

Can Children Recall Their Experiences of Admission to an Intensive Care Unit?

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ABSTRACT

Objective: *To perform a pilot study to prospectively determine children's ability to recall events experienced during admission to a paediatric intensive care unit.*

Methods: *Children's recall of the intensive care experience was evaluated using telephone interview, at four to eight weeks and six to twelve months following discharge. Separate scores were assigned to reflect children's recall of general events and painful events. Recall was classified as either limited or extensive. Statistical analysis was performed to detect change in recall status over time and the association between the ability to recall and relevant admission variables (previous admission status, type of admission, frequency/intensity of painful procedures, length of stay and administration of analgesia/sedation).*

Results: *In a sample of 50 children, recall of general events was extensive 4 - 8 weeks after discharge in 29 (58%) children and extensive in 26 (52%) children 6 - 12 months after discharge. Recall of painful events was extensive 4 - 8 weeks after discharge in 15 (30%) children and 14 (28%) children at 6 - 12 months after discharge. Thirteen (33.3%) of the 39 children who received analgesia/sedation had extensive recall of painful events at 4 - 8 weeks after discharge; 12 (30.8%) children had extensive recall at 6 - 12 months after discharge.*

Conclusions: *Children have the ability to recall many of their experiences related to admission to a paediatric intensive care unit and can continue to recall many of these experiences twelve months after discharge. Despite current methods for guiding titration of opiate infusions and intermittent administration of benzodiazepines, many children can recall painful experiences and general events encountered within the intensive care unit. (Critical Care and Resuscitation 2000; 2: 253-259)*

Key words: Paediatric, intensive care, recall

The development of specialised intensive care units has been underpinned by high technology medicine, sophisticated monitoring of organ function, and the knowledge and clinical skills of a large multidisciplinary team. Unfortunately, associated with this level of care is the potential for a number of adverse phenomena, including pain derived from invasive procedures or surgery, disorientation from sleep deprivation and loss of diurnal rhythm, and anxiety related to loss of autonomy, difficulty in communicating and fear of the unknown.¹⁻³

Pharmacological analgesia and sedation have provi-

ded the basis for the management of pain and control of awareness in patients admitted to the intensive care unit. In the presence of neuromuscular blocking agents, oral endotracheal tubes, patient dissociation and withdrawal, and disturbances in neurological function, assessment of pain and level of awareness is often difficult and may preclude optimal titration of medication in response to patient need.¹ The degree to which the patient is aware of the intensive care unit (ICU) environment may frequently be unknown to the clinician. However, Cheng¹ purports that recall, rather than awareness, is more likely to have a significant impact on the well-

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being of a patient recovering from a life threatening illness. Unlike awareness, which is defined as a state of being awake, conscious or cognisant, recall indicates the presence of explicit memory, which signifies the acquisition of new information, storage of this information and the potential to retrieve it.⁴

The recollection of patients' experiences in the intensive care unit has been widely explored in the adult population.^{3,5-10} In a review of 26 research studies conducted between 1967 and 1997, Stein-Parbury and McKinley¹¹ concluded that between 30% and 100% of patients could recall all or part of their stay in the ICU. Prior to 1990, the majority of studies were based upon the premise that the ICU experience was problematic and, therefore, focused upon negative aspects of the experience. More recent studies have used an open ended approach to questioning from which information from the patient has been relayed from a more personal context, and included recollections that are positive, negative and neutral.

Only a small number of studies pertaining to children's recall of the hospital experience have been performed and have been confined to hospitalisation of the preschool aged child,¹² recall of intraoperative events during anaesthesia^{13,14} and recall of treatment in the accident and emergency room.¹⁵ Research has also focused on children's memory for medical procedures¹⁶ and the impact of stress on children's ability to recall medical experiences.¹⁷

The ability of children to recall their experience of the intensive care unit has never been ascertained or explored. This paucity of literature stems, in part, from the belief that children lack the verbal skills, conceptual abilities, recall and overall narrative competence to convey their experiences reliably.¹⁸ However, studies have now shown that children as young as three years old can give accurate free-recall accounts of past events, the detail of which increases with age,^{15,18,19} and provide graphic descriptions of experiences related to illness.²⁰⁻²³

We therefore performed a pilot study to prospectively determine children's ability to recall events experienced during admission to a paediatric intensive care unit. The authors have made no attempt to provide a qualitative assessment of the content of experiences recalled.

