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The Process of Assembling A Prognosis in Nicu

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Abstract
The uncertainty of prognosis and the importance of prognosis are in tension with one another, especially in modern neonatal intensive care units (NICU). Prognosis, along with diagnosis, forms the cornerstone of making decisions. Reaching a shared consensus often happens without the participants being fully aware of the process. Child psychiatrists can be helpful in a team to make explicit where the team, the family and the outside specialist teams are up to in arriving at consensus and how they might move beyond times of impasse. Child psychiatrists have not traditionally had a large role in NICU except in relation to the adult mental health. This paper emerged from two child psychiatrists, both pediatric neuropsychiatrists, quietly "observing" and describing the everyday business of a NICU. It elucidates the process of how NICU clinicians in one children's hospital, and the families they care for, arrive at a consensus despite the uncertainties and the complexities. What is extraordinary is that this process is usually managed without complication.

Prediction is very difficult, especially about the future.
Niels Bohr (1)
"It appears to me a most excellent thing for the physician to cultivate Prognosis"
 The Art of Prognostics Hippocrates circa 470 BCE (2)

1. The Centrality of Uncertainty and The Future In NICU.

Uncertainty and its management are central features of being human [3]. Our hopes and anxieties circle around uncertainty, especially the things we value most [4]. Along with managing specific illnesses, medicine has always been preoccupied with managing uncertainty [1]. Along the other recalcitrant characteristics and predicaments we have named the seven inescapables of clinical medicine. Thoughts of our children and their futures are freighted with our uncertainties and the value that children hold in our lives make these uncertainties matter. Prognosis and the process of assembling a prognosis are often summarized by wholly inadequate words such as 'guarded', 'worrying', 'encouraging' and 'problematic'. Prognosis for individual diseases in medical textbooks can be very brief indeed while the questions of parents and patients can be very long and searching.

The seven inescapables of clinical medicine	
Uncertainty	Not knowing as clinician or team and the fear of not knowing with associated sense of threat.
Helplessness	When helping does not help or we feel we do not know what to do. We do not know what to do next and experience decision paralysis.
Hopelessness	When hope finds no reality basis, or we can no longer see it, so that the clinician or the team experience a sense of futility and loss of motivation.
Help-Rejection	When help is not accepted in practice, even if sought and accepted in principle, and the clinician or team experience frustration with those needing help.
Clinical Impasse	"stuckness" - the inability to move forward to make clinical progress - stalemate. The clinician and the treatment team find themselves unable to plan, demotivated and going over the same unproductive discussions again and again.
Fear of Change	The fear that change may make things worse and when treatment can be as feared as the condition; the fear of leaving hospital or the fear of going back to hospital.
Too muchness	Overloaded and overwhelmed after too much for too long with too little support and resources. The clinician or the team feel crushed, exhausted and defeated.

Table 1. The seven inescapables of clinical medicine

There are few situations where assembling a prognosis and a consensus around that prognosis are more difficult than on the neonatal intensive care unit. The comparison of the weight and length of an uncertain future of an 85-year-old with 5 weeks of life left, compared to a 5-week-old with 85 years of life left, can be stark. The familiarity gained over years with someone we hold dear can make the leaving hard. But the potential hopes for the new little stranger, recently arrived, also have a special poignance in formulating what the shape and contours of their future might be. Actively managing the future expectations and ambiguities around a child within the treatment team and the family is a key responsibility of the leadership in a neonatal intensive care unit.

Prognosis means 'knowing ahead or before'. It is not confined only to the likelihood of living or dying. There are many types of prognoses. Prognosis for a particular symptom or sign improving; prognosis for recovery from an episode; prognosis for response to a particular treatment or relapse after being treated; prognosis for going to school, seeing and hearing, having friends, being able to walk, work or have a family; prognosis for developing particular complications or having limits to length or quality of life. All of these different prognoses reflect the struggle between the wished-for and the likely futures for a child and their family. They may begin with the short-term seeking of relief from distress and uncertainty and slowly reassemble into a greater appreciation for the longer-term realities, burden of care and quality of life involved. The hopes for the potential life and aspirations for a child are tempered by the potential for the long-term difficulties, suffering and predicaments for child and family.

