distress was 180 (60–360 [5 – 3,600]) sec ($p = 0.405$, factorial analysis of variance).

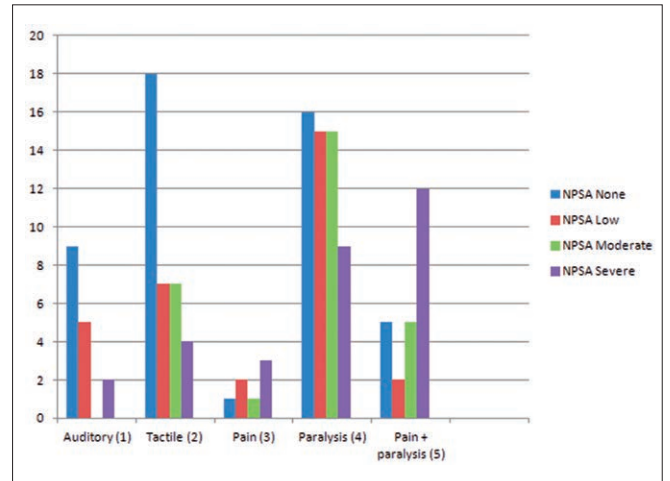
Figure 7.6. Boxplot of duration of perceived AAGA vs Michigan score: no distress (white bar); distress (shaded bar)



7.48 Overall, 41% of cases were judged to have moderate to severe longer-term harm, and this was more common in patients experiencing pain and/or paralysis: 51% of these patients reported moderate to severe harm compared with 25% of those reporting only auditory or tactile sensations. Of note: the methodology of NAP5 meant that psychological impact was usually measured at the time of reporting the AAGA event and as a result of early reporting some episodes of longer term harm may have been missed. Equally, early reports may have indicated psychological impact that did not continue into the longer term.

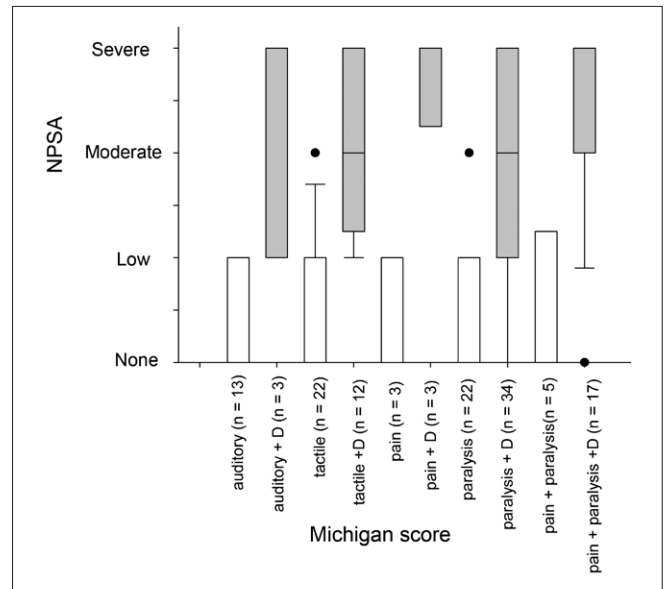
7.49 Importantly however, severe longer-term harm was not restricted to those experiencing pain or paralysis. It also occurred in patients experiencing only auditory or tactile symptoms (Figure 7.7)

Figure 7.7. Relative proportions (n) of modified NPSA scores (none to severe) by Michigan score



7.50 Distress during AAGA was strongly associated with longer-term sequelae (Figure 7.8). Fifty-five of 70 (79%) patients reporting distress had moderate to severe longer-term impact, compared with only 2 of 68 (3%) of patients without distress during AAGA, giving an odds-ratio for developing longer-term sequelae following distress during AAGA of 121.

Figure 7.8 Boxplots of NPSA score vs Michigan score: no distress (white bars); distress (shaded bars) for those Certain/probable and Possible cases where both NPSA and Michigan scores were assessable. Distress during AAGA is notably associated with longer-term poor outcome



7.51 Severe reactions to the episode of AAGA were characterised by re-experiencing the event through ‘flashbacks’ and nightmares, hyperarousal (increased anxiety, sleep disturbance) and avoidance (e.g. of lying flat, future anaesthetics). The process of cognitive appraisal at the time of the trauma (i.e. during the episode of awareness) is thought to be central to the development of PTSD

and there were several examples of catastrophic interpretation, where the patient thought they were going to die or be permanently paralysed.

