The Development and Evaluation of a Scale to Assess Pain in the Post-Operative Neonate.

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Abstract.

Debate surrounding the issue of pain management in neonates has mushroomed over the last ten years. Previously held beliefs that neonates do not feel pain because their anatomical make up is different from that of an adult, and that they do not remember pain therefore there is no need to relieve it have been demonstrated as erroneous. Studies such as Volpe (1981), Gilles, Shankle and Dooling (1983) and Beyer and Wells (1989) refuted previously held physiological misconceptions. Anand and Hickeys' 1987 study did much to raise our awareness of the deleterious effects of unrelieved pain in neonates.

The impetus for the present study was the wish to improve analgesic techniques in one such group of infants - postoperative neonates. Valid assessment is foundational to improving analgesia and measuring the efficacy of interventions thus broadening our knowledge of safe, effective methods of preventing undue pain in newborns.

The research presented here follows four distinct phases. The primary aim of the research was to develop a pain assessment tool. This was initially developed by use of an observational research technique, watching and cataloguing the behaviour of newborns (n=25) over a number of hours in their home environment. Video recordings of normal neonatal behaviour and development were also viewed and empirical evidence from neonatal behaviour experts such as Wolff (1966), Brazelton (1977) and Trevarthan (1977) was drawn upon to provide a detailed overview of neonatal behaviour.

Observations were then made on a surgical group of babies (n=34) around normal caregiving episodes. Each observation lasted a number of hours. Some of these episodes were videod for later viewing by 3 clinical psychologists.

The qualitative data collected from the observations of these babies (n = 59) was transcribed. The unstructured observations of both real life and video recordings collected by pen and paper provided rich, descriptive information to be analysed qualitatively. Glaser & Strauss (1967) term these "field notes". The field notes were then reduced in order to summarise the information by teasing out themes around which behaviours were clustered (Miles and Huberman 1984). These categories were organised into a detailed scoring system. This was called the Liverpool Infant Distress Score (LIDS).

Following initial development the scale was subjected to rigorous reliability and validity tests. After piloting the scale on a further 10 babies undergoing surgery, adjustments were made to the initial scale. The scale was then applied to 31 babies in the peri operative period and a control group of 10 non surgical babies. Validity of LIDS was demonstrated.

The value of an assessment tool such as LIDS also lies in its ability to be reproduced consistently and accurately by differing carers. (Melzack 1984). The next part of the study addressed this issue. By teaching the scale to a group of 4 nurses and testing their scores over a number of assessments, inter rater reliability was demonstrated.

The final phase of the study compared the subjective scores of two groups of nurses - one experienced neonatal nurses, one paediatric nurses- to the more objective LIDS scores. The results from this final phase of the study suggest that despite an increase generally in nurse awareness regarding pain cues in neonates, pain assessment is still open to subjectivity.

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CHAPTER 1.

Introduction and overview of the Thesis.

This chapter will give an overview of the thesis, looking at background theory and issues relating to neonatal pain. A brief outline of the study rationale, method and results is presented. Thesis layout is also discussed. The chapter then provides an overview of the study undertaken to develop and test the reliability and validity of the Liverpool Infant Distress Score. Firstly an account of the steps taken to collect data regarding infant behaviour both in painful and non painful circumstances is given. This data was organised and classified into the LIDS. The chapter will then proceed to the second stage of the study and discuss how issues related to the reliability and validity of LIDS were addressed.

1.1 Background research.

Perhaps no issue in neonatology has over the past ten years become more controversial than the issue of pain recognition and management. The issue of whether or not neonates feel pain has been debated for centuries, as has the question of whether analgesics should be routinely used with this age group. Misconceptions held by many included the belief that neonates, because of their immature nervous system, did not have the anatomical connections necessary in order to conduct painful stimulli.

Another popular misbelief was that even if neonates *could feel* pain, having no previous experiences to interpret the sensation they thus could not *perceive* pain.

Alongside these misconceptions ran the problem that even if neonates could feel and perceive pain, there was a lack of understanding about how it could be relieved. Fears for the safety of the infant if opiates, with their potential for respiratory depression, were used led to minimal or no analgesia being prescribed.

We virtually all experience pain as adults, and many infants are exposed to experiences which older children and adults would describe as painful; these include heelpricks for blood sampling, cannulations and injections, as well as minor and major surgery.Yet Elander and Hellstrom (1992) demonstrated great differences in the number and frequency of analgesia doses given to children and adults undergoing comparable cardiac surgery. In a cohort of 100, children received far fewer doses of analgesia and over a shorter time span than adults. Marshall (1989) explains such occurrences as being due to the fact that children, and in particular infants, are pre verbal and do not have direct ways of saying when something hurts. All this had led to the problem of neonatal pain being largely ignored.

1.2 Changing perceptions.

Peutrell (1992) postulated that we needed to assume that what is painful for the adult would also be painful for the infant. Studies such as Volpe (1981), Gilles, Shankle and Dooling (1983) and Beyer and Wells (1989) refuted previously held physiological misconceptions. Anand and Hickey's 1987 study did much to raise our awareness of the deleterious effects of unrelieved pain in neonates. A number of research studies further demonstrated that neonates do respond behaviourally to pain. Measures used included facial expression (Grunau and Craig 1987), cry (Johnson and Strada 1986), motor responses (Franck 1986) as well as physiological changes in relation to heart rate and respiratory rate (Field and Goldson 1984) and increased palmar sweating (Harpin and Rutter 1982).

Gauvray, Jolivet and Vielh in 1977 had called for more physiological, rational data rather than philosophical statements to support changes in pain management practices. Together with such changing views has come the desire to improve analgesic techniques in children generally, and in neonates in particular.

Anand and Hickey (1987) emphasised that further studies on pain, particularly in infants, needed to utilize diagnostic and therapuetic procedures already part of newborn care, in order to protect the rights of the patients being studied.

1.3 Initial aim of the study.

The impetus for the present study was the wish to improve analgesic techniques in one such group of infants - postoperative neonates. Prior to the study commencing paracetemol was the standard analgesic drug prescribed after surgery. This was considered one of the relatively few "safe" drugs for use in neonates. It can have good analgesic properties when used regularly and proactively to prevent pain. However it was mostly prescribed as a PRN drug- that is to be given when necessary. Due to the wide variations in judgements, "when necessary" in practice translated as "as little as possible". Considering some of these babies were going for major abdominal or thoracic surgery, improvements in the use of analgesia were overdue (Choonara 1992).

The initial study aim therefore was to measure which analgesia was most effective while still remaining safe for neonates in the peri operative phase. The drugs of choice were Paracetemol per rectum, the control; and Morphine, the experimental drug to be given intravenously. The hypothesis was that Morphine would provide more effective analgesia in post operative neonates. Whilst Morphine was accepted as an effective analgesic drug widely utilised in other areas, its use in neonatal pain management was limited due to its perceived potential to cause respiratory depression. The research instigator had widely studied neonatal pain and metabolism of morphine, and postulated its safer use as a continuous intravenous infusion.

1.3.1 Change of study direction.

The author became involved in the study as the nurse researcher who would monitor pain levels of the study babies, in order to compare the efficacy of the two trial drugs. The pain scores were to be collected on two groups of babies in the post operative phase: one group had been given paracetemol, and the intervention group had received morphine. In order to collect the data a pain assessment tool adapted from a study of non acute postoperative pain in infants was to be used (Attia, Amiel- Tison and Mayer 1987) (Appendix 1). Once the study commenced and I had measured 13 babies in the peri operative period, it became apparent that the tool available with which to measure the pain scores was not sufficiently specific and detailed. I was attempting to measure subtle changes in behaviour using general parameters each of which had scores of 0,1,2. The detail regarding behaviours which would score 1 not 2 were not specific enough to make decisions. For example there was very little guide as to the difference between a score of 0, 1 and 2 within the facial expression of pain category, the choice being between "calm" "intermittent" and "constant".

This meant a subjective opinion was involved. A search of the literature at the time revealed no better tools available. Thus the study took a backward step. This is not an uncommon occurrence in research. I began to concentrate on developing a tool specific enough to show and measure the subtle differences in the babies' pain behaviours.

1.4 Aims of the research.

The primary aim of this research was to develop a pain assessment tool. This was initially developed by use of an observational research technique. This was called the Liverpool Infant Distress Score (LIDS). Following initial development the scale was subjected to rigorous reliability and validity tests, a necessity in the formation of any assessment tool.

The second aim was to consider the use of this scale in clinical practice in order to help improve the management of neonatal post operative pain.

1.4.1 Thesis overview.

Chapter two firstly provides a number of definitions of pain. The number of such definitions highlights the inherent difficulty there is in recognising pain in anyone other than oneself. It then further examines the historical background to pain management in neonates. This chapter focuses on healthcare workers' perceptions of pain in this vulnerable group and provides a rationale for the formation of an objective neonatal pain assessment tool.

Chapter three explores the basis for the earlier misconceptions and subsequent changes in philosophy regarding neonatal pain. An overview of the anatomy and physiology of pain in adults is followed by a consideration of the anatomy and physiology of neonatal pain. The chapter then explores the dimension of the pain experience in relation to perception and response. Once again the format is to review this in relation first to adults before exploring the differences and similarities in neonates. The interruptive powers of opioid analgesia to the perception of pain are reviewed.

Chapter four orientates the reader to the difficulties in assessing pain in a pre verbal group and discusses the three main methods which have been utilised in an effort to assess pain objectively:

biochemical markers

physiological indices

behavioural parameters.

The chapter then explores neonatal behaviour in general before specifically discussing the literature regarding those behaviours which have been studied in direct relation to pain. Finally the chapter contains a review of nurse's ability in relation to pain assessment and pain assessment tools available at the outset of this study. This leads to a rational argument for the development of a multi-dimensional behavioural pain assessment tool for neonates.

Chapter five considers methodological issues surrounding the use of an observational technique and includes ethical considerations. It also considers the concepts of reliability and validity in relation to tool formation.

Chapter six provides an overview of the methods used. The study progressed through four key stages and these are described.

Chapters seven, eight, nine and ten take each of these stages separately and provide a full discussion as to the method, sample, results, analysis and application of such findings.

Chapter eleven summarises the research study and provides the reader with an overall discussion. Recommendations for both future research and implications for clinical practice are also presented.

1.5 Introduction to present study.

1.5.1 Researcher background.

My nursing background was entirely in the neonatal and paediatric intensive care fields and this provided a breadth of practical knowledge and awareness from which to start the research. Nurses are adept at observing and identifying abnormal behaviour, and it is often this largely intuitive process, based on both knowledge and experience (English 1993), which leads to first identification that an infant is "not as well as he/she was". It must be said that although as a nurse I had considered myself fairly proficient at recognising signs of distress in neonates, once the study was underway and knowledge of pain increased I began to realise just how much had been missed over the years.

While it is acknowledged that the use of the personal pronoun in academic work is not common, the research reported here developed directly from my clinical practice. As a nurse researcher I was consequently very involved in the development and progress of the work and it's effect on practice. The first person is therefore used throughout.

1.5.2 Observational study.

The study involved initially watching and cataloguing the behaviour of 25 newborns in a variety of situations in a normal environment. These 54 episodes included watching babies at home, in hospital but not for surgical intervention over a number of consecutive hours, and by viewing video recordings of normal infant development. The babies were sleeping, having nappy change, awaiting feed, being held and demonstrating developmental cues. From these observations a baseline knowledge of babies' normal behaviour was formed. Empirical evidence from neonatal behaviour experts such as Wolff 1966, Brazelton 1977 and Trevarthan 1977 was also used.

Neonates admitted for surgery (n=35) to the regional neonatal surgical unit were then observed both pre operatively and post operatively each over a number of hours. The babies were studied intensely during the first three days post operatively. None of the babies was ventilated. This was because ventilated infants are often given sedation and/or muscle relaxants to aid ventilation which would mask behaviour. Again their behaviours were catalogued.

1.5.3 Formation of LIDS.

Observing babies is remarkably enlightening. They do so much more than sleep. They are not boring and each has his or her own individuality, reacting and interacting with what is going on around them in unique ways. When the observed actions were classified however, common threads could be seen among them. After discussion between myself, clinical psychologists interested in the study of infant behaviour and the consultant supervising the study, these actions were organised into a score system - The Liverpool Infant Distress Score (LIDS). The score system is organised into eight categories each with a 0-5 score along a continuum (Appendix 2).

Any observation of behaviour, whether it is self recorded or recorded by others is open to the subjective opinion of the observer. Carers can become adept at identifying infant responses to certain events and patterns of behaviour can thus be seen. Organisation of such intuitive, subjective observations into classified categories can lead to objective description and identification of cues. Once the scale had been developed it was tested for reliability and validity.

1.5.4 Validity and reliability tests.

Construct validity was ascertained in three studies. Firstly infants operated on for major,moderate and minor surgical interventions were compared for pain scores over a period of 48 hours post operatively. Their scores were not significantly different, although they were high immediately post operation decreasing to a low level by 48 hours. This suggested that a minor operation may be as painful for an infant as a more major one. In all cases however LIDS pain scores decreased as healing took place. Individual record analysis showed markedly lower scores following the administration of analgesia. Both these results supported the validity of the score.

The score was subsequently tested on a number of post operative neonates and a control group of neonates who had not had surgery. Statistical analysis of these scores demonstrated, as expected, the scores for the control group were significantly lower than those of the surgical groups over 43 hours providing good evidence of construct validity.

Inter rater reliability studies following teaching of the tool to four nurses and a clinical psychologist produced correlations of 0.82- 0.95 (mean = 0.87) indicating it was reliable.

Finally the scores for a number of babies using LIDS were compared with the subjective scores, using a visual analogue scale, of two groups of nurses. One group were experienced neonatal intensive care nurses and the other group nurses working in a surgical ward with neonates. Analysis showed many differences between the scores nurses allotted to the same baby, differences not only between the group but between individuals within the group highlighting the discrepancies between individual pain assessments.

SUMMARY

The ability to relieve pain in those patient who cannot tell us of their pain verbally may be enhanced by objective assessment. This chapter has presented an overview of the present study which is an attempt to provide such an objective pain scale for use within neonatal surgical care. The following chapter presents the historical background to the management of pain in infants.

CHAPTER 2.

Historical background to neonatal pain management.

Babies were thought by some in the past not to feel pain and although attitudes are changing this is still sometimes the case today. In considering reasons for this conflict in beliefs a number of areas need to be addressed:

- perceptions of staff caring for neonates in potentially painful situations;
- the immature development of the neonates' physiological and biochemical systems;
- the neonates' cognition of pain and neonatal behaviour;
- the ability of staff to recognise and manage pain.

Each of these areas will be reviewed in turn in order to address the key questions:

" Do neonates feel pain? If so what can be done about it ?"

This chapter will review the literature surrounding healthcarers' ability to assess and manage pain in neonates and provide a rationale for the change in attitude toward the need to limit pain in neonates. It begins however by introducing the reader to a number of definitions of pain. The fact that there are so many ways of defining pain demonstrates how difficult a concept it is to interpret. This inevitably has an effect on our ability to appreciate it objectively in another.

2.1 Definitions of pain.

Historically Descartes described pain as a *spark from a fire* that stimulated *threads in the skin to ring bells in the brain.* While we now appreciate this was a very simplistic view of pain, attempts to describe the experience in another are difficult.
The International Association for the Study of Pain (IASP) (Merskey, Albe Fossard and Bonica 1979) has produced a widely used definition taking into account the components of both sensation and emotion:

"An unpleasant sensory or emotional experience associated with actual or potential tissue damage, or described in terms of such damage." (pg.249)

Perhaps one of the best definitions in relating ones ownership of ones pain is McCaffery's (1972) widely used phrase - pain is what the person experiencing the pain says it is, occuring whenever he says it does. In directly applying this to children's pain Llewellyn (1996) clearly points out the problem of children not always speaking of their pain. Even behavioural cues from children may be misleading as they employ coping strategies and dissemble. It may be argued that neonates are the least able to mask pain. However they are only able to "speak" their pain behaviourally.

2.2 Types of pain.

Acute pain is a negative, subjective response to an unpleasant, noxious, tissue damaging, or potentially tissue damaging experience. Acute pain is usually highly localised, sharp and transitory and is experienced during a traumatic procedure or spontaneously as a result of colic etc. Chronic pain is intractable and persists over a period of time - normally considered to be over three weeks. It is generally associated with specific disease processes.

Post operative pain does not fit neatly into either of these categories, lasting often for 2-3 days post operative. It is also a mixture of deep somatic pain arising from stretching muscles, tendons and ligaments; visceral pain generated by organ involvement, and the brighter more localised pain of a skin incision (Melzack 1984). It is this type of pain experienced by neonates that is the focus of the present study.

It may be seen from the above how many variables there are to consider when assessing and managing pain in neonates.

2.3 Healthcarers' ability to manage neonatal pain.

When we can accurately measure another's pain then we can treat it more effectively (McCaffery 1983). However management is hampered by the fact that pain represents a host of experiences which are unique and subjective for each individual (Price 1990).

It follows therefore that the better our understanding of pain in others, the greater our decision to use pain relief (Cleminson1986). In 1991 Bush and Harkins asked the pertinent question whether the developmental differences between infants and older people were so profound as to make it "*improper to speak of pain in infants*? "(pg 4). Purcell-Jones, Dorman and Sumner (1988) called for medical staff to develop the confidence and knowledge to prescribe appropriate analgesia for neonates. Elander (1992) postulated that analgesia is given less readily to younger or older age groups because they are simply less able to communicate their needs. Shapiro (1993) adds that the limited number of valid and reliable neonatal pain assessment tools needs to be extended in order to improve pain management in this group.

Mc Laughlin, Hull, Edwards, Cramer and Dewey (1993) studied the attitudes and practices of neonatal physicians and reported that in contrast to previous studies most now believed that neonates do feel pain. Previously Swafford and Allen (1968) reported that children needed little analgesia for they tolerated pain well. Franck (1987) documented that 50% of the nurses she surveyed felt neonates did not experience pain in the same way as adults, feeling pain less intensely. In a survey of 352 neonatal physicians, McLaughlin et al. (1993) found most believed neonates did perceive pain and should receive anaesthesia and consequently they administered per-operative analgesia much more readily. However post-operative analgesia was used less, mainly because post-operative pain was less readily recognised and reported. This was similar to earlier studies demonstrating less analgesia was given to infants and children post operatively (Beyer, DeGood, Ashley and Russell 1983; Elander, Lindberg and Qvarnstrom 1991). McLaughlin also found however, that post- operative pain relief was variable and subject to the ability to recognise signs of pain in the post operative phase.

Brill (1992) believed that the ability not only to appreciate pain in another but to be able to assess and respond with appropriate treatment is an essential attribute for neonatal nurses. Craig and Grunau (1991) identified a substantial lag between the rapidly developing understanding of pain in the very young child and its application in practice. Bonica in 1980 had identified exactly the same problem. In a recent study by Nagy (1998) the effect of nursing neonates in pain on nurses' psychological state was examined. Nurses working in neonatal units and other "high tech" areas are shown to experience high stress levels. This study compared the levels of stress between neonatal nurses and nurses working in a burns unit. Pain generated greater anxiety in the nurses working within the burns unit but they also had a greater sense of personal competence and control over the management of such pain. The neonatal nurses did not feel such control and this factor contributed greatly to their stress. Lack of objective assessment tools in order to effectively demonstrate pain in neonates and monitor the adequacy of instigated pain relief techniques was identified as a factor in diminishing their confidence. Bucknall and Thomas (1997) studied a group of 230 critical care nurses with regard to their decision making. They found generally that although the nurses were often more knowlegeable than SHO's they lacked the confidence to make decisions themselves on patient care. Hodgkinson, Bear, Thorn and van Blaricum (1994) in their report on a method of relaying information regarding a neonate's pain, stated that nurses were often faced with difficulty in "defending and validating their assertions" that neonates in their care were in pain.

It may be seen therefore that despite recognition of the pain associated with many of the procedures neonates undergo, there has been a reluctance to prescibe analgesic agents and thus relieve it. This has been at least partly due to the perceived side effects of some drugs (Lloyd Thomas 1990). Porter in 1989 identified the recommendation for providing anaesthesia and analgesia for neonates as problematic due to the inadequate information available regarding risk/benefit ratio as well as for suitable dosage. The greatest concern is regarding respiratory depression. Fears were cultivated based on incorrect assumptions that children in general are at greater risk of respiratory depression and subsequent addiction to opioids (Mahan and Strelecky 1991).

SUMMARY.

Healthcare professionals have adjusted their acknowledgement of pain in another from being a necessary part of illness and hospitalisation, to being a phenomenon which can and should be anticipated and managed so as to present as much relief as possible to the patient. The public generally have begun to expect some form of pain management as standard treatment (Franck 1992). Why then do some clinicians still believe that infants do not feel pain, and that it is neither necessary nor desirable to use analgesics or anaesthetics during painful procedures? A number of reasons are used to justify non-treatment:

- Neonates are not sufficiently developed physiologically to feel pain.
- They do not remember pain anyway so there is no reason to prevent it.

- Health professionals deny the presence of pain as a coping strategy. Having perceived pain in another implies a responsibility to relieve the pain, and there have been perceived difficulties in relieving neonatal pain.
- There are difficulties in assessing neonatal pain.

Each of these issues will be explored fully in the ensuing chapters.

CHAPTER 3

Physiological responses to painful stimuli and the perception of pain.

This chapter will provide an overview of the anatomy and physiology of pain. Although there have been numerous theories of pain postulated, currently the Gate Control Theory (Melzack and Wall 1965,1988) is perhaps the most well documented hypothesis. An overview of this theory will be given. The chapter will then present the literature surrounding the arguments about neonatal anatomy and physiology in relation to painful stimuli. The chapter will finally introduce the reader to the perception and subsequent experience of pain in the human and how we respond to these. This provides the final pieces in the jigsaw that constitutes pain - a multi dimensional experience encompassing both anatomical, physiological, sensory and behavioural and experiential aspects. The chapter relates all these aspects to the neonate, highlighting differences and particular problems. The chapter will also provide a brief overview of how pain perception may be interrupted.

3.1 The nervous system and pain.

The nervous system is divided into two separate but interacting components: the central nervous system (CNS) and the peripheral nervous system (PNS).

Pain perception begins with a sensory stimulus in the PNS, which is then transmitted to and processed by the CNS resulting in perception of the pain by the person. Nerve endings located throughout the surface of the skin (nociceptors) carry the sensory impulses through a network of neurones toward the brain. The velocity of the impulse is influenced by the size of the nerve fibre and the presence of myelin along the fibre sheath. Myelinated, or A-delta fibres have a greater conduction velocity than smaller, unmyelinated C fibres (Tortora & Anagnostakos 1987). Impulses are conducted from one neurone to another across a synaptic space due to the presence of chemical neurotransmitters. These may be classed as excitatory or inhibitory transmitters.

3.2 The gate control theory.

The transmission of potentially painful impulses to the level of conscious awareness may be affected by a gating mechanism. The gate control theory developed in 1965 by Melzack and Wall postulates that pain impulses arrive at the Substantia Gelatinosa which acts as a gating mechanism by allowing a degree of modulation of pain impulses to take place. Opiate receptors have been identified in the Substantia Gelatinosa and the limbic system of the brain in which emotion is interpreted, and naturally occurring Morphine like substance encephalins have also been isolated. The theory is based on complex physiological arguments and, although it has its critics (McCaffery 1983), it remains the most accepted pain theory today. Its greatest strength lies in the multi dimensional approach it provides. Pain perception may be affected by emotion and cognition as well as sensation. In pain perception there is a real difference between acute and chronic pain, as defined in the previous chapter. There is an important connection between unrelieved, or on going pain and the ability to cope. The implication for neonates is that as cognition is relatively undeveloped, the modulation of pain impulses is less likely to take place. Hence neonates may experience more pain than older children and adults.

3.3 Neonatal physiological arguments.

Without doubt the physiology of neonates differs from that of older children and adults. Neonates have higher circulating endorphin levels and immature pain conducting pathways and receptor systems (Hatch 1987). This immaturity of the nervous system led to traditional beliefs that neonates could not feel pain, could not distinguish it from other sensations and could not remember it, all contributing to ensuring it remained an underestimated and undertreated problem (Choonara 1992). Strong statements from researchers, carers and parents brought pressure to change the management of pain in this vulnerable group. For example Anand and McGrath (1993):

"The present routine policy of ignoring pain in the very young and de-emphasising the occurrence of pain in all children, needs to be abandoned and replaced with routine measurement of pain in all age groups and the development of validated and widely accepted ways of preventing and treating pain."(pg. 40)

The underlying principles to examining the physiology of pain in neonates can be grouped under three headings;

the *anatomical* organisation of neurones

the *activity* - the electrical and chemical phenomena involved

the sensory and motor processes that form a *behaviour*.

3.3.1 Anatomical considerations.

Traditionally lack of myelination has been proposed as an index of immaturity in the neonatal nervous system. Volpes' (1981) work showed that complete myelination of nerve tracts was not necessary in order to conduct painful stimulii. This work counteracts the belief that neonates were incapable of feeling pain due to this immaturity. Furthermore Gilles, Shankle and Dooling (1983) demonstrated complete myelinisation of nociceptive nerve tracts in the spinal cord and CNS during the 2nd and 3rd trimester of gestation. Melzack and Wall (1988) note that the incomplete myelinisation argument is simply wrong. Even in adults nociceptive impulses are conducted primarily via unmyelinated and thinly myelinated fibres in peripheral nerves. The intercostal distance is comparatively shorter in the neonate and therefore lack of myelination of nerve fibres is compensated (Beyer & Wells 1989). Babies present well before term with a full complement of the necessary neurones and at 20 - 24 weeks gestation the connection is made between the cerebral cortex and the thalmus, synaptogenesis taking place (Anand & Hickey 1987). Such findings suggest that neonates' physiological makeup is sufficiently mature to feel pain.

3.3.2 Electrical and chemical considerations.

In addition neurotransmitters necessary to signal pain are present from relatively early in gestation (8 to 10 weeks), although the question of when they are present in sufficiently large quantities to signal pain has not yet been established (Fitzgerald 1993). It has been shown neonates mount a stress response to surgery (Anand et al 1985) which is reduced by peri operative analgesia (Gauntlett 1987). This is further evidence that neonates respond to painful stimuli. Anand et al's classic 1987 study, demonstrating the presence of nociceptors before birth did much to raise our awareness of the deleterious effect of pain in the newborn. It is known that the relationship between pain perception and injury is highly variable, and that this is due to our perception of whatever else is taking place at the time. Nociception is thought of as the perception of pain due to actual or possible tissue damage (Anand and Hickey 1987).

Pathways which affect the perception of pain are the descending inhibitory pathways from higher centres to the spinal cord. Wall and Melzack (1989) have studied these in depth, and as discussed earlier, these inhibitory pathways are central to their Gate Control theory of pain Fitzgerald (1985) postulates an increased sensitivity to pain in the neonate due to the neurotransmitters that enhance pain perception being produced earlier than those endogenous opiates which dampen down pain impulses. Thus neonates may feel even more pain than older children in similar circumstances (Anand 1988).

3.3.3 Behavioural considerations.

Both peripheral receptors and nociceptive reflex arcs are developed and functional before birth. The latter are important, as the flexor reflex (i.e. the withdrawal of a limb from noxious stimulation) appears to be a useful measure of CNS nociceptive function; for example the threshold corresponds to perceived pain in adults, and this is also true when analgesics such as morphine are given. Withdrawal reflexes in children are exaggerated and occur at lower thresholds than those in adults . Similar responses are seen in pre-terms where thresholds are much lower, particularly prior to 30 weeks gestation.These findings are supported by work by Fitzgerald et al (1988) which demonstrated a decreased cutaneous flexor reflex threshold in premature infants less than 30 weeks gestational age. Pre-terms showed increased sensitisation following repeated stimulation, removed by local anaesthetic (Anand 1992). Although not conclusive proof this might imply that neonates are if anything *more* sensitive to noxious stimuli than are adults.

3.4 Pain perception.

Noxious stimuli travel along the A-delta and C fibres within the spinothalmic tract toward the thalmus, hypothalmus and cerebral cortex where information about the impulse is processed (Tortora and Anagnostakos, 1987). With cortical stimulation, a particular type of pain at a particular intensity is felt. The ability to locate the source of the pain is related to past experiences. Children learn for example, often through negative experience, that fire is hot and hurts. Once pain has been perceived it usually results in the manifestation of a pain behaviour. In adults this takes the form of withdrawing from the source of pain, or resting the affected body part in order to allow healing to take place. These two behaviours may be directly related to the purpose of pain which is to protect the organism from further harming itself. The adult is also usually able to verbalise their hurt and access some form of pain relief. Pain may be controlled by interrupting the relay of the impulse between the receptor site and the interpretation centre of the brain. This is usually achieved by drugs but may be achieved by our own inbuilt dampening down response activated by coping strategies, surgery, acupuncture, massage or electrical stimulation.

3.5 Analgesia and pain.

Opioids produce their analgesic effect by binding to opioid receptor sites situated throughout the central nervous system, thus mimicking the effects of endogenous opioid peptides Morphine is perhaps the most studied and most commonly used opioid for pain relief. It is widely available, effective and cheap.The respiratory depressant effect of morphine is well documented (Maguire and Maloney 1988) and is most apparent in neonates due to their higher proportion of Mu-2 opiod receptor sites and may be enhanced even further according to Way (1965) by their more permeable blood -brain barrier allowing the increased delivery of water soluble opioids (Morphine being one) to the receptors in the brain. The risk of toxicity, with its sequalae, can be lessened however by the use of continuous infusion rather than intermittent bolus doses (Choonara 1992), although the longer half life of the drug in the newborn may lead to drug accumulation over time. Drug elimination in neonates is also variable particularly in the compromised ill neonate, therefore prediction of dose effect is difficult (Peutrell 1992). However neonates who are undergoing such invasive intervention necessitating opioid pain relief will usually be nursed in a controlled environment where observations of vital signs may be made regularly and the effects of such drugs monitored. Farrington, McGuiness, Johnson, Erenberg and Leff (1993) evaluated the efficacy and safety of continuous infusions of Morphine sulphate in a group of 20 neonates post operatively. The mean duration of the Morphine infusion was 34 hours (± 15 hours). No adverse reactions were found in any of the babies and there was a significant reduction in serum beta-endorphin content following onset of the analgesia.

Paracetemol is another commonly used analgesic with few contra indications. It is used in neonatal care and despite their immature livers can be given safely (Choonara 1992). Its best effect is achieved if given regularly and as a pre emptive analgesia as paracetemol exhibits a ceiling effect. When the dose of the drug is increased beyond that which achieves maximum analgesia, there is no further therapuetic effect.

Therefore a more potent drug is required if analgesia has not been attained (Mahan and Strelecky 1991).

3.6 Neonates and the pain experience.

There are difficulties if we attempt to apply McCaffery's (1972) definition of pain – as being what the experiencing person says, and existing whenever he says - to children, let alone pre verbal infants. They do not or cannot always "say". For this reason some researchers have preferred to use the word 'distress' rather than 'pain' (Katz 1977). However Anand and McGrath (1993) argue for the specific use of the word 'pain', referring to the experience that is associated with actual or potential tissue damage. Self-reports are not possible for neonates and very young children, thus behavioural and physiological measurements are necessary to identify the *unspoken* cues given. These however have been subject to a number of attempts to disprove their reliability. The fact that we do not require self-reports to believe in the perception of pain in animals where stringent controls are applied to control potentially painful procedures (ASAP 1986) makes its necessity when dealing with infants appear ludicrous.

The focus of research has then centred on whether the behavioural and physiological responses associated with this experience can be differentiated from those shown to other 'distressing' experiences such as hunger, cold, overstimulation etc.In addition Cunningham (1993) has disputed the interpretation of the phrase 'subjective experience'. She notes that the argument usually advanced by the proponents of the 'infants can't experience pain' group, is that pain is a subjective experience; it is intimately tied to consciousness and the ability to think about events. Neonates cannot do this, so all they are showing is behavioural and physiological responses to noxious stimulation i.e. they are not actually *experiencing* pain. Cunningham disagrees, pointing out that by 'subjective' we mean that we can only infer others' experiences and sensations; we cannot directly observe them. All we can observe directly are behavioural (including verbal responses) and physiological responses. Thus to doubt that infants experience pain, is to refuse to use the analogies we use for older children and adults to infer that they have the same experiences of pain that we ourselves do.

Outside a medical context , in a home situation, caregivers would be severely criticised if they did not respond to the pain signals of their infants. It seems that it is only within a medical setting that the general belief that we should not hurt babies, or allow them to be in pain if we can do something to prevent it, is suspended. This may be partly due to the prioritisation of interventions doctors and nurses have. Page and Halvorsen (1991) state that pain is given a low priority by nurses in Paediatric Intensive Care Units (PICU) who see resuscitation efforts as more important. While no one belittles the necessity to provide resuscitation quickly and effectively, Hall (1995) argues that the two need not be mutually exclusive and pain management should be more highly prioritised. Lisson (1987) highlighted pain management as a critical ethical issue because of its "*capacity to de humanise the human person*" while also recognising the difficulties around treating a "*subjective,qualitative experience*" in an "*objective, quantitative, empirical minded healthcare environment." Pg. 651.*

3.7 Neonates' behavioural responses to pain.

The appearance of characteristic behavioural responses to noxious stimulation is seen from birth in premature babies from at least 28 weeks gestational age (Martin, Glenn, Padden and Berry 1995). Darwin (1872) was one of the first to argue that these were important social signals to caregivers. It is crucial for the survival of the infant to be able to signal to caregivers that potentially tissue damaging stimulation is occurring in order that this can be removed. Darwin therefore argued that this ability would be present very early in development. For this reason it could be argued, pain would be one of the earliest emotions to be experienced. One school of thought held that infants demonstrate their pain in a myriad of perceptible ways (Keefe & Gil 1986). Yet in 1986 Hatch and Sumner postulated that due to the neonates' inability to react to painful stimuli in a specific fashion and their higher circulating levels of beta endorphins, they had a need for less analgesia than other groups (pg. 35). Several studies have dispelled some of the myths surrounding this misconception. Barrier et al (1989) demonstrated changes in behavioral cues centred around facial expression,cry and movement by observing post operative infants. These changes differed between two cohorts - one who had pre operative Fentanyl and another who were given a placebo, supporting not only the existence of pain perception in neonates, but the ability of analgesia to alter it. A similar study by Marchette, Main and Redick (1989), randomly assigned infants undergoing circumcision to one of three groups. During circumcision one group received routine care which did not include analgesia, and the two intervention groups had either music or intrauterine sounds played to them. Their hypothesis was pain would be reduced in the intervention groups. Using physiological parameters of heart rate, blood pressure and transcutaneous oxygen levels; and coding of facial expression using the Maximally Discriminative Facial Movement Coding System (Izard 1983), the forty eight infants were scored for pain. Although mean heart rate was lower during the procedure for the intervention groups, facial expression showed all three groups displayed pain behaviours. Many of the studies into neonatal pain management hinged on neonates undergoing circumcision which in many centres was carried out without anaesthesia or analgesia. It is from these studies that changes in pain management were instigated.

3.8 Neonates' rememberance of pain.

The evidence to suggest that attitudes are changing and protocols for the prevention and management of pain in neonates are growing, presents amid increasing evidence that early pain experiences may have long term effects reflected in altered pain thresholds later in life in pre term infants (Andrews and Fitzgerald 1994). Cohorts of ex premature infants and control full term infants are being followed up at five year intervals and differences are apparent in their attitude to and ability to cope with pain. (Grunau,Whitfield and Petrie 1994). Significant differences in attitudes to pain have been documented when such children are compared to their siblings. These range from the youngsters who have been in Neonatal Intensive Care Units (NICU) not feeling or responding to some degree of pain; to responding inappropriately to minor pain stimulii. There were also significant differences in children depending on their initial length of stay in NICU. Those with longer stays had the most response to pain. This goes some way to challenging the early belief that because neonates could not remember pain the need to prevent it was less. Although these children may not consciously remember the pain they felt as neonates, nevertheless their experiences may have long lasting effects on their responses to painful stimuli in later life.

SUMMARY.

In a review of the neurobiology of pain development in newborns Fitzgerald and McIntosh (1989) conclude that the elements of the CNS required for the transmission of painful stimuli are present in infants born at full term and pre-term at as little as 24 weeks gestation. The organisation and maturation of the system continues after birth.

The final argument has been whether neonates subjectively experience pain. This is addressed in the second part of the chapter. Thus it may be seen that pain is a complex phenomenon involving biological, psychological and social factors. It seems likely from the evidence reviewed and presented here that neonates do experience pain and require effective analgesia. Franck (1987) identified a need for nurses to have valid and reliable methods for assessing neonatal pain in order to compare treatment methods and establish standards.

