Chapter 1

Introduction

1.1 Terminology

Procedure-Induced Anxiety (PIA)

By definition **Procedure-Induced Anxiety (PIA)** is anxiety that is induced by any procedure whether in anticipation of this procedure or as the direct consequence of the experience at the time.

Operative Procedure-Induced Anxiety (OPIA)

Referring to PIA as opposed to peri-operative anxiety is intentional. Perioperative anxiety, by definition, references anxiety associated with operative procedures, and excludes that experienced by the numerically superior non-operative medical procedure group. As such, it is not an overarching term. With a view to seeking such overarching, definitive terminology, perioperative anxiety can be redefined as **Operative Procedure-Induced Anxiety (OPIA)** which would represent a subgroup of children within the overarching group who experience PIA.

Procedure-Induced Psychological Trauma (PIPT)

Procedure-Induced Psychological Trauma is the psychological morbidity experienced as a direct consequence of PIA.

Post-procedure Dysfunctional Behaviour (PPDB)

Post-procedure Dysfunctional Behaviour is defined as new, dysfunctional behaviour that develops as a direct consequence of PIPT.

Post-operative Dysfunctional Behaviour (PODB)

As with the terms PIA and OPIA, **Post-operative Dysfunctional Behavior (PODB)** is a subset of PPDB in that it only references new dysfunctional behaviour, manifested as a direct consequence of operative interventions.

1.2 Anxiety, Fear and Fight/Flight

It is understandable, even to be expected, that a child attending hospital for a medical procedure will experience some degree of anxiety. Anxiety in and of itself is a natural response. It is the physical and psychological manifestation of the body's preparation to defend itself against an unknown threat. Research suggests that the response to a *known* threat is different, evolving via a different pathway in the brain and manifests as fear.

It is worth noting that individuals with high trait anxiety, revealed on testing using the STAIC questionnaire (State-Trait Anxiety Inventory for Children – Spielberger) (1), show early activation of the neurophysiological pathway involved in the generation of anxiety (2).

While unpleasant or uncomfortable, the sensation of feeling anxious does not cause further harm unless it is allowed to grow unchecked in the presence of continued anxiogenic stimuli. This can happen if the child has no coping strategies or the stimulation increases due to inappropriate handling or mismanagement by the family or medical team. If the anxiety continues to go unchecked, it may evolve further into a full-blown fight or flight response.

Some children experience such extreme anxiety and fear that they develop a phobic patterned response to medical interventions and all stimuli associated with them. If an anxious and reluctant child is forced to comply so that a medical procedure can take place, it can be terrifying, making development of phobic responses more likely. The experience of being terrified yet being forced to comply by grown adults can cause such psychological trauma that a fear of fear itself can evolve and persist long after any fear of medical interventions has resolved.

With regards to the fight–flight response that we are so familiar with from the literature, we should note that calling it a fight–flight response is incorrect. Generally what one will see is best described as a freeze–flight–fight response. The first action will be to become noticeably still and attempt to avoid attention by adopting a body position that may make you physically smaller or involve turning away to avoid engagement. If this fails, the option may be taken to move away or even run and hide. A last resort, if all else has failed, will be to offer physical resistance, to fight (3).

In a perfect world, all clinicians would be trained to minimise and effectively manage anxiety. There should be a screening system in place to detect those at greatest risk of experiencing this emotion with a view to preventive intervention.

On a more positive note, a child can develop a phobic state through conditioning, yet this same process can help any child move in the opposite direction, towards a more positive state, albeit with time, patience and appropriate support.

1.2.1 Nature of the Anxiety State

The state is dominated by a ramping of anxiety towards fear, with a parallel ramping of the physiological changes encountered when the freeze–flight–fight response is triggered. The triggering of the pituitary adrenal axis and release of catecholamines is responsible for many of the physical and psychological consequences that we are all familiar with. But as adults our appraisal of the experience we gain from such an event will be very different to that of a child, particularly children under 5 years of age.