A patient recalled talk about hallucinations associated with ketamine, and then having their neck extended, a plugging sensation of something in the mouth and a suffocating feeling. The patient tried to cry so that they could show people that they were awake. The patient recalled being positioned on the operating table and pain of the start of surgery. The patient did not think they would survive. The patient developed PTSD with flashbacks, panic attacks, fear of the dark (seeing the anaesthetist's face when asleep), an inability to lie flat and was referred to a psychologist.

On waking in recovery an elderly patient reported having heard voices and feeling some pain. The following day the description became clearer and the patient described a sharp agonising pain of a knife slicing into skin and of flesh pulled apart. The patient tried to move but was unable to and was terrified of "enduring the torment". The patient experienced flashbacks, re-living experiences and felt traumatised.

After incomplete reversal of neuromuscular blockade a patient reported being unable to talk or to move, the feeling of a tight chest "I was very scared, I thought I will be paralysed and unable to move. It was really a bad experience." The patient developed anxiety and fear about anaesthesia, needing psychological support.

A patient felt a tube in their throat and could not breathe. They panicked and thought they were going to die. Then they 'passed out' but then heard a voice reading from the notes "saying I was a smoker; this is when I realized I was alive". The patient developed a fear of anaesthetics and sleep disturbance.

- 7.52 In counterpoint to the catastrophic interpretations, there were cases where the patient's own understanding of anaesthesia, spontaneous benign interpretation, or explanations provided by staff during the experience, appeared to reduce the impact of AAGA.

A patient reported for a few minutes hearing voices, and experiencing paralysis and abdominal pain. The patient wanted to ask theatre staff to give painkillers but could not speak. The pain was unpleasant; but the paralysis was not a great worry because the patient knew "you were supposed to be paralysed during the operation". The patient was later not worried about having another anaesthetic.

Inadvertently a patient was given suxamethonium before induction. The anaesthetist immediately recognised the error and induced anaesthesia. The patient experienced paralysis, was afraid they were dying from a stroke and had flashbacks for 2-3 days afterwards. However the patient was very reassured by the anaesthetist's immediate explanation, "I know what's happening and I can fix it", during the critical event and had minimal long-term sequelae.

A patient recalled hearing voices, seeing bright lights, not being able to move or communicate and being terrified, thinking they were going to die. The patient went home and mentioned it to their family and was reassured when they all apparently had a report of awareness "...it happens to all my family - we all wake up. Please can you give me a bit more?"