In this paper, we want to capture just a small amount of the role of the NICU in structuring these uncertainties and enabling the often slow (but sometimes all too fast) aggregation of settled expectations about the future of a child. It is these expectations which are powerfully determinative for the well-being and mental health of the children and adults that are cared for in the NICU [5]. Both hope for themselves as parents, as individuals and vicarious hopefulness for their children begin to be shaped in this very unusual environment. If the neonatal unit is to manage children whose future is imperiled, the staff need a coordinated, collaborative, and concerted approach. This requires a 'good enough' consensus if uncertainty is to be negotiated with the best available outcomes and the least avoidable pain, finding what hope can be had and what despair can be averted.

2. The Role of Child Psychiatry in NICU

NICU Teams are constantly addressing issues of psychological importance around the care of the unwell neonate. There is a very considerable existing psychological expertise in any neonatal unit in assisting families with their baby's distress and illness, death and dying and comprehending the possibility of emerging disability [6]. Consultants and nurses, along with the social workers and the full range of allied heath contributors to the team, move seamlessly between blood gases, ventilation requirements and the emotional crises of the moment with family meetings, negotiating grief and the struggle parents have in order to find the 'signal in the noise' of their child's care. The quiet, less dramatic contribution of child psychiatrists can often seem, and be, out of place in such an active, 'hands-on' environment. There are three ways in which child psychiatrists may contribute in a small way to the larger task of assembling a shared prognosis within a neonatal unit. *Child psychiatry specializes in responding to the seven inescapables* with listening and helping others finding their way through them when time-poor. Visiting reliably can provide a small window of respite for consultant neonatologists and other team members, such as the team social worker and nurses to talk about specific children of concern as they think about the likely future of the child and what help they will need when leaving the unit. *Learning from the unit what the unit doesn't know about itself.* It has been surprising that sometimes the team themselves are not aware of what they do in 'business as usual' that is quite remarkable in complexity. Each member of the clinical team around a child and family is continually providing psychologically sophisticated interventions for struggling families and other team members. The ability to give words to these interventions and a place within a larger psychological framework for some of the help given often provides reassurance to clinicians who have intuited

what was needed to manage psychologically fraught situations. This is of course true for the whole of medicine and paediatrics in particular. But it has a special poignancy in the context of parents dealing with a potential crisis of survival in the first weeks of life.

Focusing on the specific role of infant and toddler neuropsychiatry in which the early signs of future vulnerability to neuro-behavioral, neuro-emotional and neuro-social difficulties and disabilities can be identified and followed up after leaving the NICU by the psychiatric team members. This is a new area of child psychiatry to enable the earliest intervention with neurovulnerable children.

This has involved the team becoming familiar with a group of fellow professionals (psychiatrists) who know so little about the detailed work of keeping babies alive and do so little when it comes to any of the daily crises that characterize even the quietest of days on a NICU. This involvement of those who might intervene beyond the walls of the NICU is part of the investment in the developing mind of the child and finding ways in which parents might help to make it happen. The formulation of the prognosis of the child includes the developing brain and the mind that emerges within it.

Part of doing this is to foster the 'mind' of the NICU so that it is aware of the sheer complexity of its own work and the task of shaping the future of the child in the minds of parents, team members and other hospital teams assisting in the care of the child. This is not the exclusive work of child psychiatrists but it is a task to which they can make a significant contribution.

3. The Process of Decision-Making in NICU

How are decisions made about the likely future of children at such an early age? Decision-making in this context is fraught with uncertainty, high stakes and brings people from such different experiences and backgrounds to work together. It begins with an 'enforced trust' for who else in the community has any idea what to do for these very ill little ones. The trust has been imposed upon the parents by the illness of their child and the lack of alternatives. But as time goes on an acquired trust in the treatment team develops based on the parents' direct experience, watching care in action, receiving explanations that put pieces of the bewildering puzzle that is their child's together. This sort of decision-making is resource intense with ward round after ward round, discussion after discussion, talking with this nurse, that specialist, this occupational therapist and that social worker to reach decisions that have enough in common – an emerging consensus - to move forward. Sometimes this happens effortlessly and at other times the process feels hard, awkward and fragmented. Nevertheless, it is quietly coordinated by the lead consultant and the team.

