**Another piece of the puzzle – psychosocial risk factors *before* PICU admission R1**

**(1470 words)**

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The slogan ‘critical care without walls’ is often heard at intensive care meetings and is repeated in many national guidelines outlining future directions for intensive care as a specialty. It refers to the need to think outside the box - beyond the confines of the pediatric intensive care unit (PICU) - and to be more curious about the lives patients go on to lead after they leave our care.  In response to the growing evidence of continuing psychological and physical morbidity in patients and caregivers, there are calls for more follow up and better coordinated links with rehabilitation programmes after discharge. This represents an important paradigm shift for a field that by definition has had a critical focus, dealing with the short term emergency and then handing back clinical responsibility for the patient to the referring specialty, once the danger has passed. Now increasingly we are moving from a position of seeing ‘critical illness as a single event to realization that it is just one part of a trajectory’1 as reflected in a recent research prioritisation exercise in pediatric intensive care.2

And yet with regard to outcomes, and psychological recovery in particular, our understanding of risk and protective factors is still sketchy. In relation to paediatric patients there is some evidence of a link between acute experiences on PICU (such as deleriogenic hallucinations3 and the number of procedures the child has to undergo4) and later post-traumatic stress, but the evidence for any link with illness severity or length-of-stay (LOS) is inconsistent. Le Broque et al5 have found that early symptoms of post-traumatic stress disorder (PTSD) in parents are associated with a poorer recovery trajectory in children. But there is also evidence that the relationship between parental symptoms and those of the child can work the other way around, with another longitudinal study finding that early avoidant symptoms in children are predictive of higher rates of PTSD symptoms in parents, a year after PICU discharge.6

Now, in a paper by Nelson et al7 in this edition of *Pediatric Critical Care Medicine,* we are invited to consider the potential impact of what has happenedto the child *before* they come through‘the walls’in the first place.

In this study, information on the previous exposure to traumatic events and pre-morbid quality of life is described in n=111 children aged 8-17y admitted to PICU. It emerges that the sample had high rates of baseline trauma exposure and lower quality of life than average *before* they were admitted and that both these factors were significantly associated with their acute stress. The paper concludes that there needs to be greater awareness that children may be at elevated risk of PTSD, not just because of their difficult experiences in hospital but because of their prior adverse experiences which make them more vulnerable to stress.

It has been previously shown that higher post-traumatic stress is associated with lower quality of life in children a year after PICU discharge.8 This study adds another piece to this puzzle, in that it shows an association between *pre-admission* quality of life and subsequent development of acute stress during admission. This acute stress was then, in turn, found to be associated with elevated post-traumatic stress scores at 3 months post-discharge, in a companion paper on the same sample.9

It is useful to be reminded that people who have a history of trauma or other mental health difficulties are more likely to be adversely affected by a subsequent trauma. It is also helpful to be provided with data which appears to show that children admitted to PICU may be at increased risk of developing stress reactions to the admission by virtue of their pre-existing vulnerabilities, which were stronger predictors of acute stress than LOS, illness severity or pain.

Strengths of this study include its large *n* for a study of this type, the use of direct interviews with the children and the fact that it considered the impact of pre-morbid psychological status, which is not usually reported. However only 34% of the variance in acute stress was explained, indicating the need for more research. There were also significant problems with recruitment and attrition between consent and baseline data completion.

The authors are nevertheless to be congratulated on obtaining self-report data from over 100 child patients and on explaining where the data losses occurred along the way, for the benefit of others trying to do similar studies. There are a number of good reasons why there are so few reports of children’s direct experience in this setting – these studies are difficult to do. It took four years to recruit sufficient numbers in this study in part because of the age group of interest, which was determined by the requirement to complete self-report questionnaires. The age distribution of patients admitted to PICU is significantly skewed towards the under-fives, who are not sufficiently verbal to complete standardized interviews. (Although recently updated definitions of PTSD now include descriptions of how it manifests in younger children and have led to the development of a number of scales measuring these symptoms in children as young as 3y10 which may be useful in future screening.)

Another limiting factor in relation to trying to obtain direct report of symptoms from children is the high proportion in the PICU population with significant levels of developmental delay and acquired neurological injury. In Nelson et al’s study,7  46% who were otherwise eligible had to be excluded because of cognitive impairment.

Parents can also be reluctant to allow their child to be interviewed because of fears of distressing or over burdening them, or the (comforting, but mistaken3) belief that the child does not remember anything of their PICU experience. Parents may also be unwilling themselves to revisit what happened, because of their own distress. Alternatively they may not appreciate the value of research examining psychosocial factors in the early days, when their focus is understandably largely on physical recovery.11

It is also difficult recruiting acutely on a PICU unless there is coverage available for weekends and evenings, because of the need in practice to make several attempts to make contact with the family in order to obtain consent and get their permission to speak to the child. And even when an appointment is agreed, the child may be asleep or having a radiology investigation when the researcher returns. This study illustrates this point, in that 23% of eligible cases could not be approached because of logistics relating to the availability of the parents or the researchers.

Butt has recently commented on similar experiences reported by other researchers aiming to examine links between acute factors and later outcomes, pointing out how much information we still do not know.12 He has suggested that an additional clause about consent to being followed up could be included in the general consent to treatment process, as one possible way around these difficulties.

In relation to the implications of Nelson et al’s study,7 clearly we cannot be held responsible for what happens to children before they come in to PICU and most units do not have the resources or the skills currently to support them psychologically after PICU admission. But these data add to a body of literature on the prevalence of distress in this population and on associated pre-morbid risk factors. It could be argued that by using screening tools based on the current state of knowledge in this area, we should be flagging up those most at risk to the specialty teams and primary physicians taking over their care on discharge, so that more support can be sought locally for the families identified as being of potential concern.

It would be possible to collect information routinely at discharge on acute stress13 and on previous trauma exposure, using such measures as the Adverse Childhood Experiences scale.14 Assessment of pre-morbid health related quality of life could also be collected for comparison with subsequent data, using scales such as the one used in this study, the PedsQLTM , which is available for use with children as young as 1 month old.15

There is still a great deal we do not understand about why some children are more distressed than others in this situation - but these findings have highlighted the importance of considering their lives before admission, as well as demographics and medical variables, when trying to determine which of them might be at the greatest risk. This study reminds us that our patients, even as young children, are not blank slates. They come with varying degrees of support available to them at home and have sometimes already lived through difficult life experiences, which may in turn affect their ability to cope with the ordeals they must face in the PICU. By understanding more about them, we will be better placed to help them and their families on the road to recovery.11

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