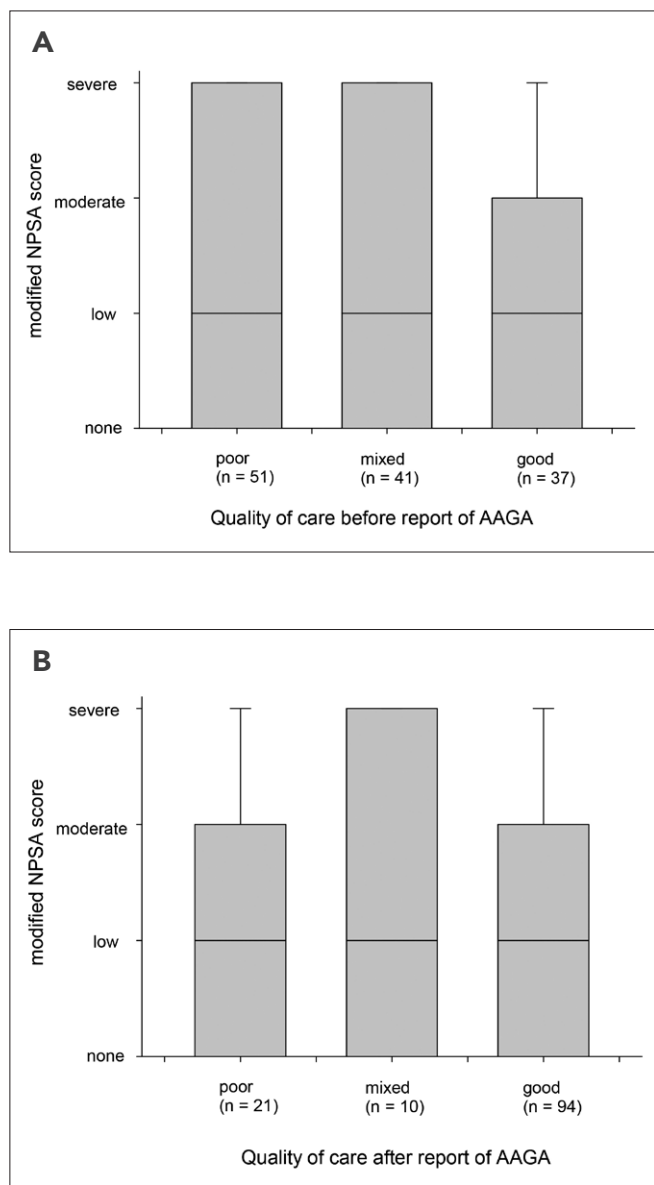
- 7.53 In several cases, early support and empathy after the occurrence of AAGA appeared to influence the nature of longer-term reactions. This is also highlighted in Chapter 22, Medicolegal. In contrast, in a minority of cases patients were reported to have become angry or upset by an apparently unsupportive reaction by staff and in some cases this engendered greater unhappiness than the actual experience.

A young patient was panicky in recovery and reported that they heard people talking, felt stitching and a choking sensation. The patient was very upset as they could not speak or do anything until they managed to move a little. In recovery they felt they were re-experiencing the events. The patient was upset that they did not get support from the nursing staff in recovery or on the ward, who told the patient it was a bad dream and there was nothing to worry about. It was only when the patient spoke to the anaesthetist and recounted what happened that they felt they were believed.

A patient became aware of intubation during a difficult rapid-sequence induction intubation. The anaesthetist later explained the need for rapid-sequence induction. The patient was not distressed and thanked the anaesthetist for their care and attention.

- 7.54 However, there was no relationship demonstrable between the quality of care and the longer-term outcome as judged by modified NPSA score, in a quantitative manner, either for clinical care leading up to the report of AAGA, or for care after report of AAGA Figures 7.9 and 7.10.
- 7.55 The adverse impact of a report of AAGA on anaesthetists should not be overlooked. Two reports indicated that AAGA could be as much a surprise to them as it was to the patient. One confessed to changing their anaesthetic techniques after an episode and one judged themselves very harshly: "I simply screwed up. Fortunately it was brief and the patient forgiving".

Figure 7.9. Boxplots of modified NPSA score and Panel judgement on quality of care, in Certain/probable and Possible cases, for: Panel A (top) care up to the point of report of AAGA and Panel B (bottom) care after report of AAGA



DISCUSSION

- 7.56 Experiences of AAGA varied widely, from isolated and sometimes vague sensory experiences of sounds, touch, or movement, to full and clear awareness including pain and paralysis. The range of experiences was comparable to that reported in literature using the modified Brice interview.
- 7.57 Consistent with previous literature (Ghoneim et al., 2009), only a third of the reports were made on the day AAGA occurred and fewer than half within the first 24 hours. Only a quarter were received by the anaesthetist who provided the care. It was common for AAGA to be reported for the first time during preparation for a subsequent procedure, and in some cases psychological sequelae only emerged at this time, when the patient became anxious about AAGA happening again. There was no clear relationship between the perceived duration of AAGA (which was generally brief) and psychological impact, or between reporting delay and impact. Brief experiences could be severely distressing and experiences reported after a delay were no less distressing or harming than those reported immediately.
- 7.58 In about half the cases, recall was expressed in a neutral way, focused on just a few seemingly isolated aspects of the experience.
- 7.59 However, in about half of cases there was distress at the time of AAGA, and this distress was strongly associated with longer-term psychological impact. Distress generally led to longer-term harm, even if it occurred during a 'patchy' experience of AAGA where the patient heard voices or felt sensations without pain or paralysis. Not surprisingly, distress was particularly likely to accompany paralysis and pain, and complaints of being unable to alert staff by moving or speaking were common.
- 7.60 Although patients sometimes interpreted AAGA experiences as dreams or described them as dreamlike, we only received one report of a patient interpreting dreams as AAGA (however, other dream reports may not have reached NAP5). There were rare descriptions of disembodied experiences that may be interpreted in several ways: (a) as attempts to interpret the sensation of paralysis (and hence distressing); (b) a misinterpretation of the unusual experiences as dreams (perhaps because the patient cannot see where they are and what is happening, so the experience lacks full context); (c) a representation of what has been variously termed 'dysanaesthesia' (Pandit, 2014), 'disconnectedness' (Sanders et al., 2012), or 'cognitive unbinding' (Mashour, 2004).