As medical professionals you will be aware of the effects of adrenaline and noradrenaline on the body. A child will experience all of these including the racing heart, tachypnoea, dry mouth and stasis of the gastrointestinal system with associated nausea. Those most severely affected may feel the need to defaecate or micturate. Experiencing these physical changes, the sense of losing control and the disruption of a child's familiar and predictable existence with the disorientation that brings can be understandably terrifying.

From any physician's perspective, it is distressing to experience a child so severely affected that you can feel them sweating, the heat they are generating and their heart pounding through the T-shirt they are wearing as you rest a supportive hand on their shoulder. You may see them hyperventilating and attempting to shrink from sight by moving towards their best approximation of the foetal position. They may even soil themselves if their distress is not noted and appropriately managed. In this situation,

anything less than diffusing the situation by generating space and releasing the pressure will at best reinforce the conditioned response and at worst further severely traumatise the child.

Additional changes we will be unaware of in this situation are sensory changes experienced by the child. Changes in the field of vision and auditory sensitivities may vary from child to child. Needless to say, they will be in a state of hypervigilance. From a cognitive perspective they may find it difficult to understand more complex communication and abstract concepts. You may find that, in order to help them extract themselves from this extreme state, you need to connect utilising highly simplified forms of verbal communication and, as they emerge from the fog associated with this state, you can move slowly towards more age-appropriate and complex forms of dialogue.

Of particular note, we should draw attention to the fact that this anxiety state is characterised by an *internal focus* with *internal dialogue*, the subject and content of which are dictated by the state itself. They will be squarely focused on how awful this experience is for them and how it makes them feel. This focus and dialogue represents a further barrier to any individual attempting to manage the anxiety or help them manage it themselves. In order to implement any successful strategy, you will first need to reach the child and, in so doing, move them from an internally focused state with their own internal dialogue, towards an externally focused state, fully engaged with some external stimulus and distracted from any internal monologue. Techniques specifically designed to achieve this are described and highlighted as such in later sections.

There is new evidence relating to the freeze–flight–fight response and fear. Some researchers have discovered that catecholamines have a profound effect in the amygdala. We know that memories associated with fear tend to be very powerful and vivid. It is thought that catecholamines released during frightening experiences augment memory formation making them more vivid and longer lasting (4–6).

Understanding this process further informs us with regards to the development of anxiety states and PTSD. Additionally, this significantly contributes to our appreciation of conditioned phobic response following extreme anxiogenic stimuli and the realities of children experiencing PIA, PIPT and the consequential morbidity (6).

1.2.2 Threat until Proven Otherwise and Overwhelming Message: Non-threat

It is important to grasp that the process we are referring to and the behavioural pattern we see as a consequence have positive survival benefits. They are core primitive responses, coded deep into the essence of who and what we are. Unsurprisingly, activation of this process is significantly influenced by past negative experience and patterned response can evolve following repetitive exposure. In the presence of such conditioning, individuals that are affected in this way will likely treat any and every stimulus within their vicinity as a threat until unequivocally proven otherwise.

With this in mind, we can appreciate a core principle in the management of PIA – that the goal of any management strategy is to broadcast an *overwhelming message of non-threat*. This is achieved by utilising a mixture of effective strategies that contribute to an overwhelming and congruent message of non-threat, that is communicated continuously until hypervigilance is brought under control, trust is established and an alternate narrative incorporating an effective coping strategy is implemented.

1.3 Why Some Children Manage Their Anxiety and Others Don't

The ability to manage anxiety hinges on two factors. The first factor is the anxiogenic load the child is exposed to. No matter how able or capable a child might be, there is a limit to any individual's capacity to cope. In the presence of an anxiogenic stimulus of sufficient magnitude, all children will fail to manage their PIA. Within the realms of normal hospital practice, the vast majority of interventions, if not all, can be managed clinically and psychologically in such a way that PIA and further PIPT is minimised. In the presence of significant PIPT, to achieve such a positive outcome it may be imperative that elective therapy is undertaken to address such trauma before further medical interventions can proceed. If this does not happen, the child is likely to sustain additional PIPT as a consequence. The second factor is the child's possession and ability to deploy effective coping strategies.