Decisions are grown rather than made. The daily work of neonatology incorporates growing decisions, maintaining the biochemistry and physiology of the children, minimizing their pain and distress, maximizing their comfort, confidently reassuring the parents and clinical team in their doubts and

concerns, 'sitting with uncertainty' while a consensus emerges, or is forced upon all. Nursing staff are often closer to the child for longer periods than anyone else on the treatment team and 'feel' for the children and their distress so much that they can find the process and time taken to arrive at a consensus personally distressing, morally distressing and sometimes intolerable. They can find the pain they see experienced by the child during this time as 'a futile pain'. The team as a whole, the consultant staff and the unit leadership are often asked to balance the needs of the child, the needs of the nurses and the needs of the family. All staff struggle to disentangle their own feelings from the actual experience of the child. They are all directed to answering those profoundly important questions of parents, "Is my child going to be alright? [3]. Are we doing the right thing? and, in a small number of cases, 'How will we know when enough is enough?' Of course, decisions are not made in isolation from others outside the unit with specific expertise. Asking for advice, incorporating the advice into the treatment plan, deciding which part of the advice should be acted upon, which team consulted needs to be brought further in, or diplomatically 'ectomised' from the process, are all part of the neonatologist's role [7]. At each point, leadership and teamwork foster trust, or don't. The style of some is to be 'often wrong but never uncertain' and others to have 'never made a mistake because they never made a decision'. For most, decision-making fluctuates in the hinterland between the two – confident but not rigid, open to changing direction but still decisive.

4. The Child, The Family and The Treatment Team

Amidst this complexity of decision-making three critical aspects of managing the uncertainty about a child's future shape the issues. *Agreement about the child's condition* – within the family, the treatment team and between both. The more the child is improving the more easily disagreement can be negotiated. Disagreement can jeopardize the management of uncertainty most when the child is deteriorating. Occasionally, where neither decline nor progress is being made, chronic impasse may set in. Impasse, or 'stuckness', around disagreement poses special threats to the effective work of a clinical team and can result in organizational splitting (divisions and conflict among staff that impede the effective working of the unit) [8,9]. This requires the urgent support from those administratively outside the unit to help strengthen decision-making by those making decisions in the unit. It is made worse if those outside the unit amplify the divisions or put increased pressure on the unit to act for political reasons rather than clinical reasons. *The cooperation of the family* – The degree to which the family can or will cooperate can make a great deal of difference on the post-care outcome for the child and the morale of the unit, including parents of other children. It helps from the beginning to have the family actively working to shape the uncertainty with the treatment team. Again, the improvement, deterioration, setting-in of stalemate or impasse in the baby's condition prevents, or puts special strains on, the commitment to cooperate by the parents.

The consistency of the treatment team – Differences of approach and emphasis emerge in the most consistent of treatment teams. Differences may be as simple about parental visiting or

difficult decisions as to whether the child is in pain or not. But where these differences grow over time, are recurrent rather than sporadic, are associated with traumatic cases or lead to frustration and low morale on the unit, a coherent formulation of the child's future is difficult to communicate. Again, this is made worse in the context of deterioration or impasse or family non-cooperation. These different issues can be simplified using very basic decision-making matrices (See Tables 2., 3., and 4.).

	Family Agree among themselves	Family Disagree among themselves
Clinical Team Agree among themselves	The task is simplified to getting family and clinical team to agree with each other	The task is to help the family move toward working together
Clinical Team Disagree among themselves	The task is to help the clinical team move toward working together	Struggle to find any common ground and the condition of the child may shift the situation. This is a serious situation that requires team leadership

Table 2. Agreement WITHIN Parties and Decision-Making Matrix

	Child Improves	Child Deteriorates
Agreement between Clinical Team and Family	Unusual to have difficulties unless psychopathology in family or treatment team	Usual to have ongoing renegotiation of trust unless disagreement occurs within the family or the treatment team
Disagreement of Clinical Team and Family	Moving to lower level of care is expedited	This is a scenario of potential conflict and risk for all involved. Moving to facilitating an alternate place of care.

Table 3. Agreement BETWEEN parties, the condition of the child and decision-making matrix

	Child Improves	Child Deteriorates
Clinical Team Agree among themselves	Morale and sense of achievement remain good	Morale may be affected in the shorter term but tempered by professionalism and other successes
The Clinical Team Disagree among themselves	The team are likely to agree to disagree and the problem remains unresolved but not fraught	The team are likely to becomes demoralized and have a sense of futility which may become chronic background disagreement unless some degree of resolution is achieved

Table 4. Agreement WITHIN clinical team, the child's condition and decision-making matrix