- 7.61 All reports described here in the Certain/probable and Possible category were supported by anaesthetic notes. Reports classed as Unassessable or Unlikely were typically confused about the timing of peri-operative events or were too vague and sparse to be interpretable (Chapter 25). This uninterpretability on the part of the Panel assessors may in turn relate to the difficulty the patients themselves had in making sense of events, as alluded to above, so these may still represent genuine AAGA events: it is impossible to know. The Panel judged that there were no malicious reports.
- 7.62 The fact that a minority (25%) of Certain/probable and Possible reports of AAGA were first made to the anaesthetist responsible for the case might reflect a difficulty of following up every case (e.g. if patients are discharged or transferred, etc) or an early opportunity for the patient to report to another healthcare worker. It could also reflect delayed recall, with the memory not emerging until other staff had taken over responsibility for the patient's care. Avoidance on the part of the patient due to fear or concern is a possibility, though we note that the majority of the cohort with the greatest distress (the cases of accidental paralysis due to drug error or syringe swap – see Chapter 13, Drug Errors) reported to the original anaesthetist. There was no evidence that reports made to someone other than the anaesthetist were less trustworthy or serious.
- 7.63 The disparity between the 'incidence' reported using Brice questionnaire (~1:600) and NAP5 methodology (~1:20,000) is striking. It is discussed in full elsewhere in the Report. The number of cases of AAGA that were reported for the first time after considerable delays suggests that some patients may be reluctant to report AAGA when they first recall their experiences. Practice implications depend on discovering the reasons for this and why it apparently seems to be overcome by Brice interviewing. It would seem that routine active questioning could help elicit earlier reports of AAGA that would allow earlier and more effective intervention, but it is not yet known whether this could risk eliciting false but still distressing memories of AAGA, as well as improving recall of genuine memories.
- 7.64 Longer-term sequelae included symptoms associated with PTSD, including nightmares, flashbacks and anxiety. Anxiety sometimes emerged only when the patient needed a subsequent anaesthetic.
- 7.65 As in other types of traumatic experience, catastrophic interpretations of awareness experiences (e.g. the patient believing they are dead, dying or permanently paralysed) at the time of the trauma, were strongly associated with serious longer-term sequelae. Conversely, understanding what was happening seemed to be protective. Hearing staff explain the problem while it was happening appeared helpful. Consistent with this conclusion, studies with informed volunteers have shown that paralysis per se need not be distressing if it is expected and understood, though associated sensations of being unable to breathe do tend to cause distress (Heier et al., 2001; Topulos, Lansing & Banzet, 1993). Therefore, anaesthetists suspecting inadequate anaesthesia should focus on talking to the patient in reassuring ways, indicating an understanding of their predicament. This is likely more important than attempting to abolish memory retrospectively using drugs.
- 7.66 Quantitatively, there was no apparent association between quality of care and longer-term impact of AAGA. This null result should be interpreted with caution because (a) the Panel judgement of care quality was highly dependent upon the sometimes scant information provided; (b) overall more than half of events led to no or low impact; (c) the large majority of cases were associated with good care after AAGA, so true impact of poor care was difficult to assess (Figure 7.9, 7.10). Our data do not differentiate cause and effect in terms of good care and outcomes. Thus, good care could have been offered after registering that the impact of AAGA had been severe, in which case it is misleading to imply lack of association.
- 7.67 There were cases where a sympathetic response to the report of AAGA seemed to mitigate the impact of the experience, and cases where unsympathetic responses seemed to exacerbate the adverse impact. Around 15% of cases were judged to have received poor care, where no attempt was made to follow up reports of AAGA to ensure patients had access to psychological treatment if they needed it. We suggest that there should be a plan for supporting patients who indicate an experience of AAGA. The Appendix to this chapter provides a suggested response pathway. We propose that the efficacy of this pathway should be tested formally to enable any suitable modifications over time.

