Great Ormond Street Hospital for Children
NHS Trust

Psychosocial Aspects of ITU

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GOSH Guidelines:

Please see GOSH document library for the following GOSH policies:

- When a child dies – information for staff.
- Preventing harassment, aggression and violence from parents
- Resolving conflict between parents and staff
- Alcohol and substance misuse policy.

This compliments teaching in the Reflective Practice Slot with ICU Psychologist

Fundamental Knowledge:

List of topics relevant to PICU that will have been covered in membership examinations. They will not be repeated here.

- Effects of sleep deprivation and its consequences

Information for Year 1 ITU Training (basic):

Year 1 ITU curriculum
- The Impact of ICU and methods of minimizing distress in patients & families
- The role of communication in the effective functioning of an ICU
- Principles of conflict resolution and negotiation
- Skills in breaking bad news

Curriculum Notes for Year 1:

The Impact of ICU and methods of minimizing distress in patients & families

Adult Intensive Care patients suffer from significant rates of post traumatic stress after admission, with symptoms relating both to distressing memories of the admission **(Ref 1),** and memories of delusional experiences such as nightmares and hallucinations **(Ref 2).** Only recently has the impact on children been investigated (**Refs 3, 4 & 5**). Colville (**Ref 4**) reviewed the literature on the psychological impact of PICU on children which showed a 'mixed picture of resilience and distress'. A study carried out at GOS (**Ref 5**) revealed that a significant minority of children may have posttraumatic stress months after admission including distress over factual or delusional memories of their stay. Delusional memories were associated with duration of opiates/benzodiazepines and risk of post-traumatic stress. Good review peds CCM (**Ref 6**). Increasingly, children are awake while on ICU and are exposed to numerous stressors including: having invasive procedures (cannulation & suctioning); witnessing other children having procedures, crash calls and sometimes the death of another child; awareness of the loss of their previous functioning which may mean they are unable to communicate (e.g. if intubated or brain damage has occurred); they may experience side-effects of pain medication or being weaned offsedation as well as the 'usual' stressors of being in hospital (separation from family, feeling unwell, experiencing pain, loss of routine and home comforts).

One of the ICU team's role in supporting children and families is to try and minimize their stress (where possible) in order to prevent a normal traumatic stress reaction persisting and running the risk of developing into PTSD. While this appears principally the domain of psychosocial staff, medical staff have the most contact time with patients and families so an understanding of their perspective and good communication is key. Colville (**Ref 7**) writes:

"Distress in a conscious child during admission may present as marked lack of engagement or as active resistance. The latter directly impacts on the child's medical condition; an anxious child may resist mechanical ventilation, and increases in heart and metabolic rate place further demands on an already critically ill patient."

To reduce distress in children on ICU, effective pain management is vital. Studies have shown that neonatal experience in pain can predict future pain sensitivity (**Ref 8**) as well as its obvious role in causing stress in patients and families. For awake children, it is important to involve the play specialist to program activities so that the child is more occupied and can gain a sense of control over their environment, and the speech and language therapist to encourage alternative methods of communication between the child and family and staff. The Psychologist can assess the child and family to consider their psychological, developmental play and communication needs. The Psychologist may then work with the child and family to strengthen their strategies to cope with the experience of being on ICU and adjusting to different functioning. A powerful method of maximising coping in children while on ICU is to interview parents about their child's strengths and resources in the presence of the awake child.

Considering the research on PTSD in mothers of premature infants (**Ref 9**), it is likely that much applies to many of our parents. However, "it is important to strike a balance between acknowledging the strain on families on PICU and 'over-pathologising' their reactions" (**Ref 7**). Research with families whose children have been in ICU indicates they found the following helpful (**Ref 10**):
- Being allowed to stay with child as much as possible
- Staff being sensitive to child's overall needs
- Being treated with genuine concern and caring
- Being able to telephone unit at any time
- Having explanations about equipment and tubes

The role of communication in the effective functioning of an ICU
Only fairly recently has open communication with patients and their families been seen to be good practice. However, before we communicate information to children and families we need to consider differences in people's information style and what they are able to cope with at the time. It is well known that when individuals are in a state of high emotional arousal the brain's ability to encode, store and retrieve information is compromised. Additionally, numbness and avoidance of feelings are normal in stress and trauma reactions. This all makes the clinician's job harder when trying to communicate sensitive information. Poor communication results in patient dissatisfaction, higher incidents of complaints and increased litigation (**Ref 11**).