Effective units are likely to have a strong commitment to formulating the child's probable future from the point of view of the child as they grow and become aware, or, making best guesses as to whether they can grow and become aware. They will likely have a strong commitment to giving the family an informed understanding beyond the current distress, or lack of distress, to the likelihood of normal development, disability, life-limiting illness or death. All of these are subject to errors of judgment but much is often known from a medical point of view that, were parents to understand, would helpfully shape their perceived future of their child earlier. Parents will appreciate the significance of central nervous system and other organ system impairment gradually. Some issues will take years and different members of the family have differently paced adjustment and different styles of assimilating emotionally toxic information. Nevertheless, the adjustments required to respond to their child appropriately also have to be paced by the developmental needs of their child from the beginning. These longer-term needs are initially less insistent with all the support of the neonatal unit around them. They become all too insistent when the parents take the child home.

Sometimes it is just too painful to contemplate the future experience of the child as they grow. Sometimes the parents will be so close they cannot see the larger picture or distance themselves and not engage with the present child and the future at all. 'The child in their head is interfering with the child in the bed'. The treatment team may be fragmented or at odds with the family. "Why are they taking so long to face the inevitable?" On the one hand, the treatment team may try to just 'get on with the day-to-day care of the child' because doing otherwise is unproductive. On the other hand, clinical team members may find themselves unable to stop thinking about the children and their futures with the children still on their minds away from work. Part of managing the NICU's team uncertainty is protecting staff from an uncertain and unformulated future. This can reduce the post-traumatic casualties of this work [10]. The point of action is the point of drawing upon what consensus there is about the child's future and likelihood of responding to treatment; to intervene or not to, to do more or less, to bring together the disparate voices into a decision and a plan the treatment team slowly assemble a more complete picture, a more meaningful long-term understanding of the child's likely

future. The family struggle to adopt a common position within the family and with the treatment team. Sometimes this happens without any formal 'meetings' without many words being said. Sometimes the child's condition, or change of condition, forces the hand of team and family.

The perspective on behalf of the child's future from all involved around their care reaches beyond the child's expressions of distress, or the parental exhaustion, to a settled acceptance that this is the best of the available options to avoid the worst of the available complications.

A workable convergence of what is needed to take the next steps is settled upon. Enough agreement about the child's condition, sufficient cooperation from the family and adequate consistency in the treatment team enable effective action on behalf of the child. This iterative and re-iterative process takes place until the uncertainty around the child's future takes on familiar contours even if the edges of the path ahead and horizons of outcome remain blurred.

5. A Converging and Incomplete Consensus
Medical units requiring high levels of reliability of performance for difficult to manage conditions do not survive without a baseline of cooperation [11]. A high reliability organization is an organization that has succeeded in avoiding catastrophes in an environment where normal accidents can be expected due to risk factors and complexity [8].

They are characterised by 1) sensitivity to operations (*ie*, heightened awareness of the state of relevant systems and processes); 2) reluctance to simplify (*ie*, the acceptance that work is complex, with the potential to fail in new and unexpected ways); 3) preoccupation with failure (*ie*, to view near misses as opportunities to improve, rather than proof of success); 4) deference to expertise (*ie*, to value insights from staff with the most pertinent safety knowledge over those with greater seniority); 5) and practicing resilience (*ie*. to prioritize emergency training for many unlikely, but possible, system failures) [8]. Consensus and cooperation usually develop around protocols, traditions and 'we don't do that here' or 'we find that this works better' and invisible rules governing behaviour. Conflict is inevitable in any unit and non-acute teams and outpatient teams normally have more room to discuss differences, tolerate dissent and alternative views. Making implicit rules explicit and open to examination contributes towards safety.

Working towards a consensus involves resolving conflict quickly, cleanly with as much ongoing goodwill for the next need to cooperate as possible. As we have seen, conflict about differences in view on what is best for the baby may be between parent and parent, extended family members, team members and those with various areas of expertise outside of the unit whose advice is sought. The role of the NICU treatment team is to integrate this very parcelled advice into a whole-of-child-in-the-family prognosis and not a single organ prognosis. Single organ prognoses can be extremely helpful. However, even straightforward situations of complete organ health or complete organ failure need to be contextualized into the entirety of the child's condition within the family context. Just as the consultant team cannot afford to be 'single organ doctors' neither can the family be encouraged to be focused on one organ, or single parameters, at the cost of an appreciation of the whole baby and the whole of the baby's future and what they are being asked to do. Helping families shape their child's future rather than just narrowing the focus on their baby's heart or lungs or brain is essential.