Despite a change in attitude in considering the effects of pain on neonates there remain considerable methodological difficulties involved in studying it. Furthermore ethical and moral issues also need consideration, and can have an impact on the design of research studies. Many of the research findings available have been as a result of studying acute painful episodes in newborns in the form of routine heel stabs, immunisation and circumcision. The effect of and response to more long term pain viz. post-operative pain has been less studied.

CHAPTER 4.

The assessment of pain in neonates.

Anand and McGraths' 1993 prediction regarding the improvement of neonatal pain management being imminent, provided the impetus for much research in the field of neonatal pain assessment. This chapter will begin by reviewing the literature surrounding the concept of pain assessment in neonates from a more general perspective highlighting the nurse's role and difficulties. The chapter then addresses the three main areas that have been researched in order to try to fulfil their prediction. The chapter proceeds to explore research regarding infant behaviour in general. This demonstrates the way infants use behaviour in order to survive. The chapter proceeds to relate this eliciting of care to the pain experience before examining the behaviours studied specifically in relation to pain. As these provide the theoretical framework to support the present study, they will be covered in some detail. No one behavioural cue on its own is a definitive indicator of pain in an infant. The chapter will finally discuss the literature regarding the need for objective assessment criteria. This follows a review of literature demonstrating the inconsistencies in subjective assessment of neonatal pain. The chapter concludes by exploring the tools available at the start of the study presented here, thus providing a rationale for the study.

4.1 Assessment in general.

Objectivity is the key to providing pain relief for others and thus the purpose of any assessment tool. Human infants survive because they are born with the ability to elicit care from others. It is vital therefore that carers identify pain cues correctly in this vulnerable group. Als (1982) argued that in order to know whether what we are doing is right, we first needed to learn the language of neonatal behaviour. The difference between pain and restless behaviours is subtle, requiring, according to Broome and Tanzillo (1990), " *careful assessment and planned interventions by nurses* "(pg 56) Nurses are at the forefront when it comes to the assessment of children's pain and should be instrumental in instigating pain relief. Franck (1992) reviews the major forces that have influenced neonatal pain research and concludes that nurses can be key instigators in changing practice.

A lack of methodology for the accurate asessment of neonatal pain has contributed to the practice of giving little or no analgesia to post-operative neonates especially to those who are not ventilated. Because of this lack of adequate assessment tools the efficacy of analgesic techniques has hitherto been very difficult to quantify in the pre-verbal infant, and this has led to less than optimum pain relief being achieved. Valid assessment is foundational to improving analgesia and measuring the efficacy of interventions thus broadening our knowledge of safe, effective methods of preventing undue pain in newborns. Merskey (1986) defined the differences between a ***measurement*** of pain as being a *quantifiable* amount measured in figures; and the much broader encompassing of the multiple facets of the *experience* of pain by *assessment*. Shapiro (1993) identified the limited number of valid and reliable neonatal pain assessment tools as a barrier to nurses achieving effective pain relief in this group.This lack of valid assessment tools must be overcome. Brill (1992) defines objective assessment in neonates as a challenge - yet essential for healthcare workers.

" *The clinical management of pain associated with the care of newborns..... is at the threshold of dramatic change .....* "

(Anand & McGrath 1993 pg. 1)

4.2 Methods of assessment.

Many approaches have been taken in striving to find a perfect method to assess neonatal pain.These have included physiological, biochemical, and behavioural measures. Each will be examined in turn.

4.2.1 Physiological measures.

Significant changes in cardiovascular parameters, pressure of serum oxygen levels (tcPO2) and palmar sweating have been noted in neonates undergoing painful clinical procedures (Tyler and Krane 1990). Randich and Maixner (1984) identify the close coupling of those systems controlling cardiovascular function to the systems modulating the perception of pain. While physiological measures such as apex beat, oxygen saturation levels and respiratory rate are clinically easy to measure these indices are not specific enough to pain when the infant may already have an altering physiological state due to the underlying illness. Blood loss, infection, raised temperature are all variables which have the potential to alter physiological parameters regardless of pain. Their main usefulness may lie in identifying the effect of acute painful stimuli on the neonate, although Craig, Whitfield, Grunau, Linton and Hadjistavropoulos (1993) in a detailed study of pre term and full term neonates' reaction to heel stab demonstrated "*substantial variability of the infants on the physiological measures*". (pg 295) While physiological measures of heart rate, respiratory rate and oxygen saturation rose as a result of the heel stab from a baseline measure, the response was not sustained. Significant differences were also demonstrated between the groups studied with return to baseline not consistent. Some babies were left with higher and some lower readings after the heel stab. Owens and Todt (1984) demonstrated that while apex beat rate rose immediately as a response to heel stab (mean rise 49 beats), within ten minutes the rate had returned to pre insult rate with an average return time of only 3.5 minutes. Blood pressure increase has also been demonstrated to return quickly to baseline levels after painful insults (Beaver 1987). Stevens, Johnston and Horton (1993) examined physiological and behavioural responses to pain during heel stab. Although during the most painful part of the procedure heart rate and intracranial pressure increased significantly while oxygen saturation decreased these changes could not be directly attributed to the painful stimulus. They conclude that physiological measures were not specific to acute pain.

Non painful handling is postulated as causing distress in children with subsequent change in physiological parameters (McIntosh 1994). Benini, Johnston, Faucher and Aranda (1993) randomised 27 term neonates undergoing circumcision to either the study group receiving EMLA cream or the control group receiving no analgesia prior to surgery. Both groups demonstrated changes in physiological measures of apex beat, saturation of oxygen from baseline measures as well as in facial expression. Greatest changes were demonstrated during the most painful part of the procedure-cutting of the foreskin. The study group had statistically less change than the control group across all parameters. However the act of restraining the babies also caused significant change in baseline parameters. Noise has also been demonstrated to increase heart rate (Gray and Crowell 1968).

McCaffery (1977) postulated that physiological adaptation to the situation occurs in the event of long term pain and Porter (1989) felt this was due to the infant's capacity to recover from procedure induced pain. There appear no definitive results to support the use of physiological measures alone to measure pain in the neonate. Thus as a measure of longer term pain they are as ambiguous as other measures (Bours et al 1996). No studies examining physiological measures and pain in post operative neonates were found prior to the research study reported here. Although physiological parameters of apex beat, respiratory rate and oxygen saturation were recorded on all the babies during the research reported here, return to pre operative baseline results within two hours post operative was identified. This data could be the focus of future research to examine the relationship between amount and length of physiological change and the pain score given.

4.2.2 Biochemical measures.

Metabolic and hormonal levels have also been monitored as measures of reaction to painful stimuli. Anand et al (1985) found increases in endocrine and metabolic levels in neonates during surgery. Using minimal anaesthesia hyperglycaemia and hyperlactataemia were demonstrated following surgery. This manifests itself in a high serum glycaemia level post operatively. Significant differences between premature and full term infants were seen with full term infants having a higher level of insulin over the first 24 hours post operatively. Anaesthesia and analgesia are known to affect the stress response. Anand and Hickey (1992) examined hormonal and metabolic stress responses during and after cardiac surgery in young children. Deep anaesthesia during the operation and analgesia after lowered the hormone and stress response. Altering hormonal levels may therefore not be totally reflective of a pain response. There are also implications from drawing frequent blood samples from a neonate in order to estimate such responses as an ongoing pain indicator.

Palmar sweat estimation has been another method studied (Harpin and Rutter 1982). They found significant increases in palmar sweat during heel prick which returned to baseline levels as recovery from pain ensued. While providing useful information this is not a practical method for estimating pain in an ongoing clinical situation. Palmar sweat is difficult to collect in sufficient quantities from a neonate's tiny palm. Analysis is not often attainable at the cotside which would be necessary in order to provide an easily assayable estimation of analgesic efficacy. The stress response and therefore increase in palmar sweat in the post operative phase is also not considered specific to pain (Bours, Huijer-Abu Saad, Hamers and van Dongen 1996).

4.2.3 Behavioural measures.

Many studies have looked at behaviour change as a response to pain and behaviours have perhaps been the most useful and most widely accepted indicators so far of neonatal pain. The focus of much of the research has been on individual parameters such as cry, facial expression and movement. These are all explored in detail later in the chapter. Firstly, and overview of infant behaviour is given.

4.3 Infant Behaviour.

Early psychologists had low expectations of the newborn seeing them as largely helpless. Gesell (1940) stated the human infant to be not fully born until about four weeks of age! There was a tendency to evaluate their immature behaviours against those of the adult, demonstrating a limited appreciation of their subtle adaptations (Stratton 1982). However in the last thirty years with increasingly sophisticated technology and new methods such as habituation and preference paradigms, researchers have found the neonate to be much more competent than previously thought (Slater and Bremner 1989). Within this growing realisation that neonates were highly complex came the awareness that in fact newborns are programmed to adapt to conditions from birth. The newborn infant is now presented as a constantly changing creature, influenced by both external and internal factors. Under the effects of such influences the baby's responses are multi-faceted (Prechtl 1988). Gillis (1988) states that the world of the infant being a small one, any disturbances in it can have major repurcussions. The newborn infant cannot consistently regulate emotional arousal without caregiver assistance and frequently becomes overaroused and disorganised (Thompson 1988). Eliciting nurture can reduce negative emotional experiences.

Emotions develop chronologically depending on their value as a survival strategy for the infant (Thompson 1988). The pain reaction develops early as it is critically important for survival that caregivers respond to potential damage (Roberts 1988).

Although infants cannot speak, (from the Latin "*infans*" meaning incapable of speech) they can provide behavioural clues to indicate pain. Stratton (1982) highlighted this sophisticated functioning as an adaptation process to environmental conditions.

" *An adaptation, by its nature, raises the probability of one class of events and necessarily reduces the probability of others. For example the neonate experiencing a lowered body temperature will metabolise brown fat to generate heat.* " (pg 7).

At some point the neonate would need caregiver intervention in order that this adaptation did not lead to growth and metabolic problems. So caregivers would provide warmth for the neonate. Thus in order to adapt without suffering side effects, they often need the intervention of caregivers and are adept at eliciting care from those around them. The ability to adapt without caregiver intervention is highly unlikely in respect of unrelieved painful stimulii. It follows that neonates in pain will signal their need for caregiver intervention. It then behoves caregivers to recognise the cues, however subtle, that the newborn is giving.

Thus we now know that infants are much more competent than previously thought; they can perceive, learn and display behaviour. This makes it even more likely that they can perceive and learn about painful situations. The chapter will now review the neonatal behaviours which have been studied in relation to pain.

4.4 Neonatal pain behaviours.

As long ago as 1872 Charles Darwin identified individual behavioural indices of pain in neonates. These were confirmed by D'Apolita (1984) and include -

- cry; also studied for example by Johnson & Strada (1986),Grunau et al (1990).
- facial expression; also studied for example by Izard (1979), Grunau and Craig (1987).
- body movements; also studied for example by McGraw (1941), Franck (1986)
- sleep; also studied for example by Wolff (1966), Anders and Weinstein (1972).

4.4.1 Cry is one obvious indicator of pain and an important way a neonate communicates. Dunn (1977) reports that infants have developed the capability of intentional crying well before they are a year old. Differing cries evoke differing responses.Wolff (1966) described the pain cry as having an exceptionally long expiratory phase followed by a long rest phase. The high pitched cry of the baby with cerebral irritation has long been used for diagnostic purposes. Golub (1985) and later Porter (1988) demonstrated how the stress of pain and decrease in vagal tone increases striated muscle tension, disorganises infants' physiological state, elevates voice pitch and produces an atypical cry. Thus the pain cry elicits a much more urgent response from caregivers.Some studies have focused on categorizing and analysing the acoustic qualities of infant cry (Murray 1979;Pineyard 1994). While Johnson & Strada (1986) identified changes in pitch and velocity as a result of an acute painful stimuli, their studies also showed that cry is the most variable measure. The pattern of cry they identified was initially high pitched followed by a period of apnoea and a lower pitched, rhythmic rise and fall cry. This was as a result of immunisation - acute painful stimuli. Anand and Hickey (1987) relate the differences in cry to indications of altered cortical functioning. Stevens, Johnston and Horton (1994) in a study of the cries of 124 infants during heel stab found significant increase in frequency, structure and spectral energy, modified by the severity of underlying illness of the baby. Again this study was during an acute painful insult. Infants in a continuing pain situation may, Newman (1986) postulates, cease crying as an indicator of pain. If cry does not elicit contingent behavior and ward off the pain experience, the infant stops using this method of alert. This finding was demonstrated by a longitudinal study in a neonatal unit where infants were, in the course of treatment, subjected to heelstabs over a three week period. Initially all 10 infants studied cried on heelstab but by week three only 3 infants cried the rest displaying withdrawal behaviour. Infants in circumstances associated with severe pain have been reported to lie still and remain silent (Gauntlett 1987).Thus observations of crying alone as an indicator of pain have limitations.

4.4.2 Facial activity is seen by Stevens et al (1994) to be the most consistent response to tissue damage across studies of infants, children and adults. In their Facial Action Coding System (FACS) Ekman and Friesen (1976,1978) identified approximately 50 anatomically based discrete actions that constitute the action of facial muscles. Most expressions use a combination. Those used to explain pain in the FACS system are very similar to those described by the Neonatal Facial Coding System (NFCS) (Grunau, Johnston &Craig 1990) supporting convergent validity. In a study by Craig et al (1994) they associated well with facial pain indicators in older children and adults. These indicators include furrowing of the brow, eyes screwed up causing wrinkles around them and a square mouth. Tense cupping of the tongue was also shown to be a possible sign of pain. Grunau et al. (1990) stated this to be in line with other studies of infancy indicating that a variety of states and emotions are inferred through examination of the face.

Hadjistavropoulos et al (1994) showed that facial activity rather than cry accounts for the major variations in caregiver judgements of pain. In a study involving 16 women observing 36 neonates receiving Vitamin K injection and a non painful thigh rub, pain was consistently identified by the participants. There was considerable variability in ratings for the pain however. It was also apparent that while cry commanded attention it was facial activity interpretation which accounted for the differences in caregiver estimations of pain. The authors state that although cry "is salient" facial activity is the more important parameter.

4.4.3 Body movements of healthy neonates have an organised, fluid appearance with a gradual onset, small in amplitude and of moderate speed (Hopkins and Prechtl 1984).They are descibed by McGrath(1987) to have a gradual onset.In contrast the movements of a neonate in pain are rigid and disjointed in appearance, often diminishing as pain is unrelieved. It is argued that this is an effort on the part of the baby to shut out external stimulii. (McGrath 1987, Horgan et al 1996, Horgan and Choonara 1998). Flexion dominates the healthy neonate's posture (Holt 1991).
This flexor type pose becomes less after the first few days of life with limbs becoming extended and relaxed while the baby is in a resting position (Prechtl 1965).

4.4.4 Limb movements were identified by Franck (1986) as having the potential to inform carers of a neonate's depth of pain. She suggested an objective pain assessment tool could be based on number and velocity of leg movements. This would appear to limit the interpretation of neonatal pain cues to only one aspect of the neonates' repertoire of movements. Leg movements are also notoriously unreliable to judge. In their comparative studies of newborn motor activity Prechtl and Beintema (1964) identified differences in the amount, speed and amplitude of movements between babies who had uncomplicated delivery and those who had complicated delivery. While these differences are here related to neurological disturbance, it is postulated the differences may be seen as a response to any disturbance to the infant.

4.4.5 Sleep was described by Wolff (1966) as being a normal neonatal sleep pattern if the infant had no spontaneous eye movements with eyelids firmly closed and little motor activity. During irregular sleep however, the baby had greater muscle tonus, with occasional stirring, grimaces, pouting and sucking. In a study of 26 term neonates undergoing circumcision Emde, Harmon, Metcalfe, Koenig and Wagonfeld (1971) identified an increase in non rapid eye movement (REM) sleep compared with a control group.

During experiments utilising tickling as a more ethical stimulus than acute pain stimulii, Wolff demonstrated a significant response from sleeping infants, in the form of increased activity and cry. Using a feather stroked on the sole of the foot to provide a stimulus, Brazelton (1977) described the neonate initially in irregular, light sleep becoming drowsier with repeated stimulation, eventually becoming deeply asleep with tightened flexed extremeties and jerky startles. On cessation of the external stimulus the neonates reverted to their initial restful state. External stimuli can thus been seen to have an affect on sleep patterns causing either disturbed sleep or deep sleep but unrelaxed sleep. These differences must be recognised by caregivers if the interpretation of pain cues is to be correct.

4.5 Nurses' ability to assess neonatal pain.

4.5.1 Cues.

Early studies showed quite a lot of variability in cues used by nurses to assess pain in the neonate. Pigeon, McGrath, Lawrence and MacMurray (1989) in their questionnaire study of 43 neonatal nurses' perception of neonatal pain, found that while nurses were adept at using similar classes of behaviour e.g. cry and movement, to indicate pain in their patients, they varied in specific indicators for differing levels of pain. While some nurses felt the non crying baby to be pain free others judged this may not be so. Hamers, Abu-Saad, Halfens and Schumacher (1994) found that the vigour of the child's vocal expression mainly influenced the decision to give pain relief. If neonates don't cry they may not receive appropriate analgesia. Similarly with the babies who were moving slightly. Shapiro's 1992 study concluded that nurses' judgements of pain in two cohorts of neonates were influenced by the vigour of the neonates' behaviour. The quieter, often weaker neonates were deemed to be in less pain during similar procedures than the ones whose behaviour was more overt. This may not be true. Brazelton (1977) noted that neonates confronted with disturbing, repetitive stimuli - which could be the unrelieved internal stimuli of pain- "shut down" and reduce movement and cry in an effort to remove themselves from the stimuli.

The carer's response may be a wish to contain the infant - to shut down on his/her disturbing motor activity by touching or holding, not necessarily instigating analgesia. In addition the context of the baby and carer will affect the judgement made. However Mayers and Jacobson (1995) state that by paying attention to those infant behaviours which indicate tolerance of interventions, carers can ensure that neonates remain physiologically stable. Sparshott (1996) postulated that any intervention (e.g. cuddling) which enforces a feeling of well being will have an analgesic effect. While this may indeed be so, any intervention be it pharmacological or non pharmacological needs to be evaluated objectively for effect.

There appears to be lack of objectivity in deciding ***what*** it is about the behaviours that influence judgements about the amount of pain the baby has. James (1991) suggested pain behaviours being video taped for use as teaching tools so that nurses' assessment skills could be improved. Selekman and Malloy (1995) also recognise the importance of correct identification of cues in influencing caregivers' perception of the pain infants are experiencing.

4.5.2 Context.

Other studies have shown that context, medical condition for example, is a variable used by nurses to estimate pain. Hamers et al (1994) in a qualitative study of factors influencing nurses' pain assessment found that medical diagnosis played a key part in legitimising being in pain. All 10 nurses in the study group mentioned this fact with the more severe diagnosis being credited with more pain. "*The surgical removal of the tonsils (severe diagnosis) is more painful than the surgical removal of the adenoids* *(mild diagnosis)"* (pg. 855). Recommendations from this study were that nurses needed more knowledge of behavioural pain cues in children, regardless of context which is interpreted individually, in order to improve pain assessment and thus management.

4.5.3 Experience.

Experience has been shown to be a variable with some inconsistent results. For example experience alone is not sufficient to manage pain effectively in neonates. Giboney Page and Halvorson (1991) studied the differences between non critical nurse assessment of pain and critical care nurses assessment. Interestingly they found pain ratings among non critical care nurses and subsequent analgesia administration to be higher. More recently a study by Hamers, van den Hout, Halfens, Abu- Saad, and Heijltes (1997) indicated expertise did not directly influence assessments of pain intensity. Their hypothesis that length of experience would increase knowledge of pain cues was not upheld, with novices assessing pain as well as experienced nurses. Experience did however increase nurse's confidence in their assessments, which in turn increased administration of analgesia. This substantiated earlier work by Giboney Page et al. (1991).

Practical experiences are seen as equally necessary to theoretical knowledge if improvements to pain management are to be made. Choules (1999) surveyed staff attitudes to pain experienced by neonates in a neonatal unit and found huge differences between staff in the perception of pain in a neonate. This led to staff recognising pain inconsistently and therefore pain relief being inconsistent. Anecdotally, I am frequently made aware of this when talking to practitioners. One nurse looking after a baby during a shift may be administering analgesia regularly due to their perception of the baby's pain while the nurse taking over may have a completely different perception and withhold analgesia. Porter (1989) identified that due to non standardisation of behavioural scales "*the same infant could be treated in dramatically different ways for the same pain depending on the individual observer's criteria for pain.*"(pg 553) Charlton (1999) also highlighted "considerable variation in the use of analgesic agents .... in our neonatal surgical unit" (pg 21). Before making changes to practice, Charlton surveyed 26 specialist neonatal surgical nurses for their preferred areas of observation when assessing neonatal pain. The range of observations mirror prior studies, including areas such as facial expression and cry. There was a heavy reliance on vital signs however.

Recent reports (Craig et al 1993; Hadjistavropoulos et al. 1994) had shown caregivers' estimates of pain in another are generally low. This is consistent with the study by Page & Halvorsen (1991) showing that training improved identification of pain. Nurses who had undergone instruction into paediatric pain cues were more adept at recognising pain than those who had not, and were, therefore more ready to give appropriate analgesia. Phillips (1995) stated that nurses have a unique opportunity to improve pain management in neonates. The success of this however, not only depends on the availability of an assessment tool which meets that Units particular needs, but staff being taught how to use the tool correctly in order to "*objectively communicate the baby's response*" to others (pg. 196). This objectivity is necessary to minimise variables of experience and context which underpin healthcare worker's evaluation of pain in another. Franck (1997) further reviews these points from an ethical perspective and holds that one of the ways neonatal nurses can ensure pain alleviation is by "*assessing infants' nonverbal signs of pain*" (pg 83). This is still far from easy despite a number of methods of assessment to choose from reviewed by Franck and Miaskowski (1997).

4.6 Development of behavioural assessment scales.

The word "pain" represents a catalogue of experiences which are unique to the individual yet there are behavioural displays common to humans experiencing pain (Price 1990). Much of the research on assessing children's pain has failed to demonstrate how qualitative differences in children's behaviour may constitute quantitative differences in pain levels. Consequently,

> *"Behavioural responses are generally more difficult to record, measure and document when compared with 'harder' physiological data."*
>
> (Carter 1994 pg.124).

Yet, as we have seen, "hard" physiological measures are neither sensitive nor specific to the ongoing pain situation. Virtually all pain scales designed to measure pain in infants are distress scales, there being difficulties in distinguishing between pain and other forms of distress using observational behaviour (Alder 1990). Bozzette (1993) in a small exploratory study found "characteristic patterns of distress" and postulated that the definition of common behaviours could assist in the identification of pain and therefore the administration of appropriate interventions.

"The differences between pain and restlessness behaviors is subtle requiring careful assessment and planned interventions by nurses."

(Broome & Tanzillo 1990 pg. 54).

As Anand and McGrath (1993) predicted, over the last five years there have been a number of assessment scales developed, which were not available at the commencement of the present study. However most of these have been validated for use during acute pain episodes.

4.7 Acute v ongoing pain assessment.

Because it has been necessary to study routine clinical situations in which an infant is exposed to pain, neonatal pain research has hitherto focused on the bright, easily localised cutaneous pain of the heel stab, Vitamin K injection and circumcision. There are less studies into pain which is present over a longer period - postoperative pain being one of those areas. Assessment tools formed to measure acute pain may not be valid in the ongoing pain situation. Choonara (1992) stated "*It is important one does not extrapolate observations following acute painful stimuli to the non acute situation.*" (pg 33). Cote, Morse and James (1991) identified changes in behavioural parameters in a small study of neonates post-operatively. The study reports identifiable changes in facial expression, movement and cry patterns in babies observed in the immediate post operative phase by studying detail on video recordings. The study proposes that such changes could be quantified and the authors suggested that a multi dimensional behavioural assessment tool was needed.

Elander, Hellstrom &Quarnstrom (1993) reported a study of 12 infants observed in the first 24 hours post operatively. Video tapes where made and a scoring system (Attia et al 1987) used to analyse the tapes. Results indicated pain management to be inconsistent and unsatisfactory in 36% of the episodes analysed. Care routines were also a factor with infants woken by blood sampling shortly after being medicated for pain. A limitation of the study acknowledged by the authors was the use of an unvalidated pain tool for this group of infants. This concurred with my findings at the start of the present study and was the impetus for creating a more sensitive assessment tool (LIDS) which could be subjected to validity and reliability studies.

In 1994 McGrath called for "more research on behavioral signs of longer term pain in neonates" and suggests that while no one behaviour constitutes an "unequivocal measure of an infants' pain," analysis of distress behaviours demonstrate emerging patterns.

A method which would differentiate the modalities of pain from related modalities of anxiety, stress and agitation is the aim and despite great strides in this area remains elusive. Thus the focus of much research has been on testing reliability and validity of assessment tools developed for use in neonatal care. Bours et al (1996) provides us with an excellent review of many of those now available. Among those reviewed is the scale which has been the subject of this study (Horgan, Choonara , Al-Waidh, Sambrooks and Ashby 1996; Horgan and Choonara 1998).

4.8 Rationale for present study.

At the commencement of the study, from the literature reviewed, it may be seen that neonatal pain management was ready for improvement. Many of the previously held misconceptions regarding neonatal inability to feel and perceive pain had been dispelled. Caregivers were being stimulated to reduce the pain experienced by neonates. Anand and McGrath (1993) had identified that the improvement in pain management hinged on the ability to correctly assess pain in neonates. The pain assessment tools available at that time were limited, were mainly for acute pain episodes and were largely unvalidated. Thus it was decided a valid and reliable pain assessment tool for assessing neonatal post operative pain was necessary. Lack of specificity regarding physiological and biochemical markers to pain led the researcher to the development of a behavioural assessment tool. Observing only the behaviours of babies who had been operated upon could have led to confusion as to which behaviours were normal neonatal behaviours and which due to pain. Therefore a number of non surgical neonates episodes (n=54) were observed in a number of normal situations and a range of 'ordinary' neonatal behaviours identified. This was an essential pre requisite before the development of the rating scale.

SUMMARY.

While the study of physiology and biochemistry detailed above has improved knowledge regarding neonatal pain, neither can be said to provide a definitive measure of pain in neonates. The chapter has demonstrated the difficulty in using some of the measures identified as a practical method of assessing a baby's pain particularly in the post operative phase. While still far from perfect, measurement of behavioural change appears to provide the most useful information regarding this group. The research reported here focuses on behavioural measures as a suitable method of measuring ongoing pain in post operative neonates. Ellison & Kopp (1984) suggest that a sound conceptual foundation is necessary before one can utilise the meaning of past research efforts to understand the topic under consideration. In recent years a great deal has been learnt regarding the complexity of infant behaviour using innovative techniques (Slater and Bremner 1989). The chapter provided a brief review of some of this relevant work before going on to consider pain behaviour specifically. The purpose of infant behaviour was demonstrated as attempts to adapt to and interact with the environment. Infants are unable to make such adaptations on their own, and the behaviour is used to elicit sufficient care in order to survive. Applying these findings to the concept of pain in the newborn, the chapter has demonstrated how neonates need healthcare workers to be able to identify the behaviours they are using in order to communicate their need for care.

Maletesta (1985) postulated that interpretations of facial and vocal activity are reinforced by subsequent infant behaviour. If change in behaviour is not noted and effective analgesia not instigated then a negative feedback cycle may be entered into.

This results in the infant "shutting down". In an effort to protect themselves from as much stimulation as possible neonates may attempt to withdraw themselves completely from their surroundings , not only closing their eyes tightly but closing their arms and legs into their trunk and conserving movements. Neonates learn by interacting with the stimuli the environment offers them. If too much stimulation is presented, the infant closes their eyes or becomes upset until the stimulation is changed (Emde 1969). The neonate may not however be able to distinguish between external and internal stimuli, such as pain.

" *A well organised term baby can pass from one state to another to control levels of stimulation whereas the sick, pre-term or disorganised baby may be incapable of doing so.* " (Sparshott 1996 pg 6).

Johnston and Strada (1986) stated the need to extrapolate from our knowledge of neonates and from our growing knowledge of pain and synthesise these to form an appropriate assessment scale. While neonatal behaviour may not be a precise measure of their pain it provides a *"quantitative index of their overt distress"* (Brill 1992, pg 204). The rest of the chapter therefore explored the nurse's role in neonatal pain assessment and the assessment tools available to aid this.

Although assessment tools existed at the commencement of this study, they were largely assessment of acute painful incidents rather than the ongoing nature of post-operative pain. They also had not been subjected to rigorous reliability or validity measures. Additionally, many studies had shown that even experienced nurses are not necessarily very accurate at neonatal pain assessment. In order to provide the detail regarding infant pain behaviour necessary to improve nurses ability to recognise and more importantly quantify such behaviours, the formulation of a detailed pain assessment score was considered necessary. The following chapters identify the research conducted to achieve this.

CHAPTER 5.

Methodological and Ethical considerations.

This chapter will first discuss issues relating to observational research methods before considering the factors involved in developing an assessment scale. The chapter then proceeds to examine the concepts of reliability and validity in relation to scale formation. The chapter concludes by acknowledging some of the ethical principles necessary to guide any research. Any ethical questions which arose during the study are discussed in the relevant following chapters.

5.1 Observation as a research methodology.

Many clues, according to Polit and Hungler (1993) to improve nursing practice may be gained by observational research techniques. Initially in the study reported here the focus was on obtaining descriptive data regarding neonatal behaviour. This was gathered by employing a direct observational technique, within a real life, uncontrolled environment. Observational studies are grounded in real events, based on actual behaviour of the individuals. They are however open to criticism from empiricists (Cooper, Costello and Douglas 1974). Naturalistic studies are hampered by myriad extraneous variables yet are true to real life situations. It is within these real life situations that neonatal pain occurs and therefore it was felt its study could not take place within an artificial, restrictive experimental paradigm. It is also not possible from an ethical perspective. It is however acknowledged that what we "choose" to observe or discard from observations is influenced by our individual theoretical perspective (Swanwick 1994).

An important research task is to describe behaviours and changes in behaviours in their natural context. It is not possible therefore to control all the variables when studying neonates. Precise experimental control is unachievable yet real life relevance is high. McVey (1995) argues that a sufficient sample size can put extraneous variables, if measured, into a statistical analysis as co-variables. Variables such as infant state and health status may affect behaviour. Objectivity is seen as a major problem. According to Endacott (1994) clearly defining the terms of what is to be observed is crucial. In the study reported here behaviour of the infant less than 28 days old was observed. 'Field notes' were then reduced in order to summarise the information, to tease out themes and provide clusters of behaviours (Miles and Huberman 1984). Cavanagh (1997) sees this content analysis as a systematic method leading to the drawing of inferences. Such was the intention of the study - to itemise neonates' pain behaviours. Conceptual mapping was utilised to indicate relationships between areas of behaviour. The content was thus categorised, grouped and reduced by combining repetitious behaviour. Ashworth (1994) acknowledges that literature may be reviewed prior to qualitative data collection and used to guide this categorisation. This was the process adopted by the researcher. Clinical psychologist input was invaluable in verifying the decisions reached regarding grouping (Guba and Lincoln 1981).Once the categories had been saturated i.e. no new behaviours were being identified, the scoring system encompassing a number of categories was formed.

5.2 Ethical considerations.

Research should leave the participants with as little or no harm done to them as they would expect to be exposed to in everyday life. In order to ensure this occurs Ethics Committees exist to approve/disapprove all research before it may commence, and to oversee it once it has commenced. Each stage, in the study related here, went before the appropriate ethics committee. Verbal and written consent was sought from all the participants' parents (Jolley 1995). At each stage a parent information sheet was first provided (Appendix 3).

Informed consent is governed by the Nuremberg code of Ethics in Medical Research set up after the Second World War, further revised by the Helsinki Code (1964,1975). Before consenting to be involved in research, or allowing dependants to be involved, the participant must be fully aware of the purpose, process and implications of any research. There must always be an opt out clause, so that even after commencement in the study participants have the right to withdraw with no consequence to themselves or their treatment (Sim 1991). I was so conscious of this clause and at such pains to point it out to parents that one mother asked me did I want her to say no to her child being involved in the study!

No treatments were withheld from the babies nor alterations made to their care in order to conduct the research (Raatikainen 1989). Parents whose babies were video taped as part of the study agreed beforehand and to the tapes being used for teaching purposes. A short video of their baby, when comfortable, was often made and given to the parents as a thank you. These were gratefully received and the process is often used nowadays in units to help maintain contact between families and their ill babies. One could argue that non participant observation is one of the least invasive research techniques. As a nurse I often wanted to intervene and had to resist in order not to confound the study (Morrow and Richards 1996). However, on the occasions where not to have intervened would have been detrimental to the baby, e.g.when physiological changes occured while observation was taking place, action was taken, which was felt to be morally and ethically correct (Robertson &Boyle 1984). This resulted in alerting nursing staff to the babies' diminishing respiratory effort on two occasions and highlighting the fact that a baby would perhaps benefit from some analgesia on a number of occasions. The nursing staff, and parents too to some extent, began to rely on myself to indicate if a baby was in pain. Again this reflected the general attitude to analgesia at the time - administered as a reactive rather than a pro-active intervention.

5.2.1 Nurse as a researcher.

The role of the researcher is paramount in an observational study. As a nurse observing patients and cataloguing responses is an everyday occurence. What distinguishes scientific observation is the way in which the observations are made, under precisely defined areas - specifically, objectively and with careful record keeping in order to monitor trends. One of the limitations of using an observational technique is the effect of the research and the researcher on those being observed (Parahoo 1997). My neonatal background gave me credibility with the nursing staff on the unit. Holloway and Wheeler (1996) argue this is crucial if co-operation is going to be gained. It certainly helped in gaining access to the babies. This confidence in the researcher needed to be valued and not misused. I strictly maintained my role as non participant observer rather than being active in care as I had been previously. The problems of having to intervene on occasion have been dealt with above.

5.3 Formation of an assessment scale.

According to Polit and Hungler (1993) a scale is designed to assign a numeric score to subjects to place them on a continuum with respect to the attribute being measured - in this case pain. Their use in measuring psycho-social states is widespread. Such a scale in neonatal pain would allow efficient quantification of subtle gradations in the intensity of pain experienced by neonates.

Polit and Hungler (1993) state one of the most important attributes of such a score is that it has " *careful and explicit definition of the behaviors .. to be observed.*" Pg.217. This is to enable users of the score to have clear cut criteria in order to assess the occurrence of the category or to rate the phenomena along a descriptive continuum.

5.4 Reliabilty.

To measure pain effectively a pain assessment tool must be valid and reliable (Twycross 1998). A pre condition of validity is reliability (Gibbon 1998). Reliability refers to the consistency with which the tool measures that which it is supposed to measure (Polit and Hungler 1993). Reliablity of a tool is thus proven if it is repeatable with similar results (Keck et al 1996).

There are a number of different reliabilities; test/re test; inter rater; split half. Test-retest reliability assesses the stability of the tool over a span of time. It is also necessary to examine inter rater reliability so that the tool may be considered for its ability to give equivalent readings when two or more observers measure the same phenomena. These results will obviously affect the tool's clinical applicability. Such reliability tests may utilise correlational measures to show the agreement between observers. The nearer the correlational co efficient to 1.00 the more reliable the tool is deemed. Split half reliability test is a method for estimating internal consistency of an instrument by correlating the scores on one half of the measures within the scale with the scores of the other half. The items are split, often as alternate, scored independently and reliability measures applied (Polit and Hungler 1994). This test was not used in this study.

5.5 Validity.

Validity refers to showing the assessment tool does actually assess pain and not fear or anxiety (Abu Saad et al 1994) and may be measured in a number of ways.

5.5.1 ***Face validity*** refers to the relevance of the items within the tool to the concept. Weber (1995) views this as a weak form of validity testing focussing only on a single variable at a time.

5.5.2 ***Content validity*** means that all relevant aspects of the phenomena are covered within the tool. A tool may be said to have content validity when expert judges deem the constructs adequately cover the phenomena. Clinical psychologists, consultant and neonatal nurses made up an expert panel to provide judgements on content validity.

5.5.3 ***Concurrent validity*** establishes the relationship of the tool with some other criterion. For example post operative pain is known to be most intense in the first hours following surgery, diminishing as healing occurs. There is also a positive correlation between amount of tissue damage and pain. Relating a pain assessment tool to either of these criteria would be beneficial in examining concurrent validity.

5.5.4 ***Construct validity*** assesses the way constructs within the tool relate to each other and to the phenomena being measured. One method of examining this aspect of validity in relation to a pain tool would be to examine scores awarded in relation to analgesia administration. It would be expected that a valid pain score would decrease after analgesia. Similarly utilising a "known group" scenario means that one can postulate that applying the score to a group who are not deemed to have pain should result in low scores.