Factors that inhibit communication
- Focusing purely on physical aspects early
- Giving advice & premature reassurance
- Using closed, leading and multiple questions

Factors that promote good communication
- Consider psychological morbidity
- Being empathic
- Making educated guesses about how a patient/relative is feeling
- Summarizing patient/relative's comments
- Active Listening – showing that you are listening and have heard
- Cue Recognition - responding to verbal and non-verbal cues
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As we have seen good communication is crucial in facilitating coping in children and parents, and it also reduces the potential for conflict.

Principles of conflict resolution and negotiation:
"Health professionals may struggle…with…pulls to erupt, blame or criticize (either themselves, each other, the parents, family or their own families at home) when the emotional stakes are high and helplessness around an inability to cure or fix begins to peak." (**Ref 12**)

"I cried inconsolably, inconsolably when my baby's heart rate could not be controlled. I want to be with her in NICU, but it kills me to see her so sick; her body thrashing; needles piercing her perfect head; machines glued to her tiny frame; my utter helplessness. Even when I go home to rest at night, my mind is filled with dread, no peace… The uncertainty is a knife through my very being. I'm angry, sad, frightened, exhausted all at once. Anger grips me but knows no focus. With whom can I be angry? Myself? My innocent baby? The doctors who practiced sound medicine?" (**Ref 12**)

Common sources of conflict on ICU
- Parents not feeling they have had enough information
- Staff feeling they have told families information many times
- Differences of opinion between staff and families
- Different ideas about hope and prognosis
- Poor communication
- Perceived or real lack of respect for another discipline
- Family conflict as family members in a stressful environment and/or may not have seen each other for a long time due to previous family conflict

The following 'difficult' behaviours may be observed in parents: Distress, anger, wanting to protect their child at all costs, experiencing difficult emotions that they cannot process, lack of sleep, not thinking clearly, they may temporarily lack the cognitive capacity to reflect on their behaviour, not understanding the system, not understanding/being able to take in medical information…

To avoid situations escalating into conflict, it is useful to try and consider the situation from other perspectives. We might consider the different role and responsibilities another professional may have. We can also try and understand more about the family's perspective and how admission to ICU can impact on their behaviour. For example, when we experience extreme emotions it is often because something that we hold important and value is being threatened. This may not only be the sick child being 'threatened' but may be threats to the parents ability to parent for instance their ability to protect their child and feel they are unable to do so. If a parent raises concerns e.g. about their child's care, instead of viewing it as a problem we could consider this as a coping mechanism and a means of maintaining their parental role. It could be said that by, say, asking lots of questions parents can perceive themselves as looking after their child and having some control over their care.

Skills in breaking bad news
In intensive care, contradictory pressures can arise in decisions about continuing treatment. In recent years, intensive care unit physicians and nurses have promoted family-centered care on the basis that adequate and effective communication with family members is the key to substitute decision-making, thereby protecting patient autonomy. For doctors, enhancing end-of-life skills may be a matter of improved listening skills, attention to the proper environment for end-of-life discussions, and a willingness to facilitate end-of-life decision-making (**Ref 13**).

Bad news is any information that changes a person's view of the future in a negative way. Withholding bad news from patients was commonly practiced until recently. In recent decades one that emphasizes patient autonomy and full disclosure has replaced the paternalistic model of patient care. Honest disclosure of diagnoses, prognoses, and treatment options allows patients to make informed healthcare decisions that are consistent with their goals and values. The most important factors for patients and families when they receive bad news are the physician's competence, honesty, and attention; the time allowed for questions; a straightforward and understandable diagnosis; and the use of clear language. Families rank privacy; the physician's attitude, competence, and clarity; and time for questions as important. How a physician delivers bad news may affect patients' understanding of and adjustment to the news as well as their satisfaction with their physician (**Ref 14**).