IMPLICATIONS FOR RESEARCH

Research Implication 7.1

Research is needed into whether and what type of early and supportive response at the time of and after a report of AAGA mitigates longer-term psychological sequelae. In particular, the efficacy of the proposed NAP5 Awareness Support Pathway warrants investigation.

Research Implication 7.2

The observation that many cases of AAGA are reported only after considerable delay warrants further investigation. Is there a delay in consolidating the memory? Do memories of recovery interfere with the AAGA memory? Is AAGA hard to recall because source memory is poor and there may only be partial sensory information (e.g. a memory of voices but not of tactile sensations)? Or does it take time for patients to come to terms with their experience and feel able to discuss it?

Research Implication 7.3

Building upon existing work, research is needed to establish if implicit memories for anaesthesia have consequences for patients' wellbeing on recovery.

Research Implication 7.4

It would be important to assess if the method of Brice interview (i.e. repeated questioning over several occasions) might lead to the creation of any false memories of AAGA, or conversely help patients to retrieve genuine AAGA memories.

Research Implication 7.5

Research is needed to ascertain the incidence of PTSD or other adverse psychological impact arising from AAGA. It needs to be established if the evolution of these is influenced by the nature of the AAGA experience at the time, by early response and intervention, by any delays in reporting, or if there is a difference between incidence of psychological harm with spontaneous reporting of AAGA versus that ascertained after Brice interview.

Research Implication 7.6

It would be interesting to explore patients' interpretations of the sensation of paralysis during AAGA, and the extent to which catastrophic interpretations of being dead or permanently paralysed may be prevented through pre-operative information or the impacts ameliorated by post-operative explanation.

Research Implications 7.7

Comparative research into psychological responses to paralysis at the time of a cerebrovascular accident or other acute neurological disorders, versus the paralysis of AAGA would be important to ascertain if the response to the latter has a unique basis.

Research Implication 7.8

Cross-cultural research to ascertain if patient attitudes to AAGA are similar across countries and cultures would be illuminating, perhaps encompassing the interaction of religious beliefs, societal influences, acceptance of regional anaesthesia, etc, in attitudes to notions of suffering, 'consciousness' or 'self'.

Research Implication 7.9

Research is needed into individual risk factors for developing long-term sequelae following AAGA. It is not known if a patient's personality or levels of anxiety influence the experience of AAGA and its aftermath, nor whether previous traumatic experiences increase vulnerability.

Research Implication 7.10

Little is known about the precise symptomatology of PTSD following AAGA. A comparison of NAP5 findings with estimates of AAGA from Brice studies suggests that many experiences of AAGA go unreported. They may nonetheless have psychological impact, therefore it would be useful for psychologists and psychiatrists to know if AAGA-induced harm has a signature pattern of symptoms.

RECOMMENDATIONS

RECOMMENDATION 7.1

If AAGA is suspected intra- or peri-operatively, anaesthetists should speak to patients to reassure them that they know of their predicament and are doing something about it.

RECOMMENDATION 7.2

Conversation and behaviour in theatres should remain professional, especially where there is a situation or concern that AAGA is a risk (e.g. RSI, prolonged intubation, transfer). Adverse impact of any recall may be mitigated where the patient is reassured by memories of high quality care.

RECOMMENDATION 7.3

All reports of AAGA should be treated seriously, even when sparse or delayed, as they may have serious psychological impact. If reported to someone else, every attempt should be made to refer the case to the anaesthetist responsible.

RECOMMENDATION 7.4

The anaesthetist who provided the anaesthesia care at the time of a report of AAGA should respond promptly and sympathetically to the patient, to help mitigate adverse impacts.