The study used test/ re test and inter rater reliability for reliability assessment and construct, concurrent and content validity were also measured.

SUMMARY.

The main ethical/moral principles involved in research are to do no harm to participants who fully understand and consent to being research subjects. In this instance parents consented for their children to be studied.

This chapter began by introducing observation as a research methodology and continued by examining some ethical principles and applying them to the study reported here. The chapter then proceeded to examine the areas of research method necessary to formulate a new assessment tool; namely the principles of reliability and validity. The following chapters expand on and apply these methods within the study reported.

CHAPTER 6.

Development of the Liverpool Infant Distress Score.

The present study had the general aim of developing and evaluating a neonatal pain assessment scale to be called the Liverpool Infant Distress Score (LIDS). The study was planned in four phases. Phase one was an open ended observational study of non operated and operated babies' behaviour. Following categorisation of these behaviours stage two refined these categories with independent raters thus providing content validity. These observations were categorised into an assessment scale - the LIDS. Phases two and three tested the scale's reliability and validity and issues surrounding inter rater reliability. Phase four examined the potential usefulness of the scale in clinical practice by comparing scores for neonate's pain following surgery utilising LIDS and neonatal nurse's subjective pain scores. Phase one is described in this chapter.

6.1 Phase 1. The Observational Study.

Stage i)

Extensive observations of behaviours were carried out of neonates who were :

a) not exposed to potentially painful procedures,

b) were born with a potentially painful condition which required surgery

c) following surgery to treat such conditions.

6.1.1 Non surgical group.

The 25 babies were all less than 28 days of age i.e. neonates, at the time of observations. Some babies were observed on more than one occasion, while some were observed for a number of hours at a time. A total of 54 observational episodes were catalogued. The observations were dictated by the availability of the babies and at the discretion of their parents, some of whom allowed access to the babies within their own homes.

6.1.2 Surgical group.

The second group observed were 34 newborns in the peri-operative phase, that is, those babies who were about to have or who had just undergone surgery. Again the babies were neonates. This group of babies were studied in the regional neonatal surgical unit; before and after they had been to theatre for a variety of surgical interventions - from repair of an inguinal hernia, to major abdominal surgery. The babies observed were all nursed on the same neonatal unit and once again different situations were observed and the babies' behaviours catalogued each over a number of hours. Fifty nine observational episodes were catalogued. The babies whose parents consented to their inclusion in the study, were chosen at random from admissions over a four week period. There were no constraints to observations. The babies under observation received the standard care and analgesia was administered on an " as necessary" basis. At the time of the data collection, Paracetemol per rectum was the analgesia of choice.

6.2 Method.

The study undertaken involved initially watching and cataloguing the behaviour of these newborns over a number of hours (ranging from 0.5 hour to 2 hour periods), some in their home environment some in hospital. The behaviours took place within "normal" caregiving episodes, during feeding, nappy change, clinical observations, sleep and play in their cots. Video recordings of normal neonatal behaviour and development were also used.

I was influenced somewhat by the categories in the Attia et al (1987) scale I had been attempting to use at the commencement of the original study. My notes attempted to itemise the *type* of behaviour. For instance " slow, stretching movements";"grunts and snuffles"; "face calm-no frowns". Drawings were made to demonstrate amount of flexion and tone in an attempt to capture the "looseness" and "relaxed stance" or tenseness of the babies. A small dictaphone was used to tape the baby's cry.

It became apparent how much babies interact with their carers and their environment. Babies were observed concentrating on their mother's speech, watching what was happening around and even interacting with the camera. It was a strange process to write down what I was observing when the behaviour appeared "normal" and initially my descriptions were short and vague (Appendix 2 i). I had felt adept as a neonatal nurse at identifying normal movements even though most of my observations hitherto had been aimed at recognising the abnormal. My descriptions became lengthier and I tried my hand at drawings to illustrate what I meant (Appendix 2 ii). Colleagues asked what I was looking for. Initially I didn't know! At the same time as my observations I was extending my theoretical knowledge about neonatal behaviour. I found myself on a steep learning curve. Empirical evidence from neonatal behaviour experts such as Prechtl (1964), Wolff (1966), Brazelton (1977) and Trevarthan (1977) was drawn upon to help provide a detailed overview of neonatal behaviour. Previously I had not realised how much had been studied about neonates, and just how interactive their behaviour was. Thus over time my observations became more detailed (Appendix 2 ii). Ashworth (1994) acknowledges that literature may be reviewed prior to, or during qualitative data collection and used to guide categorisation. This was the process I adopted.

Observations were then made on the surgical group babies. Both verbal and written consent were obtained from the parents of the babies before they were observed, after careful explanation of the study. Observations were made around the normal caregiving episodes. These included feeds, nappy change, physiological observations and periods of rest when the babies were observed lying in incubators or cots. Each observation lasted a number of hours, ranging from 2 to 6 hours. During the time of the observations I was on the unit simply as an observer and did not give routine care to the babies. An example of the observations made at this point can be seen in Appendix 2 (iii).

6.3 Analysis.

The qualitative data collected from the observations of these surgical and non surgical babies (n = 59) was transcribed. The unstructured observations of both real life and video recordings collected by pen and paper (Appendix 2) provided rich, descriptive information to be analysed qualitatively. Glaser & Strauss (1967) term these "field notes". So an overall picture of the behaviour began to emerge. Meetings were held between myself, three clinical psychologists and the paediatric consultant every two or three weeks. At these meetings we discussed neonatal behaviour in light of the transcripts. Some of the episodes had been video taped and were viewed by myself and the group (Appendix 2 iv). Again notes were made regarding the movements and discussion as to their significance took place in establishing content validity.

With the group's input, the field notes were reduced in order to summarise the information by teasing out themes around which behaviours were clustered (Miles and Huberman 1984) . Cavanagh (1997) sees this content analysis as a systematic method leading to the drawing of inferences about which behaviours appeared to signify that the baby was in pain.

The content was thus categorised, grouped and reduced by combining repetitious behaviour until observations had been saturated i.e. no new behaviours were being identified. Thus the scoring system encompassing a number of categories was formed.

The data was analyzed and itemized, initially into the following 10 areas of behaviour :

spontaneous motor activity,

social contact,

spontaneous excitability,

flexion of fingers and toes,

tone,

sucking,

facial activity,

cry quality,

cry quantity,

sleep pattern.

This group description identified key areas within which relationships between variables were identified (Cavanagh 1997). Conceptual mapping was utilised to indicate relationships between areas of behaviour. Behavioural data collected was then formed into gestalts of cues and thus quantified, classified and organized. A least to most continuum was used.

An example of the detailed description for one of the categories is shown here.

SPONTANEOUS EXCITABILITY

Score

0. Slow, gentle reactions/movements, no cry or jitteriness, may be unmoving.

1. Blinks and slightly screws up face transiently. Mild movements for 10 seconds at a time, then resettles - may not really wake if asleep.

2. Either 1 to 5 episodes of mild jittery type movements without cry, or one startle type reflex without cry in 10 minute assessment. Settles quite quickly and is at rest in between.

3. Between 5 and 10 episodes of jittery type movements without cry, or one startle type reflex with a cry in 10 minute assessment. Settles quite quickly and is at rest in between.

4. All reactions/movements are excitable/hyperactive. Almost continuous movements associated with cry. Arms held up and away from body shaking.

5. Very jumpy and jittery continually. Arms and legs extended during movements and held tensely. Weak cries with movements.

Targeting areas and developing such a checklist meant that future observations could be focused. Such was the intention of the study - to quantify neonates behaviour.

6.4 Stage ii) Content Validity.

Ongoing discussion and input with experienced psychologists, neonatal nurses and doctors throughout these stages led to confirmation of identified behaviours and provided content validity to the grouping of cues. Clinical psychologist input was invaluable in verifying the decisions reached regarding grouping (Guba and Lincoln 1981). The varied content of the differing items thought to be assessing pain supported the previous work of researchers who have understood neonatal pain as encompassing a diversity of characteristics. Individual differences in these behavioural items were apparent and were quantifiable.

6.4.1 Pilot study.

The coding system was trialed on a further nine surgical babies, each over fourteen assessment periods.

6.4.2 Sample.

The babies were all less than 28 days old (mean age 12 days , range 1-27 days). There were 3 girls and 6 boys. They had undergone surgery as follows:

repair of inguinal hernia (2)

duodenal atresia repair (1)

formation of colostomy (2)

removal of cyst (1)

anoplasty (1)

pyloromyotomy (1)

urethral valvotomy (1)

6.4.3 Method.

Each baby was assessed after a fifteen minute observation period by myself. At the end of the observation a score for each category within the pilot LIDS was given. The scale was applied in the same order consistently. The babies were assessed twice pre operatively. The timing of these assessments were dependent on the length of time the baby was on the unit before proceeding to theatre. At a minimum there was one hour between each assessment. Post operatively the babies were assessed every hour for the first six hours, then at 18,19, 23, 24, 42, 43 hours post operatively. Video recordings of 20 assessment points were made and viewed by two clinical psychologists.

6.4.4 Analysis.

As I became more proficient at making the assessments certain problems and inconsistencies became apparent. Discussion with the clinical psychologists took place following their own viewing of the videoed assessments and the scale's classification changed slightly as the study progressed. There were four main changes.

1. The category for flexion of fingers and toes initially had been given a 0-3 potential score. In practice during the pilot study it was sometimes difficult to allot a score as either fingers or toes were flexed. The use of the three point score markedly diminished the sensitivity of the items. The category thus developed to 0-5 as these differences between how and when the digits became more flexed were further identified.

2. The category "social contact" in the early stages of the study included the babies ability to engage with the researcher in order to assess "state". In practice this was very difficult to elicit and often would result in disturbing the baby. Questions as to whether this was ethical or necessary were raised with the psychologists. It was deemed detrimental to the babies and inconsistent in its monitoring when some babies slept. It was subsequently dropped from the scale.

3. A dummy was also initially used to ascertain how well the baby sucked. Questions were raised as to whether each baby therefore **had** to be offered a dummy. The psychologist asked how many times did I offer the dummy during an assessment? For research rigour this should be standardised. This raised another ethical question. Some parents prefer their baby not to be given a dummy. Also offering a dummy to every baby simply to ascertain if they would suck was deemed disruptive. This led to further clarification being made. Sucking was moved into the "spontaneous movement" category, it fitting into the normal practice for a baby. Thus if the baby already had or used a dummy then sucking could be assessed. Sucking fists, tubes or making sucking movements could also be included. However dummies were not to be introduced purely for research purposes.

4. The assessments using the score were originally carried out over 15 minutes. This was subsequently reduced to 10 minute assessments after the scores were monitored at both time points and found to be the same in the majority of assessments (113 = 90%).

Refinements were also made to some of the key words used to describe the cues within each category. Score 4 within spontaneous movement category for example, now holds more detail about the amount of movement.

6.5 Discussion.

The purpose of the study was to observe babies in "natural" pain free situations as well as situations where they were possibly in pain in order to identify a range of pain behaviours in babies. Utilising direct observations of babies both in normal and peri operative situations, empirical evidence and ongoing group discussion between myself, clinical psychologists and a paediatric consultant. An overall picture of infant behaviour emerged.

Observing babies behaviour is remarkably enlightening. They do so much more than sleep. Babies are born with the ability to elicit care from caregivers - their only method of survival. It may be *expected* therefore to see similarities in behaviour. While each has his or her own individuality, reacting and interacting with what is going on around them in unique ways, when these actions were catalogued, common threads were seen among them. These common threads, it is postulated, are cues meant to convey information to care givers. These cues were grouped into 8 categories of behaviour. Within each of these categories, types of behaviour were further identified and classified on a least to most 0 –5 scale. This constitutes the LIDS scale, section 10.6.

The scale is thus a measure of baby's behaviour. It is postulated that the classification of the behaviours within each category reflects the intensity of cues the baby is giving in relation to their distress level with 0-2 being the normal, comfortable behaviour of a baby who is not distressed and 5 being the most distressed behaviour. The detail of the explanations of each score enriches our knowledge of, and ability to recognise, neonatal behaviour and therefore enable us to quantify distress cues.

In healthy neonates, movements have an organised appearance- fluid and variable. Movements have a gradual onset and differ in speed and amplitude throughout the movement (Hopkin &Prechtl 1984; Mc Grath 1987). Picture a baby waking, stretching his/her limbs, wriggling slowly, yawning and smacking lips while slowly opening his/her eyes and scanning the immediate environment. Vocalisations may be small grunts and low pitched murmurs.

Abnormal movements are documented as being of a more rigid and awkward appearance. The data collected from the surgical group revealed that neonates progress from this relaxed stance through episodes of increasing rigidity until the babies who appeared to be in great pain lay in an extremely tense stance. Tone was markedly increased and body and limbs held rigid and flexed. Movements were diminished, which may not be recognised by caregivers who could consider the baby lying quietly to indicate comfort. This pattern of behaviour is much more likely to be heeded by caregivers of older children. A "closed" stance is adopted. Tone becomes increasingly more tense and rigid. The neonate tightly shuts his/her eyes and there are many frown lines around the brow and mouth - this may be interpreted as an effort to shut down the stimuli the baby is experiencing. It is postulated that the neonate in pain cannot distinguish between external and internal stimulii and so the baby in pain reacts in a similar manner to babies overloaded with sensory stimulation.

A phenomenon which was apparent in much of the data collected in babies who were considered to be in pain was that a space developed between the big toe and the rest of the toes which remained for much of the assessment time. Also the thumb was increasingly held inside the clenched fist.

The sleep pattern of babies likely to be in pain was of a jumpy, disturbed type often disrupted by startles, resulting in short periods of rest with bursts of crying. Emde (1978) reported that neonates fall into exhausted sleep as a result of unrelieved pain. The present author would disagree with this, having observed neonates' pain causing very disturbed, short,spasmodic sleep periods. While the amount of cry the babies engaged in diminished when the baby was considered to be in increasing pain, possibly in an effort to conserve diminishing energy reserves , the pitch of the cry changed considerably. This went through a "shocked wail" probably meant to summon help immediately, to eventually a grunty, high pitched and choppy cry.

It is postulated the upper end of the continuum within LIDS are cues given by the baby to indicate they are distressed. Because the surgical group reported here may be assumed to be in pain due to tissue damage having occured, it is further postulated their distress is due to pain.

With regard to the Hawthorne effect- it was thought a neonate would be one of the least likely subjects to alter their behaviour as a result of being observed. It must be acknowledged however that on occasion when the infant was less ill and studied, they did engage in communication seeking behaviours. One infant in particular who was used to being carried around in a papoose appeared to be using a signal cry - stopping and starting - while looking at the researcher, almost as though he were saying "come on then -pick me up as usual."

Each of the eight categories of LIDS has a potential score of 0-5, with 0 indicating a relaxed, comfortable baby. The purpose of such a score is to quantify a babies behaviour in terms of pain/distress. Thus a baby may score between 0 - 40 with the lower scores indicated low levels or absence of distress and the higher score indicating distress. The ability to quantify distress in this way can initially identify distress and can act as an ongoing assessment of efficacy of interventions.

In an attempt to objectify assessment of behaviour, each score within each category is carefully defined, by detailed description of the behaviour, as identified in the full scale which follows.

6.6 LIVERPOOL INFANT DISTRESS SCALE

SPONTANEOUS MOTOR ACTIVITY WITH SUCKING

Score

0. Completely still but relaxed. Slow movements of head from side to side. Arms and legs stretching and recurling. Elbows and knees, frog like, arms away from body. Yawning or smacking lips. Sucking will be energetic and sustained, retaining dummy in mouth. May have spontaneous "startles" during which baby does not wake.

1. Wriggling and squirming main trunk. Arms and legs extending and recurling at a ratio of 50:50 with (0) type movements. Sucking is energetic chewing on dummy, stops, may cry, then chew again. Dummy usually remains in mouth during cry but if falls out and is replaced - is accepted immediately.

2. Restless agitation. Spates of quick, sharp movements. Legs move up and down (may be one at a time). Crawling if on tummy. Arms move in front of body, then settles and is still. Ratio of 75:25 with (1) in 10 minute assessment. If sucking, will not be sustained. Dummy falls out frequently - cry to suck 75:25% of time. If replaced, baby takes a while to fix.

3. Sharp, tense movements. Quick thrashing of arms and legs, legs more than arms. Fists held clenched, head slightly back. Will only take dummy after much persuasion and then doesn't sustain sucking. Too much crying to co-ordinate properly.

4. Sharp, tense movements of rigidly held body. Guarding of certain body areas with arms and knees. Fists clenched tightly. Chin shrunk down on to chest. A closing in of baby on themselves, as though to protect. Amount of movement diminishing - very little attempt to retain dummy or to suck.

5. Almost completely still and tense. Holding body guardedly. Thumb inside tightly clenched fist. Does not take dummy at all, conserving energy to breath which will be distress type gasps. No blinking and little eye movement.

SPONTANEOUS EXCITABILITY

Score

0. Slow, gentle reactions/movements, no cry or jitteriness, may be unmoving.

1. Blinks and slightly screws up face transiently. Mild movements for 10 seconds at a time, then resettles - may not really wake if asleep.

2. Either 1 to 5 episodes of mild jittery type movements without cry, or one startle type reflex without cry in 10 minute assessment. Settles quite quickly and is at rest in between.

3. Between 5 and 10 episodes of jittery type movements without cry, or one startle type reflex with a cry in 10 minute assessment. Settles quite quickly and is at rest in between.

4. All reactions/movements are excitable/hyperactive. Almost continuous movements associated with cry. Arms held up and away from body shaking.

5. Very jumpy and jittery continually. Arms and legs extended during movements and held tensely. Weak cries with movements.

FLEXION OF FINGERS AND TOES

Score

0. Fingers loosely curled as round a pencil. Thumb outside fist. Toes straight and together.

1. Intermittent relaxing and curling of digits.

2. Digits partly curled in more acutely than "0" score and held that way for some minutes.

3. Fingers OR toes held tightly curled.

4. Fingers spread out rigid and extended. Feet pointed downwards and held stiffly. Toes curled down tightly.

5. Tightly clenched fist continuously - thumb inside fist. Toes curled downwards, feet turned upwards at a sharp angle to leg. Space between big toe and other toes.

TONE

<u>Score</u>

0. Relaxed. Arms and legs open and away from body, either spread out or frog like, if babe on tummy. Elbows and knees at about 45° to arms and legs.

1. Intermittent relaxing and tightening of limbs.

2. Arms and legs held stiffly. Fists clenched or fingers fully extended and stiff. Elbows bent tightly. If on tummy, knees drawn up and arms as (2) but continuously, without relaxation.

4. Limbs held rigidly, knees drawn up, fluctuating with whole body being held rigidly and knees straight.

5. Whole body held taut. Knees held straight. Arms held stiffly close to body - continuously. If moves whole stance remains taut.

CRY QUANTITY

<u>Score</u> In each 10 minute assessment:

0. No cry.

1. Small, short bursts of grumbling up to three times in 10 minutes about 1 minute total crying.

2. 2-4 minutes spent crying either in bursts or as a fairly continuous lusty cry / 1/5 total time of assessment.

3. 4-6 minutes spent crying / 2/5 total time of assessment.

4. 6-8 minutes almost continual cry / 2/3 total time of assessment.

5. 8-10 minutes continuous / almost all time.

CRY QUALITY

Score

0. Neutral vocalisation - occasional short mutter, low pitch. May be absent altogether.

1. Grumbling low pitch about 10 second duration. Stops/starts. Mouth closed - a 'beginning to cry' cry forced from the chest. May settle and stop or proceed.

2. A cross, moderately pitched, lust cry. Imperative tone to it - intended to signal. Builds up to a crescendo of amount. May stop and start, pauses anticipating a response.

3. A higher pitched wail, quicker to reach crescendo, more sustained and uncomfortable. A siren like cry, insistent and without pauses.

4. Shocked startled sudden start to cry. An intense, abrasive hard high pitched piercing cry. Long and sustained then may settle and start again without external provocation (e.g. noise). Tense 'cupping' to tongue. May have breath holding on inspiration.

5. Mewing, pitiable cry. Few and interspersed - may alternate with (4). A chopping quality may be present due to the baby's hyperventilated breathing rate.

SLEEP

Score In a one hour period majority of type determines score.

0. Greater than 10 minutes at a time.

1. 5-10 minute naps.

2. None, but alert, aware and looking around.

3. 2-5 minute naps.

4. Less than 2 minute naps. Frequent waking - probably unsettled.

5. None - uneasy and unrestful with it.

FACIAL EXPRESSION

<u>Score</u>

0. Eyelids closed and relaxed - no lines, lips slightly apart. No movement of nostrils or face.

1. Eyelids remain closed but face slightly screwed up with lines around mouth, eyes and over brow. Very transient expression and may be repeated often. Baby still asleep but may make mewing noises and sighs with consequent expression.

2. Attentive, receptive expression. Awake and aware and responding to surroundings. Paying interest, no lines on face, slow blinking of eyes. Mouth slowly opening and closing with tongue moving slowly in and out.

3. Eyes partly closed with lines around. Mild furrowing of brow. Face slightly contorted into frown expression. Chin may quiver - gaze be squinted and brow look 'wary'. May be a transient expression throughout assessment.

4. Moderately furrowed brow. Eyes closed and screwed up tightly causing many lines around eyes. Nostrils sharp and flaring. Lips tightly held therefore thin line to mouth when crying. Jutting lower lip may be constant or transient at a ratio of 50:50 with either (3) or (5).

5. Practically all the time without relief, a constant deeply furrowed brow. Very flared nostrils, unnaturally open mouth with tightly held lips. Eyes tightly shut. A grey pallor to face.

SUMMARY.

This chapter has described and discussed the first stage in the development of LIDS. The score was formulated after an extensive observational study of infant behaviours was categorised in line with available theoretical constructs.

"*The task of converting observations into numbers is the hardest of all, the last task rather than the first thing to be done. It can only be done when you have learned beforehand a great deal about the observations themselves." (Thomas, 1983 pg.148).*

Any observation of behaviour, whether self recorded or recorded by others is subject to reactivity. Carers can become adept at identifying infants responses to events, and patterns of behaviour can be recognised. In common with Carter (1995) I felt I had good observational skills. The skills of research observations are different however necessitating objectivity. The system reported here attempted to organise intuitive and subjective observations into an objective scoring system. In order to test the scores ability to provide such objectivity, the study progressed through the examination of issues of reliability and validity, discussed in the following chapters.

CHAPTER 7.

Phase 2. Initial reliability and validation studies.

This first part of the study resulted in a list of neonatal behaviours categorised into a scoring system, the higher scores being characteristic of painful situations. The second phase, reported in this chapter, tests the list of behaviours to ascertain validity and reliability. In neonates one can never be certain that one is measuring pain, indeed there has been debate as to whether nociception would more accurately describe the neonates' experience. In view of this thinking at the time of the scale formation it was termed a "distress" scale. On reflection, it may have been more accurate to term it a "pain" scale.

However one could argue that as the scale identifies and categorises ALL neonatal behaviour, it is the score awarded that determines how much distress the infant is in. The context of that score will indicate what is the likely cause of the distress; what intervention should take place to limit that distress; and as important, has that intervention worked or is further intervention needed.

This chapter relates the further development of the study.To test construct validity the hypothesis was that using LIDS, the scores for babies undergoing surgery would reflect their pain levels.

A sample of infants undergoing operations of different severity were studied. The rationale was :

a) infants undergoing more major surgery would show more pain
b) infants with painful conditions would be likely to show pain prior to surgery
c) following analgesia pain scores would be less
d) pain would diminish as healing takes place

The final part of this chapter addresses the issue of inter rater reliability.

7.1 Method

Using the LIDS, structured observations were made on a number of babies in the pre and post operative phase.

7.1.1 Consent.

Once a baby had been identified for possible inclusion in the study, I approached the parents of the baby after first being introduced by one of the staff caring for the baby on the unit. The timing of this first contact was carefully planned to avoid distressing the parents even more at an already distressing time for them. The researcher had worked on the unit until the commencement of the study and this provided an insight into the best time to approach parents. The study was explained to the parents and an information sheet given to them. (appendix 3) Their written and verbal consent was obtained. Three of the families approached declined to take part in the study. One family had already been asked to be participants in another research study going on at the same time. The other two families simply preferred not to be included and their wishes were respected.

7.1.2 Sample.

The babies were admitted to the same regional surgical unit over a period of twelve months. Selection for inclusion in the study was random and governed by my being informed of the new admission, my own availability and parental consent. Some babies, having been identified for inclusion in the study were subsequently excluded as they returned to the NICU for a period of ventilatory support. This meant that many behaviours thought to reflect pain were restricted.

A total of 40 babies were identified for inclusion. 9 babies were subsequently "lost" to the study when they required ventilatory support following operation and were returned directly to the NICU. A group of 31 neonates in total were assessed. The babies age ranged from 10 hours to 28 days. There were 16 boys and 15 girls.

The study group were classified as -

(i) a group of newborns undergoing major surgery (n =13)

6 boys and 7 girls mean age 141 hr. (5.8days) range 10 hr.-528hr.

(ii) a group of newborns undergoing moderate surgery (n= 11)

5 boys and 6 girls mean age 217.3 hours (9days) range 12hr. - 672hr.

(iii) a group of newborns undergoing minor surgery (n=7)

5 boys and 2 girls mean age 22.8 days range 14 - 28 days

After the babies had been studied confirmation of categorisation of surgery type was effected by neonatal nurse specialists (n=3), neonatal anaesthetists (n=3) and neonatal surgeons (n=6), collated by means of a questionaire. 14 operations common to the neonatal population were listed and participants were asked to categorise these into "high" "medium" and "low" according to perceived level of invasiveness. This was used as an index of severity. Overall results were as follows in Table 1.

Table 1. Categorisation of surgery.

OPERATION.	LEVEL OF INVASIVENESS.		
	High.	Medium.	Low.
Repair of Myelomeningocele.	9 (75%)	3 (25%)	0%
Formation of Oesophagostomy.	5 (41%)	7 (59%)	
Gastroschisis repair.	12 (100%)		
Insertion of ventriculo-Peritoneal shunt.	8 (66.6%)	4 (33.3%)	
Ladds procedure.	11(92%)	1 (8%)	
Duodenal atresia Repair.	11 (92%)	1(8%)	
Inguinal hernia Repair.	1 (8%)		11(92%)
Closure of ostomy.	10 (83.4%)	2(16.6%)	
Gastrostomy formation.	4 (33%)	8 (66%)	
Ileal atresia Repair.	11 (92%)	1(8%)	
Formation of Colostomy.	9 (75%)	3 (25%)	
Choanal atresia Repair.	6 (50%)	6 (50%)	
Anoplasty.	4 (33.4%)	6 (50%)	2 (16.6%)
Uretheral valvotomy.	5 (41%)	4 (33.4%)	3 (25.6%)

While the subjectivity of this approach is recognised the respondents were knowledgeable in their field and their opinion is classed as expert. The exercise also served to highlight the differences in such expert perception as to what constitutes levels of invasiveness and subsequent pain in neonates. Using this information, the operations were classified using the highest score to determine within which category the operation was placed. Thus,

Major surgery included-	myelomeningocele repair
	Ileal/duodenal repair
	formation of colostomy
	closure of ostomy
	repair of Gastroschisis
	insertion of ventriculo-peritoneal shunt
	urethral valvotomy
	Ladds procedure
Moderate surgery included-	oesophagostomy formation
	gastrostomy formation
	anoplasty
Minor surgery included -	inguinal hernia repair

Only one operation, choanal atresia repair was indetermined by this exercise. I, as a knowledgeable neonatal nurse, used my opinion to put it in the moderate category.

7.1.3 Data collection.

Assessments using the LIDS score were carried out over 10 minute periods by myself sitting at the incubator/cot side. The scoring was carried out on each of the 31 babies twice pre-operatively, hourly for the first six hours post-operatively and then at 18, 19, 23, 24, 42 and 43 hours after operation; making fourteen assessments each. The times were chosen to reflect the accepted pattern of post operative pain in children i.e. more intense in the immediate post operative phase, diminishing over 48 hours (Berde 1989). Every category was given a score at the end of the ten minute observation cycle, using the LIDS detailed description. The application of the scale was standardised for each assessment. I observed the baby for ten minutes timed on a timer. Immediately following this period of observation I used the LIDS score sheet to allot a score for each parameter. The score sheet was used to compile a score for each category and the scores for each assessment totalled at the end of the 48 hours observations. The score sheet is Appendix 4.

Any qualitative data such as parental visits, feeds, dressing changes or procedures were recorded in a column on the score sheet. A record of interventions - either caregiving, medical/surgical interventions, or comfort measures -occuring during the observation was also kept. The record of analgesia administration was gained from the baby's drug chart after the period of observations had been completed.

At the same time as the assessment was being carried out on the baby, I made video recordings of 20 babies' assessments. Parental consent was gained for this. Prior to this part.of the study I had spent three days within the media department of the University, learning how to use a camcorder, and how to edit film - a technique which was vital further into the study.

Camera angles were dependent on the position of the baby's incubator in the unit. The camera and tripod were positioned to capture as much of the baby on video as possible while maintaining easy access to the baby in case of emergency and causing least disturbance to the running of the unit.

7.2 Results.

Assessments were made on 31 babies and LIDS was found to be usable and sensitive for identifying post-operative distress in newborn infants (Table 2). The 31 patients were divided into three groups according to the degree of surgical intervention (major, moderate and minor respectively). The criteria for the group differentiation had been determined by the anaesthetist/surgeon survey previously carried out (page 84).

In order to look at pre operative pain scores, babies were divided into those likely to have pain prior to the operation as a result of their condition (these are marked with a * in the table), and those with less painful conditions.

Babies i-vii incl. = minor surgery group (group 3) (n=7)

Babies viii- xviii incl. = moderate surgery group (group 2) (n=11)

Babies xix- xxxi incl. = major surgery group (group 1) (n=13)

Table 2 LIDS SCORE for 31 post operative babies.

Baby. Pre op. Hours Post op.

Minor surgery.(Group 3) key : scores underlined indicate when analgesia was given.

	i)	ii)	1	2	3	4	5	6	18	19	23	24	42	43
i			14	7	8	4	5	7	8	0	2			
ii	7	0	4	1	1	2	2	1	<u>0</u>	1	2	0	2	2
iii	0	-	12	14	11	4	8	1	3	2	0	-	-	-
iv	2	0	1	5	2	1	0	0	1	1	1	0	0	-
v	0	-	11	7	7	3	4	-	0	-	-	-	-	-
vi	5	-	<u>14</u>	4	7	6	-	-	4	-	13	-	-	-
vii	3	-	15	7	8	2	-	-	2	-	-	-	-	-

Moderate surgery. (group 2)

viii	30	3	24	8	11	7	13	7	4	4	5	3	15	2
ix	6	17	9	7	7	29	12	21	8	2	6	1	1	0
x	0	11	11	8	12	14	10	6	1	0	4	4	1	0
xi*	-	-	10	7	5	5	0	6	5	1	6	1	0	0
xii	18	2	0	4	2	2	1	0	6	12	0	3	10	16
xiii	3	4	3	8	9	18	14	7	4	4	5	4	15	2
xiv	1	2	2	3	0	5	4	4	4	12	0	13	3	5
xv*	2	19	7	2	0	1	2	-	3	3	3	2	10	4
xvi	18	8	6	0	6	5	1	-	4	1	1	18	2	2
xvii	8	2	8	4	11	6	4	-	0	3	12	0	10	-
Xvii	15	16	2	4	2	5	13	21	17	21	5	4	15	3
i*														

Major surgery. (group 1)

xix*	10	10	5	13	5	3	9	5	2	5	8	8	0	2
xx	-	-	5	11	8	20	2	5	1	6	4	4	1	4
xxi*	29	12	32	33	29	25	18	14	17	7	8	9	4	8
xxii*	27	15	15	8	9	22	25	7	12	6	19	8	1	2
xxiii*	1	2	9``	6	25	19	2	3	3	3	3	20	7	2
xxiv*	2	-	1	1	2	3	11	7	17	12	8	5	6	9
Xxv *	8	10	1	4	5	5	5	11	29	9	9	9	26	30
xxvi	7	2	5	5	5	6	5	8	16	8	5	5	-	4
xxvii*	1	0	2	3	2	2	2	-	1	2	4	4	6	2
Xxvii i*	32	24	5	8	1	23	12	8	20	17	2	8	1	2
xxix*	4	3	5	3	12	6	3	7	0	2	1	2	6	2
xxx*	8	11	1	5	4	3	3	7	2	1	0	2	2	1
xxxi*	15	6	1	2	6	11	12	9	1	3	0	1	24	4

The mean group scores are presented in the following tables.

Table 3. Scores for major surgery group.

Assessment time.	Mean	Std. Dev.	Range.	Min.	Max.
Pre op 1	11.83	11.29	31	1	32
Pre op 2	8.64	7.06	24	0	24
Hours post op 1	6.69	8.57	31	1	32
2	8.08	8.37	32	1	33
3	8.69	8.7	28	1	29
4	10	9.07	24	1	25
5	8.92	6.84	23	2	25
6	7.5	3.03	12	2	14
18	9.46	9.52	29	0	29
19	6.15	4.56	16	1	17
23	5.38	4.94	19	0	19
24	4.69	2.66	8	1	9
42	7.33	8.67	26	0	26
43	5.46	7.49	28	1	29

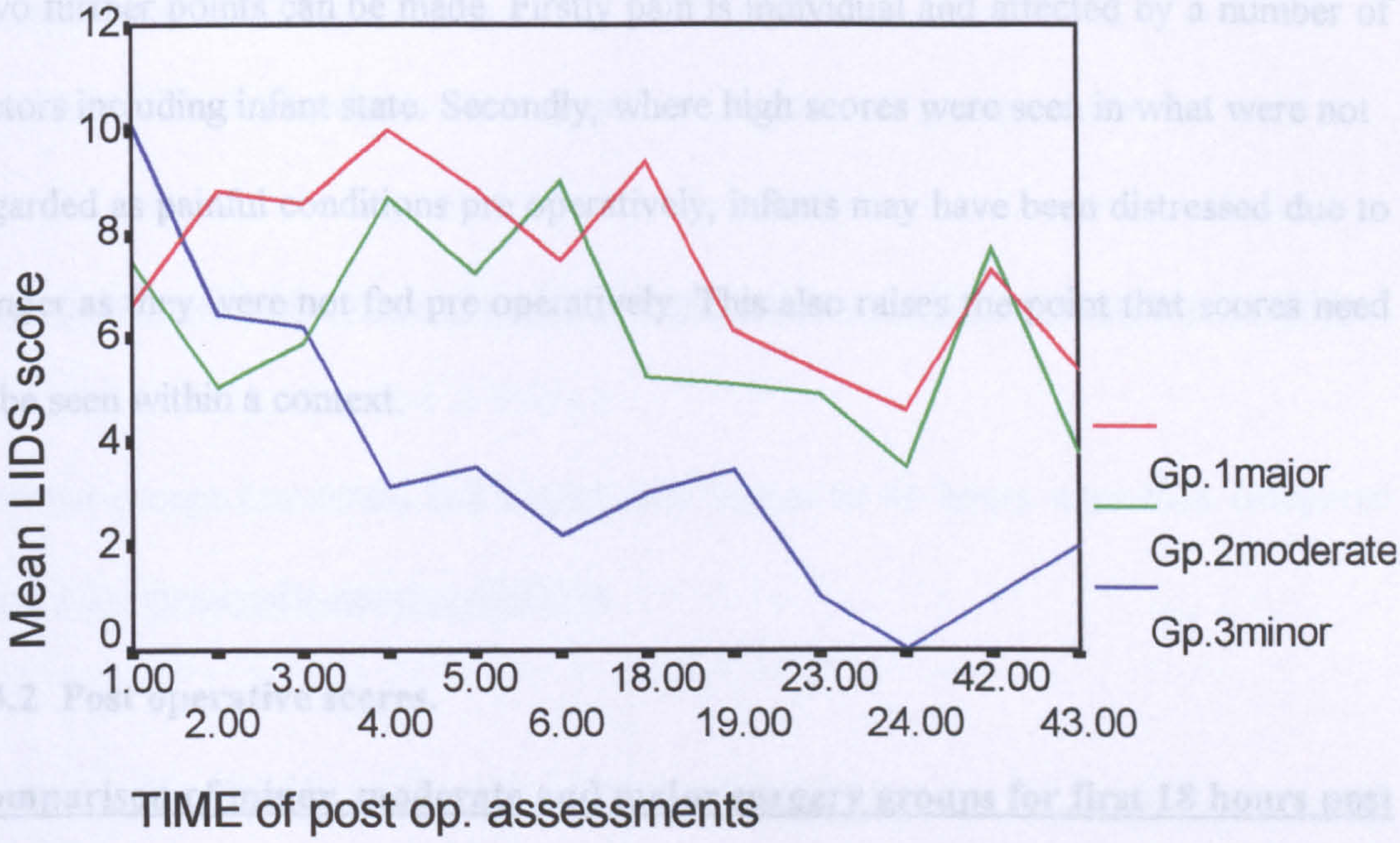
Table 4. Scores for moderate surgery group.

