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Patient perspectives on intraoperative awareness with explicit recall: report from a North American anaesthesia awareness registry

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Abstract

Background: Awareness during general anaesthesia is a source of concern for patients and anaesthetists, with potential for psychological and medicolegal sequelae. We used a registry to evaluate unintended awareness from the patient's perspective with an emphasis on their experiences and healthcare provider responses.

Methods: English-speaking subjects self-reported explicit recall of events during anaesthesia to the Anesthesia Awareness Registry of the ASA, completed a survey, and submitted copies of medical records. Anaesthesia awareness was defined as explicit recall of events during induction or maintenance of general anaesthesia. Patient experiences, satisfaction, and desired practitioner responses to explicit recall were based on survey responses.

Results: Most of the 68 respondents meeting inclusion criteria (75%) were dissatisfied with the manner in which their concerns were addressed by their healthcare providers, and many reported long-term harm. Half (51%) of respondents reported that neither the anaesthesia provider nor surgeon expressed concern about their experience. Few were offered an apology (10%) or referral for counseling (15%). Patient preferences for responses after an awareness episode included validation of their experience (37%), an explanation (28%), and discussion or follow-up to the episode (26%).

Conclusions: Data from this registry confirm the serious impact of anaesthesia awareness for some patients, and suggest that patients need more systematic responses and follow-up by healthcare providers.

Key words: anaesthesia, general; intraoperative awareness; patient preference; patient satisfaction; registries

Awareness during general anaesthesia (GA) with explicit recall has been reported to occur with a frequency of 1–2 per 1000 patients during general surgery, when the Brice methodology is utilized for case identification.[1 2] Although uncommon, awareness is a source of concern for both patients and anaesthetists with potential for psychological[3–7] and medicolegal[7 8] sequelae.

The ASA established the Anesthesia Awareness Registry in 2007 to address the concerns of patients and others in the anaesthesia community. The Registry aimed to collect patient self-reports of intended awareness during GA to provide a patient perspective on their expectations and experiences of awareness. The Registry was designed to be consistent with the emerging philosophy of 'patient-centered' care.[9] This includes a focus on respect for patient preferences, needs, and values, as a central pillar to clinical decision-making. In keeping with this philosophy, the Anesthesia Awareness Registry adopted a patient-centered

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Editor's key points

- A North American registry for anaesthesia awareness was analysed for patient experiences and care team responses to the event.
- Of 68 subjects reporting awareness during general anaesthesia most experienced auditory recall and inability to move.
- Most respondents were dissatisfied with the way their experience was managed, and would prefer clear communication, experience validation, and follow-up.

definition of anaesthesia awareness as the outcome of interest. While all patient recruitment materials defined anaesthesia awareness as a phenomenon associated with GA, patient reports of awareness during regional anaesthesia and sedation were accepted into the registry database. The current study includes only confirmed reports of awareness during GA. The long-term goal of this patient-centered Registry is to improve provider-patient communication surrounding anaesthesia expectations and risk, and to improve intervention strategies for patients who experience awareness. The Registry is currently funded by the Anesthesia Quality Institute, Schaumburg, IL, USA, https://www.aqihq.org.

The aim of this study was to characterize patient experiences and expectations for healthcare provider responses to unintended awareness during GA based on patient reports to the Anesthesia Awareness Registry.

Methods

This study was approved by the University of Washington Institutional Review Board. Written informed consent was obtained from subjects who mailed in Registry materials. The requirement for written informed consent was waived by the review board for subjects who submitted their information online. English-speaking subjects ≥13 years of age who self-reported explicit recall of events during GA were recruited for The Anesthesia Awareness Registry through a website (www.awaredb.org) and a Facebook page (www.facebook.com/AnesthesiaAwarenessRegistry). Many (n=49) of the subjects in this study were included in the GA comparator group in a study by Kent and colleagues, which found that unexpected explicit recall of intraoperative events during sedation, or regional anaesthesia, might be associated with distress and persistent psychological sequelae comparable with those that occur with anaesthesia awareness during GA.[10]