RECOMMENDATION 7.5

Healthcare or managerial staff receiving a report of AAGA should (a) inform the anaesthetist who provided the care; (b) institute the NAP5 Psychological Support Pathway (or similar system) to provide patient follow up and support.

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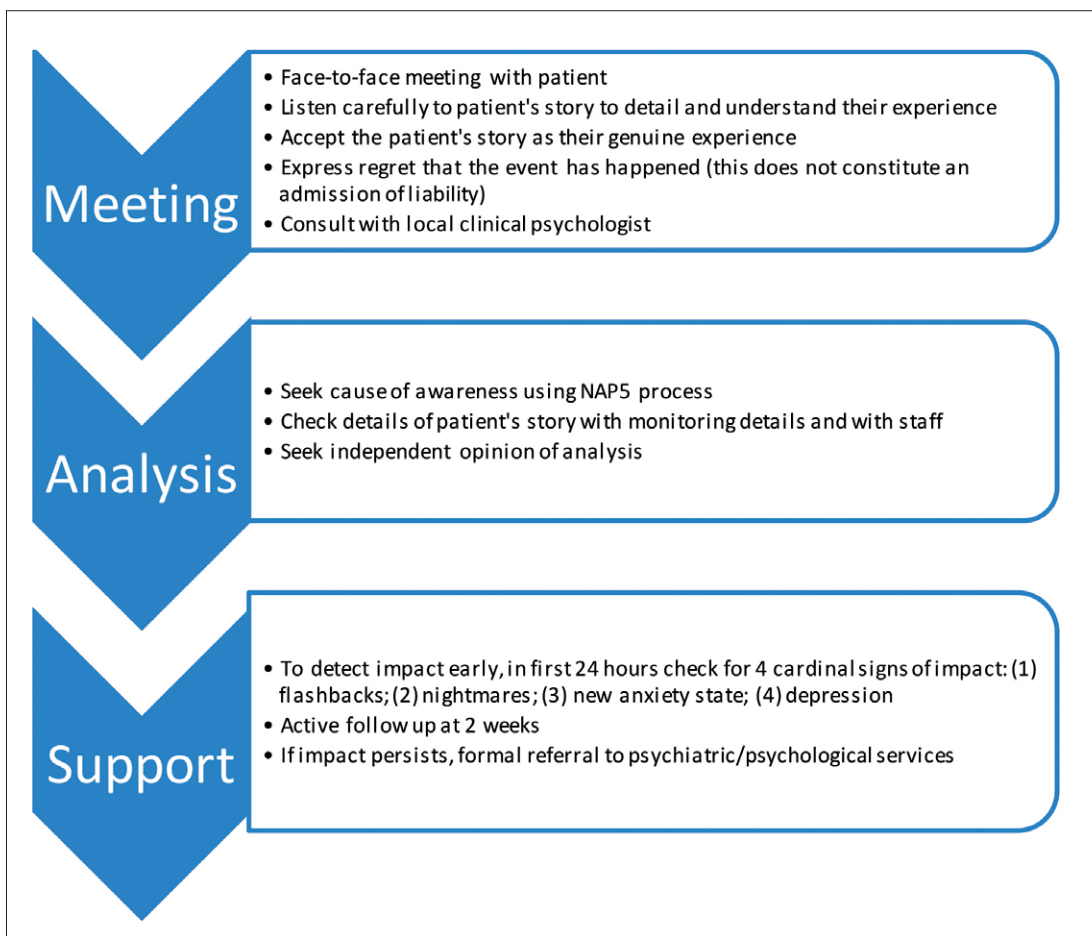
NAP5 Awareness Support Pathway for AAGA

NAP5 Awareness Support Pathway

This pathway is created on the assumption that psychological trauma of AAGA is compounded by lack of or insensitive post-operative management. This can compound the long-term severity of psychiatric consequences which if untreated become progressively more difficult to ameliorate. Early identification, monitoring and psychological intervention (where necessary) of AAGA are known to be likely to reduce psychological morbidity and costs. NAP5 revealed many cases of AAGA where patients were minimally distressed with little need for psychological

support; typically where simple support had been offered promptly. This is a basis for the meeting stage of our Psychological Pathway, emphasising the value of empathetic communication. The second stage, analysis, seeks to identify causes of AAGA to inform continuing dialogue and prevent recurrence. The third stage, support, stems from evidence that psychological sequelae of AAGA, including memories, increase in the weeks following anaesthesia and are amenable to treatment (NICE PTSD Guidelines).