METHODS

All children over the age of eight years admitted to a 16 bed multidisciplinary paediatric intensive care unit were eligible for entry into the study. Children who had a preexisting cognitive disability, or children who required admission for traumatic or non-traumatic brain injury were excluded, with the exception of children who had sustained a minor head injury (Glasgow coma

score >12) with transient loss of consciousness. Ethics approval for the study was obtained from the ethics committee for human research at the Royal Children's Hospital, Melbourne. Parental consent was obtained at admission to the intensive care unit following explanation of the purpose of the study, and notification of interview following discharge.

Data collection consisted of type of admission (elective/emergency), number of previous admissions to the ICU and length of stay. The association between these variables and children's ability to recall experiences in the intensive care unit was ascertained. Diagnosis and source of admission to the intensive care unit were also documented. All procedures performed on each child during the course of their stay in the intensive care unit were documented and classified according to the following criteria:

- a) A minor procedure: a procedure in which no increase in background analgesia or sedation would be provided. This would include peripheral venous cannulation, venipuncture/arterial puncture for blood sampling, endotracheal suction, chest X-ray and elective endotracheal extubation.
- b) A moderate procedure: a procedure performed following adjunctive analgesia with or without additional sedation. This would include elective endotracheal intubation, insertion of a central venous line and insertion of a chest drain.
- c) A major procedure: a procedure performed in an emergency situation where administration of analgesia and sedation is withheld due to time constraints or concerns relating to haemodynamic stability. This would include emergency intubation, cardiac massage and emergency defibrillation.

These procedures were graded with a score of one, two or three respectively to reflect their potential as a source of pain or discomfort. At discharge from the intensive care unit, these scores were added together to provide a total painful procedure score (PPS). Administration of neuromuscular blocking agents (e.g. pancuronium, vecuronium), sedatives (e.g. diazepam) and narcotic analgesics (e.g. morphine) were also noted. Any significant events that had occurred in the same room as a child entered into the study were documented; these included cardiac arrest or death of a child, or overt distress of a child or family member.

Children were interviewed by telephone four to eight weeks following discharge from the intensive care unit. Each interview was conducted by one research fellow in intensive care. Interview format consisted of the opportunity for free recall by each child in response to general questioning: "Tell me about when you had your accident. What happened?", followed by probed recall with more specific questioning: "Who was with you?"

Why couldn't you sleep?". These questions were often shaped by events or procedures that had taken place during the child's stay in the ICU and had been recorded during data collection. All questions were posed in an attempt to avoid "Yes" or "No" responses to maximise the amount of information obtained. A second interview, using an identical format, was conducted six to twelve months after discharge from the ICU.

The ability of the child to recall experiences during admission to the intensive care unit was then classified according to the following criteria:

0. no recall
1. scanty recall on specific questioning
2. scanty recall on general questioning or detailed recall on specific questioning
3. detailed recall on general questioning

Separate scores were assigned to each child to reflect recall of general events (including types of equipment, characteristics of other patients in the room or names of staff members) and recall of painful events. These scores were then classified as extensive recall (a score greater than or equal to two) or limited recall (a score less than two).

Statistical analysis of the data was performed using Stata 5.0

RESULTS

Sixty patients, admitted during a consecutive twelve month period to the paediatric ICU, fulfilled all entry criteria and were entered into the study. Ten children were subsequently withdrawn as three died, six were lost to follow-up and one child sustained unexpected neurological damage. The mean age of the remaining 50 children was 13.7 years (range 8 to 20 years). Thirty one (62%) children were elective admissions following cardiac surgery. The remaining 19 (38%) children were emergency admissions; six children were admitted with asthma, three with multiple trauma, three with ingestion, two with upper airway obstruction, two with cardiomyopathy and the remaining three children with a dysrhythmia, epilepsy and toxic shock respectively. Thirteen (26%) children had been previously admitted to the intensive care unit, of which ten were elective admissions following cardiac surgery and three were emergency admissions as a result of asthma.