Enrolled subjects completed a written survey about their anaesthesia awareness experience (Supplementary Appendix S1). The survey opened with a structured interview, modified from that used by Sandin and colleagues.[1] The survey also included questions about the procedure and age at time of awareness, recall of sensations during the procedure, impact on relationships, satisfaction with how subject concerns were addressed, and what might have been done differently to address their concerns. After submitting the survey, subjects had the opportunity to discuss their experience in more detail with a member of the study team via telephone. Medical records pertinent to anaesthetic care were requested. Type of anaesthesia (general, regional, monitored anaesthesia care, or sedation without an anaesthesia provider) was abstracted from medical records. Three of the investigators (KD, CK, GM), all of whom had experience in reviewing awareness events in other studies, reviewed survey responses and medical record data and independently judged whether the patient had explicit recall during anaesthesia, and in which phase of anaesthesia care [pre-induction, induction, maintenance, emergence, post-anaesthesia care unit (PACU), or intensive care (ICU)], the explicit recall occurred. The investigators judged whether the patient definitely had anaesthesia awareness, possibly had anaesthesia awareness, or did not have anaesthesia awareness. Definite anaesthesia awareness was defined using the criteria outlined in the ASA Practice Advisory,[11] as explicit recall of events during induction and/or maintenance of general anaesthesia, specifically excluding explicit recall during the time before GA was fully induced or during emergence from GA.[11] Agreement by at least two investigators was required to include the respondent as having definite anaesthesia awareness.

Inclusion criteria for the present study were a patient-reported episode of explicit recall of events during GA and availability of medical records from the procedure associated with the episode. Episodes of recall associated with sedation, monitored anaesthesia care, or regional anaesthesia were not included. Respondents reporting recall of events only before induction of GA, during emergence, or postoperatively in PACU or ICU were excluded.

Age, awareness experience, additional episodes of anaesthesia awareness, harm, and satisfaction or dissatisfaction with the healthcare provider and institutional responses to the reported experience, came from patient survey data and post-survey telephone discussions. Survey data were assessed using the Michigan Awareness Classification for levels of sensation and distress.[12] Levels of sensation were classified as isolated auditory perceptions, tactile perceptions, pain, paralysis, or pain and paralysis. A designation of 'D' for distress was used for reports of fear, anxiety, suffocation, sense of doom, sense of impending death, or similar reports that indicated emotional distress during the anaesthesia awareness experience.

Preoperative medications and comorbidities, anaesthesia data, possible signs of awareness, and use of a brain function monitor were abstracted from the medical records. Possible signs of awareness were defined as tachycardia (HR >100 bpm), hypertension (systolic arterial pressure ≥160 mm Hg), and patient movement. Anaesthesia details abstracted from the medical records included presence or absence of a volatile anaesthetic agent, concentration of volatile anaesthesia agents, and doses of hypnotic drugs (e.g. propofol, thiopental, etomidate, methohexital). Low concentration of volatile anaesthetic was defined as estimated or documented end-tidal volatile anaesthetic concentration, at time of awareness, consistent with ≤0.5 MAC. Age-adjustments were not made. When normal anaesthetic agents and doses for the patient's age, ASA status, and comorbidities were administered and no potential cause for anaesthesia awareness could be determined, the patients were assessed as having normal anaesthetics. Cases with absent or unclear anaesthesia records, where agents and doses could not be confirmed, were classified as unassessable.

Results

From a total of 312 respondents who completed surveys from December 2007 to August 2014, about recall of events during anaesthesia, medical records were available from 103. Almost all were from North America. Review of those records indicated that 28 respondents reported explicit recall of experiences during regional anaesthesia (n=7), sedation (n=11), or monitored anaesthesia care (n=10), and so did not meet inclusion criteria. Of the remaining 75 respondents with available medical records, 7 were excluded because of explicit recall pre-induction (n=1), during