NAP5 Awareness Support Pathway for AAGA



Accompanying notes

Meeting stage

1. **Face-to-face meeting with patient.** Ideally this should include the anaesthetist who provided the anaesthesia care and where this is a trainee, a suitably senior colleague. Where this is not possible or desirable, a senior colleague should take their place.
2. **Listen to patient story and experience.** Blatant fabrication by the patient is extremely rare; however, careful note should be taken of all details provided by the patient. Particular attention should be devoted to the type of experience (e.g. from auditory sensations only, to touch, or pain and/or paralysis). This enables classification according to the Michigan scale. An attempt should also be made to classify the patient's situation according to the modified NPSA guidelines as a measure of severity of medium to long-term impact. Careful account of information that could be corroborated, or refuted, is very important to establish the veracity of the report.
3. **Accept the patient's story as their genuine experience.** This means listening carefully and empathically to the patient's account, without interruption or contradiction (even if there are inconsistencies) and take verbatim notes of the patient's account.
4. Express regret. This can be done using words like "I am sorry to hear of your experience; we need to establish what has happened". This is not an admission of error or medicolegal culpability.

Analysis

1. **Seek cause of awareness using NAP5 process.** In addition to establishing the Michigan and modified NPSA score, this involves classifying the report as Certain (or refuted) or Probable (Class A); Possible (Class B); a case where sedation was intended (Class C); a case in the ITU (Class D); Unassessable (Class E); Unlikely AAGA (Class F) or Unintentional paralysis due to drug error (Class G). A Class H may be used for cases not fitting any of these classifications. The purpose is to help create a common terminology for later group analysis.
2. **Check details of patient's story.** For cases that are Certain/probable or Possible (Class A/B) causality can be determined by careful analysis of the anaesthetic chart and anaesthetist's report. Note, as confirmed by NAP5, that some cases have no apparent cause and may be due to insensitivity to anaesthetic drugs. As NAP5 and other studies have shown, patients may be mistaken in several ways. They may not have

had an anaesthetic at all, or may have experienced an unpleasant dream not involving specific surgical events. Events during the immediate post-operative or pre-operative period may be incorrectly attributed as intra-operative. Therefore proper analysis is important and any such confusion should be addressed gently, with care and understanding.

3. **Seek independent opinion.** The Analysis process may be undertaken by a small group with appropriate skills and knowledge (independent of the hospital if necessary), who can provide an unbiased opinion as to the classification, impact and likely causality, in much the same way as NAP5 has done.

Support

1. **Detect impact early.** Inpatient review or follow up telephone consultation for day-cases is essential within 24 hours to establish if there are flashbacks, nightmares, any new anxiety state or symptoms of depression. If early symptoms cause concern, early referral to an appropriate psychologist or psychiatrist is advised.
2. **Two-week review.** The same follow-up should be conducted at two weeks. Even where true AAGA is unlikely, NAP5 has shown that the patient interpretation is of such importance that the impact of peri-operative unpleasant experiences may be severe and psychological support may still be needed.
3. **Support for impact.** If impact persists, a formal psychological review is needed. Once referral to a psychologist or psychiatrist is found necessary, in accordance with NICE Guidance, PTSD-type reactions should be treated with either trauma-focussed Cognitive Behavioural Therapy or Eye-Movement Desensitisation and Reprocessing. If there are none of the four cardinal signs of impact (flashbacks, nightmares, a new anxiety state or symptoms of depression), then the patient can be encouraged to make contact if they later have concerns. However, there is a need for an ongoing national case registry (as recommended by the NAP5 Report), so that the longer term evolution of any symptoms in those judged not to need specific support after two weeks can be assessed.

Ideally, each geographical area or Trust should have access to a psychologist or psychiatrist who has expertise in PTSD and can be 'on call' for unintended incidents.

SUPPORTING REFERENCES TO APPENDIX

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