Information for Year 2 ITU Training (advanced):

> **Year 2 ITU curriculum**
> - End of Life: Anticipating & Responding to Grief and Loss
> - Principles of crisis management and debriefing
> - Brief notes on personal functioning within the workplace and coping mechanisms

Curriculum Notes for Year 2

End of Life: Anticipating and Responding to Grief and Loss

There are many different models about grief and loss, most of which suggest that mourning follows a set pattern where the goal is to accept the death and move on. Examples of these include Freud's 'Grief Work' (**Ref 15**), Kubler-Ross' Grief Model (**Ref 16**) and Worden's Task Theory of Bereavement (**Ref 17**).
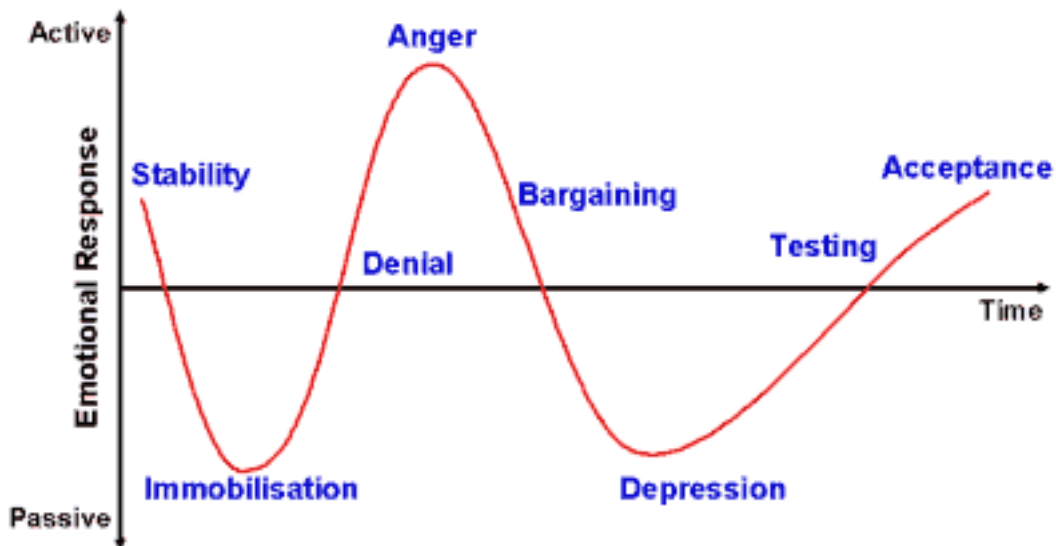
(Kübler-Ross, **Ref 16**)

While these models can be useful as a framework for understanding families' behaviour and our own reactions, we need to consider their drawbacks. For instance, people's grieving may not follow set stages in sequenced order, but may move around between different states or they may experience different emotions simultaneously e.g. be angry and sad, questioning and resigned. Bereavement models can raise more questions than providing answers: What about other emotional reactions if they do not fit into the models? Mourning behaviour can depend on the families' cultural, religious and social background and this may differ from the 'norm' expected for the UK, or by the hospital or individual staff member. What really constitutes a 'normal' or 'abnormal' grief reaction when we are talking about the death of a child? If we consider models with a 'final stage' that people are meant to get to, additional questions can be raised such as can parents ever 'get over' the death of a child? Is letting go always best for people?

We might also consider anticipatory grief reactions which can occur before a child dies and do not fit with most grief models. Psychological research and clinical experience tells us that it is common for bereaved parents to re-experience loss at different stages of the life cycle. For instance, at anniversaries or milestones (e.g. when child may have gone to secondary school, University, had children etc). It is useful to consider our definitions of loss as this will also include the family's hopes and dreams for that child perhaps not being fulfilled. Thus this can occur even if the child survives. This is especially true of an ICU stay if a previously well child leaves with neurological damage and/or physical health problems.

Michael White (**Ref 18**) critiqued normed bereavement models for encouraging disconnection and also people may feel that they have failed to say goodbye properly due to the emphasis on letting go. Psychologically this can significantly impact on the grieving person and increase the likelihood of 'pathological' distress as it can lead to the grieving person disconnecting from themselves and suffering a loss of self. Therefore bereavement may not be about 'working through grief' but more like finding one's own way of living post-loss. White (1988) encourages people to reclaim important aspects of the relationship with the dead person e.g. what the child's experience of them as parents might have been.