Of course, in every unit there will be times when conflict prevails between parents, the treatment team and between these two parties. This is most acute when the consultant medical team are in conflict. The concern is not that conflict occurs, or that it is necessarily unhealthy. The concern is to have sound mechanisms of conflict resolution in which agreement begins to occur so that the medical team finds points of agreement. This provides the basis for the clinical team as a whole to find a broader platform of agreement. The family can then join the consensus in whole or part. Total consensus and cooperation are not necessary or realistic. The minimum sufficient consensus and cooperation are what is required. Slowly ambiguous 'possibles' turn into 'probables' and the 'unlikely' becomes much more clearly 'impossible'. These sort of clarities emerge and the treatment team and family find common ground [12]. It is a minority of situations and clinical cases where this common ground is not found. When consensus is not found and cooperation is not forthcoming, anxiety abounds.

6. The Place of Listening in A Busy Clinical Setting
NICU's are very strange environments to most medical outsiders. There is a lot of noise but strangely not from the patients. Crying babies are much less prominent than expected. There is a lot of action but strangely not from the parents. They seem almost inert even while caring for their children. The treatment team are focused on stabilisation, survival and the minimisation of complications. The parents wait for rounds and meetings with an unspoken pressure to resolve long term uncertainty and to find some basis of hope for their child. The babies cry quietly, the parents wait anxiously and the staff work continuously. Listening for what people are doing right and trusting their expertise as they put into words what they are trying to do can clarify direction. Psychiatric help aims to take the pressure off the need for resolution, not to increase it [13]. Psychiatrists mostly aim to be apart from the action – not at the centre. Psychiatry aims to be around when all the noise has died down and the emptiness, isolation and difficulty finding direction sets in.

The parents' anxious path forward with a vulnerable child, facing the long haul of disability, trying to pick up life after the death of a child, are all roles that child psychiatrists and other clinicians are only beginning to play to bring forward intervention for those most at risk when they leave NICU. The three futures, corresponding to the immediate, medium term and long-term time frames, clarify the priorities at different phases of treatment. The safety, stabilisation and symptomatic treatment of the child dominate the immediate management of the child in NICU. The medium-term is preoccupied with defining the

underlying problems, the cause, defining the extent of enduring morbidities and arriving at a definitive diagnosis. The long- term management will largely take place beyond the unit and be focused on monitoring, early intervention, optimising treatment and reducing complications. It helps to be clear which future we are addressing when we are talking with parents and making plans for discharge.

7. The Future in The Present Uncertainty

Managing the perceived future of a patient, the expectations of the clinical team and the family, is an essential clinical skill. This is in the broadest sense what we mean by giving a prognosis. When a child's care is awash with uncertainty, describing what is happening, why it is happening and where we will go from here helps to reduce the tyranny and threat of that uncertainty [14]. Structuring uncertainty into the immediate, the medium term and the long-term helps define the different levels of uncertainty, the tasks for each phase of uncertainty and makes it easier for the family and the team to endure the future as it comes upon them. The reiterative process of doing this is seen so clearly in the NICU and pursued actively and deliberately. A minimum sufficient consensus emerges within the treatment team, the family and between them both. Stating the obvious often helps because what is obvious to the treatment team is not always as obvious to the parents. What is obvious within the NICU is not always obvious outside the NICU. Clarifying as much as possible what is modifiable and not modifiable, treatable and non-treatable, manageable and non-manageable are the points where the expected future and the present meet. The ambiguous hinterland between the two – the 'might be modifiable', 'might be treatable', 'might be manageable' - is where most heartache of not knowing lies. Removing the obstacles of consensus and the cooperation that comes from it requires patience and professionalism and, just occasionally, some outside help.

As medical leaders identifying *what we do* know helps us cope with what we don't know. Telling the treatment team and the family *what we do* know helps them cope with uncertainty. Helping on the things we can do also reduces our sense of helplessness. When the medical leadership of a unit communicates to the treatment team and the family, everyone knows what they each can do. However modest, this clarity reduces their sense of helplessness and the other clinical inescapables such as hopelessness and impasse. We need to be clear on what we can hope for in terms of pain relief, reduction of distress and providing physical and emotional comfort. This provides the initial hope that makes longer term relief, distress reduction and comfort, when promised, credible. It also makes credible our longer term predictions of what is likely. The future is assembled into something that marries, however awkwardly, the realism of what must be accepted and the optimism of what might be possible.

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