1.3.1 Coping Strategies

What are they? They are:

> constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.
>
> (R. S. Lazarus & S. Folkman, *Stress Appraisal and Coping*, Springer, 1984)

Essentially, coping strategies are a means to cope with a stressful situation or anxiogenic stimulus.

In the absence of these, minimally stressful or anxiogenic stimuli can very quickly overwhelm a child. Additionally, coping strategies may, for whatever reason, be present but inaccessible leading to a similar negative outcome. Lastly, we must accept that any coping strategy, no matter how effective, will not maintain the status quo indefinitely. If the stimulus is of sufficient magnitude or longevity, any strategy will eventually be overwhelmed.

Coping strategies fall into one of two broad categories. They either allow the child to alter their perspective or evaluation of the situation, or they allow them to focus on something else, often by accessing positive resources (discussed in Section 1.4).

Examples of techniques allowing re-evaluation of any threat would include a cognitive approach such as establishing in one's own mind that although the situation is unpleasant, there is value in accepting what needs to be done in order to get better. Similarly, fixating on a future positive outcome as a result of the intervention, such as following some type of plastic surgery that will significantly alter the child's appearance in a positive way, would have a similar effect. One last example would be to highlight what we see in far too many children who have had multiple negative experiences from an early age over a long period of time and have been negatively conditioned. If we manage to intervene in a manner that changes this experience in a way that it becomes manageable and less unpleasant, it is possible for them to relearn and be reconditioned. In such a situation, they may still have an overwhelming conditioned drive for self-preservation in any medical environment, but if the process of rebuilding has begun in association with new, more positive experiences, they may be able to counter any negative internal dialogue by fixating on more recent positive experiences and challenge any negative thoughts that arise. Again, this is a cognitive approach.

Internal distraction techniques that allow a child to focus on something more positive such as memories or experiences linked to positive emotions is another form of coping

strategy. The ability for such an approach to achieve the desired effect will inevitably depend on the child's ability to manage such an approach effectively. This type of strategy has been noted as developing in older patient groups and is an abstraction of reality only possible at more advanced stages of cognitive development. Younger children are less likely to be able to use such techniques. A positive outcome in this situation hinges on the balance between the negative stimulus and the positive strategy. There are many techniques mentioned in later sections that utilise this type of approach. In fact, it is probably the most common core strategy. Examples include guided imagery, whether formally taught or deployed as the consequence of natural aptitude, humour and formal distraction. And there are many others. The presence or absence of strategies is influenced by cognitive development, personality traits, family and past experience.

In terms of cognitive development, the age group most likely to struggle with procedure-induced anxiety (PIA) are children who are 5 years old and under. Within this group, the ability to understand the reasons for intervention, the sense of self and the ability to construct associations and understanding of a more complex nature are limited. As a result, the ability to develop and deploy coping strategies is limited. Naturally, the presence of learning difficulties and the associated impairment of cognitive function may result in similar difficulties in older children.

The child's personality traits inevitably influence their outlook and the nature of the process leading to formulating coping strategies. With the advent of Spielberger's State Trait Anxiety Inventory (STAI), there followed a multitude of research papers describing the traits associated with an increased vulnerability in terms of PIA. Historically, these traits have been defined as high emotionality combined with low sociability, which translate to highly emotional or more emotional children who are less socially capable or more introverted. As noted above, those with these traits tend to show early activation of the neural pathway whose function is the signalling of anxiety, in comparison to children without these traits. Why one child develops this pattern of personality traits as opposed to another is complex and multifactorial. It may depend on genetics, conditioning, family structure, relationships within the family and physical interaction with the environment.

The influence of family relationships and structure is unsurprising. For anyone working with children, the influence stressed or anxious parents have upon their children will be very familiar. The family environment will dictate a child's expectations of life and their behaviour. They will learn what to do from parents and siblings, and they will utilise modelling behaviour by observing their family members in different situations and copying them. If parents or siblings are themselves anxious by nature, then this will significantly influence the nature of others in the unit. Lastly, there may be negative influences at play within the unit in the form of a situation where negative behaviour including dependence and emotional dysfunction are actually encouraged. This is often due to actual or perceived secondary gain experienced by other family members. This influence can be transgenerational, as its aetiology may be from the grandparents or beyond, and the aetiology of such behaviour may be negative past medical experience on behalf of the perpetrator.