Thirty nine (78%) children received sedation with diazepam (0.1 - 0.3 mg/kg four hourly as required) and analgesia via a continuous infusion of morphine (10 - 40 µg/kg/hr). Eleven (22%) children received no sedation or narcotic analgesia, however two children required general anaesthesia for the insertion of an endotracheal tube. One child was sedated as a result of a drug ingestion necessitating admission to the intensive care unit.

A painful procedure score of five or less was assigned to 39 (78%) children whereas 11 children received a painful procedure score greater than five. Forty (80%) children stayed in the ICU for less than 48 hours, the remaining ten children had a length of stay greater than 48 hours. Thirty nine (97.5%) of the 40 children who stayed in the ICU less than 48 hours had a painful procedure score less than five. One child had a painful procedure score greater than five. All of the ten children who stayed in the ICU greater than 48 hours had a painful procedure score greater than five (Fishers exact $p = <0.001$).

Recall of general events was extensive at 4 - 8 weeks following discharge in 29 (58%) children compared to 26 (52%) children at 6 - 12 months. Twenty one (42%) children had limited recall of general events at 4 - 8 weeks whereas 24 (48%) had limited recall 6 - 12 months after discharge (Sign Test $p = 0.02$). Recall of painful events was extensive at 4 - 8 weeks following discharge in 15 (30%) children compared with 14 (28%) children at 6 - 12 months. Thirty five (70%) children had limited recall of painful events at 4 - 8 weeks after discharge whereas 36 (72%) had limited recall at 6 - 12 months (Sign Test $p = 0.18$).

The analysis of data to detect the association between factors relevant to admission to the intensive care unit and children's ability to recall the ICU experience revealed the following:

Sedation

Recall of general events

- a) 4 - 8 weeks following discharge: ten (91%) of the 11 children *not sedated* had extensive recall. One child (9%) had limited recall. At 6 - 12 months following discharge: The same proportion of children had extensive recall and limited recall of general events
- b) 4 - 8 weeks following discharge: nineteen (48.8%) of the 39 children who *did receive sedation* had extensive recall of general events, while 20 (51.2%) had limited recall. At 6 - 12 months, 16 (41%) children had extensive recall and 23 (59%) had limited recall.

The association between recall of general events and sedation was statistically significant at 4 - 8 weeks (Fishers exact $p = 0.02$) and at 6 - 12 months (Fishers exact $p = 0.01$).

Sedation

Recall of painful events

- a) 4 - 8 weeks following discharge: two (18.2%) of the 11 children *not sedated* had extensive recall. Nine (81.8%) children had limited recall. At 6 - 12

months following discharge the same proportion of children had extensive recall and limited recall of painful events.

- b) 4-8 weeks following discharge: 13 (33.3%) of the 39 children who *did receive sedation* had extensive recall of painful events, while 26 (66.6%) had limited recall. At 6-12 months, 12 (30.8%) children had extensive recall and 27 (69.2%) had limited recall.

The association between recall of painful events and sedation was not statistically significant at 4 - 8 weeks (Fishers exact $p = 0.47$) or 6 - 12 months (Fishers exact $p = 0.71$).

Previous admission

Recall of general events

- a) 4-8 weeks following discharge: 24 (61.5%) of the 39 children who had *no previous admissions* had extensive recall. Fifteen (38.5%) children had limited recall. At 6 - 12 months following discharge: 21 (53.8%) children had extensive recall and 18 (46.2%) children had limited recall.
- b) 4 - 8 weeks following discharge: 5 (45.5%) of the 11 children who *had previous admissions* had extensive recall. Six (55%) children had limited recall. At 6 - 12 months following discharge: the same proportion of children had extensive recall and limited recall of general events.

The association between recall of general events and previous admission was not statistically significant at 4 - 8 weeks (Fishers exact $p = 0.49$) or 6 - 12 months ($\text{Chi}^2 p = 0.62$).

Previous admission

Recall of painful events

- a) 4 - 8 weeks following discharge: 13 (33.3%) of the 39 children who had *no previous admissions* had extensive recall and 26 (66.6%) children had limited recall. At 6 - 12 months following discharge: 12 (30.8%) children had extensive recall and 27 (69.2%) children had limited recall.
- b) 4 - 8 weeks following discharge: 2 (18.2%) of the 11 children who *had previous admissions* had extensive recall and 9 (81.8%) had limited recall. At 6 - 12 months following discharge: the same proportion of children had extensive recall and limited recall of painful events.

