The psychological impact of PICU admission on the family

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Why look at this group?

- Theoretical high risk of PTSD in children and parents
- Potential for preventative work and intervention
- Predictable steady workload (as compared with after disaster)
Inherent Difficulties

• Patients unconscious
• Carers in extreme distress (capable of informed consent)
• High risk of death
• No formal follow up structure
• High proportion of deprived families
• Majority of patients aged under 5y
Plan

- Literature on Children
- Research at St George’s and Great Ormond St
- Literature on Parents
- Research at St George’s and Great Ormond St
Children
Growing interest in outcomes after ICU generally, and in rates of post traumatic stress symptoms in paediatric populations and their parents.

Potential stressors
1) pre admission - acute illness/ accident
2) admission - invasive procedures, pain, witnessing others’ distress
Adult ICU findings

- Menzel (1998) fear tube in situ
- Schelling et al (1998) long lasting PTSD
- Scragg (2001) link between ICU experiences and PTSD
- Jones et al (2001) on link between delusional memories and PTSD
Child ICU findings: short term

• Only 67% remember anything, predominantly neutral/positive (n=40)

  *Playfor et al (2000)*

• 100% remembered something, 50% negative memories (n=50)

  *Karande et al (2005)*
Child ICU findings: longer term

- PTSD higher in children (52% v 9%) 6-8 wks after critical illness
  
  *Landolt et al (1998)*

- PTSD higher in children (26% v 0%) 6-12m after critical illness (n=35)
  
  *Rees et al (2004)*

- Association between no. of invasive procedures and PTSD symptoms at 6 months (n=60)
  
  *Rennick et al (2004)*
Research on Children

1) Pilot interviews with SGH child survivors aged over 7 (n=15)

2) Interviews with GOS child survivors 3 mths and 1yr after discharge (n=102)
1) Pilot Interviews @ 8 mths (n=15)

- 13/15 could remember the admission
- 4/15 scoring above cutoff for PTSD at 9 months
What I remember about PICU
Children’s Quotes

“I feel like I am the odd one out of everybody”

“I am not as scared as I was …now when I get a cut it is just nothing”
Fear Schedule SD scores
Children’s Quotes

“I fell asleep and dad was holding my hand and then I saw these people getting their heads chopped off”
2) Children’s Memories Project (n=102)

- Relationship between memories and post traumatic stress
- Relationship with parental distress
Great Ormond Street Hospital
Design

• Interview at 3m

• Telephone follow up at 1y

Also collected measures of parent’s post traumatic stress, anxiety and depression at both timepoints
Psychological measures

- Child Revised Impact of Event Scale (post traumatic stress)
- ICU Memory Tool (factual v delusional memories)
Sample

- Survivors over 7 years of age (n=102/132)

Exclusions

- Learning difficulties; readmitted to PICU; professional refusal (e.g., palliative care); long term ventilation; self-harm
Reason for admission

- Elective surgery
- Trauma
- Other
Factual Memories

63% remember some aspect of admission

- Pre PICU
  accident, collapse, feeling unwell
- During PICU
  family, staff, machines, (breathing tube 20%)
August 2004

8 Sunday

Morning

2004

Afternoon

Evening

M
T
W
T
F
S
S
Factual Memories

63% remember some aspect of admission

- Pre PICU
  accident, collapse, feeling unwell
- During PICU
  family, staff, machines, (breathing tube 20%)
- Post PICU
  ward, injections, ambulance to local hospital
“It was very hard to be sick lying down obviously…”

13y boy, head injury
Delusional Memories (1 in 3)

- “This isn’t my head!” “Where are my fingers?”
- Rats in cups moving across the wall
- Parents replaced by impostors
- Staff trying to kill patient
- Terrorist attack
“When I came back from the hospital I was seeing lots of things on the walls…..Um wherever I looked I would see some things …..Yea crawly things”

10y girl, cancer
“Scorpions everywhere! On my feet and on the walls – then when I woke up again I could see through them.”

10 year old boy (RTA)
Post traumatic stress symptoms

“Came into my mind and sort of like a video clip and going towards the edge yes and then the whole of my body just chucked itself forward as if I was crashing. It was really weird”

13y boy, head injury
Predictors of Post-traumatic stress

3 mths
• Emergency admission (p<0.01)
• Delusional memories (inc hallucinations) (p<0.05)

1 yr
• Post traumatic stress score at 3m (p<0.01)
Post traumatic stress cases

[Graph showing the percentage of new cases and cases at 3 months for 3 months and 1 year.]
Main findings (1)

• Significant minority of children recall hallucinations and bizarre dreams during hospital stay

• Hallucinations and emergency admission predict Post traumatic stress at 3 mths
Main findings (2)

• Post traumatic stress at 3 mths strongest predictor of score at 1y

• Half of post traumatic stress cases at 1y are NEW cases
Parents
Literature on Parents