Past experiences can significantly affect a child's ability to cope. If a child has had positive experiences when undergoing medical interventions, this can act as a resource for them and is likely to positively influence their outlook and response to subsequent interventions. Naturally, not all experiences are guaranteed to be pleasant, yet an unpleasant experience managed effectively may act as a positive resource, bolster a child's confidence and help them manage challenging situations in the future.

In truth, there are many significant ingredients that contribute to a positive experience, from clinical effectiveness to psychological elements such as being told the truth – not being lied to. Even in the presence of significant negative past experiences, a well-thought-out, effective management plan can begin the process of repairing damage done to a child as the consequence of poorly managed PIA.

Children who have experienced poorly managed PIA from an early age and on multiple occasions will not only have difficulty coping with any medical interventions, they are also likely to develop a phobic response to all aspects of hospital care, including sensory stimuli that have never been associated with anxiogenic stimuli. Simply attending the hospital can be enough to precipitate a panic attack, autonomic activation or a full-blown freeze–flight–fight response. This illustrates the manner in which severe anxiety can evolve and manifest as a malignant, invasive psychological condition. Those who have worked with children experiencing this type of difficulty will recognise this description and may accept the term 'global malignant anxiety disorder' as an overarching term. For some children, the anxiety they may experience as a consequence of hospital care can lead to anxiety spreading and invading other, unrelated aspects of their daily existence. These individuals require specialist multidisciplinary support and interventions if a more balanced existence is to be re-established.

Those looking for an excellent and comprehensive account of research in this subject area should read the work of Rudolph et al. (1995) (7).

1.4 Resources

What are they?

Resources fall within two broad categories. First is information that aids in rapport building. Examples would include the child's favourite things, their hobbies, songs they like, if they have any pets, if they have brothers or sisters and any other interests they might have. Such information will inform conversation that will interest and engage the child, while at the same time allowing the other participant in the conversation to interact with them on a more intimate level; in essence, building rapport or an equity between child and clinician. We will discuss rapport in more detail in Section 1.5.

The second category includes a child's memories, experiences and interests that are associated with positive memories, conditioned behaviour and emotions. Memories stored in context, based upon an experience and of any nature, positive or negative in valence, were described by Tulving as episodic memories – memories that include context and on retrieval of which the individual will relive the experience in all associated aspects and in its original context. This will inevitably include reliving the emotional content of such memories (8, 9).

Knowledge of this type of memory or the ability to access a stereotypically predictable memory by referring to it in broad and general terms, such as asking the child to remember their favourite place in the whole world, will aid in management of PIA by helping the child relive a positive experience and therefore any associated emotions, rather than focusing on the negative ones they may be currently struggling to deal with. In truth, there is no need to know specifics with regards to a child's memories or experiences. Even when a child offers no details of such experiences, simply asking them to remember or access something that made them feel happy and safe or made them laugh, in association with other supportive measures, may be enough to help them access positive resources, emotions and a more positive emotional state.

An understanding of this type of resource offers a clinician the means to shift the focus of attention in any interaction, away from a challenging and potentially negative clinical situation, towards the positive memories, emotions, feelings and behaviour encapsulated within the episodic memory. This represents a powerful coping strategy that can be deployed instantly by any attending clinician with a view to helping any child struggling to manage PIA.

1.5 Operative Procedure-Induced Anxiety (OPIA)

The majority of children admitted to hospital will experience anxiety. The risk of experiencing anxiety will inevitably increase if a child undergoes some form of intervention.

From the anaesthetists' perspective, we will mainly be interested in research defining perioperative anxiety, but should appreciate that anxiety associated with intervention is not unique to anaesthesia and surgery. It occurs as a consequence of any medical intervention.