Assessment time.	Mean.	Std. Dev.	Range.	Min.	Max.
Pre op. 1	10.10	9.81	30	0	30
Pre op. 2	8.40	6.85	17	2	19
Hour post op.					
1	7.55	6.64	24	0	24
2	5	2.76	8	0	8
3	5.91	4.48	12	0	12
4	8.73	8.28	28	1	29
5	7.27	5.64	14	0	14
6	9	7.87	21	0	21
18	5.27	4.5	17	0	17
19	5.18	5.98	18	0	18
23	4.09	3.42	12	0	12
24	3.55	3.39	13	0	13
42	7.73	5.44	14	1	15
43	3.82	4.60	16	0	16

Table 5. Scores for minor surgical group.

Assessment time.	Mean.	Std. Dev.	Range.	Min.	Max.
Pre op 1	2.83	2.79	7	0	7
Pre op 2	0	0	0	0	0
Hours post op 1	10.14	5.46	14	1	15
2	6.43	3.99	13	1	14
3	6.29	3.55	10	1	11
4	3.14	1.68	5	1	6
5	3.5	2.81	8	0	8
6	2.25	3.2	7	0	7
18	3	2.83	8	0	8
19	3.40	5.41	13	0	13
23	1	1	2	0	2
24	0		0	0	0
42	1	1.4	2	0	2
43	2		0	2	2

Fig. 1 Graph depicting the 3 surgical groups mean scores.



7.3 Analysis.

7.3.1 Comparison of pre operative scores.

The scores of babies with conditions likely to be painful (marked * Table 2) were compared with those likely not to cause pain, using an independent t-test. Although the means were in the predicted direction i.e 6.86 ± 5 for non painful and 11.5833 ± 8.3 for painful conditions, the results were not significantly different.

$t_{21} = 1.62$ $p = 0.12$ 1 tailed $= 0.06$

Discussion.

These results can possibly be attributed to the fact that small numbers are used in the study. Although the hypothesis that there would be higher pain scores in those with painful conditions was not upheld, there was a trend for this to be the case (p=0.06). Two further points can be made. Firstly pain is individual and affected by a number of factors including infant state. Secondly, where high scores were seen in what were not regarded as painful conditions pre operatively, infants may have been distressed due to hunger as they were not fed pre operatively. This also raises the point that scores need to be seen within a context.

7.3.2 Post operative scores.

Comparison of minor, moderate and major surgery groups for first 18 hours post operative.

Analysis of pain scores following operation was carried out over the three different types of surgery up to 18 hours. There was missing data in the minor surgical group. Due to the nature of the surgery which these babies had undergone, they were well enough to be discharged home before data collection was complete. Comparison therefore between the three groups is only made for hours 1 - 18 post operative. Two way mixed measures ANOVA was used to compare groups and analysed over time, with factor 1 being group (independent) and factor 2 being time (repeated).

Time - Not Significant $F_{6,114} = 0.16$ $p= 0.99$

Group over time - Not Significant $F_{12,114} =0.84$ $p =0.61$

Group $F_{2,19} =0.7$ $p=0.51$ No significant differences.

Note however, that apart from baby vi (table 2) all scores after 18 hours in the minor group are very low.

A number of further analyses were carried out to compare group results.

Comparison of moderate and major surgery groups for 43 hours post operative.

The two groups (moderate and major) with scores to 43 hours were then compared using a 2 way mixed measures ANOVA.

Time - Not Significant $F_{11,176} = 1.44$ $p = 0.16$

Group over time - Not significant $F_{11,176} = 0.31$ $p = 0.984$

Group - $F_{1,16} = 0.65$ $p = 0.433$ No significant differences.

Comparison of pre and post analgesia administration.

Another way of validating the scale was to see if it was sensitive to the use of analgesia. Table 6 demonstrates the LIDS score before and after the administration of analgesia for babies identified in Table 2.

Table 6. Analgesic administration.

BABY	LIDS score when analgesia given.	Next LIDS score (1 hour later).	Score trend.
ii)	0	1	↑
vi)	14	4	↓
xi)	10	7	↓
xii)	0	4	↑
xiii)	18	14	↓
xiv)	2	3	↑
xxi)	33	29	↓
xxi)	25	18	↓
xxii)	15	8	↓
xxii)	19	8	↓
xviii)	5	8	↑
xviii)	20	17	↓

Results.

Comparisons were made pre and post analgesia administration over all infants, using a related "t" test.

$t_{11} = 2.36$ 2-tailed $p = 0.04$ demonstrating a significant difference.

This demonstrates the ability of the LIDS score to reflect the effect of analgesia.

Discussion.

No significant differences were found between the surgery groups although as can be seen from the graph (fig.1) the minor group did have lower mean scores after the first three hours following surgery. After twenty-four hours there was no relationship between the severity of the operation and the score obtained. The fact that the babies' scores consistently reflected the expected pattern of peri operative pain i.e. decreasing over time, links the observed behaviours to pain and to some extent demonstrates concurrent validity. We know that the more invasive the surgery, the greater the tissue damage - resulting in more pain; and that as healing occurs pain lessens, usually over the first 48 hours post-operatively. Completing this argument therefore, where there has been no tissue damage there should be no pain, an issue which will be explored in chapter 9.

A further two points can be made. If we look at the scores for infants with minor surgery who remained up to 43 hours, these are very low compared to the moderate and major groups. Unfortunately the numbers are so small that statistical comparison is not possible. Secondly, the point regarding individual response to painful stimuli must be re-emphasised. Inspection of individual infants' scores may be used to demonstrate this. This is supported by the following analysis of individual cases. Finally, analysis of the scores pre and post analgesia administration demonstrates a significant difference in scores. It is important to note the infrequency that analgesia was actually administered and that analgesia was sometimes given inappropriately - when pain scores were low. These findings substantiate current literature regarding analgesia administration and are further discussed in the final chapter.

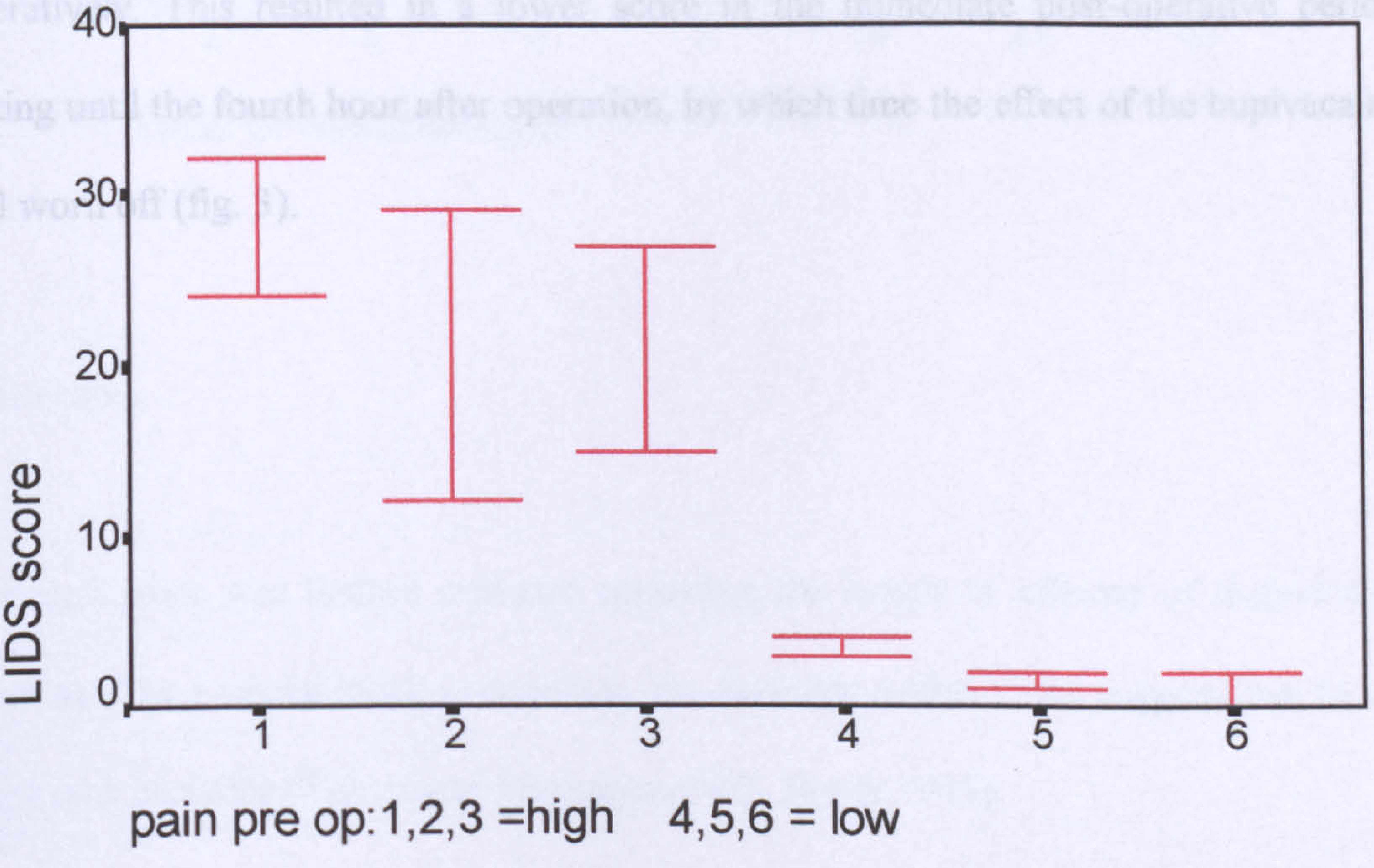
7.3.3 Individual data analysis.

There were marked differences in pre-operative scores and this was related to the fact that some infants requiring major surgery - for gastroschisis repair and intestinal obstruction - were in considerable pain pre-operatively (fig.2).

Fig 2 Pre operative scores -

Babies 1,2,3 had Gastroschisis or Hirschsprungs disease.

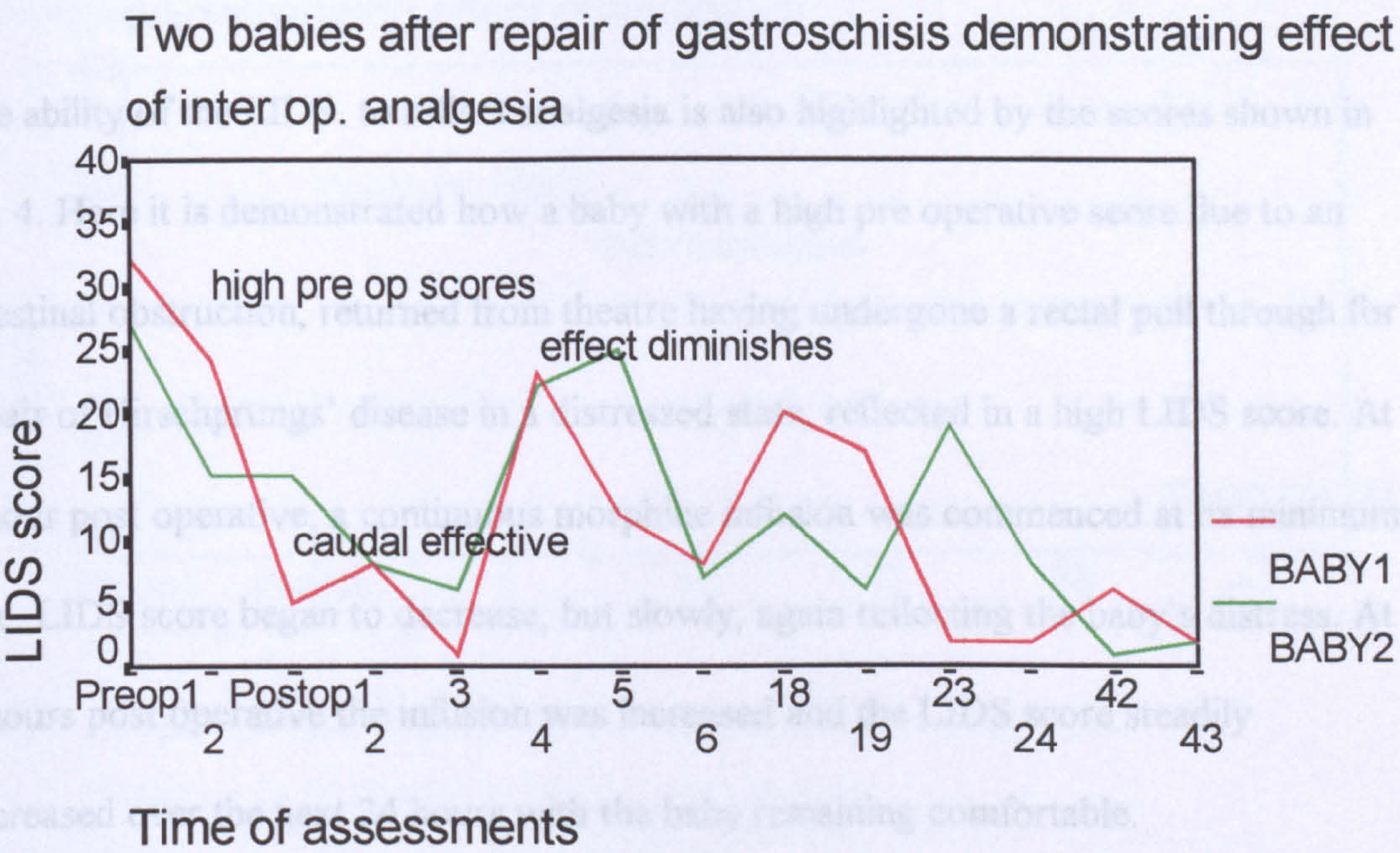
Babies 4,5,6 had Choanal atresia or a Gastric polyp



Individual response to analgesia.

Two infants had high scores pre-operatively and this related to the distress associated with their surgical condition, gastroschisis (table 2 baby xxii, baby xxviii). These two infants had been born in the same hospital on the same day, and transferred over to the neonatal unit together in the same ambulance. One was a boy and the other a girl. They were both seen by the same anaesthetist who subsequently anaesthetised them, and they were consecutively operated on by the same surgeon. When the infants were assessed pre operatively by the Consultant Anaesthetist she noted the infants apparent pain. As a result the anaesthetist administered caudal bupivacaine to them both per operatively. This resulted in a lower score in the immediate post-operative period lasting until the fourth hour after operation, by which time the effect of the bupivacaine had worn off (fig. 3).

Fig 3 Depicting effect of analgesia.



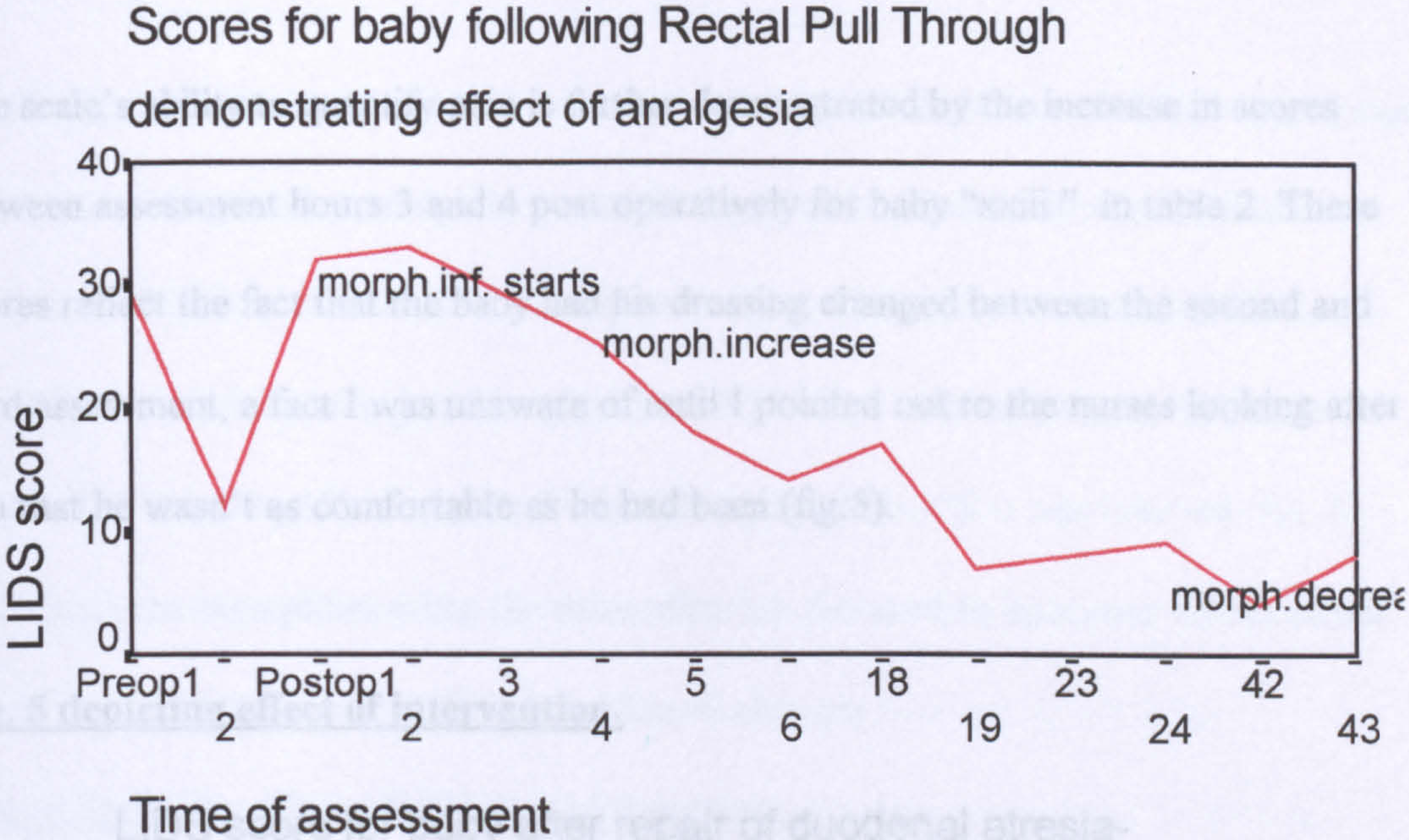
Discussion.

Although there was limited evidence regarding the length of efficacy of Bupivicaine when used as a caudal block in neonates, the available evidence did suggest four to six hours was probable (Tobias and Flannagan 1992, Berde 1993).

As the awareness of the need to provide effective analgesia for neonates has grown, the prescription of analgesia for this client group has altered both in a general capacity, and in the unit under study over the course of this research. Analgesia continued to be prescribed and administered throughout the study, and this influenced the scoring. As table 2 demonstrates, analgesia was often administered on an ad hoc basis and not very often. As the study progressed however, so did the coordination of the administration of analgesia. Thus babies such as "xxi", "xxii" and "xxviii" (table 2) received analgesia earlier than they may previously have done.

The ability of the LIDS. to reflect analgesia is also highlighted by the scores shown in fig. 4. Here it is demonstrated how a baby with a high pre operative score due to an intestinal obstruction, returned from theatre having undergone a rectal pull through for repair of Hirschprungs' disease in a distressed state, reflected in a high LIDS score. At 1 hour post operative, a continuous morphine infusion was commenced at its minimum rate. LIDS score began to decrease, but slowly, again reflecting the baby's distress. At 3 hours post operative the infusion was increased and the LIDS score steadily decreased over the next 24 hours with the baby remaining comfortable.

Fig.4 Depicting effect of analgesia.



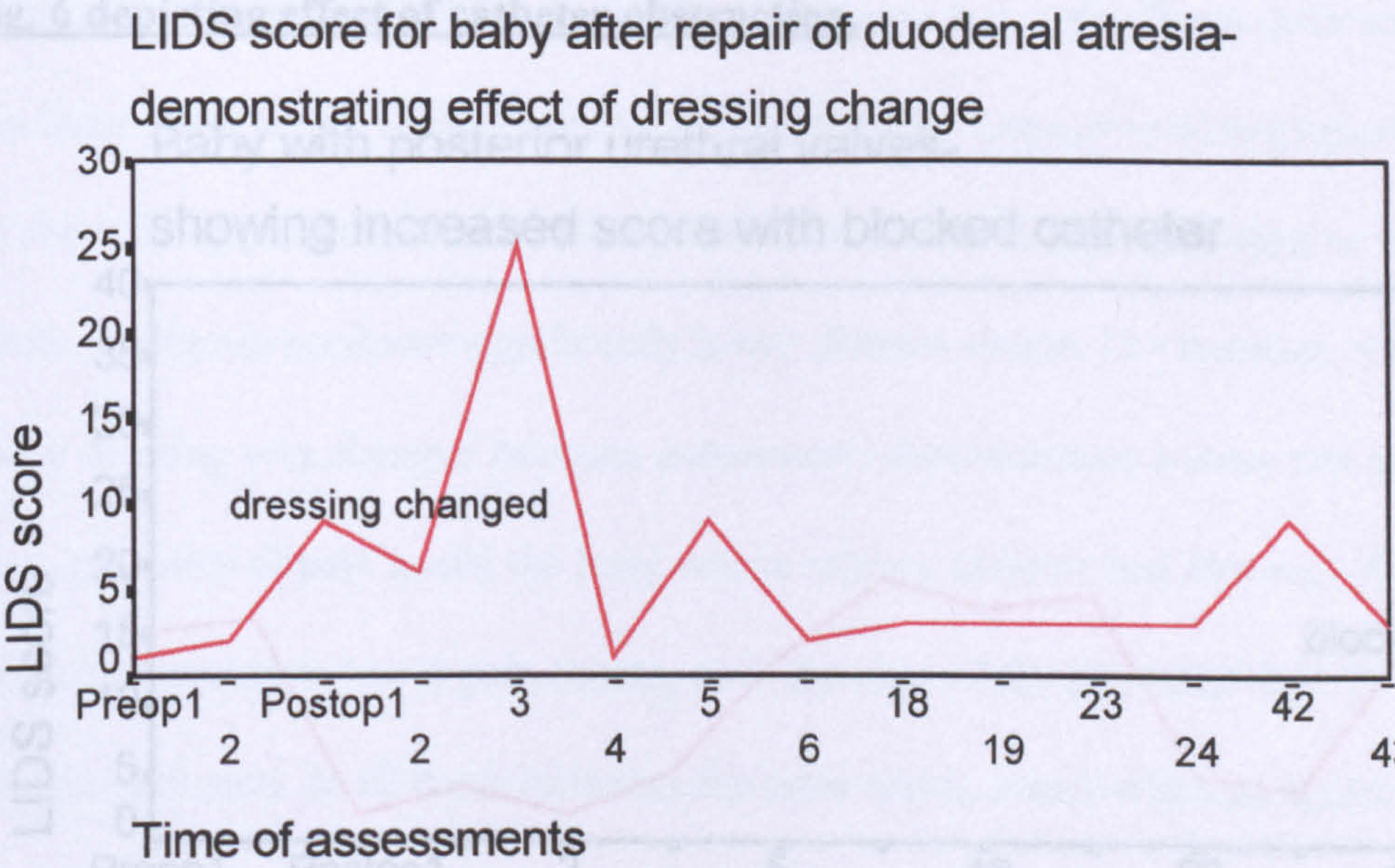
Discussion.

The ability of an assessment tool to reflect analgesic competence while seeming paradoxical can assist in increasing the validity if scores are shown to alter as an expected response to analgesia. The above results demonstrate this as do the significance of the group results (Table 6). The analysis of individual record scores is important as infant responses are individual and reflect each infant's experiences.

Dressing change.

The scale's ability to quantify pain is further demonstrated by the increase in scores between assessment hours 3 and 4 post operatively for baby "xxiii " in table 2. These scores reflect the fact that the baby had his dressing changed between the second and third assessment, a fact I was unaware of until I pointed out to the nurses looking after him that he wasn't as comfortable as he had been (fig.5).

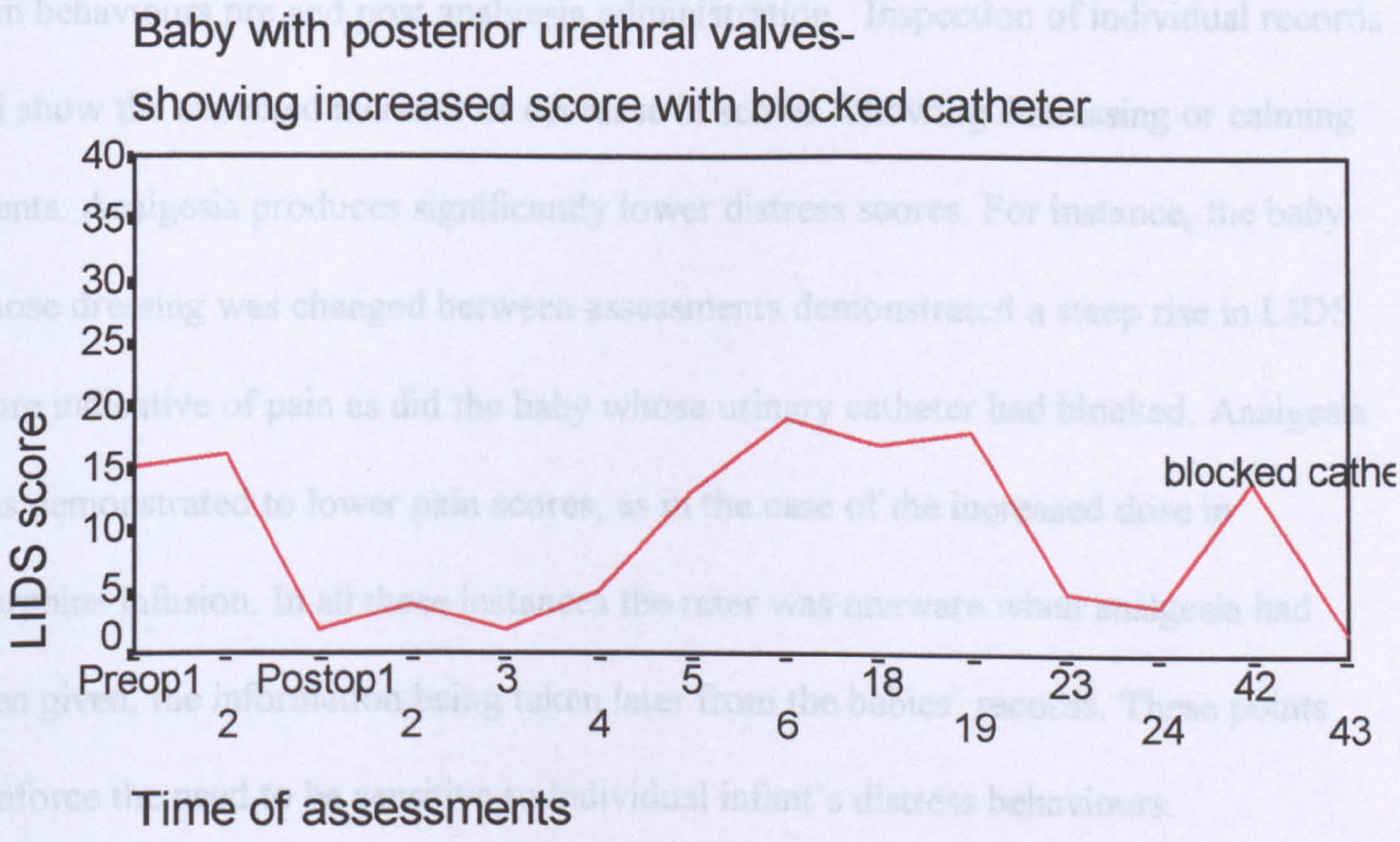
Fig. 5 depicting effect of intervention.



Blocked catheter.

Similarly, the patient with posterior urethral valves (table 2: baby xviii) had an increase in pain as peri-operative analgesia wore off five hours post-operatively. This did not settle until 24-25 hours and then a sharp increase at 42 hours was recorded. On investigation by the nursing and surgical staff a blocked catheter urinary catheter was found. The score rapidly diminished when the urine obstruction was relieved (fig. 6). This instance exemplifies when the researcher felt the need to intervene on the babies' behalf by alerting nursing staff to behavioural changes.

Fig. 6 depicting effect of catheter obstruction.



SUMMARY.

Construct validity was tested in two ways. Firstly groups of infants undergoing minor, moderate or major surgery were assessed using LIDS, and secondly individual infants scores were examined in relation to events likely to increase (e.g. dressing change) or decrease (administration of analgesia) distress.

Group comparison showed no significant differences between the groups i.e. there was no support for the hypothesis of difference in pain behaviours for infants undergoing different types of surgery. However there was a significant difference in pain behaviours pre and post analgesia administration. Inspection of individual records did show the expected increase or decrease in scores following distressing or calming events. Analgesia produces significantly lower distress scores. For instance, the baby whose dressing was changed between assessments demonstrated a steep rise in LIDS score indicative of pain as did the baby whose urinary catheter had blocked. Analgesia was demonstrated to lower pain scores, as in the case of the increased dose in morphine infusion. In all these instances the rater was unaware when analgesia had been given, the information being taken later from the babies' records. These points reinforce the need to be sensitive to individual infant's distress behaviours.

Even a minor operation may cause infants to be in pain post operatively, demonstrated by some high LIDS scores in the minor and moderate groups. However in order to demonstrate that it was *pain* causing these behaviours a further comparative study was undertaken with neonates not undergoing surgery. This is discussed in chapter 9.

This chapter has described and discussed the first part of the second phase in the development of the LIDS by addressing initial issues of reliability and validity. It has demonstrated the scale's ability to assess pain in neonates in the post operative phase and shown good reliability. The second half of this phase examines the issue of reproducability of the scale by other observers and is presented in the following chapter.

CHAPTER 8.

Further reliability studies.

The value of an assessment tool such as LIDS also lies in its ability to be reproduced consistently and accurately by differing carers (Melzack 1984). The following chapter descibes the next part of the study examining the ability of other observers to use LIDS.

8.1 Inter rater reliability.

In order to assess inter-rater reliability a number of different raters rated babies independently.

8.1.1

A selection of 8 of the video recorded assessments were subsequently scored by a clinical psychologist. (Table 7)

Table 7 Researcher and Clinical Psychologist scores.

Baby	Research nurse score	Psychologist score
A	18	19
B	3	2
C	1	3
D	16	22
E	24	20
F	7	7
G	9	9
H	16	19

Results.

Pearson's correlation Coefficient was applied with 95% confidence intervals. Results demonstrated a correlation of $r = 0.95$ $p = 0.00$ (significant) providing content validity for the components of the score. (fig.7 and fig. 8).

Fig. 7 depicting correlation of researcher & clinical psychologist scores.

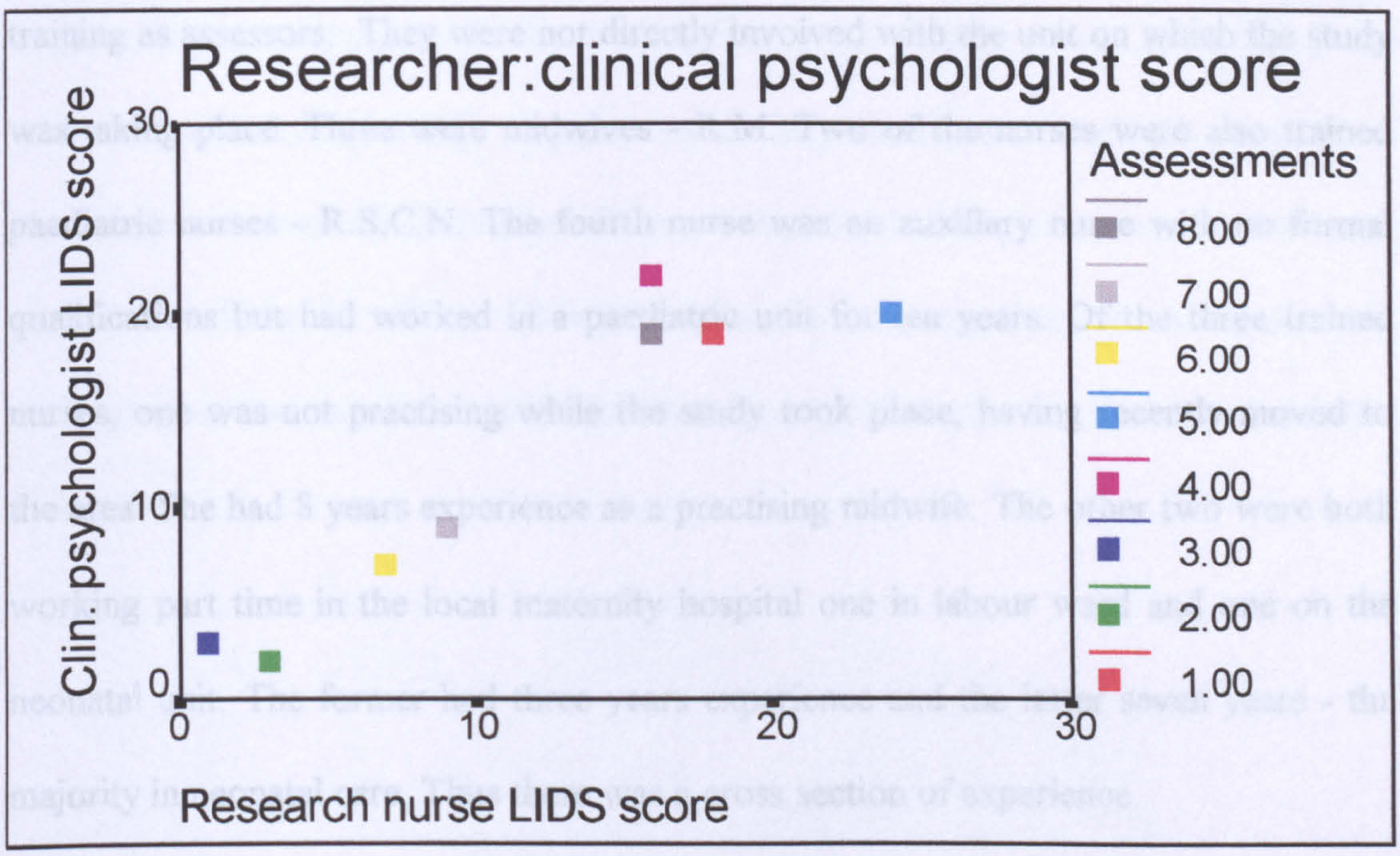
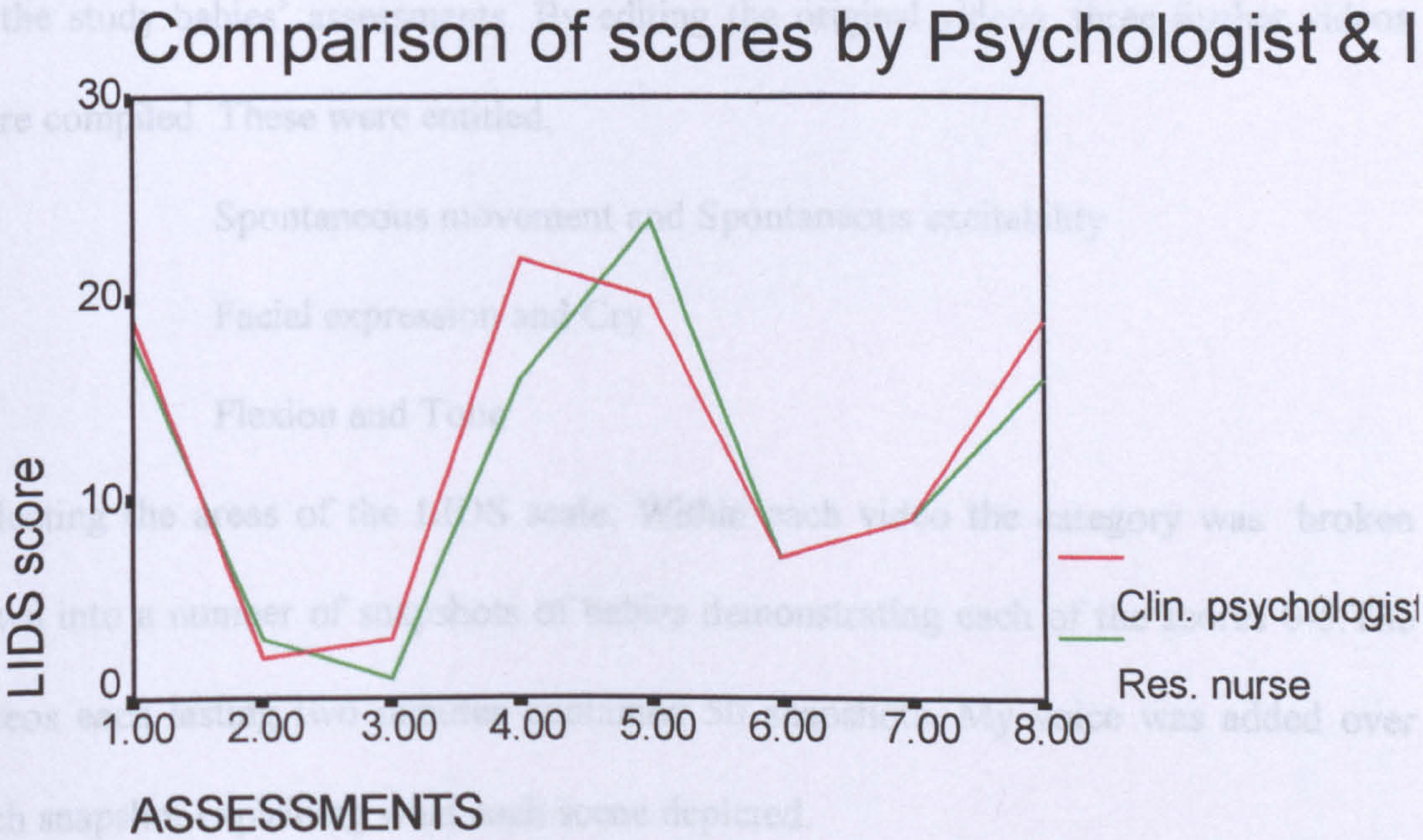


Fig. 8 Graph comparing research nurse & clinical psychologist scores.