The association between recall of painful events and previous admission was not statistically significant at 4 - 8 weeks (Fishers exact $p = 0.33$) or 6 - 12 months (Fishers exact $p = 0.41$).

Type of admission

Recall of general events

- a) 4 - 8 weeks following discharge: 14 (73.7%) of the 19 children admitted as an *emergency admission* had extensive recall and 5 (26.3%) children had limited recall. At 6 - 12 months following discharge: 13 (68.4%) children had extensive recall and 6 (31.6%) had limited recall.
- b) 4 - 8 weeks following discharge: 15 (48.4%) of the 31 children *electively admitted* had extensive recall and 16 (51.6%) had limited recall. At 6 - 12 months following discharge: 13 (41.9%) children had extensive recall and 18 (58.1%) had limited recall.

The association between recall of general events and type of admission was not statistically significant at 4 - 8 weeks ($\text{Chi}^2 p = 0.08$) or 6 - 12 months ($\text{Chi}^2 p = 0.07$).

Type of admission

Recall of painful events

- a) 4 - 8 weeks following discharge: 5 (26.3%) of the 19 children admitted as an *emergency admission* had extensive recall and 14 (73.7%) children had limited recall. At 6 - 12 months following discharge: the same proportion of children had extensive recall and limited recall of painful events.
- b) 4 - 8 weeks following discharge 10 (32.3%) of the 31 children *electively admitted* had extensive recall and 21 (67.7%) had limited recall. At 6 - 12 months following discharge: 9 (29%) children had extensive recall and 22 (71%) had limited recall.

The association between recall of painful events and type of admission was not statistically significant at 4 - 8 weeks ($\text{Chi}^2 p = 0.66$) or 6 - 12 months ($\text{Chi}^2 p = 0.84$).

Length of stay

Recall of general events

- a) 4 - 8 weeks following discharge: 22 (55%) of the 40 children who stayed in the intensive care unit *less than 48 hours* had extensive recall and 18 (45%) children had limited recall. At 6 - 12 months following discharge: 20 (50%) children had extensive recall and 20 (50%) had limited recall.
- b) 4 - 8 weeks following discharge: 7 (70%) of the 10 children who stayed in the intensive care unit *more than 48 hours* had extensive recall and 3 (30%) children had limited recall. At 6 - 12 months following discharge: 6 (60%) children had extensive recall and 4 (40%) had limited recall.

The association between recall of general events and length of stay was not statistically significant at 4 - 8

weeks (Fishers exact $p = 0.49$) or 6 - 12 months (Fishers exact $p = 0.73$).

Length of stay

Recall of painful events

- a) 4 - 8 weeks following discharge: 9 (22.5%) of the 40 children who stayed in the intensive care unit *less than 48 hours* had extensive recall and 31 (77.5%) children had limited recall. At 6 - 12 months following discharge: 8 (20%) children had extensive recall and 32 (80%) had limited recall.
- b) 4-8 weeks following discharge: 6 (60%) of the 10 children who stayed in the intensive care unit *more than 48 hours* had extensive recall and 4 (40%) children had limited recall. At 6 - 12 months following discharge: the same proportion of children had extensive recall and limited recall of painful events.

The association between recall of painful events and length of stay was statistically significant at 4 - 8 weeks (Fishers exact $p = 0.05$) and 6 - 12 months (Fishers exact $p = 0.02$).

Painful procedure score (PPS)

Recall of painful events

- a) 4 - 8 weeks following discharge: 9 (23.1%) of the 39 children with a PPS *less than five* had extensive recall and 30 (76.9%) children had limited recall. At 6 - 12 months following discharge: 8 (20.5%) children had extensive recall and 31 (79.5%) had limited recall.
- b) 4 - 8 weeks following discharge: 6 (54.5 %) of the 11 children with a PPS *greater than five* had extensive recall and 5 (45.5%) had limited recall. At 6 - 12 months following discharge: the same proportion of children had extensive recall and limited recall of painful events.