Principles of crisis management and debriefing
Doctors who spend a longer time caring for their patients get to know them better but this also makes them more vulnerable to feelings of loss when these patients die. Medical teams may benefit from debriefing within the department to give junior doctors an opportunity to share emotional responses and reflect on the patient's death (**Ref 19**).
Debriefs at GOS ICU are often requested in the context of the following issues:
- Lots of deaths in a short period
- Family reaction to death different/extreme
- Withdrawal
- Child been on ward a long time (for ICU)
- Previously well child dies suddenly
- Child Protection
   - Parents/family meant to protect & nurture
   - Crime scene – cannot do clinical tasks

How we cope with working with death
- Avoidance/switching off
- Numbing/getting used to it → becomes our norm
- Focus on success stories
- Knowledge that we do our best
- Death as positive outcome –end of suffering, release & life after death
- Supports in workplace – peer support, debriefs, bereavement follow-ups,
- Dark humour
- Focus on life outside of hospital: friends, family, partners, exercise, hobbies etc…

Brief notes on personal functioning within the workplace and coping mechanisms
It could be said that in medicine there is a culture of independence and coping stoically. In a busy ICU where ourselves and our colleagues are stretched it is understandable that we do not wish to make demands on others and may develop a 'shell to deflect and anaethetise emotion' (**Ref 12**). People with this 'shell' are good in a crisis as being unemotional can make them more efficient. However it could be costly if this shell becomes permanent.

Research on stress experienced by staff in critical care units has predominantly focused on the nurses; however, a small number of investigations have centred on intensivist neonatologists and paediatricians. Fields et al (**Ref 20**) reported a high incidence of burnout among pediatric intensivists with 50% at risk or burned out. They found "no association between Burnout Scores and training, practice specialties, or practice settings, nor was there an association with aspects of practice that are physically taxing. However, perceptions about the value of their work and feelings of success and satisfaction were highly associated with those respondents classified as burned out. Routine exercise (a strategy used by some for stress reduction) was associated with lower Burnout Scores". Coomber et al. (**Ref 21**) measured stress in UK intensivists and found nearly one in three appeared distressed and 12 % depressed; a rate similar to other specialties. However, stress and depression were predicted by five stressors: "lack of recognition of own contribution by others"; 'too much responsibility at times'; 'effect of stress on personal/family life'; 'keeping up to date with knowledge'; and 'making the right decision alone'.

Job satisfaction is known to defend against burnout. It may be that the kinds of people drawn to intensive care work could have a high tolerance to stress in the first place. One of the Psychologist's roles on ICU is to try and make discussion of the impact of intensive care work as shame and stigma-free as possible. Acknowledging that intensive care work *has* an impact on us does not mean we are 'not coping'; in fact it could be protective in itself.

There has been considerable research into medical consultations. Mishler (**Ref 22**) has shown how a struggle goes on in many consultations between the 'voice of medicine' and the 'voice of the lifeworld'. Launer (**Ref 23**) considers *Reflective Practice* as a key process to mediate these two worlds.

Reflective Practice is a "mode that integrates or links thought and action with reflection. It can consider clinical work and the potential impact it has on ourselves (personally and professionally) and how we cope in difficult situations. Considering these factors means we can learn from situations and take things forward. Traditionally, Reflective Practice groups have focused on complex or challenging cases but reflection on cases that have worked well is highly useful. This need not always be strictly 'positive' e.g. on ICU a death that has been managed well.

Resiliency & Adaptive Coping Strategies
- What tells you that you are coping?
- How do others tell?
- What tells you that your methods of coping are adaptive for you?
- What strategies do you notice others using well?
- What would you like to do more of?

Other sources of information:

Websites
http://www.childbereavement.org.uk/
        -UK charity aims to improve professionals' support to grieving families
http://www.childdeathhelpline.org.uk/index.html -The Child Death Helpline
http://www.act.org.uk/pages/start.asp
        -only UK organisation working to improve care/services for children with life-
        threatening or terminal conditions and their families
http://www.americanhospice.org/articles.htm -free articles on grief and bereavement

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6. PEDS CCM Pharmacology of ICU sedatives + muscle relaxants NB **only for info**-see our protocol on ICU guides
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