8.2 To test reliability of the scoring system further, four nurses were selected for training as assessors. They were not directly involved with the unit on which the study was taking place. Three were midwives - R.M. Two of the nurses were also trained paediatric nurses - R.S.C.N. The fourth nurse was an auxillary nurse with no formal qualifications but had worked in a paediatric unit for ten years. Of the three trained nurses, one was not practising while the study took place, having recently moved to the area. She had 8 years experience as a practising midwife. The other two were both working part time in the local maternity hospital one in labour ward and one on the neonatal unit. The former had three years experience and the latter seven years - the majority in neonatal care. Thus there was a cross section of experience.

Method.

Materials. I had compiled three teaching videos by utilising the video recordings made of the study babies' assessments. By editing the original videos, three further videos were compiled. These were entitled,

Spontaneous movement and Spontaneous excitability

Facial expression and Cry

Flexion and Tone

reflecting the areas of the LIDS scale. Within each video the category was broken down into a number of snapshots of babies demonstrating each of the scores 0-5.The videos each lasting two minutes contained 50 snapshots. My voice was added over each snapshot explaining what each scene depicted.

This process had been achieved over a number of sessions with the media department, first to identify suitable shots from the original tapes, then to learn to transfer these and copy to another video tape. Finally reading from a pre written script (Appendix 5) my voice was added to each tape to point out the important features of each shot and to state the score awarded. Examples of this are depicted by the pictures on the following pages taken from the videos. Obviously these are only snapshots- each score within each category shown on the video tapes lasted several minutes and thus can be studied at length.

Figure 9

Demonstrating LIDS Score taken from video recording –" flexion and tone."

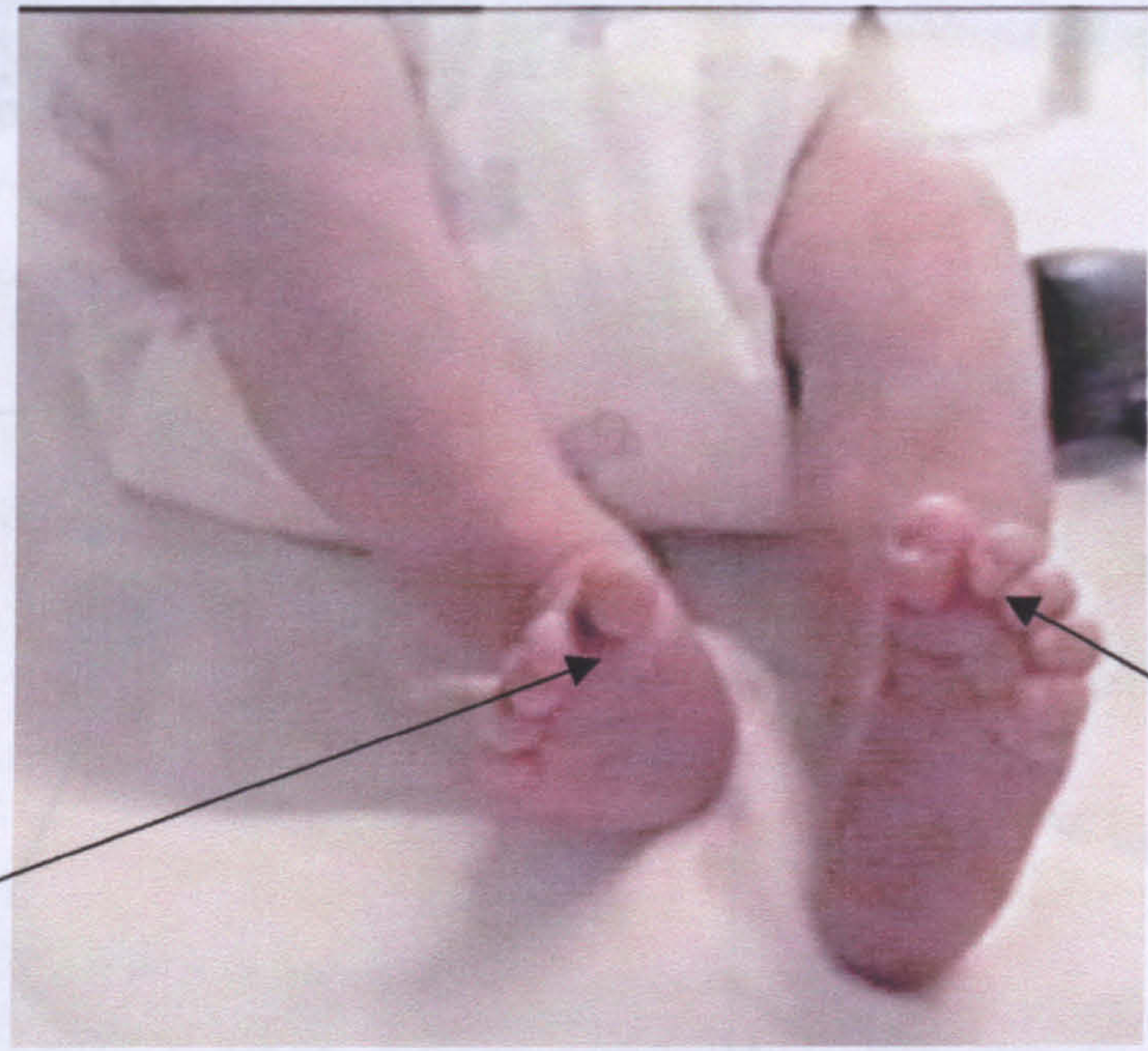
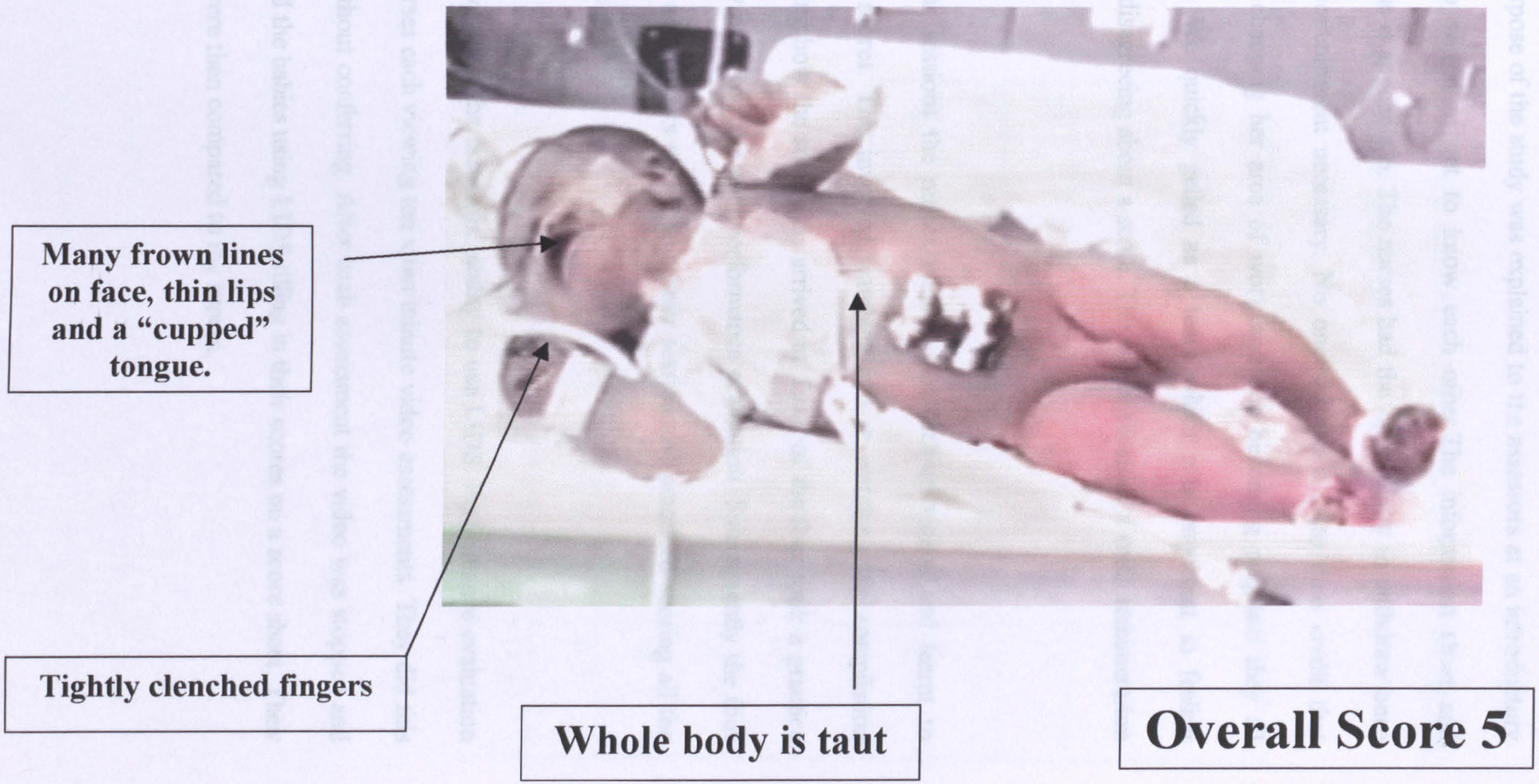


Figure 10

Demonstrating LIDS Score taken from video recording " movement and excitability".



Procedure. The purpose of the study was explained to the assessors at an introductory session which also served to get to know each other.The information sheet and teaching programme is appendix 6. The nurses had the opportunity to withdraw once they realised the committment necessary. No one did and it is to their credit that despite one nurse changing her area of work and one becoming pregnant they all stayed the course. We quickly gelled as a team which was important in feeling comfortable about disagreeing about a score. The nurses received a small remuneration for their work.

Over six, two hour sessions the nurses viewed the teaching videos and learnt to identify individual scores. This involved watching and re watching the compilation videos and discussing how the score was arrived at. Each of the four took a practice tape home to study prior to their own performance evaluation. Subsequently the four viewed ten minute assessments over a two hour session and practiced scoring all the categories together.

The final session evaluated the assessors' ability to use LIDS. Performance evaluation consisted of the nurses each viewing ten x ten minute video assessments. They did this individually and without conferring. After each assessment the video was stopped and the assessors scored the babies using LIDS filling in their scores on a score sheet. Their composite scores were then compared to my scores.

Results.

Table 8. Total scores awarded by trainee assessors and researcher for 10 test assessments at end of teaching programme.

Assessment	Research nurse	Assessor A	Assessor B	Assessor C	Assessor D	Mean of assessors
A	2	3	2	3	5	3.25
B	15	13	19	16	16	16
C	22	21	23	22	20	21.5
D	19	22	15	20	26	20.75
E	6	7	5	6	5	5.75
F	11	8	9	3	6	6.5
G	23	23	23	29	25	24.75
H	22	13	12	10	19	14
I	12	9	5	10	10	8.5
J	11	15	13	14	13	13.75

.

Table 9. To show the significant correlations on 1-tail analysis between assessors test scores and research nurse scores using LIDS.

ASSESSOR	Correlation value	Significant value
A	0.876	0.002
B	0.832	0.005
C	0.821	0.007
D	0.895	0.001
MEAN	0. 876	0.002

Discussion.

There was a high correlation between the research nurse and the four nurses in their assessments. No assessor scored consistently higher or lower than the others despite the fact that the assessors were scoring from video recordings which are artificial and much more difficult to score from than real life.

These results came after a detailed teaching programme, in a step by step process regardless of the assessors prior knowledge of neonates. Thus they illustrate the fact that the score can be learnt by both new and more experienced neonatal nurses. The assessor with most up to date neonatal experience found it useful in organising her previously intuitive observations of a neonate's distress into an objective score. The assessor with the least neonatal experience proved as adept at scoring as the research nurse once teaching had taken place. According to McGrath (1987) a pain scale needs to be reliable and relatively bias free, providing the same information despite the opinions of the people administering it.

8.3 The consistency of scoring by different observers was further tested by a detailed assessment of five further post operative newborn infants using these same four nurses. Five babies, three boys and two girls whom had undergone differing operations were identified. The operations were:

colostomy formation for ileal atresia

gastroschisis repair

rectal pull through

urethral valvotomy

myelomeningocele repair.

Procedure.

I scored each of these babies using LIDS for fourteen assessments -

pre-operatively X 2;

at 1-6 hours inclusive;

and at 18,19,23,24, 42,and 43 hours post operatively.

At the same time each assessment was video recorded. At the completion of this data collection the videoed assessments were transferred to another tape in a predetermined randomized sequence. This ensured the other assessors were blind to the timing of the surgery and in which order the assessments presented. The assessors were also unaware of the type of surgery the baby had undergone and whether the baby was a boy or girl.

I then delivered one by one the five new tapes to each of the four assessors separately, swapping between them as appropriate. The assessors watched each video individually. Each of the assessors thus scored each of the five babies fourteen times according to the L.I.D.S. There was no communication between the assessors throughout this period. Scores were marked for each category on the score sheets the assessors were familiar with, and were collected by myself along with the videos when the assessors were finished.

Results.

There was a high correlation between the initial score awarded by the research nurse and the scoring by each of the four independent assessors (Pearson's correlation Coefficient) (Table 10).

Table 10. To show correlation scores between research nurse and each assessor for 5 surgical babies - 14 assessments each.

BABY A		Correlation value.	Significant value.	Level of significance.
Researcher :	Assessor 1	0.60	0.02	< 0.05
	Assessor 2	0.81	0.00	< 0.01
	Assessor 3	0.92	0.00	< 0.01
	Assessor 4	0.84	0.00	< 0.01
	Mean	0.86	0.00	Significant

BABY B		Correlation value.	Significant value.	Level of significance
Researcher :	Assessor 1	0.82	0.00	< 0.01
	Assessor 2	0.92	0.00	< 0.01
	Assessor 3	0.79	0.00	< 0.01
	Assessor 4	0.82	0.00	< 0.01
	Mean	0.88	0.00	< 0.01

BABY C		Correlation value.	Significant value.	Level of significance.
Researcher :	Assessor 1	0.62	0.01	0.01
	Assessor 2	0.78	0.00	< 0.01
	Assessor 3	0.66	0.01	0.01
	Assessor 4	0.72	0.00	0.01
	Mean	0.78	0.00	< 0.01

BABY D		Correlation value.	Significance level.	Level of significance.
Researcher :	Assessor 1	0.43	0.10	> 0.05
	Assessor 2	0.76	0.00	< 0.01
	Assessor 3	0.52	0.04	< 0.05
	Assessor 4	0.73	0.00	< 0.01
	Mean	0.76	0.00	Significant

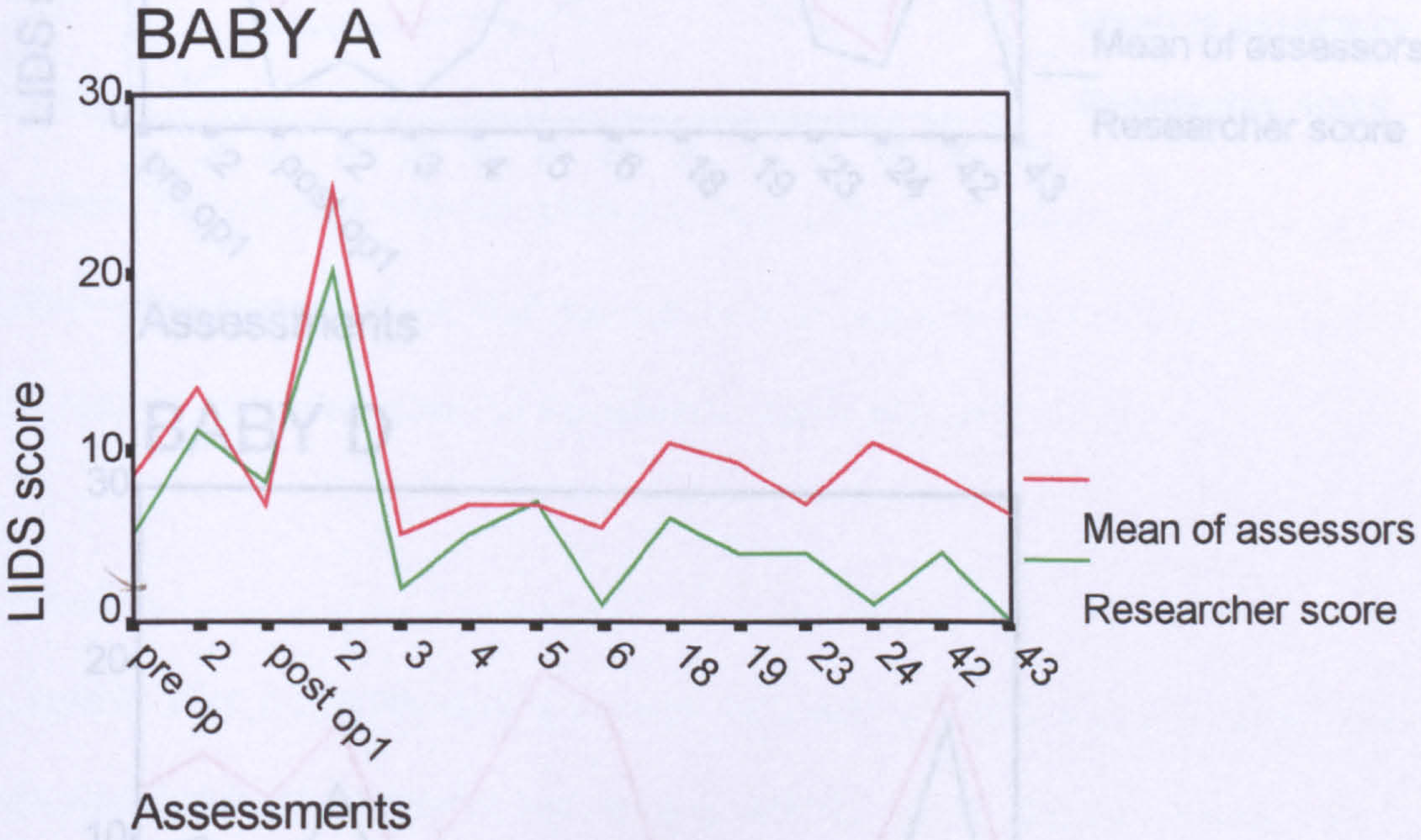
BABY E		Correlation value.	Significant value.	Level of significance.
Researcher :	Assessor 1	0.58	0.02	< 0.05
	Assessor 2	0.40	0.14	> 0.05
	Assessor 3	0.92	0.00	< 0.01
	Assessor 4	0.68	0.00	< 0.01
	Mean	0.54	0.04	< 0.05

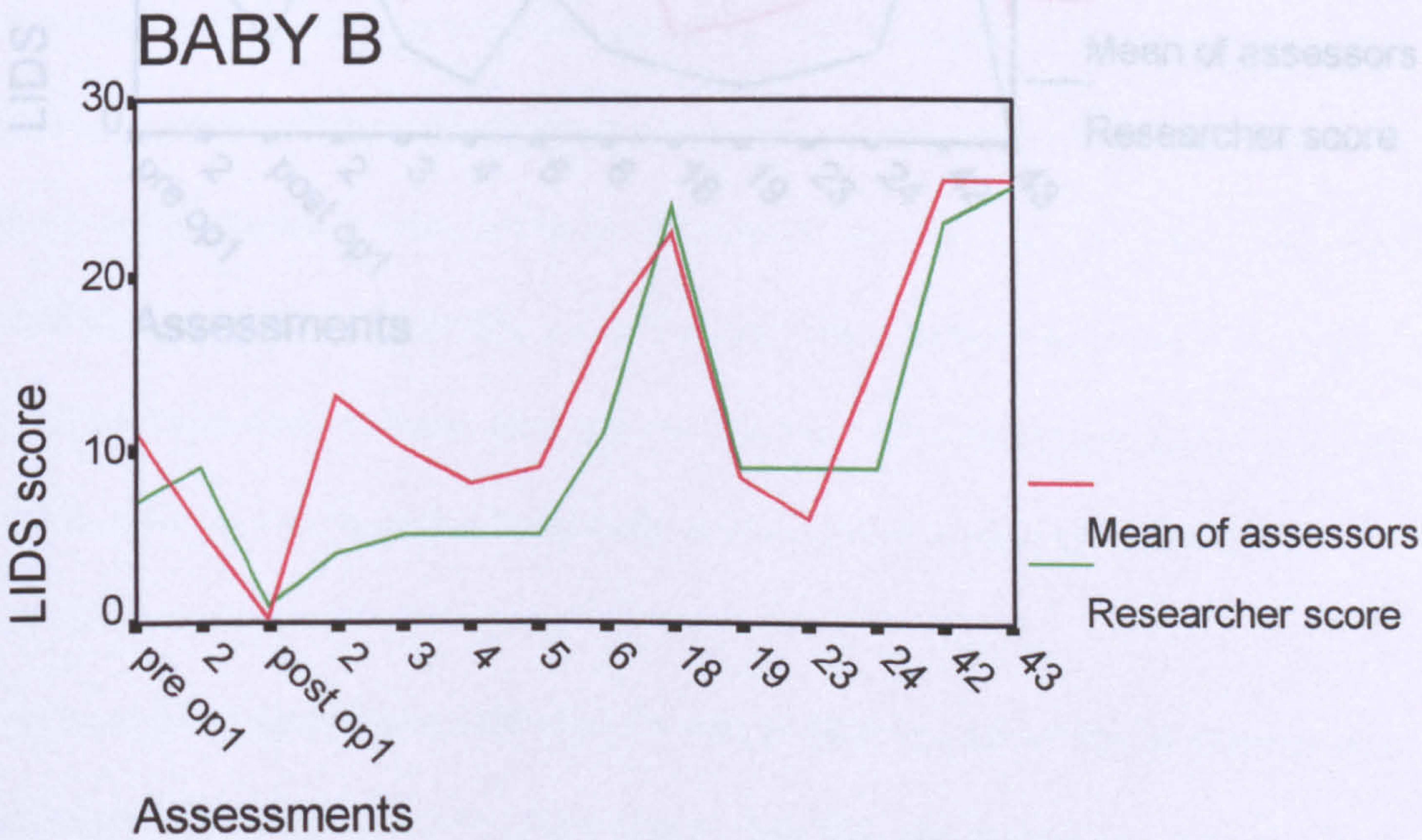
Discussion.

Although the mean correlations are high, table 9 demonstrates that assessor 1 tended to have less agreement than the other assessors. This assessor was the least experienced of the four having no neonatal experience. The results suggest that more training in interpreting LIDS may be necessary for the less experienced.

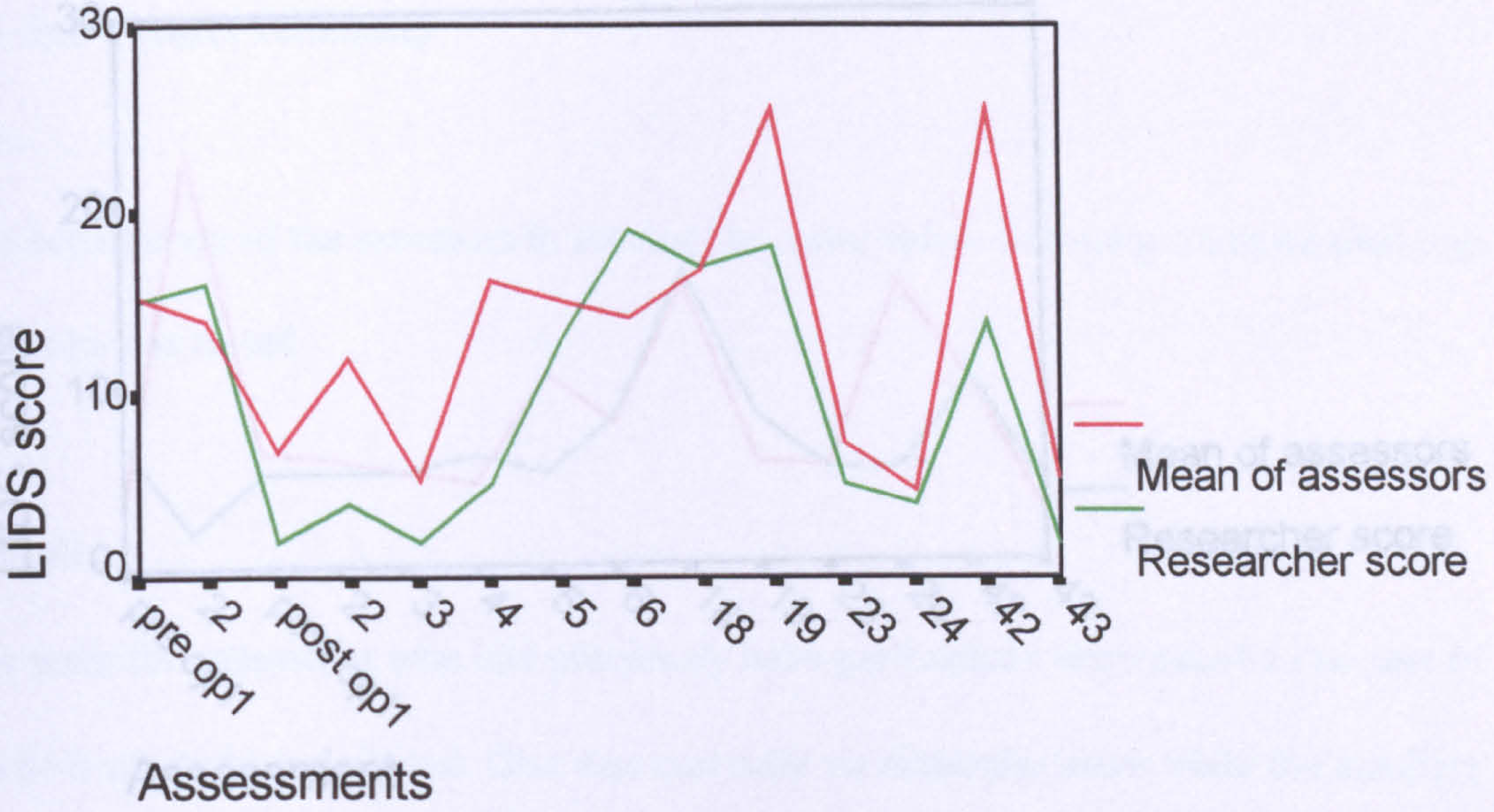
The four assessors did consistently score higher than the research nurse (fig. 11). However the scoring was consistently higher and was not affected by the degree of distress the patient was experiencing as the ranking was very similar. (Altman, 1991).

FIG.11 To show mean score of assessors compared to research nurse for each of the five surgical babies - 14 assessments.

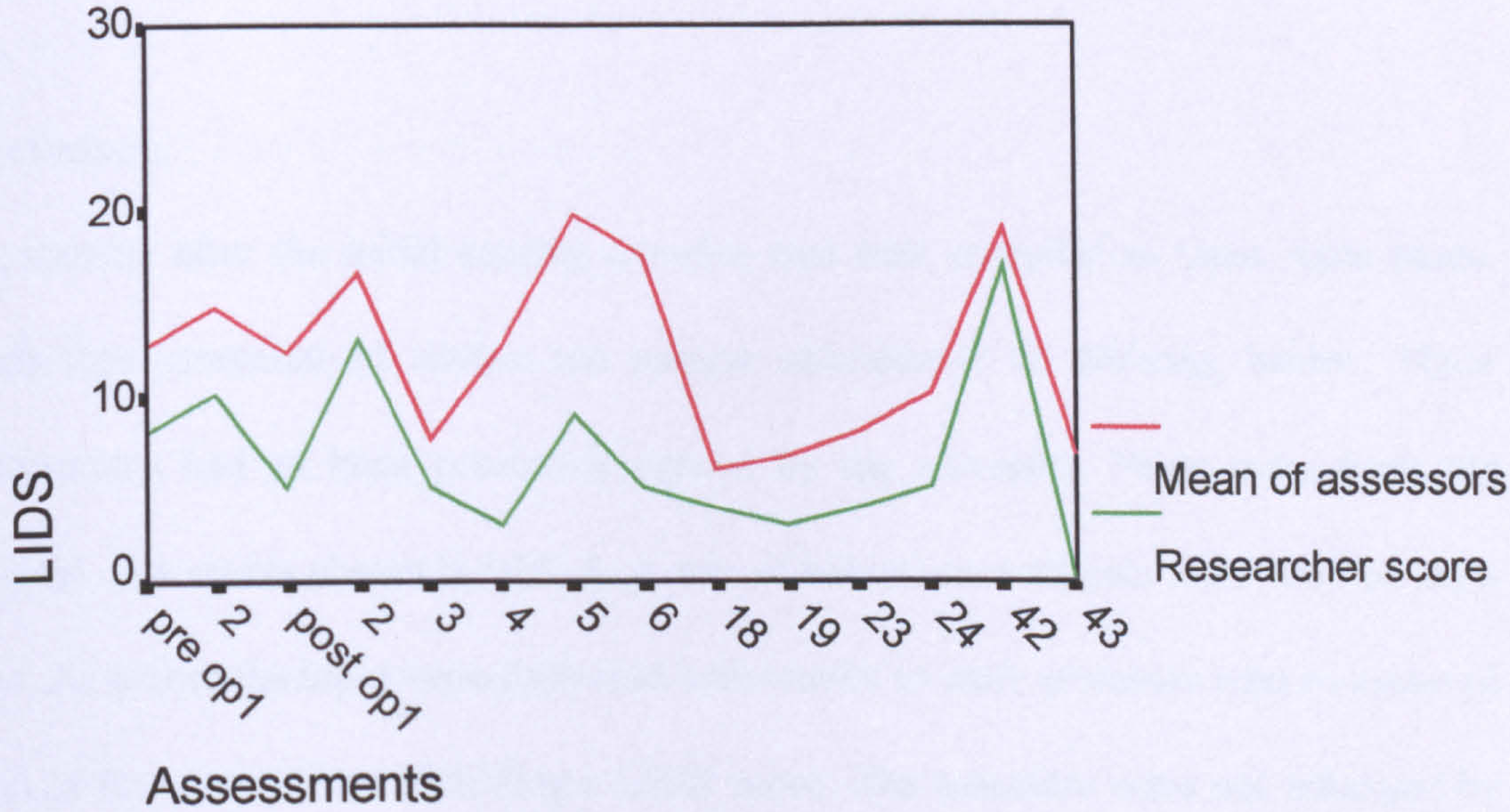




BABY C


30
20
10
0
LIDS score
pre op1
2
post op1
2
3
4
5
6
18
19
23
24
42
43
Assessments
Mean of assessors
Researcher score

BABY D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LIDS
pre op1
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post op1
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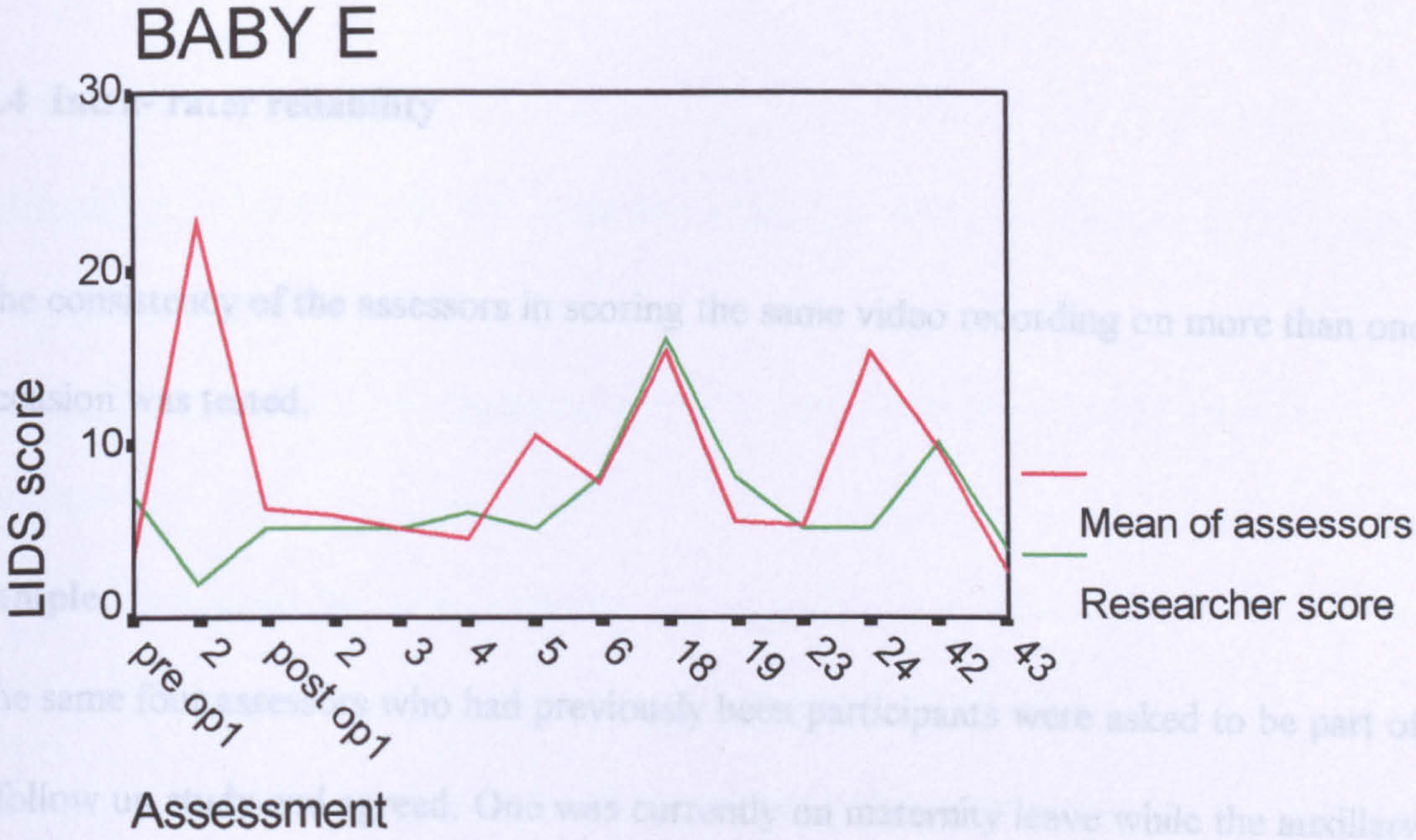
Assessments
Mean of assessors
Researcher score



BABY E
30
20
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LIDS score
pre op1
2
post op1
2
3
4
5
6
18
19
23
24
42
43
Assessment
Mean of assessors
Researcher score

8.4 Intra- rater reliability

The consistency of the assessors in scoring the same video recording on more than one occasion was tested.

Sample.

The same four assessors who had previously been participants were asked to be part of a follow up study and agreed. One was currently on maternity leave while the auxillary nurse was now working as part of a paediatric community team.

Procedure.