Carter & Miles (1989) Parental Stressor Scale (PSS:PICU) – 7 dimensions of experience

Child’s appearance  Sights and Sounds
Procedures          Parent’s role
Child’s behaviour   Staff behaviour
                    Staff Communication
Board & Ryan-Wenger (2002)

• PICU mothers (n=31) significantly more distressed than general ward mothers (n=32) 6 months after discharge

- 27% PICU parents (n=33) screened positive for PTSD compared to 7% general ward parents (n=29), 6-12 mths post discharge

- 272 parents completed stress questionnaire on discharge
- 161 followed up at 4 mths
- 21% PTSD at follow up
- PTSD correlated with distress at discharge but not with illness severity (PRISM)
Research on Parents

1) Mixed method interview study at 8 months (n=34 mothers, n=18 fathers)

2) Longitudinal study of child-parent pairs seen at 3mths and 1yr (n=66 pairs)
1) Parent Interview @ 8 months

n=34 mothers; 18 fathers

• Recollections of admission - stress and coping
• Current distress
• Views on follow up

Colville GA & Gracey D (2006)
Intensive and Critical Care Nursing 22 (1) 49-55
QUANTITATIVE DATA
Mothers’ and Fathers’ Post Traumatic Stress scores

![Box plot comparing mothers' and fathers' post-traumatic stress scores. The box plot shows higher stress scores for mothers compared to fathers, with a statistical significance indicated by an asterisk (*) between the groups.](image-url)
Association between talking at time and stress at follow up

![Graph showing Total Impact of Event Scale (IES) score for 'no' and 'yes' talked about experience at the time.](image)
Type of follow up desired (n=52/54)

- Medical: 10%
- Medical + Psychological: 29%
- Psychological: 29%
QUALITATIVE DATA
QUOTES: CHILD’S APPEARANCE

• “she looked totally drugged, dazed, gone, she was just out, puffy”

• “she just looked horrific, bright red face, tubes coming out of every possible place “
“she was so bloated and she looked terrible, I just could not make myself to go near her.
QUOTES: TRANSFER TO WARD

• “planets apart“

• “The room from hell. When I saw it, I couldn't stop crying. “

• “The difficulties were … before and after. PICU itself was fine”
Transfer to General Ward

- Responsibility for child’s care
- Child’s emotional demands
- Parents’ resilience
- Level of staffing
- Staff expertise
QUOTES: POSITIVE ASPECTS

“Because of the accident, he is very, very, special to me.”

“We saw the best of people during that time”

“I re-valued my life totally. This house could burn down tomorrow as long as my family stood out there I wouldn't worry”
Staff behaviour that parents appreciated

• “I just thought they were all fantastic, they never did anything without letting you know what they were going to do”

• “They were very good with us even when we asked silly questions”
• “They weren’t patronising, they were just normal and nice”

• “All the staff there were very good, if you wanted to talk you talk, if you didn’t want to talk you didn’t.”
Difficult Staff Behaviour

• Conflicting Information

“You do tend to get completely conflicting answers from two different doctors”
• Not knowing who people were

“When they do introduce themselves they sort of mumble their names and you think who the hell was that!”
• Perceived Criticism of child or parent

“She sort of implied that X had been a bit of a nuisance by not settling down”

“We were made to feel a little bit as though we were neglecting her by not staying in”
• Anxiety re staff inexperience

“Everyone has got to learn, but not when it is my child”
2) Child-parent pairs at 3mths and 1yr

n=66 pairs

Post-traumatic stress symptoms assessed at 3 months and 1 year post discharge
Parent PTS

Post Traumatic Stress above cut off

- 3 months
- 1 year

Chart showing the percentage of Parent PTS above the cut-off from 0% to 50% over a period of 3 months to 1 year.
Parents: new cases at 1 yr

![Bar chart showing new cases at 3 months and 1 year.](chart.png)

- 3 mths: 50% new case, 20% case at 3m
- 1 year: 30% new case, 10% case at 3m
Parent and Child
Post Traumatic Stress

3 months 1 year
Predictors* of Post traumatic stress: Parents

3 mths
• Emergency admission (p<0.001)

1 yr
• Emergency admission (p<0.001)
• PTS score at 3m (p<0.001)
• Anxiety score at 3m (p<0.001)
• Depression score at 3m (p<0.001)

* Spearman correlations
Spearman correlations for PTS scores (n=66)

3m 1y

parent PTS

0.02

child avoid

-0.08

child intrus
Spearman correlations for PTS scores (n=66)

3m 1y

parent PTS

0.38**

child avoid

child intrus

-0.08
Post traumatic stress patterns at 1 year

- Parent PTS
- Child PTS
- Parent ok
- Child ok
Other research

- RCT evaluation of follow up clinic
- Post traumatic growth in parents after PICU
- Parents’ experiences of retrieval
- Screening for risk of PTSD
- Gender differences in parents’ psychological reactions

Thank you

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