The association between recall of painful events and PPS was not statistically significant at 4 - 8 weeks (Fishers exact $p = 0.07$) but statistically significant at 6 - 12 months (Fishers exact $p = 0.05$).

Painful procedure score (PPS)

Recall of general events

- a) 4 - 8 weeks following discharge: 22 (56.4%) of the 39 children with a PPS *less than five* had extensive recall and 17 (43.6%) children had limited recall. At 6 - 12 months following discharge: 20 (51.3%) children had extensive recall and 19 (48.7%) had limited recall.
- b) 4 - 8 weeks following discharge: 7 (63.6%) of the 11 children with a PPS *greater than five* had extensive recall and 4 (36.4%) had limited recall. At 6 - 12 months following discharge: 6 (54.5%)

children had extensive recall and 5 (45.5%) had limited recall.

The association between recall of general events and PPS was not statistically significant at 4 - 8 weeks (Fishers exact $p = 0.74$) or 6 - 12 months (Fishers exact $p = 1.00$).

DISCUSSION

The results of this study indicate that children have the ability to recall experiences following admission to a paediatric ICU, and can continue to recall many of these experiences six to twelve months following discharge. Recall of general and painful experiences is more likely when a child's length of stay is greater than 48 hours (during which time there is likely to be a greater frequency and/or intensity of painful procedures), or if the child does not receive analgesia via a continuous narcotic infusion, and sedation with intermittent administration of diazepam.

The ability of children to recall painful experiences at 6 - 12 months after discharge and its association with the intensity and frequency of painful procedures performed, raises questions as to the efficacy of methods guiding administration of analgesia and sedation in our ICU. This is unlikely to be a reflection of poor choice of medication but rather inadequate titration of analgesia and sedation in response to patient need.

The assessment of children's level of pain and degree of awareness by clinicians in the intensive care unit has historically relied upon crude interpretation of physiologic variables, such as blood pressure and heart rate, and visible signs of patient agitation including sweating and restlessness. The need for more accurate assessment has been appreciated and heralded the introduction of patient specific scoring systems^{24,25} and advances in neurophysiologic monitoring, including the development of bispectral analysis. While the latter provides some promise of accurate assessment of awareness and level of sedation, its appropriateness for use in the intensive care unit is still unknown.²⁶

The ability of children to interact with the intensive care environment is, at times, necessary for the implementation of procedures such as extubation, and the ability of children to be actively involved in choices surrounding their own care. While many of the experiences within the ICU may be uncomfortable, painful or distressing to a child, many interactions with staff, other children and family members can be positive and enriching and could potentially have a positive influence on future recovery.²⁷

The ability of children to recall experiences over time needs to be viewed with an appreciation of a number of factors; the amount of information spontaneously reported by children continues to increase

with age,^{15,28} the willingness of parents to discuss events involving their children may serve as a form of instruction to children about how to remember an event,²⁹ and multiple interviews with the same child often has the effect of increasing memory of an experience.³⁰ Peterson¹⁵ found that children interviewed at one year after injury maintained greater accuracy and completeness of recall of hospital treatment events when interviewed at two years, compared with children who did not receive the additional interview at one year.

The limitations of this study are borne from its intended design as a pilot study to ascertain whether children have the ability to recall experiences following admission to a paediatric ICU. A future, and more definitive study, to evaluate the content of experiences recalled by children is required. The value in obtaining and critiquing these experiences is dependent upon an interview process that will easily enable children to convey their experiences, and a sample size which will allow analysis of these experiences in relation to other health related and situational variables including age, severity of illness at the time of admission, ethnic, religious and socioeconomic orientation and state of health at time of interview. The opportunity to view the intensive care environment from a child's perspective will provide a basis from which current practice can be critiqued, further research developed and a greater potential will exist for improving quality of care.

CONCLUSION

Children have the ability to recall many of their experiences related to admission to a paediatric intensive care unit and can continue to recall many of these experiences twelve months after discharge. Despite current methods for guiding titration of opiate infusions and intermittent administration of benzodiazepines, many children can recall painful experiences and general events encountered within the ICU. Further studies are required to evaluate the content of experiences recalled and their potential impact on future recovery.

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