There is a wealth of published research defining perioperative anxiety, its prevalence and consequences. In exploring this data, as anaesthetists examining the association between anxiety, anxiety at induction of anaesthesia and the consequent morbidity, it is important to acknowledge that the anaesthetic or surgery itself are not causative. The psychological trauma and morbidity that we see in children after an intervention is the consequence of the anxiety and fear these children experience. Any new post-hospital or post-intervention dysfunctional behaviour seen in these children is an outward manifestation of this trauma.

1.5.1 Incidence of OPIA

The prevalence of OPIA can vary significantly from study to study. One recent study stated the number of children experiencing anxiety during their intervention was in the nineties, percentage wise. A more consistent median range, taken from studies within a suitably extensive timeframe, would suggest 40–60% prevalence would be more accurate (10). Therefore, it may be that the majority of children under our care suffer from anxiety.

1.5.2 Consequences of OPIA

Anxiety in and of itself is unpleasant. If it is not managed effectively, if it intensifies to a point where the child cannot cope, if it evolves into fear or terror, or it triggers a freeze–flight–fight response, then the child is likely to sustain some degree of Procedure-Induced Psychological Trauma or PIPT as a consequence. This may manifest itself in a number of different ways and for a variable time following surgery. The most extensively studied and reported manifestation is in the form of Postoperative Dysfunctional Behaviour – PODB. These patterns of behaviour can be seen on a short-term and long-term basis. There is some research that prompts the question as to whether early childhood psychological trauma might be linked to life-long consequences and even a reduced lifespan.

1.5.3 Short-Term

Short-term dysfunctional behaviour generally refers to new dysfunctional behaviour seen within the first 3 weeks to 3 months following any intervention. Research published throughout the last century, reports a prevalence of PODB between 24 and 60% of children within the initial post-intervention period (11–15).

These new behaviours resolve quickly in the majority of children. However, in some these patterns of dysfunction will persist into the medium and long-term post-intervention period. It goes without saying that this is both disturbing for the child and their parents.

The list below is not exhaustive but illustrative, and includes patterns reported in the literature over the last 100 years.

- Regression of developmental milestones – for example returning to requiring nappies
- Bed wetting
- Nightmares or night terrors
- Problems sleeping
- Problems with eating
- Separation anxiety
- Temper tantrums
- Problems with authority
- Fear of strangers or the dark
- Fear of the unfamiliar
- Fear of doctors and procedures or pain
- Fear of being lied to
- Fear of being held down

Three generic papers that grant an overview of the extensive body of research from this period are referenced here (16–18).

1.5.4 Long-Term

For some children, these patterns of behaviour persist. Between 4 and 12% of children continue to display new dysfunctional behaviour for more than a year following surgery (15, 19). Undoubtedly, if there are multiple interventions that precipitate fear and extreme anxiety over a period of time, the consequences are likely to be significant and long-lasting. Examples of the types of behaviour that may be seen are included in the list below. Again, this list is illustrative.

- Low self-esteem
- Anxiety neuroses
- Global malignant anxiety – a generalised progressive invasive anxiety
- Eating disorders
- Phobias
- Depression
- Immune suppression
- PTSD

1.5.5 Life-Long?

There is a growing body of evidence that adverse childhood events and experiences are linked to compromise in mental health in later life. Patterns of behaviour that have been linked to childhood trauma include depression, alcohol dependence, self-harm, suicide, drug abuse, conduct disorder and violence. Of particular note, childhood trauma is clearly linked to PTSD (20, 21).

One landmark research project conducted by Vincent Felitti and his team was published in 1998 (22). The Adverse Childhood Experiences (ACE) study looked at the impact of adverse childhood events or ACEs on both mental and physical health in adult life. This study unsurprisingly illustrated an incremental relationship between the number of adverse childhood events experienced and the risk of developing mental health illness in later life. What was surprising to some degree was that the study also revealed an incremental relationship between the number of ACEs experienced and lifestyle choices that were linked to physical illnesses such as heart disease, diabetes and chronic lung disease. As such, this research made a connection between psychological trauma in childhood and lifestyle choices that were directly linked to physical illness in later life and a reduction in life expectancy. Additional evidence supporting an association between negative experiences in childhood, morbidity and reduced lifespan has continued to emerge over the years since Felitti's work was first published. A recently published meta-analysis of research in this area of interest supports an association between certain types of early life adversity, the early onset of puberty, structural changes within the brain and reduced lifespan (23).