Six months after the initial scoring exercise two new compilation tapes were made. Each tape consisted of twelve ten minute assessments of differing babies. These assessments had all been previously scored by the assessors. None were from the original test scores shown in table 8. A mix of babies' assessments were used on each tape. As before the tapes were delivered individually to each assessors who re-assessed each of the assessments, awarding a LIDS score. The assessors were not informed by myself that these were re tests, although two of them did vaguely remember the baby from the previous scoring and subsequently asked me if they were the same baby.

I then took the original score each assessor had allotted to each of the 24 assessments, and compared by correlation tests, how similar their first and second scores were. Then I compared the score I had allotted for the babies assessment to both the assessors first score and then their second score.

Results.

Table 11 Correlation results between assessors first : second scoring and researchers score.

1st compilation tape of 12 assessments previously scored by assessor and researcher.

Assessor 1 -

Asessors' first score: her second score	r = 0.57 p = 0.03 sig.
Research nurse: assessor first score	r = 0.82 p = 0.00 sig.
Research nurse : assessor second score	r = 0.69 p = 0.00 sig.

Assessor 2 -

Asessors' first score: her second score	r = 0. 87 p = 0.00 sig.
Research nurse: assessor first score	r = 0.84 p = 0.00 sig.
Research nurse : assessor second score	r = 0.76 p = 0.00 sig.

Assessor 3 -

Assessors' first score: her second score	r = 0.81 p = 0.00 sig.
Research nurse: assessor first score	r = 0.80 p = 0.00 sig.
Research nurse: assessor second score	r = 0.83 p = 0.00 sig.

Assessor 4 -

Assessors' first score: her second score	r = 0.85 p = 0.00 sig.
Research nurse: assessor first score	r = 0.67 p = 0.00 sig.
Research nurse :assessor second score	r = 0.84 p = 0.00 sig.

2nd compilation tape of assessments previously scored by assessors and researcher.

Assessor 1-

Assessors' first score: her second score	r = 0.66	p = 0.03 sig.
Research nurse :assessor first score	r = 0.79	p = 0.00 sig.
Research nurse :assessor second score	r = 0.69	p = 0.00 sig.

Assessor 2-

Assessors' first score: her second score	r = 0.96	p = 0.00 sig.
Research nurse : assessor first score	r = 0.91	p = 0.00 sig.
Research nurse :assessor second score	r = 0.93	p = 0.00 sig.

Assessor 3 -

Assessors' first score :her second score	r = 0.85	p = 0.00 sig.
Research nurse : assessor first score	r = 0.86	p = 0.00 sig.
Reearch nurse : assessor second score	r = 0.89	p = 0.00 sig.

Assessor 4 -

Assessors' first score: her second score	r = 0.94	p = 0.00 sig.
Research nurse : assessor first score	r = 0.87	p = 0.00 sig.
Research nurse :assessor second score	r = 0.92	p = 0.00 sig.

All correlation results were significant demonstrating the nurses ability to reproduce LIDS scores over time.

SUMMARY.

Three inter rater reliability studies and one intra rater reliability study were carried out. The former showed significant reliability between 5 different raters. The latter showed good reliability over a six month period. This demonstrates that nurses are able to use LIDS reliably, and over time, following training. The question then arises as to whether such training is necessary. Can experienced neonatal nurses recognise pain cues without training? This question was studied and is reported in chapter 10.

On first impression the LIDS scale may not appear "user friendly". Nurses need simple, accurate tools that may be used quickly in the clinical area (Harrison 1991). This may not be possible or even effective with this group of patients. When behaviours such as tremulousness or irritability are noted, according to Brazelton (1977) the standards of evaluation are subjective. The relatively objective scoring of LIDS provides more exact measurement through the rich, behavioural description of the score. More subtle changes in behaviour may be missed without the detail available.

The **LIDS** is highly detailed in its description of behavioural cues providing the nurse with evidence of small behaviours in order to deepen understanding of neonatal pain behavior. In line with pain behaviours of all young children (Woodgate & Kristjanson

1995) neonates are much more subtle with their displays of behaviour, with cues diminishing as pain is increased or unrelieved. LIDS scores reflect the diminishing movements of a baby in pain by scoring these highly. Unlike the quietly still, comfortable infant scoring low, the baby in greater pain will often be still, but with a much more tense, unrelaxed demeanour. Another factor was the widened space between the neonates big toe and the rest of the toes noted as a common occurence in babies with increasing pain scores.

Videos of these cues within the eight categories have been used for teaching purposes to help neonatal nurses recognise pain cues. Once they are internalised, recognition of these changes can inform practice and increase neonatal nurses' ability to make objective assessment of infant pain behaviours and enable them to convert observations of behaviour into quantitative data. It may then be possible to adapt LIDS to a less lengthy scale. It would be a matter for further research to see if this would make judgements less sensitive or less valid. This is further discussed in chapter 10.

The study progressed by examining the validity of the score by investigating construct validity in more depth, by comparison with a group who should not be in pain. This is developed in the following chapter.

CHAPTER 9.

Phase 3 - Control group study.

This chapter will describe and discuss the use of a known group scenario to examine in more depth the construct validity of LIDS. Given non significant differences between the three types of surgery and the proposed explanation that this reflected individuals response to painful stimuli, a further test of validity was required. As discussed in chapter 9 this refers to the ability of the scale to measure that which it says it is measuring. In order to achieve this it was hypothesised that a comparative, control group not subjected to surgery, and not deemed to be in pain would have low LIDS scores. If the scale was indeed measuring distress due to pain in the neonate, support for this hypothesis would provide further evidence of construct validity.

9.1 Sample.

A group of newborns was identified (n=10) who had been born by elective caesarian section following spinal anaethesia. This selection provided a group of newborns who had been subject to the rigours of surgery but without tissue damage. The babies were all full term. Thirteen parents were approached - two sets of parents preferred not to take part in the study; one mother who agreed to the study proceeded to general anaesthesia and so was excluded from the study.

There were 5 boys and 5 girls studied. None had any physiological problems at birth.

9.2 Method.

The research was approved by the ethics committee of the local maternity hospital. A parent information leaflet and consent form were developed (Appendix 6). The ante natal ward staff informed the researcher when a potential 'control' baby was due. The parents were approached initially by the midwife and then by the researcher and after full explanation of the study, consent obtained to study their baby after delivery. There were no a priori benefits to the patients who participated.

9.3 Data collection.

The ten control babies were each observed for ten minutes each hour for the first six hours post delivery; and at 18,19,24,25, 42 and 43 hours post delivery. At each of these 12 assessments the baby was given a LIDS score. At no time was normal routine disturbed for the baby. The first assessments took place in the delivery suite and subsequently on the post natal ward. This enabled comparison with the post operative scores of the infants who had undergone surgery.

9.4 Results.

The scores awarded for the control group are shown in table 12.

Table 12. LIDS scores for control babies over first 43 hours after delivery.

Baby	Hour 1	2	3	4	5	6	18	19	23	24	42	43
Z	2	0	3	0	0	0	0	0	0	0	0	0
Y	3	0	3	0	0	3	0	0	0	0	4	0
X	7	7	1	5	2	0	1	0	11	0	0	0
W	3	2	4	2	0	0	1	2	0	2	0	0
V	11	2	0	0	3	0	4	1	0	0	3	0
U	5	7	5	0	0	4	7	0	2	0	0	6
T	10	5	2	2	0	0	0	7	0	3	4	0
S	7	0	7	0	2	0	0	0	5	0	0	0
R	12	13	6	0	0	3	2	1	0	0	0	3
Q	10	5	10	0	1	0	0	1	0	2	0	0

Fig. 12 Mean score for each hour for control group babies.

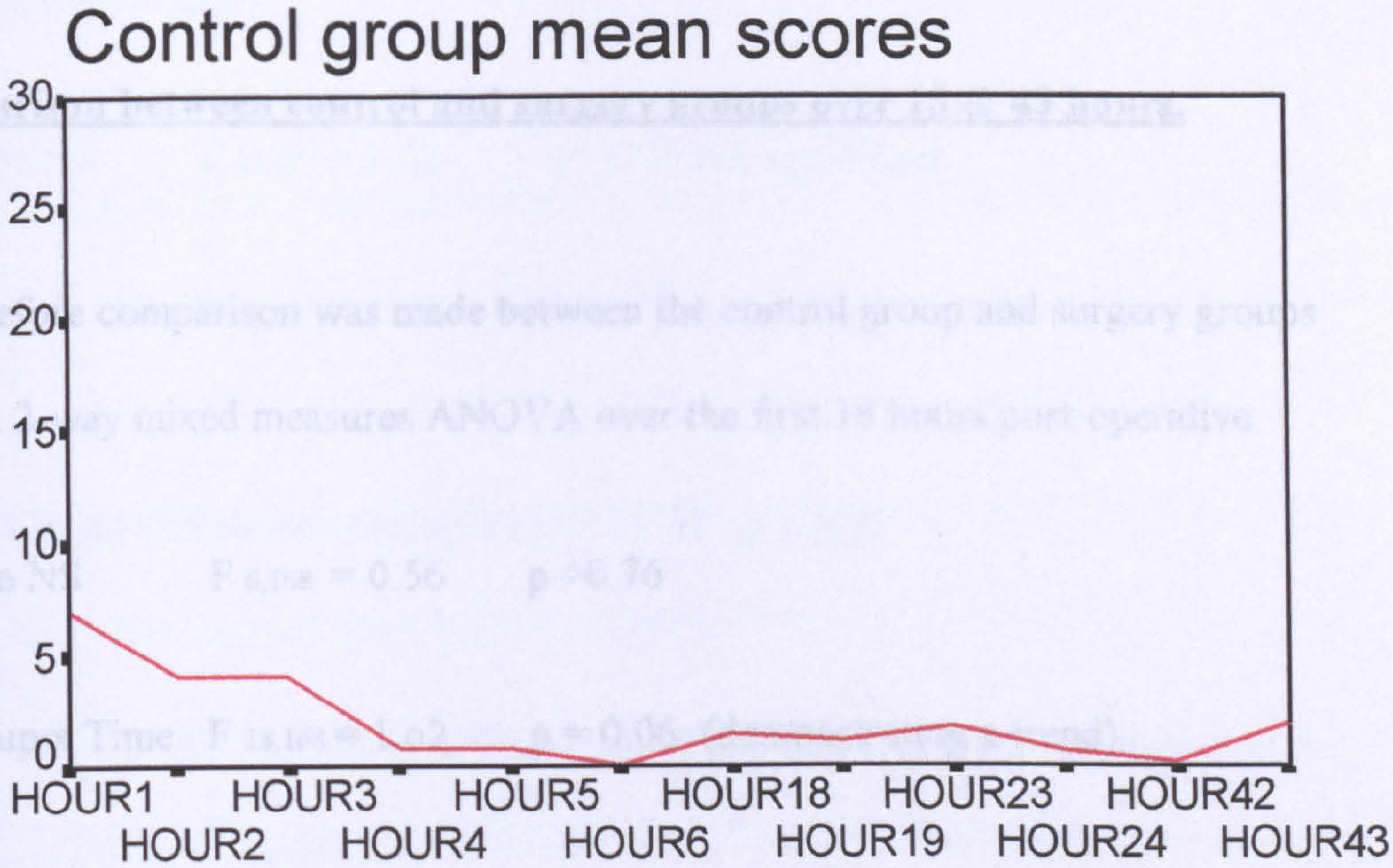
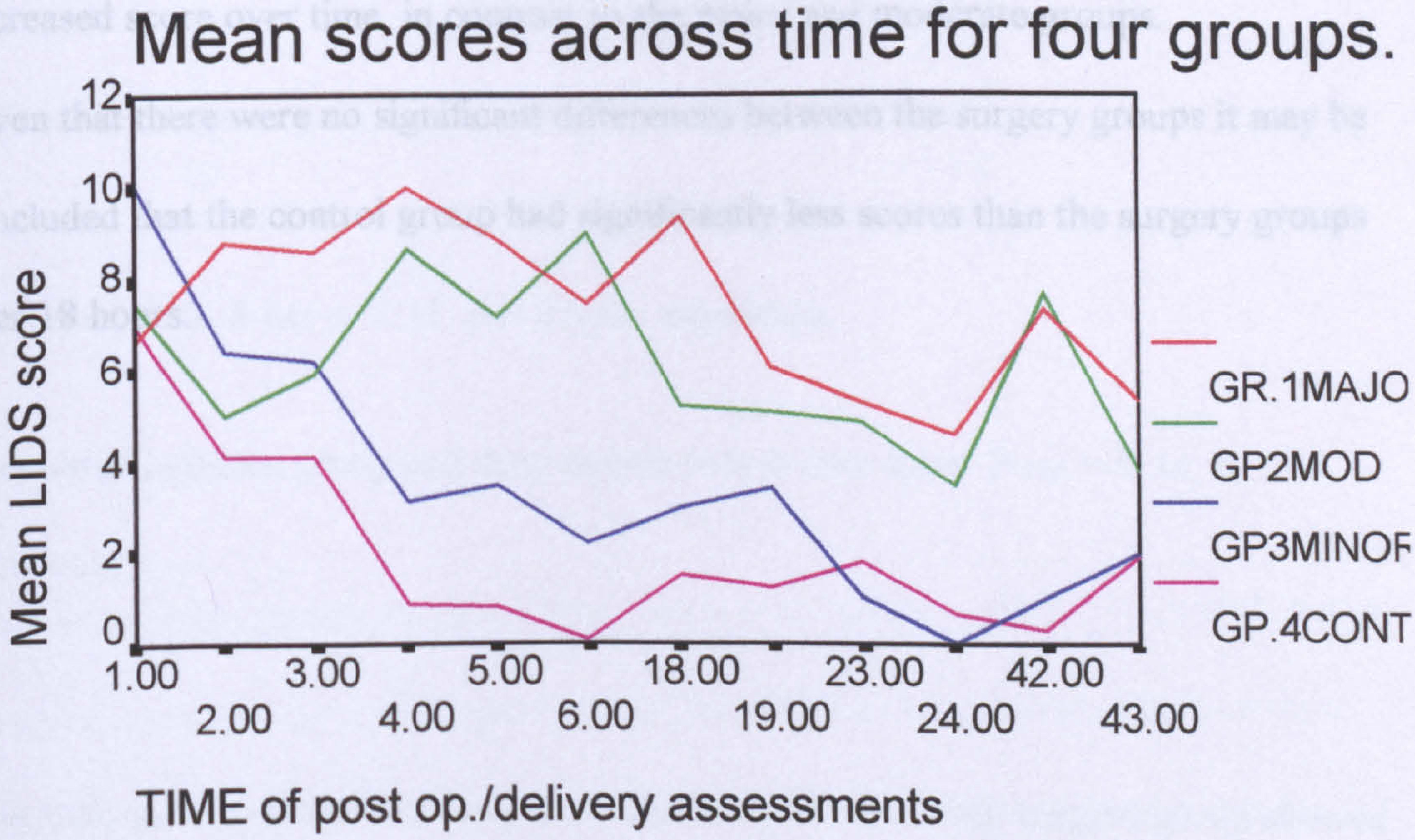


Fig 13 compares the control group scores (group 4) with the three surgical group scores.



9.5 Analysis.

Comparison between control and surgery groups over 18 & 43 hours.

i) As before comparison was made between the control group and surgery groups using a 2-way mixed measures ANOVA over the first 18 hours post operative.

Time NS $F_{6,168} = 0.56$ $p = 0.76$

Group x Time $F_{18,168} = 1.62$ $p = 0.06$ (demonstrating a trend)

Significant difference between groups $F_{3,28} = 4.33$ $p = 0.01$

It can be seen from figure 12 that the control and minor surgery group tend to show a decreased score over time, in contrast to the major and moderate groups.
Given that there were no significant differences between the surgery groups it may be concluded that the control group had significantly less scores than the surgery groups over 18 hours.

ii) A comparison was made between the control group and the moderate and major groups over 43 hours.

Time NS $F_{11,275} = 1.62$ $p = 0.09$ not significant

Group x time $F_{22,275} = 1.15$ $p = 0.30$ not significant

Significant difference - Group $F_{2,25} = 11.37$ $p = 0.00$

The control group had significantly lower scores than the surgery groups over 43 hours.

iii) Comparison between minor surgery group and control group over first 18 hours demonstrates a significant difference between the two.

Difference between pain scores $F_{1,11} = 4.66$ $p = 0.05$

Drop over time $F_{6,66} = 8.11$ $p = 0.000$ significant.

Interaction between group and drop in pain scores over time $F_{6,66} = 0.34$ not significant.

This analysis was carried out in order to test whether the minor surgery group showed more signs of pain than the control group. Thus it can be seen that there is a significant drop over time for both minor and control groups, and also significantly higher scores in the minor group than the control.

iv) In addition, to further support reliability, internal consistency calculations (using Cronbach's alpha) were carried out for the first 18 hours post operative, over the 41 infants assessed. The first 18 hours were used because of the number of infants in the minor surgery category who had missing data after this due to their discharge.Results showed high internal consistency between categories.

Table 13 Internal consistency between categories demonstrated using Cronbach's Alpha.

HOUR - POST OPERATIVE	CRONBACH'S ALPHA
1	$\alpha = 0.86$
2	$\alpha = 0.84$
3	$\alpha = 0.88$
4	$\alpha = 0.94$
5	$\alpha = 0.90$
6	$\alpha = 0.87$
18	$\alpha = 0.93$

9.6 Discussion.

There are highly significant differences between the groups with higher overall scores in the surgery groups. The surgery groups have high scores over the first two days post operatively, while control group scores are low. Often the surgery group had lower scores immediately post operation rising after three to four hours. This is consistent with the effect of analgesia given during operation wearing off. The control group however displayed their highest scores immediately post delivery, rapidly diminishing over the first 2 hours. The score of the control group were also significantly lower than even the minor surgery group. However it can be seen from fig. 13 that the latter group does decrease scores over time and when the results are analysed with the control group both groups show a significant decrease over time. All the above comparisons support the validity of LIDS.

Table 13 demonstrates the consistency between scores within categories and supports the use of a multi dimensional approach to assessing behaviour.

9.6.1 Different behaviours in LIDS.

Although some of the scores for the control group appear high, when analysed it is seen that these scores occur immediately after birth with scores rapidly settling. Given the fact that the infant has just been delivered some distress is to be expected .The highest scores in this group were given for 'CRY QUALITY" and "QUANTITY". At delivery normally the baby's cry is welcomed indicating its ability to breathe to its parents.

Facial expression scores were high in those babies studied after surgery , clearly indicative of pain/distress whereas the control group consistently scored lower in this category.

Many of the control babies scored "2" for facial expression which is described in the score system as being

> Attentive, receptive expression. Awake and aware and responding to surroundings. Paying interest, no lines on face, slow blinking of eyes. Mouth slowly opening and closing with tongue moving slowly in and out.

This raised their overall score. In this group of infants again this is to be expected.The infant is already open to learn from his/her environment and is coping with the external stimulation he or she is exposed to without problem. This did raise the question however of whether this particular group of facial expression cues should score less, or be excluded from the score as potentially misleading in influencing the overall score.The scores for tone and flexion at the same time were low giving no indication that the baby was closing in on his/herself in an attempt to shut out unwanted stimuli unlike the babies in the study group who scored highly in these categories. The study babies, it is postulated, were already coping with pain as a stimulus and were therefore attempting to shut outside stimuli in an effort to protect themselves.

The control group babies slept far more than the study group and the sleep was of a quiet, restful nature with none of the jumpy startles seen in the study group. Indeed one mother commented on how much more settled this baby was compared to her first son who had been born by emergency caesarian section, and spent his first four days in special care. This could be attributed to the effect of anaesthesia. A comparison between babies born by caesarian section under general anaesthetic and a group born under epidural should be made to see if there are any differences. Future research is needed to determine whether anaesthesia does produce different behaviours in control babies.

It is accepted with any multi-factor measuring scale that individuals may achieve the same overall score while responding very differently to particular items. Therefore while facilitating broad classification, the primary purpose of a scale, individual differences may be obscured (Adams 1998). It is necessary therefore to interpret LIDS scores within context. Any observations are dependant on the context in which they are made and our care giving is naturally influenced by that context. The babies in both study and control groups were given comfort measures - containing, touch, feed, analgesia - as deemed appropriate by the nurse/midwife caring for them. The babies in the control group generally responded quickly and positively to simple measures, reflected in the change in their scores.

SUMMARY.

This chapter has discussed the comparison of a control group of babies not expected to be in pain with the previously studied surgical groups. Significant differences were shown between the scores allotted to the control group and the surgical groups, demonstrating validity of LIDS to measure pain in newborns.

It is postulated that the ability of LIDS to reflect such changes in infant behaviour can only enhance nurses' ability to evaluate pain, as well as the efficacy of interventions such as analgesia. The ability of nurses to measure and relieve pain in neonates is examined in the following chapter.

CHAPTER 10.

Phase 4 - Ability of nurses to identify pain without using LIDS.

The previous studies provided support for the reliability and validity of LIDS. The aim of the final study was to determine how useful LIDS would be in clinical practice. Can neonatal and paediatric nurses already make consistent, reliable judgements of pain or is further training necessary? In order to answer these questions a comparison was made between paediatric and neonatal nurses' subjective assessment of pain in a number of babies and the assessment of the same babies using the LIDS scale. In order to test for effect of experience, nurses with differing levels of experience and education were selected. Two questions were posed:

i) How does the LIDS score compare with nurses judgements?

ii) Is there an effect of experience?

10.1 Sample.

Two groups of nurses were identified in a hospital other than the original study hospital. The senior sister on two wards was approached and the study explained. They discussed the research at their next staff meeting and the ward teams agreed to become part of the research. A mutually agreeable day was decided upon between the staff and myself on which to visit the ward. Thus the sample was one of convenience, being composed of those nurses on duty at the time of the visit, who were available to be included. While the limitations of this approach to sampling are recognised, this was a real life situation and the sample group reflected the typical skill mix of the two wards on any one day.

Group A.

7 nurses who worked on the NICU, and were therefore experienced in work with neonates, were included. These staff worked exclusively with neonates. Length of experience ranged from 5 days to 14 years (mean 63 months).

Qualifications :

Registered General nurse (RGN)/ Registered Sick Children's nurse (RSCN) / Specialised course in neonatal nursing (ENB 405 course) - 4 nurses

BSc MSc RGN/RSCN/ ENB 405/998 (teaching) courses - 1 nurse

RGN/RSCN/Specialised course in childrens' cardiology (ENB 160) - 1 nurse

BSc /RN (child) - 1 nurse

Group B.

5 nurses who worked on a paediatric surgical ward were included. These staff nursed a range of children aged between 1 day - 16 years who had undergone surgery, however they were less experienced with neonates than group A.

Length of experience in paediatrics ranged from 18 months to 13 years (mean 64 months).

Qualifications :

RN (child) - 2 nurses

RGN - 1 nurse

RGN/RSCN - 1 nurse

RGN/RSCN/ BSc - 1 nurse

10.2 Procedure.

The research proposal was approved by the Ethics committee of the hospital, Great Ormond Street Children's Hospital. I contacted the senior sisters on the two wards within the hospital where neonates were nursed post operatively on a regular basis. The hospital had been chosen because I knew, in a professional capacity, the pain nurse specialist who worked there and the staff were interested in reviewing their neonatal pain management. She effected introductions for me to the ward sisters. I was invited to attend a ward meeting on each ward to meet the staff and talk about the study. Some staff were aware of LIDS through publication, although none had used the scale. The staff in both areas agreed to be included in the study and a future date arranged to visit the wards. Both wards were visited separately but the format of the study was identical.

A number of video recordings of babies in the post operative phase were selected to be watched by both groups of nurses. The videod babies had been previously scored by myself using LIDS. In an attempt to gain some quantifiable measure from the study nurses, they were asked to score using a visual analogue scale (VAS) (0-10). This scale is a well known, accepted method of measuring pain and both the nurse study groups were confident in using one. It was reasoned a decision on quantity of pain from each nurse would add strength to the comparison. However, on reflection, this method does not allow an effective comparison. The LIDS score is measuring behaviour while the VAS was measuring pain.

Each video clip lasted 10 minutes and 8 assessments (i.e. 80 minutes in total) had been selected to demonstrate a range of pain cues. The nurses were blind to the type of surgery each baby had undergone, hours post operative, and analgesia administration. The video clips were shown through a television/video unit in a room on each unit. Although the nurses sat together for the viewings they were asked not to confer before allotting a score.

10.3 Measures.

Using a feedback sheet (appendix 7) for each baby, the nurses were asked to answer the questions :

a) Did you think the baby showed signs of pain? - A 5 point rating scale was used : yes,not much, no, unsure, hunger.

b) What signs did you see? - open ended.

c) How much pain did you think this baby was in?

    i) in your own words? - open ended.

    ii) on a scale of 0 - 10?

d) Ideally how would you like to see this baby being managed? - open ended.

With the participants' consent, I collected qualitative data throughout the viewings on the comments or questions made by the nurses.

10 .4 Results.

The 7 nurses on the neonatal unit assessed 8 babies each, while the 5 nurses on the surgical ward assessed 5 babies each. The difference was due to workload constraints on the nurses taking part. Both qualitative and quantitative data was collected from the two groups of nurses. These are presented separately.

10.4.1 Questionnaires.

In answer to question

a) Did you think the baby showed signs of pain?

BABY a LIDS score = 5	**YES**	**NOT MUCH**	**NO**	**UNSURE**	**?HUNGER**
NICU nurses	57% (4)	14.3% (1)	14.3% (1)	14.3% (1)	0%
Paediatric nurses	0%	0%	100% (5)	0%	0%

BABY b LIDS score = 29	**YES**	**NOT MUCH**	**NO**	**UNSURE**	**?HUNGER**
NICU nurses	43% (3)	0%	14.3% (1)	14.3% (1)	28.6% (2)
Paediatric nurses	80% (4)	0%	0%	20% (1)	0%

BABY c LIDS score = 33	YES	NOT MUCH	NO	UNSURE	?HUNGER
NICU nurses	100% (7)	0%	0%	0%	0%
Paediatric nurses	80% (4)	0%	0%	20%(1)	0%

BABY d LIDS score = 3	YES	NOT MUCH	NO	UNSURE	?HUNGER
NICU nurses			100%(7)		
Paediatric nurses			100%(5)		

BABY e LIDS score =29	YES	NOT MUCH	NO	UNSURE	?HUNGER
NICU nurses	14.3% (1)	14.3% (1)	43% (3)	28.6%(2)	28.6% (2) same 2 as "unsure"
Paediatric nurses	10%(1)	0	0	90%(4)	40%(2)from the "4"who were unsure

BABY f LIDS score =26	YES	NOT MUCH	NO	UNSURE	?HUNGER
NICU nurses	100% (7)	0	0	0	0

BABY g LIDS score = 21	YES	NOT MUCH	NO	UNSURE	?HUNGER
NICU nurses	28 .6%(2)	0	28 .6% (2)	28 .6% (2)	14.3% (1)

BABY h LIDS score = 7	YES	NOT MUCH	NO	UNSURE	?HUNGER
NICU nurses	0	0	100 % (7)	0	0

It may be seen from these results that there is a lot of variation in pain judgements. Although the neonatal nurses agreed for 2 babies that no pain was felt and that 2 babies were in pain, for 4 babies (50% of sample) there was disagreement. In contrast the paediatric nurses were in more agreement. However were they accurate? This is assessed in section c.

b) What signs did you see?

Neonatal nurses used "grimace" "frown" "arching back" "clenched fingers and toes" "startled awake" "intermittent cry" "rigid limbs, stiff position,guarding" "pain cry" "moving head from side to side" "normal posture" "relaxed" " drawing up legs, high pitched cry, frowning, pinched face" "persistant cry with short periods of rest". They also used respiratory effort and rate as an indicator - " slightly laboured breathing", "irregular resps.", "erratic breathing".

The paediatric nurses used fewer descriptors; they all mentioned "cry", with only one mentioning facial expression and this was "calm, relaxed face". " Restless moving", "pulling up limbs" were also used, as were "jerky movements" and "rigid body".

These have been arranged in accordance with the categories used in LIDS (table 14).

Table 14 Comments grouped using the headings within LIDS.

	Facial expression	Cry	Flexion/ tone	Movement/ excitability	Sleep	Respiratory effort
NICU nurses	Grimace, Frown, Pinched face.	Intermittent persistant	rigid, stiff position, guarding, relaxed, clenched fingers,toes	Arching back,drawing up legs,head moving side to side.	Startled, awake.	Irregular, laboured, erratic
Paediatric nurses	Calm, Relaxed, peaceful	Cry. No cry	pulling up limbs. Rigid body	Restless, jerky jittery, turning head	Exhausted sleep	

It may be seen that neonatal nurses' descriptions are richer in detail and identify more subtle changes in demeanour. Sleep is alluded to briefly in the nurses' descriptions yet LIDS uses both type and amount of sleep to be indicative of differing scores. Cry also features only as a quantity in the nurses' evaluations and again is divided into quality and quantity in LIDS.

c) How much pain did you think this baby was in?

i) Qualitative descriptions.

Neonatal nurses.

"small amount" "not a great level" "mild" "possible" "minimal" "slight" "unsure" "only discomfort" were the terms used by the NICU nurses and equated with their 0,1,2,3 scores.

Words such as "discomfort" "moderate" "painful enough to cause distress" "considerable amount" and "fair amount" equated with the NICU nurses 4,5,6 scores. Scores of 7,8,9 were described qualitatively as "fair level" "considerable amount (9)" "severe (7)" "quite severe/intense" "unsettled, in a lot of pain" "continual pain, quite intense".

Paediatric nurses.

"a lot (8)" "quite a lot (8)" "moderate, maybe,certainly uncomfortable (5-6)".

Again it may be seen that the neonatal nurses used more discriminatory categories.

Quantitative data.

ii) Tables 15 & 16 show the nurses score and my score for each baby. In order to compare the nurse score given by use of a visual analogue scale (VAS) with 0 = no pain and 10 = greatest pain.

Table 15 (page 156) shows the NICU nurse's scores. While the correlation between the two scores overall is 0.73 ($p < 0.05$) suggesting that nurses' judgements are reliable, this figure obscures large individual differences (see bottom of table). Only nurse A correlated significantly with LIDS. This nurse had undertaken a specialist course in neonatal nursing and had 7 years experience on the NICU. Note also the consistent underestimation (mean) of pain score compared to LIDS.

Table 14 NICU nurses scores and comments.

	NURSE A	B	C	D	E	F	G	Mean +sd	LIDS score.
BABY a	1	2	4	5	2	4	1	2.71 ± 1.6	5
	"small amount"	"not a great deal"	"discomfort"	"discomfort"	---	"moderate"	"appears comfy"		
BABY b	4	7	2	2	1	6	1	3.29 ± 2.4	29
	"painful enough to cause distress"	"fair level"	"mild pain"	"distressed at times"	"don't know"	"moderate"	"possibly"		
BABY c	9	7	5	8	7	9	7	7.43 ± 1.4	33
	"considerable amount"	"severe"	"moderate / severe"	---	"quite severe"	"tense, continual"	"quite severe"		
BABY d	0	0	0	0	0	0	0	0	3
	"none"	"none"	"none"	"none"	"none"	"none"	"none"		
BABY e	7	0	0	3	2	2	1	2.14 ± 2.4	29
	"unsettled, in a lot of pain"	"none ?hungry"	"none"	"distressed ?cause"	"slight"	"very unsure"	"only discomfort"		
BABY f	6	7	8	6	6	2	6	5.86 ± 1.8	26
	"moderate"	"considerable amount"	"quite severe"	"quite a lot- periods of none but may be tiring"	"moderate"	"minimal"	"considerable amount"		
BABY g	5	0	0	1	6	1	5	2.57 ± 2.6	21
	"hungry or moderate pain"	"none"	"none"	"more distress than pain"	"fair amount"	"hungry"	"discomfort"		
BABY h	0	0	1	1	0	0	1	0.43 ± 0.5	7
	"none"	"none"	"none"	"none"	"none"	"none"	"none"		
Correlations	0.93	0.6	0.32	0.48	0.67	0.54	0.65		
	(sig.)				p = 0.07		p =0.08		

Table 15 Paediatric nurses scores and comments.

	NURSE H	I	J	K	L	Mean + sd	Research nurse.
BABY a	1	0	0	0	0	0.96 ±	5
	"none"	"no"	"no"	"none"	"no"		
BABY b	2	8	7	8	8	6.4	29
	"settles after a while"	"quite a lot"	"reasonable amount"	'quite a lot"	"a lot"		
BABY c	8	2	8	8	8	6.8	33
	"a lot"	---	"a lot"	"a lot"	"a lot"		
BABY d	0	0	0	0	0	0	3
	"comfy, no pain"	"no"	"no"	"no"	"no"		
BABY e	4	6	0	5	6	4.2	29
	---	"certainly uncomfy"	"probably not"	"maybe"	"moderate"		
Correlations.	0.79	0.74	0.71	0.96	0.98		

Again correlation suggests reliability of judgements overall, but there is an inconsistent variation in judgement (table 17).

Table. 17 Mean scores for babies scored by both groups of nurses.

BABY	Mean score	MIN. SCORE	MAX. SCORE	LIDS score
a	1.5	0	5	5
b	4.66	1	8	29
c	7.16	2	9	33
d	0	0	0	3
e	3	0	7	29
f	5.7	2	8	26
g	2.5	0	6	21
h	0.5	0	1	7

Discussion.

While paediatric nurses appear to correlate better with the researcher score (table 15), it must be noted that the five babies (a -e) scored by these nurses fell into either "no" pain or "much" pain categories. However it is babies who fall into the middle category who may not have pain adequately recognised, and thus inadequately treated (see following section - d). This could lead to their experiencing greater pain for longer than is necessary. The same words were used by nurses to describe pain yet completely differing values were allotted. For instance "quite a lot" and "a lot" both scored 8 on the VAS -a high score. "Quite a lot" was used also to describe a score of 6 while "a considerable amount" was also used to describe this score. This exercise exemplifies how subjective and open to differing interpretation descriptions of pain in another are.

The greatest discrepancy between nurses' judgements appears to be in those babies displaying moderate amounts of pain (Table15,16). For example the baby scoring 29 by myself using LIDS i.e. a baby in a moderate/severe amount of pain, was given a score mean of 2.57 (± 2.4) by the NICU nurses and 4.2 (± 2.4) by the Paediatric nurses. This underpins the fact that nurses may be adept at recognising when babies are in no pain or a great deal of pain; but are less able generally to recognise the cues showing moderate amounts of pain. It is at these moderate points that analgesia and/or comforting measures may be at their most important in preventing deterioration in the baby's distressed state. Therefore it is important that nurses are able to recognise and act on these cues.

In order to explore these points more fully, a further examination of the category scores in relation to the total score awarded to the 41 study babies was made. When all LIDS scores were included there are significant correlations between all 8 behaviours and total score

Table 18. Correlations between all behaviours and total LIDS score.

CATEGORY	CORRELATION	
Cry quality	0 .83	Significant
Excitability	0 .77	Significant
Facial expression	0 .76	Significant
Flexion	0 .57	Significant
Movement	0 .76	Significant
Sleep	0 .76	Significant
Tone	0 .73	Significant
Cry quantity	0 .80	Significant

This was not the case however for behaviours for babies in moderate amounts of pain. 18 total LIDS scores of between 15 - 25 were identified from the babies studied. These were deemed to constitute a "moderate" pain score. To investigate these further, correlations (Pearson product moment) were calculated between total score and individual behaviours. These are shown in table 19.

Table 19. Correlations between total LIDS score and individual behaviour scores for 'moderate' pain scores (n=18).

CATEGORY	α Correlation	p =	
Cry quality	0.41	0.09	not significant
Cry quantity	0.19	0.42	not significant
Excitability	0.22	0.36	not significant
Facial expression	0.34	0.16	not significant
Flexion	0.78	0.00	Significant
Movement	0.53	0.02	Significant
Sleep	0.60	0.008	Significant
Tone	0.67	0.002	Significant

It can be seen that for 'moderate' pain scores, the score for flexion, movement, sleep and tone contribute most to the total score. This differs from the investigation of all the scores for the 41 babies which demonstrated all LIDS categories contributed significantly (table 18). While this may seem paradoxical it may be explained by the fact that LIDS takes account of the fact that babies in great pain have diminishing amounts of cry and the higher scores in these LIDS categories reflect this. It has already been argued that cry may not be used by a baby in great pain to indicate their distress and this finding supports that point.

This is an important finding in light of the fact that the study nurses' assessments often focused on facial expression and cry. If the cues employed by neonates in moderate pain are not sufficiently recognised and acted upon by nurses, it was postulated the baby may experience worsening pain. Thus the 18 moderate scores were further examined. Of the 18 babies awarded such scores only 5 received analgesia at that time. Each had a subsequent lowering of score. One baby not given analgesia at the point he was awarded a score of 17, scored a higher score of 21 at his next assessment. It should be remembered that at the time of this data collection analgesia was being given on an ad hoc basis and therefore analgesia was not given in direct response to the LIDS score.