When we consider the impact of PIA and hospital admissions and in particular the experience of children undergoing multiple interventions associated with pain, anxiety and fear, it is impossible *not* to view these episodes as adverse childhood events. As such, does this not imply that exposure to such events will have consequences similar to those found in the research outlined above. Is PIA linked to long-term psychological and physical morbidity with a consequent reduction in lifespan?

1.5.6 Transgenerational

The transgenerational effect of PIA is commonly seen by clinicians working with children and their families. We have all met parents and grandparents with their own past negative experiences of healthcare and PIA. Many of them struggle with feelings and emotions precipitated either by the medical environment itself or witnessing the experiences of the child they are supporting through treatment. These emotions and feelings are stored with their own episodic memories from the past and surface as a type of negative resource (8). When these emotions surface, the parents' or grandparents' behaviour may become maladaptive as they struggle with their feelings and memories of the anxiety and fear they experienced themselves. If this happens, they may offer commentary on the current situation and by sharing their own past negative experiences, they may negatively influence the child they are attempting to support. It is worth noting, although this might make both the child's situation more difficult for them to manage and our management of the situation more of a challenge, it does not represent a deliberate act of sabotage. Additionally, we must acknowledge that the successful management of a child's anxiety will inevitably require the management of anxiety experienced by any influential member of their family.

1.6 Post-operative Dysfunctional Behaviour: UK Statistics

To illustrate the significance of PIA, research statistics have been used to project actual numbers of children affected in The UK each year. Data published by The Office For National Statistics and NHS Digital are used to assist in this goal.

Population UK < 18y (House of Commons Report 2016)	13,881,000 (24)	
NHS Digital – Hospital Episodes Statistics 2017–18 Admitted patient procedures < 18y	100%	784,814
Children experiencing anxiety at induction of anaesthesia	40–60%	313,925–470,888
Children displaying PODB 3w after surgery	24–60%	188,355–470,888
Children displaying PODB 1y after surgery	4–12%	31,392–94,177

To put these figures into context, if you accept that on average around 8% of children undergoing surgery still display PODB one full year after the intervention, the number of children affected in one year represents approximately 0.5% of the UK population under the age of 18.

1.7 Critical Elements of Child–Clinician Interaction

1.7.1 Rapport

> A close and harmonious relationship in which the people or groups concerned understand each other's feelings or ideas and communicate well.
>
> *Oxford English Dictionary*

We are all aware of rapport to some extent, with some of us more sensitive to it than others. How to build rapport in a positive manner will be discussed later as part of the management strategy section (Section 1.3.1). For now, it is enough to draw attention to its importance in the anxiety management process and caution against damaging rapport. At the core of the definition above, is the implication that the central element in rapport is a connection underpinned by attentiveness and an intention to reach an understanding. People respond positively to those they feel they have a rapport with and equally negatively to those with whom rapport is damaged or completely lost.

It is unfortunate that rapport can so easily be lost. A clinician's role serves both purpose and process, with the purpose being to care for the patient in body and mind. The process inevitably involves sifting through information garnered by posing a network of questions, designed to reach a medical diagnosis, and requiring careful documentation. Such a process can easily dominate any interaction, particularly for the inexperienced or functionally overloaded practitioner. The result can be that this process obscures and undermines rapport building by preventing the formation of a therapeutic connection between patient and clinician.

1.7.2 Trust

Trust is of paramount importance as a core principle in the management of PIA. Children rely on parents and adults to ensure their safety, wellbeing and stability in their lives. With this in mind they trust their parents or adult guardians. From an evolutionary perspective there is a positive survival benefit in this, as a vulnerable child will depend upon adults for everything. With this in mind, medical interventions present an issue for some family units. For some adults, informing their child that they will be having a possibly painful and distressing intervention represents a task well outside their experience and absent from their