The remaining 12 babies actually scored less on their next assessment. This does not support the hypothesis that moderate pain, if not rectified, may lead to greater distress levels - from a statistical viewpoint. This result may be due partly to the small numbers in the study and partly to the fact that the babies, being in the post operative phase, were overall experiencing diminishing pain levels due to wound healing taking place. Nevertheless, if sustained pain is unrelieved when it is causing moderate distress to the baby, it has the potential to worsen and cause greater distress to. This is an issue which needs further research.

d) Ideally how would you like to see this baby being managed?

From the NICU nurses this question evoked responses such as " change position" "observe if pain increases and give analgesia" "swaddle" "dummy" "review analgesia" " ? ventilate" "nothing" "pick up and cuddle" " feed if able".

The paediatric nurses mentioned "cuddling, feed, dummy and analgesia" while one also suggested "aspirating naso gastric tube".

10.4.2 Qualitative discursive data

I was present throughout the viewings. This gave me the opportunity to observe the nurses completing the questionaires and troubleshoot should any problems arise. I also transcribed the questions and comments they made while viewing.

NICU nurses.

The most commonly asked question was " *What operation has the baby had*?" Comments made included wanting to know the physiological readings for the baby. Some professed a difficulty distinguishing between hunger and pain and "*knowing the baby was very important.*" Generally this group was a very quiet group with minimal dialogue between one another.

Paediatric nurses.

Again the most frequent question was regarding what operation the baby had had. This, nurses said, would influence if one thought the baby may be in pain or not. Physiological observations were also seen as necessary to make an informed decision. One nurse said at one point that it was difficult to decide if it was pain or hunger the baby was showing. Another disagreed. "*You can tell when it is pain.*" There was then discussion about the lack of context and other information making it hard to judge if the baby was showing pain or not.

On one video the baby began to cry during the assessment. At this point all the nurses immediately began to write on their questionaire sheets.

Two video clips were of the same baby though at different times post operative. The nurses recognised it to be the same baby and commented that his cry was different now. The cry now made them feel uncomfortable. "*Give him a dummy/ pick him up*" were comments made by the nurses.

This group also identified how "false" it felt watching a baby for a number of minutes. " *In real life you are in and out of the cubicle and there are other constraints on your observations.* " Yet they acknowledged *"You see things differently when you watch over a number of minutes."*

10.5 Discussion.

The results presented here exemplify how subjective and open to differing interpretations perception of pain in another is. While overall nurses' subjective estimation of pain in the study babies may appear to correlate well with the more objective LIDS score indicating nurses were able to estimate pain in the babies, there was great variation in the nurses' judgements. This fact leads to inconsistent estimation and therefore treatment of pain. If analgesia is not given in required doses and at regular intervals it is less effective.

The same words were used by nurses to describe pain yet completely differing values were allotted. For instance "quite a lot" and "a lot" both scored 8 on the VAS - a high score. "Quite a lot" was used to describe a score of 6 while " a considerable amount" was also used to describe this score. This differing use of language is relevant when considering the type of information that is passed between nurses and doctors regarding the need for analgesia for individual babies. If subjective descriptions only are used they are open to a vast difference in interpretation, which again may lead to the under prescription or use of analgesic agents. The fact also that pain was consistently underestimated by the nurses in this study is in accordance with other literature on nurses' estimation of pain in another.

While it is acknowledged the sample groups in the research reported here were small, nevertheless one can highlight issues which increase our understanding, and suggest important areas for future research.

Fuller and Connor (1996) interviewed 64 nurses of different experience. Unlike the study reported here, after viewing videos of babies in varying situations, the participants were given notes with the baby's history, diagnosis and physiological signs before being asked to score the baby for pain. Discussion as to how the score was reached ensued. From these interviews 62 cues were identified as used by the nurses to evaluate pain. The length of experience had some influence on the type of cue recognised but in the main the cues identified corresponded with present literature and knowledge regarding infant pain across all levels of nurse, and included parameters such as facial expression, cry and movement. This is interesting in light of the examination of individual categories within LIDS which showed flexion, sleep, tone and movement to be the most significant for moderate pain. When comparison of individual behaviours with total LIDS score for all the 41 babies studied was made, all behaviours correlated significantly with the total score indicating they are all necessary. It should be remembered however that the higher LIDS scores within the categories of cry quality and cry quantity reflect the baby's diminishing efforts, rather than the overt behaviour demonstrated by a higher score in other pain assessment scales reviewed in Chapter 11.

Both sets of nurses in the present study used similar parameters when describing whether the babies they were viewing were in pain. Seymour, Fuller, Pedersen-Gallegos and Schwaninger (1997) studied the information 60 paediatric or neonatal nurses selected in order to assess infant pain. In their descriptions of how they arrived at scores for videoed infants, each showed a "repertoire of knowledge and strategies" (pg 35) including knowing the baby, reference to clinical notes re condition as well as personal knowledge base regarding pain theory and infant cues. In the Seymour et. al. study, words such as " grimacing, disorganized, guarding and fisting" were used. The more experienced nurses in Seymour's study demonstrated a wider repertoire of pain management strategies than did the less experienced nurses.

In the present study although the NICU nurses used more descriptive words, both groups identified categories in accordance with current knowledge regarding neonatal pain cues using parameters such as cry and movement. The NICU nurses differed in using the babies' respiratory pattern both to assess pain and to gain more information about the baby's condition. This may be because they are used to observing respiratory effort particularly in the NICU, where many babies may be respiratorily compromised. The participants in Seymour et.al (1997) also identified physiological parameters as important but recognised the unreliability of using vital signs alone. These, the participants felt, ought to be interpreted alongside other information. In contrast , Charlton (1999) found in a study of 26 neonatal surgical nurses that cry and vital signs were their most important cues in monitoring neonatal pain. He suggested a pain assessment scale with a value "weighting" incorporating vital sign measurement.

Also in common with the Seymour study, the participants in the present study requested clinical information about the child, i.e. diagnosis and length of time since surgery. This information was seen by the nurses in both studies as an important consideration when making an assessment. Hamers et.al.(1994) identified diagnosis as an important issue in nurses' perception of pain in neonates. However this may be misleading. Phase 2 of this study for instance found no significant differences between pain scores and different types of operation. This is a potential problem as nurses, perceiving an operation to be "minor", may judge that only a minor amount of pain can be experienced. Some of the pain scores for babies undergoing "minor" operations in the present study were indeed high demonstrating yet again the uniqueness of the pain experience to the infant.

In the paediatric nurse group the baby's cry prompted them to write on their assessment sheets. They didn't like the baby crying and verbalised "pick him up". This is similar to a previous study by McCain and Morwessel (1995) where cry, irritability and inability to be consoled were the most frequently identified pain cues from a group of 181 registered paediatric nurses. During the data collection a baby's cry evoked a response from the paediatric nurses. This has ramifications if cry is relied upon as an indicator of pain for if the baby in great pain does not cry, cues could be missed. Mayers and Jacobson (1995) suggested carers want to "contain" a baby when in pain. This was reflected in the paediatric nurses wanting the baby picked up yet not apparent from the NICU nurses who may be more used to "minimal handling".

A significant finding from Fuller and Connor (1996), which supported earlier work by Pigeon et.al (1989), was the fact that the cues recognised by the participants did not differ across levels of pain. A convenience sample of experienced and less experienced nurses assessed video taped infants in varying degrees of pain. 45 of the 62 cues identified by nurses as indicative of infant pain were recognised as present whether the baby was in pain or not, as well as whether the pain was mild, moderate or major. Differentiation of level of pain was not achieved. As in the present study, nurses used "cry" as a cue, yet subtle differences in cry quality or amount were not identified, similar to the findings in the Fuller and Connor study. The authors state that such cue recognition is of "little potential clinical usefulness as predictors of infant pain." (pg180). They conclude by indicating that novices may benefit from learning *which* infant behaviours suggest pain.

Within both groups in the study reported here, there were considerable differences in the pain score they would allot to the same baby and subsequently what intervention they would like.

For example one baby was given both a score of 8 and a score of 2 (Table 16). In this case depending on the nurse looking after the baby he could have received "a low dose morphine infusion" or " a change of position".

Hamer et.al.(1997) found that expertise did not influence neonatal pain assessment. It did however have an effect on the knowledge of, and confidence in using analgesia. Critical care nurses in their study were more likely to administer pharmacological analgesia than non critical nurses. Most recently a study by Choules (1999) identified different perceptions held by neonatal nurses on the same regional neonatal unit regarding the degree of pain caused by particular procedures. This had the potential for inconsistencies in care. Many staff also had developed their own comforting measures for infants during and after certain procedures. Sparshott (1996) postulated that any intervention of this sort could have a positive effect on the neonate's condition. Nevertheless, without objective evaluation as to the efficacy of such interventions, this cannot be substantiated.

It was also noted that despite being asked not to confer before scoring the baby, there was much more discussion in the paediatric nurse group than the NICU group. Although the discussion was not directly regarding what score to give, there was discussion as to whether the baby was hungry, uncomfortable or in pain. Again I feel this is a reflection of how the two groups of nurses were used to working, the NICU nurses being more used to caring alone for individual babies often within cubicles.

SUMMARY.

The study reported here adds to the evidence we have regarding the inconsistency which still surrounds neonatal pain assessment. Pain is without doubt a difficult concept to quantify in another. In the neonate the difficulty is magnified. Increasing our knowledge base not only about neonates and their behaviour but also regarding nurses' assessment and management strategies, can only serve to improve techniques.

The artificiality of watching a video recording must be taken into account. Watching a video for ten minutes seems much longer than it actually is and one is focused entirely on the baby and his or her cues. The paediatric nurses felt uncomfortable and said they were not used to working like this. There are many interruptions on an open paediatric ward. Indeed, one of the reasons for there being fewer infant assessments made by the paediatric nurses in this study were the demands on their time. It might be possible that information is being missed regarding pain cues of neonates when assessment is not focused and occurs quickly. A balance needs to be struck between a pain assessment scale which is clinically applicable - and this often equates with being simple and quick to apply- and one which is discriminating enough to ensure objectivity and consistency of score across assessors.

In summary it is postulated that nurses may not be using a full range of cues to inform them regarding neonatal pain. A useful assessment scale needs to include behavioural cues other than, or as well as facial expression and cry.

CHAPTER 11.

DISCUSSION.

This chapter will first summarise the research study presented here before providing an overall discussion. The chapter then discusses the implications for clinical practice and recommendations for future research are also provided.

11.1 Research study.

The impetus for the study was the need to measure the efficacy of analgesia in post operative neonates. The ability to achieve this was severely hampered by the lack of a valid and reliable assessment scale which was sensitive enough to quantify the often subtle changes in neonate's behaviours when displaying pain (Elander et. al. 1993). The formation of LIDS has facilitated the ability to measure with more accuracy, the effectiveness of analgesic interventions. It is also postulated that LIDS offers a description of neonatal behaviour which has the ability to increase our awareness of subtle neonatal behavioural cues.

The research developed through four distinct phases:

- Phase 1 The observational study, culminating in the formation of LIDS.
- Phase 2 Initial reliability and validity studies of the scale.
- Phase 3 Control group study.
- Phase 4 Ability of nurses to identify pain without using LIDS.

11.1.1 Observational study.

The behaviour of 25 newborns during normal caregiving episodes was observed by myself both directly and by video recording. These observations, combined with the empirical evidence of experts such as Wolff (1966), Brazelton (1977) and Trevarthan (1977), provided a detailed overview of neonatal behaviour. After discussion between myself and clinical psychologists, interpretation of this behaviour gave us a baseline from which to develop. I then made observations on a surgical group of babies (n = 34) around normal caregiving episodes. These included feeds, nappy change, physiological observations and periods of rest. The babies were observed lying in their incubators or cots. Each observation lasted a number of hours. Videos of some of these episodes were viewed by 3 clinical psychologists. The qualitative data collected from the observations of these babies (n = 59) was transcribed. This was subsequently reduced in order to summarise the information by teasing out themes around which the behaviours clustered. These categories were organised into a detailed scoring system. This was called the Liverpool Infant Distress Scale (LIDS).

This scale provided much more detail than the scale available at the time (Attia et.al. 1987) as it had been formed as a result of detailed observation of post operative babies in pain over time. Charlton (1998) states that although much pain caused to neonates is as a result of painful procedures and most pain scales have been developed as a result of studying such pain, it should not be assumed that acute pain is the same as post operative pain. Pain as result of heel stab, cannulation and circumcision is bright, sharp and localised. Post operative pain however can be as a result of both cutaneous and visceral pain receptor stimulation and be of a duller, nagging nature.Therefore the same pain scales cannot necessarily be used (Charlton 1998). Since this study commenced, a number of scales have been developed and reviewed (Bours et.al. 1996). These scales will be compared to LIDS in section 11.1.4.

11.1.2 Validity and reliability studies.

Following initial development the scale was subjected to rigorous reliability and validity tests. After piloting the scale on a further 10 babies undergoing surgery, adjustments were made to the initial scale. The scale was then applied to 31 babies in the peri operative period. The babies were categorised into three levels (minor, moderate and major) according to invasiveness of their surgery and scores compared. No significant differences were found between the surgery groups although the minor group did have lower mean scores after the first three hours following surgery. This lack of significance could be due to small numbers or could be attributed to the fact that there were variations in the infants response to surgical intervention, reflecting the individualness of the pain experience. As Charlton (1998) states, not all neonates require post operative analgesia. The babies' mean scores consistently reflected the expected pattern of peri operative pain i.e. decreasing over time as healing took place. However, individual differences in pain behaviours were such that this difference over time was not significant. Analysis of individual data demonstrates the scores' ability to reflect changes in infant behaviour as a result of painful and comforting caregiving episodes. This is substantiated by analysis of the scores pre and post analgesia administration which demonstrates a significant decrease in scores.Validity of LIDS was thus demonstrated. Using pre and post analgesia scores, this was further studied in phase three of the study.

The value of an assessment tool such as LIDS also lies in its ability to be used consistently and accurately by differing carers. (Melzack 1984). The next part of the study addressed this issue. By teaching the scale to a group of 4 nurses and testing their scores over a number of assessments, correlation results of 0.82- 0.89 (mean 0.87) were demonstrated. Inter rater reliability was further demonstrated by assessment of a further 5 babies x 14 assessments, the timing and severity of which the group of nurses were blind to. The consistency of the assessors in scoring the same video recording on more than one occasion gave correlations of 0.57 - 0.96, demonstrating the nurses ability to reproduce LIDS over time. The wide gap in correlation results however may have been attributable to the fact that the nurses had differing levels of expertise in neonatal care with the least experienced achieving the lower score. This area was further developed in the final phase of the study.

11.1.3 Control group.

Given non significant differences between the three types of surgery and the proposed explanation that this reflected individuals' responses to painful stimuli, a further test of validity was required. As discussed in chapter 9 this refers to the ability of the scale to measure that which it says it is measuring. In order to achieve this it was hypothesised that a comparative, control group not subjected to surgery, and not deemed to be in pain would have low LIDS scores. If the scale was indeed measuring distress due to pain in the neonate, support for this hypothesis would provide further evidence of construct validity.

A control group of 10 non surgical newborns born by elective caesarian section was selected and assessments made over their first 48 hours. Significant differences between the groups with higher overall scores in the surgery groups was demonstrated. The surgery groups have high scores over the first two days post operatively, while control group scores are low. Often the surgery group had lower scores immediately post operation rising after three to four hours. This is consistent with the effect of analgesia given during operation wearing off. Control group however displayed their highest scores immediately post delivery, rapidly diminishing over the first 2 hours. The score of the control group were also significantly lower than even the minor surgery group. However it can be seen from fig. 13 (page 138) that the latter group does decrease scores over time and when the results are analysed with the control group both groups show a significant decrease over time. All the above comparisons support the validity of LIDS.

Finally internal consistency was measured by calculating Cronbach's alpha for the 41 babies over the first 18 hours. Cronbach's alpha demonstrated high internal consistency ($\alpha = 0.84$-0.94 mean 0.89).

11.1.4 Comparison to other pain scales.

Subsequent to commencement of the LIDS study, a number of other neonatal pain scales have been developed, reflecting the growing interest in providing better pain management for neonates.

Bours et. al. (1996) reviews 13 available neonatal assessment scales. Only 3 (including LIDS) were developed specifically as post operative pain scales for neonates. These were The Neonatal Infant Pain Score (NIPS) published by Lawrence (1993) and CRIES (Krechel and Bildner 1995). Issues regarding validity and reliability of such scales were addressed.

NIPS was adapted from the Childrens' Hospital of Easter Ontario Pain Scale (CHEOPS) developed by McGrath et. al. (1985). Although the CHEOPS scale is a post operative scale it was developed for use within the anaesthetic room immediately post operative.

The NIPS scale consists of both behavioural and physiological parameters :

- facial expression
- cry
- arm movement
- leg movement
- state of arousal
- breathing

A 0,1 or 2 score is attainable for each category. For example:

Cry	**Legs/Arms**
0 - No cry	0 - Relaxed/restrained
1 - Whimper	1 - Flexed/extended
2 - Vigorous cry	

The lack of detail regarding cues within the categories limits the extent to which behaviours may be quantified. For example the present study found that the babies in an ongoing pain situation who scored highly did not always have a "vigorous cry". In fact few did.

Although CHEOPS was developed as a post operative scale for older children, the NIPS scale was tested for validity and reliability around acute painful procedures such as capillary and venous punctures. Pereira, Guinsburg, de Almeida, Monteiro, dos Santos and Kopelman (1999) have reported it's validity using a randomised trial on healthy newborns undergoing the acute pain of venapuncture. This may make it less appropriate as a measure of ongoing pain (Charlton 1998).

The CRIES numonic refers to the five categories which compose this scale and was developed by Krechel and Bildner (1995). The authors liken it to the Apgar score. It also was developed as a post operative pain score. Each category can again score 0,1 or 2.

- crying
- requires oxygen to maintain saturations > 95%
- increased heart rate/ blood pressure
- expression
- sleeplessness

For example:

Cry	Facial expression
0 - No cry	0 - None
1 - High pitched	1 - Grimace
2 - Inconsolable	2 - Grimace/grunt

Tests for validity and reliability demonstrated the scale's ability to reflect analgesia administration. Comparison to nurses' subjective assessment of pain correlated well. The main criticism regarding both these scales is the lack of detail within each of the categories allowing a large element of subjectivity when awarding a score. This may mean that if pain is identified and analgesia is given the scores do decrease and as such measure analgesia efficacy. The problem still remains that initial subtle signs of pain may not be recognised nor analgesia given to prevent pain. Modern analgesia techniques are aimed at preventing pain, as far as possible, rather than being reactive. Applying this to neonates we would not wish to wait for severe distress before implementing pain relieving strategies, but rather recognise cues earlier and instigate relief proactively.

This issue was demonstrated in the final phase of the present study, which highlighted the disparity among nurses when assessing neonatal pain and could account for the lack of impact of assessment scales on analgesia administration thus far.

When reviewing LIDS Bours et.al. (1996) comment that significance levels are not given. This reflects the fact that they were reviewing an earlier report on LIDS. Significance levels are now reported in the thesis in line with Abu-Saad, Bours, Stevens and Hamers (1998 pg.413) call for research to be aimed at "strengthening the properties" of measures for infants with chronic pain.

Bours et.al. also state that criterion validity is not demonstrated. Criterion validity is obtained by relating the tool to some other criterion. There are two types of criterion related validity: predictive validity and concurrent validity. Predictive validity refers to the ability of the scale to predict some future measure. This, the authors agree, is very difficult to establish when considering pain, as long term effects of infant pain are not known and extremely difficult to measure. Concurrent validity is established when the scale scores are correlated with scores on external measures, for example, physiological measures. Again this is difficult for the reasons expressed in section 3.2.1. Physiological measures may return to normal in chronic pain situations. Similarly, biochemical markers may alter due to the stress response to tissue damage rather than pain itself, as discussed in section 3.2.2.

Bours et al (1996) also comment on the fact LIDS is termed a distress and not a pain scale. As previously stated, on reflection, the scale developed could have been termed a pain scale. There has been an ongoing argument within the literature regarding the choice of word to describe in neonates what would in older children be called pain. Due to the fact that neonates cannot say it is pain they are experiencing, words such as nociception and distress are used in its place. While the research reported here initially set out to develop a pain score for neonates, the scale that developed provides a global measure of neonatal behaviour. The lower end of the scale describes behaviour considered the normal behaviour – slow, relaxed and open in stance- of a baby who is comfortable. The scale is then arranged so that the higher scores reflect the most acute changes in a neonate's behaviour, and these changes are indicative of *distress*. Thus the scale will indicate distress due to hunger or discomfort. Therefore the likely cause of the distress must be related to the context of the behaviour, and should be taken into account when instigating distress relieving strategies.

For example the control group study assessed babies who were deemed to be probably not in pain. Analysis of these scores demonstrated that the majority of scores given to the babies were low. High scores were usually given on the first to third hours after delivery when, it is postulated, babies could be expected to be at their most distressed. Those who were given higher scores responded quickly and well to comforting measures such as cuddling, containing and feeding. Conversely, the post operative group babies scored higher overall, reflecting their higher distress levels. These scores responded to pharmacological analgesia techniques, when given.

Thus LIDS should be used to inform nurses of the behavioural state of any baby they are caring for, not just those deemed likely to be in pain. Practice should be aimed at keeping babies score within the lower range i.e. 0-10. If the baby's score is higher then care giving should be aimed at reducing it. This may be by feeding if appropriate, or comfort measures such as non nutritive sucking (Stevens and Ohlsson 2000), touch (Henrikson and Birks 1997) changing position or environmental factors such as sensory control (Franck and Lawhon 1998). If these are ineffective and the score rises then other relief may be needed such as pharmacological or non pharmacological analgesia. Similarly, if the initial LIDS score is high, i.e. over 20, behaviours seen in the post operative cohort are being demonstrated and analgesia should be given. Furdon, Pfeil and Snow (1998) in a review of pain management practices, demonstrated differing practices and under- assessment of pain in a neonatal unit. The provision of guidelines which included assessment criteria improved pain management on the unit. Grunau, Hoisti and Whitfield (2000) studied the movements and activity of a convenience sample of 64 extremely low birth weight infants in response to invasive procedures. They concluded that while squirming, arching of the body, startles and twitching were not observed more during the procedures than baseline levels, facial expression, finger splay and leg extension were significantly different from baseline. They postulate that these changes may be different in longer lasting pain and call for more in depth study of behaviour patterns. These findings are interesting particularly when compared to LIDS. Although the behaviours were studied in full term neonates the score does demonstrate diminishing movements, fingers held spread out and rigid "splayed" as well as a space between the big toe and the other toes. The babies in the present study did however demonstrate "jumpy, jittery" extensor type movements which differed from the babies in the Grunau et al (2000) study.

Unlike other scales the LIDS does take account of the progressive nature of the scores of infants who are too ill or exhausted to respond by activity and cry. Henrikson (1997) recounts reflection of a critical incident within clinical practice. A neonate who had been subjected to a length of time in NICU and therefore a plethora of invasive procedures was undergoing another heel stab. The infant neither cried nor attempted withdrawal of the foot. Henrikson suggests this is "learned helplessness" as identified by Seligman (1975). This concurs with the present study which found babies in the later stages of their pain experience became quieter and more still, often crying less. This is duly reflected in the LIDS scale by higher scores being allotted for decreased activity in the presence of increased tenseness, rather than high scores being awarded for more overt behaviour. There is also a wider band of discriminatory scores reflecting the progressive nature of behavioural cues.

In addition, LIDS does consider longer lasting pain. However it would be virtually impossible to repeat the study reported here in the local region. Analgesic techniques in neonates have improved considerably over the course of the study and many of the babies who received little or no analgesia at the start of this study would do so now. Pain management protocols are now in place in most NICUs. However assessment tools are rarely part of practice. Pain relief may still be given inconsistently due to individual differences in nurses perception of pain. Charlton (1998) also postulates that these scales have, as yet, had little impact on analgesic administration to neonates in pain. This may be due to the perceived usefulness of such scales by nurses in practice. Twycross (1998) highlights the fact that despite a great increase in knowledge regarding pain in children, still more education is needed in this area in order to improve pain relief even further. There has been an increase in the number of pain study days and courses available for paediatric and neonatal nurses. Dissemination and sharing of good practices via other routes such as benchmarking may also improve the utilisation of assessment scales. Dunbar (1997) suggests benchmarking as an effective way of ensuring practice is based on best evidence. Her neonatal benchmark for pain management puts a pain assessment scale used regularly for all babies as best practice. Bours et. al. conclude that none of the pain scales reviewed were "*ideally suited*" (pg.63) and recommend that future research focus on

- examining the ability of multi dimensional scales to be sensitive to different levels of pain,
- the clinical utility of scales,
- measuring longer lasting pain.

We are very unlikely to be able to say definitely that a neonate is experiencing pain. However the behaviours demonstrating increased distress levels reported here have been generated by studying neonates in post operative situations. These are most likely to be as a result of pain. These are old arguments. Are we to theorise about whether neonates are in pain or distress rather than implement relief strategies?

The second problem in gaining a scale's acceptance in clinical practice is the ease with which nurses perceive they may use the scale, and the length of time taken to score. Neonates are not an easy group to assess for pain. A successful assessment scale therefore is not necessarily going to be easy to apply. Assessments may need to be made over a number of minutes rather than by a cursory glance, in order that subtle cues are not lost. Assessments need to be made by those who are experienced in identifying these subtle cues. This expertise may not be evident as a result solely of experience. Education in identifying such cues needs to be made available. The detail within LIDS may provide such detailed knowledge. Once internalised, the cues should enable nurses to be more receptive to the cues neonates are demonstrating. This would enable nurses to instigate pain relieving strategies at an earlier point and so work proactively. This point was highlighted by the more experienced neonatal nurse who worked on the reliability phase of LIDS (section 6.2) and felt her previous intuitions regarding pain were given a more objective and quantifiable basis. She in turn became more confident in her ability to recognise and deal with babies' pain.

The necessity for neonatal nurses to have an objective measure of pain was borne out by the final phase of the study.

Charlton (1998) further criticises the research base of neonatal pain scales with regard to the grading of individual neonate responses and the relative importance of one sign to the next. Standardisation of the weighting of pain assessments should lead to more consistent and accurate quantification of neonate's pain, and this has been achieved within LIDS.The importance of this point is acknowledged and could be the focus of future research, examining in more detail the individual categories within LIDS.

Thus the testing for validity and reliability of such scales is ongoing. Studies will be strengthened by the comparison of scales within the clinical area and by feedback from clinicians using such scales.

11.4 Nurse's ability.

The final phase of the study compared the subjective scores of two groups of nurses - one experienced neonatal nurses, one paediatric nurses- to the LIDS scores. While overall nurses' subjective estimation of pain in the study babies correlated well with the objective LIDS score indicating nurses were able to estimate pain in the babies, there was great variation in nurse's individual judgements. This fact leads to inconsistent estimation and therefore treatment of pain. The same words were used by nurses to describe pain yet completely differing values were attached to those words. While the NICU nurses used more descriptive words in their assessments, both groups used parameters such as cry and movement and overt behaviour was seen as a demonstration of greater pain. As with previous studies (Pigeon et. al. 1989; Fuller and Connor 1996) differentiation of level of pain was not made by the nurses. The greatest degree of discrepancy between scores was in the "moderate" pain category. It has previously been argued that if pain is recognised and relieved at this point, the baby may be less likely to progress to greater distress levels. For moderate pain scores flexion, movement, sleep and tone were found to be significantly correlated with total score. It is suggested that further investigation of these behaviours would be useful.

The results from this final phase of the study suggest that despite an increase generally in nurse awareness regarding pain cues in neonates, pain assessment is still open to subjectivity.

In their review Hamers et al (1998) suggest two explanations for the inadequate relief of pain in neonates: " ***inadequate presciption (of analgesia).... and insufficient administration of prescribed medication.*** " (pg. 41) . This is due to the fact, they postulate, that PRN prescriptions mean nurses are making decisions about when and how often to give pain relief. These decisions are often based on erroneous beliefs and perceptions. This may lead to little or no analgesia being administered if the nurse is not proficient at recognising the neonate's pain behaviours. The situation may also be compounded by the inconsistency between carers in pain estimation. One of the main features of a PRN prescription is that in order to achieve effective, continuous pain relief, that is proactive rather that reactive, the analgesia must be delivered regularly. As a number of nurses may be caring for a baby over a 24 hour period post operatively, inconsistencies in pain estimation such as those highlighted by the present study could lead to an interruption in pain relief.

Choules (1999) surveyed medical staff and neonatal nurses in a regional unit and ascertained their perceptions of pain as a result of a number of commonly performed procedures. Results demonstrated very different perceptions between staff as to degree of pain with the administration of analgesia not always relating to the degree of pain perceived. This study supports the findings in the present study, and highlights the need for more education in recognising neonatal pain cues, underpinned by the implementation of an objective pain assessment scale in clinical practice.

In another study Krechel and Bildner (1996) evaluated practice and identified barriers to the effective management of pain in their neonatal unit. They went on to examine the impact on practice of introducing the use of a scale and demonstrated improvements in pain management and direction for a standard of care. The scale was not the sole implementation. A pain team, increased education and a flow chart itemising pain management were also introduced. The emphasis was on the importance of a coordinated approach to pain management with multi disciplinary team members working together. The pain team's remit was to improve pain management. One of the ways this was achieved was by the incorporation of the pain assessment scale - CRIES - on a flow chart to encourage its use regularly.

Choules (1999) suggests a number of positive points from his research. Firstly the fact that simply carrying out the survey raised people's awareness of the problem of neonatal pain management. This stimulated discussion and reflection on practices which could change attitudes and have positive outcome on practice.

Secondly a number of staff highlighted the fact that agitation/distress from non painful but unpleasant stimuli should settle with simple comfort measures and thus can be distinguished from pain. This supports a point made earlier in discussing the use of "distress" v "pain". When utilising a scale which is measuring neonatal behaviour, some account of the context has to be made. In the control group babies who were given moderate scores (i.e. 10 - 20), the comfort measures implemented such as swaddling, rocking and feeding were effective in lowering their score and, it is postulated, their distress. A similar score in the post operative babies may not respond to such measures and further intervention would be necessary in order to prevent the babies' distress level worsening. This is the prime object of regular pain assessment - to ascertain effectiveness of intervention. LIDS is intended to be used as an ongoing assessment of babies' ability to cope with stimuli and the efficacy of supports be they pharmacological or other.

In addition LIDS is of use not only to measure distress, but also to assess whether or not a baby is comfortable. The lower range of scores (0-10) signify a baby who is either asleep or displaying interest in his or her environment. The lower range of scores reflect the behaviour which nurses should aim to support in infants. Thus LIDS could be used routinely in NICUs to assess babies, not only to measure distress but also to ensure the infant is comfortable. Any measures taken to reduce distress could be checked against the lower levels of score.

CONCLUSION.

LIDS has been shown to be reliable, internally consistent and valid. Thus it could fulfil the purpose for which it was first developed viz measuring the efficacy of different analgesics. The scale is being used as a research tool measuring differences in behaviour between babies born following Ventouse extraction and those born via normal delivery, and the efficacy of analgesia for the former group. The scale has also been included in the recently published RCN. Paediatric pain guidelines (1999). In addition the lower scores on LIDS could be used as a goal toward which any intervention should aim.

The issue of the need to train neonatal nurses in the recognition of subtle pain cues has been highlighted. The study demonstrated that "moderate" pain especially may not be recognised consistently by nurses. This is an important point when it is at this stage that the instigation of analgesic or comforting measures may prevent deterioration in the pain experience for the baby. Only 5 of the 18 babies with moderate pain scores had been given analgesia in the present study. More research in this area is indicated, studying the behaviours and how they change over time post operatively. There is an ethical question to raise however regarding such research. With an increased awareness of pain cues withholding analgesia in order to observe behaviour would be unethical. A counter argument is that it may be better for the greater group of neonates future pain management to demonstrate liklihood of pain, given the inconsistencies seen in nurses.

The use of a detailed objective assessment scale should improve the differences in subjective opinion and lead to more consistent pain relief. Future research could focus on the ability of the scale to influence practice. At present, LIDS is used as a teaching tool in order to demonstrate the differences in cues and improve nurses' recognition of pain. The focus of future studies should be aimed at examining the question whether this is sufficient or whether LIDS should be implemented as a behavioural assessment scale on the ward in order to influence caregiving episodes. Observational studies of nurses' practice would be informative.

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APPENDICES

1. Attia, Amiel-Tison, Mayer assessment tool.

2. Selection of field notes.

3. Liverpool Infant Distress Scale.

4. Information and consent forms for parents.

5. LIDS Score sheet.

6. Example script of Teaching video.

7. Assessors information sheets and teaching plan.

8. Nurse information sheet for Great Ormond Street Children's Hospital.

9. Nurse's Feedback Sheet.

10. Publications.

APPENDIX 1.

Attia, Amiel-Tison, Mayer (1987) assessment tool.

APPENDIX 1.

ATTIA, AMIEL-TISON, MAYER ASSESSMENT TOOL.

		0	1	2
1.	Cry quality	No cry	Moderate	Screaming, high pitched.
2.	Cry quantity (in 15min.period)	None	Once	Twice or more
3.	Facial expression of pain.	Calm	Intermittent	Constant
4.	Spontaneous motor activity	Normal movement	Occasional agitation	Not moving
5.	Spontaneous excitability	Quiet	Moderately reactive	Excessively reactive
6.	Excessive flexion of fingers and toes	None	Intermediate	Marked
7.	Tone	Normal	Moderately hypertonic	Markedly hypertonic
8.	Sucking	Normal	Intermittent. Stops with crying	Absent or disorganised
9.	Sleep pattern (15mins observation and history from nurses)	>10min.at at a time	Short disturbed naps	None
10.	Social contact (eye to eye; response to voice or smile)	Normal	Difficult to obtain	Absent
11.	Pulse,in comparison to preoperative values	<5min.-1 increase	5-10min.-1increase	>10min.-1 increase
12.	Systolic blood pressure in comparison to pre operative values	<5mm increase	5-10mm increase	>10mm increase

APPENDIX 2

Field notes

At home - over 3/4 hrs

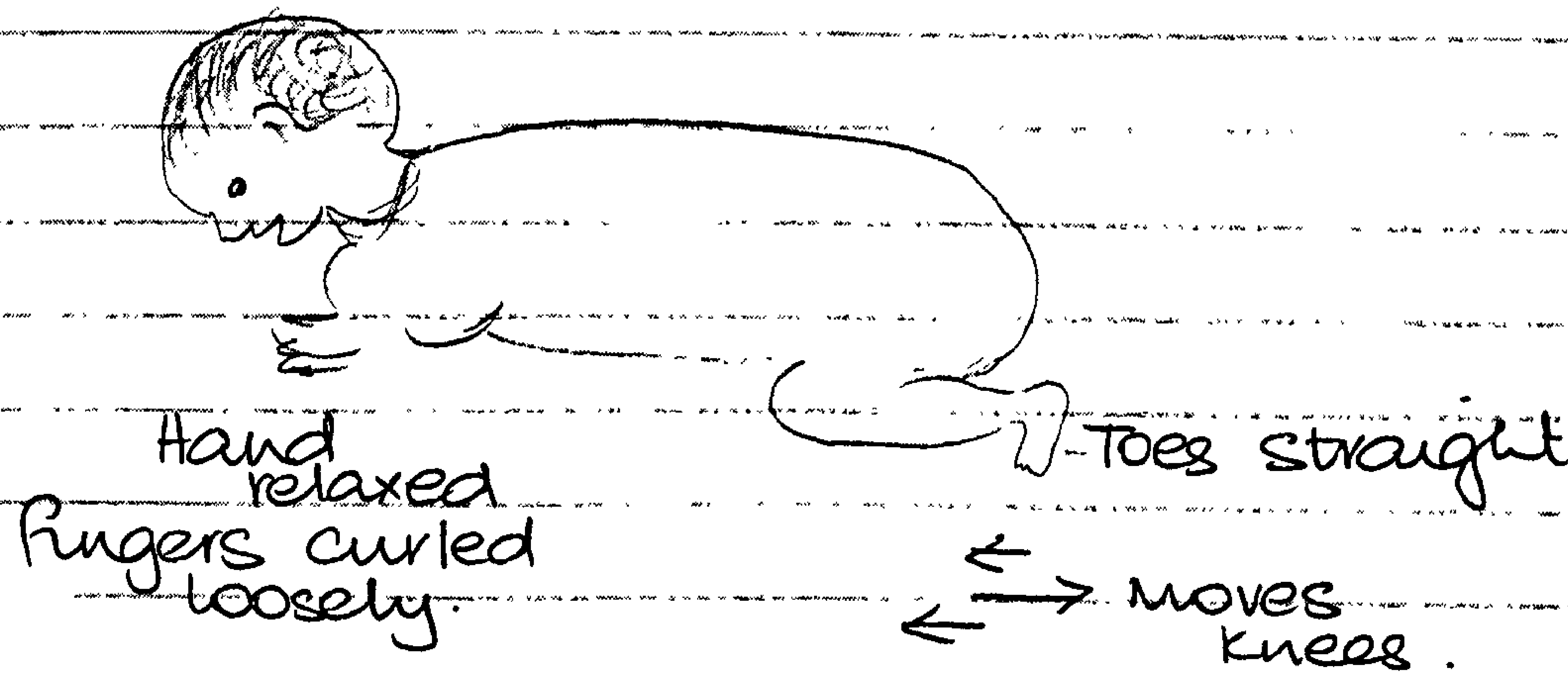
Verity 4/7.

On arrival Sleeping in cot on (Rt) side curled up with blanket loosely over. Little sighs resps. Face relaxed, eyes closed loosely no frown lines. Right hand in front of face fingers curled loosely back of hand on cot. Other arm under blanket.

2mins Little cough. Baby "mooching" around cot. Snuffly type sounds / Grunts. Begun to stretch Rt arm extended, fingers opened & extended
Legs move out of curled up position Stretching slowly, arching back Eyes opening, flickering Yawn. Settles - eyes open, hands in front of face. Eyes open & looks around. Opening & closing fingers.

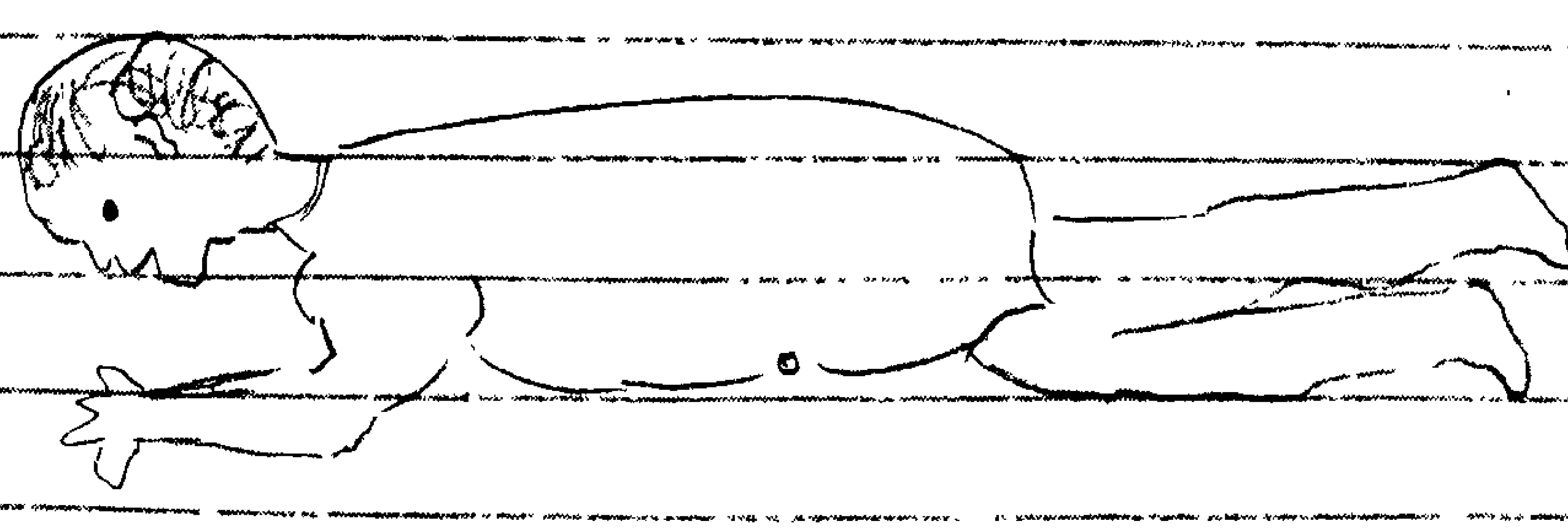
Alan 8/7 old Social Admission.

10^{10} Prone moving legs up & down crawl like. Settles - grumbly cry for 30 second Settles



Appeared to go back to sleep. Face no frown -calm.

10^{25} Begins to wake - mouth & face making little movements. Arms & legs stretching slowly extending & flexing - very controlled slow movements. little grun snuffly sounds.



10^{35} Settles again a little. Few more grunts & moves. a "beginning to cry" cry. Moving legs up & down again. Face becomes screwed up. Mouth open &

beginning to cry. Moving face side to side. Starting to cry now - a low pitched " I'm awake" cry.

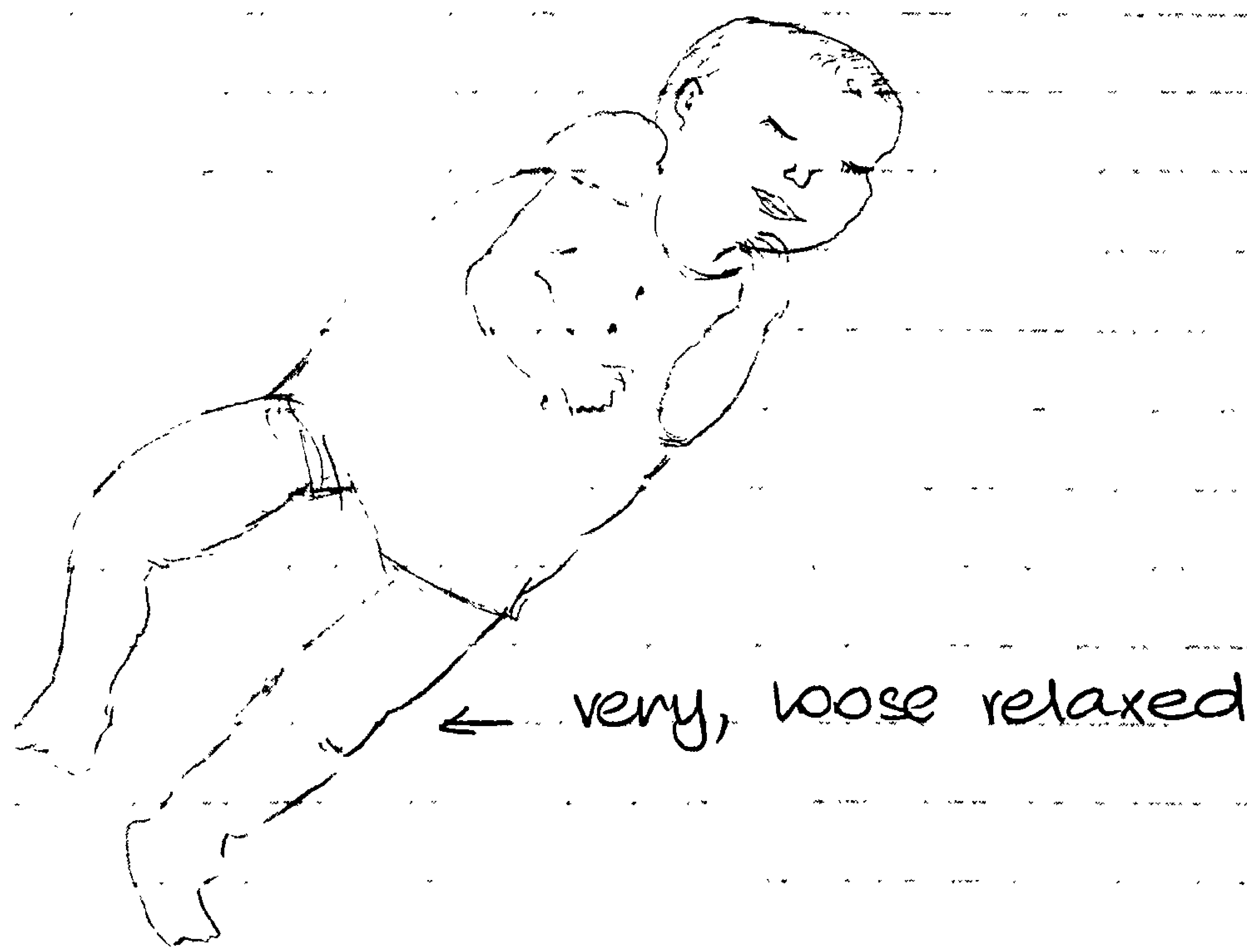
10.50 ish Nurse comes in - talks ... picks up babe.

Cry - grumbling / less / more - Baby cuddles into nurse. Proceeds to bath

Snuffly grumbles & intermittent cry. Moving arms & legs in air waving & circling. Kicking legs. Floppy & relaxed muscles.

"JODIE" 10/7 30 mins in 4 episodes over 3 hours.

0↓
4 50 mins lying still on (L) side. Lt hand twitches x 3



5 44 mins Screws up face transiently. Both arms bent up - hand across mouth & switching back & forth. Both knees draw up.

6 14 Wriggles, squirms & stretches. 1 x jitter. Settles again.

Relaxed looking. Mouth open. Left arm twitch - doesn't wake.

7 43 curls Rt arm up to lie on face. Hand slowly slips down over face.

Telephone rings doesn't wake.

840 Pursing lips mouth closed eyes tight shut.

1 hr later

Stretches Rt leg right out. Squirms & curls, unfolds arms & legs Hands in front of face - settle

Pokes Ⓛ eye with finger - Startle jump movements ++ stretching moving — Yawn eyes open transiently settles. arms bent & relaxed.

Feet waiving around gently.

Sleeps.

All movements are slowish & controll almost. no sounds really.

1 hr later.

moving arms & legs wiping face with hands. movements get quicker

Sudden jump & cry x 5 secs low pitch / grumble. Sleeps again
Fingers curled loosely. Face no frowns.

Stretching both arms up - screws up face - mouthing another minimal grumble. Rubbing eyes c̄ hand
Startle legs going up & down
Mouthing - Yawn. Settles.

½ hour later.
21-43 ↓ Cry - mod pitch x 30 secs. Wide mouth moving arms & legs up & down - A little grumbly cry
Wah wah - rolls on to back. now, quiet cry picking up in crescendo.

Wah, ah ah ah - cry beginning to be persistent now Arms & legs waving up & down. Cry on & off.

Cry becoming more sustained & louder. Still up & down tho - wah
Arms moving around legs kicking

Tone not tight - relaxed in between movements. Cough. Cry abating.
Grumbling.

Wants picking up & feeding!

25.11 Settles again arms out & fingers curled loosely legs relaxed. no cry
? asleep again, - not for long

Can see lips.

Mouth wide open & cry now becoming louder. / Settles Relaxed.

Feet move up & down. Big toe taut x 5 secs then relaxes.

Open eyes for first time properly
Fingers in mouth - sucking. Cry again
Face screwed up & vigorous cry & movements.

Cry now long & sustained, louder,
28/6 Baby looking more unhappy.

Settles again. Relaxed stance
eyes closed, face no frown. Asleep!

- iii)

Josh

Post op Inguinal Hernia repair 10/7.01c

Hr ① Mod high pitched grunty cry. stops & starts. Legs held quite stiffly. Arms bent out away from body. sleeps.

Sleeping. Lt leg held stiffly.

Moving legs up & down & a little stiffly. Lt hand moves in front of face. Mewing sound. Stretches. A jitter & a grumbly cry - highish pitch.

Face screwed into frown lines. Sucking & rooting. Tongue flat. Cry starts picking up. Sucking & rooting at fingers.

"Sad" cry - ah ah ah ah.

Opens eyes - looks around - cry grumbly.

Legs stiffer than arms. Moving legs up & down.

NB. Crying too much & making himself worse. Crying makes more crying. If had intervened & consoled (normal practice) then ? wouldn't have got so bad.

Hr ② Josh awake aware looking around. Tone relaxed. Legs look still stiff. Begins a mod. pitched cry.

Movements - kicking arms up & down.
unhappy ++
↓
intervened.

Given dummy to suck - sucks furiously & settles. sucks on dummy +++
Relaxes, arms bent at elbows even legs look more relaxed.

Post op Baby (2/7)-old

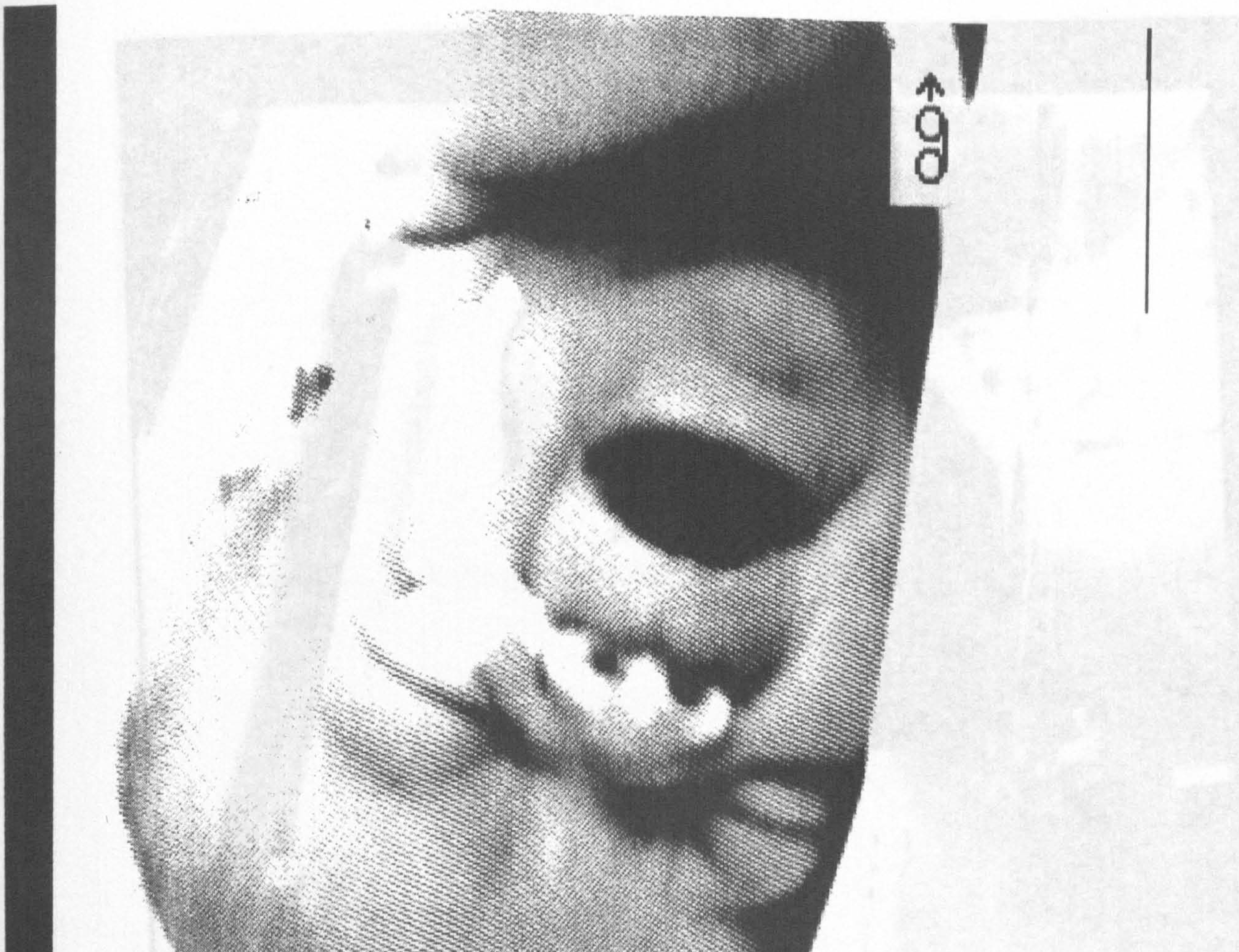
Baby returned from theatre after 3 ho
quiet, sleeping with a relaxed tone.
However baby had a mild frown over
her nose. Movements were infrequent

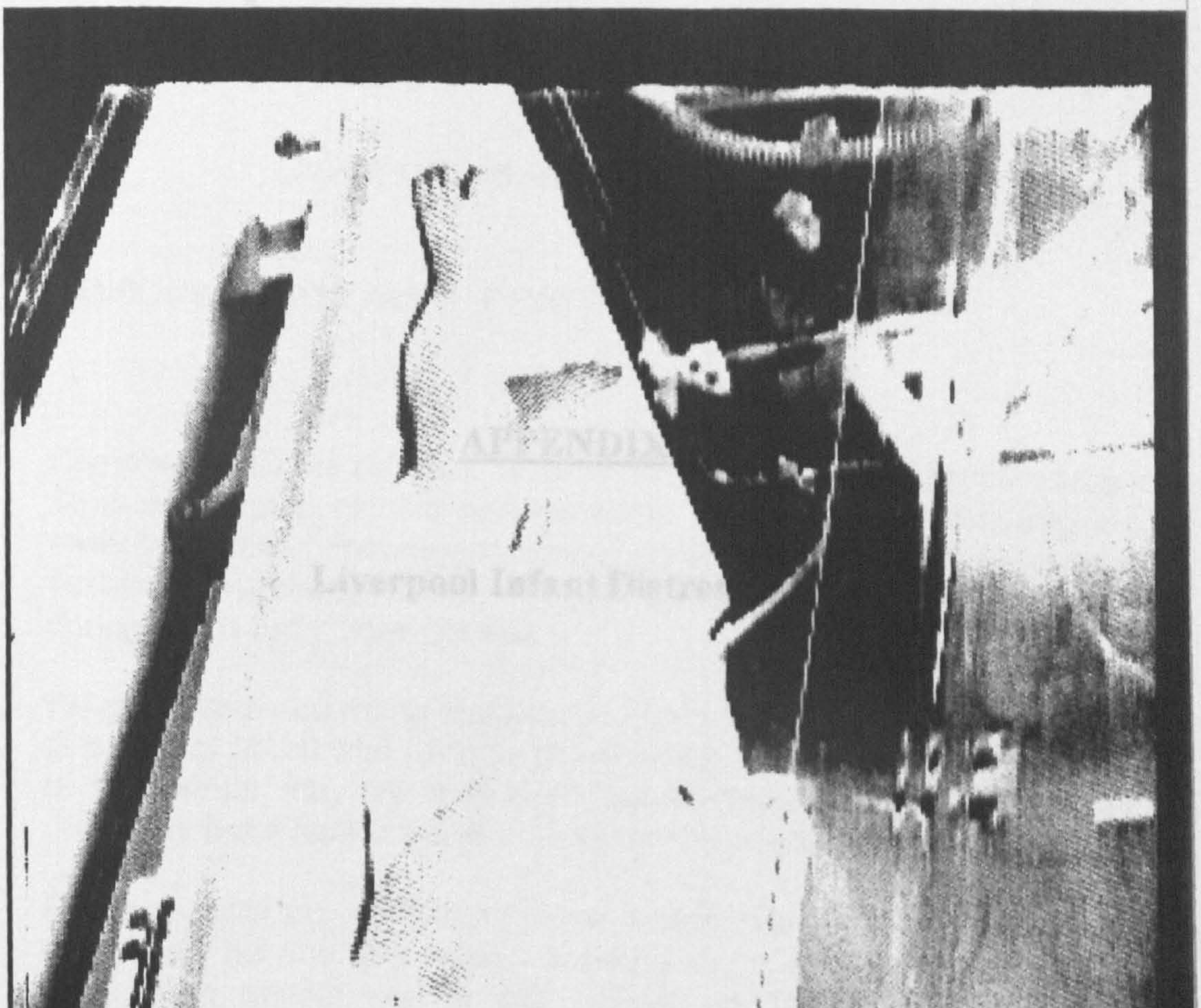
Baby remained much the same over
next two ~~years~~ hours! apart from frow
over nose extending to become deeply
furrowed around nose & brow, and
eyes became surrounded by lines.

About 3 hours baby awoke distressed
cry mewing, pitiable & interspersed
with tugging respirations. His face
had a deeply worried look with
deeply marked lines around eyes & bro
He held his legs taut & straight, flexed
acutely at ankles with toes spread
& held rigidly especially big toes.
Arms were held close to his body
with fists clenched tightly. Thumb
locked inside fist on (Rt) hand. (Lt)
visible.

Nurses comments included:

"pale & not very settled."
"pale & unsettled - rested for short
periods".





APPENDIX 3.

Liverpool Infant Distress Scale.

LIVERPOOL JOHN MOORES UNIVERSITY

SCHOOL OF HEALTH

LIVERPOOL INFANT DISTRESS SCORE

SPONTANEOUS MOTOR ACTIVITY WITH SUCKING

Score

0. Completely still but relaxed. Slow movements of head from bent side to side. Arms and legs stretching and recurling. Elbows and knees, frog like, arms away from body. Yawning or smacking lips. Sucking will be energetic and sustained, retaining dummy in mouth. May have spontaneous "startles" during which baby does not wake.

1. Wriggling and squirming main trunk. Arms and legs extending and recurling at a ratio of 50:50 with (0) type movements. Sucking is energetic chewing on dummy, stops, may cry, then chew again. Dummy usually remains in mouth during cry but if falls out and is replaced - is accepted immediately.

2. Restless agitation. Spates of quick, sharp movements. Legs move up and down (may be one at a time). Crawling if on tummy. Arms move in front of body, then settles and is still. Ratio of 75:25 with (1) in 10 minute assessment. If sucking, will not be sustained. Dummy falls out frequently - cry to suck 75:25% of time. If replaced, baby takes a while to fix.

3. Sharp, tense movements. Quick thrashing of arms and legs, legs more than arms. Fists held clenched, head slightly back. Will only take dummy after much persuasion and then doesn't sustain sucking. Too much crying to co-ordinate properly.

4. Sharp, tense movements of rigidly held body. Guarding of certain body areas with arms and knees. Fists clenched tightly. Chin shrunk down on to chest. A closing in of baby on themselves, as though to protect. Amount of movement diminishing - very little attempt to retain dummy or to suck.

5. Almost completely still and tense. Holding body guardedly. Thumb inside tightly clenched fist. Does not take dummy at all, conserving energy to breath which will be distress type gasps. No blinking and little eye movement.

SPONTANEOUS EXCITABILITY

<u>Score</u>

0. Slow, gentle reactions/movements, no cry or jitteriness, may be unmoving.

1. Blinks and slightly screws up face transiently. Mild movements for 10 seconds at a time, then resettles - may not really wake if asleep.

2. Either 1 to 5 episodes of mild jittery type movements without cry, or one startle type reflex without cry in 10 minute assessment. Settles quite quickly and is at rest in between.

3. Between 5 and 10 episodes of jittery type movements without cry, or one startle type reflex with a cry in 10 minute assessment. Settles quite quickly and is at rest in between.

4. All reactions/movements are excitable/hyperactive. Almost continuous movements associated with cry. Arms held up and away from body shaking.

5. Very jumpy and jittery continually. Arms and legs extended during movements and held tensely. Weak cries with movements.

FLEXION OF FINGERS AND TOES

<u>Score</u>

0. Fingers loosely curled as round a pencil. Thumb outside fist. Toes straight and together.

1. Intermittent relaxing and curling of digits.

2. Digits partly curled in more acutely than "0" scoreand held that way for some minutes.

3. Fingers <u>**OR**</u> toes held tightly curled.

4. Fingers spread out rigid and extended. Feet pointed downwards and held stiffly. Toes curled down tightly.

5. Tightly clenched fist continuously - thumb inside fist. Toes curled downwards, feet turned upwards at sharp to leg. <u>Space between big toe and other toes</u>.

TONE

Score

0. Relaxed. Arms and legs open and away from body, either spread out or frog like, if babe on tummy. Elbows and knees at about 45° to arms and legs.

1. Intermittent relaxing and tightening of limbs.

2. Arms and legs held stiffly. Fists clenched or fingers fully extended and stiff. Elbows bent tightly. If on tummy, knees drawn up and arms as (2) but continuously, without relaxation.

4. Limbs held rigidly, knees drawn up, fluctuating with whole body being held rigidly and knees straight.

5. Whole body held taut. Knees held straight. Arms held stiffly close to body - continuously. If moves whole stance remains taut.

CRY QUANTITY

Score In each 10 minute assessment:

0. No cry.

1. Small, short bursts of grumbling up to three times in 10 minutes about 1 minute total crying.

2. 2-4 minutes spent crying either in bursts or as a fairly continuous lusty cry / 1/5 total time of assessment.

3. 4-6 minutes spent crying / 2/5 total time of assessment.

4. 6-8 minutes almost continual cry / 2/3 total time of assessment.

5. 8-10 minutes continuous / almost all time.

CRY QUALITY

Score

0. Neutral vocalisation - occasional short mutter, low pitch. May be absent altogether.

1. Grumbling low pitch about 10 second duration. Stops/starts. Mouth closed - a 'beginning to cry' cry forced from the chest. May settle and stop or proceed.

2. A cross, moderately pitched, lust cry. Imperative tone to it - intended to signal. Builds up to a crescendo of amount. May stop and start, pauses anticipating a response.

3. A higher pitched wail, quicker to reach crescendo, more sustained and uncomfortable. A siren like cry, insistent and without pauses.

4. Shocked startled sudden start to cry. An intense, abrasive hard high pitched piercing cry. Long and sustained then may settle and start again without external provocation (e.g. noise). Tense 'cupping' to tongue. May have breath holding on inspiration.

5. Mewing, pitiable cry. Few and interspersed - may alternate with (4). A chopping quality may be present due to the baby's hyperventilated breathing rate.

SLEEP

Score In a one hour period majority of type determines score.

0. Greater than 10 minutes at a time.

1. 5-10 minute naps.

2. None, but alert, aware and looking around.

3. 2-5 minute naps.

4. Less than 2 minute naps. Frequent waking - probably unsettled.

5. None - uneasy and unrestful with it.

FACIAL EXPRESSION

Score

0. Eyelids closed and relaxed - no lines, lips slightly apart. No movement of nostrils or face.

1. Eyelids remain closed but face slightly screwed up with lines around mouth, eyes and over brow. Very transient expression and may be repeated often. Baby still asleep but may make mewing noises and sighs with consequent expression.

2. Attentive, receptive expression. Awake and aware and responding to surroundings. Paying interest, no lines on face, slow blinking of eyes. Mouth slowly opening and closing with tongue moving slowly in and out.

3. Eyes partly closed with lines around. Mild furrowing of brow. Face slightly contorted into frown expression. Chin may quiver - gaze be squinted and brow look 'wary'. May be a transient expression throughout assessment.

4. Moderately furrowed brow. Eyes closed and screwed up tightly causing many lines around eyes. Nostrils sharp and flaring. Lips tightly held therefore thin line to mouth when crying. Jutting lower lip may be constant or transient at a ration of 50:50 with either (3) or (5).

5. Practically all the time without relief, a constant deeply furrowed brow. Very flared nostrils, unnaturally open mouth with tightly held lips. Eyes tightly shut. A grey pallor to face.

APPENDIX 4.

Information and consent forms for parents.

PARENT INFORMATION DOCUMENT.

M.F.Horgan (Researcher)

Prof. S. Glenn (Supervisor)

Prof. I. Choonara (Supervisor)

We are trying to find the best way of achieving satisfactory pain relief in newborn babies following surgery.We therefore wish to assess babies after surgery by observing and sometimes videoing their movements, positions and facial expressions.

The assessments will be carried out at the bedside by the researcher, who has a nursing background. The observations will in no way alter or interfere with your baby's care. If videos are made they will be viewed by the researcher and also may be used for teaching purposes in the future. Not all babies will be videod; you will be specifically asked first if your baby may be.

THE RIGHT TO WITHDRAW.

YOU ARE FREE TO REFUSE TO HAVE YOUR BABY JOIN THIS STUDY, OR MAY WITHDRAW YOUR BABY AT ANY TIME AND YOUR DECISION WILL IN NO WAY AFFECT THE CARE YOU AND YOUR BABY RECEIVE.

THANK YOU.

CONSENT FORM.

I/We give permission for my/our baby :---

to be included in the study of neonatal behavior.

The purpose and nature of the study is to assess and video babies reactions in the first 48 hours of life.

I/We understand that my child's participation in the study is entirely voluntary and that I/We have the right to withdraw my/ our child at any time without giving reason and without affecting his/her treatment.

I/We have also read the explanatory leaflet for parents for this study and understand we have the right to request further information in relation to the study from the supervising nurse.

Signature: --

Date : ----------------------

APPENDIX 5.

LIDS Score sheet.

LIVERPOOL INFANT DISTRESS SCALE SCORE CHART

NAME: C/S NO. D.O.B D.O.OP

OP. AGE AT OP. GEST. TIME OF OP.

	pre-op			HOURS post-op												
	1.	2.		1.	2.	3.	4.	5.	6.	18.	19.	24.	25.		42.	43.
Spont. movement																
Spont. excitability																
Flexion of fingers/toes																
Tone																
Cry quantity																
Cry quality																
Sleep																
Facial Expression																
TOTAL																
Pulse																
Sa O2																
B/P																
COMMENTS/ ANALGESIA																

APPENDIX 6.

Example of script from teaching video.

Example of pre written script to accompany video shcts.

Spontaneous Activity and Excitability.

In this video we will be concentrating on the babies spontaneous movements and the amount of excitability demonstrated by the baby. To begin with certain actions will be pointed out to you. At the end of the scene the score for movement, excitability or both will be given. You may wish to rewind and re watch the scene to see why the score was given referring to your score sheet.

This scene shows a relaxed baby making normal stretching movements extending her arms and legs wriggling and squirming while asleep.

01 : 58 min. SCORE 1 for activity.

02 : 07 min. This shows similar movements, slow curling up of limbs and body .....

15 : 30 min. Again note this baby's rigidly held legs and body with arms tucked closely in guarding himself – completely different to the baby seen earlier in an open relaxed stance.

15 :55 min. SCORE 4 for movement.

20 : 28 min. Stop the video here and have a break.

Now I will tell you the scores for activity and excitability at the start of the scene – it is up to you to identify the actions which go with the score. Rewind the tape whenever necessary......

APPENDIX 7.

Assessors information sheets and teaching plan.

ASSISTANTS to a NEONATAL RESEARCH PROJECT.

TO ASSIST IN THE DEVELOPMENT OF AN INFANT DISTRESS SCORE FOR USE IN EVALUATING POST-OPERATIVE PAIN IN NEWBORN INFANTS.

The project will take 60 - 90 hours of your time over several months.The initial teaching sessions will allow you to become proficient at assessing and scoring infants using the Liverpool Infant Distress Score. These will take place at the Institute of Child Health, Alder Hey. Subsequent scoring of video recordings of post-operative babies will be done independently at your own convenience.

The project requires a degree of committment, and if you are interested and would like to know more; please contact either-

DR. IMTI CHOONARA or MAUREEN HORGAN
(research nurse)
INSTITUTE OF CHILD HEALTH,
ALDER HEY CHILDREN'S HOSPITAL,
EATON ROAD,
LIVERPOOL L12 2AP.

Remuneration will be £6 per hour.

DEVELOPMENT OF AN INFANT DISTRESS SCORE.

CONTRACT FOR ASSESSORS.

Supervisors: Miss M.Horgan. Dr. Imti Choonara.
Mrs. Jean Sambrooks. Mrs. Juliet Morton.
Dr. Andrew Bowhey.

Training sessions: Approximately 10 hours teaching- length of sessions to be negotiated between group members & supervisors.

Venue: Institute of Child Health,
Alder Hey Children's Hospital,
Liverpool.

Thank you for agreeing to help with this project.

The purpose of the training sessions is for you to become proficient at using the Liverpool Infant Distress Score(L.I.D.S.) as a fore runner to validating the score. Once validated, L.I.D.S. will be used as a method of measuring neonatal distress so that improvements can be made in the type of analgesia babies recieve after operations. It has been difficult to scientifically identify before now that babies are in pain although many professionals have thought they were. We feel we have in our score identified behaviours which indicate distress and pain. We now need to prove the score system can be used by others-hence your role.

Once you are confident and competent at using L.I.D.S. you will be asked to watch a number of pre-recorded assessments-
15 babies x 14 assessments x 10 mins ea.
and score each assessment on score sheets provided. These recordings may be viewed at your own convenience, in your own home. Parental permission to video these babies has been obtained but I am sure as professionals you understand the need for confidentiality when you view the videos. How you spread this workload over your time depends on your own circumstances but we would hope the project would take about 6 months from the start.

I would like to invite you to an informal meeting to discuss the project and give you an idea of the assessments and score ------

at Institute of Child Health,
Alder Hey Children's Hospital,
Eaton Road, L12 2AP.

I look forward to meeting you.

Yours sincerely,

Maureen F. Horgan.

Research nurse (neonatal unit.)

TRAINING PROGRAMME.

SESSION 1.	Introduction. 15 min. video demonstrating different amounts of stress. Scoring system explanation.
SESSION 2.	45 min video " Flexion & tone". Discussion. Ironing out any problems for future sessions.
SESSION 3.	1 hour video " Activity & Excitability." Discussion.
SESSION 4.	1 hour video "Facial expression & Cry." Discussion.
SESSION 5.	1 hour video of assessments for you to score. Discussion.
SESSION 6.	Review of last weeks scoring. Discussion re future scoring.

Refreshments and "time out" will be organised at each session.

M.F.H. Jan 1993.

ASSESSMENT. Week 5

Don't worry - this isn't a TEST!
You have been given scoring sheets.

Run through them.

We'll now watch a number (11) of assessments. They are not all 15 minutes long.

At the end of each assessment I will pause the video and give you time to mark on the score sheets what you feel should be the score given for each of the categories we have learnt over the past weeks.

Please do not discuss the scoring among yourselves. It is your individual ideas we want.

If you cannot give a score – for whatever reason – please make a simple note why you can't and go on to the next one.

Remember it isn't to test you we are doing this but rather my teaching and the score system!

We'll stop after ½ hour or so for a break .OK? Thanks.

APPENDIX 8.

Nurse information sheet for Great Ormond Street Children's Hospital.

NURSE INFORMATION SHEET .

The clinical application of a scale to measure post operative pain in neonates.

We would like to ask your permission to be included in this project.

1.THE AIM OF THE STUDY.

The aim of this project is to investigate the effect of a specific scale - the Liverpool Infant Distress Score (LIDS) - on nurses' ability to measure babies' pain in the post operative period.

2.WHY IS THE STUDY BEING DONE?

It is very difficult to recognise and measure pain in babies, yet it is vital in order to know if the pain relief we are giving is working adequately. We have formed a scale (LIDS) which gathers together all the signs we feel babies use to tell us they are in pain. We wish to know if this scale would be useful for nurses to use when they are assessing babies for pain.

3.HOW IS THE STUDY TO BE DONE?

General description.

As a nurse you will regularly make judgements about your patients' pain after their operation. It is proposed that the researcher will ask you how much pain you judge your patient to be in, and at the same time assess your baby using the LIDS scale. The two scores will then be compared to see when they are similar or differ. There will be no changes made to the babies normal routine or care. Following this period of data collection it is proposed that a number of nurses will be taught the LIDS scoring system and will begin using it in practice with the researcher again comparing scores.

Details of what the study will involve.

Assessments are made by observing the baby's movements, facial expression, sleep pattern and cry. The assessments will be made for ten minutes, a number of times over the first forty eight hours after his/her operation.

4.WHAT ARE THE RISKS AND DISCOMFORTS?

There are no anticipated risks to this project.

5.WHO WILL HAVE ACCESS TO THE CASE/RESEARCH RECORDS?

Only the researcher, her academic supervisor and a representative of the Research Ethics Committee will have access to the data collected during this study.

This research has been approved by an independent Research Ethics Committee who believe that it is of minimal risk to you and the child. However, research can carry unforeseen risks and we want you to be informed of your rights in the unlikely event that any harm should occur as a result of taking part in this study.
No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This will require you to prove a fault on the part of the Hospital and /or any manufacturer involved.

6. WHAT ARE THE POTENTIAL BENEFITS?

This study will not bring any immediate benefits to the child. However it is hoped that this will further our understanding of pain in neonates and raises the posibility of being able to relieve pain in babies even more effectively in the future.

7. DO I HAVE TO TAKE PART IN THIS STUDY?

If you decide now or at a later stage that you do not wish to participate in this research project, that is entirely your right.

8. WHOM DO I SPEAK TO IF PROBLEMS ARISE?

If you have any complaints about the way in which this research project has been , or is being conducted please, in the first instance, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee , by post via the Research and Development Office, the Institute of Child Health, 30, Guilford St. London WC1N 1EH, or if urgent ,by telephone on 0171 242 9789 ext 2620 and the committee administration will put you in contact with him.

9. DETAILS OF HOW TO CONTACT THE RESEARCHER:

Until the study begins - 0151 231 4134.

Once the study commences I will be available on the ward.